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Agenda Supplement – Health, Social Care and Sport Committee

Meeting Venue:
Committee Room 3 – Senedd
Meeting date: 15 September 2016
Meeting time: 09.15

For further information contact:
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Please note the documents below are in addition to those published in the main Agenda and Reports pack for this Meeting

– Consultation Responses: Priorities for the Health, Social Care and Sport Committee

Y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Ymatebion i'r Ymgynghoriad

Medi 2016

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Health, Social Care and Sport Committee

Priorities for the Health, Social Care and Sport Committee

Consultation Responses

September 2016

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Alcohol Concern Cymru
Response from: Alcohol Concern Cymru

Thank you for the opportunity to contribute to this process. Of the subjects that have already been suggested, there are three that we think are particularly appropriate. Our comments on them can be seen below, in the order of priority to us.

Gambling addiction

The Committee's list of possible topics refers to our report "A Losing Bet?", on the overlap between alcohol and gambling. Although alcohol is the main interest to us as a charity, we recognize that alcohol problems often coincide with other forms of dependency. Many people who gamble excessively also abuse alcohol, and many people who are dependent on alcohol also turn to gambling as a means of escape at times. Since the publication of "A Losing Bet?" we have worked with the University of South Wales and the University of Roehampton in order to better understand the relationship between drinking and gambling, especially in the context of online gambling (which is the area where the gambling industry is growing fastest). As a result of this collaboration, we have a great deal of useful evidence that we can present to the Committee.

To conclude, I would say that we, and many others working in the field, believe that it is high time that we discuss gambling as a public health issue, rather than as a regulatory issue only. An investigation into reliance on gambling by the Assembly Health Committee would show that this is an idea which is accepted in Wales.

Loneliness and isolation among older people

We currently have a community development project in Pembrokeshire, which aims to reduce alcohol problems by strengthening social bonds. Interestingly, when the project began in 2014, we asked local people what were the priority issues for them in terms of alcohol. There was a strong consensus that isolation amongst older people contributed greatly to alcohol abuse among the older generation. Consequently, a number of our project activities have focused on bringing together young people and older people to socialize and share experiences, rather than dealing directly with alcohol as a subject. In essence, we are dealing with the underlying causes of poor health rather than its symptoms. We believe that, here, we have a good model for health promotion for older people, and we would be very happy to present evidence on that to the Committee.

Sport and public health

We agree that participation in various sports (especially through local community clubs) is very beneficial to people's physical and mental health, and also helps to strengthen social bonds. We consulted with a large amount of such clubs, and one thing we have seen is that they often have a paradoxical role. On the one hand, sports clubs and fitness centres promote fitness and excellence on the playing field. On the other, they are often also places to drink heavily and places where is seems that alcohol is part of the culture. In a survey that we held, spokespeople on behalf of 90% of clubs told us that they thought it was important that clubs sell alcohol responsibly; but 66% said that club members regularly binge drink.

As well as the negative effects of excessive drinking on the health and performance of a team, if people know that the club is noted for heavy drinking, they may stay away. More specifically, such clubs are unlikely to appeal to families with children (the future of the club) or to people from ethnic communities where alcohol is not usually drank or is not acceptable. It is also possible that the 'machismo' culture of heavy drinking is not attractive to women. We believe, therefore, for sports clubs to be centres for the promotion of good health and centres that promote a community spirit,

they must ensure that alcohol is sold and drank sensibly in the club. We have many examples of ways to do that, which we could submit to the Committee.

Andrew Misell
Director
Alcohol Concern Cymru

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Cymdeithas HIV Prydain
Response from: British HIV Asociation

Response from the British HIV Association (BHIVA)

BHIVA notes that the Health, Social Care and Sport Committee seems to have an extremely broad remit and the Association is aware that HIV may not be a topic that is regularly on the agenda for the Committee. However, BHIVA would like to mention the issue of Pre Exposure Prophylaxis (PrEP) for HIV, which the Association feels is unresolved in Wales, as it is in England.

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Hafal
Response from: Hafal

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18 August 2016

Response to Committee's consultation on its Forward Work Programme

Priorities for the Health, Social Care and Sport Committee

We think the main priorities of the Committee should centre on the following four questions:

1. **How beneficial has the integration of health and social care services been for people who directly use these services, and for their families, particularly as it applies to those using mental health services?**

2. **How far are we reducing health and social care inequalities in Wales, especially for people with mental illness?**

3. **Is prudent healthcare working, and is it ensuring best outcomes and best value for people with mental health problems?**

4. **How well are we meeting the physical health care needs of people with mental health conditions, how important is the role of sport, and how are we increasing access for people with psychological problems?**

Integration of health and social care services

We hear from many people who use secondary mental health services about how they feel let down because of weaknesses in delivering fully integrated services across health and social care agencies. Health boards and local authorities have varying interpretations and are at different stages of developing fully integrated mental health services.

We would like to see examples provided from health boards and local authorities across Wales of where they provide holistic and coordinated services to people through a single, fully integrated and jointly funded service, and what evidence is available to support the notion that people achieve better clinical and social outcomes as a result.

Examples could include:

- Where a single health and social care assessment process for people accessing mental health services has been developed

- Where there is single budget for mental health services across health and social care
- Where there are single integrated performance frameworks or single outcomes frameworks that have been established

What has been the impact on those in greatest need as a result of a general trend of moving from specialist community mental health support services to more generic support services?

Reducing health and social care inequalities in Wales

The scale of inequality for people with a diagnosed psychiatric condition is huge. People with mental illness have the lowest employment rate for any main group of disabled people, endure greater poverty, have poorer housing, have fewer training and educational opportunities and experience greater social isolation.

Poverty and mental illness often go hand in hand, and people with a diagnosed psychiatric condition are far more likely to be in debt and be reliant on welfare benefits:

- People with mental illness are around three times more likely to be in debt and have financial problems
- People with mental illness are over five times more likely to cut down on the use of the telephone, gas, electricity and water than the general population
- When people using mental health services are asked about the major issues that concern them in their daily lives, personal finances are consistently identified as a major source of difficulty and distress

Currently the economic activity rate of people with a mental illness is the lowest for any group with long-term health problems:

- People with mental illness are far more likely to be jobless than the general population
- People with mental illness are far more likely to lose their job because of their illness
- Around 40% of people who claim benefit due to incapacity to work have a mental health problem

We would like to see examples from Public Health Wales and from the Welsh Government of how and where they have targeted specific vulnerable and marginalised groups of disabled people to ensure that these health and social care inequalities are being addressed and being reduced. We would also like to see accessible data being made available that demonstrates clear progress being made in reducing health and social care inequalities.

Prudent healthcare and achieving best outcomes and best value for people with mental health problems

In its *"Achieving prudent healthcare in NHS Wales"* paper (2014) Public Health Wales emphasizes that, "the main driver behind prudent healthcare in NHS Wales is not saving money, but ensuring the people of Wales receive the best possible care from the available resources". This captures what prudent healthcare should be about. It should promote services which are as effective as possible at getting patients well - and as efficient as possible in achieving this.

There is a need to look at the human cost and the financial cost when developing services. The good news is that those costs are not inversely proportionate: recovery-focused services with an emphasis on co-production mean better outcomes for service users/patients and a reduction in financial cost.

In the attached paper we highlight 5 mental health case studies to show how prudent healthcare can work in practice: **Prudent Health Care in Practice: 5 Case Studies**

We would like to see practical examples of where both health boards and local authorities are applying prudent healthcare principles that are resulting in better outcomes for service users and achieving best value for money.

The physical healthcare needs of people with mental health conditions and the important role of sport

People with a serious mental illness and their carers face many inequalities when it comes to their physical health. People with a serious mental illness such as schizophrenia or bipolar disorder can have a life expectancy between 15 to 20 years lower than the general population (Wahlbeck et al, 2011); over 8 in 10 carers have seen a negative impact on their physical health as a result of their caring responsibilities (Carers UK, 2013).

Welsh legislation and policy aims to tackle this inequality. For example, the Mental Health Measure (2010) prescribes a holistic Care and Treatment Plan for people using secondary mental health services which includes a section for setting, “Personal Care and Physical Well Being” goals.

“Together for Mental Health: A Strategy for Mental Health and Wellbeing in Wales” (2012) states that, "People who experience mental health problems should be assisted to enjoy the same life expectancy and quality of physical health as the general population", and advocates, "tackling less healthy lifestyles, smoking and poor diets, and increasing opportunities for physical exercise, including in inpatient settings".

Attached is a guide for mental health services on how to promote physical health for service users and carers: **Let's Get Physical!: A guide for mental health services**

We would like to see examples of where Public Health Wales are targeting people with mental health conditions and taking action to increase life expectancy for this highly vulnerable group of people. We would also like to see to what extent Public Health Wales, along with health boards and local authorities are promoting and encouraging the use of sport amongst people with mental health problems, and how this is playing an important part in a person's recovery. How are local authorities in particular, increasing accessibility to sport and leisure services for people with psychological problems, as they would for people with physical disabilities?

About Hafal

Hafal (meaning 'equal') is the principal organisation in Wales working with individuals and families affected by serious mental illness. We are managed by the people we support, and our 195 staff and over 100 volunteers provide direct help and support across Wales to over 1500 people with a serious mental illness and 1600 carers.

The charity is founded on the belief that people who have direct experience of mental illness know best how services can be delivered. In practice this means that at every project our clients meet to make decisions about how the service will move forward, and the charity itself is led by a Board of elected Trustees, most of whom either have experience of serious mental illness themselves or are carers of a person with a mental illness.

Our mission is to empower people with serious mental illness and their families to enjoy equal access to health and social care, housing, income, education and employment, and to achieve a better quality of life, fulfill their ambitions for recovery, and fight discrimination.

For any further information about this paper please contact: peter.martin@hafal.org

P 04

Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Cymorth Canser Macmillan

Response from: Macmillan Cancer Support

Purpose:	**Macmillan's response to inform the NAfW Health, Social Care & Sport committee priorities**
Contact:	**Lowri Griffiths, Policy & Public Affairs Manager (Wales)** [redacted] **Tel:** [redacted]
Date created:	**18 August 2016**

1. Introduction

1. 1 Macmillan Cancer Support welcomes the opportunity to support the formulation of priorities of the Health, Social Care & Sport committee during the fifth Assembly.

1. 2 Although more people are surviving, there are still too many people dying from cancer in Wales or not living well beyond their treatment. They may have long-term side effects such as fatigue, incontinence or lymphoedema.[1] We need an ambitious approach to match the changing nature of cancer and its treatment, so that many more people survive and many more people live well with and beyond a cancer diagnosis.

1.3 In Wales, 19,000 (WCISU Feb 2015) people are diagnosed with cancer every year and more than 130,000 people are currently living with or beyond cancer, almost 4.5 percent of the population. By 2030 it is expected that 250,000, almost eight percent of the Welsh population, will have been affected by a cancer diagnosis and one in two of us will be affected by cancer at some point in our lives.

1.4 The good news is that survival rates are steadily improving and many people recover. On average 70 percent[2] of Welsh residents diagnosed with cancer can expect to survive at least one year. However, improving survival rates in Wales need to be considered in the context of even better survival rates in many other European countries.

1.5 We know the NHS is struggling now to meet current demand. A transformation in the way we treat and care for patients with and beyond cancer is needed if we are to close the gap between Wales and our European counterparts. This is the challenge we all face. We must change now to meet future demand, increase quality for patients and reduce instances of unacceptable variation.

[1] "Cured But at What Cost?" Macmillan Cancer Support (2013)
[2] Welsh Cancer Intelligence and Surveillance Unit Official Statistics 2012 data. Published 10 April 2014

2. Previous work with the committee

2.1 During the fourth Assembly we welcomed the opportunity to work in partnership with the Committee to convene a number of focus groups to engage with people affected by cancer. Macmillan is a strong advocate of involving people affected by cancer in the scrutiny, development and refinement of services, utilising their first hand experiences to identify trends and drive improvements increasing consistency across Wales. We hope that this type of engagement will remain a strong feature of how the committee seeks to learn from firsthand experience and expertise during the fifth Assembly.

2.2 We welcomed the committee's exploration of a number of key elements of cancer care in Wales, including:

- Macmillan's tools to support GPs in recognising cancer at an earlier stage
- Recognition that partnerships could be improved to provide a more consistent approach to service provision in Wales
- The challenges experienced by some patients in accessing a Cancer Nurse Specialist

3. Priorities identified by the committee

3.1 We welcome the priorities highlighted by the committee at present and feel many of these correspond with Macmillan's work in Wales. In particular the areas of; integration of health and social care, waiting times, primary care, efficiency within the NHS and modern management practices, ambulance services, loneliness and isolation among older people and sport and public health have varying levels of cross-over with both our service delivery and policy work. We look forward to informing the committee on the specific challenges and opportunities in relation to cancer care in Wales within these areas.

4. Macmillan's priorities for cancer care in Wales

4.1 In responding to the legacy consultation considering the work of the committee during the fourth Assembly we provided the following feedback on priorities going forward and believe these remain relevant to informing the work of the committee:

- **Cancer must remain a top priority**, underpinned by a refresh of Welsh Government's cancer delivery plan that delivers cancer care and treatment

and outcomes which matches the best in Europe, no matter where the person lives, their age or what type of cancer they have.

- **Person centred care must be embedded** as the cornerstone of this ambition, which ensures every cancer patient receives well co-ordinated holistic care and treatment to live well with and beyond their caner, or receive high quality end of life care in the most desirable setting for that individual.

- **Strengthened and transparent national leadership and governance** to clearly set out the ambition to deliver on all elements within the cancer delivery plan both locally and nationally linked to robust monitoring and reporting mechanisms.

5. Embedding Person Centred Care

5.1 Access to a specialist cancer nurse has been shown to play a vital role in delivering high quality, person-centred care and treatment to people with cancer. Patients allocated a specialist cancer nurse are more positive about the experience of their care. The results of the Wales Cancer Patient Experience Survey evidence this.

5.2 There are a number of factors required in order to deliver person-centred care consistently and to a high quality. These are:

- Personalised and holistic needs assessments and written care planning
- Coordinated and continuity of care
- Good communication
- Timely information and support – including access to Welfare Benefits Advice services.
- Routine signposting to financial, practical and emotional support

5.3 Specialist cancer nurses are central to providing consistent, high quality person centred care. Specialist cancer nurses are part of the cancer multidisciplinary team and are usually recognised as the key worker. They use their skills and expertise in cancer care to provide physical and emotional support, coordinate services and to inform and advise patients on clinical as well as practical issues, leading to better patient outcomes.

6. End of Life Care

6.1 Macmillan expects Welsh Government to be committed to the delivery of **high quality palliative and end of life care**. For people who are no longer curative and are dying from cancer, their ongoing care and treatment needs to be planned holistically. With the support of primary care and through advance care planning, every effort should be made to ensure that people are cared for and, wherever possible, are able to die in the place of their choice. Avoidable emergency admissions to hospital during this stage of illness should also be prevented where possible.

6.2 **Advance Care Planning (ACP)** is an important tool to understand people's wishes, needs and preferences at the end of life and facilitates planning to meet them. Sadly, if people are not identified as approaching the end of life, and professionals do not initiate conversations to understand peoples' needs and preferences, it is less likely that plans can be put in place to meet those needs. There is evidence to suggest that the use of processes such as ACP to establish a person's wishes around their care at end of life can increase the likelihood of those wishes being met.

7. Enhancing National Leadership and Governance, Accountability

7.1 The Welsh Government's Cancer Delivery Plan should have driven national change and improvement and ensured consistency in services and standards for patients throughout Wales. The Chief Executive of NHS Wales stated in the Foreword ***'I will hold LHBs to account on the outcomes they deliver for their populations'.*** This has not happened across Wales across all themes on a consistent basis, producing variation in experiences and outcomes for patients.

7.2 The strategic direction set out in the Cancer Delivery Plan was widely welcomed in 2012 but its operational implementation to date has been limited. Although a number of standards and targets were identified within the plan, monitoring against all of the objectives set out in it have not been met. In addition, there is still no comprehensive national plan which clearly sets out how and when all of the aspirations in the Cancer Delivery Plan will be achieved over time or the milestones which have been set for measuring progress along the way.

7.3 Furthermore, consequences of non-compliance e.g. against NICE guidance, cancer and peer review standards and other policy targets by individual NHS organisations have not been properly addressed (or seen to be addressed) due to lack of clarity about governance, self reporting processes and absence of any real levers that drive action and change. There is insufficient rigour and grit in the current

system to systematically reduce variation and tackle performance where it is lagging or unacceptable for all cancer patients across Wales.

7.4 We also want strengthened arrangements for national governance and accountability to be implemented without which, we believe the scale and pace of reform in the NHS in Wales will languish and the aspirations to provide cancer care and outcomes that matches the best in Europe will not be possible.

7.5 We believe the **Committee should consider exploring the governance arrangements underpinning the delivery plans for acute conditions such as cancer.** We want to see transparency and accountability at the heart of these plans to ensure delivery can be positively scrutinised and supported to produce the desired outcomes for patients.

8. Conclusion

8.1 Whilst we broadly agree with the topics identified by the committee to explore further during this Assembly term we strongly believe a specific focus on the governance arrangements underpinning the implementation of delivery plans is required as a focus during the committees early work. Such scrutiny would ensure that monitoring and implementation mechanism for these plans are well understood by all.

8.2. We look forward to working with the committee on an ongoing basis to ensure first hand experiences of people affected by cancer are brought to the forefront of policy scrutiny and consideration.

If you would like any further information on any of the content included in this response, please contact **Lowri Griffiths (Policy & Public Affairs Manager) –** [redacted]

P 05

Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Age Cymru

Response from: Age Cymru

Y grym newydd sy'n cyfuno
The new force combining

AGE Concern Cymru

HELP THE AGED WE WILL
Help the Aged yng Nghymru
Help the Aged in Wales

Consultation Response

Priorities of the Health, Social Care and Sport Committee

August 2016

Introduction

Age Cymru is the leading charity working to improve the lives of all older people in Wales. We believe older people should be able to lead healthy and fulfilled lives, have adequate income, access to high quality services and the opportunity to shape their own future. We seek to provide a strong voice for all older people in Wales and to raise awareness of the issues of importance to them.

We are pleased to respond to the Health, Social Care and Sport Committee's consultation on its future priorities. We have ordered our response to focus on priorities for the first 12-18 months of the Committee's work and then comments on the potential longer-term work programme for the second half of the Fifth Assembly.

Priorities for the first 12-18 months:

- We welcome the committee's decision to look immediately at the issues of winter preparedness and the sustainability of the health and social care workforce in Wales. The issue of excess winter mortality disproportionately affects older people, for example through avoidable slips, trips and falls or due to cutting back on heating out of fear of the cost. We will respond separately to the call for evidence to this inquiry.
- The sustainability of the health and social care workforce is an issue of central relevance to the older people of Wales. We therefore welcome the Committee's commitment to an inquiry investigating the resilience of the current and future workforce to ensure that it is fit for purpose and sustainable into the future.
- With regard to other priorities that we would be keen to see the Committee pursue in its initial period, the sustainability of social care funding continues to be an issue of considerable concern. We note that it has not been outlined in the initial discussions for the longer-term work programme. Whilst we acknowledge that the Health and Social Care Committee of the Fourth Assembly did a considerable amount of work on social care legislation and policy, this was largely led by the legislative programme and did not directly address the question of funding and sustainability. We note from a recent release of National Strategic Indicators from Statistics for Wales that the rate of older people supported in care homes by local authorities has declined. However, the rate of older people being supported in the community has also declined[1], suggesting that funding squeezes are impacting on the care of vulnerable older people. This is a cause of considerable concern for us, given that Wales has an ageing population and that the Welsh Government's stated objective is for older people to be given care support in the community in order to delay or prevent the need for residential or nursing care. If

[1] Welsh Government (29 June 2016): National Strategic Indicators, 2014-15 Revised

people are not provided with sufficient and timely social care support this can result in growing pressure upon the NHS.

Priorities for the second half of the Fifth Assembly:

- We welcome the Committee's intention to look at the issue of integration of health and social care services. Improved integration of health and social care, with the aim of providing a person-centred service was a key ask of the Age Cymru 2016 National Assembly for Wales manifesto. We would like to see any such inquiry cover the operation of intermediate care services in Wales and the impact that the Intermediate Care Fund has had on helping keep older and vulnerable people out of hospital and in their own home.
- Likewise, we welcome the intention to hold an inquiry into the issue of loneliness and isolation among older people. This is an increasingly important issue for older people. We recognise this issue potentially cuts across the work of more than one Assembly committee, for example because many of the issues that contribution to greater social isolation of older people (which may contribute to their feelings of loneliness) derive from the broader social and environmental context in which older people live, for example cuts to transport services and closure of community assets and facilities that older people were using where they would have benefited from contact with other people. However, it is widely accepted that feelings of loneliness can impact negatively upon both physical and mental health. Tackling loneliness in a preventative fashion would therefore have beneficial impacts for both the individuals affected and potentially the health and social care services that end up supporting them.
- We are pleased to see the Committee's intention to look at the use of antipsychotic medication in care homes. However, we note from both the Andrews Report (Trusted to Care) and the Tawel Fan inquiry that the inappropriate use of antipsychotic medication, especially for people living with dementia, is not restricted to care homes and we would therefore encourage the Committee to look at the issue in this broader context.
- We would recommend that in the second half of the Fifth Assembly the Committee consider reviewing the initial impact of the Welsh Government's dementia strategy which it is proposing to release at the end of 2016. Age Cymru carried out the research that underpinned the Older People's Commissioner's 'More than Words' report and we believe it is essential that significant improvements are made to the quality of life for people living with dementia in Wales and their carers. Monitoring the implementation of the Welsh Government's strategy is a key element in ensuring improvements are taking place.
- Finally, we believe it is imperative that in the second half of the Fifth Assembly that the Committee consider the effectiveness of the implementation of the Social Services and Well-being (Wales) Act 2014. In fact we were surprised to see this topic absent from the list of priorities initially discussed for the longer-term work plan. If there is to be a significant shift towards a preventative agenda, with consequent positive impacts for both health and social care services in Wales, it is essential that the implementation of the Act is scrutinised to ensure that it is having the intended effect. For example the provision of appropriate and accurate information and advice, the operation of the eligibility criteria and the commissioning and use of advocacy should be kept under review to ensure that the preventative ethos is being embedded in practice.

We hope these comments are useful and would be more than happy to provide further information if required.

P 06
Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Claire Kay
Response from: Claire Kay

[Via email]

Priorities for Health, Social Care & Sport Committee Consultation

To Whom it may concern,

I have just been sent a link to this Consultation, but I am unsure exactly how to present my views, so I shall write them here & ask that they are included in the consultation please.

I founded & lead a small Community Organisation with limited private funding in North Wales called Birth Story Listeners.

Our priority is to offer Peer Support & encouragement to women in North Wales (specifically Conwy County, North Gwynedd & parts of Anglesey) who experienced a distressing or traumatic birth & have gone on to develop symptoms of PTSD, Anxiety or PND, or for whom these symptoms have developed as a postnatal illness.

We offer a facebook support group, one-to-one meetings with myself where members can share their birth experiences, & a small Peer Support Group meeting in local café's where our Mums can connect with one another to reduce isolation & to gain encouragement & support.

I also campaign to reduce the likelihood of birth trauma developing by giving talks to student midwives at Bangor University, by writing a campaign poem about perinatal PTSD following user research at the Birth Trauma Association which has been read out at various maternity Services conferences, & writing a booklet called 'mental health matters' to fill the void of information available to pregnant women in regards to looking after their mental health.

In the coming couple of years I would like to see much more of an emphasis placed on perinatal mental health by the Health Board with a campaign for it to be 'of equal status as physical health during that perinatal period.' This also means that any consultations in relation to proposed changes to maternity services in this region should place the impact of those changes to women's mental health as a top priority rather than an afterthought.

I would like to see more investment & partner working across the region in terms of promoting mental wellbeing in the perinatal period.

I would also like to see Health Professionals educated to a much higher standard about the importance of protecting mental health & wellbeing, & recognising the symptoms of illness should they occur.

Please could you pass this on to the relevant parties.

Diolch yn fawr,

Claire Kay.

P 07
Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: UK Public Health Register
Response from: UK Public Health Register

23 August 2016

National Assembly for Wales – Priorities for the Health, Social Care and Sport Committee – UKPHR's response to the Committee's consultation

Introduction

UK Public Health Register (UKPHR) welcomes the opportunity to contribute to the consultation on the priorities for the Health, Social Care and Sport Committee during the Fifth Assembly.

UKPHR urges the Committee to adopt an approach which draws together health and social and primary care and examines them through the prism of public health. The aim would be to "go upstream" and devise a preventive approach delivered not just by Wales' core public health workforce but engaging the wider workforce, carers and communities also.

Background

UKPHR was set up as a result of a Tri-Partite public health community initiative, supported by the Department of Health and the Chief Medical Officer, Liam Donaldson in 2003. Today UKPHR's register is accredited by the Professional Standards Authority and registers public health specialists, public health practitioners and public health specialty registrars.

Public health practice requires population based approaches to address wider determinants of health and health inequalities. By its very nature, public health practice requires multidisciplinary approaches and therefore a multidisciplinary workforce. UKPHR's register brings together this diverse multidisciplinary workforce in one regulatory "home".

Wales has always been committed to the success of UKPHR - the very first registrant, a public health specialist, was from Wales. The first public health practitioner we registered was from Wales. The first Specialty Registrar we registered was from Wales.

A preventive approach - public health practice

Wales has experienced a strong track record in improving and protecting the population's health. However, people are generally living longer and this is resulting in new challenges facing the health and social and primary care systems. For example, £73m is the cost of obesity to the NHS in Wales, according to an academic study commissioned by the Welsh Assembly Government.

A shift in focus from tackling illness to prevention can lessen the otherwise predictable growth in the strain on health and social care budgets affecting both the NHS and local authorities. It is also the socially just course for Welsh society – tackling health inequalities and promoting not only longer lives but also healthier longer lives.

The strategic framework, *Our Healthy Future* re-committed the Welsh Government to improving people's quality and length of life and ensuring that everyone has a fair chance to lead a health life.

Its vision includes:

- Providing children and young people a good start in life that supports their long-term health and wellbeing.
- Inspiring everyone to achieve a healthy and fulfilling working life.
- Providing older people the knowledge, skills or support to make informed choices about living independent and fulfilled lives.
- Improving the level of health of individuals experiencing greatest disadvantage to the levels found among the more advantaged.
- Supporting healthy sustainable communities – places where people want to live, work, play and flourish – are sought for all.
- ***Ensuring health and social services place greater emphasis on prevention and early intervention.****
- ***Health and wellbeing as a shared goal for all.****
- ***Public health policies and interventions that are based on good evidence and monitored. ****

*** Our emphasis*.

Obesity has become more prevalent since the Welsh Health Survey started in 2003/4 and to date there has been no sign that this trend will be turned around without a radical upgrade in prevention and public health.

In holding the Welsh Government to account in relation to improving public health in general and reducing obesity levels in particular, UKPHR believes that the Committee should champion a public health approach which:

- Engages the wider workforce, carers and communities in a consistent, holistic preventive programme (demonstrating the strategy is joined up);
- Applies evidence and innovation in support of the programme (demonstrating determination to use all the right tools);
- Puts public sector organisations at the forefront of implementation including across health and social and primary care settings (demonstrating leadership and setting an example); and
- Invests in the skills, competence and commitment of Wales' core public health workforce (demonstrating commitment to quality of services).

The Public Health Workforce

Creating a healthier, happier and fairer Wales for everyone[1], introduced the strategy for Public Health Wales (PHW) for 2015-18. One of the seven priorities outlined in the document is 'Making sure our workforce is doing its best for you'. It has been identified that the public health workforce in Wales should be supported to ensure they achieve excellence in their respective roles and that the best possible workforce is recruited and retained.

[1] http://www.wales.nhs.uk/sitesplus/documents/888/PHW%20Introducing%20the%20strategic%20plan%20booklet%20E.pdf

It is important for public policy makers to recognise the central and vital role of the core public health workforce in the commissioning, co-ordinating and delivery of effective public health interventions and services.

Now more than ever, the public health workforce is required to work in diverse settings and bring to bear a range of complementary disciplines. The professional standards, competence and commitment of all who work in public health are vital components in ensuring that the public's health is protected, improved and cared for.

The role of the senior leadership group is particularly demanding: demonstrating by example the multidisciplinary skills and knowledge of the public health workforce, advocating for public health and working with partner organisations to make every contact count in the delivery of holistic and consistent public health interventions.

UKPHR registration is an assurance of competence of the public health specialists who comprise this senior leadership group. Registration is open to those completing the Speciality Training Programme, those who are GMC-registered or GDC-listed as specialists in public health and those who achieve registration by way of retrospective portfolio assessment.

UKPHR also registers public health practitioners. Achievement of practitioner registration gives public health employers assurance that this registered front line workforce is competent to work autonomously (equivalent to Level 5 and above in the Public Health Skills & Knowledge Framework). However UKPHR practitioner registration is currently not included as a desirable criteria in all job descriptions and person specifications. This should change if employers, policy makers and the public are to be assured that public health practitioners, comprising the overwhelming majority of the core public health workforce, are competent to practice and possess knowledge and skills that are fit for purpose.

In many respects, UKPHR's practitioner registrants are also leaders. They have roles in managing other public staff, in public engagement and working collaboratively with others.

Arising out of PHW's experience of practitioner registration, the Professional and Organisational Development Team at PHW has developed a means of recognising advanced practice in public health. This is aimed towards those in the practitioner workforce who have developed additional skills and knowledge and taken on additional responsibilities, including roles in management of public health services and partnerships.

We are grateful to our colleagues in PHW for setting up this pilot which we believe has the potential to improve a distinctive public health career ladder and contribute in future to a making careers in public health all the more attractive to talented people seeking careers which will be challenging and satisfying.

UKPHR recognises the importance of ensuring that registrants who establish their competence in public health practice at the time when they achieve registration thereafter maintain and enhance their skills, knowledge and competence. We provide for this by applying mandatory standards for continuing professional development (CPD) and revalidation.

Registration of the public health workforce is increasingly bringing greater appreciation and visibility of this valuable workforce. It is also of interest to the wider workforce – people who may be delivering public health interventions but do not see their current jobs as "public health" – providing an encouragement to consider a career more directly in public health.

In conclusion

UKPHR wishes the Committee well in its work and hopes that a more comprehensive strategy and implementation plan for a preventive and public health approach in Wales will be something the Committee will work for.

UKPHR urges the Committee to recognise the crucial contribution which the core public health workforce already makes to improve the public's health and wellbeing and reduce health inequalities in Wales. With greater attention and investment, this workforce can be even more effective and impactful and help the Committee to achieve more ambitious goals in health and social and primary care.

Registration by UKPHR offers assurance to employers, policy makers and the public of the competence of this key core workforce.

UKPHR would suggest that promotion of registration of this workforce by public policy makers and public health employers fits with the objectives both of the Committee and also Public Health Wales.

Evaluations[2] and leadership perspectives[3] on practitioner registration in PHW to date reinforce the view that participating in the process of public health practitioner registration positions PHW all the better to be able to plan and implement public health measures.

Contact
Please address all enquiries about this communication to:
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18c Mclaren Building, 46, Priory Queensway, BIRMINGHAM B4 7LR
Tel. 0121 296 4370 d.kidney@ukphr.org

[2] http://www.ukphr.org/wp-content/uploads/2014/06/EvaluationWalesExecSummary.pdf
[3] http://www.ukphr.org/wp-content/uploads/2014/06/EvaluationPHWPHleadersviews.pdf

P 08
Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Comisiynydd Pobl Hŷn Cymru
Response from: Older People's Commissioner

Older People's Commissioner for Wales
Comisiynydd Pobl Hŷn Cymru

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Dai Lloyd AM
Chair
Health, Social Care and Sport Committee
National Assembly for Wales
Cardiff
CF99 1NA

26 August 2016

Dear Dai Lloyd AM,

Priorities for the Health, Social Care and Sport Committee

I am writing in response to the opportunity to comment on the priorities of the Health, Social Care and Sport Committee.

I welcome the priorities that the Committee has already identified, many of which are highly relevant to the lives of older people across Wales. However, there are four areas in particular which are very closely aligned to my own forward work plan and Framework for Action, and I would strongly support the Committee undertaking work in these areas.

Integration of Health and Social Care services:

Previous work that I have undertaken into the integration of health and social care services and the impact on older people can be found here.

Primary Care:

I am currently undertaking work to understand older people's access to and experiences of GP services, through group discussion sessions and a questionnaire. I will publish a report in early 2017. Therefore, I feel that work by the Committee in this area would be well placed after the publication of my report.

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Use of antipsychotic medication in care homes:

The Committee rightly identifies the concerns that I raised about the inappropriate use of antipsychotics in my care home review. The proposal for the Committee to assess the scale of the problem, and examine possible solutions is to be welcomed. I will be undertaking a 'care home review follow up' over the next year.

Loneliness and isolation among older people:

The Committee rightly identifies the concerns that I raised regarding levels of loneliness and isolation amongst older people, which should be seen as a key public health issue. Loneliness and isolation is one of the five key strands of the Ageing Well in Wales programme, for which I am Chair. Further information can be found here.

Please follow these links to a briefing outlining my own forward work plan, my Impact and Reach Report 2015-16 and Framework for Action as these may provide useful background information to the Committee's work. Do let me know if you would like a further discussion about any of the work I have identified in this letter as the Committee's planning takes place.

Yours sincerely,

Sarah Rochira

Sarah Rochira
Older People's Commissioner for Wales

P 09
Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Coleg Brenhinol Pediatreg ac Iechyd Plant
Response from: Royal College of Paediatrics and Child Health

Consultation: Priorities for the Health, Social Care and Sport Committee
Response from the Royal College of Paediatrics and Child Health (RCPCH)

In order to help inform its Forward Work Programme, the Committee is interested in hearing your views on what the priorities of the Committee should be during the Fifth Assembly. In particular, the Committee is keen to learn what you see as the key priority areas that should be considered during the next 12 to 18 months.

1. Who we are

1.1. The Royal College of Paediatrics and Child Health (RCPCH) works to transform child health through knowledge, innovation and expertise. We have over 550 members in Wales and over 17,000 worldwide. The College is responsible for training and examining paediatricians. We also advocate on behalf of our members, represent their views and draw upon their expertise to inform policy development and the maintenance of professional standards.

1.2 For further information please contact Gethin Jones, External Affairs Manager for Wales: gethin.jones@rcpch.ac.uk or 029 2045 5414.

2. Our priorities for the Health, Social Care and Sport Committee

2.1 Our priority for the Health, Social Care and Sport Committee is to consider the impact of Welsh Government policy, legislation and expenditure on the health and wellbeing of children and young people in Wales. We would urge the Committee to examine the need for a cross-departmental child health strategy, given that policy, legislation and expenditure that will have an impact on child health is spread across many areas of government. We would encourage the Committee to consider, in particular, the following:

3. Prevention and Early Intervention

3.1 Children who enjoy better health and wellbeing now will grow up to be resilient adults. In addition to the benefit to the population this also means reduced pressure on the health service and all public services that children and families use. With more than a quarter of children in Wales at reception age overweight or obese[1] and most adult mental health problems starting in childhood[2], early intervention and prevention for children's mental and physical health is crucial. We would like to see the Committee scrutinise Welsh Government plans for prevention and early intervention and ensure this is a priority. In particular, we would like the Committee to:

[1] NHS Wales, Child Measurement Programme for Wales Report 2011/12
http://www.wales.nhs.uk/sitesplus/documents/888/Child%20Measurement%20report%20(Eng).pdf
[2] See Chapter 13 p3 and Annex 9 p11 Our Children Deserve Better: Prevention Pays (Annual Report of the Chief Medical Officer 2012)
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/255237/2901304_CMO_complete_low_res_accessible.pdf

- Hold the Welsh Government to account on action to reduce consumption of food and drinks high in fat, sugar and salt
- Scrutinise Welsh Government plans relating to the introduction of evidence-based personal and social education (PSE) programmes across primary and secondary schools covering social inclusion, bullying, drug and alcohol use, mental health and healthy relationships that foster children's social and emotional health and wellbeing
- Call for the timely publication and implementation of the 2016-19 Together for Mental Health Delivery Plan and ensure that the multi-agency Together 4 Children and Young People project is effective in delivering Together for Mental Health objectives as they relate to children and young people.

4. Tackling Child Health Inequalities

4.1 Poverty, inequality and where a family lives have a direct relationship with child health. Child death rates in the most deprived parts of Wales are 70% higher than in the least deprived parts[3]. Every opportunity must be taken to reduce inequalities to improve the health of children and young people in Wales. We ask that the Committee makes holding the Welsh Government to account on reducing child health inequality a priority. Specific areas that require scrutiny include:

- Ensuring that the Welsh Government delivers parity of esteem for child mental and physical health
- Establishing what plans there are to improve support for children with medical needs in education settings and how all schools can be made to comply with these plans, challenging the Welsh Government on how this can be ensured in the absence of a mandatory duty on schools to do so
- What plans there are to address the known risk groups and factors to reduce child deaths across all ages[4], ideally as part of a cross-departmental child health strategy.

5. Involving children and young people in decision making in Wales

5.1 At present the voice of children and young people and their families is often lost within the adult-centric nature of health and social care provision. Children's services are not a bolt-on to adult services and should be co-produced with children and young people. Their voices must be heard and listened to with their views given due weight. We would urge the Committee to establish how the Welsh Government will achieve this. Again, we would suggest specific actions:

- We would urge that the Committee itself engages directly with the views of children and young people across Wales to ensure they are included in decisions about their health and wellbeing
- We would also suggest that the Committee scrutinises the collection and use of data we have about child health and wellbeing. Currently, the National Survey for Wales does not

[3] Public Health Wales Child Health Review Programme 2014
http://www.wales.nhs.uk/sitesplus/documents/888/38446%20PHW%20CDR%20Annual%20Review%20E.PDF
[4] See RCPCH Why Children Die report http://www.rcpch.ac.uk/news-campaigns/campaigns/why-children-die/why-children-die-rcpch-campaign

include children under 16 years old and does not take survey responses directly from children.

6. A joint commitment on health for children and young people

6.1 Integrating all care around the needs of children, young people and their families is crucial to improving health outcomes. Working across professional and service boundaries should be the norm for all those who work with children and young people. We would urge the Committee to scrutinise work across government departments and hold government to account collectively if action on child health is not joined up.

6.2 We also need to address the paediatric workforce across Wales, which is facing considerable pressures in recruiting and retaining paediatricians and addressing shortfalls. The Committee has a role in scrutinising the Welsh Government's successes or otherwise in recruiting and retaining paediatricians.

6.3 We would suggest specific actions by the Committee to:

- Make the case for a cross-governmental child health strategy
- Scrutinise the work and success of Public Health Wales in raising awareness of unexpected sudden infant deaths and of known risk factors such as parental smoking; and to increase awareness of safe sleeping habits
- Scrutinise the effectiveness of measures to address shortfalls in the paediatric and child health workforce
- Scrutinise the implementation of the RCPCH's Facing the Future: Standards for Acute General Paediatric Services and Facing the Future: Together for Child Health Standards.

7. Areas the Committee may wish to include in its longer term work programme, based on initial, informal discussions.

Neonatal services:
The Fourth Assembly's Children, Young People and Education Committee previously reported on neonatal services. The Committee could undertake an inquiry to monitor progress, specifically looking at ongoing concerns about staffing and the sustainability of services.

7.1 A recent report by Bliss showed that services for premature and sick babies in Wales are facing staffing shortages, putting babies' safety and long-term health at risk. RCPCH will publish the annual National Neonatal Audit Project (NNAP) report in late September, which covers Wales, Scotland and England.

7.2 We would recommend that the Committee engages with both of these reports to scrutinise the effectiveness of neonatal services in Wales overall, as well as progress on the Fourth Assembly's Children, Young People and Education Committee report on this. RCPCH can brief members of the Committee after publication of the NNAP report and would welcome the opportunity to do so.

Sport and public health:
The Welsh Health Survey 2015 shows that obesity levels in Wales have increased since the 2014 survey, with 24% of adults classified as obese and 59% of adults classified as overweight or obese. 58% of adults reported doing at least 150 minutes of at least moderate intensity physical activity, in blocks of 10 minutes or more, in the previous week.
Given the inclusion of sport in the health portfolio, the Committee could examine its potential health benefits and the role of NHS Wales in promoting sport and physical activity generally.

7.3 More than a quarter of children in Wales at reception age are overweight and obese[5]. With this in mind, we would ask that the Committee looks at the benefit of sport and physical activity for children and young people as well as adults.

7.4 We need joined up action across Welsh Government to make the necessary changes. We have called for action to ensure that local authority planning decisions include a public health impact assessment to consider the likely impact of planning decisions on, for example, physical activity and obesity. We have also suggested that tax powers being devolved to Wales should introduce further levies on food and drinks high in fat, sugar and salt.

7.5 We would encourage the Committee to scrutinise the child health outcomes of Welsh Government policy and expenditure across the board, taking a particular interest in levels of physical activity and actions to reduce childhood obesity.

References

Facing the Future: Standards for Acute General Paediatric Services
http://www.rcpch.ac.uk/facingthefuture

Facing the Future: Together for Child Health http://www.rcpch.ac.uk/facing-future-together-child-health

Why Children Die report http://www.rcpch.ac.uk/news-campaigns/campaigns/why-children-die/why-children-die-rcpch-campaign

Consultation on Together for Mental Health Delivery Plan 2016 - 19
http://gov.wales/consultations/healthsocialcare/delivery-plan/?lang=en

Together for Children and Young People
http://www.wales.nhs.uk/togetherforchildrenandyoungpeople

Bliss Baby Report 2016 http://www.bliss.org.uk/campaigns-and-policy-reports

National Neonatal Audit Project (NNAP) http://www.rcpch.ac.uk/improving-child-health/quality-improvement-and-clinical-audit/national-neonatal-audit-programme-nn-3

[5] NHS Wales, Child Measurement Programme for Wales Report 2011/12
http://www.wales.nhs.uk/sitesplus/documents/888/Child%20Measurement%20report%20(Eng).pdf

P 10
Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Ymddiriedolaeth Canser yr Arddegau
Response from: Teenage Cancer Trust

www.teenagecancertrust.org

Teenage Cancer Trust response to Health, Social Care and Sport Committee consultation on priorities

Contact: Caroline Brocklehurst, Policy Manager, Teenage Cancer Trust
c.brocklehurst@teenagecancertrust.org
020 7612 0724

1. Introduction to Teenage Cancer Trust

1.1 Teenage Cancer Trust is the only UK charity dedicated to improving the quality of life and outcomes for the seven young people aged between 13 and 24 diagnosed with cancer every day. We fund and build specialist units in NHS hospitals and provide dedicated staff, including specialist nurses and Youth Support Coordinators. The units bring young people together so they can be treated by teenage cancer experts in the best place for them.

1.2 Through education of young people about the signs of cancer and working with health professionals to improve their knowledge, we seek to significantly improve their diagnosis experience. And through our own research and working with our partners in the NHS, across the UK governments, and organisations both nationally and internationally, we strive to improve outcomes for young people.

1.3 Around 2,500 young people are diagnosed with cancer each year across the UK[1]. In Wales approximately 114 new patients will be diagnosed annually, while around the same number again will continue to receive care for cancer or relapse[2]. These patients will be treated at the Teenage Cancer Trust unit at the Principal Treatment Centre for cancer, University Hospital Wales in Cardiff, or their may receive care within a local hospital.

1.4 We are proposing one key area for the Health, Sport and Social Care Committee to consider for its future work programme. Improving access to age-appropriate services for teenagers and young adults with cancer will make a significant, positive impact on the lives of young cancer patients in Wales and we would welcome the Committee's attention on this matter.

2. Access to age-appropriate services for young people with cancer

2.1 In 2005, the National Institute for Health and Clinical Excellence (NICE) published their guidance on Improving Outcomes for Children and Young People with Cancer[3] which is recognised as best practice across England and Wales. The guidance stipulates that, following diagnosis, all young people with cancer should be notified to the Teenage and Young Adult Multi-Disciplinary Team (TYAMDT) at their nearest Principal Treatment Centre, in order to ensure they can access the best possible treatments and specialist support. The importance of this pathway was also highlighted in the 2012 National Standards for Cancer in Teenagers and Young Adults (TYA) in Wales. Providing a framework for the delivery of NICE Guidance for this age group, the TYA Standard lays out areas for focus across the whole care pathway for young people with cancer, including staffing needs and treatment requirements.

[1] Cancer Research UK (2013), Cancer Stats Report: Teenage and young adult cancer
[2] Cancer Research UK (2013), Cancer Stats Report: Teenage and young adult cancer
[3] National Institute for Health and Clinical Excellence (2005), Guidance on Cancer Services: Improving Outcomes in Children and Young People with Cancer

2.2 Despite these standards being adopted in Wales, we know that currently this referral only occurs in around half of all cases[4], meaning that many young people are missing out on the care and support they deserve.

2.3 Increased notifications and referrals of young people with cancer to TYAMDTs will enable the NHS to deliver against the Wales Cancer Delivery Plan and National Standards, also make a tangible difference to the lives of young people. Referral to the TYAMDT at University Hospital Wales in Cardiff, where Teenage Cancer Trust's unit is based, is the best way for young people with cancer in Wales to access holistic support from specialist staff, be informed of and recruited to clinical trials, and benefit from age-appropriate facilities.

2.4 Teenage Cancer Trust and CLIC Sargent have been working together to raise awareness of this issue, and we support their separate submission to the Committee on this topic. We have written together to the Cabinet Secretary for Health, Wellbeing and Sport on this issue (the text of this letter is pasted below).

Dear Mr Gething

Congratulations on your re-election and appointment as Cabinet Secretary, it's great to have someone with your background and knowledge about cancer services in Wales in this important role and we very much look forward to working with you.

Teenage Cancer Trust and CLIC Sargent are the two largest charities representing the needs of children and young people with cancer in Wales and across the UK. We are members of the Wales Cancer Alliance and work in partnership to influence policy and deliver in practice to ensure all children and young people with cancer have access to services that meet their needs and support them to live their lives to their full potential.

The next few years are critical to embedding changes in Welsh Cancer Services that could make real improvements for young people with cancer and their families; and there is much to be done. There are around 180 new diagnoses of cancer each year in 0-24 year olds, with many more on active treatment at any one time. Although survival rates are over 80% on average cancer remains the single largest cause of death from disease in children in the UK and for some cancers survival is as low as 50%. Very few young people are being picked up by traditional methods of assessing services, like peer review and the Cancer Patient Experience Survey, and many children and young people are having to travel hundreds of miles from home to access support.

We've been very disappointed that children, teenagers and young adults have had so little focus in the Cancer Delivery Plan and lack of priority gives to these areas of improvement. This must change in order for young people with cancer to have their needs met.

A commitment from the Welsh Government to referring every patient to a paediatric or teenage and young adult MDT should be made a priority for health boards which they are measured against. This one commitment will help NHS services know where each patient is, be able to offer them support and access to research as well as follow up with them after treatment. It will also enable us, as charities, to provide much needed specialist care and support to them through our work with the MDTs are the designated Principal Treatment Centres.

[4] O'Hara C, Khan S, Flatt G, North West Cancer Intelligence Service (2011), How many teenagers and young adults with cancer are being referred to specialist care in England?

We call on you to champion the needs of this vulnerable group of patients who too often fall between services and priorities leaving them disadvantaged and missing out on support that is available to them.

If you would like to meet to discuss this then we are very happy to do this at your convenience. We're aware the Cancer Delivery Plan is due to be refreshed and so are keen that this one commitment is part of any new plan or strategy.

2.5 In order to ensure improvements in outcomes for teenagers and young adults with cancer in Wales it is essential that action is taken to ensure that the recommendation for referral to specialist age-appropriate care and support is enforced. This is the single most important action that could be taken on behalf of young people with cancer in Wales. Without proper monitoring and evaluation of Health Board activity to ensure they are held to account for referrals of 16-24 year olds to the appropriate TYA MDT, experience and outcomes cannot be improved for this patient group. Young people will also not be able to access specialist support services or relevant clinical trials until this is achieved.

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Diabetes UK Cymru
Response from: Diabetes UK Cymru

Dear Members of the Health, Social Care & Sport Committee,

We are the leading charity in diabetes in the UK. Diabetes prevalence in Wales is currently 7.1% of the population aged 17 and over. This means that 183,000 people in Wales are living with diabetes. It is estimated that approximately 60,000 people in Wales have undiagnosed diabetes.

90% of people living with diabetes have Type 2 diabetes and 10% have Type 1 diabetes. 1,500 children and young people have Type 1 diabetes in Wales.

Diabetes accounts for 10 per cent of the annual NHS Wales budget. This is approximately £500m a year. Eighty per cent of this figure is spent on managing complications, most of which could be prevented.

Since the introduction of *Together for Health: A Diabetes Delivery Plan*, we have welcomed the focus and progress in improving diabetes services and systems in Wales. However, we believe that there are some areas that require reform to make a real difference to children and young people living with diabetes in Wales. We have detailed these below for the Committee's considerations and have attached our latest report for background and evidence.

1. Medical needs in schools:

There is a need for a change in legislation in Wales to introduce a statutory duty of care for children with medical needs in schools. There is an opportunity to include this within the newly proposed Additional Learning Needs (ALN) Framework.

The Welsh Government's proposed ALN Framework documentation states that children with medical needs will not be covered by the ALN Bill (see page 30 of the draft ALN Code of Practice).

We ask the Committee to consider the inclusion of medical needs in the Additional Learning Needs Framework.

The current guidance frameworks for the management of medical conditions, including Type 1 diabetes, in a school setting differ in Wales and England. In England, the Children and Families Act 2014 came into force on 1 September 2014. Section 100 contains a statutory duty to support pupils with medical conditions, meaning that in practice schools **must** make additional arrangements for supporting pupils at schools with medical conditions.

The legislation does not apply to schools in Wales. The rights of children and young people with medical needs in Wales during the school day are not protected in law to the same level as children in England. The current system in Wales puts children with medical conditions in Wales at an academic disadvantage in comparison to their peers in England

and does not protect them whilst they are at school. We regularly receive enquiries from families of children whose attendance, attainment and overall educational experiences are compromised because of their condition and the lack of guaranteed support from the current framework. It is vital that children are kept safe and healthy whilst they are learning to enable them to achieve their full potential.

Providing support to children and young people with Type 1 diabetes to enable them to participate in all aspects of school life requires a co-ordinated effort. As a patient organisation, we represent the views of families affected by Type 1 diabetes at school. We attach our recent evidence report, "An Excellent Chance: Type 1 diabetes in schools in Wales" to this consultation response.

It includes evidence from families and healthcare professionals showing that there is a need to support children and young people with diabetes in schools. We ask that you read the report with a focus on the Executive Summary. The report is co-authored by the Children and Young People's Wales Diabetes Network, as well as senior paediatric clinicians in Wales.

We ask the Committee to consider the current situation and ask whether there is a need to bring the rights, support and protection provided to children and young people living with Type 1 diabetes in Wales in line with those in England.

There is currently a unique and rare legislative opportunity to do this during this Government's legislative programme.

2. Early diagnosis of Type 1 diabetes in primary care:

There are 1,500 children with Type 1 diabetes in Wales and each year approximately 100-150 are newly diagnosed. Around 15 per cent of cases of Type 1 diabetes in children are diagnosed after they develop life-threatening Diabetic Ketoacidosis (DKA). This rises to 24% for children under the age of five. To avoid DKA, it is crucial that Type 1 diabetes is identified early and treatment is administered as quickly as possible.

Early identification and symptom recognition are key to the prompt diagnosis of Type 1 diabetes. For this reason, it is vital that healthcare professionals across Wales, particularly GPs and other frontline staff working in a community setting, are made aware of the symptoms.

Since the death of Cardiff teenager, 13 year old Peter Baldwin in January 2015, we have been working with the Baldwin family to raise awareness of the identification of Type 1 diabetes.

The Petitions Committee is currently considering Petition P-04-682 – Routine Screening for Type 1 Diabetes in Children and Young People (http://www.senedd.assembly.wales/mgIssueHistoryHome.aspx?IId=14661).

The petition has received 2,750 signatures in Wales. An associated petition to the UK Government received 3,670 signatures and was presented to Downing Street by the family

earlier this year.

From the transcript of the Petitions Committee's first meeting to discuss the petition, we believe that there is a possibility that this petition may be referred to you or to the Health, Social Care and Sports Committee for further consideration as an important policy area.

Type 1 diabetes in schools in Wales - "An Excellent Chance"

March 2016

Sara Moran – Diabetes UK Cymru
Dr Justin Warner – Lead Consultant in Paediatric Diabetes (Cardiff & Vale University Health Board), Clinical Lead for the National Paediatric Diabetes Audit for England & Wales, Diabetes UK Clinical Champion for Paediatric Diabetes
Jon Matthias – National Co-ordinator, Children & Young People's Wales Diabetes Network

Executive Summary

Providing support to children with Type 1 diabetes to enable them to participate in all aspects of school life requires a co-ordinated effort. This report provides evidence that there is an unmet need for an enhanced diabetes educational requirement to support children and young people with diabetes in schools.

Type 1 diabetes is the most common metabolic disorder in childhood, affecting around 1,500 children and young people in Wales. Although Type 1 diabetes occurs at random, there are inequalities in outcomes that are significantly affected by socio-economic status.

Treatment regimens for Type 1 diabetes have become increasingly intensified over the last decade with proven health benefits. To maintain such benefits and reduce the risk of costly long term complications and premature death, frequent monitoring is required.

Schools, local authorities, health services and parents should work together to ensure that the needs of the child are met. The current guidance frameworks for the management of Type 1 diabetes in a school setting differ in Wales and England. In England, the Children and Families Act 2014 came into force on 1 September 2014. Section 100 contains a statutory duty to support pupils with medical conditions, meaning that in practice schools must make additional arrangements for supporting pupils at schools with medical conditions. The legislation does not apply to schools in Wales.

There is a concern that the rights of children and young people with medical needs in Wales during the school day are not protected in law to the same level as children in England, putting them at risk of an academic and health disadvantage in comparison.

Evidence gathered from two surveys (one for families and one for healthcare professionals caring for children with diabetes), the experiences of nearly 200 families who have contacted Diabetes UK's bespoke Care in Schools helpline across the UK and a number of physical meetings with family groups across Wales has provided an overwhelming picture of unmet need for children with diabetes during the school day that requires urgent attention.

When families in Wales were asked how often their child's diabetes disrupts their school day:

- 39% stated more than once a day.
- 51% advised that they have had an issue with the care provided by their child's school.
- 36% reported that their child had been sent home early or withdrawn from school because of their diabetes and
- 4% had been forced to move their child to a different school.

Many families report experiencing exclusionary measures that prevent a child with Type 1 diabetes from participating in after school clubs, sports and school trips, which could contravene disability discrimination legislation.

Many schools in Wales appear to rely on high levels of parental involvement:

- 62% of parents have stayed at home from their own work because of issues relating to their child's diabetes and
- 53% have had to leave their own work place during working hours to attend their child's school.

There are issues relating to low awareness, understanding and confidence of school staff in managing Type 1 diabetes:

- 33% of parents have been told by their child's school that they experience a lack of support and information on providing care to a child with the condition.

From the survey of healthcare professionals in Wales:

- 88% of professionals have experienced school staff being reluctant to inject insulin;
- 75% have experienced school staff being reluctant to calculate insulin dosage levels on insulin pumps;
- 63% have experienced school staff being reluctant to perform essential blood tests; and
- 75% reported that school staff have concerns about a child with diabetes participating in activities, school trips and Physical Education (PE) lessons.

Healthcare professionals report that many schools have applied restrictions to crucial elements of insulin treatment, with 83% reporting children with diabetes being prevented from performing diabetes related tasks unless in a designated area.

Variability in provision of care provided in schools is a profound issue. All issues raised by parents and professionals acknowledge different levels of understanding and practice in schools across Wales.

Schools regularly articulate their concerns regarding their legal position in caring for children with diabetes and view the lines of responsibility as unclear.

The Welsh Government's diabetes strategy, 'Together for Health: A Diabetes Delivery Plan (2013)', commits to providing the people of Wales with the following: "Where diabetes does occur, an excellent chance of living a long and healthy life, wherever they live in Wales." In particular, it states a commitment to "ensure children and young people with diabetes have the best possible start in life and are given the opportunity to fulfil their potential."

Following the introduction of 'Together for Health: A Diabetes Delivery Plan (2013)', the Welsh Government committed to the initiation of a consultation process to update 'Access to Education and Support for Children and Young People with Medical Needs (2010)'. This report has been produced to inform this consultation.

Recommendations

- There is a need for a change in legislation in Wales, with the introduction of a statutory duty of care for children with medical needs to bring it into parity with the English legislative system. Greater clarity and direction for schools would reduce variability and avoid confusion as to the roles and responsibilities of all involved.

- There is a need for improved and updated guidance for managing chronic diseases in schools. New guidance would need to identify measures to reduce adverse variability in provision and to standardise policies and procedures for schools as much as possible.

- There is a clear need for enhanced support for children with diabetes to be delivered in conjunction with schools and parents. This will improve patient, family and schools'

experience and also allow currently recommended therapies which will impact on improved outcomes.

- Schools, local education authorities, health services and parents should work together to ensure that the needs of the child with diabetes are met and that they are not unduly stigmatised at school because of their condition.

- Paediatric Diabetes Educators for schools are required across Wales to reduce variability in care during the school day and to enhance the understanding and improve the confidence of school staff who are providing this support.

Further information:

- In Wales, Cardiff & Vale University Health Board have realised the need for further investment in a schools Diabetes Educator role and have funded a post until April 2017. Consideration will be given to a jointly funded post between health and education services.

- Diabetes UK Cymru is happy to make available it's Make the Grade bilingual information packs and resources to Welsh Government. Schools are also able to receive a 'Good Care in Schools Award' from Diabetes UK as an acknowledgement of good practice.

- The Children and Young People's Wales Diabetes Network represents all paediatric diabetes teams working in NHS Wales. It has recognised that care in schools is a serious concern throughout Wales. Improving care in schools is one of the Network's priorities. Training videos aimed at schools were launched in January 2016.

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Introduction

This report provides an overview of the current system of care for children with Type 1 diabetes in schools in Wales. Whilst initially this can be viewed as medical care provided in the day to day management of Type 1 diabetes, providing care for a complex medical condition in a school setting is far from simple and other factors should be noted. These include broader practical and logistical considerations, as well as significantly wider experiences relating to the child and their family's educational, social and economic life.

Providing children with the support they need to participate in all aspects of school life requires a co-ordinated effort. Schools, local education authorities, health services and parents should work together to ensure that they meet the needs of the child with Type 1 diabetes. It is in the interests of both the child and the school to manage diabetes and thus minimise its impact on the child.

This report provides background to the current support expected of schools in Wales and compares this with that expected in England, where recent legislative developments have placed a statutory duty on schools to provide support. It provides an overview of the methodology behind how the information presented was collected, analysed and presented.

It also explains the complexities of Type 1 diabetes, the treatment options, and how this fits into the daily life of a child whilst at school. Finally, it highlights several key needs, all relating to the management of children with diabetes at school, that research has found to be prevalent across Wales, regardless of geographical area, school type, school year or the age of the child.

Understanding Type 1 Diabetes

There are around 1,500 children and young people in Wales with diabetes aged 0-17 years (All Wales Registry and National Paediatric Diabetes Audit 2013/14), 96% of these have Type 1 diabetes.

Type 1 diabetes is an auto-immune condition resulting from the destruction of insulin-producing cells of the pancreas. Insulin is a hormone which helps the body to use glucose contained in foods. Without insulin, glucose from food cannot be used, causing blood glucose levels to rise in the bloodstream. This causes tiredness, weight loss, excessive thirst and frequent passing of urine. Other symptoms include difficulty concentrating and negative moods that can lead to irritability and aggressive behaviour.

Although Type 1 diabetes cannot be cured, it can be treated effectively. The aim of treatment is to keep blood glucose levels close to the normal range. This involves:

- Delivering insulin either by at least 4 injections a day or the use of a continuous insulin pump.
- Eating regular meals containing carbohydrate and snacks throughout the day.
- Finger prick blood tests as a minimum before each meal to ascertain current blood glucose levels and thereafter to carry out appropriate treatment (insulin injection or a snack/meal).

- Failure to comply with these requirements puts a child with diabetes at risk of acute life-threatening complications such as Diabetic Ketoacidosis and/or hypoglycaemic coma. Furthermore, long term poor diabetes control increases the lifetime risk of chronic complications such as kidney failure and blindness and a reduced longevity of life. There is also good evidence that getting good diabetes control in childhood will continue to adulthood and reduce the burden placed on the patient, family and health service.

When a child is treated and supported they should feel well, enabling them to concentrate and participate fully in all school activities.

Children with diabetes spend 22% of the waking day per annum in school (equating to 1,300 hours per year). The active management of their diabetes during this time is therefore of prime importance. If diabetes is not managed well, it will limit the ability of a child to learn and concentrate and can also lead to increased absence from school. When families were asked how often their child's diabetes disrupts their school day, 39% of respondents in Wales advised more than once a day, highlighting the need to regularly monitor the condition.

Legislation & Guidance: Medical conditions in schools in England & Wales

The laws relating to looking after children with medical conditions in school in the UK vary by nation. The following is a summary of the relevant legislation and guidance in England and Wales.

Equality Act 2010

The NHS, local education authorities and schools in England, Scotland and Wales have duties towards children with medical conditions, many of whom are legally defined as being disabled. Fee-paying independent schools are also legally obliged to meet the duties in the Equality Act 2010. The relevant aspect of this act to schools is that governing bodies or proprietors must make reasonable adjustments to ensure that children and young people with a disability are not put at a substantial disadvantage compared with their peers.

Importantly, this duty is anticipatory, which means adjustments must be put in place in advance to prevent disadvantage from occurring. This is particularly relevant to schools in making sure they have enough staff trained so that a child with a medical condition can take part in all aspects of school life. If all the trained staff leave, contingency plans must be in place to train up replacements quickly. The Equality Act also states children with a disability must not be discriminated against, harassed or victimised.

England

Following representations by the Health Conditions in Schools Alliance (a coalition of children and health organisations from the third sector), schools in England now have a legal duty to support and care for all children with medical conditions in schools (*section 100; Children & Families Act 2014*). This provides the legal basis for all children in England to be supported in schools, with accompanying guidance providing detailed, directive and clear instructions on the responsibilities of all parties involved. This is a legal duty in England and the legislation does not apply in Wales.

The Children and Families Act 2014 came into force on 1 September 2014. Section 100 contains a duty to support pupils with medical conditions, meaning that in practice schools must make arrangements for supporting pupils at schools with medical conditions (full text of the Act can be found in Appendix D). In meeting that duty, they must have regard to the statutory guidance issued by the Secretary of State. This is entitled 'Supporting pupils at school with medical conditions' and is intended to:

> *"….help governing bodies meet their legal responsibilities and sets out the arrangements they will be expected to make, based on good practice. The aim is to ensure that all children with medical conditions, in terms of both physical and mental health, are properly supported in school so that they can play a full and active role in school life, remain healthy and achieve their academic potential."*

The document provides statutory guidance for the appropriate authorities and non-statutory advice for others who may have a role in helping to support pupils with medical conditions. It provides clear instruction on and directs schools to immediately carry out or put in place the following:

- The production, adherence and review of a school's key documents, such as its medical conditions policy and Individual Healthcare Plans (IHPs) with additional information on their implementation.

- Procedures for when a child is first diagnosed, record keeping, medicines management and emergency procedures.

- Procedures for day trips, residential visits and sporting activities.

- Roles and responsibilities of all parties, including governing bodies, head teachers, school staff, school nurses, other healthcare professionals (GPs and paediatricians), pupils, parents, local authorities, providers of health services, Clinical Commissioning Groups and Ofsted.

- Staff training and support.

- Unacceptable practice, liability and indemnity issues and complaints.

Following the introduction of the statutory guidance framework, feedback from families indicate that those involved with the provision of care are better able to understand their role and responsibilities in supporting a child with medical needs.

Furthermore, with the statutory guidance now including more directive and clear language, calls to the Care in Schools Helpline appear to suggest that the nature and the complexities of the issues being raised have changed. There appears to be less of a requirement for complicated mediation because those involved are clearer on their roles.

Wales

The current guidance document produced by the Welsh Government in 2010 is entitled 'Access to Education and Support for Children and Young People with Medical Needs'. It has been produced to provide advice to schools and local education authorities on meeting the needs of children and young people with medical conditions. The document provides information for all medical

conditions and includes more specific information on common conditions, such as epilepsy, anaphylaxis and diabetes (Type 1 and Type 2).

Throughout, it encourages schools to adopt good practice recommendations. The guidance references the previous strategic framework, the 'National Service Framework for Diabetes in Wales (2003)'. Key areas of the document are:

- Policies and Individual Healthcare Plans.
- Food and diabetes during the school day.
- Staff training.
- Emergency procedures.
- School trips

Feedback from the survey responses in this report relates to families' experiences of care delivered through this guidance framework.

The new diabetes strategy in Wales, 'Together for Health: A Diabetes Delivery Plan (2013)' replaced the 'National Service Framework for Diabetes in Wales (2003)'. 'Together for Health: A Diabetes Delivery Plan (2013) articulates a refreshed approach to diabetes care and contains specific instructions to support children and young people with diabetes at school. It identifies the need for structured support in the school environment:

> *"To support the care for children with diabetes, healthcare staff, schools and family need to be educated to ensure that children have the best possible opportunity to fulfil their potential. Policies need to be put in place to support the management of diabetes in school."*

It also commits Local Health Boards to:

> *"Working with education authorities to ensure policies are in place to manage diabetes in schools and to develop management systems to support individual pupils to play a full part at school."*

Following the introduction of 'Together for Health: A Diabetes Delivery Plan (2013)', the Welsh Government committed to the initiation of a consultation process to update 'Access to Education and Support for Children and Young People with Medical Needs (2010)'.

Background

As a UK-wide third sector organisation, Diabetes UK hosts a range of services for people living with diabetes. Through regular contact with families, children and young people with Type 1 diabetes, Diabetes UK is able to gain an understanding of the issues they face. Below is information on each of the services provided by Diabetes UK to support children and families with diabetes with particular emphasis on their school life.

Care in Schools Helpline

Diabetes UK has a Supporter Care Centre, which is a public-facing phone service. Due to the high level of calls received regarding issues with schools, a bespoke helpline was established. Diabetes UK's Care in Schools Helpline, launched in October 2014, is a dedicated helpline to support parents to resolve any issues they are having at their child's school. The helpline provides rights-based information and support to make sure children with Type 1 diabetes are happy and healthy at school and that families are aware of their rights.

The Care in School Helpline is provided by trained volunteers, who can talk families through their options, tell them where to find additional information, draft emails/letters and help families navigate the school's complaints process. The service receives 'one-off' enquiries and cases which require ongoing support. The majority (60%) of parents contact Diabetes UK about issues their child is facing in a local authority run primary school, with 39% from secondary school and a further 1% from sixth form colleges (UK wide data).

Parents regularly contact Diabetes UK for a number of reasons which commonly include:

- Their child has been told they can't go on a school trip,
- Their child isn't allowed to treat their symptoms whilst in lessons,
- Their child's school won't provide any support to their child so they are having to go into school to treat their child.

During its first academic year, the service has supported 179 families, providing them with rights based information and advocacy support (7 cases were recorded in Wales, although 41 cases went without a recorded location). 28% of parents who contacted the Care in School Helpline had never contacted Diabetes UK before.

Make the Grade campaign:

Diabetes UK launched the Make the Grade campaign in 2014 to make sure all children with Type 1 diabetes get the support and care they deserve at school so that they have the same opportunities as other children.

The UK wide campaign introduced a range of products to support families, schools and healthcare professionals. These include bilingual information packs for parents, schools and healthcare professionals, as well as a school log book, advocacy pack, template documentation and policies for schools to adapt. A Care in Schools Award and Film Competition were also introduced in 2015, providing schools with opportunities to receive recognition for good practice of diabetes care.

To date, Diabetes UK has sent out over 22,000 information packs to schools and parents.

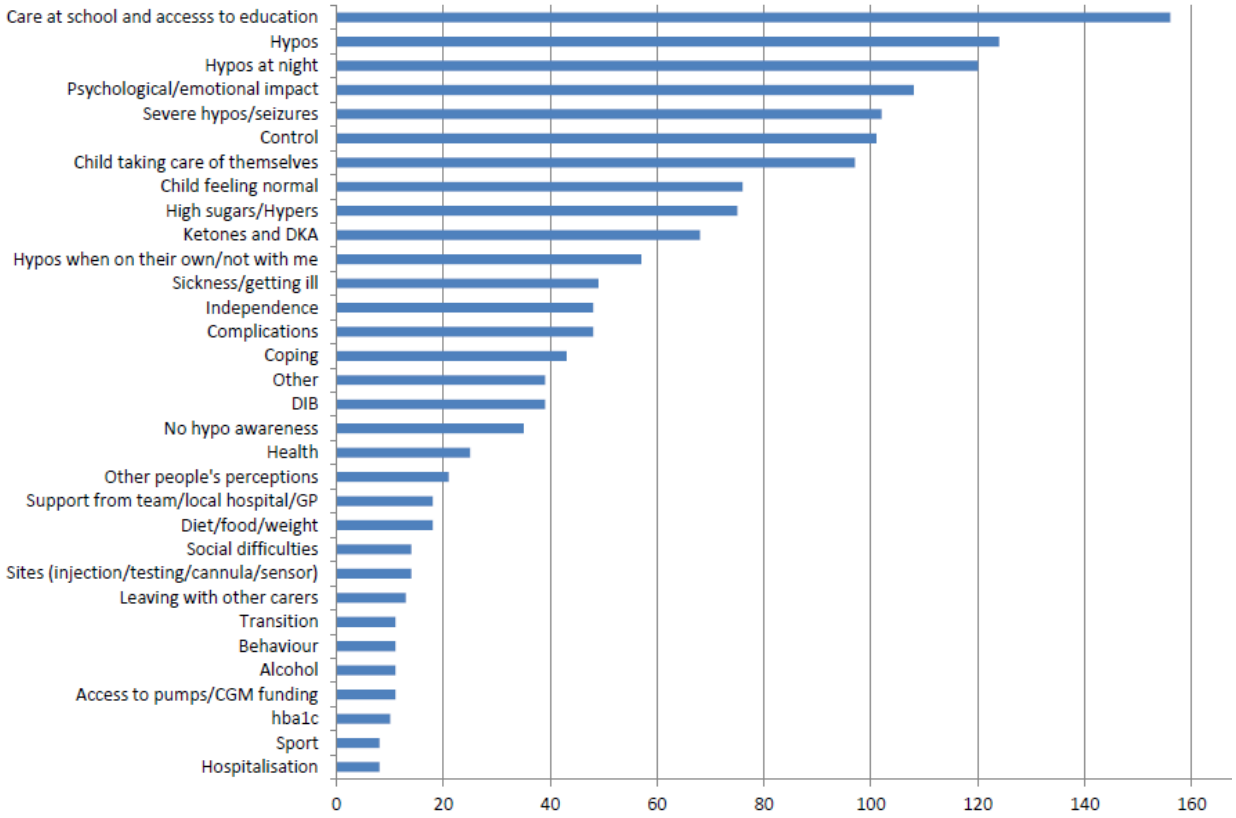
Family Groups:

Diabetes UK's volunteer-run Family Groups are local networks made up of parents, guardians and the extended family members of children with Type 1 diabetes. They hold regular monthly meetings in person as well as hosting active social media network groups to provide support and information

to each other. There are 7 Family Groups in Wales, each linked to their corresponding Paediatric Diabetes Clinic. Each Family Group is in regular contact with Diabetes UK Cymru and provides a summary of issues raised at meetings.

Previous Surveys:

In 2014, the Families with Diabetes National Network conducted a survey of parents across England and Wales. When asked their main short term concern about their child was, care in schools and access to education ranked higher than any other concerns (See figure below, Outcomes Survey 2014; Families with Diabetes National Network):



A Diabetes UK survey in 2014 showed variation in the level and quality of support provided to children with Type 1 diabetes in schools. Whilst some schools have excellent policies and procedures in place, some have incomplete, poor quality or no policies and procedures for children with medical conditions. Some children are unable to actively participate in activities and school trips and parents are having to take a key role in managing their child's diabetes during the school day.

All-Wales Surveys (2015)

As a direct result of the information and feedback received to date, further research was warranted to understand the extent of the problem in Wales. Diabetes UK Cymru, the Diabetes UK Paediatric Diabetes Clinical Champion for Wales and the Children & Young People's Wales Diabetes Network therefore conducted specific, Wales-only survey work to ascertain the parental and professional views and experiences of diabetes care in schools.

Methodology and Results

Diabetes UK designed and circulated a survey amongst families of children with Type 1 diabetes in Wales from September to November 2015 to determine their views relating to the diabetes care provided at school. The Family Survey received 59 responses. The majority have children who attend primary school, although there are also respondents whose children attend nursery, secondary schools and colleges. Responses were received from 12 of the 22 local education authority areas in Wales, equating to approximately 55% of LEA areas (see Appendix A).

The Children & Young People's Wales Diabetes Network (CYPWDN) circulated a survey to Paediatric Diabetes Specialist Nurses (PDSNs) to determine their views of care for children with diabetes in schools. PDSNs provide initial training to schools, as well as ongoing support in person or by phone. 40% of the PDSN workforce in Wales responded to the survey.

Both sets of survey questions expand on issues that families and healthcare professionals regularly raise with Diabetes UK. Questions were designed that would result in a combination of quantitative and comparable data, as well as qualitative data where respondents were able to provide as much detail as they could. Questions were agreed between Diabetes UK Cymru, the Diabetes UK Paediatric Diabetes Clinical Champion and the CYPWDN. A full list of questions can be found in the appendix (Appendix B and Appendix C).

Diabetes UK utilised its voluntary Local Group network of adult and family groups as well as social media networks online of almost 7,000 followers to collect responses. They encouraged social media networks to cascade the survey to their extended contacts as part of an expansive approach to obtain as fulsome a response as possible. Working alongside the CYPWDN, Diabetes UK encouraged frontline paediatric staff to inform parents of the survey in their day to day clinical appointments and to complete their own corresponding survey.

In assessing the results, text analysis software synthesized the large volume of text responses and performed quantitative analysis on open-ended questions. This highlights important terms and phrases in qualitative research and allows for open-ended responses to be categorised into the key findings. The ability to analyse what respondents have said has provided an insight into their attitudes and concerns regarding their children's care whilst at school.

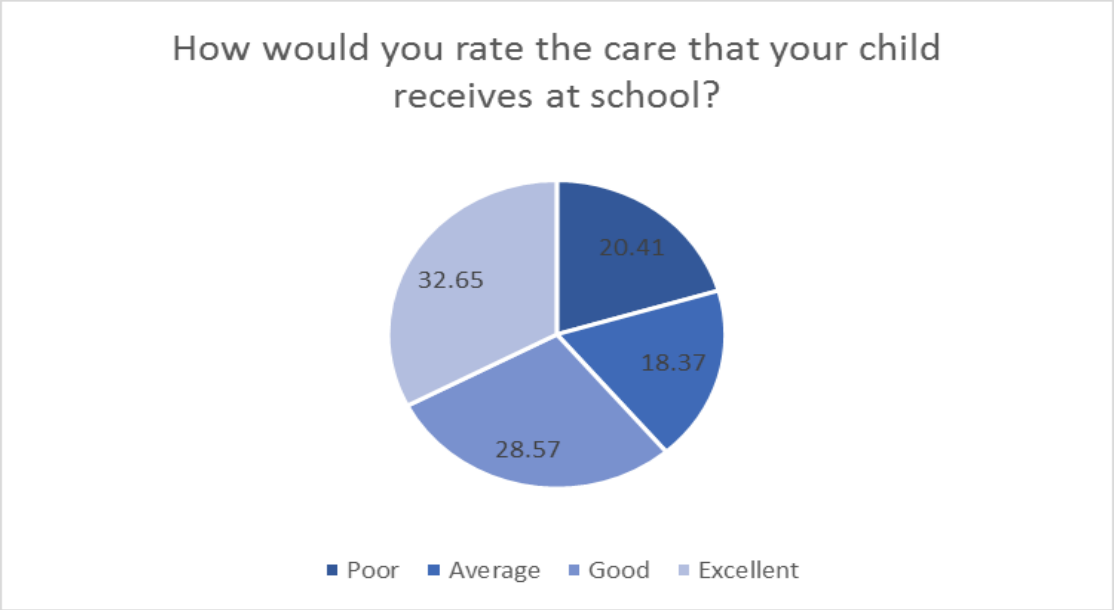
Key findings from surveys in Wales

Several key themes emerge from both surveys carried out by Diabetes UK Cymru and the CYPWDN. These are regularly cited as issues in feedback from the various services described above. They are discussed in greater detail below.

Variability in school care

The Family Survey shows that while many families across Wales experience good, supportive school environments for their children, the lack of uniformity and application of the current guidance framework appears to be leading to an overtly negative impact on significant numbers of children.

The survey asked families how they would rate the care that their child receives at school. Although just over 60% of respondents rated the care as excellent or good, almost 40% rated it as average or poor (20%).



When asked if they had ever had any issues with the care provided by their child's school, just over half (51%) of respondents advised that they had an issue. The accompanying responses provide a detailed overview, with several different elements of school life impacting on care. For example, some families have experienced changes to the level and quality of care as a result of routine staff changes made within their child's school. One mother told us:

> *"Initially whilst at nursery, the care was very good, but when a new headmistress started the care standards dropped. There was no continuity of care or understanding of the seriousness of the condition and I had to fight for care. I have rated the school 'average' in the previous question, however care is now actually 'good' but only because I have fought for this."*

Some families also described variability between school years within a school:

> *"My 7 year old was diagnosed in August 2014. In Year 2 last year he had a class Teaching Assistant and she was amazing. She kept an eye on him and was great with communication etc. Looking back, we were spoilt. This year in Year 3 he has no additional support."*

Other families have experienced variability between school types. The following family's experience highlights this:

> *"They (the primary school) just didn't deal with anything. She was constantly bullied and nobody was interested in her diabetes. We were told that the classroom assistant was not there for her and that they would not do anything diabetes related! She never went on a school trip without us and was excluded*

from residential trips. She has now moved to secondary school and they are amazing and cannot do enough for us."

There is also clear variability in the policies and procedures in place within schools. A child with a medical condition should have a clear Individual Health Plan (IHP) (sometimes referred to as a care plan) in place. From the survey results, it is clear that there is an inconsistent approach to having a plan in place, that the plan may not reflect reality (for example, the child's condition or treatment regime) and an unwillingness to deviate from what is in the plan.

Child has been sent home early or withdrawn from the school day

36% of families told us that their child has been sent home early or withdrawn from school because of their Type 1 diabetes. There is a strong consensus amongst respondents that this is due to a lack of understanding by school staff, including school nurses, of the condition:

"My daughter has learnt not to go to the school nurse if she is feeling low. She has a mobile phone and contacts us herself. This is because if she goes to the nurse, she is inevitably sent home. As she is extremely academic, she is reluctant to miss lessons."

"I have found it safer for my son to contact me for advice from now on. We have insisted he be allowed to call me whenever he needs to."

Child has been excluded from after-school activities

13% of families advised that their child has been excluded from after-school activities. One mother advised that:

"After school activities seem to be run by parents, which I would feel uncomfortable asking them to be trained up. I attend them with my son if he wishes to go."

Another respondent, who is a member of staff in a school office, advised:

"One of our children was offered an out of school active course over the weekend. Her mother was offered a place to attend but unfortunately they didn't take the offer as the mother couldn't go."

Child has been excluded from sports

Physical activity will nearly always have an effect on blood glucose levels. This is because the body uses up more glucose as fuel when active. Sporting activities therefore need careful consideration and more planning than usual day-to-day activities. One parent explained that whilst her son's school did include him in an activity, doing so was dangerous because they had not taken this into consideration:

"We had carefully planned a cycle ride of approximately 5 miles and made adjustments to his insulin basal rates on the pump. The ride was changed to a

different location and the miles doubled but no one thought to ask if this was ok or to inform me. They didn't even inform my son of the changes."

Child has been excluded from school trips

13% of families advised that their child had been excluded from going on both day and residential school trips. Most schools will expect a parent to attend with their child to be on hand to provide support and treatment rather than train a member of staff or ensure that a trained member of staff attends. Several parents explained a similar scenario to the following:

"I have to be with my daughter if she has a school trip. If I or my husband don't go, then my daughter would not be able to go on a school trip. We have 'wasted' days of our annual leave to go on a trip with her."
**Since completing the survey, the family has advised Diabetes UK Cymru that the care provided by the school has improved.*

"I had to go on a school trip, otherwise she couldn't go. I had to lose a day in work."

Trips abroad also present difficulties for families with Type 1 diabetes, with families across Wales again experiencing variability in care provided by schools. One family explained:

"We were told that a health care plan meeting was not needed to go on a trip to France."

Whilst another explained that:

"Support was given when my daughter went on a school trip to Rome. We had a full meeting with the teachers before the trip."

A particularly difficult situation arose for one family, whose daughter was offered places on two separate trips:

"My daughter is a keen member of the choir and orchestra. The school offered a school trip to Europe with the music department. My daughter (a very keen pupil) asked to go. We did not know how we could cope with the logistics but I am a GP and have DBS clearance. I offered to go to accompany her. We were also willing to pay for her LSA (Learning Support Assistant) from her primary school to go, just so that she felt part of the school and didn't miss out. The head of music phoned us and asked if we knew she wanted to go. We said we did and that we wanted to support her. He said he would look into it and speak to the Local Education Authority. That is the last we heard. The next we knew, the trip was booked and our daughter was not included."

The same parent goes on to describe a separate occasion:

"In order for our daughter to go on a school skiing trip, we paid for the whole family (6 of us) to also go to the same resort so that she didn't miss out. Luckily, we were in receipt of DLA which we feel is to be used to support her. However, this has now been

stopped so any further trips will mean annual leave for me and funding issues. This is such a shame. There are LSAs who are trained to look after children with diabetes but the school won't fund them to go on school trips (or even let us fund them!)"

The variability in care provided by schools can be highlighted by comparing the above scenario with another family's experience, where the school was very inclusive. They provided medical forms for the family to complete and provided an opportunity for the parents to speak to the organising teacher. They also purchased a blood tester kit for the child when this was left behind at their hotel.

In addition to families, the majority of PDSNs knew of cases where children were excluded from off-site activities and residential trips:

"I have not seen them being refused to attend, but when this entails a younger child the parents have been requested to attend too. If the parents are unable to attend, I don't know if the school would refuse to take the child. I haven't come across this as yet."

Child has had to move schools

4% of families have had to move their child to a different school to improve the care that their child receives. Whilst this is rare, it is not unheard of. A further small number of parents have advised us that they have considered this option:

"We have had big issues. I ended up taking her out of school for 2 weeks due to reception telling her to go back to class when her levels had dropped dangerously low. I wouldn't recommend anyone with an illness go to this school."

The above cases can again be compared with the following example of good practice:

"While he was in secondary school and during his first year at college, he has received first class care. He was not treated differently, but he had a very good relationship with the school nurse and he was given privacy to do his injection and test his bloods."

From the survey results, it's evident that different families are experiencing different levels of support from their child's school. The level of support directly impacts the level of inclusion or exclusion that a child is experiencing, causing disparity in the system and leaving some children at a distinct educational disadvantage.

Parental involvement during the school day

The majority of respondents have had to attend their child's school during the school day to carry out tasks relating to their child's diabetes, although they do not see this as a negative element of their child's care. However, this will have a detrimental effect on their own working day, as well as a wider economic impact.

For example, 62% of respondents have stayed at home from their own work because of issues relating to their child's diabetes and 53% of respondents have had to leave their own work place

during working hours to attend their child's school but some of those same respondents believe that the care at their child's school is good or excellent. The results suggest that parental involvement is not on a one-off basis, but is a regular and relied-upon routine with them having to provide regular and sometimes daily treatment for their child:

> *"The school refuses to allow staff to administer insulin injections to my daughter. As a result, I have to visit the school every lunchtime to inject her."*
> **Since completing the survey, the family has advised Diabetes UK Cymru that the care provided by the school has improved.*

> *"They won't administer insulin, so I have to go into school every lunch time to inject my daughter, who is 6 next week. I also had to go on a school trip, otherwise she couldn't go. Therefore, I had to lose a day in work."*

> *"On diagnosis, we as parents had to attend school EVERY day to inject at lunch time from the start of October until the beginning of January."*

As well as attending the school to inject insulin, 62% of parents advised that they are being relied upon to carry out other diabetes related tasks. 26% of these include supervising their child's diet or meal times at school. Some families described how they have had to attend the school in person to provide a small snack to their child because the school has refused to do so.

One parent advised that her daughter's school won't

> *"….allow her to have a fast pass to get food as soon as lunch starts. She is questioned regularly by staff when food needs to be eaten."*

In extreme cases, some parents have left or lost their own job because of issues relating to their child's diabetes. One father told us that:

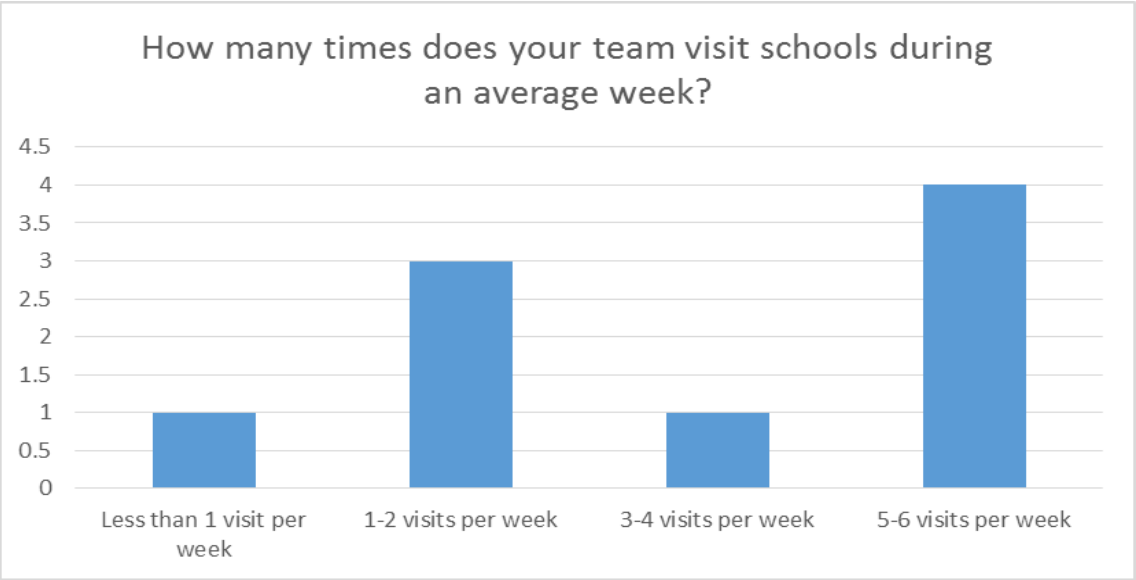
> *"My wife doesn't work as she is so worried about anything happening with the children. We have two children who have Type 1 diabetes. She is at their beck and call, should they need her."*

It appears that whilst some schools rely on parental involvement immediately after diagnosis only, some are reliant on parents several months and even years afterwards to provide a high level of support during and/or throughout the school day.

The role of the PDSN in care at schools

PDSNs are responsible for providing training to at least 2 (ideally 3) members of staff within a school. There is usually a minimum requirement of having 2 trained members of staff to be able to provide cover for annual leave or sickness absence. The training will be tailored to the child's treatment regime and is usually arranged between the PDSN and school directly on school premises. Thereafter, the PDSN will provide training updates and ongoing support in person or remotely. However, PSDNs are finding this role increasingly time-consuming, with all children with diabetes now requiring treatments that impact on the school day. This includes intensive insulin regimes and increasing numbers going on to continuous insulin pump infusions.

The PDSN Survey asked how many visits to schools their team makes during an average month. The results can be seen below, with the majority of PDSN teams visiting schools more than once or twice a week and most teams carrying out 5-6 visits per week.



In addition to physical visits to schools, PDSN teams are contactable by phone for both schools and parents. 44% of PDSNs receive 1-2 calls per week from parents regarding school issues, 33% receive 3-5 calls and 22% receive more than 6 phone calls per week. A third of PDSNs surveyed advised that almost all calls from schools identified training needs for educational staff.

School's staffing: Capacity issues

The survey results indicate that there are not enough trained adults to provide an adequate level of care for children with Type 1 diabetes in a school setting, despite the high level of support provided by the PDSNs described above. Many parents advise that senior staff members at their child's school, such as a Head Teacher or Deputy Head Teacher, are very reluctant for any staff to be responsible for diabetes management. Some explain that they experience delays in schools signing off staff members who have received training, whilst others describe capacity issues where no staff are available to identify hypoglycaemic symptoms or to accompany their child to inject at meal times. The training of supply teachers also presents difficulties for some families.

In turn, schools have advised parents that they experience significant issues relating to the provision of diabetes care and support. 29% of respondents' schools cited staff training issues as the predominant barriers in provision. One family explained:

> *"I have been told by school that their staff are not medically trained and therefore they shouldn't have to inject the insulin. However, there are staff trained in carbohydrate counting and injections in the school, as they have previously had a Type 1 pupil."*
> **Since completing the survey, the family has advised Diabetes UK Cymru that the care provided by the school has improved.*

One mother described a recent situation that occurred at her son's school, where he does not have additional support and relies on his teacher for treatment:

> *"I had recently spoken to the Head Teacher and made him aware that my son's teacher has to treat him straight away if he feels unwell and that she has to almost disregard the other 29 children to treat him. He assured me that the teacher is prepared to do this and realised the importance etc. Today, my son was told that although he felt unwell at 11:45ish, it was nearly lunch time so she'd sort him out then. By that time, she tested him and he was dangerously low (2.8). I've spoken to the Head Teacher again tonight but surely this is unacceptable? It's frightening to think what could have happened."*

One family advised:

> *"There is only the teacher with the class. I believe they need an additional adult to recognise signs/symptoms of a high/low blood sugar, as it affects learning drastically. Also, to be able to treat a hypo immediately, as it's unreasonable to ask a teacher to treat a diabetic hypo whilst managing a class of 30 children."*

Once more, the above families' situations can be compared with the following examples of good practice elsewhere in Wales:

> *"The school my son attends have been extremely helpful. They make sure that all staff that will work with him have been fully trained to administer his insulin."*

The above scenarios can be further compared with one PDSN team member advising that:

> *"All schools [have] concerns but with support have been very willing [to support the child]. The delays occur due to lack of PDSN time in that the practical training to give injections can only be done at lunch time and, due to the geographical area, at one school per day. Verbal education and training is more flexible as it can happen before, during or after the school day."*

Another PDSN supported this assertion, explaining that:

> *"Time isn't being allocated to staff for provision of support - it all needs to happen during their break and this feels unfair. Teachers want to be teachers, not medical staff."*

School staffing: Confidence and understanding of the condition

Issues relating to families' concerns about staff training and knowledge levels are not due to lack of training from PDSNs, rather that the member of staff is not confident or a staff member who did not receive the training has been tasked with caring for the child with Type 1 diabetes.

Families regularly encounter varying levels of understanding and/or confidence about Type 1 diabetes from teachers and members of school staff that they meet. 32% of parents have been told by their child's school that they experience a lack of support and information on caring for children with Type 1 diabetes. A further 21% of parents stated that their child's school has advised them that they have a lack of contact with healthcare professionals and so struggle to provide adequate care.

Two separate families who have tried to engage their child's school with their Type 1 diabetes explain:

> *"They maintain they have no problems. They do not give children with diabetes the care they need and staff are not aware how serious the condition is."*

> *"The school, teachers and so-called nurses at the school clearly have little idea of what diabetes is and what is involved with the condition. They are totally ambivalent over the illness."*

It seems that neither family are alone in describing challenging scenarios. Another two families explain:

> *"We would not dream of sending our daughter on long trips due to total lack of understanding of most staff."*

> *"(….) at times, it is a struggle to make staff understand that I have to talk to the carer during school hours."*

Many of the parents who responded to the survey spoke of a general lack of knowledge, understanding and compassion. This is supported by yet another family's case that:

> *"Several times my daughter has had issues with teachers complaining about school time lost due to diabetes appointments. The school seem more concerned with targets than with children's health."*

Impact on educational attainment: Exams

During exam times, many parents advised that their child has been offered a private room to be able to treat their diabetes during the exam, if necessary. Diabetes UK receives regular calls from supporters advising that exam conditions are an issue with schools. Some parents describe situations such as this one, where their child has suffered additional stress and concern at what is already a difficult time:

> *"When doing exams, we were assured by the Head of Year that all examination overseers would be aware of her, her condition and what actions can be taken in the event of a hypo. When phoning to check the day before, no one knew anything about special considerations."*

In direct contradiction to the scenarios described above, one family advised that:

> *"We have been lucky to have the school this involved and willing to provide that care. We don't expect it to be perfect, we make mistakes ourselves. That has given them the confidence to work with us."*

Treatment: Equipment and medication

Almost 90% of PDSNs have experienced school staff being reluctant to inject insulin, whilst 75% of PDSNs have experienced school staff being reluctant to calculate insulin dosage levels on insulin pumps. This corroborates the experience of Diabetes UK, which receives regular phone calls from parents and schools regarding this issue.

The majority of PDSNs have experienced schools being reluctant for children to test glucose levels or receive insulin in a public area of the school or for children to participate in normal school activities. It is presumed with support from PDSNs that these reservations were overcome in the majority of cases.

Most PDSNs also report that said schools have applied restrictions to crucial elements of insulin treatment, such as blood glucose testing. We heard from parents who were very concerned that their child's school had lost blood glucose kits and stored hypoglycaemic treatment within reach of other students. One mother described a recent situation where the school failed to provide the opportunity to resolve an issue in a clear and transparent way:

> *"We had an incident where two other children messed with my son's meter kit. One child pricked the other on the thumb. Yesterday, the Head Teacher completely washed her hands of the situation after speaking with the parent of the other child. I had to go in to do his bloods, stay for after school club and he had to go behind a screen to test. I walked out in tears. Today, they are back to doing things exactly the same as before and are looking out for him again!"*

This again can be compared with a different school's approach:

> *"In secondary school, they have been very supportive on the rare occasion things have gone wrong (even popping to the shop to buy replacement batteries for his pump when his spare ones failed!)."*

Child privacy when managing their condition

Some schools provide a private room for children to test their blood glucose levels and to inject insulin. This is because both tasks often require injections into areas of the body usually covered by clothing, such as the stomach area or upper leg. Yet again, we have seen a variability in experiences from school to school, with some parents advising that their child's school does not provide

adequate room for injecting and others advising that their child is given privacy to do their injections and to test their blood.

School's confusion over their legal position

Among the PDSN Survey results, the professionals raised concerns that schools regularly articulate their concerns regarding their legal position in caring for children with diabetes:

> *"[Schools raise the issue of] not being covered legally in the event of an error. The lines of responsibility are very unclear."*

Conclusion and Recommendations

This report provides an overview of the care in schools provided to children with Type 1 diabetes in Wales based on the views of a range of parents and healthcare professionals directly involved in the provision of support within a school environment.

The survey results suggest that the current guidance framework in Wales has not resolved the issue of variability, which can be found at every level and in every aspect of care for a child with Type 1 diabetes. The results show that children are routinely experiencing exclusion from the school day, after-school activities, sports, school trips and in extreme cases, are having to move schools. The high level of parental involvement in their child's school day indicates an over-reliance on families to perform diabetes-related tasks and highlights issues in school staff capacity. The survey results further show that this can be linked to levels of staff confidence and aptitude in managing Type 1 diabetes in schools, resulting in different children experiencing different practices around their treatment and medication regimes and the wider practical aspects of their care.

Support is not received in equal measures by children with Type 1 diabetes and differs greatly from child to child and from school to school. This can be expected to some degree in the treatment and care of a long term, individualised condition, but the degree of variability is surprising. As shown in the survey results, many families across Wales experience good and supportive school environments for their children, however, the evidence clearly outlines the need for uniformity. The application of the current guidance framework appears to be leading to an overtly negative impact on significant numbers of children, as evidenced above. Early evidence from the implementation of the new statutory guidance in England suggests that this variability has been reduced with a more directive guidance framework.

The large range of feedback gained through the surveys from families and professionals provides a picture of what a good supportive school environment should be for every child. One PDSN response to Diabetes UK has been included below in full to illustrate this:

> *"In general, I feel that having named staff responsible for the diabetes management and the staff getting allocated time for training and carrying out the procedures are crucial for success. This along with good communication and a good relationship*

between school and home all help in ensuring diabetes is managed well at school. An understanding Head Teacher definitely leads the way in making their staff feel supported and able to volunteer to help with diabetes managements at school. The Head Teacher is very much the gatekeeper of what can occur in school and if the Head doesn't want staff involved in supporting the child's diabetes management then we really struggle to avoid the need for parents to be permanently on call for blood glucose testing and insulin administration."

The following recommendations need careful consideration and implementation to ensure all children and young people in Wales receive an 'excellent chance' to prosper and succeed.

- There is a need for a change in legislation in Wales, with the introduction of a statutory duty of care for children with medical needs to bring it into parity with the English system. Greater clarity and direction for schools would reduce variability and avoid confusion as to the roles and responsibilities of all involved.

- There is a need for improved and updated guidance for managing chronic diseases in schools. New guidance would need to identify measures to reduce this and to standardise policies and procedures for schools as much as possible.

- There is a clear need for enhanced support for children with diabetes to be delivered in conjunction with schools and parents. This will improve children, young people, their family and their schools' experience and also allow currently recommended therapies which will impact on improved outcomes.

- Schools, local education authorities, health services and parents should work together to ensure that the needs of the child with diabetes are met and that they are not unduly stigmatised during the school day from their condition.

- Paediatric Diabetes Educators for schools are required across Wales to reduce variability in care during the school day and to enhance the understanding and improve the confidence of school staff who are providing this support. Cardiff & Vale University Health Board have led the way in funding the first Paediatric Diabetes School Educator in Wales. This now requires partnership working between Health and Education to implement an all-Wales approach to ensure consistency across Wales.

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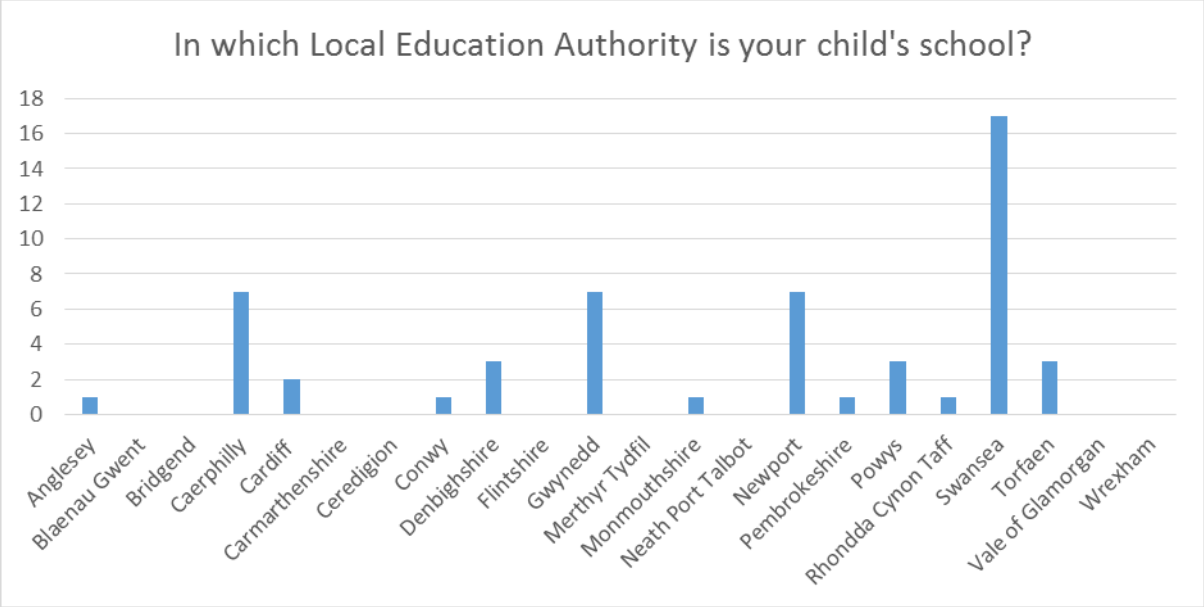
Appendix A:

Respondents to the Family Survey by Local Education Authority



Appendix B: Family Survey questions

The Family Survey asked the following questions:

- Is your child at nursery, primary, secondary school?
- In which Local Education Authority is your child's school?
- Have you had any issues with your child's school providing care for their diabetes (past or present)?
- How would you rate the diabetes care your child receives at school?
- Have you ever had any of the following occur? (Multiple choice)
  - Attended school during the school day to administer insulin
  - Attended school during the school day to supervise diet/meal times
  - Attended school during the school day to carry out other diabetes-related tasks
  - Left your own place of work during working hours to attend the school
  - Stayed at home from work because of issues relating to your child's diabetes
  - Left of lost your job because of issues relating to your child's diabetes
  - Moved your child to a different school
  - Child has been sent home early/withdrawn from school
  - Child has been excluded from school trips
  - Child has been excluded from after school activities (clubs etc.)

- On average, how frequently does diabetes disrupt your child's day at school?
- Has your child's school ever told you that it has experienced any of the following difficulties in managing children with diabetes? (Multiple choice)
  - Shortage of trained staff
  - Shortage of staff willing to volunteer to care for your child
  - Lack of contact with healthcare professionals
  - Lack of support and information on caring for children with diabetes

- How can the care that your child currently receives at school be improved?

Free text boxes were provided for further comment.

Appendix C:

Paediatric Diabetes Specialist Nurse (PDSN) Survey questions

The PDSN Survey asked the following questions:

- How many times does your team visit schools during an average week?
- How many calls do you estimate you receive from parents regarding issues with schools per week?
- How many of those calls require additional training and support for school staff?
- In your experience, which of the following has caused school staff to raise issues regarding diabetes care? (Please tick all that apply)
  - Reluctance to inject insulin using an injection pen
  - Reluctance to calculate doses for an insulin pump and input numbers
  - Reluctance to perform blood tests
  - Fear of hypoglycaemic episodes
  - Concern about children administering own insulin
  - Concern about children doing blood tests/injecting insulin in classroom or public area
  - Concerns about hypo treatment, especially giving a child snacks and/or sweets
  - Concerns about a child with diabetes being able to participate in activities, school trips and PE lessons
  - Other – please list
- Have you seen children who have been affected in any of the following ways? (Please tick all that apply)
  - Refused a place in a preferred school
  - Refused permission to engage in normal activities e.g. PE lesson
  - Refused permission to engage in off-site activities, including day trips and residential trips
  - Discouraged from taking part in school activities
  - Prevented from testing blood, injecting insulin or other diabetes-related activity unless in a designated area
  - Other – please list

Free text boxes were provided for further comment.

Appendix D: Children & Families Act 2014

100 Duty to support pupils with medical conditions

(1) The appropriate authority for a school to which this section applies must make arrangements for supporting pupils at the school with medical conditions.

(2) In meeting the duty in subsection (1) the appropriate authority must have regard to guidance issued by the Secretary of State.

(3) The duty in subsection (1) does not apply in relation to a pupil who is a young child for the purposes of Part 3 of the Childcare Act 2006 (regulation of provision of childcare in England).

(4) This section applies to the following schools in England—
(a) a maintained school;
(b) an Academy school;
(c) an alternative provision Academy;
(d) a pupil referral unit.

(5) In this section
"the appropriate authority for a school" means
(a) in the case of a maintained school, the governing body,
(b) in the case of an Academy, the proprietor, and
(c) in the case of a pupil referral unit, the management committee;

"maintained school" means
(a) a community, foundation or voluntary school, within the meaning of the School Standards and Framework Act 1998, or
(b) a community or foundation special school, within the meaning of that Act.

(6) The Education Act 1996 and this section are to be read as if this section were included in that Act.

Appendix E:

Early evidence of the impact of the Children & Families Act 2014

In England, the Children and Families Act 2014 came into force on 1 September 2014. Section 100 contains a statutory duty to support pupils with medical conditions, meaning that in practice schools must make additional arrangements for supporting pupils at schools with medical conditions. The legislation does not apply to schools in Wales.

Whilst the implementation of the legislation is in its infancy, early indicators document a clear increase in schools' engagement with medical conditions. Diabetes UK has seen a marked increase in the number of healthcare professionals who are nominating a school in their area for Diabetes UK's Good Care in Schools Award.

Comparative evidence gathered annually by Diabetes UK shows that the situation in England is improving year on year:

Indicators	**2013**	**2014**	**2015**
1. Percentage of parents who are satisfied with the diabetes care provided to their child at school	67%	71%	72%
2. Percentage of parents who state that an individualised care plan is in place at school which meets their child's needs.	51%	66%	85%
3. Proportion of schools that have access to Type 1 diabetes training	66%	66%	73%
4. Proportion of schools with appropriate policies and procedures in place to provide children with Type 1 diabetes with consistent, individualised care (including IHP that cover extracurricular activity)	7%	58%	71%

*Figures from 2013, 2014 and 2015 annual surveys of parents and schools conducted online by Diabetes UK.

The following case study highlights the beneficial and direct impact that the introduction of a statutory duty has had in practice:

On a forthcoming residential trip at a primary school, an 11 year old child with Type 1 diabetes was told that their parent would also have to attend to provide care for them. The school advised that the child would have to stay in a separate room away from their peers, which the parent felt was very unfair.

The parents contacted Diabetes UK's Care in Schools Helpline for assistance. The volunteer who supported the parent explained the need for a thorough Individual Healthcare Plan (IHP) for their child, which the school should have in place. The IHP would need to be adapted and updated to include additional provisions in relation to any school trips.

They discussed the need for the school to undertake a risk assessment in advance of the trip, where they could highlight potential issues. The risk assessment should also describe what steps the school would take and what measures they would put in place to help mitigate these risks.

The Care in School Helpline wrote to the School Governors citing their responsibilities under section 100 of the Children & Families Act 2014 to support the child on the trip without the need for a parent having to accompany them. As a result, the school acknowledged that they had not complied with their statutory duties. They acknowledged that they had treated the child unfairly and that the child should be treated equally. The parent felt that the school had made improvements and were now better informed of their responsibilities. The child enjoyed the residential trip along with their peers.

P 12
Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Rhwydwaith Diabetes Cymru i Blant a Phobl Ifanc
Response from: Children and Young People's Wales Diabetes Network

Priorities for the Health, Social Care and Sport Committee

Consultation Submission

This is an official response made on behalf of the Children and Young People's Wales Diabetes Network (& Brecon Group), which represents all NHS Wales staff working in paediatric diabetes units in all health boards in Wales. Our network is composed of consultants and other doctors, diabetes specialist nurses, paediatric dietitians and paediatric psychologists.

The Children and Young People's Wales Diabetes Network is in a unique position in Wales as our members work with all 1,500 children and young people with diabetes. The majority of children with diabetes (96 per cent) have Type 1 Diabetes, which is not linked to lifestyle factors, and requires multiple daily treatments with insulin, or continuous treatment through an 'insulin pump'.

The Network would ask the Health, Social Care and Sport Committee to consider the following areas of healthcare, where we have identified improvements could be made to support children and young people with Type 1 Diabetes.

1. Medical needs for children and young people with diabetes in schools and colleges

2. Improving diagnosis of Type 1 diabetes in primary care

3. Improved 'transition' from paediatric healthcare services to adult services for children with chronic conditions

4. Equitable access to healthcare technology and medical devices across Wales

Members of the Network would be very pleased to provide evidence to the Committee about these concerns.

1. Medical needs in schools

Children in Wales do not have the same rights in law as children in England if they have Type 1 diabetes. The Families Act in England specifically states that children and young people with medical needs *must* receive support in schools.

The experience of NHS Wales staff supporting children with diabetes shows huge variation in the support offered to children with diabetes in school. Our members regularly report instances of schools refusing to help with the administration of insulin. Because of their medical needs, many children experience exclusion from activities in school, and also from school trips.

We believe there is a need for a change in legislation in Wales to introduce a statutory duty of care for children with medical needs in schools. In England, the Children and Families Act 2014 contains a statutory duty to support pupils with medical conditions (section 100), meaning that in practice schools must make additional arrangements for supporting pupils at schools with medical conditions. This legislation does not apply to schools in Wales, meaning the rights of children and young people with medical needs in Wales during the school day are not protected in law to the same level as children in England.

The benefits of protecting the rights of children in Wales through introducing a statutory duty for schools to support children with medical needs are as follows:

- Improving attendance, attainment and overall educational experiences for children in Wales, which will also reduce the academic disadvantage in comparison to their peers in England who are protected at school.
- Children with diabetes will be safer and healthier.
- Children and young people with Type 1 Diabetes will be able to participate in all aspects of school life.

There is an opportunity to include this statutory duty of care within the newly proposed Additional Learning Needs (ALN) Framework. Currently, the Welsh Government's proposed ALN Framework documentation states that children with medical needs will not be covered by the ALN Bill (p. 30, draft ALN Code of Practice). As a Network we request the Committee to examine the Additional Learning Needs Framework with the intent of including all medical needs, and particularly diabetes.

As a network we have already produced evidence for Welsh Government about the need for a statutory duty of care in schools. We have co-authored a report with Diabetes UK Cymru, called "An Excellent Chance: Type 1 diabetes in schools in Wales", which we can also share with the Health, Social Care and Sport Committee.

2. Early diagnosis of Type 1 diabetes in primary care

Each year between 100-150 children in Wales are diagnosed with Tupe 1 Diabetes. Around 15 per cent of children are diagnosed after they develop life-threatening Diabetic Ketoacidosis (DKA). This rises to 24 per cent for children under the age of five. To avoid DKA, it is crucial that Type 1 diabetes is identified early and treatment is administered as quickly as possible.

Early identification and symptom recognition are key to the prompt diagnosis of Type 1 diabetes. As a Network we are aware that many new diagnoses are delayed due to the proper testing procedures not being followed when diabetes is suspected. Children should be tested immediately, not referred for blood tests the following day or at a later date.

As a Network we are working to engage healthcare professionals in primary care to alert them to the life-threatening implications of delays in diagnosis. We believe it should be a priority for NHS primary care services. We would ask the committee to consider recommending

all NHS Wales organisations investigate cases where children and young people are not tested and referred according to the established pathways, particularly if this has resulted in DKA. We believe that failure to comply with the testing policy should be investigated as a serious clinical incident. We would welcome the support of the committee in raising this issue with health boards and primary care leads across Wales.

3. Improved 'transition' from paediatric healthcare services to adult services for children with chronic conditions

'Transition' is the term used to describe the period of life when a child moves into adulthood. Within a healthcare context, children with chronic conditions, such as diabetes, stop receiving care from paediatric teams around the age of 16-17 and begin being cared for by adult services.

There are a number of issues across Wales in 'Transition' services and we would ask the committee to consider examining this whole area as a matter of concern. The impact of poor transition is seen in poorer health outcomes and shorter life expectancy as adults. In some ways, 'transition' represents the 'end of childhood', and this time period tends to be neglected in comparison to the early years of childhood. We would argue that good work done in the early years is often undone by poor transition services, reducing the impact of the investment made in the lives of young children.

There is a national co-ordinator for Transitional Diabetes Care but this is a short fixed-term post. We would ask the committee to investigate the value of a long-term commitment by NHS Wales to improving transition services in diabetes and other chronic conditions.

4. Equitable access to healthcare technology and medical devices across Wales

There is notable variation between health boards in Wales regarding access to technology and medical devices that improve diabetes care and the quality of life for children and young people with diabetes and their families. Devices such as insulin pumps and continuous glucose monitors are distributed in a haphazard way across Wales, with different criteria used in health boards. NICE guidance and nationally agreed criteria are often ignored.

We would ask the committee to consider investigating this geographical inequality and support efforts to produce an all-Wales approach to ensure fair and equitable distribution of technological treatment options across Wales. Where children and young people meet the NICE criteria, they should be offered the technology options that are recommended. Locally produced policies and health board financial considerations should not prevent people from receiving the best available treatments as recommended by NICE.

For further information

Please contact:
Jon Matthias
Network Co-ordinator, Children and Young People's Wales Diabetes Network (& Brecon Group)

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Conffederasiwn GIG Cymru

Response from: Welsh NHS Confederation

	The Welsh NHS Confederation response to the priorities for the Health, Social Care and Sport Committee consultation
Contact:	Nesta Lloyd – Jones, Policy and Public Affairs Manager, the Welsh NHS Confederation. **Nesta.lloyd-jones@welshconfed.org** Tel: 02920 349857
Date created:	30 August 2016

Introduction

1. The Welsh NHS Confederation represents the seven Health Boards and three NHS Trusts in Wales (our members). The Welsh NHS Confederation supports our members to improve health and well-being by working with them to deliver high standards of care for patients and best value for taxpayers' money. We act as a driving force for positive change through strong representation and our policy, influencing and engagement work.

2. We welcome the opportunity to contribute to the Health, Social Care and Sport Committee consultation. We hope that our response, which has been developed with our members, can inform the Committee's Forward Work Programme and highlight the areas where the NHS recommends that the Committee should priorities and consider. Our response builds on the information provided to the Fourth Assembly's Health and Social Care Committee's Legacy Consultation and the information that we provided to all political parties during the National Assembly elections.

The role of the Welsh NHS Confederation

3. As the biggest user of public money in Wales, it is essential that the NHS is accountable, and Assembly inquiries allow this to happen. The Welsh NHS Confederation has built a strong relationship with the clerks from the Health, Social Care and Sport Committee during the Fourth Assembly and this will hopefully continue into the Fifth Assembly. This relationship has been very beneficial for Local Health Boards and NHS Trusts and also for Committee members, with 80 appearances by Local Health Boards and NHS Trusts to the Health and Social Care Committee during the Fourth Assembly.

4. Prior to Committee inquiries and oral evidence sessions, the Welsh NHS Confederation liaises with the clerks to ensure that the most suitable representatives from the NHS in Wales provide evidence to the Committee. We contact the Health Boards and Trusts on behalf of the Committee clerks for all inquiries to ensure that the Committee hears from representatives from across the NHS in Wales. On behalf of our members we discuss with the clerks the key areas that the Committee is considering, the possible issues that may be discussed during the evidence session and liaise with the clerks after the session when draft session transcripts are sent to representatives from the NHS. We hope this relationship continues during the Fifth Assembly term to ensure that the Committee hears from experts within the NHS and to ensure that the Committee can fully understand the policies and processes of the NHS.

5. In addition to liaising with the clerks, the Welsh NHS Confederation provides significant support to representatives from Local Health Boards and NHS Trusts providing evidence to the Committee. The range of support that we provide includes practical information on what to expect on the day, organising pre-meetings to discuss some of the potential areas of questioning the Committee or

Members may focus on and providing support to NHS representatives on the day, including attending the Senedd with NHS representatives.

The priorities for the NHS in Wales

6. We support the areas highlighted by Committee members in initial discussions around the key issues that could be taken forward. However, we recommend that **any consultation or inquiry that is prioritised should assist and support the transformation required to modernise health and social care services in Wales.**

7. The next five years represents a critical period of transformation in health and care services. Changes in how people live their lives and the success of the NHS in keeping people alive for longer means demand for care is rapidly rising. An ageing population, combined with more people having increasingly complex needs, means that demand for health and social care services is predicted to grow rapidly in coming years. With increased demand it is clear that the NHS needs to modernise and adapt when it comes to the way it approaches care and treatment for people. For the long term sustainability of the NHS to be secured, and for it to continue to deliver high quality care, it cannot do things in the same way.

8. To meet these challenges the NHS needs to be appropriately resourced to modernise and adapt the way it approaches care and treatment. Many services will need to be redesigned to deliver radically different models of care which better fit the needs of people and reflect advances in technology and medical treatment. We also need to identify innovative ways to overcome historic boundaries between organisations which hamper seamless care for patients.

9. There is now an opportunity for the Welsh Government, through the planned Parliamentary Review into health and social care in Wales, to take forward the following key priorities which have been identified by NHS Wales leaders. The seven priorities that could be considered by the Committee over the Fifth Assembly term are:
   a. To develop a long term vision and ten year strategy for sustainable health and care services in Wales;
   b. To develop a deliverable workforce and organisational development plan to support the long term strategy;
   c. To make best use of the physical, financial, workforce and technological resources available;
   d. To co-design, commission and provide joined up health services and to work with partners to provide patients with an integrated health and care experience;
   e. To work with public sector partners to invest time and resources in services and actions that promote health, well-being and personal responsibility;
   f. To drive consistently high quality services and outcomes and develop a performance management framework that supports this; and
   g. To provide clear and consistent leadership and take strategic decisions on national priorities and programmes.

Priority areas for the Committee to take forward (not in priority order)

Workforce

10. We support the Committees recently launched inquiry into the sustainability of the health and social care workforce. We will be providing a detailed response to the inquiry and as part of the Welsh NHS Confederation Policy Forum, which consists of over 40 health and social care organisations, will be publishing the "'One workforce': Ten actions to support the health and social care workforce in Wales" document. The document highlights the key issues that Assembly Members will need to consider to ensure a sustainable health and social care workforce.

Long-term conditions and Welsh Government Delivery Plans

11. We would recommend that the Committee undertakes more strategic inquiries rather than condition specific inquiries; as were conducted in the Fourth Assembly.

12. Instead of individual inquiries on specific Delivery Plans (for example cancer, stroke) we would recommend that the Committee looks at long-term conditions and all the Delivery Plans developed by the Welsh Government during the Fourth Assembly. The issues highlighted around the implementation of one Delivery Plan will be very similar for the other Delivery Plans (for example early identification, assessment and care planning, having a key worker and providing information to patients). In addition a number of patients have more than one long term condition so it is important that their care pathways are not seen in silos.

The impact of poverty on people's health and well-being

13. We would recommend that the Committee considers the impact that socio-economic deprivation has on people's health and well-being.

14. As highlighted in our briefing, "From Rhetoric to Reality – NHS Wales in 10 years' time: Socio-economic Deprivation and Health"[i] the socio-economic inequalities in life prospects and health are stark. Socio-economic deprivation has a significant impact on child development, on people's lifestyle choices, on healthy life expectancy, including living with an illness or chronic condition, and life expectancy.

15. As part of the inquiry the Committee could consider the impact that welfare reform is having on people's health. In our briefing "The impact of welfare reform on people's health and well-being"[ii] we highlighted how the changes to welfare benefits are having a significant impact on people in Wales and have led to an increase in a wide variety of health-related conditions. Research highlights that welfare reform could include an increase in a wide variety of health-related conditions including:
    - Mental health problems;
    - Cardiovascular and respiratory illnesses;
    - Obesity-related illnesses;
    - Substance misuse and associated alcohol and drug related harms; and
    - Suicides, homicides and domestic violence.

Public Engagement

16. We recommend that the Committee considers how the Welsh Government and public bodies better engage with the public.

17. There is a need for an open and honest conversation with the public about what the NHS can provide in the future. While the NHS is free at the point of contact, it is not free of obligation, and

the public will need to be supported in taking more responsibility for their own health. Patients need to become partners in managing and improving their health, rather than passive recipients of healthcare. Communication and co-production with patients, the public, third and independent sectors will be required with more support in influencing the public message regarding co-production and self-management. Without support across all sectors for these messages, it will not succeed and the Committee has a role to consider where we are in Wales at the moment.

Carers

18. We would recommend that the Committee undertakes an inquiry into the support provided to unpaid carers in Wales.

19. There are at least 370,000 carers in Wales and the amount of care provided by unpaid carers saves the Welsh economy £8.1bn every year.[iii] While there are a number of pieces of legislation affecting carers in Wales, including the Social Services and Well-being (Wales) Act 2014 and the Regulation and Inspection of Social Care (Wales) Act, the Committee could consider the specific needs of unpaid carers, especially young carers, the adverse impact that caring can have on carers' health and well-being.

Welsh Language and Health

20. With the introduction of the Welsh language standards, it would be an opportunity for the Committee to consider Welsh language provision across health and social care.

21. The ability to provide services in Welsh is one of the key elements to delivering a quality service, especially for vulnerable groups who find it easier to express themselves in their first language. The Welsh Government developed "More than just words" in 2012, providing a strategic framework for Welsh language services in health, social services and social care, and the inquiry could consider how this is being implemented across Wales before the new Welsh language strategy comes into force from April 2017. The Committee could also consider the recommendations put forward by the Welsh Language Commissioner in her report "My Language, My Health: The Welsh Language Commissioner's Inquiry into the Welsh Language in Primary Care"[iv] and the progress made.

Intermediate care services.

22. We would recommend that the Committee undertakes an inquiry into the intermediate care services in Wales and the impact that the Intermediate Care Fund has had on helping keep older and vulnerable people out of hospital and in their own home.

23. Intermediate care describes a range of services providing time limited support to [NHS] patients (up to six weeks) which promotes independence by avoiding unnecessary hospital admission or admission to long term care, facilitates timely discharge from hospital and forms a bridge between hospital, home, dependence and independence. Intermediate care is provided on the basis of a comprehensive assessment resulting in a structured individual care plan that involves active therapy, treatment, social work intervention, or opportunity for recovery. The Intermediate Care Fund was introduced by the Welsh Government in January 2014 and funding provided to encourage integrated working between local authorities, health and housing. Funding is targeted at supporting older people, particularly the frail elderly, to maintain their independence and to be cared for in their own home. Funding is also provided to encourage innovation and developing new models of delivery to ensure sustainable integrated services. With the demands on acute provision in Wales it would be beneficial for the Committee to consider the impact that the Intermediate Care Fund has had.

Mental health

24. We would recommend that there is an inquiry considering mental health provision in Wales and whether mental health is valued equally with physical health, or "Parity of Esteem".

25. One in four people will experience mental health problems in any given year and the cost of mental health problems in Wales is an estimated £7.2billion per year.[v] Mental health has risen up the agenda during the last two Assembly terms, with cross party support for new policy and legislation such as Together for Mental Health and the Mental Health (Wales) Measure, but the Committee could consider how we further develop high quality mental health services in Wales and address attitudes to mental health. The inquiry could include CAMHS services, as recommended in the Children and Young People Committee's legacy report, dementia provision in Wales and also the impact long-term conditions have on people's mental health.

Feedback on the areas highlighted by Committee members in initial discussions (in order of priority)

Sport and public health:

26. We recommend that an inquiry considering public health should be a priority for the Committee and should consider the role and impact of a preventative approach to health services and work to educate the general public about the preventative agenda, as recommended during the Health and Social Care Committee legacy report. The potential health benefits and the role of NHS Wales in promoting sport and physical activity generally was only recently considered by the Communities, Equality and Local Government Committee in their inquiry into participation levels in sport which was completed in March 2014.

27. Prevention and early intervention to improve population health is a national priority for the Welsh NHS Confederation as we all recognise that it is key to improving the health and well-being of the whole population, while helping to manage demand on secondary care. Wales faces a significant number of public health challenges, including high levels of obesity, drinking above the guidelines, smoking and poor levels of physical activity. The impact of such behaviours on our health is resulting in significant demand being placed on the health service. The Committee could consider the role and impact of a preventative approach to health services and work to educate the general public about the preventative agenda.

Integration of Health and Social Care services:

28. The Welsh NHS Confederation would support an inquiry looking into the implementation of the Social Services and Well-being Act 2014 and other policies dealing with the integration of health and social care services.

29. The Welsh NHS Confederation believes that Wales, given its size, structure and close links, has a golden opportunity to achieve so much when it comes to integration. The Welsh NHS Confederation works with ADSS Cymru, Wales Council for Voluntary Action, Care Forum Wales, the Welsh Local Government Association and Community Housing Cymru to support the continued implementation of the Social Services and Well-being (Wales) Act 2014. However, to provide patient centred care, collaborative working and transformational change is vital across all of the public sector.

30. Integration needs to happen, both within and outside the health service and therefore it is important to look at integration across the public sector. The NHS will not be able to rise to the challenges it faces without the help of our colleagues in other sectors, including housing, education and, in particular, those in social services.

Primary Care

31. We would support an inquiry considering primary care because over recent years there has been a number of areas of development within primary care that the Committee could hear about. The NHS in Wales aims to provide modern, fit for purpose primary care facilities that support and enables the delivery of safe and sustainable care at or close to home. This includes the provision of integrated facilities where appropriate – "the one stop shop" – to further support the shift of NHS community services to more local settings, as well as the delivery of the wider health and well-being agenda with other public and third sector delivery partners.

32. Health Boards in Wales have formally developed arrangements for 64 Cluster networks (Clusters) of GP practices and partners to work collaboratively to develop services in the community, serving populations of between 30,000 – 50,000. GPs in the Clusters play a key role in supporting the ongoing work of a locality network (in some areas these are known as neighbourhood networks). The Clusters are charged with working together and with primary and community care partners within health and social care to meet local need and through working together and supporting individual practices it will hopefully enable GP practices to be more sustainable in the future.

Efficiency within the NHS and modern management practices:

33. We would support an inquiry considering the efficiency within the NHS. The rise in demand, coupled with constrained financial resources, has made delivering health and care services in the current model increasingly difficult. The NHS is committed to working more efficiently in order to rise to the challenges that it faces. However, it has become increasingly clear that traditional methods of savings are unlikely to deliver what is needed in the future.

34. According to the Wales Audit Office's (WAO's) report,[vi] since 2011, the NHS has reported making around £800 million in savings. The vast majority of NHS respondents to the WAO survey said that their organisations' financial savings had come entirely or mostly from improved efficiency. Overall, revenue spending on health remained below 2010-11 levels until it rose in 2014-15. According to the WAO report the majority of spending in the NHS goes towards the costs of providing hospital and community based healthcare services. In 2010-11 and 2014-15 spending on these services has increased by around £52 million (1.4%).

35. It is important that we are realistic about the current and future costs of health and care services and we need to work with all stakeholders to understand the future resources required to secure the system. Later this year the Health Foundation will be publishing a report looking at efficiency in healthcare which the Committee could consider the findings in more detail.

Waiting Times:

36. The Welsh NHS Confederation would support an inquiry considering waiting times but recommends that the remit should focus on patient outcomes rather than tier 1 targets. Waiting times are a key priority for the NHS and there is much work going on to try to improve waiting time targets. While targets have a role to play, we must also look at the bigger picture, which is about instigating a whole system change in the way treatment is delivered to patients and providing the best service we can within the resources that we have. It is vital that we develop a performance management framework that supports this, focusing more on outcomes rather than

processes, as has been done during the Clinical Response Model introduced in October 2015 for ambulance targets.

37. NHS Wales is the first system in the UK to move to a national pilot of a new ambulance model. The piloting of a new Clinical Response Model (CRM) for 12 months from October 1, 2015 by the Welsh Ambulance Services NHS Trust (WAST) recognises the importance of clinical indicators as a measure of quality, rather than exclusively time-based targets. The pilot reflects clinical advice and evidence that the use of an out-dated, time-based target is not a good measure of performance, clinical care or patient outcome.

Other areas discussed by the Committee

38. While the Welsh NHS Confederation is supportive of the inquiries into neonatal services, ambulance services, loneliness and isolation among older people, the use of antipsychotic medication in care homes and gambling addiction, we do however believe that the issues highlighted above are of greater strategic significance and will support the transformation required within the health and care system.

Conclusion

39. As highlighted in our response there are a number of significant strategic areas where the Committee could take forward and consider. With the number of challenges health and care services face we recommend that any future consultation or inquiry considered by the Committee assists and supports the transformation required to modernise health and social care services in Wales.

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[i] Welsh NHS Confederation, June 2015. From Rhetoric to Reality – NHS Wales in 10 years' time: Socio-economic Deprivation and Health.
[ii] Welsh NHS Confederation, March 2015. The impact of welfare reform on people's health and well-being'
[iii] Carers Trust Wales, 2016. Investing in Carers, Investing to Save.
[iv] Welsh Language Commissioner, June 2014. My Language, My Health: Inquiry into the Welsh language in Primary Care.
[v] Mental Health Foundation, October 2015. Fundamental Facts About Mental Health 2015.
[vi] Wales Audit Office, December 2015. A Picture of Public Services 2015.

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Dr Justin Walker
Response from: Dr Justin Walker

[Via email]

Priorities for Health, Social Care & Sport Committee Consultation

There are many children and young people who have healthcare needs that need addressing during the school day. I am a paediatrician working with children and young people with diabetes where healthcare needs require constant monitoring if a child is to achieve their full educational potential and reduce the risk of burdenful complications from the disease..

Keeping children and young people safe during the school day and reducing the long term risk of complications from diabetes requires intensive disease management. Modern technology and intensive diabetes management provides overall better blood glucose control. Since the level of blood glucose control is directly related to the risk of complications, such as blindness, kidney failure requiring dialysis or limb amputations, it becomes vitally important to manage it as effectively as possible throughout the day and night, seven days per week and 365 days per year. Poor diabetes control in childhood will lead to a high risk of complications and reduce life expectancy placing a large social burden and stress on families but also a massive financial burden on the NHS.

Children spend 30% of their day in school and therefore it is of paramount importance that schools participate in the daily management of children with diabetes. This requires training and constant updates as children move through different classrooms and levels of education. In Wales there are approximately 1500 school age children with type 1 diabetes.

Unlike in England there is currently no statutory requirement in Wales for schools to participate in the healthcare needs of children with diabetes who require help during the school day. Although many schools in Wales are extremely engaging with such healthcare needs, this is by no mean universal.

I, along with Diabetes UK, performed a survey amongst families of children with diabetes and specialist nurses about school engagement and published ‘An excellent chance’ documentation on the results and recommendations from this survey. It includes evidence from families and healthcare professionals showing that there is a need to support children and young people with diabetes in schools. I ask the committee to read the report with a focus on the Executive Summary. The report is co-authored by the Children and Young People’s Wales Diabetes Network, as well as senior paediatric clinicians in Wales.

This document has already been shared and discussed with the SCMO for Woman’s and Child Health, Dr Heather Payne and is attached (it has also been sent to the WG separately by DUK and the Children and Young People’s Wales Diabetes Network).

‘An excellent chance’ clearly highlights there are inequalities across Wales in the provision of care for children with diabetes, in some circumstances children being excluded from school activities. This is unacceptable and requires action.

There is a need for a change in legislation in Wales to introduce a statutory duty of care for children with medical needs in schools. There is an opportunity to include this within the newly proposed Additional Learning Needs (ALN) Framework.

The Welsh Government's proposed ALN Framework documentation states that children with medical needs will not be covered by the ALN Bill (see page 30 of the draft ALN Code of Practice).

I would urge the Committee to consider the inclusion of medical needs in the Additional Learning Needs Framework.

The current guidance frameworks for the management of medical conditions, including Type 1 diabetes, in a school setting differ in Wales and England. In England, the Children and Families Act 2014 came into force on 1 September 2014. Section 100 contains a statutory duty to support pupils with medical conditions, meaning that in practice schools **must** make additional arrangements for supporting pupils at schools with medical conditions.

The legislation does not apply to schools in Wales. The rights of children and young people with medical needs in Wales during the school day are not protected in law to the same level as children in England. The current system in Wales puts children with medical conditions in Wales at an academic disadvantage in comparison to their peers in England and does not protect them whilst they are at school. It is vital that children are kept safe and healthy whilst they are learning to enable them to achieve their full potential.

In my role as a senior clinician in Wales and appointed as a Diabetes UK clinical champion to improve the quality of care for children with diabetes, I urge the Committee to consider the current situation and ask whether there is a need to bring the rights, support and protection provided to children and young people living with Type 1 diabetes in Wales in line with those in England.

Dr Justin Warner, Paediatric Endocrinologist &Honorary Senior Lecturer Cardiff University

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Coleg Brenhinol y Meddygon
Response from: Royal College of Physicians

Royal College of Physicians | Coleg Brenhinol y Meddygon (Cymru)

Inquiry into priorities for the Health, Social Care and Sport Committee

RCP Wales response

About us

The Royal College of Physicians (RCP) aims to improve patient care and reduce illness, in the UK and across the globe. We are patient centred and clinically led. Our 30,000 members worldwide work in hospitals and the community across 30 different medical specialties, diagnosing and treating millions of patients with a huge range of medical conditions.

Involving patients and carers at every step, the RCP works to ensure that physicians are educated and trained to provide high-quality care. We audit and accredit clinical services, and provide resources for our members to assess their own services. We work with other health organisations to enhance the quality of medical care, and promote research and innovation. We also promote evidence-based policies to government to encourage healthy lifestyles and reduce illness from preventable causes.

Working in partnership with our faculties, specialist societies and other medical royal colleges on issues ranging from clinical education and training to health policy, we present a powerful and unified voice to improve health and healthcare.

For more information, please contact:

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From the RCP vice president for Wales
O'r is-lywydd yr RCP dros Gymru
Dr Alan Rees MD FRCP
[redacted]

From the RCP registrar
O'r cofrestrydd yr RCP
Dr Andrew Goddard FRCP
[redacted]

02 September 2016

Dear colleague,

Inquiry into priorities for the Health, Social Care and Sport Committee

Thank you for the opportunity to respond to your consultation on the National Assembly for Wales committee inquiry into priorities for the Health, Social Care and Sport Committee.

Our response

RCP Wales will be responding to the current inquiries on the sustainability of the NHS workforce and winter preparedness for 2016-17. Based on the proposed forward work programme of the new Committee, the RCP would also support further work on:

- Integration of health and social care services
- Waiting times
- Efficiency within the NHS and modern management practices
- Sport and public health

Depending on the terms of reference, we may also want to respond to the following inquiries:

- Ambulance services
- Loneliness and isolation among older people

New models of care are needed

However, while we recognise that primary care has growing capacity and workforce problems, we need to move away from a model of care in which we invest in *either* primary or secondary care, and towards integrated team working, where hospital specialists hold more of their clinics

in the community, and GPs spend part of their time working with colleagues at the front door of the hospital. We need to build on the skillset of our current workforce to deliver new models of care in the future.

Instead of concentrating an inquiry specifically on primary care as the Committee has suggested, we would welcome a mature conversation about the future of service design in Wales, and the vision needed at a national level to develop a new way of working. Whether this is part of the proposed inquiry on integrated health and social care, or a separate inquiry, we feel that it is important that future investment into the health service does not go towards propping up the old, broken system.

The Welsh Government must promote innovative models of integration and introduce shared budgets that establish shared outcomes across the local health and care sector. Spending money on the existing system will not change anything in the long term; health boards must invest in prevention and treatment of chronic conditions and allow clinicians to innovate.

Those living in rural and remote areas must not be forgotten either; it is these areas where the crisis in primary care is hitting hardest, and where a new ambitious model of care has the most potential. All of this will need a drastic change in mind-set. The RCP has long called for more clinical leadership and engagement, and more joined-up thinking between service planning and training needs. Now it is time to re-think how the future NHS workforce will train, develop their skills and practise medicine.

Our priorities for the next five years

The RCP in Wales has identified four major priorities for the next Assembly term:

1 **Implement a new patient-centred approach to NHS change**
Change must be patient centred, clinically led and evidence based, and must not be about cutting costs. Reconfiguration should be based on the Future Hospital model of care, in which care comes to the patient and is coordinated around their needs.

2 **Invest now in the Welsh NHS to ensure good care in the future**
Our hospitals are under-resourced and under pressure – an increase in funding is needed. Health boards and politicians must support clinicians to develop innovative solutions to the NHS crisis, especially in rural and remote areas. A renewed focus should be placed on developing models of integrated care and improving the experience of frail patients and their families.

3 **Focus on developing and supporting the medical workforce**
It is time for a national medical workforce and training plan for Wales, including a new strategic approach to recruitment. Junior doctors and medical students must be encouraged to stay in Wales with new training pathways, improved workload and more clinical leadership opportunities.

4 Reduce health inequalities and improve public health

Politicians and government must show national leadership on public health. Legislation should be used where there is evidence to support its use, including standardised packaging for tobacco products, a minimum unit price for alcohol of 50p per unit, and exploring the use of taxes on sugary soft drinks to help combat obesity.

For more information, please contact Lowri Jackson, RCP senior policy and public affairs adviser for Wales, at [redacted]

With best wishes,

Dr Alan Rees
RCP vice president for Wales
Is-lywydd yr RCP dros Gymru

Dr Andrew Goddard
RCP registrar
Cofrestrydd yr RCP

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Yr Athro Sue Jordan
Response from: Professor Sue Jordan

[Via email]

Priorities for Health, Social Care & Sport Committee Consultation

Use of antipsychotic medication in care homes

The Older People's Commissioner and the Flynn Review [Opens in a new browser window] both highlighted concerns about the inappropriate use of antipsychotics to control the behavioural and psychological symptoms of people living with dementia. The Committee could seek to assess the scale of the problem, and examine possible solutions.

We have developed and tested an intervention which has been shown to reduce the use of sedative medicines, including antipsychotics, in care homes. Our intervention is the West Wales Adverse Drug Reaction (WWADR) Profile for mental health medicines (to be sent on request). It lists problems that might be associated with or exacerbated by these medicines, and asks nurses to monitor these and inform prescribers or pharmacists. We have shown in randomised controlled trials and observation studies that structured nurse-led medicines' monitoring using the WWADR Profile benefits patients, for example, by reducing pain and sedation, encouraging behavioural interventions and identifying high risk cardiovascular conditions. Our trials indicate that the intervention does not cause harm, and there is potential for considerable cost saving. The comments of the care home managers, some papers, endorsements and our video are below.

I should like to discuss how our evidence-based solution could contribute to the consultation and be operationalized.

I look forward to hearing from you,

Professor Sue Jordan

Some key open access papers with links Jordan S, Gabe-Walters ME, Watkins A, Humphreys I, Newson L, Snelgrove S, Dennis M. (2015) Nurse-Led Medicines' Monitoring for Patients with Dementia in Care Homes: A Pragmatic Cohort Stepped Wedge Cluster Randomised Trial. PLoS ONE 10(10): e0140203. doi:10.1371/journal.pone.0140203
http://dx.plos.org/10.1371/journal.pone.0140203

Jordan S, Gabe M, Newson L, Snelgrove S, Panes G, Picek A, Russell IT, Dennis M. (2014) "Medication Monitoring for People with Dementia in Care Homes: the Feasibility and Clinical Impact of Nurse-led monitoring," The Scientific World Journal, vol. 2014, Article ID 843621, 11 pages, 2014. doi:10.1155/2014/843621. http://www.hindawi.com/journals/tswj/2014/843621/

Our video & website
https://youtu.be/E_CPDgsmA4s
http://www.swansea.ac.uk/wwadr/#

Care Homes Managers who participated in the RCT (Jordan et al 2015)

- Home Manager said " The profiles are very useful and have enabled us to review and discuss the medications with the GP and CPN. As a result, for example we have stopped some antipsychotic medications that the patient no longer requires". (Wilson, Care Home Manager, Glan Garnant)
- Paula Aplin said " The WWADR profiles are really useful and the staff are more educated and informed about drug reactions. The increase in staff confidence has made a big difference to medication management for the service users in our care ".

- Aldo Picek Clinical nurse manager said “The tool increased the nurse knowledge and improved attitudes towards accountability. Increased confidence helped to identify side effects and change medications”.
- Sue Levy the Home Manager said " I use the checklist routinely in my practice and for the few minutes it takes, it provides a patient centred care for the person which makes it worthwhile. It has made me reflect and think of things that I wouldn't have prior to using the profile".

The work is endorsed by Age Cymru. Age Cymru are supportive of this piece of research.

Alzheimer’s Society, Wales will be supporting our research in forthcoming discussions with Welsh Government.

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Coleg Brenhinol yr Ymarferwyr Cyffredinol

Response from: Royal College of General Practitioners

Royal College of GPs Wales' response to:

Priorities for the Health, Social Care and Sport Committee in the Fifth Assembly

Deadline: September 2, 2016.

RCGP Wales is a members organisation representing GPs and doctors who are training to be GPs from across Wales. We welcome the opportunity to respond to this consultation on the priorities for the Welsh Assembly's Health, Social Care and Sport Committee.

We would like the Committee to prioritise the following areas:

1. **Primary Care**

RCGP Wales believes that primary care should be the top priority for the next Health, Social Care and Sports Committee.

Primary care, largely delivered by GPs and their staff but also including a wide variety of health and social care professionals, has been an enduring success of the NHS in Wales. It delivers nine out of ten patient contacts and provides accessible, high quality, personal care in familiar, local surroundings. More services are moving from secondary across into primary care but the associated resource is not moving in the same direction. The effectiveness and integrity of general practice is now under threat and barely sustainable. GP teams are struggling to cope with the demand and remain responsive to the needs of their patients and communities. Practices are closing or reducing services. Morale is low. More staff are needed and new models of care need to be explored whilst retaining the high quality and type of care patients value. It is absolutely vital that it is adequately resourced and supported.

If we are to help keep our patients out of hospital and care for them effectively in the community in which they live then we must focus on primary care.

2. **Sport and public health**

Secondly we would like sport and public health prioritised. In order to remain healthy it is absolutely necessary that people are equipped to care for themselves. Access to parks and recreational activities is vital and accessible information about the need to remain active and to eat a healthy diet is more important than ever.

Effective public health campaigns are proven to change people's lifestyles. Smoking and drink driving are examples of these. Public awareness of the need to manage our own health and be responsible for healthy eating habits and exercising would go a long way to improving the nation's health. We recognise that sport isn't just for athletes . Opportunities to take exercise or be physically activity must be available to everyone. In particular we would like to see a greater collaboration between health, local authorities and national bodies to prioritise sport and activity in schools and communities with the provision of green spaces, leisure centres and cycling routes in both rural and urban areas

Public health campaigns need to be far reaching and accessible to all ages.

3. **3. NHS Efficiency**

Improving efficiencies means that the NHS can provide better care for all patients in Wales. Efficiencies in transfer between general practice/primary care and hospitals need to be improved reduce waiting times for access to advice or treatment and quicker safer return to communities.. Technology needs to be utilised so that communication between sectors is more effective for example, duplication of investigations should be reduced by effective use of laboratory and radiology IT links for all relevant professionals to see results both from and in primary and secondary care.

4. **Loneliness and Isolation in older people**

Wales has an ageing population and many of those living longer are alone or isolated. Loneliness leads to depression and other mental health problems which in turn adversely impact on general health and wellbeing. It is vital that these people are identified, are linked into appropriate activities in their communities and receive timely health and social care. This is a whole community responsibility.

5. **Integration of Health and Social Care**

RCGP Wales believes that health and social care cannot be separated, particularly as Wales has some of the most deprived areas of the UK. Improving social care for patients can prevent admissions and speed discharge reducing expensive stays in hospital. There is still insufficient cooperation between care sectors arising from ingrained cultural differences and rigid funding boundaries with insufficient emphasis on patient centred care.

Good examples of cross-sectoral working(both statutory and voluntary) need to be shared and promoted. Patients need to be sign-posted to services more effectively. A Wales-wide online network would be a very important step in the right direction and GPs would benefit greatly from access to such a database of information.

6. **Emergency services**

   Responsive emergency services are essential to maintaining access to urgent care. The ambulance service needs to be appropriately responsive guided by realistic and flexible targets. Paramedics have a bigger role to play in emergency and urgent care in the community and new ways of working with general practices and clusters need to expanded. Effective transport must be supported by efficient A & E services which are appropriately used by the public and community clinicians. Currently there are still unacceptable delays in urgent transfers and long waiting times in A & E

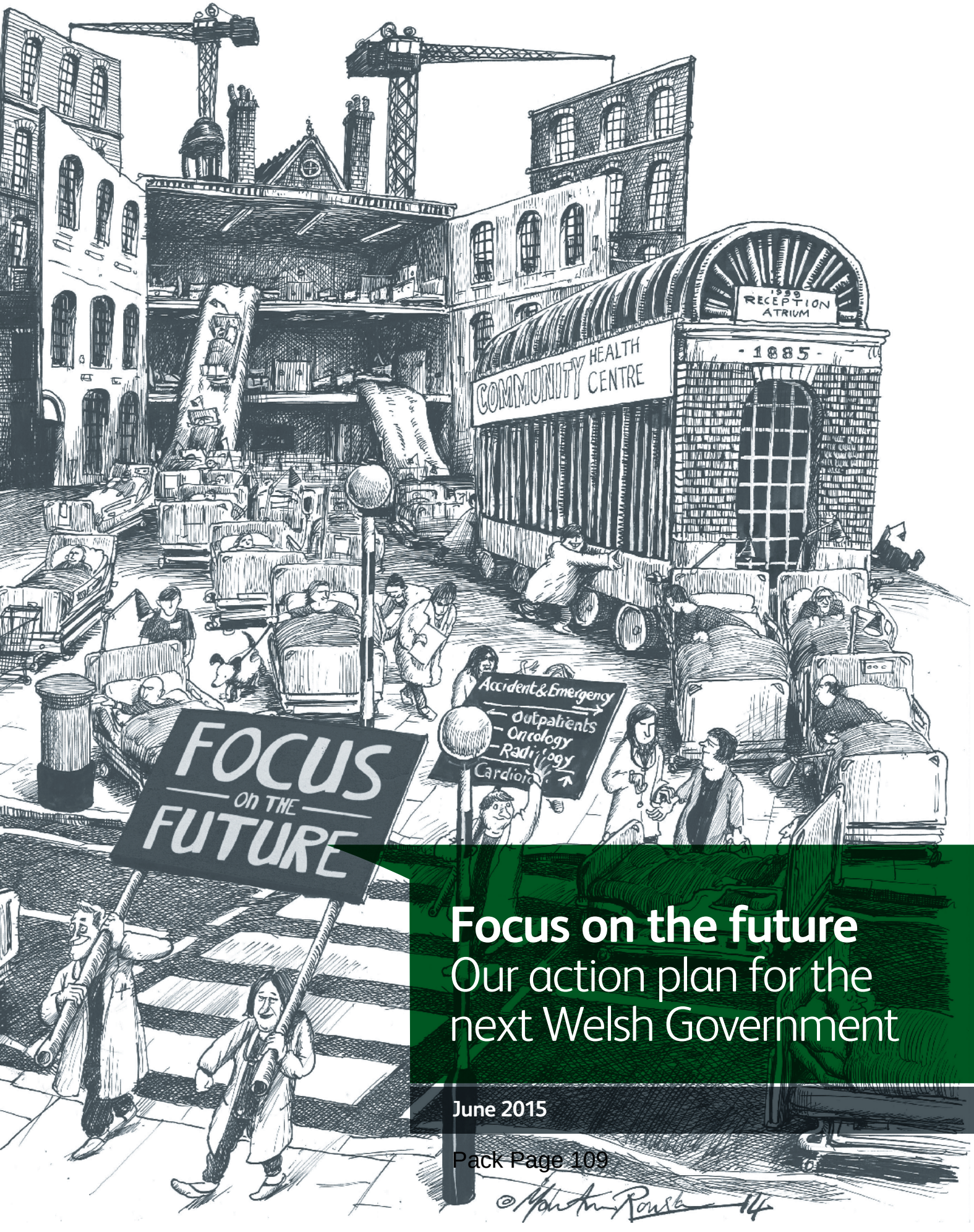
which need resolving using a whole system approach. This includes looking at the role primary care can and does play in urgent care.

Finally, the Royal College of GPs Wales requests that the Committee holds an inquiry in the near future (next term if possible) to:

Assess the current state of general practice and evaluate what actions have been taken to date and actions needed to be taken to realise the aspirations of the Government's Primary Care Plan.

Royal College of Physicians

Coleg Brenhinol y Meddygon (Cymru)



Focus on the future

Our action plan for the next Welsh Government

June 2015

Foreword

The next National Assembly for Wales election will take place in May 2016, and it is already clear that health policy will play a central role in the campaigns of all political parties. The Royal College of Physicians (RCP) believes that this debate must be depoliticised. It is the responsibility of every healthcare professional to lead improvements in care, supported by politicians and managers. Any future changes to care must be patient centred, evidence based and clinically led.

This will require a huge culture change. The NHS is a complicated and bureaucratic system in which outpatients can spend hours waiting for a 5-minute appointment with their consultant, only to be told that the test results are not back yet. Every admissions unit in Wales is overflowing, yet some patients can spend weeks on wards waiting to be transferred home, or into community care. The system is not currently organised around the patient – the patient is expected to fit in with the needs of the NHS.

This is why physicians in Wales are calling on the next Welsh Government to put the patient at the centre of care. We are asking all political parties to support the Future Hospital model and to help clinicians work with patients to ensure excellent care.

Delivering the future hospital

In 2013, the RCP's independent Future Hospital Commission proposed a radical model for the future of health services.[1] This important vision set out how hospital services can adapt to meet the needs of patients, now and in the future. The RCP is working directly with individual hospitals, health boards and clinicians to develop this vision and achieve real change across health and social care. Politicians can support us by promoting the Future Hospital model in national and local discussions about the design of health services, and by removing barriers to its delivery.

In 2014, the RCP published *Rising to the challenge: Improving acute care, meeting patients' needs in Wales*,[2] which interprets the Future Hospital vision for the Welsh health service. Through our 'local conversation' visits to hospitals across Wales, we have gathered numerous case studies where fellows and members are driving forward the Future Hospital vision and improving patient care. The need for change is clear; health professionals must now be given the freedom to innovate. It is time for politicians, health boards and NHS trusts to listen to clinicians and allow them to lead.

Dr Alan Rees
RCP vice president for Wales

The RCP's action plan for the next Welsh Government

The RCP calls on all political parties in Wales to commit to our four-point action plan for the next Welsh Government.

1 Implement a new patient-centred approach to NHS change

Change must be patient centred, clinically led and evidence based, and must not be about cutting costs alone. Reconfiguration should be based on the Future Hospital model of care, in which care comes to the patient and is coordinated around their needs.

2 Invest now in the Welsh NHS to ensure good care in the future

Our hospitals are under-resourced and under pressure – an increase in funding is needed. Health boards and politicians must support clinicians to develop innovative solutions to the challenges facing the NHS, especially in rural and remote areas. A renewed focus should be placed on developing models of integrated care and improving the experience of frail patients and their families.

3 Focus on developing and supporting the medical workforce

It is time for a national medical workforce and training plan for Wales, including a new strategic approach to recruitment. Junior doctors and medical students must be encouraged to stay in Wales with new training pathways, improved workload and more clinical leadership opportunities.

4 Reduce health inequalities and improve public health

Politicians and government must show national leadership on public health. Legislation should be used where there is evidence to support its use, including standardised packaging for tobacco products, a minimum unit price for alcohol of 50p per unit, and exploring the use of taxes on sugary soft drinks to help combat obesity.

1 Implement a new patient-centred approach to NHS change

The RCP supports a model of care that promotes health and wellbeing, values patient experience and is coordinated around patients' medical and support needs. Safe, effective care should be organised around the patient and make it easier for hospitals, GPs and social care teams to work together rather than separately.

Change must be patient centred and evidence based. Clinicians must be listened to and allowed to lead. Health boards and NHS trusts must commit to using the Future Hospital model when redesigning medical specialist care. Service redesign must take a whole-system approach – the NHS can no longer look at individual services in isolation. Decision-makers must consider whether their plans work effectively with acute and critical care medicine, as well as primary care and community services.

We call on the next Welsh Government to:

- **Publicly support the patient-centred Future Hospital model in manifestos and during the first days of the next Welsh Government.** The Welsh Government should promote the patient-centred Future Hospital model as a template for clinically led service redesign. The Department of Health and Social Services should talk to local health and social care services about how they are embedding Future Hospital principles. Health planners should support clinicians by removing barriers to delivering the future hospital. The RCP will continue to work directly with health boards and clinicians by sharing good practice from Future Hospital partners across the UK.

- **Commit to working with physicians to redesign acute and specialist medical services.** Reconfiguration must be patient centred, clinically led and evidence based. It must not be about cutting costs alone. Hospital services must be redesigned using a whole-system approach and secondary care clinicians should be at the very centre of this service planning. According to local context, hospitals and health boards should establish the role of chief of medicine, supported by a chief registrar, providing a direct clinical link between management, physicians and trainees.

- **Develop a long-term plan for the future of the Welsh health service.** The Welsh Government should show national leadership and use long-term planning to create stability and support transformation. This will require real investment in the Together for Health agenda,[3] especially in clinical delivery plans. All spending decisions should be underpinned by a long-term objective to increase investment in new models of integrated health and social care.

- **Promote informed public debate on local health service redesign, nationally and locally.** Politicians in all parties have a real responsibility to support clinically led, evidence-based change that will deliver better care for patients. Health boards and the Welsh Government must ensure that change is genuinely led by patients and clinicians, and not presented as a 'done deal' at a late stage in the planning process.

- **Establish a national programme for sharing good practice.** The Welsh Government must support new networks for sharing good practice across the system. This will improve patient care, increase efficiency and support informed local variation. One example is the RCP Future Hospital Partners' Network, which aims to link together healthcare professionals across the UK in order to promote collaboration and innovative practice.

- **Promote clinical leadership and clinically led quality improvement projects.** The next Welsh Government should provide public and financial support for professionally led quality improvement projects and leadership work. Such schemes drive up quality and have the potential to transform the NHS in Wales.

- **Focus on patient experience, recovery and self-management.** The Welsh Government and health boards should make recovery and self-management central to all policies. Patient experience should be a priority for all health and care services. The Welsh Government should invest in community services, with the long-term aim of a 7-day social care system that works effectively at weekends. Patients must be supported to leave hospital and move into primary or community care as soon as possible after hospital admission. Good practice should be shared at national level and promoted in national policy.

- **Commit to a new e-health strategy that clearly references the need for electronic patient-centred records based on an approved common national standard.**[4] Electronic records should focus on the individual patient, and not on their disease, intervention or the context of care. Achieving this long-term Welsh Government goal would improve patient care, reduce unnecessary duplication of care, and enable the development of more sophisticated ways of measuring outcomes. Integrated patient records and information systems should be accessible 7 days a week to patients, carers, clinicians and professionals in primary care-, community- and hospital-based settings, and social services.

People aged 65 years and over now make up almost one-fifth of the population of Wales, or around 563,000 people.[5] This number is projected to increase by around 181,000 between 2010 and 2026.[6] One-third of the adult population, or around 800,000 people, have at least one chronic condition[6] and Wales has the highest rates of long-term limiting illness in the UK.[7]

2 Invest now in the Welsh NHS to ensure good care in the future

It is time to invest in patient care. Our hospitals are under-resourced and under pressure. A significant increase in funding is needed to prevent a crisis in the NHS. Healthcare costs are rising, and improved efficiency and reconfiguration will not deliver the savings that we need to balance the books.

We also need to remove barriers to patient-centred care. This includes transformation funding to support the move to new models of integrated care, particularly specialist healthcare provided in the community. Supporting patients to recover and manage their conditions must be a priority in all policies. Health boards and local authorities must work together more effectively to provide high-quality patient care across all services. Integrated, standardised patient records must aid the collection of accurate information and data to improve care.

We call on the next Welsh Government to:

> **Increase health service funding.** The Nuffield Trust estimates that there could be an unprecedented funding gap of £2.5 billion by 2025/26 in Wales.[8] The level of funding for the health service is a political choice and has an impact on the level of care available to patients. However, the Welsh Government must promote innovative models of integration and introduce shared budgets that establish shared outcomes across the local health and care sector. Spending money on the old system will not change anything in the long term; health boards must invest in prevention and treatment of chronic conditions and allow clinicians to innovate.

Increasing specialisation inevitably tends to result in more and more hospital services being concentrated onto fewer and fewer hospital sites that, in turn, tend to be set within the larger towns and cities of Wales. For rural communities, this has the effect of driving many hospital services out of long-standing local hospitals, placing them many miles away.[9]

Between 2012–13 and 2013–14, the total number of NHS beds in Wales fell by 254 (2%) to 11,241. Over the 10 years from 2003–04 to 2013–14, the total number of NHS beds fell by 2,968 (21%) and their occupancy rate increased from 83.0% to 85.9%.[10]

> **Establish a transformation fund for new models of care.** The Welsh Government should set up a transformation fund to support new ways of delivering services. Additional financial support will keep necessary services going while new models of care are developed. The fund should be available to every health board to drive the move towards models of care that will lead to more efficient, integrated care in the future.

> **Commit to investing in rural and remote healthcare services.** The Welsh Government should invest in all hospitals with an acute take, including rural and remote hospitals, to ensure patient safety. The RCP welcomes the work of the Mid-Wales Health Collaborative, and has committed to supporting physicians working in rural and remote parts of Wales. When looking at service redesign, politicians and health boards should consider the specific catchment area of a hospital and take into account issues such as geography, tourism, transport, population need, and access to social care and rehabilitation. One size will not fit all, and patients and clinicians must be allowed to lead change. An all-Wales emergency transport plan should be a priority and the Welsh Government should invest in rolling out telemedicine projects, such as the RCP Future Hospital CARTREF programme, which is being led by clinicians and patients in north Wales.

> **Commit to a maximum bed occupancy rate of 85%.** Current bed occupancy rates are often >90% and investment is needed to change this. When hospital beds are scarce and staff are stretched, patients are often moved between wards without clinical need. Every bed move increases the length of stay – it disorientates patients and upsets patients' family members. Patients should be able to receive care in the place where their needs can best be met – not in the only available bed.

> **Remove barriers to timely access to specialist diagnosis and treatment.** Patients who need specialist medical care should get it promptly: delays in access to expert care cause harm. The Welsh Government should renew focus on bringing down outpatient waiting lists across all specialties and invest substantial resource in clinical delivery plans to ensure that targets are met. We support the development of 'intelligent targets', but only where these are clinically led.

In general hospital settings, people aged 65 years and over currently account for 70% of the total number of bed days. An increasing number of patients are older and frail, and around 25% of inpatients have a diagnosis of dementia.[11]

> **Develop a national plan to improve care for frail, older patients with complex needs.** We need to focus particular attention on improving health and social care for the frail, older patient. Our reliance on hospital admission for this group of patients is having a huge impact on our emergency departments and our medical assessment units, on ambulance waiting times, and on the flow of patients through our hospitals. A national strategy to target and proactively plan care for this group of patients will encourage joined-up thinking and share best practice.

- **Invest in new and innovative ways of improving frailty care in the community**, such as the Frail Older Person's Advice and Liaison (FOPAL) service in Cardiff and the Gwent Frailty Programme in Torfaen. Clinically led programmes like these should be rolled out nationally as soon as possible; we need to keep frail patients out of hospital in the first place if possible. Primary and community care professionals must be supported by hospital specialists to provide proactive and coordinated care for these patients.
- **Promote and encourage comprehensive geriatric assessment (CGA)**, a model of care that is expert, multidisciplinary, informed by regular assessment and led by a single health or social care professional in a case management capacity. CGA has been shown to improve outcomes for frail older people in hospitals and in other community settings.[12] Hospitals should use frailty charts to identify those at risk, so that we can manage more care in the community.

> **Commit to national action to support improvements in end-of-life care.** In 2013, 57% of deaths were in hospital, 23% at home, 14% in care homes and 6% elsewhere (including hospices). In Wales, the proportion of deaths in hospital is significantly higher than England.[13] It is estimated that 75% of the 32,000 people who die in Wales each year will need some form of palliative care, yet only 17% receive specialist palliative care. This drops to 5% if cancer is taken out of the equation.[14] The provision of palliative care in hospitals for those in the final days of their life must be improved and national action taken to standardise its delivery across health boards. The Welsh Government should invest substantially in palliative transition services for young adults and adolescents. Clinical audits to ensure continued improvement in the care of dying patients should be supported and promoted at national level, and the provision of care for the dying should be monitored by Healthcare Inspectorate Wales.

3 Focus on developing and supporting the medical workforce

Good care in the future depends on good training now. Medical education and training must be prioritised when designing health services. The Welsh Government must work with NHS bodies and the Wales Deanery to develop a national medical workforce and training strategy which ensures that staff are deployed and trained effectively, now and in the future.

Workforce planning must be a key priority during the entire process of service reconfiguration. Internal medicine must be valued and urgent action taken to ensure that more physicians contribute to the acute take. Trainee and medical undergraduate numbers must be increased, and junior doctors and medical students must be supported and encouraged to stay in Wales by offering them innovative new training pathways, an improved workload, and more opportunities to take part in clinical leadership and quality improvement programmes.

We call on the next Welsh Government to:

> **Develop a national medical workforce and training strategy.** Good care in the future depends on good training now. Service planners must make medical education and training a priority when designing health services. Health boards should review existing service planning arrangements to ensure that they do not threaten the sustainability of the medical workforce, especially in rural and remote areas.

> **Show national leadership on the balance between service and training.** The Welsh Government, health boards and the Wales Deanery must acknowledge the delicate balance between service needs and training issues. Every hospital in Wales depends on its trainees and there are huge implications when a unit loses its training status. Physicians working in rural and remote hospitals should be supported by colleagues working in other hospitals, not only with service provision, but also with teaching time. Hospitals across Wales should work as a collection of formal, structured alliances operating hub-and-spoke, or integrated care, networks. Politicians must show national leadership and support innovative solutions to keep these units sustainable.

> **Focus on addressing recruitment and training challenges**, particularly in north and west Wales. The number of medical undergraduate and core medical training (CMT) posts in Wales should be increased. Rota changes should allow trainees to work within the same teams for a block of time, to improve continuity of care and enhance training and learning on the job. For those hospitals with poor trainee feedback, CMT roles should be timetabled to ensure clinic time and dedicated teaching time.

'I thoroughly enjoy my work, but my first 6 months in a rural hospital has given me very little clinical training. It has not prepared me for the MRCP(UK) Part 2 Clinical Examination (PACES) or my future work as a registrar.' Junior doctor in Wales

- **Improve the support available to junior doctors in rural areas.** The rota gaps in many smaller, rural hospitals in Wales can result in isolated working for junior doctors. They also mean that there is not enough face-to-face consultant teaching time for some trainees. Training pathways specialising in rural and remote healthcare should be developed in Wales and advertised across the UK to encourage the best trainees to apply. To recognise how healthcare will change in the coming years, these rural training jobs should be built around the integrated patient journey, and made more attractive through new opportunities to gain postgraduate qualifications or formal experience in service improvement or leadership roles.

- **Encourage health boards to implement the Future Hospital workforce model.** Hospitals should move towards a 7-day consultant presence – this will require a more even distribution of the acute take between the medical specialties, as well as an increase in the number of internal and acute physicians working in Wales. Integrated working and shared outcomes with health and social care partners should be the norm; physicians and medical teams should spend part of their time working in the community.

- **Legislate on safe staffing levels.** The RCP has supported safe nursing staffing legislation in the National Assembly for Wales, and we would support this legislation being extended to other health professionals, where appropriate. Nursing and medical staffing data must be made publicly available and easily accessible, and should be displayed in every ward on a daily basis.

In Wales, 85% of hospital consultants say that there are times when they feel as though they are working under excessive pressure, and almost half say this happens often or always. Almost two in three consultants tell us that they often or always find themselves doing jobs that would previously have been done by a junior doctor.[15]

- **Ensure that future changes to medical training are reflective of the needs of patients**. In the future, we will need more doctors with general medical skills to care for the increasing numbers of patients coming to hospital with multiple medical conditions, particularly frail older patients. However, training a good doctor who can provide generalist care as well as specialist expertise will require adequate time. This is why the RCP supports the expansion of general medicine, the dual accreditation of physicians at Certificate of Specialty Training (CST) level, and an increase of flexibility in training, and we urge action in these areas. We will oppose any shortening of training time for physicians, which would compromise both the quality and the safety of care.

- **Develop and embed other clinical roles into the Future Hospital model in Wales.** Excellent patient care depends on cohesive, organised and well-resourced team working. Staff and associate specialist grade posts in Welsh hospitals should be encouraged, and these doctors should be supported in their career progression. The roles of advanced nurse practitioner and physician associate should be developed as core members of the clinical team. However, any increase in staffing numbers for these posts should not be at the expense of consultant expansion.

- **Invest in research and innovation, locally and nationally.** There should be national investment in innovation and new technologies, which have the potential to revolutionise care and to position Wales as a world leader. Academic research should be considered when planning and delivering health services. All health boards should receive a regular report of research activity, and hospitals should be publicly supported to build a culture of research and allow their staff time out of service for research. Mandatory reporting of research findings should be established to share intelligence. Patients should be given the opportunity to participate in ongoing research activity and should also be involved in setting research priorities.

- **Make staff health and wellbeing a national priority.** The Welsh Government should invest in the health and wellbeing of its NHS workforce by implementing National Institute for Health and Care Excellence (NICE) public health guidance for employers on obesity, smoking cessation, physical activity, mental wellbeing and the management of long-term sickness. Staff engagement and wellbeing are associated with improved patient care and better patient experience.[16–19] The Welsh Government should consider staff health and wellbeing as part of the proposed national medical workforce and training strategy, and promote national sharing of good practice on staff health and wellbeing.

4 Reduce health inequalities and improve public health

We need to build a health and care system that focuses on preventing ill health and promoting wellness, rather than just treating illness. Physicians and medical teams have a key role to play, not only in managing ill health, but also in supporting people to lead healthier lives. Harnessing the skills and expertise of hospital doctors across the system can help to build a healthier future for individuals, communities and the UK.

Politicians and government must show national leadership on public health. Legislation should be used where there is evidence to support its use. This includes introducing standardised packaging for cigarettes to reduce the harm caused by smoking, introducing a minimum unit price for alcohol of 50p per unit to reduce alcohol-related harm, and exploring the use of taxes on sugary soft drinks to help combat obesity.

We call on the next Welsh Government to:

Show leadership on public health and inequality

- **Commit to independent and authoritative leadership in public health** by giving public health professionals the independence, authority and resources to make a difference.
- **Introduce a duty on all ministers to consider the health impact of all government policies**, with a specific focus on the potential impact on access to healthcare and disparity in health outcomes.
- **Support new measures to promote better care for vulnerable people at national level**. This should include measures to promote parity of esteem between physical and mental health, and services that are sensitive to the needs of people with learning difficulties.
- **Lobby the UK Government to reinvest a proportion of tobacco and alcohol duty, as well as VAT on soft drinks, fast food and confectionery, in public health promotion**. Both the UK and Welsh Governments should also explore the use of taxes on unhealthy foods, including sugary soft drinks.
- **Introduce a public health licensing objective** that gives local authorities the power to consider public health when making licensing and planning decisions, including alcohol licensing and planning for food outlets.

There are high levels of poverty and health inequality in Wales: 680,000 people live in low-income households.[20] Research shows that people in the lowest socio-economic groups have a life expectancy that is 7 years shorter, and live with 17 more years of ill health, than those in the highest groups.[21] In Wales, 21% of adults smoke, and 58% of adults and 34% of children are overweight or obese.[22]

Take national action on obesity

- **Implement the All Wales Obesity Pathway in full as a matter of urgency.** Health boards must invest in multidisciplinary, clinically led level 3 weight management services across Wales.
- **Develop a cross-governmental obesity strategy with a cross-governmental lead.** Obesity puts patients at high risk of developing conditions such as diabetes, high blood pressure and stroke. It costs the Welsh NHS over £73 million a year[23] and, without action to develop level 3 and 4 obesity services, hospital admissions will continue to rise.
- **Lobby the UK Government to set maximum limits on levels of fat, salt and sugar in food marketed substantially to children**. Diets high in fat, salt and sugar, and low in fruit and vegetables, can result in obesity and heart disease. 5.5% of all cancers in the UK are linked to excess body weight.[24]
- **Place the promotion of physical activity at the centre of public health policy** with new, easily understandable recommended levels of physical activity and a new national ambition. This should include joined-up activity on the Active Travel Bill, public health programmes, and legislation on public health and the wellbeing of future generations.

Take national action on tobacco

- **Place a renewed focus on meeting the aims of the Welsh Government Tobacco Control Action Plan**, especially the target to reduce adult smoking levels to 16% by 2020.
- **Introduce standardised packaging for tobacco products and a ban on smoking in cars when children are present** as soon as possible, in conjunction with the UK Government.
- **Support the 'Smokefree Spaces' campaign** by ensuring that all spaces in Wales where children and young people congregate – such as school gates, beaches and parks – are smoke free. This should form part of all future planning across Wales.
- **Take action to help young people stop smoking** by funding youth-specific smoking cessation and prevention services.

Currently 21% of adults in Wales smoke[25] and it is estimated that 14,500 young people in Wales take up smoking each year.[26] Smoking accounts for approximately 5,450 deaths every year in Wales,[27] and evidence suggests that the smoking rate is higher in the most deprived parts of the country.[28]

- **Implement effective regulation of e-cigarettes**, including a ban on the sale of e-cigarettes to people aged under 18. We also call for measures to prevent marketing to children and non-smokers, and the regulation of e-cigarette products to guarantee quality standards and protect consumers.

- **Tackle illegal tobacco in Wales** by investing in a Wales-wide public awareness campaign and partnership enforcement work.

- **Ensure that all pharmacies across Wales offer advanced smoking cessation level 3 services**. All pharmacies are expected to offer healthy lifestyle advice to smokers and/or to take part in national or local health promotion campaigns. This is agreed on a local health board basis, which means that delivery of these services is inconsistent across Wales and some areas have no level 3 pharmacy provision at all.

Take national action on alcohol and substance misuse

- **Implement a statutory minimum unit price for alcohol of 50p per unit**. The heaviest drinkers currently pay only 33p per unit of alcohol, with some high-strength ciders costing the equivalent of only 6p per unit. The impact of minimum unit pricing on low-risk drinkers is negligible – the average low-risk drinker already pays around £1 per unit of alcohol.[29]

- **Invest in integrated alcohol and substance misuse treatment and prevention services**. These should be established urgently where there are service gaps, and existing services should be integrated across primary, secondary and community care, local authorities and public health teams.

- **Implement the Welsh Government liver disease delivery plan in full**, supported by the necessary funding.

- **Conduct a major review of licensing legislation**. Where possible, the Welsh Government should introduce restrictions on alcohol availability, independent regulation for alcohol promotion, a reduction in the drink-driving limit and a public health licensing objective.

- **Call for the alcohol duty escalator to be reinstated**. The alcohol duty escalator was scrapped by the UK Government in 2014 following intense lobbying by the alcohol industry. At a time when the NHS is under increasing pressure from preventable alcohol-related admissions, and the cost of excess alcohol to NHS in Wales is around £70 million per year,[30] scrapping the alcohol duty escalator will cost the Treasury over £1.5 billion over 5 years.

Making the future hospital a reality in Wales

In September 2013 the Future Hospital Commission, set up by the RCP, set out a radical new vision for the future of health services.[1] The Future Hospital model aims to deliver:

- **high-quality, 7-day care** for all who need it
- **expert coordination of care** for patients with a range of medical and support needs
- **rapid access to specialist care** when it is needed
- **continuity of care** for all patients, including when they enter or leave hospital
- **strong teams** that provide effective, compassionate care, and support and develop staff
- **good relationships** between teams working across health and social care.

How will the future hospital work?

Care will come to patients, when and where they need it. Teams from across health and social care will work together to coordinate care around patients' medical and support needs. Teams that care for people with a medical illness will come together within the hospital – from the emergency department and acute and intensive care beds, through to general and specialist wards. This will not stop at the hospital door: specialist medical teams will work closely with GPs, mental health and social care teams. Specialist medical care will not be limited to patients in labelled specialist wards or those admitted to hospital. Medical teams will spend time working in the community; primary and social care teams will have greater involvement when patients are in hospital. By supporting each other, professionals will be better able to support patients. >>>

<<< **Patients will be swiftly assessed and supported to recover, in hospital and at home.** Patients will be reviewed by a senior doctor as soon as possible when they arrive in hospital. This will help patients return home on the same day if they do not need to stay in hospital (with ongoing support if they need it) or to move swiftly to the best bed for them. Patients who are in hospital will be moved between beds and wards as little as possible. Care for patients with multiple conditions will be coordinated by a named doctor, who will pull in other teams when needed. Health professionals will be supported to reflect on their own performance, focus on helping patients to recover, and empower patients to make informed decisions about their care. Patient experience will be valued as highly as clinical outcome.

Management structures will focus on coordination of care, patient experience and recovery. A senior doctor will take lead responsibility for making sure that hospitals deliver this coordinated approach to care. Teams will work in the interest of patients, with common goals and shared outcomes, supported by management structures that make working together easier than working apart. The information that we keep about patients' needs will be based on common standards, so it can be better accessed and understood by both patients and the professionals who support them. Patients with more than one complex or lifelong condition – including frail older people – will be at the centre of medical training.

How can we take forward the future hospital?

There will not be a one-size-fits-all model across communities. The Future Hospital model provides a template for local service design. Patients, professionals, politicians and communities should come together to adapt the model so that it meets their needs and circumstances. The RCP is now working with individual hospitals, local health boards and patients to put the Future Hospital model into practice. As this work progresses, we will need national and local action and support to promote change and remove barriers to delivering this innovative, patient-centred model of care.

How can the RCP help?

Influencing change in Wales

This RCP four-point action plan follows the publication of *Rising to the challenge*, which sets out our vision for acute care and the Future Hospital model in Wales.[2] Through our policy development, our work with patients, and our 'local conversation' visits to hospitals to meet physicians, trainees and health board managers, we are working to achieve real change across hospitals and the wider health and social care sector in Wales.

Setting standards for clinical care and health services

The RCP sets standards for a wide range of medical services, and works directly with healthcare teams to improve the quality of care that they provide for patients. From our innovative clinical audits to recent groundbreaking reports on asthma and end-of-life care, all our work is based on evidence and driven by what patients need. Patients are involved in all our work. They help us develop expert guidance on topics from patient experience and shared decision-making to standards for patient records. Through our Future Hospital Programme, we are driving changes to the way that the health service is organised, nationally and locally. Our network of 30,000 members allows us not just to lead debate, but to change the way that healthcare is delivered on the ground.

Delivering education and training

The UK has one of the best systems of medical education and training in the world, with the RCP at its forefront. Our focus on excellence in education helps physicians to deliver the highest standards of patient care. We work collaboratively to set the curricula for specialist doctors in training, and assess them to make sure they are able to provide the care that patients deserve. We support doctors to lead and to share their knowledge with the next generation of doctors. We provide leadership to the medical profession, working with our members and patients to define what it means to be a good doctor.

Public health and research

Drawing on the expertise of leaders in their field, the RCP offers evidence-based recommendations for addressing the major public health challenges that we face. Our ambition is to support people to lead healthier lives – whether through our coordination of the Alcohol Health Alliance, the knowledge of our Tobacco Advisory Group, or influential reports on obesity and health inequalities. We also promote research, so that the next generation of patients has access to innovative new treatments.

The RCP can provide expert advice to government, health boards, trusts and policymakers. If you would like more information on any of our work, email wales@rcplondon.ac.uk

Get involved

On the RCP website, you can read about existing examples of innovative practice and listen to doctors talking about how they achieved change in their hospital. You can also inform the RCP's work in Wales by sending us your comments, ideas and examples of good practice.

To help shape the future of medical care in Wales, visit:
www.rcplondon.ac.uk/wales

To tell us what you think, or for more information, email:
wales@rcplondon.ac.uk

About us

The RCP aims to improve patient care and reduce illness, in the UK and across the globe. We are patient centred and clinically led. Our 30,000 members worldwide, including 1,100 in Wales, work in hospitals and the community across 30 different medical specialties, diagnosing and treating millions of patients with a huge range of medical conditions.

Involving patients and carers at every step, the RCP works to ensure that physicians are educated and trained to provide high-quality care. We audit and accredit clinical services, and provide resources for our members to assess their own services. We work with other health organisations to enhance the quality of medical care, and promote research and innovation. We also promote evidence-based policies to government to encourage healthy lifestyles and reduce illness from preventable causes.

Working in partnership with our faculties, specialist societies and other medical royal colleges on issues ranging from clinical education and training to health policy, we present a powerful and unified voice to improve health and healthcare.

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Association of Breast Surgery
Response from: Association of Breast Surgery

[Via email]

Priorities for Health, Social Care & Sport Committee Consultation

Dear Sir or Madam

This response is being sent on behalf of the Association of Breast Surgery. Our regional representative for Wales, Richard Johnson (Consultant Surgeon, Princess of Wales Hospital), has canvassed the members in Wales and identified the following issues in breast care, for consideration as a priority in the next Assembly:

1) There is currently a critical shortage of breast radiologists in Wales. This is a UK wide problem and is affecting clinic capacity in Wales. At present the capacity to assess patients is being restricted by these shortages.
2) There is an issue around access to new cancer drugs in Wales, in light of the cancer drugs fund being continued in England.
3) It is anticipated that in the next 5 – 10 years a large number of breast surgeons in Wales are likely to be reaching retirement age. It is necessary therefore to look ahead to this time and put training/ recruitment in place now to avoid this becoming a serious issue later.

We hope this is of assistance. Please let us know if you require any further information.

Association of Breast Surgery

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Cŵn Tywys Cymru
Response from: Guide Dogs Cymru

[Via email]

Priorities for Health, Social Care & Sport Committee Consultation

Reablement and habilitation services for blind and partially sighted people in Wales

We have serious concerns about the decline in reablement and habilitation services for blind and partially sighted people in Wales.

The Welsh Government recognises more needs to be done and we are encouraged by references included in their recently published Codes of Practice in relation to the Social Services and Well–Being (Wales) Act and other matters. It was particularly helpful to see the references to habilitation in paragraphs 185-186 in the Part 2 Code and the reference to free reablement services for longer for people with visual impairment in paragraph 5.12 of the Part 4&5 Code.

We strongly recommend that the Committee should look at the state of reablement and habilitation services for blind and partially sighted people in Wales and assess whether Welsh Local Authorities are meeting the requirements of the new Codes of Practice.

With regard to children's services Guide Dogs Cymru recently published the attached Research Study of Habilitation Services for Children and Young People with a Vision Impairment in Wales. As a result of the report Guide Dogs Cymru is calling for:

1. Local authorities to raise the importance of habilitation services for children and young people with a visual impairment, and be reminded of their responsibilities in relation to Social Services and Well-being (Wales) Act.
2. For joined up working between health, education and social services to ensure a prompt and effective referral pathway to habilitation services (which is a requirement of the All-Wales Integrated Pathway for Children and young People (0-25 years) with Vision Impairment, and their Families).
3. For all local authorities to have access to a habilitation specialist. Welsh Local Authorities should be working towards 1 qualified habilitation specialist per 100 children and young people with a visual impairment.
4. For all local authorities (education and social services) to use the NatSIP Eligibility Framework for Scoring Support Levels when

delivering services to children and young people with a visual impairment and their families.

5. In addition to this, we would suggest that Local Authorities are required to evaluate the numbers of qualified staff needed to ensure that the identified provision is available to the CYP who require it – this includes both qualified teachers of the visually impaired (QTVIs) and habilitation staff.

If the Committee wants to improve health and well-being of a particularly vulnerable cohort of the Welsh population they will examine this issue and include it in the Forward Work Programme.

Guide Dogs Cymru

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Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Stonewall Cymru
Response from: Stonewall Cymru

Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Ymateb Stonewall Cymru

Cefndir

Stonewall Cymru yw'r elusen Cymru gyfan dros gydraddoldeb i bobl lesbiaidd, hoyw, deurywiol a thraws (LHDT). Sefydlwyd Stonewall Cymru yn 2003, ac rydyn ni'n gweithio â busnesau, sefydliadau cyhoeddus, ysgolion, Llywodraeth Cymru, Cynulliad Cenedlaethol Cymru ac ystod eang o bartneriaid mewn cymunedau ar draws Cymru i wella profiadau pobl lesbiaidd, hoyw, deurywiol a thraws.

Trosolwg

i. Mae Stonewall Cymru yn croesawu'r cyfle i ymateb i'r ymgynghoriad hwn ar flaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon.

ii. Cyn etholiadau y Pumed Cynulliad, cyhoeddasom Maniffesto Stonewall Cymru 2016: Cydraddoldeb i bobl lesbiaidd, hoyw, deurywiol a thraws yng Nghymru[1]. Mae'r maniffesto yn amlinellu blaenoriaethau ar gyfer cydraddoldeb ar draws meysydd allweddol megis iechyd a gofal cymdeithasol, addysg, a chydraddoldeb yng Nghymru ac yn rhyngwladol. Seiliwyd yr argymhellion ar ein profiad o weithio gyda rhanddeiliaid ar draws Cymru ac arolwg o flaenoriaethau ein cefnogwyr ar gyfer cydraddoldeb LHDT.

iii. Credwn fod awgrymiadau'r Pwyllgor am ei raglen waith yn cynnwys nifer o syniadau da ac yn mynd i'r afael â nifer o faterion o bwys. Amlinellwn syniadau ychwanegol am flaenoriaethau isod.

Rhaglen waith y Pwyllgor

iv. **Gofal iechyd i bobl draws yng Nghymru**

Mae pobl draws yn adrodd amrywiaeth o brofiadau negyddol gyda Gwasanaeth Iechyd Gwladol Cymru (GIG Cymru), gan gynnwys diffyg dealltwriaeth difrifol gan weithwyr gofal iechyd proffesiynol a llwybrau gofal caeth sy'n seiliedig ar ddealltwriaeth gyfyng o hunaniaeth rhywedd.

Mae pobl draws yng Nghymru sy'n cael diagnosis o ddysfforia rhywedd yn gorfod teithio i Lundain i gael gofal angenrheidiol, ac yn wynebu teithiau hirion, amseroedd aros sy'n aml yn fwy na'r terfyn statudol, costau uchel ac anawsterau o ran dod â theulu a chyfeillion cefnogol i gadw cwmni iddynt. Mae hyn i gyd yn gallu achosi straen ychwanegol yn ystod proses sy'n gallu bod yn anodd yn aml iawn. Mae darparu gwasanaethau hunaniaeth rhywedd arbenigol, hygyrch o ansawdd yn agos at gymunedau Cymru yn lleihau'r risgiau iechyd sy'n gysylltiedig â dysfforia rhywedd, gan gynnwys problemau iechyd meddwl a hunanladdiad.

Mae Pwyllgor Gwasanaethau Iechyd Arbenigol Cymru ar hyn o bryd yn ystyried sut i newid y llwybr gofal dysfforia rhywedd presennol. Gallai'r Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon archwilio'r broses hon, mesur cynnydd ac ystyried yn fwy cyffredinol i ba raddau mae GIG Cymru yn darparu'r gwasanaethau gofal iechyd effeithiol y mae gan bobl draws yr hawl i'w ddisgwyl.

[1] http://www.stonewallcymru.org.uk/cy/ein-gwaith/ymgyrchoedd/etholiad-2016

v. **Rhoi gwaed yng Nghymru**
Mae'r Pwyllgor Cynghori ar Ddiogelwch Gwaed, Meinwe ac Organau (SaBTO) ar hyn o bryd yn adolygu'r meini prawf ar gyfer rhoi gwaed, ac mae'r Grŵp Hollbleidiol Seneddol ar Roi Gwaed yn San Steffan hefyd yn archwilio'r achos am newid y meini prawf presennol, gan gynnwys y gwaharddiad 12 mis ar ddynion sy'n cael rhyw gyda dynion yn rhoi gwaed. Gall y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon gynnal ymchwiliad i gydfynd â'r gwaith hwn yng Nghymru, gan ystyried yr achos dros symud tuag at system yng Ngwasanaeth Gwaed Cymru o asesu risg unigol rhoddwyr gwaed.

vi. **Iechyd meddwl ac anghydraddoldeb**
Mae yna dystiolaeth gref bod pobl o grwpiau lleiafrifol neu'r rheiny sy'n wynebu gwahaniaethu â risg sylweddol uwch o brofi problemau iechyd meddwl na'r boblogaeth yn gyffredinol. Mae hyn yn wir am bobl ddu a lleiafrifoedd ethnig, menywod, pobl anabl a phobl lesbiaidd, hoyw, deurywiol a thraws. Gall y pwyllgor archwilio'r cysylltiad rhwng anghydraddoldebau cymdeithasol a phroblemau iechyd meddwl, ac i ba raddau mae gwasanaethau iechyd meddwl yng Nghymru yn diwallu anghenion grwpiau amrywiol.

vii. **Iechyd rhywiol yng Nghymru**
Gall y Pwyllgor archwilio iechyd rhywiol yng Nghymru a llwyddiant ymdrechion i atal lledaeniad heintiau a drosglwyddir yn rhywiol, gan gynnwys arolygiaeth o ddarpariaeth gwasanaethau iechyd rhywiol cyffredinol ac arbenigol ar draws Cymru. Dylid hefyd ganolbwyntio ar waith ataliol ym maes iechyd rhywiol a'r achos dros bolisïau ataliol megis addysg rhyw a chydberthynas ystyrlon ym mhob ysgol, darparu triniaeth Proffylacsis Cyn-Gysylltiol (PrEP) drwy GIG Cymru ar gyfer y rhai sy'n wynebu risg uchel o ddal HIV ac ymestyn y rhaglen frechu yn erbyn Feirws Papiloma Dynol (HPV) i gynnwys pob dyn ifanc er mwyn diogelu'r boblogaeth gyfan rhag HPV.

viii. **Gwahaniaethu yn y gweithlu iechyd a gofal cymdeithasol**
Canfu ymchwil Stonewall Cymru, *Agweddau Afiach* (2015)[2] bod 36 y cant o staff iechyd a gofal cymdeithasol yng Nghymru heb dderbyn unrhyw hyfforddiant ar gydraddoldeb ac amrywiaeth gan eu cyflogwr. Mae'r effaith yn glir: canfu'r ymchwil hefyd dystiolaeth o lefelau uchel o wahaniaethu gan staff iechyd a gofal cymdeithasol yn erbyn pobl LHDT, a diffyg dealltwriaeth difrifol o'u hanghenion fel cleifion. Gall y Pwyllgor archwilio y gwaith sy'n digwydd ar hyn o bryd o fewn GIG Cymru i daclo gwahaniaethu o bob math, yn arbennig i ba raddau mae rhaglenni hyfforddiant cychwynnol a datblygiad proffesiynol parhaus yn paratoi staff i ddiwallu anghenion gofal cymunedau amrywiol.

Gwybodaeth bellach
Am wybodaeth bellach, cysylltwch â:
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[2] http://www.stonewallcymru.org.uk/cy/ein-gwaith/ymchwil/agweddau-afiach

By virtue of paragraph(s) vi of Standing Order 17.42

Document is Restricted

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Cymdeithas Diwydiant Fferyllol Prydain
Response from: Association of the British Pharmaceutical Industry Cymru

Health, Social Care and Sport Committee
National Assembly for Wales
Pierhead Street
Cardiff
CF99 1NA

1st September 2016

1.1 Thank you for the opportunity to help inform the Forward Work Programme of the Health, Social Care and Sport Committee at the National Assembly for Wales.

1.2 We appreciate that, in the short-term, the Committee will focus its discussions around some of the major, strategic challenges and opportunities facing the NHS in Wales, particularly workforce planning, recruitment and retention. However, we would draw the committee's attention to another of the greatest challenges the NHS in Wales still faces: addressing the low level of patient access to innovative medicines.

1.3 We hope the development of a New Treatments Fund in Wales will help address the current early, inequitable access to innovation. However, the Committee may consider that they have an important role in reviewing:

- The creation of the new funding mechanism, ensuring equitable and consistent patient access to the latest medicines, no matter the disease area nor location, by monitoring the implementation of NICE and All Wales Medicines Strategy Group (AWMSG) guidance across all Health Boards and Trusts in Wales;
- The delivery of appropriate accountability for patients' rights to access new medicines, on the advice of their clinician; and
- The processes of the AWMSG, confirming they are appropriate, timely and transparent, supporting patients' consistent access to the latest clinically-proven and cost-effective medicines.

1.4 This third point has particular relevance given the increasing importance of precision medicines (also sometimes called "stratified" or "personalised" medicines), which aim to enable healthcare professionals to provide the right treatment, to the right person, at the right time and adhere to the principles of Prudent Healthcare. Precision medicines represent a "disruptive technology", but one which stands to benefit all parties, especially patients, over the next 5-10 years.

1.5 These medicines enable health systems to evolve from the era of mass, or blockbuster, usage of medicines into more tailored treatments, responsive to an individual's specific set of circumstances. Whilst the pharmaceutical industry is gearing up for this new era, other sectors in the healthcare landscape face significant challenges to their traditional ways of operating. If the undoubted benefits to patients are to be realised, all stakeholders will need to recognise and play their part.

1.6 Given their widespread ramifications, all parties need to be working together constructively and flexibly. NHS Wales and the Welsh Government will need to address the opportunities that these new medicines provide to patients' health in Wales. Balancing the short-term, additional resource need that may be required to introduce them, against the longer-term efficiency and productivity gains. The Committee may wish to consider these opportunities and challenges, following the publication of the Welsh Government Strategy on Genomics and Precision Medicines towards the end of 2016 / early 2017.

1.7 Globally, one of the greatest challenges facing society and healthcare is the threat of Antimicrobial Resistance (AMR). In addition to the human costs, there is a substantial economic cost from AMR. Globally, estimates suggest that, in 10-years AMR will cost $625 billion, reducing global GDP by 0.6%. However, the current scientific, regulatory and financial obstacles serve as a disincentive for pharmaceutical companies from developing new antibiotics.

1.8 Under the auspices of the AWMSG, Wales has recently held a *Citizens Jury* looking into *"What should we all be doing to fight antibiotic resistance?"* The Committee may choose to consider its report, when published, especially how best to address the wide-scale ramifications that protecting the wellbeing of Welsh citizens may have in a world where the current antibiotic arsenal is becoming less effective.

1.9 Finally, and potentially fitting with the Committee's early thoughts around efficiency within the NHS and modern management practices, the pharmaceutical industry is increasingly offering opportunities to work collaboratively, not only with healthcare professionals, but also with healthcare organisations and Government bodies. This work is closely regulated, but brings with it opportunities for securing experience in business and industry skills within NHS Wales, which may help in looking for efficiency opportunities, in both support and clinical services.

2.0 Thank you again for the opportunity to provide this response to the Committee. We look forward to working with you over the coming years.

Your contact details

Name:	Joanne Ferris
Are you responding as an individual or on behalf of an organisation?	Organisation
Organisation (and role if applicable):	Operations Manager – Association of the British Pharmaceutical Industry (ABPI) Cymru Wales
Telephone / Mobile number:	02920 454297 / 07912 540254
Email:	jferris@abpi.org.uk
Are you happy for the Committee to publish your submission	Yes

The Committee may wish to invite you to provide further evidence at a later date whether in writing, a formal evidence session, or as part of informal evidence gathering.

Are you happy for the Committee to contact you for this purpose?	**Yes**	

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Cymdeithas Clefyd Niwronau Motor
Response from: Motor Neurone Disease Association

motor neurone disease
association
cymdeithas
clefyd motor niwron

Response to the Health, Social Care and Sport Committee's consultation on future priorities

Introduction

i. Few conditions are as devastating as motor neurone disease (MND). It is a fatal, rapidly progressing disease of the brain and central nervous system, which attacks the nerves that control movement so that muscles no longer work. There is no cure for MND.

ii. While symptoms vary, over the course of their illness most people with MND will be trapped in a failing body, unable to move, swallow, and ultimately breathe. Speech is usually affected, and many people will lose the ability to speak entirely. Up to half of people with MND will also experience changes in cognition, some of whom will develop front-temporal dementia.

iii. There are up to 5,000 people living with MND in the UK at any one time, of whom approximately 210 live in Wales. It can affect any adult, but is most commonly diagnosed between the ages of 55 and 79. MND kills a third of people within a year of diagnosis and more than half within two years, typically as a result of respiratory failure. A small proportion of people experience slower progression and live with MND for longer, but survival for more than ten years is highly unusual.

iv. The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with approximately 90 volunteer-led branches and groups, and 3,000 volunteers. The MND Association's vision is of a world free from MND. Until that time we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and to die with dignity.

v. We wish to make two recommendations to the Committee: one for a possible inquiry within the next 18 months, focusing on diagnosis; and another in response to one of its suggestions for possible inquiry topics, where we recommend the committee investigate what may be a serious misunderstanding by the Welsh Government in its attempts at service redesign.

1. Right diagnosis, right time

i. We recommend that the Forward Work Programme of the Health, Social Care and Sport Committee include a detailed look at waiting times, including processes of referral and diagnosis for MND.

ii. People with MND – a rapidly progressive condition - need the right care in the right place at the right time. A timely and accurate diagnosis is a fundamental part of not just identifying but anticipating these needs and ensuring the best possible quality of life. The Association has given detailed consideration to this issue in Wales as part of its 2016 report *MND Won't Wait* (enclosed) from which the following analysis has been adapted.

iii. Wales has made some progress: the *Neurological Conditions Delivery Plan* of 2014 made diagnosis one of its key priorities.[1] In 2014, the Government also asked the Health Boards to distribute our *Red Flag* tool. Created with the Royal College of General Practitioners, this tool helps GPs identify possible signs of MND and refer to neurology.[2] However, in our last two surveys of people with MND in 2013 and 2016, one in five people with MND surveyed in Wales waited longer than a year after first having visited their GP to see a neurologist for diagnosis.

iv. Despite the creation of fast-track processes for people with rapid progression, once a referral is made delays still occur. The Welsh Government's *Neurological Conditions Delivery Plan Annual Report* from 2015 suggests that more than one in ten people with a neurological condition in Wales wait more than half a year for their first neurology outpatient appointments.[3]

v. In our report *MND Won't Wait*, we have asked the Welsh Government (and where appropriate Assembly members) to champion the prompt and accurate diagnosis of MND, including:
   - Requesting future neurological reporting includes data on diagnosis, so performance in this area can be monitored
   - Working with and incentivising care professionals and Health Boards to improve existing processes of referral and diagnosis
   - Supporting and evaluating the ongoing dissemination of the *Red Flag* tool to GPs and other health professionals by the Health Boards
   - Promoting the new Welsh-language version of the *Red Fl*ag tool.

vi. In our view, a sustained focus by the Health, Social Care and Sport Committee on waiting times, including for referral and diagnosis, would improve scrutiny in this area as well as generating ideas for optimising service delivery. This is turn would support a timely and accurate diagnosis of MND in more cases, enabling a better management of care and quality of life for people with this rapidly progressive disease.

2. Service redesign and 'primary care'

i. Our second recommendation is that the Committee should proceed with its proposed scrutiny of the Welsh Government's work on primary care.

[1] Welsh Government, Together For Health – A Neurological Conditions Delivery Plan, 2014
[2] MND Association, Red Flag diagnosis tool, 2013.
[3] Welsh Government, Together for Health Neurological Conditions Delivery Plan, Annual Report, 2015

ii. The Welsh Government is seeking to address the common challenges associated with an ageing population, including by shifting care out of hospitals and into the community. There is a clear case for making such changes, both to secure the financial sustainability of services and to improve experiences of care.

iii. However, the Welsh Government Strategy for Primary Care Services construes 'community services' as meaning 'primary care'. This is a major error: community services used by people with MND are mostly secondary or tertiary care. More specifically, the strategy defines primary care accurately, but goes on to assert that it also involves co-ordinating access to wider (ie secondary and tertiary) community services. This is not true for MND: care co-ordination is vital, but typically does not happen in primary care. We have previously warned of this error, for instance in our response to the green paper 'Our Health, Our Health Service'.

iv. The strategy aims to create 'primary care clusters' for planning services at population levels of 25,000 to 100,000. This is clearly too small for less common diseases such as MND, which has a prevalence of at most 7 per 100,000: these clusters will typically contain numbers of people with MND far too small to plan any viable services around. It may be correct to note that there is a consensus in favour of planning primary care at this population level, but this underlines the error of confusing community services overall with primary care.

v. We have conducted research into how care services for people with MND can best be arranged. Our Models of Care report identifies four key characteristics of MND care:
   - It must be co-ordinated
   - It must be multidisciplinary
   - It must involve MND specialism
   - It must involve community services.[4]

vi. The points about co-ordination and specialism go hand-in-hand: effective MND care is co-ordinated by a professional with expertise in MND, either in the community or in a hospital clinic. The multidisciplinary teams that deliver MND care are not co-ordinated from primary care, and we are concerned that this initiative from the Welsh Government may undercut existing arrangements, and lead to effective MND provision being deliberately designed out of the system.

vii. These concerns will be true not just of MND but of many rarer conditions, and no doubt some common ones. We recommend that the Committee investigate the impact of this strategy so far, and interrogate whether the apparent error contained within it is having, or will have, negative consequences for services. It might also ask: if the strategy is not having consequences for service redesign, good or bad, is it achieving anything?

[4] MND Association, Models of Care in MND, 2016

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September 2016

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: UNSAIN
Response from: UNISON

UNISON Cymru/Wales response: Priorities for the Equality, Local Government and Communities Committee

Introduction

1.1 UNISON Cymru/Wales is Wales' largest public sector trade union. UNISON has 100,000 members working in public services across Wales. We welcome the opportunity to feed into the National Assembly Wales priorities for the Health, Social Care and Sport Committee.

1.2 We represent full-time and part-time staff who provide public services, although they may be employed in both the public and private sectors.

1.3 UNISON's health service group welcomes members employed or contracted by the NHS in all four UK countries. Our members are from all non-medical occupational groups including: nurses and health care assistants; midwives; health visitors; administrative, finance and HR staff; ambulance staff including paramedics, technicians, control room and maintenance staff, therapy and healthcare science staff; estates and housekeeping staff; technicians and maintenance staff; commissioning staff; allied health professionals; scientific staff; healthcare managers.

1.4 This paper will outline issues UNISON has identified as being a priority. We will also respond to the Committee's Forward Work Programme proposals.

Mental Health

2.1 Mental health is a long standing and complex health issue. One in four people will experience mental health problems at some stage in their life. Mental health is still surrounded by prejudice and stigma. UNISON believes that mental health should be given equal status with other health and community services.

2.2 Mental health problems are increasingly associated with workplace stress which in turn leads to a significant number of lost work days. Workers in the public sector are expected to meet a growing demand on services at a time of financial pressure. This is an inevitable cause of stress and anxiety. UNISON is aware of public sector workers who have experienced mental health issues as a direct consequence of workplace stress. In addition, many public sector workers are involved in the delivery of services that those with mental health problems access.

2.3 As a union, we are dedicated to supporting the welfare of our members and have launched a campaign to establish mental health champions in workplaces across Wales. Our mental health champions have completed training designed and run with the assistance of a mental health practitioner.

2.4 Mental health champions are not responsible for providing counseling but are working to raise the profile of mental illness and elicit a cultural change in workplaces. Champions are working to ensure that effective action is being taken

against causes of workplace stress, and to ensure that employees suffering mental health problems are adequately supported by their employers.

2.5 The Health, Social Care and Sport Committee could consider the value of UNISON's mental health champion campaign for wider use across workplaces in Wales.

2.6 In addition, the committee could consider UNISON's proposal that the Welsh Government should appoint a Mental Health Minister. We believe a Mental Health Minister should have responsibility for improving access to mental health services, particularly for children and young people. A Minister could also focus on removing the stigma often associated with mental health.

Integration of Health and Social Care services

3.1 UNISON supports the committee's proposal to assess the progress of integration of health and social care. Our member's experiences demonstrate that there is a lot of work yet to be done in this area.

3.2 UNISON believes that the integration of health and social care would be of benefit to everyone. We want to be fully involved in discussions for the future of the care sector.

3.3 It is important, however, to recognise there are distinct challenges faced by health and social care as separate entities, and that culturally there is a lot of work to undertake to ensure a true integration of the services.

3.4 Allowing the private sector a greater role in social care has not increased the quality and choice for all patients. It has created an unregulated sector where there is little incentive for employers to invest in training.

3.5 In addition, we believe there should be an end to the two-tier workforce that exists between health and social care workers, and that raising the generally inferior social care employment conditions should be a priority.

3.6 Care workers, including those whose work is informal, must be provided with professional support. Additionally, we seek formal registration of care workers paid for by the Welsh Government.

3.7 Many of these principles are outlined in UNISON's Ethical Care Charter.[1] The over-riding objective behind the charter is to establish a minimum baseline for the safety, quality, and dignity of care by ensuring employment conditions which do not shortchange clients and ensure the recruitment and retention of a more stable workforce through more sustainable pay, conditions and training levels.

3.8 In order to achieve this, the focus needs to move away from profit-making in the care sector and realign with the publically delivered ethos of the Welsh NHS and so local authorities should directly deliver care services

[1] UNISON's Ethical Care Charter is available online: https://www.unison.org.uk/content/uploads/2013/11/On-line-Catalogue220142.pdf

3.9 An Ethical Care Charter could be implemented across NHS Wales and the care sector. The implementation of this charter would allow for greater parity between the workforce in health and social care.

3.10 Furthermore, in order to progress the integration agenda benchmarking needs to occur and areas of good practice need to be identified. This needs greater direction at governmental level.

Emergency Services

4.1 Whilst UNISON supports the committee's plan to consider Ambulance Services, we also believe emergency care in its' entirety should form a part of the Forward Work Programme.

4.2 There is rising demand on emergency care, including 999 and emergency departments. We believe that the committee could consider the Welsh Government's approach to educating people about the misuse of emergency services, or the alternative services that are available. Anecdotal evidence suggests that GP practices and nursing homes are amongst are amongst those who use emergency services inappropriately.

4.3 The Choose Well campaign has been given very limited funding and we are concerned at the ability to produce an effective, far-reaching campaign with such limited resource.

4.4 Furthermore, it is our view that the committee should keep a watching brief on the 111 services about to be launched in ABM Health Board.

Ambulance Services

5.1 UNISON agrees the committee should continue the work of the previous committee and examine the outcomes of the new clinical response model.

5.2 UNISON campaigned for the new model, although we have been made aware of concerns in rural areas such as Ceredigion and some parts of Powys where the eight minute clock for serious, life threatening red calls is being stopped by volunteer community first responders with ambulance resources sometimes 20 minutes behind.

5.3 Community first responders are clearly essential for effective working in rural areas especially around stroke, cardiac arrest and other life threatening conditions. However, the role of the community first responder is to stabilise patients in those early minutes and not to effectively nurse the patient for a 30-40 minute period before an ambulance arrives.

5.4 Ambulance workers are experiencing waits outside of Emergency Departments. This clearly has impacts on patients, but also on staff who over-run their shifts staying with patients. The new agreement to allow fresh crews to take over from those at the end of shifts only works where there is available resource – this is a particular issue in rural areas.

Conclusion

6.1 UNISON Cymru/Wales welcomes the opportunity to feed into the priorities for the Health, Social Care and Sport Committee.

6.2 We understand this consultation exercise is to set the future work for the committee and we would welcome the opportunity to feed in further detail and evidence to inquiries relevant to UNISON members and public services.

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Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Coleg Nyrsio Brenhinol Cymru
Response from: Royal College of Nursing

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1 September 2016

Dr Dai Lloyd AM
Health, Social Care and Sport Committee
National Assembly for Wales
Cardiff
CF99 1NA

Dear Dr Lloyd AM,

Thank you for your invitation to comment on the priorities for the Health, Social Care and Sport Committee.

The Committee has a crucial role in contributing to policy making in Wales by gathering evidence and views, scrutinising performance and developing recommended policy actions.

The Royal College of Nursing recognises that the time and attention of the Committee is necessarily limited and we have therefore suggested particular areas where we feel the Committee focus would add significant benefit to the policy area. In addition we have provided brief comment on the suggested areas of work already identified by the Committee.

In addition to these comments on priority areas we would ask that the Committee consider carefully the merits of ensuring that a sufficiently long enough consultation period to external organisations to allow for a considered response.

Continued…

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Mae'r RCN yn cynrychioli nyrsys a nyrsio, gan hyrwyddo rhagoriaeth mewn arfer a llunio polisïau iechyd

The RCN represents nurses and nursing, promotes excellence in practice and shapes health policies

Mae'r Coleg Nyrsio Brenhinol yn Goleg Brenhinol a sefydlwyd drwy Siarter Frenhinol ac Undeb Llafur Cofrestr Arbennig a sefydlwyd o dan Ddeddf Undebau Llafur a Chysylltiadau Llafur (Cydgrynhoi) 1992
The RCN is a Royal College set up by Royal Charter and a Special Register Trade Union established under the Trade Union and Labour Relations (Consolidation) Act 1992

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A short consultation period does allows the Committee to move quickly into the scrutiny process but it may well compromise the quality and comprehensiveness of the evidence.

It would also be helpful to stagger the response dates to public consultations where the Committee is undertaking several consultations at once. For example the Committee has asked for comment winter pressures, priority areas and workforce concerns all within the same timeframe.

The Royal College of Nursing always endeavours to respond accurately and helpfully to the Committee. Staggering the response dates between each consultation could aid immeasurably in ensuring our expert members are effectively mobilised to provide the information you require.

I do hope you find this response helpful and we would be delighted to meet further to discuss.

Kind regards

Yours sincerely

TINA DONNELLY CBE, TD, DL, CCMI
DIRECTOR, RCN WALES

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Coleg Nyrsio Brenhinol Cymru
Royal College of Nursing Wales

Royal College of Nursing Wales Suggested Priority Areas

On the 14th September at the National Assembly for Wales the Royal College of Nursing Wales will be launching its new campaign **Leading Nursing, Shaping Care.**

Leading Nursing, Shaping Care sets out the areas of nursing and health and social care policy that the Royal College of Nursing Wales sees as a critical priority for the Welsh Government, the National Assembly for Wales and indeed for the Royal College itself. They are:

- Implementing and Extending the Nurse Staffing Levels (Wales) Act 2016

The 2016 Act was a historic first for patient care in the UK. The evidence is clear that nursing numbers and skills have a significant impact on patient outcomes including mortality. The Act protects patient lives and safety. The Royal College of Nursing Wales will be closely engaged with the Welsh Government's forthcoming consultation on the guidance that supports the implementation of this Act.

In addition a number of important suggestions have been made (including by the Health and Social Care Committee of the Fourth Assembly) about how this Act could be extended to safeguard patients in other areas including children, maternity and mental health inpatient care and care in the community. It is the view of the Royal College of Nursing that these potential areas should be seriously examined with a view to extending the Act as soon as possible. The Committee may well have a role in facilitating this examination.

- Investment in Nursing Education

The Government has taken the decision in England to abolish student nursing bursaries. The Royal College of Nursing has serious concerns that this will have a significant negative impact in the following areas:

  - Ability of potential students to undertake nursing as a degree
  - Viability of offering nursing as a degree for Higher Education Institutions
  - Shortage of registered nurse affecting patient care in the NHS and independent sector
  - Damage to sustainable workforce planning for healthcare professionals and health service planning and development.

The Scottish Government has ruled this option out in Scotland. The Welsh Government has taken no decision as yet.

- Nurse Leadership at Every Level

Nursing Leadership is a fundamental part of improving outcomes for people who receive care. Clinical Leadership empowers nurses to reflect on practice, improve care and adopt innovative approaches. Are there sufficient numbers of nurses with advanced and extended skills practicing in the community to provide the level of care required in Wales? What of specialist or consultant nursing numbers? As financial pressure increase on the NHS there is a pressure to stop appointing to these posts or reduce the number hours practitioners can work at this level. A national examination of the specialist and consultant nursing workforce in Wale sis long overdue.

Interpersonal leadership should provide nurses with the ability to communicate with, trust and support each other. Organisational Leadership drives effective succession planning, the empowerment of the nursing workforce and the creation of a positive working environment. The lack of national succession planning for Nurse Director posts has left wales vulnerable and reliant of recruitment from other UK nations.

- Value Nursing

There are many ways to recognise and celebrate the value of nursing as a profession. Foremost amongst these of course is are Fair Pay and Protection of Terms & Conditions. In addition there is the important area of access to continuous professional development (CPD). The NHS and other employers very often does not grant nursing the same access to CPD as medical colleagues and both patient care and personal professional development suffer as a result.

The first area of concern the Royal College of Nursing will be highlighting the sharp and alarming drop in numbers of District Nurses in Wales. If the decline in numbers continues at the current pace there will no District Nurses left in Wales within 5 years.

Is the role of the District Nurse valued? Is delivering healthcare in the community valued? If this is a concern to the Committee we would most strongly suggest an Inquiry is held into the demise of the District Nurse, community nursing in Wales or more broadly care delivered in the home.

Royal College of Nursing Wales comment on Committee Suggested Priority Areas

- Integration of Health and Social Care services

We would agree this is a priority area for discussion. The national direction of travel is unclear to those in the service and discussion appears dominated by consideration of local government mergers rather than patient care.

- Waiting Times

Waiting times are a significant indicator or service efficiency. However any discussion of waiting times will invariably lead to discussion of factors that influence waiting times e.g. the workforce, capacity (both in the acute and community setting) and demand (leading to discussion of public health etc). The discussion then becomes very broad.

It may be more beneficial to the Committee therefore to either examine one of these factors specifically or to pick a specific areas e.g. orthopaedics. etc. to ensure a more focused outcome.

- Primary Care

We would agree this is a priority are for consideration.

  - access to primary care
  - quality of primary care and performance management
  - the primary care team and workforce issues.
  - interaction with acute or secondary care and with care in the community

- Efficiency within the NHS and modern management practices

This is certainly an important area to consider.

- Neonatal services

We would agree this is a priority are for consideration. The Bliss report earlier this year highlighted significant concerns over the provision of neonatal care across Wales including nursing shortages and lack of investment in the future workforce.

In addition there is significant remodelling of services underway in each Health Board which would benefit forma national perspective.

- Use of antipsychotic medication in care homes

This is an important area of consideration in its own right but potentially the Committee may also wish to consider the administration of medicine more generally which raises further areas of concern to patient care.

- Ambulance Services

It would be provident to follow-up on the similar Inquiry undertaken by the Health and Social Care Committee in the Fourth Assembly.

- Loneliness and isolation among older people

This is an important area to consider. In terms of organisations submitting the most useful evidence it would be helpful to be clear in terms of reference whether the Committee wishes to exclude or include related mental health issues such as depression and areas such as substance misuse.

- Gambling addiction

This is certainly an important area to consider.

- Sport and public health

If the potential Inquiry were widened to “public health and physical activity” the Royal College of Nursing would certainly recognise this a very important priority area for investigation.

Increasing participation in Sport is, of course, a significant part of increasing physical activity and thus public health. However physical activity understood more broadly (which would include leisure and work activities such as walking to work, gardening etc) is undertaken by the whole population and the public health challenge is to increase this whilst recognising that different approaches work best with different people. We would welcome the opportunity to contribute to such an Inquiry.

ABOUT THE ROYAL COLLEGE OF NURSING (RCN)

The RCN is the world's largest professional union of nurses, representing 430,000 nurses, midwives, health visitors , health care support workers and nursing students, including over 25,000 members in Wales. RCN members work in a variety of settings including the NHS and the independent sector. The RCN works locally, nationally and internationally to promote standards of care and the interests of patients and nurses, and of nursing as a profession. The RCN is a UK-wide organisation, with its own National Boards for Wales, Scotland and Northern Ireland. The RCN is a major contributor to nursing practice, standards of care, and public policy as it affects health and nursing.

Oddi wrth / From: **Parch./Revd Gethin Rhys**
Swyddog Polisi'r Cynulliad Cenedlaethol / National Assembly Policy Officer

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Cytûn

Response from: Cytûn

Oddi wrth / From: **Parch./Revd Gethin Rhys**
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1 Medi 2016

Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

1. Ysgrifennir yr ymateb hwn ar ran Cytûn – Eglwysi Ynghyd yng Nghymru, yn dilyn ymgynghoriad gyda'n haelodau. Ceir rhestr lawn o'n haelodau yma: http://www.cytun.org.uk/ni.html Mae ein haelod fudiadau yn cynnwys rhyw 172,000 o aelodau unigol ar draws Cymru, ynghyd â miloedd yn rhagor sy'n cefnogi eglwys leol neu un o'r mudiadau Cristnogol eraill mewn gwahanol ffyrdd.

2. Rydym yn gyffredinol gefnogol i awgrymiadau cychwynnol y Pwyllgor am ei raglen waith ar gyfer 2016-21, yn enwedig yr ymchwiliad i unigrwydd ymysg pobl hŷn.

3. Yn ychwanegol, hoffem awgrymu cynnal yn ystod y tymor hwn ymchwiliad i **ofal dementia** yn y cartref ac mewn lleoliadau preswyl, a ffyrdd o asio darpariaeth anffurfiol gan eglwysi a sefydliadau cymunedol eraill â darpariaeth statudol. Rydym fel eglwysi yn darparu cryn dipyn o ofal atodol anffurfiol i bobl sydd yn byw gyda dementia, ac yn sgîl hynny fe fuom yn cyfrannu at waith Cyngor Gofal Cymru yn llunio canllawiau ar gyfer gweithwyr yn y maes, a rydym yn croesawu'r gwaith a gynhyrchwyd ganddynt. Mae gofal ysbrydol yn bwysig yn y cyd-destun hwn, yn ogystal â gofal corfforol a meddyliol, a chroesawn y gydnabyddiaeth o hynny yn y canllawiau. Credwn y byddai'n fuddiol, ar ôl dwy flynedd o weithredu'r canllawiau hyn, cynnal ymchwiliad ffurfiol i sut y maent yn gweithio a pha welliannau y gellir eu cynnig.

4. Ar hyd yr un llinellau, hoffem awgrymu yn ystod y tymor ymchwiliad ôl-ddeddfwriaethol i effaith Deddf Gwasanaethau Cymdeithasol a Llesiant (Cymru) 2015 ar **ofalwyr di-dâl yn y gymuned**. Mynegwyd peth gofid am sut y byddai'r criteria cymhwysedd newydd yn effeithio ar ofalwyr a chredwn y dylid ymchwilio i hyn ar ôl rhyw ddwy flynedd o weithredu'r drefn newydd.

5. Rydym yn croesawu'r bwriad i ymchwilio i **ddibyniaeth ar hap-chwarae**. Fe fydd gan ein haelod-fudiad, Y Stafell Fyw, gyfraniad pwysig i'w wneud i'r ymchwiliad hwn yn sgîl ei waith dan yr enw Curo'r Bwci - http://www.livingroom-cardiff.com/beattheodds/beattheodds.html

6. Rydym yn ymwybodol o faes gwaith eang a phwysig eich Pwyllgor, ac y bydd blaenoriaethu ymhlith yr holl bynciau pwysig a ddaw i'ch sylw yn anodd. Dymunwn

Oddi wrth / From: **Parch./Revd Gethin Rhys**
Swyddog Polisi'r Cynulliad Cenedlaethol / National Assembly Policy Officer

yn dda i chi yn eich gwaith ac edrychwn ymlaen at allu eich cynorthwyo, ac at elwa o ffrwyth eich llafur.

Gethin Rhys
Swyddog Polisi

Gellir cyhoeddi'r ymateb hwn yn gyflawn.

By virtue of paragraph(s) vi of Standing Order 17.42

Document is Restricted

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Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: CLIC Sargent
Response from: CLIC Sargent

CLIC Sargent submission to Consultation on Priorities for the Health, Social Care and Sport Committee – September 2016

Introduction

1. CLIC Sargent is the UK's leading cancer charity for children and young people, and their families. We provide emotional, practical, financial and clinical support to help them cope with cancer and get the most out of life. We are there from diagnosis onwards and aim to help the whole family deal with the impact of cancer and its treatment, life after treatment and, in some cases, bereavement. Last year we supported over 7,000 children, young people and their families.

2. CLIC Sargent plays a key role in providing care and support to the children and young people diagnosed with cancer in Wales each year.[1] Last year we supported more than 280 children and young people with cancer and their families from Wales. We gave over 270 grants to a value of over £55,000 to help families deal with the financial impact of cancer. CLIC Sargent invests £300,000 in direct services and financial support to children and young people with cancer in Wales each year and our services in Wales include:
   - We contribute to the funding of three Clinical Nurse Specialists and a Paediatric Social Work post supporting patients in shared care arrangements throughout North Wales
   - We have a fund a Young Persons Social Worker for the North Wales region.
   - We have a Young Person's Outreach Team in South Wales consisting of two Young Person's Social Workers and a Care Support Worker supporting 16-24 year olds affected by cancer.
   - We fund a Paediatric Neuro-Oncology Nurse Specialist Key Worker in South Wales.
   - We cover the paediatric principal treatment centre in Cardiff as well as supporting patients in shared care arrangements in Bangor, Wrexham and Rhyl.

3. CLIC Sargent welcomes the opportunity to input into the Consultation on priorities for the Health, Social Care and Sport Committee. There are a number of priorities concerning children and young people with cancer in Wales that we would appreciate the Committee looking into. They include:
   - The financial impact of cancer for young people and their families.
   - Teenagers and young adults (TYA) with cancer being able to access the care they require, in appropriate settings.
   - Children, young people and parents' experiences of cancer diagnosis.
   - Lack of data on patient experience for children and young people.

[1] There are around 170 new diagnoses in Wales each year in the 0-24 age-group.

The financial impact of cancer for young people and their families

On 1 September, to coincide with Childhood Cancer Awareness Month, CLIC Sargent published new research into the financial impact of cancer for young people and their families.

Our research, *Cancer costs*: *the financial impact of treatment on young cancer patients and their families*, explores the rising costs for young people and their families when they are going through cancer treatment, as well as the decreasing income. Please find attached an embargoed copy of the report.

The **key findings** of the report include:

- Parents spent an average of £600 additional expenses a month during their child's active treatment.
- Three in five (61%) parents had accumulated some form of debt as a result of their child's cancer diagnosis, mostly owed to family and friends or to credit card companies. One in six (17%) had borrowed over £5,000.
- As a result of their child's cancer diagnosis, two in five (42%) parents stopped working, half (49%) experienced a loss of earnings, and almost a third (29%) felt they were able to do less at work.
- The top three financial worries for parents were energy bills, car-related costs and parking.
- Three-quarters (75%) of parents and over half (54%) of young people surveyed felt that managing their finances during treatment caused them additional stress and anxiety.
- Almost a third of parents (29%) were not offered parking exemptions at their main treatment hospital, despite government guidance to hospitals.
- Nearly half of young people who were in higher or further education deferred or suspended their studies during treatment. Almost a third (29%) ended their studies completely, while one in six (16%) continued in a reduced or part time way.

Our **key recommendations for change** for governments across the UK are:

1. The government should conduct an urgent review of all travel assistance available to parents and young people, and make recommendations for reform by the end of 2017.
2. Financial services and energy companies should review their vulnerable customers' policies to ensure they include parents of children with cancer and young cancer patients.
3. The government should review the financial support available for young cancer patients and their parents who are struggling to meet the costs of their energy bills.

We don't think it is right or fair that young cancer patients and their families are impacted to such an extent financially because of their cancer diagnosis. We would encourage the Committee to look into this issue more deeply.

Teenagers and young adults (TYA) with cancer being able to access the care they require in appropriate settings

4. Despite the fact that national standards for the management of TYA have now

been put in place, minimal progress has been made to increase access to the specialist support available to the 16 – 24 age group. TYA multi-disciplinary teams (MDTs) exist in South Wales (at University Hospital of Wales) and in the Clatterbridge hospital on the Wirral (to which North Wales young people would are referred). The recommendations that all TYA diagnosed with cancer should be referred to the TYA MDT's is not being complied with in many cases. For example North Wales Cancer Network has identified 10 young people who have been diagnosed with cancer in the past year who have not been referred to the TYA MDT. Analysis of this information is on-going to identify why this is the case. Overall in Wales we believe that at least a third of young people with cancer are not referred to their specialist TYA MDT for support, creating an inequity in service and depriving young people of choices in their cancer care delivery and support.

5. CLIC Sargent and Teenage Cancer Trust have been working together to raise awareness of this issue and we support their submission to the Committee for this consultation as well. We have written together to the Cabinet Secretary for Health, Wellbeing and Sport on this issue (the text of this letter is pasted below).

Dear Mr Gething

Congratulations on your re-election and appointment as Cabinet Secretary, it's great to have someone with your background and knowledge about cancer services in Wales in this important role and we very much look forward to working with you.

Teenage Cancer Trust and CLIC Sargent are the two largest charities representing the needs of children and young people with cancer in Wales and across the UK. We are members of the Wales Cancer Alliance and work in partnership to influence policy and deliver in practice to ensure all children and young people with cancer have access to services that meet their needs and support them to live their lives to their full potential.

The next few years are critical to embedding changes in Welsh Cancer Services that could make real improvements for young people with cancer and their families; and there is much to be done. There are around 180 new diagnoses of cancer each year in 0-24 year olds, with many more on active treatment at any one time. Although survival rates are over 80% on average cancer remains the single largest cause of death from disease in children in the UK and for some cancers survival is as low as 50%. Very few young people are being picked up by traditional methods of assessing services, like peer review and the Cancer Patient Experience Survey, and many children and young people are having to travel hundreds of miles from home to access support.

We've been very disappointed that children, teenagers and young adults have had so little focus in the Cancer Delivery Plan and lack of priority gives to these areas of improvement. This must change in order for young people with cancer to have their needs met.

A commitment from the Welsh Government to referring every patient to a paediatric or teenage and young adult MDT should be made a priority for health boards which they are measured against. This one commitment will help NHS services know where

each patient is, be able to offer them support and access to research as well as follow up with them after treatment. It will also enable us, as charities, to provide much needed specialist care and support to them through our work with the MDTs are the designated Principal Treatment Centres.

We call on you to champion the needs of this vulnerable group of patients who too often fall between services and priorities leaving them disadvantaged and missing out on support that is available to them.

If you would like to meet to discuss this then we are very happy to do this at your convenience. We're aware the Cancer Delivery Plan is due to be refreshed and so are keen that this one commitment is part of any new plan or strategy.

6. In order to ensure improvements in outcomes for TYAs it is essential that action is taken to ensure that the recommendation for referral to specialist age appropriate care and support to be enforced. ***This is the single most important action that could be taken on behalf of young people with cancer in Wales.*** Without all Health Boards being held to account for their inaction to achieve 100% referral of 16-24 year olds to the appropriate TYA MDT, outcomes cannot be improved within this age range. Young people will also not be able to access specialist support services or relevant clinical trials until this is achieved.

Children, young people and parent's experiences of cancer diagnosis

7. In the current plan there are some important actions around earlier detection, such as a commitment to 'raising GP awareness of symptoms to promote prompt referrals in line with national guidance, local pathways and waiting times standards', 'Auditing the pathway for each person diagnosed with advanced cancer and act on findings to improve services for early diagnosis' and 'Developing acute oncology services to support the needs of people admitted as emergencies'.

8. CLIC Sargent research, *Best Chance from the start*, we highlighted the fact that children aged 0 to 14 in England[2] are more than twice as likely to be diagnosed through emergency presentation as young people aged 15 to 24 (53%), for whom 25% are diagnosed through emergency presentation, and older adults, who have emergency presentation rates of 20%3. The impact of the disproportionate rate of emergency presentations on prognosis and outcomes for children has not been established. However, we do know that stress and anxiety caused by delay can have a profound effect. In addition, our research also found that Young people and their families have reported not feeling listened to or taken seriously when they first presented their symptoms to their GP, and that GP's themselves ranked lack of training available as one of their top three barriers to identifying cancer in children and young people.

9. We believe that clear commitments are needed to tackle disproportionate rates of emergency presentation, including undertaking a Significant Event Analysis for patients diagnosed following emergency presentation, improving initial and ongoing training in children and young people's health for primary care

[2] This routes to Diagnosis study only looked at England data although we would expect the picture would be very similar in Wales and the other UK nations
[3] http://www.clicsargent.org.uk/content/better-care-young-cancer-patients-diagnosis, Page 7

professionals and reporting on the level of access that GP practices have to paediatric and young people's health expertise.

Lack of data on patient experience for children and young people

10. It is regrettable that the recently published Wales Cancer Patient Experience Survey did not capture the experiences of patients who are under 16 years old. Patient experience is rightly valued within the health system in Wales, however, children do not have this opportunity to share their experiences and the lack of information about the current state of patient experiences of children under the age of 16 is a significant barrier to improvement. Without national patient experience data it is difficult to develop meaningful indicators to drive improvements in children's cancer patient experience. NHS England has said they will develop a methodology to collect data on patient experience for under 16s in 2017[4]. We believe that Wales should make a similar commitment. CLIC Sargent has also already done work on what a methodology for collecting data from patients who are under 16 could look like and would be happy to share this with the Welsh Government.

11. Although the Wales Cancer Patient Experience Survey did include 16 – 24 year olds, the number of young people responding to the survey is low. One reason for this might be that the survey is not age appropriate and that young people find it difficult to engage in an adult survey. The Cancer Patient Experience Survey which is operated by the NHS in England has consistently shown that TYA with cancer report poorer patient experiences than older adults. Consequently, it is critical to gauge whether this is also the case in Wales, and to take action to address any inequality of patient experience for TYA.

For further information, please contact:

Jane Darragh, Research and Policy Manager
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Simon Morgan-Jones, Services Manager for Wales
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[4] Achieving World-Class Cancer Outcomes: Taking the strategy forward, Five Year Forward View, NHS England, May 2016

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Y Samariaid Cymru
Response from: Samaritans Cymru

Samaritans Cymru consultation response

Priorities for the Health, Social Care and Sport Committee

About Samaritans Cymru:	Samaritans is a registered charity aimed at providing emotional support to anyone in emotional distress. In Wales, Samaritans work locally and nationally to raise awareness of their service and reach out into local communities to support people who are struggling to cope. They seek to use their expertise and experience to improve policy and practice and are active contributors to the development and implementation of Wales Suicide and Self Harm Prevention Action Plan 'Talk to Me 2'.
Contact:	Emma Harris (Policy & Communications Officer)
Email:	[redacted]
Telephone:	[redacted]
Website:	www.samaritans.org/wales
Address:	Samaritans, Floor 2, 33-35 Cathedral Road, Cardiff, Wales, CF11 9HB

Samaritans Cymru welcomes the opportunity to respond to the consultation on Priorities for the Health, Social Care and Sport Committee.

Samaritans Cymru exists to reduce the number of people who die by suicide. Whilst suicide can often be viewed in isolation, it is important to identify the breadth and complexity of risk factors which preclude suicide and suicide attempts. Actions to mitigate suicide risk support the wider public health initiative of increasing the resilience of communities, increasing public awareness and improving access to appropriate emotional or mental health support services.

Key Priority Areas

1) Implementation of Talk to Me 2: Action Plan

We have been active contributors to the Suicide and Self Harm Prevention Strategy for Wales, Talk to Me 2. However, there needs to be a clear and revised framework for its implementation.

- **Objective 1: Priority Action 6** - *Ensure the engagement of LHBs and local authorities in Regional Multi-Agency Suicide Prevention Fora*

As a priority, under objective 1, we support the action of ensuring engagement of local health boards and local authorities in Regional Multi-Agency Suicide Prevention Fora.

Suicide is the result of many different factors which interact in complex ways. Suicide prevention therefore requires the action of many agencies across sectors. This is why suicide prevention strategies and action plans are a key component in reducing suicide. We need to act locally to make sure the most effective ways of reducing suicide are in place.

The TTM2 priority action concerning Regional Multi-Agency Suicide Prevention Fora must be given precedence throughout the life of the strategy. The guidance detailing the creation and implementation of RMASPFs across local communities in Wales must be monitored and regularly reviewed.

Every local area in Wales has a unique profile: a unique geography, economy, and population. It follows that a profile of deprivation and associated suicide risk will also vary between local populations.

The link between socio-economic deprivation and increased risk of suicide is well established. Previous academic studies have shown us, for example, that men from the lowest social class living in the most deprived areas are at approximately ten times greater risk of suicide than those in the most affluent group living in the most affluent areas.

Local implementation of suicide prevention plans is vital for efforts to reduce suicide rates in Wales.

- **Objective 2: Priority Action 8** - *Improve the health care response to self harm*

Self harm is an important cause of admission to hospital and a risk factor for suicide. We need improved care and follow-up support for people attending A&E and returning home after a self-harm or a suicide attempt.

Self-harm among young people in Wales is currently at a five-year high. More than 1,500 patients aged between 10 and 19 were treated at Welsh hospitals between 2013 and 2014. Almost four times as many girls as boys were admitted for self-harm treatment in Wales in 2014.

For many individuals attending A&E for self-harm, this may be their first interaction with primary care staff. Those who are experiencing emotional distress or symptoms of mental illness need to access the appropriate care pathway through primary or secondary mental health support. However, due to a lack of mental health training and provision of staff and services, individuals at risk of continuing self harm or suicide are often discharged with no follow-up support.

It is vital that we ensure appropriate training is given to priority care providers who first come into contact with people who are at risk of self harm or suicide. This needs to be in conjunction with appropriate follow-up care for those individuals who are at risk and discharged from A&E. This should be viewed as a form of prevention.

2) **Improving Access to Psychological Therapies**

Timely access to psychological therapies has been identified by primary mental health staff as the top barrier to the successful delivery of primary mental health services in Wales. People with mental health problems, health professionals and charities are united on this issue - access to psychological therapies must be improved. As members of the Wales Alliance for Mental Health, we are working together to advocate for better access to psychological therapies in Wales. Access to the right talking therapy at the right time can be a form of prevention for those who may in the future need a more acute service and be at risk of suicide.

We would like to see an effective and full implementation of the Wales Psychological Therapies Plan for Adult Mental Health. We support the shared policy objectives of 'Putting Mental Health on the Agenda' of introducing waiting time measures for English and Welsh language psychological therapies across primary and secondary care and recording and publishing patient outcome data in relation to psychological therapies.

3) **Loneliness and Isolation among older people**

Older people are especially vulnerable to loneliness and isolation which can have a serious effect on mental and physical health. Half of those over 75 in the UK live alone[i] and 1 in 10 experience intense loneliness[ii]. Loneliness and

isolation is a major public health issue which increases the risk of mental health conditions and suicide.

Older people can become socially isolated for a variety of reasons such as poor health, no longer being the hub of their family, retirement, lower income, becoming a carer, and the deaths of spouses and friends.

One of the barriers to tackling loneliness and isolation in older people is difficulty in identifying those who are most at risk.

Studies have shown that people who are socially isolated experience more stress, have lower self-esteem and are more likely to have sleep problems than people who have strong social support. Loneliness and isolation puts individuals at greater risk of cognitive decline and is a risk factor for suicide in older age. Worldwide, the highest rate of suicide is seen in those over the age of 75, yet suicide prevention in older people is often a neglected area.

We believe that Loneliness Mapping should be considered as a priority action in order to reduce the rate of loneliness and isolation in Wales. Loneliness mapping allows local services and local authorities to work collaboratively to use existing data to predict where the most lonely and isolated residents live, allowing limited resources to be targeted at people and places that need them most. Loneliness mapping should be viewed as a preventative measure which can alleviate this risk in the most vulnerable individuals.

Essex County Council was the first to design and implement the use of loneliness mapping which was then further adapted by Gloucestershire County Council. Following on from this, the University of Kent and the charity, Campaign to End Loneliness, analysed the success of mapping and the positive benefits it yielded[iii].

4) **Alcohol Misuse in Wales**

In its primary context, alcohol can contribute to the development of mental health problems and can hinder or worsen diagnosed mental health management. Individuals may use alcohol to self-medicate or to manage their mental health. If suicidal ideation features as a symptom of a diagnosed or undiagnosed mental health condition, alcohol can be a risk factor. Alcohol misuse reduces inhibitions and makes acting on suicidal thoughts more likely, with as many as 65% of suicides being linked to excessive drinking. Misuse of alcohol increases the risk of suicide, particularly for men, who are 8 times more likely to kill themselves under the influence.

We believe that the introduction of Minimum Unit Pricing (MUP) would help save lives and make a significant contribution to public health in Wales, In

addition to this, we have pushed for suicide prevention training for frontline staff who work in addiction services and for others such as police officers and health officials. More widely, we believe that whilst most people are aware that drinking too much alcohol is bad for us, many are unaware of the long term effects. In particular, evidence shows that people who consume high amounts of alcohol are vulnerable to higher levels of mental health problems. Young people, men, and socially isolated and/or deprived individuals are high risk groups and as such, measures should be taken to ensure effective and targeted campaigning.

[i] **'Loneliness Research'** Retrieved from http://www.campaigntoendloneliness.org/loneliness-research/

[ii] '**Find out how we're working together to end loneliness in later life**' The Campaign to End Loneliness: London

[iii] Goodman, A.,Adams, A.,& Swift H.J. 2015.**Hidden citizens: How can we identify he most lonely older adults?** The Campaign to End Loneliness: London

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: ASH Cymru
Response from: ASH Wales

ASH Wales Cymru consultation response –

Priorities for the Health, Social Care and Sport Committee

About ASH Wales Cymru

1. ASH Wales is the only public health charity in Wales whose work is exclusively dedicated to tackling the harm that tobacco causes to communities. Further information about our work can be found at http://www.ashwales.org.uk/

2. We are engaged in a wide range of activities including:
   - Advocating for tobacco control public health policy
   - Undertaking tobacco control research projects
   - Training young people and those who work with young people to provide factual information about the health, economic and environmental effects of smoking
   - Engaging young people and professionals working with young people through the ASH Wales Filter project
   - Bringing health information and advice to the heart of the community

3. We also oversee the Wales Tobacco or Health Network (a network of over 300 individual members) and the Wales Tobacco Control Alliance

(an alliance of 35 voluntary and professional bodies in Wales), providing forums for sharing knowledge and best practice.

4. ASH Wales has no direct or indirect links with, and is not funded by, the tobacco industry.

Priorities for the Health, Social Care and Sport Committee

5. ASH Wales Cymru believes supporting tobacco control efforts to reduce smoking prevalence in Wales should represent a key priority area for the Health and Social Care Committee during the fifth Assembly

6. Smoking continues to be the largest single preventable cause of ill health and death in Wales, causing around 27,700 hospital admissions and 5,450 deaths each year[1]. Smoking harms nearly every organ of the body and dramatically reduces both quality of life and life expectancy. Smoking causes lung cancer, respiratory disease and heart disease as well as numerous cancers in other organs including lip, mouth, throat, bladder, kidney, stomach, liver and cervix. Twenty times the number of smokers that die each year suffer from disease and disability caused by their smoking[2,3]. Research looking at the social care needs of smokers found on average they needed care and support nine years earlier than ex-smokers and those who had never smoked[4].

7. Smoking therefore clearly has major repercussions for the health of the individual smoker but the activity has wider consequences too. There are also considerable health risks to non-smokers via exposure to second-hand smoke (SHS) for instance. SHS, also called 'passive smoke' and 'environmental tobacco smoke', comprises 'sidestream' smoke from the burning tip of the cigarette and 'mainstream' smoke which is smoke that has been inhaled and then exhaled by the smoker. Research suggests an estimated 603,000 deaths worldwide

were attributed to SHS in 2004, which was approximately 1.0% of worldwide mortality[5]. In addition, it has been estimated that domestic exposure to SHS in the UK causes around 2,700 deaths in people aged 20-63 and a further 8,000 deaths a year among people aged 65 years and older[6]. In 2015, as many as 29% of non-smokers aged 16+ reported being regularly exposed to passive smoke in Wales[5].

8. Children, in particular, are especially vulnerable to exposure from SHS as they breathe more rapidly, inhaling more pollutants per pound of body weight (a higher relative ventilation rate) than adults[7]. Children also ingest higher quantities of tobacco smoke pollutants due to more hand-to-mouth behaviours[8]. In addition, children have little control over their environment and are often unable to remove themselves from the risk of exposure to tobacco smoke. Research has found that after exposure to similar levels of tobacco smoke, cotinine levels (a metabolite of nicotine used to measure SHS exposure) in children are about 70% higher than in adults[9]. In Wales around 570 hospital admissions in children aged 0-14 were attributable to SHS exposure in 2010[1], with the majority due to lower respiratory infections.

9. The tendency to smoke in Wales is heavily influenced by the socio-economic status of its residents, with smoking prevalence much higher in areas of Wales associated with high deprivation. In 2015 the percentage of adults from the least deprived areas of Wales reported as being a smoker was 11% compared to a figure of 29% recorded among the most deprived adults in the Welsh population[10]. Consequently, smoking represents the single most important driver of health inequalities in Wales and is responsible for half the difference in life expectancy between the highest and lowest socio-economic groups[11]. It also has a major impact on the household incomes of poorer families. If the poorest smokers were to quit over half a million households would be lifted out of poverty[12].

10. Furthermore, smoking exerts a substantial cost on the Welsh economy, in terms of health care costs, premature deaths, excess sickness absence, smoking breaks, litter and fires. A report by ASH Wales[13] in 2013 estimated the economic cost of smoking to Wales to be approximately £790.66 million a year. Based on a 2014 Welsh population of 3,092,036 this equates to £256 per person in Wales. The total cost of smoking to the NHS in Wales specifically is £302 million per year equating to £98 per person in Wales. That is, every individual living in Wales contributes almost £100 to paying for the NHS treatment of smokers in Wales, regardless of whether they are a smoker themselves or not. Based on a smoking prevalence rate of 19% there are 482,067 current smokers aged 16+ in Wales. This therefore equates to each adult smoker costing the economy and NHS in Wales £1,640 and £626 a year, respectively.

11. The consequences of smoking are clearly widespread and it is for this reason ASH Wales Cymru believes supporting tobacco control efforts aimed at reducing smoking prevalence in Wales, through preventing the uptake of smoking and increasing smoking quit rates, should represent a key priority area for the Health and Social Care Committee during the fifth Assembly. In 2015 as many as 19% of adults in Wales were regular smokers (men: 21%; women: 18%), which continues to be too high a rate. What's more a classroom full of children take up smoking every day in Wales[14], with two thirds of smokers starting the habit before the age of 18[15], and almost 40% starting to smoke regularly before the age of 16[16].

12. Although the smoking prevalence target laid out in the 2012 Tobacco Control Action Plan of a 16% smoking rate among adults by 2020 looks on course to be achieved much further progress is required. ASH Wales Cymru is calling for more ambitious smoking prevalence targets to be set in line with the 'Smoking Still Kills' report[17], including a smoking rate among the adult population of 13% by 2020. There are also other areas of the Tobacco Control Action Plan for Wales which

have not been successful. In particular indicators such as reducing smoking prevalence amongst the three highest quintiles of deprivation at a faster rate than quintiles one and two; and increasing the proportion of smokers accessing NHS smoking cessation services in Wales to 5% of the adult smoking population, have not been achieved. In the case of the former, over the past year the smoking rate among adults from the least deprived parts of Wales fell by 2%, whereas smoking prevalence among the most deprived adults in Wales remained static[10]. In terms of access to smoking cessation services, in 2014/15 just 2.16% of smokers across the whole of Wales made a quit attempt[18], well below the 5% target. Ensuring the Tobacco Control Action Plan for Wales is fit-for-purpose, in terms of it containing sufficiently ambitious smoking prevalence targets and in terms of all its outcome measures being met, should therefore be a priority for the Health, Social Care and Sport Committee during the fifth Assembly. We suggest particular emphasis is given to addressing the growing inequalities caused by smoking as a direct result of the differential in smoking rates among the haves and have-nots in Wales. As mentioned above smoking represents the single most important driver of health inequalities in Wales and this shows no sign of ending anytime soon given the gap in smoking rates between the most and least deprived in Wales is widening.

13. Whilst smoking prevalence among the Welsh population as a whole has fallen in recent years there remain sub-groups within the population for which this is not the case. Among individuals from deprived communities, pregnant women and individuals suffering from mental illness smoking rates are much higher than the Welsh average. A priority for the Health, Social Care and Sport Committee during the fifth Assembly should be ensuring tobacco control efforts are focused on those sub-groups within the population where smoking prevalence is highest. This may involve a reconfiguration of smoking cessation services in Wales.

14. A further priority for the Health, Social Care and Sport Committee during the fifth Assembly should be safeguarding the funding of smoking cessation services. The impact of funding cuts on smoking cessation services is evident from developments in England. In the Spending Review 2015, the Government announced cuts to local council public health budgets of 3.9 per cent a year over the next five years. This is in addition to the £200 million extra in year cuts announced at the Budget 2015. This appears to be having a detrimental impact on the provision of smoking cessation services in England. According to an ASH report commissioned by Cancer Research UK[19] smoking cessation budgets were cut in 39% of local authorities in England in 2015/16, including 29% where the cut was greater than 5%. In addition, smoking cessation services were reported to be undergoing significant change across England with 53% of respondents describing some form of reconfiguration or recommissioning.

15. The Health, Social Care and Sport Committee should make the funding of smoking cessation services a priority since the combination of medication and intensive behavioural support offered by local Stop Smoking Services is among the most cost-effective interventions available in the health care sector[20]. Services have been found to quadruple the success rate of quit attempts whilst costing under £1,000 per Quality Adjusted Life Year (QALY)[21]. In comparison this compares with a cost of up to £57,000 per QALY for statins to prevent coronary heart disease[22], up to £130,000 per QALY for treatments for COPD, and as much as £100,000 for just one course of treatment of the new lung cancer treatment opdivo[23]. ASH Wales Cymru is aware of the financial constraints impacting on health services across Wales and as a result we are calling for the funding of smoking cessation services to be supplemented by the monies raised from a levy imposed on tobacco manufacturers and importers.

16. As mentioned above one of the main adverse consequences associated with smoking is the impact on non-smoking bystanders through passive smoke. One of the primary means by which exposure to passive smoke can be reduced is via the expansion of the number of smokefree spaces in Wales. Moreover, by increasing the number of spaces where smoking is banned the activity will become less visible and be viewed as less of a normal activity. Denormalising smoking in this way represents a key component of attempts to reduce smoking uptake among young people. Hence, extending the number of smokefree spaces in Wales fits exactly within the preventative agenda, which has been a primary focus of the Welsh Government during the Fourth Assembly and we feel should be continued with during the next Assembly term. As part of the 2015 Public Health (Wales) Bill the Welsh Government introduced proposals to amend the current smokefree legislation to include additional non-enclosed public places such as hospital grounds. ASH Wales Cymru is calling on the Welsh Government to continue with these proposals when the Public Health (Wales) Bill is reintroduced during this Assembly term and we believe, given the clear benefits associated with smokefree spaces, ensuring their inclusion in the Bill should represent a priority for the Health, Social Care and Sport Committee during the fifth Assembly.

17. Another element of the 2015 Public Health (Wales) Bill which we consider to be vital to reducing smoking prevalence in Wales is the introduction of the tobacco retailers register. ASH Wales Cymru believes this register will greatly assist in enforcing tobacco age of sale restrictions and tackling the illicit tobacco market in Wales. A further priority for the Health, Social Care and Sport Committee should be to ensure the tobacco retailers register is included in any forthcoming Public Health (Wales) Bill. Again, as with expanding the number of smokefree spaces, the introduction of a tobacco retailers register fits exactly within the Welsh Governments preventative agenda. Reducing the number of age of sale violations and illicit

tobacco sales will serve to make it more difficult for young people to access tobacco products, thereby reducing the uptake of smoking among this cohort of the population.

18. In summary, ASH Wales Cymru believes supporting tobacco control efforts to reduce smoking prevalence in Wales should represent a key priority for the Health, Social Care and Sport Committee during the upcoming Assembly term. Specifically, we call on the Committee to focus its attention on:

    - ensuring the Tobacco Control Action Plan for Wales is fit-for-purpose, in terms of it containing sufficiently ambitious smoking prevalence targets and in terms of all its outcome measures being met. We suggest particular emphasis is given to addressing the growing inequalities caused by smoking as a direct result of the differential in smoking rates among the haves and have-nots in Wales.
    - supporting action to reduce smoking levels among sub-groups within the Welsh population where smoking prevalence is highest, such as among individuals from deprived communities, pregnant women and individuals suffering from mental illness
    - safeguarding the funding of smoking cessation services in Wales, and calling for the monies raised from a levy imposed on tobacco manufacturers and importers to be used to boost the funding of smoking cessation services in Wales
    - ensuring proposals to increase the number of non-enclosed public places where smoking is banned, such as hospital grounds and school gates, are included in any upcoming Public Health (Wales) Bill
    - ensuring the proposal to introduce a tobacco retailers register in Wales is included in any upcoming Public Health (Wales) Bill.

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Coleg Brenhinol y Therapyddion Lleferydd ac Iaith

Response from: Royal College of Speech and Language Therapists

National Assembly for Wales Health, Social Care and Sport Committee Consultation on Priorities during the Fifth Assembly

1. **Executive Summary**

1.1 The Royal College of Speech and Language Therapists (RCSLT) Wales welcomes the opportunity to comment on the future priorities of the Health, Social Care and Sport Committee**.** We are pleased to see recognition of the importance of scrutinising workforce issues within NHS Wales as a key issue and have responded to the committee's consultation on the sustainability of the NHS Workforce separately. Our response below highlights our comments on other suggested priority areas proposed within the forward work plan which we believe may warrant scrutiny by the committee. We have divided these topics into 12-18 months and post 18 months.

1.2 We would welcome a focus on primary care, antipsychotic medication in care homes and efficiency as initial priority topics and an inquiry into health and social integration and waiting times targets at a later stage within the life of the committee.

2. **About the Royal College of Speech and Language Therapists**

2.1 The Royal College of Speech and Language Therapists (RCSLT) is the professional body for speech and language therapists (SLTs), SLT students and support workers working in the UK. The RCSLT has 15,000 members in the UK (450 in Wales) representing approximately 95% of SLTs working in the UK (who are registered with the Health & Care Professions Council). We promote excellence in practice and influence health, education, care and justice policies.

Priority areas for the first 12-18 months in addition to the sustainability of the NHS Wales Workforce

3. **Primary Care**

3.1 We agree that given increasing pressures on primary care, there is a need to prioritise an inquiry into progress on transforming models of care and shifting care from hospitals to community settings. We are of the opinion that such an inquiry may need to dovetail with the findings of the Ministerial Taskforce on Primary Care which we understand will be meeting in the Autumn.

3.2 We believe that the skills of speech and language therapists (SLTs) can be further utilised to help address challenges affecting primary care and ensure that services meet the needs of local populations and would wish any such inquiry to ensure the contribution of these professionals are fully considered. The inclusion of SLTs within new models of primary care will help to build upon the specialist skills that SLTs already bring to the primary care workforce.

3.3 There are a number of roles that SLTs already take on as part of primary care teams, for example, SLTs provide telephone triage to care homes managing the communication and swallowing problems of those in their care, removing the need for a GP visit. They provide training to care home staff and others in the community to manage decline in swallowing performance from age and disease, which reduces morbidity, mortality and prevent hospital admissions. SLT has been developing efficient and effective telehealth solutions in this regard. Published evidence already indicates that interventions delivered by SLTs can provide economic benefits. For example, social return on investment research has highlighted the value of the provision of speech and language therapy for post-acute stroke patients.[1] Evidence from a telehealth project in care homes has indicating savings of £60 on each teleswallowing assessment[1].

3.4 The design of new models of primary care requires consideration of the drivers of future patient demand and changing expectations of how NHS services are delivered. With extensive experience of providing community based care, SLTs are well placed to implement the Welsh Government's vision of offering patient care closer to people's homes.

3.5 As the Committee reflect upon ways to develop a workforce which is responsive to changes in primary care, now and in the future, it is important to acknowledge the contribution that Allied Health Professionals and in particular SLTs can make in providing effective patient-centred care and ensure this is recognised within the parameters of any inquiry.

4. Use of antipsychotic medication in care homes

4.1 RCSLT Wales would welcome a committee inquiry into the use of antipsychotic medication in care homes in relation to people affected by dementia, as suggested in the consultation document. Such an inquiry may be timely given plans to introduce

[1] University College London (2016) London Speech and Language Therapy workforce scoping project, phase 2: modelling workforce transformation example, report available upon request.

a new Welsh Government dementia strategy for consultation later this year. As part of such an inquiry, we call on the committee to consider alternative communication support available to people affected by dementia. Evidence shows a reduction of challenging behaviour when an SLT has helped the care workforce modify their communication style.

4.2 Communication difficulties occur in all forms of dementia and in the later stages these become more challenging. These problems can have emotional and physical consequences;

- People with dementia are at risk of being unable to communicate that they are hungry or thirsty resulting in dehydration, malnutrition, and possible subsequent hospital admission. They may also be unable to communicate that they are in pain
- Communication difficulty is described as one of the most frequent and hardest to cope with experiences for the family and carers. Communication breakdown can lead to frustration, challenging behavior, low mood and depression.
- Care staff view communication problems as one of the greatest challenges in delivering good dementia care
- Alzheimer's Society found that 'the ability to communicate' is one of 10 key indicators of quality of life valued by people with dementia.

4.3 Speech and language therapists (SLTs) support people living with dementia and those caring for them by assessing their needs and delivering interventions to support communication, and safe eating, drinking and swallowing. They also support others to recognise dementia-related symptoms and to support each person as an individual. A recent audit of memory loss teams in Wales revealed that only one 0.6 SLT post exists across teams to support people living with dementia. RCSLT Wales believes that all people with dementia and their families should have access to high quality speech and language therapy support when and where they need it. As part of our dementia campaign, we are calling on Welsh Government, Local Health Boards and care providers to:

- recognise people with dementia have communication, eating, drinking and swallowing needs
- ensure people with dementia have access to the speech and language therapy services they need in hospitals, **care homes** and their own homes
- provide education, support and training, and set the highest standards, for health professionals, **care home and agency staff** to understand the communication difficulties experienced by people with dementia and identify the early signs of eating, drinking and swallowing difficulties to ensure people's nutritional needs are met.

4.4 We hope that if the issue of antipsychotic medication within care homes is selected for consideration by the committee, that the terms of reference for a potential

inquiry will include staff support for communication difficulties.

5. **Efficiency within the NHS and modern management practices**

5.1 We agree that there is an urgent need to consider improved efficiency in healthcare, looking at learning and good practice from within the UK and beyond, given the scale of pressures on the system. In our view, such a review should focus on looking at new models of care. An example of which may be the Malconess Care Aims which has been adopted by a number of Speech and Language Therapy Services. The main benefits identified by services and teams using it are that the model offers:

- a standardised way of capturing and communicating clinical reasoning
- a clear and comprehensive way of demonstrating clinical effectiveness
- a systematic way of supporting and demonstrating clinical reflection
- an ability to focus resources where they can make the most difference by being outcomes driven and not demand led
- a sound framework for managing caseloads and workloads a framework to support service design, planning and evaluation

<u>Priority areas for Committee Consideration Post 18 Months</u>

6. **Integration of Health and Social Care Services**

6.1 We agree that an inquiry looking at the progress made to date and assessing the impact of Welsh Government policies and legislation on integration of health and social care services would be beneficial. We believe that this may be most fruitful later in the committee cycle once the Social Services and Wellbeing Act and the Wellbeing of Future Generations Act have had the opportunity to embed. In our view, any such inquiry should consider;

- to what extent have there been changes in culture, values and behaviour to support greater integration?
- to what extent have joint working arrangements developed including pooling of budgets and resources, training and performance management.
- to what degree is there a shared vision in health and social care?
- to what extent has there been a shift within planning and service provision to models which are preventative and which maintain wellbeing and independence?

6.2 Our members have a particular interest in the effective integration of health and social care. Approximately 40% of SLTs work in intermediate care services. SLTs work at all stages of the care pathway – from primary to secondary to tertiary care; from universal to specialist level services; from prevention to rehabilitation and

reablement to end of life care. The profession has a key role in services for all major clinical priority groups – dementia, frail elderly, stroke, cancer, learning disability, mental health. SLTs deliver integrated and effective community services, focusing on early intervention and rehabilitation which support people to live more healthily in their own home for longer.

6.3 Allied Health Professionals (AHPs), including SLTs operate on a 'social-model' - rather than treating an illness, speech and language therapists (and other AHPs) are involved in a continuous process of assessment, differential diagnosis and defining and delivering a programme of care. We urge the committee when considering an inquiry on integration of health and social care to take note of the key role of AHPs within early intervention and prevention services and assess to what extent a multi-disciplinary workforce has developed which harnesses these unique skills.

7. **Waiting Times Targets**

7.1 RCSLT Wales would cautiously welcome an inquiry into therapy waiting times as part of a broader review of waiting times targets. A focus on this area in the past has yielded extra investment in speech and language therapy services and reduced waiting times. However there is an inherent risk that such a focus leads to an industry of measurement and perverse incentives. We would be in favour of committee scrutiny into how performance measures may be refined to maintain improvements already achieved.

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Cyngor ar Bopeth Casnewydd
Response from: Newport Citizen's Advice

01 09 2016

Consultation

Priorities for the Health, Social Care and Sport Committee

Gambling

In recent years gambling has changed beyond recognition, in 2016 it is available 24/7 and widely viewed as an acceptable form of leisure. The industry is worth billions and brings huge money into the economy. However gambling comes with risk and it is vital that we address this and safeguard vulnerable people. Newport Citizens advice welcomes and urges the Welsh Government to make Gambling and Gambling Related Harm a key priority for the forth coming Fifth Assembly. Gambling related harm has a devastating impact on the physical, mental and public health well-being of the people of Wales. We have been involved in gambling harm minimisation since March 2012 and have witnessed first-hand the devastating affected problem gambling can have.

With the advances in technology, changes in regulation and increased marketing young people and other vulnerable groups are exposed to gambling in way that previous generations never were. Children and young people are especially vulnerable to gambling related harm (Gambling Commission, 2015). This can be in a number of ways directly as a result of gambling or indirectly through someone else's problem gambling. Types of gambling related harm include debt, deprivation, mental health issues, education problems and greater risk of self- harm and suicide. A third of calls to the National Problem Gambling helpline are worryingly from those under the age of 24.

If we are to learn from lessons from alcohol research it is important that we act now to prevent an epidemic of people experiencing gambling related harm. Safeguarding and education is the way forward. Despite the huge visible presence of gambling the addictive behaviour remains hidden and people are unaware of issues until lives are devastated. To prevent this we need to raise awareness; educating and offer accessible support to people. With the aim to reduce the impact of gambling related harm on individuals, families and the wider community.

In Wales there is little known about the prevalence of gambling? No statistics are gathered in our health surveys. Both Public Health England and Scotland gather information about gambling. Gambling and importantly E-gaming (blurred boundaries of what constitutes gambling) should be included in national health surveys. More research is required and support services funded. We believe that other services away from traditional addiction agencies play an important role in the identification and early intervention. Frontline advice agencies, such as Citizens Advice are already seeing vulnerable groups of clients with issues such as debt, homelessness, relationship breakdown etc. This makes them perfectly positioned to identify and

offer early intervention. The work that Newport Citizens Advice is doing is aiming to mitigate the impact of gambling related harm by training advisers to identify issues earlier.

Greater awareness should be made in the educational context in a similar way to other risky behaviours such as sex, alcohol, drugs and bullying. Teachers should be made aware of gambling behaviours. It is widely accepted that gambling is not just a problem for the gamblers; some research suggests that up to 15 people can be affected by one problem gambler. Problem gamblers are more likely to attempt suicide than any other addictive type behaviour. The cost to the economy for one suicide runs into millions! The emotional cost to a family is devastating.

In times of austerity vulnerable groups are more likely to turn to risky behaviour as a way to escape their situation or to fund their lifestyle. Now more than ever we need greater investment and support from government.

Newport Citizens Advice is delivering services across South Wales and the larger Citizens Advice Network. We can offer awareness, training, education and advice and support for anyone worried about gambling related harm. We strongly believe that Gambling should be included as a priority during the Fifth assembly and would welcome seeing it included on the agenda for long-term work by the newly established Health Social Care and Sports Committee. We are happy to get involved with any committee to discuss things further

Katie Fry

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Newport Citizens Advice

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: National Community Hearing Association
Response from: National Community Hearing Association

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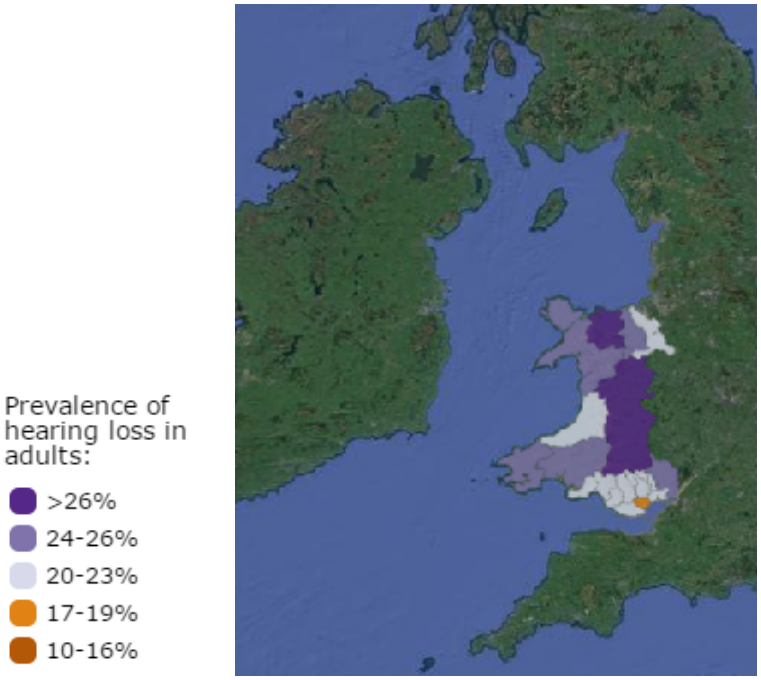
HEARING LOSS IN WALES – CASE FOR ACTION

RESPONSE TO PRIORITIES FOR THE HEALTH, SOCIAL CARE AND SPORT COMMITTEE.



Background

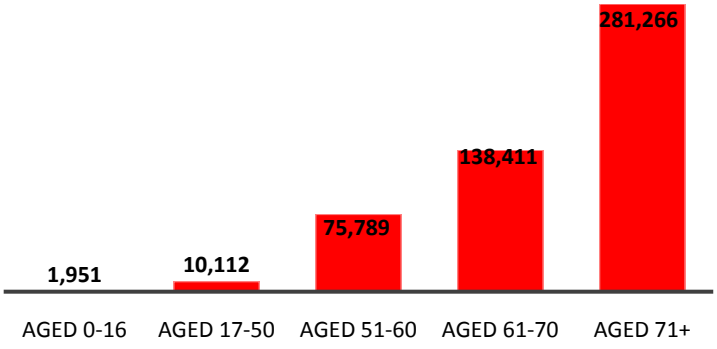
1. The National Community Hearing Association (NCHA) represents community hearing providers in Wales. NCHA members are committed to good hearing for all and have an excellent record of outcome, safety, and patient satisfaction. NCHA members are either registered Hearing Aid Dispensers (HADs) or employ a large number of HADs or audiologists. HADs are registered hearing health care professionals who are regulated by the Health and Care Professions Council (HCPC).

2. We welcome this opportunity to comment on the *Priorities for the Health, Social Care and Sport Committee*. We fully support the Committee's intention to transform primary care and tackle loneliness and isolation among older people as key elements of its long-term Forward Work Programme[1].

3. There is also a compelling case for action on hearing loss in Wales as part of wider primary care – e.g. transforming hearing services to meet the needs of an ageing population. This fits clearly within the transforming primary care and tackling loneliness and isolation among older people agendas and we urge the Committee to include transforming hearing services within in its Forward Work Programme as full parts of these work streams.

TACKLING LONELINESS AND ISOLATION – THE CASE FOR ADDRESSING UNMET HEARING NEEDS

4. Hearing loss affects over half a million people in Wales. It is a major and growing public health challenge and the 5th leading cause of years lived with disability in Wales[2]. Age-related hearing loss is the main cause of hearing loss, with nine out of ten people with a hearing loss aged 50 and over (Graph below)[3]. **Unsupported adult hearing loss** has a major impact on an individual's ability to communicate, including with friends and family, and **increases the risk of** depression[4], **loneliness and social isolation[5]**, cognitive decline[6], early exit from the workforce[7] and reduced quality of life[8].



The estimated number of people with a hearing loss in Wales.

5. Hearing support has been shown to improve quality of life and reduce these risks[9]. This means the Committee, by focussing on adult hearing loss, can also address "***Loneliness and isolation among older people.*** *The Older People's Commissioner for Wales has stated that loneliness and isolation needs to be recognised as a key public health issue. The Committee could examine the issue with an aim of understanding and raising awareness of the health and wellbeing implications of loneliness and isolation for older people*."[10] – i.e. unsupported hearing loss can result in loneliness and isolation and older people are at greatest risk of this.

TRANSFORMING PRIMARY CARE SERVICES – THE CASE FOR HEARING CARE CLOSER TO HOME

6. To achieve the ambitions of the Forward Work Programme, and to support people with hearing loss, it is essential fully to utilise the existing workforce. For example, Hearing Aid Dispensers in Wales are registered with the Health and Care Professions Council (HCPC) but are not currently commissioned to see NHS patients in the community which results in patients having to make multiple visits to hospital. This also exacerbates health inequalities in that people who can afford to go private can access care close to home whereas NHS patients are debarred from this. By permitting Hearing Aid Dispensers to see NHS patients in the community, the capacity in hearing care (currently a chronic problem and likely to grow worse as demand increases) can rapidly be expanded to support the ageing population and combat the existing unmet need.

7. There is longstanding and widespread support for delivering adult hearing services out of hospital and closer to home; for example in the 1980s the Royal National Institute for the Deaf (RNID) (now Action on Hearing Loss) stated: "*emphasis of hearing aids services should be on community delivery**.** People who require hearing aids are not ill and should not have to go to hospital. They require an essentially rehabilitative/technical service, not a medical service. They require this service to be as local and easily accessible as possible and where this delivers advice and systematic follow-up on fitting, together with back-up service to sort out quickly any problems, research has established that the use and benefit of a hearing aid is greatly increased. This would be a hearing aid service only, not a community audiological service"*[2]. Adding that the *"majority of people with a hearing loss, particularly elderly people, should be dealt with locally and not referred as a matter of course for ENT*

appointments and to hospital"[11] The RNID has repeated this call to action many times since.

8. Despite the RNID and others calling for adult hearing services in Wales to be delivered out of hospital and closer to home, today the service remains predominately hospital based. This is anomalous given that over 90% of adults with hearing loss do not need any medical intervention or review[12]. What they do need is better access to care and ongoing support.

9. The Committee can support people to age well by improving access to adult hearing services in the community**[13]**. This in turn is likely to improve outcomes, e.g. heads of NHS audiology in Wales have previously reported that care closer to home is a major benefit in terms of access for patients and ongoing use of hearing aids[14]. Delivering more care in the community has the potential to reduce pressure (and costs) on the health and social care system in Wales – e.g. because hearing aids and ongoing aftercare can reduce the psychological and social effects associated with age-related hearing loss[15].

10. The Committee, by focussing on adult hearing loss, can therefore also help the Welsh Government achieve its goal of moving *"…the balance of care and resources – including workforce and funding – out of hospitals into the community so people only go to hospital were this is appropriate"*[16]. This is particularly important given the geography of Wales which makes it difficult for people with hearing loss, and particularly older people, to access on-going support in hospitals.

11. To achieve the ambitions of the Forward Work Programme, and to support people with hearing loss, it is necessary to fully utilise the existing workforce. For example, Hearing Aid Dispensers in Wales are registered with the Health and Care Professions Council (HCPC) but are not allowed to see NHS patients in the community. This creates an artificial barrier where people who can pay to go private can access care close to home but NHS patients cannot. By enabling Hearing Aid Dispensers to see NHS patients in the community the capacity in hearing care (currently a chronic problem and likely to grow worse as demand will increase) can rapidly be expanded to support the ageing population and combat the existing unmet need.

12. Another reason for action is that in terms of delivering hearing care closer to home, Wales is now falling behind the rest of the UK. For example, the NHS in England has an Action Plan on Hearing Loss[17] and a National Commissioning Framework for hearing services[18] – with a focus on public and preventative health, helping people to age well and delivering services in the community. The SNP in its manifesto has made clear it will trial a community audiology programme[19], and Northern Ireland is exploring a community audiology pilot[20]. The Committee therefore has an opportunity to build on lessons learned from all parts of the UK and to improve hearing care for the half a million people in Wales with hearing loss and to ensure local people are not disadvantages by a postcode lottery. The Committee holds a unique position in that it can hold the system to account and ensure patient led changes happen - *"The Health, Social Care and Sport Committee was established on 28 June 2016 to examine legislation and hold the Welsh Government to account by scrutinising expenditure, administration and policy matters, encompassing the physical, mental and public health and well-being of the people of Wales, including the social care system."*[21]

SUMMARY

13. In summary, as part of ageing well, transforming primary care - .i.e. doing more out of hospital - and tackling loneliness, depression cognitive decline and dementia amongst older people – we urge the Committee to prioritise modernising hearing services as a key part of its Forward Work Programme.

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[1] National Assembly for Wales. Priorities for the Health, Social Care and Sport Committee. Accessed on 23 August. http://senedd.assembly.wales/mgConsultationDisplay.aspx?ID=222

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Cadeirydd/Chair: Arwel Ellis Owen
Prif Weithredwr/Chief Executive: Sue Evans

Cyngor Gofal Cymru
Care Council for Wales

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Cyngor Gofal Cymru

Response from: Care Council for Wales

Noddir gan Lywodraeth Cynulliad Cymru
Sponsored by Welsh Assembly Government

Sarah Beasley
Clerk
Health, Social Care and Sport Committee
National Assembly for Wales
Pierhead Street
Cardiff
CF99 1NA

1 September 2016

Dear Ms Beasley,

Consultation on the Priorities for the Health, Social Care and Sport Committee

Thank you for the opportunity to help inform the forward programme of the Committee. In order to assist with your deliberations we are sharing with you the priority areas for service improvement which have recently been identified by a Ministerial Advisory Panel, as we believe these provide evidence of some of the key issues and challenges for the sector the Committee should consider for its priorities.

The Care Council for Wales is responsible for the regulation and development of the social care workforce. In April 2017 we will be renamed as Social Care Wales and our remit will expand to include service improvement and co-ordination of research as we join forces with the Social Services Improvement Agency (SSIA). A Ministerial Advisory Panel was established to prepare the ground for the transition. As part of its work it has recommended that the priority areas for Social Care Wales' service improvement role should be:

- Improving services and outcomes for looked after children
- Improving services and outcomes for people with dementia
- Supporting the domiciliary care workforce to enable it to comply with the new registration requirements

Improving services and outcomes for looked after children

A report by our partners at SSIA found that there are no simple solutions for children and young people who are looked after[1]. Needs are complex and services should be tailored to the individual.

The report identified a need to look more carefully at the potential for and support of kinship carers, to maximise the range of local family placements, or to look beyond a 'placement' alone and secure timely access to a range of support services to secure the best outcomes for looked after children and young people.

[1] What works in promoting good outcomes for Looked After Children and Young People? SSIA, 2011

The report's other findings include the crucial importance of effective assessment, matching and planning processes undertaken by staff within the local authority and supported by an overall corporate commitment to looked after children. It found that social services commissioners should engage social work staff and managers in understanding their key role in securing better outcomes for looked after children through dogged attention to assessment, matching, planning and reviewing processes and through good key working with the children and young people themselves.

Improving services and outcomes for people with dementia

The prevalence of dementia in Wales is growing. It is projected to increase by 31% by 2021. It is projected to rise by as much as 44% in some rural areas. Most people with dementia live in the community, with around a third of people living in care homes. Promoting the independence of people with dementia is therefore vital. Services are needed which enable people with dementia to live in their own homes and in their communities for as long as possible.

In order to support this work, the Care Council has produced 'Good Work: A Dementia Learning and Development Framework for Wales', in partnership with NHS Wales. It is intended to support what matters most to the people with dementia. It captures the spirit and requirements of Welsh policy, legislation and guidance regarding the care, support and empowerment of people with dementia, carers, and the health and social care workforce.

The Framework recognises the importance of the workforce to improving dementia care. Dementia is not exclusively a condition that affects older people, although there is a strong link between older age and a diagnosis of dementia. As life expectancy increases, there will naturally be more older people and so more people with dementia. As a consequence, there is a growing need for communities and in particular the health and social care workforce to understand the issues involved in good dementia care and support. All workers need a solid awareness of dementia and the issues surrounding it to ensure that their approach supports people with dementia and carers to live well.

Supporting the domiciliary care workforce to enable it to comply with the new registration requirements

Supporting the domiciliary care workforce to enable it to comply with the new registration requirements is the third priority identified for Social Care Wales' improvement work. Furthermore, it has been identified by the Welsh Government as an area of current importance. Consequently the Care Council for Wales has been asked to develop a five year strategy for care at home, of which domiciliary care is vital component. It is an ambitious plan, which goes far beyond workforce issues to include the environment we are working in, investment, commissioning, research and improvement.

Care and support is already a large and growing area. Over the next decade demand will continue to increase both the numbers of individuals seeking care and support, alongside increasing complexity of the support needed to meet individual's well-being outcomes and personal preferences. At the same time as increasing demand, it is a sector facing significant financial pressures.

The decision to register all domiciliary care workers follows the recommendations of the previous Health and Social Care Committee on the content and form of the Regulation and Inspection of Social Care (Wales) Act, 2016. The Welsh Government commitment to registering the domiciliary care workforce by 2020 provides a major opportunity to enhance the recognition and status through recognising the complexity and importance of this work. We need to ensure that the workforce is prepared for registration. This will require a programme of learning with sufficient funding for initial registration and continuing workforce development.

We recognise that there is a fundamental importance in integrated provision of support for citizens in Wales, across education, social care, housing and health, and as such there needs to be focus across our nation on working in collaboration and partnership at a local, regional and national level.

As the Care Council for Wales and in our future guise as Social Care Wales, with an expanded role to include service improvement and co-ordination of research we look forward to working with the Committee's in future.

Yours sincerely,

Sarah McCarty
Director of Learning and Development

For more information please contact ceri.williams@ccwales.org.uk

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Crohn's and Colitis UK
Response from: Crohn's and Colitis UK

Priorities for the Health, Social Care and Sport Committee

Consultation response from Crohn's and Colitis UK – September 2016

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INFLAMMATORY BOWEL DISEASE

At least 300,000 people or 1 in 210 people in the UK have Crohn's Disease or Ulcerative Colitis, collectively known as Inflammatory Bowel Disease (IBD). **It is estimated that over 15,000 people are living with this chronic disease in Wales**. IBD is a lifelong condition that most commonly first presents in the teens and early twenties (mean age of diagnosis is 29.5 years).

In IBD the intestines become swollen, ulcerated and inflamed. Symptoms include acute abdominal pain, weight loss, diarrhoea (sometimes with blood and mucus), tenesmus (constant urge to have a bowel movement), and severe fatigue.

Symptoms vary in severity from person to person and from time to time and relapses often occur suddenly and unpredictably throughout a person's lifetime. Between 50% and 70% of patients with Crohn's Disease will undergo surgery within five years of diagnosis. In Ulcerative Colitis, lifetime surgery rates are approximately 20-30%.

Key facts about IBD:

- It's an invisible condition causing inflammation and ulceration of the bowel.
- It's a lifelong, incurable condition.
- It affects people of all ages, but commonly presents in the teens and twenties
- It fluctuates – people experience unpredictable flare-ups and remission during their life.
- It can have a devastating effect on quality of life, impacting work, education & social activity.
- Access to toilets is imperative due to urgent and frequent diarrhoea.
- **Prevalence is twice as high as for Parkinson's and Multiple Sclerosis** with **lifetime medical costs comparable to other major diseases such as diabetes and cancer** (estimated at £900m per annum UK wide).
- There is low awareness of IBD and it is both under-recognised and under-prioritised.

CROHN'S AND COLITIS UK

Crohn's and Colitis UK is a national charity leading the battle against Crohn's Disease and Ulcerative Colitis. We provide high quality information and services, support life-changing research and campaign to raise awareness and improve care and support for anyone affected by Inflammatory Bowel Disease (IBD).

Established in 1979, the charity's services include four helplines, a wide range of accredited information sheets and booklets and a nationwide network of locally-based volunteer groups. The charity raises awareness of these little known and understood conditions, campaigns for improved services and care for people with IBD, funds vital research and seeks to influence policy to ensure that it reflects and meets the needs of people living with IBD.

IBD IN WALES

People with Inflammatory Bowel Disease use and rely on gastroenterological services in Wales, with the condition primarily managed in secondary care. While standards of treatment and care for people with Crohn's Disease and Ulcerative Colitis in Wales have improved in recent years, they still fall behind the average for the rest of the UK.

Findings from the UK IBD Audit have found considerable variation between individual hospitals in the extent to which they meet the UK IBD Standards, which define what good care looks like. A number of these key findings echo the results of a atient survey of IBD services in Wales undertaken by Crohn's and Colitis UK between May and June 2015.

WHAT DO PATIENT'S THINK ABOUT IBD SERVICES IN WALES?

Key survey findings

A survey of IBD patients in Wales by Crohn's and Colitis in April 2015 with 447 responses found:

- 20% of respondents were unsatisfied with their care;
- 42% did not have access to an specialist IBD Nurse;
- 26% were not having an annual review; and
- 38% were off work for more than 4 weeks.

A survey of IBD patients in Wales by Crohn's and Colitis in April 2016 found that:

- 38% of people said that they did not have access to an IBD Nurse specialist compared to 33% in Scotland and 30% in England.

WAITING TIMES - ENDOSCOPY

NHS Wales currently has a range of waiting time targets including patient access to inpatient, outpatient and day case treatment or appointments; diagnostic and therapy services; cancer treatment; and mental health services.

There are pressure areas where waiting times remain high, such as in diagnostic and therapy services and certain specialties such as orthopaedics. The Committee could examine the issue of waiting times and scrutinise the Welsh Government's plans to tackle areas of pressure in more detail.

Crohn`s and Colitis UK would suggest that consideration is given within the scope of any waiting times scrutiny to include elective surgery waiting times for conditions such as IBD requiring colorectal surgical procedures currently lying outwith the current range of targets.

Our understanding is that this may be a particular issue in large Tertiary Centres offering specialist surgical procedures as priority is given to those with targets attached, resulting in often unacceptably lengthy waits for non cancer patients such as those living with IBD.

Crohn's and Colitis UK would be very supportive of an investigation into waiting times in the NHS as we are extremely concerned about the historical long waiting times for endoscopies in Wales.

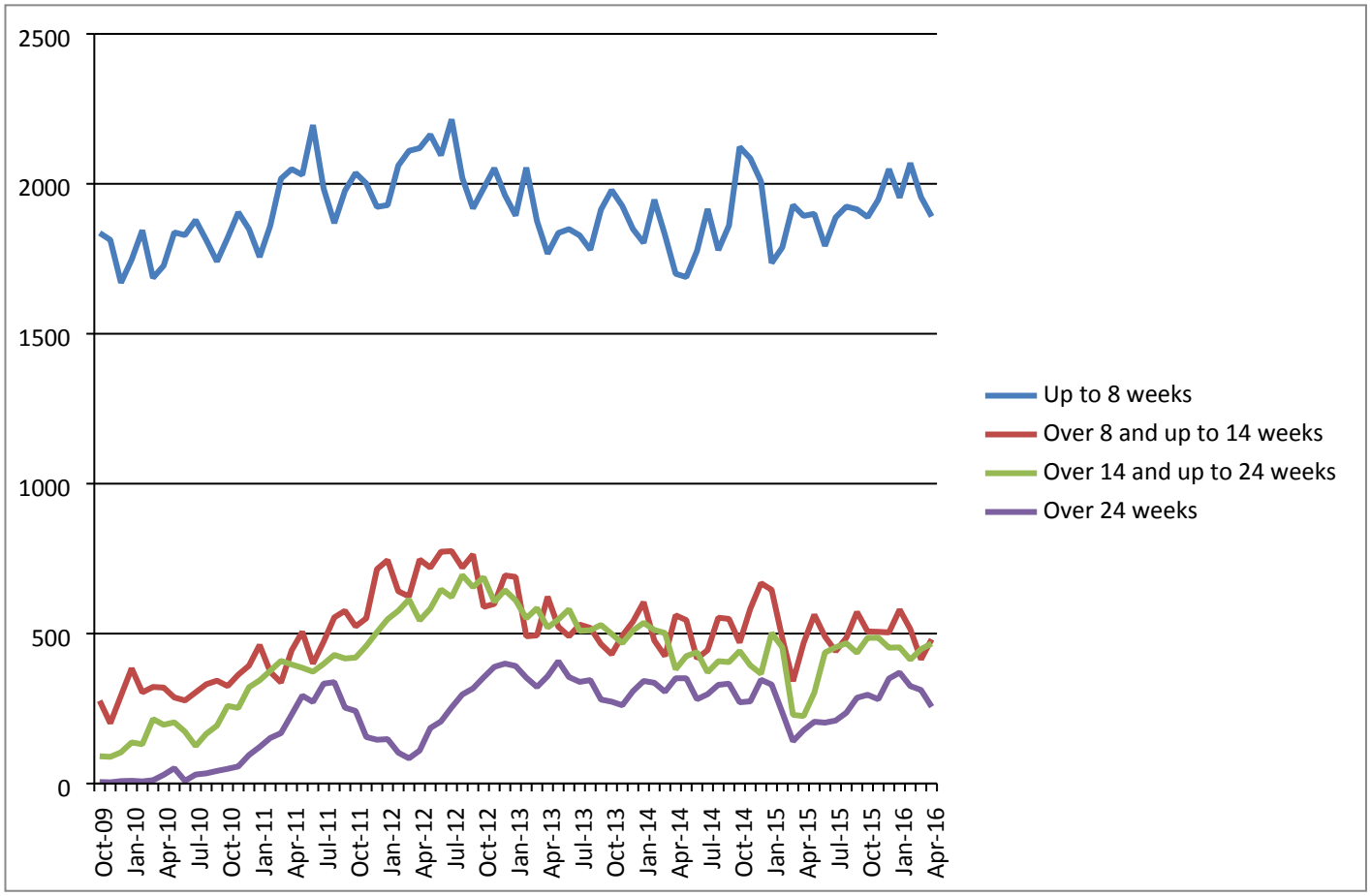
In the majority of cases, IBD can't be diagnosed until a colonoscopy has taken place, therefore receiving a timely colonoscopy ensures that patients can be diagnosed promptly and receive the correct treatment and healthcare that they need. Colonoscopies are also critical in surveillance monitoring of bowel cancer and dysplasia as those with IBD, are at a higher risk as there is an established link between IBD and an increased risk of developing colorectal cancer.

From the Government's own figures, it shows that waiting times for endoscopies has significantly increased across Wales particularly for those waiting beyond 14 weeks:

- Number of patients waiting between **8-14 weeks** has increased from 276 in October 2009 to 481 in April 2016. **This is an increase of 74%.**
- Number of patients waiting between **14-24 weeks** has increased from 91 in October 2009 to 467 in April 2016. **This is an increase of 510%.**
- **Number of patients waiting over 24 weeks has increased from just 5 in October 2009 to 256 in April 2016. This is an increase of 5000%.**

Despite investment in diagnostic services by the Welsh Government, endoscopy waiting times are still far too high and Crohn's and Colitis UK would recommend that the Committee deem this area a priority area for further investigation when looking at waiting times.

COLONOSCOPY WAITING TIMES OCTOBER 2009 – APRIL 2016



Source: Diagnostic and therapy services waiting times, NHS Wales Informatics Service (NWIS)

	Number of Weeks Waiting for Colonoscopy				All
	Up to 8 weeks	Over 8 and up to 14 weeks	Over 14 and up to 24 weeks	Over 24 weeks	
Oct-09	1836	276	91	5	2208
Apr-16	1891	481	467	256	3095

Source: Diagnostic and therapy services waiting times, NHS Wales Informatics Service (NWIS)

These are extremely worrying statistics which is why Crohn's and Colitis UK would like to see the Health, Social Care and Sport Committee look into endoscopy waiting times when investigating NHS waiting times.

PRIMARY CARE

The Welsh Government Strategy Primary Care services for Wales up to March 2018 (February 2015) recognises the growing service demand on the NHS, and primary care in particular, driven by a combination of a population which is living longer, but accompanied by higher levels of chronic long term conditions.

The previous Welsh Government recognised that action is required to move the balance of care and resources – including workforce and funding - out of hospitals into the community so people only go to hospital where this is appropriate. The Welsh Government is committed to developing the role of 'clusters' - groups of GPs, working with other health and care professionals to plan and provide services locally - as a means of transforming primary care.

While Crohn`s and Colitis UK broadly welcome initiatives to move the balance and care of resources to Primary Care, the scope of any plans to provide more services locally would need consideration of the needs of patients with long term conditions such as IBD.

IBD is primarily managed in secondary care therefore should more management be undertaken outside the traditional hospital setting, people with IBD would need to be able to access specialist Secondary Care services when their health needs required and often at short notice. Due to the fluctuating nature of IBD, rapid access to specialist services in times of flare up of the disease is essential. This rapid access will often be access to a service, such as specialist nurses who run specialist phone lines, rather than an inpatient appointment.

These needs would require consideration, therefore, in the planning process to be given to the Primary and Secondary Care interface and to the greater use of emerging e health solutions to enable rapid access when required and to assist patients to self manage their own condition as much as possible.

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Fair Treatment for the Women of Wales (FTWW)
Response from: Triniaeth Deg i Fenywod yng Nghymru

Fair Treatment for the Women of Wales (FTWW) is a third sector organisation set up to support, inform, educate, and advocate for girls and women in Wales who are suffering a range of health conditions and who are not receiving adequate (or fair) treatment. Many of the organisation's users feel that this is, in large part, due to the lack of specialist provision in Wales, and a system which currently doesn't routinely allow patients to choose and book those clinicians best able to provide care considered to be 'gold standard'.

FTWW aims to empower women to speak up with confidence amidst a medical and societal environment which often tends to privilege the male experience, sometimes dismissing women's symptoms and concerns as being 'psychological' in origin.

Currently, FTWW's focus is on endometriosis, a condition which affects one in ten women and yet which continues to be mired in misinformation and myth. With a similar number affected as by diabetes and / or asthma, the fact that diagnosis takes an average of 7.5 years is of great concern, particularly in Wales where GPs are frequently over-stretched as a result of staff shortages in many parts of the country.

FTWW surveyed its membership with regard to the consultation being carried out by Welsh Government's Health, Social Care and Sport Committee to establish priorities for the next 12-18 months and is pleased to share its findings as detailed below. We would also ask that the Committee read our report, 'Making the Case for Better Endometriosis Treatment in Wales' (available at http://www.ftww.co.uk/wp-content/uploads/2015/09/Making-the-Case-for-Better-Endometriosis-Treatment-in-Wales-Watermark-PDF.pdf), a copy of which has been previously sent to Welsh Government, and the health boards, for their consideration.

1) Integration of Health and Social Care services

1.1 It is important that policy-makers recognise that poor healthcare can ultimately lead to social services' intervention when that could have been avoided in many instances. In FTWW, many members report that diagnostic delays extending into years, and then the subsequent mismanagement of their conditions, has led to the breakdown of relationships and the development of mental health problems. The loss of a familial support network means that those women (and their children) then become reliant on social services to provide housing and other assistance.

1.2 It is absolutely essential that NHS Wales and the health boards listen to organisations like ours, groups who are on the ground and in touch with their membership every single day. We have important insight into those areas where diagnostic delays, excessive waiting lists, and poor patient

care in the interim, are having far-reaching and costly ramifications for patients, their families, communities, and the economy at large. However, it often proves difficult for third sector, user-led organisations like ours to navigate a way into the health boards, particularly those personnel who are in a position to act upon our insights in developing strategy.

2) Waiting Times

2.1 Our members frequently report waiting times for gynaecological services extending way beyond the 6 months recommended for an initial consultation – and then over a year for actual surgery subsequent to that. Unfortunately, lack of access to gynaecology doesn't make headlines in the way that access to cardiac care or orthopaedics does – partly because there is still a huge cultural reluctance to publicly discuss women's reproductive organs, and also because (as repeatedly suggested by our members) it tends to be dismissed as '*just* middle-aged women's problems'. Clearly this widely held public misconception is inaccurate in terms of age of patients but it also reflects the belief that non-cancerous gynaecological diseases are not life-impacting and therefore unimportant (and they don't directly affect men).

2.2 Our report into the treatment of endometriosis, 'Making the Case for Better Treatment of Endometriosis in Wales' tackles the subject of waiting times for gynaecology in quite some depth, with a particular focus upon how the mismanagement of this disease in the regular hospital setting is actually exacerbating the problem with waiting times (ie women on a merry-go-round of repeated ineffective surgeries with non-specialists rather than being referred immediately to a tertiary centre for a potentially one-off, gold-standard procedure). We would also draw attention to the need for investment in advanced laparoscopic skills for more gynaecologists in Wales, and the accreditation of additional specialist centres for the condition (at present there is only one-such centre in the whole of Wales – in Cardiff – which is woefully inadequate for the number of patients needing it). This would attract more appropriately qualified medics to Wales, thereby improving endometriosis patient outcomes, as well as reducing the current waiting lists for other gynaecological services.

3) Mental Health / Waiting times

3.1 Given that there is an established lack of mental health provision across Wales, it might be worthwhile exploring how third sector organisations could be better resourced (financially and in terms of additional training) to provide the support that many patients need – especially given the fact that not all mental health service users have serious / diagnosed psychiatric conditions but actually simply require a listening ear and more general support. For example, many of FTWW's members report being given anti-depressant medications inappropriately.

The reasons for this are many but include:

3.2 A widely held cultural perception that women who report physical pain / symptoms must be neurotic / over-sensitive / anxious / have mental health problems, inc. depression. There is considerable evidence to show that women's pain is taken less seriously than men's and treated less

aggressively. For example, there is much evidence to suggest that, in the emergency setting, it takes women twice as long to have their pain assessed / treated, and then with less powerful medication.

Women are more likely than men to have chronic pain conditions (such as endometriosis, adenomyosis, fibromyalgia, Chronic Pain / Fatigue Syndrome) which are not being diagnosed or managed effectively.

3.3 Some of women's pain conditions are gynaecological in origin, for example endometriosis, which requires surgical treatment. The failure to diagnose the condition in a timely manner, the shortage of gynaecologists in Wales specialising in excision of this disease, and the fact that referrals out of area to an accredited centre are not taking place, means that women are waiting years to access the treatment that could improve their lives and well-being. Consequently, they begin to suffer situational depression – the answer to which seems to be to dose them up with anti-depressants rather than seek to rectify the cause.

3.4 Lack of pain-management centres. Waiting lists for pain management can be a year or more and the GP does not have the time, expertise, or authority to create and monitor an effective pain management strategy for most female patients in need. Again, the solution seems to be to put patients on psychiatric medications because the easiest, most visible aspect of their suffering is the subsequent situational depression. It is rare that a referral to mental health services (for counselling / CBT / consultation with a psychiatrist) is made. This seems to evidence the fact that the GP does not consider these women to be legitimate 'mental health patients' – but might also indicate the unfeasible length of the waiting lists (in some instances, up to 4 years).

4) Primary Care

4.1 ***'…action is required to move the balance of care and resources – including workforce and funding - out of hospitals into the community so people only go to hospital where this is appropriate'.***

Whilst this is laudable, it is also essential for NHS Wales / policy-makers to appreciate that there are some conditions which cannot be ameliorated by lifestyle changes and which can only be effectively treated in the hospital setting. As already mentioned, most of FTWW's members have endometriosis, and a significant proportion of them describe going to the GP fifty or more times during the (average) 7.5 year wait for a referral to gynaecology. Clearly, this is not an effective strategy and comes down to an urgent need for re-education on this disease (something that FTWW is keen to work with health boards on providing). It also requires a change in culture within primary care when dealing with women's health.

4.2 In preparing for this submission, we surveyed our membership and the overwhelming request made was for GPs to take the time to *listen* to patients, girls and women being only too aware of their bodies from a young age. Our members also asked that GPs appreciate that social media / online support groups can be an invaluable source of information and that female patients may know a great deal more about the nature of their disease(s) and the best treatment(s) available than the GP (who, by his / her very nature has to be a generalist rather than a specialist). Our members

ask therefore that referrals to specialists are made in a timely manner, and not after years of attempted management in the primary care setting.

4.3 ***'The Welsh Government is committed to developing the role of 'clusters' - groups of GPs, working with other health and care professionals to plan and provide services locally'***

Part of this has to be NHS recognition and provision of alternative therapies. Many of our members have had repeated abdominal surgeries (often inappropriately / unnecessarily) and have developed considerable health problems as a consequence of this – not least post-surgical adhesions (which cost the health services a huge amount in terms of repeated (often futile) surgeries to lyse /cut them down, bowel obstructions, and pain management), nerve damage, and continuing pain. In an effort to reduce the need for long-term medication and on-going surgeries, both of which are very costly, our members ask that therapies like acupuncture, osteopathy, pelvic physiotherapy, and specialist massage be made available on the NHS, perhaps in purpose-built centres which incorporate GPs' and pharmacists' services or, if not practicable, at private clinics to which referrals could be made / NHS vouchers made available.

5) Efficiency within the NHS and modern management practices

5.1 ***'The Committee could examine the potential for securing business and industry skills to work with NHS Wales in looking for efficiency opportunities, in both support and clinical services'.***

It is our belief that the best efficiency opportunities could be established not so much by looking to 'business and industry' but by pro-actively seeking out, listening to, and working with, user / patient-led organisations who can see, first-hand, exactly where there are issues, and offer up pragmatic solutions. At the moment, it is incredibly difficult for us to get our voices heard, even when we are making suggestions that have enormous money-saving potential for the NHS in Wales. There needs to be a direct and widely publicised point of access for organisations like ours to share our expertise, and there needs to be improved communication so that we know our suggestions are being discussed further and acted-upon, as far as possible, involving and consulting with us all the while.

5.2 As mentioned already, our report into endometriosis care in Wales provides some analysis of where there are potential efficiency savings to be made – but there also needs to be a realisation that long-term investment is essential if we are to be able to move away from a culture of quick (inefficient and costly) fixes.

6) Neonatal services

6.1 FTWW would like to see much more of an emphasis placed on ante-/post-natal mental health by Health Boards, with a campaign for it to be deemed of equal status to physical health during and after pregnancy. This also means that any consultations in relation to proposed changes to maternity services in Wales should place the impact of those changes to women's mental health as a top priority rather than an afterthought.

6.2 ***'The Committee could undertake an inquiry to monitor progress, specifically looking at ongoing concerns about staffing and the sustainability of services'.***

A key part of this has to involve consulting patient groups as to where they see priorities lying. In particular, a focus on training health professionals to be aware of the warning signs / risk factors for developing mental health problems during and after pregnancy (such as hyperemesis gravidarum and resultant mineral deficiency; pre-existing anxiety conditions, etc) so that early intervention and support is available to those women, thereby potentially reducing the likelihood of severe post-natal psychosis. A great deal of support is available to pregnant women / new mothers from user-led organisations but provision is piece-meal and under-funded. Given that mental health services are already the poor relation in our NHS, it is incumbent upon policy-makers to properly resource and utilise such organisations, many of whom are far better placed to provide the listening ear, empathy, and informal support that is all many women need in order to manage their symptoms.

6.3 However, should women require more formal, medical interventions, these should also be readily available (such as local in-patient mother & baby units) in conjunction with third sector provision. There needs to be much more targeted investment and partner-working across Wales in terms of promoting mental well-being both during and after pregnancy. It is widely recognised that supporting mothers and their babies early on massively reduces long-term costs to the NHS / social services.

7) Final thoughts

7.1 Since compiling our report into endometriosis treatment in Wales, it has come to our attention that not only are patients in Wales not routinely able to access care across the border, in England, they are also prohibited from seeking treatment under other health boards within Wales. This is quite patently unfair to patients. If it could be guaranteed that all forms of treatment were identical across Wales, this might be a workable system but, realistically speaking, this is unlikely ever to be the case: there will always be discrepancies, and medics more suited to a patient's needs may well be practising just a few miles away, in another part of Wales – or, indeed, in England.

7.2 It cannot be in the patient's best interests or well-being to force them to undergo potentially inappropriate or unsatisfactory treatment within their own health board, simply because that is the (highly restrictive) strategy employed by NHS Wales. Indeed, in England, there are mechanisms in place which aim to give patients far more of a voice in devising their treatment plan: both a patients' charter and a 'choose and book' system exist so that patients may select a hospital or surgeon according to their level of expertise, waiting times, or location. Furthermore, patients in England are able to view individual hospital departments' (even surgeons') outcomes, so as to give them the opportunity to make a more informed choice. The fact that NHS Wales has not followed suit with any of these mechanisms suggests that patient autonomy is not at the forefront of its agenda when, in actual fact, according to our members, empowering the patient in this way can dramatically improve their sense of well-being.

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Diogelu Plant mewn Chwaraeon yng Nghymru

Response from: Safeguarding Children in Sport in Wales

Strategic Group for Safeguarding Children in Sport in Wales - response on the Consultation priorities for Health, Social Care and Sport Committee

Strategic group consultation response:

The Strategic Group for Safeguarding Children in Sport in Wales aims to deliver the vision of ensuring every child and young person can participate in sport and physical activity free from the risk of child abuse. We also aim to:

- influence policy on safeguarding in sport
- and represent the voice of safeguarding in sport with government and other key bodies.

In response to the Health, Social Care and Sport Committee consultation on priorities for the next Assembly Term we have set out our priorities below and would welcome the opportunity to discuss these further when appropriate. We noted in the current draft work programme limited mention of Children and Young People, we would strongly recommend children and young people remain a priority group within the sport and health priorities.

Safeguarding children and adults at risk has become a key governance issue for all sports organisations. The Governance and Leadership Framework for Wales, developed for the sector, by the sector, integrates safeguarding within and remains a focus for bodies funded by Sport Wales, this will also be strengthened by the forthcoming UK Governance Code which will be mandatory for Sport England and UK Sport funded bodies/programmes.

We would recommend two areas are prioritised for short inquiries:

1. **How safe are children in unregulated activities (that sit outside Sport Wales funded recognised partners)?.** Unsuitable adults are able to exploit opportunities available in unregulated activities to gain access to children and so we recommend the Committee runs a short inquiry into the safety of Welsh children in unregulated activities. Sport Wales supports key sports bodies to achieve recognised safeguarding standards, but there are still unregulated bodies in the private and voluntary sports sector which we feel should be subject to regulation around safeguarding. This is an area where there are likely to be recommendations which will come out of Baroness Tanni Grey-Thompson's Duty of Care review for sport https://www.gov.uk/government/consultations/sport-duty-of-care-review-call-for-evidence.

   We believe the safeguarding risks are much higher in these environments as they do not come under any regulatory body or scrutiny that recognised National Governing Bodies of Sport or other Sport Wales funded partners do.

   We also believe that safeguarding must be embedded within leadership structures and prioritised by all organisations responsible for provision. Accountability for safeguarding needs to be placed at the top of organisations through CEOs, senior management and boards and support advice and guidance prioritised to continuing this work.

2. **Talented Athletes are the highest category risk group with regards to safeguarding from all the evidence shown, mainly due to their dependence status**. Wales exceeded its medal

targets in Rio Olympic Games and there is excellent work happening to ensure talented young people exceed their potential. However, some sports manage progression and deselection well and others don't; there is often a fine line between poor practise and safeguarding issues. We would recommend a short inquiry into the safeguarding of our talented athletes to hear the views of national bodies but also athletes themselves. We would recommend that there should be support and guidance available for young people when difficult decisions are made and for a period of time afterwards and that this support should be integrated with mental health services.

There is an additional issue, which resulted from a recent decision made by Welsh Government, that we would like to bring to the attention of the Committee and we recommend that this is an area for scrutiny of the Minister responsible for community sport.

3) Scrutinising Welsh Government provision of support to improve safeguarding in Sport and Physical Activity in light of recent changes. There has been recent withdrawal of Welsh Government funding that provided free DBS checks for the third sector through the Criminal Records Unit of the WCVA. The Unit provided around 20,OOO volunteer checks per annum of which around 5,000 free volunteer DBS checks were within sport.

Welsh Government announced that they would use the resources previously spent on the WCVA Criminal Records Unit to provide support to the sport/voluntary sectors for training and other safeguarding support, enabling better links with the statutory sector. Though we were disappointed to lose this service, the Welsh Sports Association have set up a supported DBS service. We agree that there remains the need for further support for training and safeguarding support and guidance. The Strategic Safeguarding Group provides a pivotal link and communication pathway between the sector and statutory Authorities and we feel that an open procurement process should be established for this support and training in dialogue with the strategic group for safeguarding in and through sport. We would be very happy to provide additional information on this issue to inform a scrutiny session with the Minister.

Key contacts:
If you would like to further discuss any of these matters or obtain more clarification please contact the Chair of group: trish.chalk@chwaraeteg.com or lowri.woodier@sport.wales

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Sefydliad Bevan
Response from: Bevan Foundation

Priorities for the Health, Social Care and Sport Committee: response from the Bevan Foundation

1. The Bevan Foundation develops new ideas based on sound evidence to make Wales fair, prosperous and sustainable. It is an independent, non-aligned charity. In the last three years it has made a significant contribution to public policy in Wales on:
   - the outlook for the Welsh society, including health and social care, by 2020; [1]
   - improving care at the end of life (for Marie Curie);[2]
   - reducing smoking prevalence especially amongst disadvantaged groups.[3]

   We welcome the opportunity to submit our views on the Committee's priorities for the coming term.

2. Wales faces major challenges in health and social care in the next five. They include rising demand (as a result of changing demographics and expectations), increased incidence of certain diseases and conditions (mental as well as physical), new therapies and treatments, and unforeseen risks e.g. new diseases, antibiotic resistance. A focus by the Committee on preparedness for the future as well as on the present is vital.

Public Health

3. People from low income groups experience higher levels of ill-health and die at a younger age than those from higher income groups. Some of this inequality is driven by so-called lifestyle factors (e.g. diet, exercise and smoking) and by much less widely recognised environmental factors (e.g. damp housing, poor air quality). The persistence of inequalities raises questions about the effectiveness of public health interventions to date. Our recent work on new devolved taxes highlighted that the Welsh Government could shape behaviour by imposing a levy on added sugar in food and drinks and on the use of sunbeds.

4. We welcome the proposals to consider sport, loneliness and gambling as aspects of public health. **We also suggest that the Committee investigates the effectiveness of current interventions, particularly on low income groups, in respect of the big health risks, namely:**
   - **physical inactivity (i.e. wider than participation in sport)**
   - **poor diet (including malnutrition as well as obesity)**
   - **smoking**
   - **environmental factors (especially housing and air quality).**

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[1] Bevan Foundation (2015) **The Shape of Wales to Come: Wales' economy, environment and society in 2020**.

[2] Marie Curie Cancer Care and Bevan Foundation (2014) **Death and dying in Wales: An analysis of inconsistencies in access to specialist palliative care and hospital activity in the last year of life**

[3] Bevan Foundation (2013) **Hitting the Quit Target: Smoking and Low Income Groups**.

NHS Services

5. We welcome the proposals to consider neonatal services, primary care and ambulance services. **We would urge the Committee to add to this list of services to be scruitinsed those available for people with mild to moderate mental ill-health, e.g. depression and anxiety**. Mild to moderate mental illness affects around one in five of the population, has a serious effect on people's quality of life and accounts for a significant 'burden' on health services. Parental mental illness is strongly associated with poor outcomes for children, and **we recommend the Committee looks specifically at parental (and especially maternal) mental illness**.

6. We understand the concern with waiting times but do not consider that these should be the sole measure of performance. **We also recommend that the Committee scrutinises:**
   - **equity of access including to end of life care;**
   - **patient safety (including management of hospital acquired infections, compliance with best practice e.g. safety alerts, and adverse incidents);**
   - **preparedness for risks e.g. new diseases.**

7. We anticipate that leaving the EU will have an impact on the NHS including the workforce, regulation of medicines, and environmental regulation. **We suggest that the Committee scrutinise the preparedness of the Welsh NHS for these changes.**

Social Care

8. Demand for social care – both in formal settings and unpaid care – is forecast to rise but social care budgets are under considerable pressure. There are significant concerns about access to and the quality of formal care and about the human rights of those receiving formal care (e.g. deprivation of liberty).[4] The support for unpaid carers is uneven.

9. We welcome the proposal to investigate the integration of health and social care services and the use of anti-psychotic drugs in care settings. In addition we suggest that the Committee scrutinises:
   - **deprivation of liberty in formal care settings;**
   - **the impact of financial pressures on community-based social care services;**
   - **support for unpaid carers.**

10. We would welcome the opportunity to submit evidence on these matters in future.

[4] EHRC (2015) **Is Wales Fairer**?

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Ymddiriedolaeth Hapchwarae Cyfrifol

Response from: Responsible Gambling Trust

Responsible Gambling Trust
7 Henrietta Street • London • WC2E 8PS

T: [redacted]

[redacted]
www.responsiblegamblingtrust.org.uk

Ms. Sarah Beasley
Clerk to the Health, Social Care and Sport Committee
National Assembly for Wales
Pierhead Street
Cardiff
CF99 1NA

By email: SeneddHealth@Assembly.Wales

1 September 2016

Dear Ms Beasley,

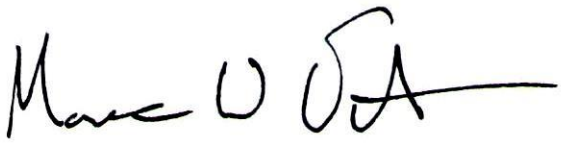
FORWARD WORK PROGRAMME

We were pleased to note that the Health, Social Care and Sport Committee is considering Gambling Addiction as a potential priority area for its forward programme.

We are the independent charity which funds the majority of the treatment for gambling-related harm available in Wales, as well as specific harm minimisation initiatives, such as our work with Newport Citizens Advice Bureau.

We would welcome this topic being reviewed and would wish to participate fully and co-operatively with the Committee's investigation.

Yours sincerely,



Marc Etches,
Chief Executive

Responsible Gambling Trust • Registered in England No 4384279 • Charity No 1093910
Chair: Kate Lampard CBE
Trustees • Henry Birch • Annette Dale-Perera • Nick Harding • Clive Hawkswood • Alan Jamieson • Brigid Simmonds • Professor Patrick Sturgis • Professor Jonathan Wolff
Chief Executive: Marc Etches

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Coleg Brenhinol Llawfeddygon Caeredin
Response from: Royal College of Surgeons of Edinburgh

The Royal College of Surgeons of Edinburgh is the oldest and largest of the UK surgical Royal Colleges, and one of the largest of all the UK medical Royal Colleges. First incorporated as the Barber Surgeons of Edinburgh in 1505, the College has been at the vanguard of surgical innovation and developments for over 500 years.

Today we are a modern, thriving, global network of medical professionals with a membership of well over 23,000 professionals who live and work in more than 100 countries around the world. 15,000 of these live and work in the UK with 625 in Wales. Our membership includes people at every stage of their career, from medical students through to trainees, consultants and those who have retired from practice.

With our interest in professional standards, the College's primary role – and the main concern of our Fellows and Members - is to ensure the safety of our patients and provide them with the best possible care. We do this by championing the highest standards of surgical and dental practice; through our provision of courses and educational programmes, training, examinations and Continuous Professional Development; our liaison with external medical bodies; and by influencing healthcare policy across the UK.

Improving the Quality of Services

Given that common conditions account for the majority of the surgical workload, the development of general surgical skills and competencies are vital, especially as surgical care should always be consultant-led and delivered as close to the patient as possible.

However as rarer conditions are best dealt with by specialist surgeons who have the training and expertise to produce the best care, we believe patients needing specialist surgery are often best served when services are concentrated in regional or national centres of excellence.

Pooling expertise in this way allows for economies of scale, better knowledge sharing and a professional environment that helps attract and retain the very best consultants and trainees. All these are a vital prerequisites of better patient outcomes. As recommended in our *Standards informing delivery of care in rural surgery*[1], it is vital that these configurations are supported by more formal collaborations between urban and rural hospitals, an increase in the number of generally trained consultants and greater multi-disciplinary working.

Similarly as per our *Trauma Care* report[2], major trauma services continue to be consolidated into a smaller number of specialist centres as they provide the most effective way of reducing mortality and disability for patients with multiple injuries.

In terms of seven day services, many of our members are already providing round the clock emergency surgery when it is needed. However, we do not believe that seven day elective surgery can be delivered without a significant increase in the surgical workforce. Likewise those services related to surgery, such as pharmacy, radiology, physiotherapy and social care, will be need to be expanded and appropriately resourced.

[1] https://www.rcsed.ac.uk/media/414891/rural%20surgery-web.pdf

[2] https://www.rcsed.ac.uk/media/167859/web_trauma%20care%20report%202012.pdf

This is just one example of the importance of an adequately funded health service. Whilst there are efficiencies that can be found, any sustainable model will depend on new sources of income. However, we believe that patients receive the best value service when funded through taxation and this principle should be the bedrock of any future model.

Therefore we feel it is important that:

- Every service meets the standards established in the Academy of Royal Medical College's Report *Guidance for Taking Responsibility*[3].
- There is a guarantee that all patients will not suffer negative consequences as a result of longer distances to specialist centres. This can be realised by underpinning services with the ability to move all patients safely without depleting local services.
- Provision for general surgical trainees in Wales to have the opportunity to spend four months in a Rural General Hospital are made.

Improving Surgical Training

Good training leads to better patient care, but we are concerned that the perennial high dissatisfaction amongst trainees and trainers with the quality of surgical training remain stubbornly unresolved.

RCSEd therefore supports the *Shape of Training* review, particularly its emphasis on developing more generalist surgical skills, a more competency based approach and an enhanced training for members of the wider surgical team. The recommendations of this review should be support by a greater use of credentialing in order to support surgeons in developing specialist skills later in their careers.

We also believe that workforce planning needs to be focussed on producing more consultants. Not only do we believe that all services should be consultant led, but are concerned that staff shortages have created an undue reliance on trainees delivering services that have little educational value.

Therefore both trainees and trainers need to have guaranteed time for training enshrined in their job plans. Further, surgical training should only be delivered by trainers using the Faculty of Surgical Trainers' *Standards for Surgical Trainers* and where possible, effective surgical trainers are formally identified and appropriately rewarded.

Surveys conducted by the College and the GMC consistently report that bullying, undermining and harassment is a frequent occurrence within the surgical profession. Not only is this harmful for the individuals affected, but these types of behaviours adversely affect patient outcomes. As such, non - technical skills training, such as around team working, leadership and patient safety should also be made mandatory.

Therefore we feel it is important that:

- Each surgical speciality is supported to determine their own training pathway to complement the implementation of the Shape of Training review in Wales.
- The focus on building competency rather than just experience in the early stages of the surgical career is increased.

[3] http://www.aomrc.org.uk/images/dmdocuments/aomrc_papers_takingresponsibility_final.pdf

- All contracts guarantee sufficient time for training but also allow flexibility within work plans.
- The Faculty of Surgical Trainers' Standards for Surgical Trainers across Wales and encourage membership of the Faculty.
- Non-technical skills training is made mandatory for the entire surgical workforce.
- The use of credentialing is encouraged to increase the flexibility within the surgical workforce.
- A single body for workforce planning, development and commissioning of education and training is established.

Improving Patient Outcomes

The sole aim of the RCSEd is to improve patient outcomes. As such, we support moves including the publication of surgical outcomes data, revalidation, and Fitness to Practice reviews as important ways of improving patient care, strengthening continuous professional development and identifying those doctors who encounter difficulties.

More can always be done to improve patient safety, so in addition to calling for an overall increase in the number of NHS consultants, RCSEd advocates greater emphasis being placed on patient safety in the revalidation process. We also believe that a statutory Duty of Candour and a common framework for reporting and learning from adverse events should be adopted.

It is also vital that we address the shortfall between the supply of donated organs and the demand. Transplantation is the best option for many patients with end-stage organ failure, improving survival and quality of life. Whilst we welcome the debate about a potential opt-out system, any legislative changes must be supported by significant investment in the necessary infrastructure.

Therefore we feel it is important that:

- A requirement for all Health Boards to publish unit level surgical outcomes data in partnership with the Royal Colleges and Surgical Specialty Associations is introduced.
- All revalidations processes are centred on patient safety.
- NHS management to strike a balance between the sometimes conflicting needs of meeting Government targets and addressing staff concerns about quality.
- RCSEd will be formally represented on all relevant consultant appointment panels, and provide a more clearly defined role for faculties, specialty organisations and Royal Colleges within the overall advisory and quality assurance structure.
- More Specialist Nurses in Organ Donation (SN-ODs) and Clinical Leads in Organ Donation (CLODs) are introduced to support families through the tough decisions they are faced with.

Improving Workplace Culture

Surveys of NHS staff regularly describe a workforce that is committed to working together and supporting one another to deliver high quality care. However the same surveys also point to a number of recurring issues that are adversely affecting staff morale. Good staff morale is a vital pre-requisite of good patient care and we believe more can be done to improve team working, transparency and openness.

Firstly more can be done to encourage all staff - regardless of their seniority or specialism - to report all unsafe care to help create a 'just culture' in the NHS. For instance where staff feel unable to raise concerns internally, then independent third party bodies need to be created for staff to pass complaints on to.

Similarly we need to have a zero tolerance attitude to bullying, undermining and intimidation wherever it occurs in the workplace. The College actively seeks to eradicate such behaviours through our education and training activities but believe staff need to be able to identify and voice their concerns without fear of personal and professional repercussions.

Secondly efforts need to be made to reduce unnecessarily long hours. Whilst circumstances may dictate that the 48 hour working week as set out by the European Working Time Directive is not always feasible, RCSEd unequivocally supports its retention and believe that accurate reporting of hours is vital to help guard against burn out and a resulting drop in standards. We also want to see more opportunities for those wishing to work or train on a less than full time basis so that personal circumstances do not deter individuals pursuing surgery as a career.

Finally, it is vitally important that that all staff feel happy and supported in their workplace. Awkwardly placed viewing screens and break rooms stocked exclusively with junk food are just two examples of how the work environment can jeopardise a surgeon's ability to perform to the best of their ability. Likewise, inadequate and ineffective IT systems can waste valuable time and energy.

Therefore we feel it is important that:

- A zero tolerance approach to bullying is enforced.
- The Welsh NHS work with the Royal Colleges to create a transparent system for raising concerns, overseen by an Independent National Whistleblowing Officer.
- Health Boards ensure working hours data is accurate and provide funding to increase rota numbers where the 48 target is being missed on a regular basis.
- There are no barriers to less than full time training and working.
- All NHS IT systems meet standards established by the Academy of Medical Royal Colleges.
- A review of the surgical working environment is undertaken in order to reduce unnecessary ergonomic problems

Public Health

As healthier lifestyles significantly improve the chances of surviving major surgery, the College supports all health interventions that clearly improve patient outcomes. This includes, but is not limited, to exercise, diet, alcohol and drugs and smoking. [4]

It is also vitally important that patients are discharged from hospital as soon as is appropriate. Patients with low cardiorespiratory health are five times more likely to die during or just after a surgical procedure than their fitter counterparts, and on average an unfit person costs the NHS an extra £6,000 when they undergo an operation, due to longer recovery times in hospital. In addition, patients who

[4] PRCSEd co-signed letter on 12 March 2016 http://www.bbc.co.uk/news/health-35785848

smoke, take drugs, or consume dangerous amounts of alcohol are more likely to develop complications, be admitted to an intensive care unit and be re-admitted after discharge.

Even when these factors are not an issue, there can be a number of reasons for delays which put the patient's wellbeing at risk. Confronting these blockages means investing in support services such as diagnostics but also in social care so patients can be supported to finish their recovery at home.

Therefore we feel it is important that:

- Spending in social care and public health is increased in order to help reduce demand on NHS resources, manage bed blocking and improve the patient pathway.
- The development of 'Perioperative Care Teams' who can undertake necessary interventions but also coordinate a patient's care along the pathway is supported.
- That every patient has the opportunity, working with their surgeon or GP, to develop an exercise plan that suits their condition and the type of operation they will undergo.
- Children and young people are protected from commercial interests which profit from recruiting new smokers or promoting unhealthy food and drink.

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Lloyds Pharmacy
Response from: Lloyds Pharmacy

The National Assembly for Wales - Health Social Care and Sport Committee

LloydsPharmacy response to the consultation on the priorities for Health, Social Care and Sport Committee

Introduction

LloydsPharmacy welcomes the opportunity to respond to the Health Social Care and Sport Committee's consultation on its future work programme.

Over the decades of working locally in Wales, we have seen communities evolve and families grow. LloydsPharmacy is placed in 83 pharmacies across Wales, where over 450 health-trained staff have a proven track record in delivering innovative and quality pharmacy services - located where people live, and across 7 Local Health Boards. Community pharmacies are located in the hearts of communities and span the boundaries of health and social care.

We strongly believe that community pharmacy can play a key role in supporting and furthering NHS Wales's priorities as part of an integrated strategy to combat increasing pressures on demand, such as enabling more capacity in GP surgeries or preventing people developing conditions through public health initiatives.

Consultation response

We would encourage the Committee to review and build on the work undertaken by the Health and Social Care Committee in the fourth Assembly through its inquiry into the contribution of community pharmacy to NHS services in Wales. Having considered the scope of the consultation and the outline headings that have been proposed, we would like to suggest that the Committee considers a further review of the role of community pharmacy in supporting the health and social care agenda in Wales and the extended role for the sector.

The Welsh Government has already recognised some of the opportunities available through the community pharmacy network and has recently invested in the implementation of the Choose Pharmacy Platform and the delivery of the national flu vaccination programme through Community Pharmacy.

We believe it would be of interest to the Committee and the National Assembly to review the range of services currently available and explore how they can be maximised to support the plan for primary care for Wales as set out by the Welsh Government. The inquiry could also explore further initiatives which utilise community pharmacies unique position and skills to support the health of the communities in Wales and the sustainability of the NHS.

Not in isolation of the above suggestion, we ask that community pharmacy is considered as a key stakeholder in discussions should the Committee progress with some of the ideas put forward in the consultation, particularly around;

- Alleviating pressure on the NHS and waiting times – community pharmacy has a significant role in providing the right care at the right time in the right place, which can support building capacity in other parts of the system.
- Supporting primary care and the health of communities – working alongside colleagues in general practice, community pharmacists can play a bigger role in the management of medicines for patients with long term conditions and prevention of avoidable hospital admissions.
- Workforce development – opportunities for the development of the pharmacist and community pharmacy team to deliver more integrated care and further support the primary care development plans for Wales.
- Efficiency within NHS and modern management practices – Pharmacy has a significant role to play, utilising the ready-made network and primary locations in service redesign around the provision of community based care, provision of care closer to home and in the most efficient and effective setting.
- Use of antipsychotic medication in care homes – community pharmacies already provide extensive services to care homes and play a role in the appropriate use of medication in this setting.

We would welcome the opportunity to work with the Committee to further scope the terms of a community pharmacy specific review, or indeed to submit responses to other areas of interest around the role that community pharmacy can play.

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Multiple Sclerosis Society Cymru

Response from: Multiple Sclerosis Society Wales

Over 100,000 of us in the UK have MS, with approximately 4,900 of us living in Wales. It's unpredictable and different for everyone. It's often painful, exhausting and can cause problems with how we walk, move, see, think and feel. But it doesn't have to be this way.

We're the MS Society. Whether you have MS, or care about someone who does, our community is here for you through the highs, lows and everything in between.

We understand what life's like with MS. And together we are stronger. We're researching,
writing, campaigning and fighting. Running, walking, caring and talking.

Together, we are strong enough to stop MS.

1. Introduction

1.1 We welcome the opportunity to respond to your request for our views on what the priorities for the Committee should be for the first 12 to 18 months, we are using the findings of our recent My MS My Needs Survey to inform our view.

1.2 We first undertook the survey in 2013 and we discovered a postcode lottery of treatment, care and support, with apparent shortcomings and disparities in the services offered both across the UK and within Wales.

1.3 This year, we undertook a second survey to build on this research. This data provides an unparalleled insight into the challenges that still remain for people living with MS when accessing vital services and support to manage their condition.

1.4 Our research has shown us that while some improvements have been made, we still have some way to go to ensure that people living with MS are able to access the right treatment at the right time, no matter where they live in Wales.

1.5 Results from the survey in Wales show that; 49% of respondents who could potentially benefit from taking a disease modifying therapy (DMT) are doing so (an increase from 30% in 2013). Whilst this increase is positive we still lag behind the rest of the UK (56%), Scotland (57%) and Northern Ireland (77%).

2. My MS My Needs Survey 2016

2.1 The MS Society conducted a survey of 11,024 people across the UK with MS between February and April 2016, making it the largest collection of patient-reported data from the UK MS community to date. The data presented here is from the 575 respondents who live in Wales.

2.2 Access to effective treatments is the top priority for people living with MS in Wales. It is also the MS Society's number one goal to ensure that people living with the condition have access to effective treatments to reduce relapses and slow disease progression until the day we can stop MS. All figures related to DMTs are calculated among those who could benefit from these treatments (i.e. those with relapsing remitting MS or secondary progressive with relapses).

2.3 There are now 11 DMTs licensed for relapsing forms of MS, all with different efficacies, side effects and methods of administration. They can decrease the number and severity of relapses and slow the progression of disability. Added to this, there is now consensus among the MS and clinical community that early treatment with a DMT can improve long-term outcomes. [i]

2.4 The recently revised Association of British Neurologists guidelines for prescribing DMTs recommends that decisions about treatment should be jointly taken by the person with MS and their neurologist, with treatment starting as early as appropriate after diagnosis. For people living with relapsing forms of MS, treating it early and effectively can suppress the disease and presents the best chance of preserving brain and spinal cord tissue during the course of the condition.

2.5 By preventing relapses and disability progression, people living with MS should be able to take greater control of their condition and their lives, directly and indirectly improving physical, economic, emotional and social outcomes. Access to treatment and services helps people living with MS manage their condition, and to identify early signs of complications and put in place prevention and treatment strategies to avoid unscheduled hospital admissions. [ii]

2.6 With the increasing number of treatments options, it's more important than ever that people living with MS are supported to make choices about their treatment, and can access the best treatment for them, regardless of where in Wales they live. In 2013 our survey found that access to DMTs in the UK was low (40% across the UK) with Wales having the lowest rate - just 30% of people with relapsing forms of MS taking a DMT.[iii] It is encouraging to see that the number of people receiving DMTs in Wales has risen to 49% in 2016. This increase in DMT uptake demonstrates a significant positive improvement in MS healthcare in Wales. This is likely to be linked to the newer treatments that have become available on the NHS, which are judged to be more effective and easier to take. However compared to the rest of the UK; England (56%), Scotland (57%) and Northern Ireland (77%), access to DMTs among those who could benefit in Wales remains the lowest in the UK.

2.7 There are several drivers that make it more likely that a person will be taking a DMT. Access to health professionals and the right information are key; 81% of people who had access to MS Specialists and the right information in the last twelve months are taking a DMT, whereas only 20% of those who haven't accessed any of these services in the last twelve months are.

2.8 There are also several symptom management therapies (SMTs) specifically licensed to treat MS, which can make a significant difference to the day-to-day lives of those living with the condition. These treatments can help with problems such as spasticity and walking or an overactive bladder. Licensed SMTs for MS include Sativex, Fampyra and Botox. Wales was the first UK nation to approve Sativex for routine use on the NHS in 2014. Yet, two years following its approval by the AWMSG, our survey revealed that only 1% of respondents are currently taking it.

2.9 People living with MS require access to professionals from all parts of the health and social care systems to best manage their condition. We believe that people with MS should have timely access to professionals and be at the centre of decision-making about their care. Published earlier in 2016, the NICE Quality Standard for MS recommends that people with MS have access to care from a multidisciplinary team with expertise in MS, and access to a comprehensive review of their treatment and care annually.[iv] This team should consist of a range of professionals including neurologists, MS specialist nurses, physiotherapists and occupational therapists, speech and language therapists, psychologists, dietitians, social care, continence specialists and GPs. Respondents to our survey were asked to indicate their need for and access to support from various professionals over the past 12 months.

2.10 With an increasing number of treatments available, each with different support and monitoring requirements, it is vital that people with MS are fully supported to make an informed choice about their treatment. Conversations about treatment options, including DMTs, should begin close to diagnosis, with follow-up after diagnosis with a specialist within six weeks and again within six months. However, feedback from the MS community and clinicians in Wales suggest that timely follow up is becoming more and more difficult resulting in less time to assess people effectively, discuss treatment options and manage risks. With this added pressure on MS Neurologist and Specialist Nurse case-loads, people living with progressive MS tell us they feel they are being pushed further down the waiting lists with little or no support.

2.11 MS specialist nurses play a crucial role in the care and support of people with MS. Their role and responsibilities can be wide-ranging and varied but typically include providing information and support on how to best manage the condition and on DMTs, initiating and monitoring treatment for people with relapsing forms of MS, providing psychological support and co-ordinating care.

2.12 88% of people who needed to see an MS nurse were able to in the past twelve months, which is comparable to the other nations of the UK. Given that Public Health Wales identify that there is an overall shortage in Wales of between 7 and 9 Specialist MS nurses it is no surprise that 11% of respondents had not seen an MS nurse but felt they had needed to. Given that people living with MS regularly cite their MS nurse as their key contact for treatment, care and support. (54% of respondents identified their MS Nurse compared to 14% who listed their GP) it is vital that this shortfall is addressed urgently.

2.13 NICE recommends that all people living with MS have a comprehensive review of all aspects of their care at least once a year, and that this review is carried out by healthcare professionals with expertise in MS. If a person is on a treatment, a comprehensive review could also be used to assess how that is working, typically including an MRI scan.There are only four neurologists who specialise in MS in Wales and all four are based along the M4 corridor in South Wales. The only other provision is provided by an MS specialist neurologist based at the Walton Centre in Liverpool who covers North Wales.

2.14 In 2013, 72% of respondents reported that they had their need to see their neurologist met. Our survey this year showed a 3% increase, with 75% of respondents saying that they had this need met. (17%) had not seen a neurologist in the past twelve months but felt that they needed to. Our survey shows that the more recently a person with MS was diagnosed the more likely they are to have seen a neurologist in the twelve months.

2.15 Many people living with MS experience bladder and urinary problems, including incontinence and infections. Continence advisers can provide people living with the condition with information, for example about products and treatments for bladder problems, and confidential advice. In Wales 75% of respondents to our survey who had required specialist continence advice had received it. However, more than one in 10 (14%) people had not received this support despite needing to.

2.16 48% of respondents had seen a physiotherapist in relation to their MS within the last year, but nearly 1 in 5 people (18%) had not seen a physiotherapist and felt that they needed to. Physiotherapy can have a significant impact on a person's rehabilitation after a relapse, or can improve movement and mobility for someone living with disability as a result of MS. Timely access to evidence based and appropriate physiotherapy should be a basic entitlement, available for everyone living with MS in Wales who could benefit.

2.17 Other services that support people living with MS to remain physically active are important in helping them to remain healthy and independent in their day-to-day lives. In addition, research suggests that support to remain physically active has resulted in a decrease in GP and hospital consultant visits and reduced hospital bed days for people living with MS.[v] More than a quarter (29%) of respondents said that they needed support to remain physically active but had not received any.

2.18 Half the number of people living with MS experience anxiety and half experience depression, with many experiencing both.[vi] Moreover, there is a strong link between mental and physical health – in 2012, £1 in every £8 spent on long-term conditions was linked to poor mental health.[vii] Ensuring people living with MS can access emotional support is vital, however 28% of respondents said that they had needed emotional support in the last twelve months but hadn't received any/enough help or support.

2.19 NICE guidelines state that people living with MS should have access to a single point of contact who acts as a care and treatment coordinator and that care and treatment should be made available through multi-disciplinary teams.[viii] Care planning and care co-ordination has a vital role to play in ensuring that people living with MS can access the full suite of support they require to best manage their condition. Our survey found that overwhelmingly people in Wales reported that they had not been offered a care plan or a review of their care plan by their health professional in the last 12 months (86%) For people to feel fully supported and empowered in their care, the MS multidisciplinary team must consist of health and social care professionals working with the person living with MS to achieve the best outcomes. When asked if they felt that the professionals who help plan their care worked well together, 18% of our survey respondents answered "not at all" meanwhile 15% responded "completely" and 34% "to some extent".

3. Conclusions

3.1 Our research has shown us that while some improvement has been made, we still have some way to go to ensure that people living with MS are able to access the right treatment at the right time, no matter where they live in Wales. It is encouraging to see that the number of people receiving DMTs in Wales has risen since 2013. However, access to DMTs among those who could benefit in Wales remains the lowest in the UK.

3.2 People living with MS require access to treatments to manage their condition to improve their outcomes. There are now 11 DMTs licensed for relapsing forms of MS approved for use but as we know only too well, they are not all equally available across Wales. With an increasing number of treatments options, it's more important than ever that people living with MS can access the best treatment for them, regardless of where in Wales they live. The unacceptable delays in accessing new treatments are caused by a variety of issues including the under resourcing and lack of infrastructure in place to monitor a new treatment or drug and the process that Local Health Boards go through to add a new drug onto their formulary.

3.3 In 2014 Welsh Government published its Neurological Conditions Delivery Plan to ensure that those affected by a neurological condition have timely access to high-quality care, integrated with social services where appropriate, irrespective of where they live and how these services are delivered. The then Minister for Health Mark Drakeford stated that "in particular it is essential that NHS Wales and its partners focus on meeting our population needs, reducing inequalities in health and variation in access to services across Wales."

3.4 As our survey illustrates there are still some areas where improvements still need to be made and we would therefore ask the Health, Social Care and Sport Committee to carry out a short Inquiry into the implementation of the Neurological Conditions Plan prior to the proposed refresh of the Plan in 2017.

[i] MS Society (2015) Time to Act – a consensus on early treatment

[ii] Nhis. Measuring the burden of hospitalisation in multiple sclerosis: A cross-sectional analysis of the English Hospital Episode Statistics database 2009-2014 http://www.nhis.com/uploads/reports/NHiS-MS-Report-2015.pdf

[iii] MS Society (2013) *A lottery of treatment and care – MS Services across Wales and the UK*

iv NICE (2016) *Quality Standard: Multiple Sclerosis.* https://www.nice.org.uk/guidance/qs108(Accessed July 2016)

[v] Physiotherapy works. Multiple Sclerosis CSP January 2012

vi Jones, Ford *et al.* (2012) A large-scale study of anxiety and depression in people with Multiple Sclerosis: a survey via the web portal of the UK MS Register. *PLoS One,* 7(7)

vii The King's Fund (2012) Long-term and mental health: the cost of co-morditities. http://www.kingsfund.org.uk/sites/files/kf/field/field_publication_file/long-term-conditions-mental-health-cost-comorbidities-naylor-feb12.pdf (accessed July 2016)

[viii] https://www.nice.org.uk/guidance/cg186?unlid=2967616602016128161311

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: AbbVie

Response from: AbbVie

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Consultation on the Forward Work Programme of the Health Committee 2016/17

AbbVie is a global, research-based biopharmaceutical company formed in 2013 following separation from Abbott Laboratories. The company's mission is to use its expertise, dedicated people and unique approach to innovation to develop and market advanced therapies that address some of the world's most complex and serious diseases. For further information on the company and its people, portfolio and commitments, please visit www.abbvie.com.

AbbVie welcomes the opportunity to contribute to the Committee's forward work programme during the Fifth Assembly. As well as considering legislation, the Committee has a key role in scrutinizing spending plans and policy matters set out by the Welsh Government. In our submission, we have focused on three key areas:

- A review of the impact of the **Prudent Healthcare** approach to health policy in Wales in order to assess the effectiveness of the policy and how the principles of prudent healthcare are being applied in practice to the benefit of patient care.

- We share the Committee's interest in looking at the progress made towards effective **integration of care**, in particular whether closer working has improved patient pathways.

- We have also highlighted an opportunity for the Committee to play a key role in scrutinizing plans to introduce a **new treatment fund** – making sure it is sustainable and delivers access to innovative medicines in Wales.

Prudent Healthcare

In 2014, Professor Mark Drakeford, Minister for Health and Social Services, defined Prudent Healthcare as "Healthcare that fits the needs and circumstances of patients and actively avoids wasteful care that is not to the patient's benefit."

The Welsh Government established principles of prudent healthcare which are centred around involving patients in decisions about their care; prioritizing care for those with the greatest need; to do only what is needed, and to do no harm; to adopt evidence based practice and reduce inappropriate variation.

With almost half of the total Welsh budget allocated to NHS spending there is increasing pressure to reduce costs and achieve efficiencies within the service to ensure sustainability in the long term.

Given that this policy drives decision making in the NHS it is important for the Committee to consider and understand the impact it is having on the day to day running of the NHS and to determine whether the principles of prudent healthcare are driving positive change in the Welsh NHS.

AbbVie supports the principles of Prudent Healthcare and believe that there is an opportunity for all of those involved in the delivery of healthcare services in the NHS to contribute to developing new and sustainable

ways of supporting people living with illness to achieve better outcomes and which help to make limited NHS resources go further.

AbbVie has established a UK-wide Sustainable Healthcare programme and has identified three key areas for opportunities to improve the sustainability of healthcare services, which we believe could form the focus of a Committee Inquiry:

- Embedding **a person-centred approach**, which considers the individual rather than a siloed focus on their condition(s)
- Using **technology** to improve the delivery of services and care closer to home and equipping individuals to self-manage
- Helping individuals to **navigate the healthcare system** and manage their condition with confidence. For example, AbbVie is supporting the development of a new, shared decision-making (SDM) tool, led by Professor Debbie Cohen at Cardiff University. The SDM tool has been designed to aid and improve conversations and decisions about health and work between patients and their healthcare professionals.

In September AbbVie in partnership with NHS Public Health Wales, will be hosting a conference on Prudent Healthcare to consider how Wales is getting it right in terms of Sustainable Healthcare.

Integration of Health and Social Care services

AbbVie would support an inquiry into progress made towards the implementation of the "Framework for delivering integrated health and social care for older people with complex needs", particularly to consider opportunities and challenges for closer working between health, local authorities and the third sector in Wales. It would also be useful to consider whether this closer working has delivered improvements to patient care pathways from initial referral to specialist services through to discharge and the provision of care at home.

Within this context, the Committee may also wish to consider is how the NHS defines and recognises 'value' in terms of the decisions that are made regarding treatment choice and the model of care. Managers across the NHS face a number of competing demands and pressures however in some cases the financial pressures and structural limitations constrain their ability to make long term decisions that may require upfront costs but which have potential to deliver savings in the long-term. In other cases, the benefits of investing in particular preventative strategies or investing in medicines or technologies may fall on the shoulders of one part of the service at a particular point in the patient pathway with the benefits of such investment, through reduced admissions and financial savings, accruing to other parts of the service responsible, but there is no mechanism to support this type of activity.

One example would be the management of long-term conditions such as rheumatoid arthritis or gastroenterology and the value that can be achieved across a whole patient pathway by patient support programmes that seek to provide bespoke support to patients receiving medicines in a way which is most impactful to them. This can reduce the amount of hospital appointments required for routine medicine administration which, alongside patient benefits, frees up hospital resource. It can also support adherence to medication reducing complications and costs that can arise from a patient failing to take their medicine. However, these wider benefits and value points that occur across the patient pathway are not always easily accounted for by the prescribing service.

Integration offers an opportunity to simplify the system to remove the barriers between primary, community and hospital based care as well as between the NHS and social care services, to achieve best value across a whole pathway. AbbVie believes in addition to these structural changes tools that encourage a wider assessment of value may be beneficial.

New Treatment Fund

The First Minister set out a commitment to work on a new NHS treatment fund within the first 100 days of his government and, on the 30th of August 2016, the Welsh Government issued a media statement which reported that within the first 100 days, they had:

"Committed £80m to establish a New Treatment Fund and to independently review patient funding requests – this is a significant step forward in ensuring treatment for life-limiting and life-threatening diseases are immediately and consistently available across Wales. The independent review panel has been agreed and we fully expect the fund to be in operational in December".

It would be appropriate and welcome for the Committee to be actively involved in the development of this fund and to monitor its implementation.

An inquiry into this policy should take into account the funding, alignment with existing HTA processes and learn from experiences in other parts of the UK.

The Committee may wish to investigate the plans in detail to ensure that a clear budgetary mechanism is established to provide sufficient and sustainable funding for access to medicines.

Aligning the fund to the AWMSG and NICE health technology appraisal process would ensure that there is clarity on how this fund can be accessed.

Introducing a new treatment fund in Wales should support the policy of Prudent Healthcare where patients have access to the clinically and cost effective medicines they need.

AbbVie believes that all partners in the health service have a role to play in delivering new patient pathways that support patients to manage their conditions and remain at home with minimal need for hospital-based care. In Wales, this work is underpinned by the Prudent Healthcare principles. As stated previously, AbbVie is hosting a conference in September in partnership with NHS Public Health Wales to look more closely at how Wales is progressing this policy and members of the Committee should have received invitations to attend this event.

I would be happy to provide more detail on any of the information provided in this submission and, should the Committee proceed inquiries into any of these issues, AbbVie would be happy to provide more detailed evidence to the Committee.

Yours sincerely,

Gail Grant
AbbVie Government Affairs Manager
E: [redacted]
M: [redacted]

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Comisiynydd y Gymraeg

Response from: Welsh Language Commissioner

Meri Huws
Comisiynydd y Gymraeg
Welsh Language Commissioner

Comisiynydd y Gymraeg
Welsh Language Commissioner

Dr Dai Lloyd
Chair
Health, Social Care and Sport Committee
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Cardiff Bay
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01/09/2016

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Dear Chair

Priorities for the Health, Social Care and Sport Committee

Thank you for the opportunity to suggest matters the Committee may wish to focus upon as part of its scrutiny of health, social care and sport during the fifth Assembly.

I envisage the Committee may be interested in specific pieces of work I will have undertaken and published information about them occasionally during the term of the fifth Assembly. Matters of interest may arise in light of research I have conducted, reports published, recommendations made to Welsh Ministers, or in relation to my responsibility for providing advice to any person. I would be more than happy to advise the Committee as and when required on strategic matters aimed at strengthening the position of the Welsh Language in Wales.

It is also possible that matters of public interest will lead to Committee discussions in light of my adjudicating on investigations into specific cases or as a result of publishing reports on investigations into failures to comply with Welsh Language Standards.

Turning to specific policy matters, it is widely recognised that effective communication is an essential element of good health and social care services. Language is integral to effective communication. That was one of the findings of the statutory inquiry I conducted in 2014 into the Welsh language within primary care, *My Language, My Health*. In accordance with powers given to me by Section 7 of the Welsh Language Measure (Wales) 2011, I made 33 recommendations to Welsh Ministers in light of that inquiry in order to improve Welsh medium primary care services in Wales. On the basis of the

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Comisiynydd y Gymraeg
Welsh Language Commissioner

significant body of evidence gathered, recommendations for improvement were made in areas such as

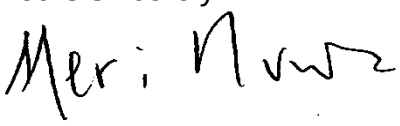
- dignity and respect for the patient
- service planning
- the need for an active offer of a service in Welsh
- workforce planning
- education and training
- data and research

I presented the findings of the inquiry to the fourth Assembly's Health and Social Care Committee in a meeting held on 2 July 2014. I note that primary care is one of the topics that the committee itself has identified as a priority for scrutiny during the fifth Assembly. It would be timely for the committee to review progress in implementing the inquiry's recommendations as part of its scrutiny of primary care.

In order to ensure that the health and social care service in Wales is able to deliver in Welsh to those who need it, the Welsh Government is implementing a strategic framework for the Welsh language within this field, *More than Just Words*. The first strategy was published in 2012 and it was revised earlier this year for the period 2016 – 2019. Four years into the implementation of this strategic framework, I believe it would be beneficial for the committee to review the success of the strategic framework in achieving its goals. By doing so quite soon, the committee's work could inform the implementation of the framework over the next few years, up to 2019.

I trust these suggestions prove useful.

Yours sincerely



Meri Huws
Welsh Language Commissioner

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Coeliac UK
Response from: Coeliac UK

Priorities for the Health, Social Care and Sports Committee:

Coeliac UK response (31st August 2016)

1. About Coeliac UK

1.1. Coeliac UK is the national charity for people with coeliac disease and dermatitis herpetiformis (DH), the skin manifestation of coeliac disease, giving support on health care and the gluten-free diet. We campaign, research and offer support and advice to people with these conditions and those supporting them. We have over 65,000 members across the UK and more than 3,000 in Wales.

2. Coeliac disease:

2.1. Coeliac disease is a lifelong auto-immune disease, affecting around 1 in 100 people (c.30,000 in Wales). It is a genetic condition that is triggered by gluten (found in wheat, barley and rye) and that is characterised by an abnormal immune response when gluten is eaten. Coeliac disease is associated with a range of symptoms including bloating, diarrhoea, nausea, wind, constipation, anaemia, severe mouth ulcers and even hair loss. It is not an allergy or simple food intolerance.

2.2. In Wales only 22% of those with the condition have a diagnosis. This means tens of thousands of people across Wales could be affected by coeliac disease and not know why they are feeling unwell. The long term health complications associated with undiagnosed and untreated coeliac disease are osteoporosis, infertility, and in very rare cases, small bowel cancer. Currently, the only medical treatment for coeliac disease is strict adherence to a gluten-free diet for life.

3. Suggested priorities for the committee:

3.1. Waiting times

3.1.1. We ask the committee to examine what action the Welsh Government is undertaking to improve waiting times, particularly with regard to endoscopy services.

3.1.2. In order to attain a diagnosis for coeliac disease there are two steps, blood test in primary care and endoscopy in secondary care. The process requires the patient to maintain a gluten containing diet in order for the testing to be effective. Withdrawing gluten from the diet at this stage could lead to inaccurate results and a missed diagnosis. Lengthy waiting times between the blood test and endoscopy can not only result in prolonged period of illness for the individual but also risk them withdrawing gluten from their diet or deciding against having endoscopy to confirm diagnosis of coeliac disease, altogether.

3.1.3. Yet endoscopy waits over 8 weeks (NHS Wales' operational standard) have risen from 8% in October 2009 to 39% in March 2014[1].

3.1.4. Endoscopy services are under mounting pressure in Wales and its clear there are a number of challenges to overcome. The Welsh Government has committed to all 19 endoscopy units attaining JAG (Joint Advisory Group) accreditation (an independent assessment of endoscopy unit standards) yet to date only 4 have achieved this standard. Two key barriers have been highlighted in our discussions with health care professionals; outdated clinical environments and waiting times.

3.1.5. Whilst clinical environments can be upgraded at unit level, there is a far more systemic challenge posed by long waiting times and we would ask that the committee examines what action the Welsh Government is undertaking to address drivers such as limited capacity, an ageing

[1] NHS Waiting Times for Elective Care in Wales Technical Report, Auditor General for Wales, January 2015, p.28
http://www.wao.gov.uk/system/files/publications/nhs_waiting_times_technical_report_english.pdf

population and reluctance of some patients to travel.

3.2. Supporting children with medical needs in School

3.2.1. There is a need for a change in legislation in Wales to introduce a statutory duty of care for children with medical needs in schools. This could be included within the newly proposed Additional Learning Needs (ALN) Framework.

3.2.2. The Welsh Government's proposed ALN Framework documentation states that children with medical needs will not be covered by the ALN Bill (see page 30 of the draft ALN Code of Practice). This is of concern to us and we ask the Committee to look at this again.

3.2.3. The rights of children and young people with medical needs in Wales during the school day are not protected in law to the same level as children in England.

3.2.4. In England, the Children and Families Act 2014 came into force on 1 September 2014. Section 100 contains a statutory duty to support pupils with medical conditions, meaning that in practice schools must make additional arrangements for supporting pupils at schools with medical conditions. This includes the creation of an individual health care plan for all children with medicals needs which in the case of coeliac disease includes measures to limit the chances of a child with coeliac disease becoming ill at school or that they are excluded from school activities due to their condition. It also provides a framework that enables parents to respond where they feel this duty is not being met.

3.2.5. The legislation does not apply to schools in Wales. The current system in Wales therefore puts children with medical conditions, including those with coeliac disease, at an academic disadvantage in comparison to their peers in England and does not protect them to the same degree whilst they

are at school. This is an inequity with which we feel the committee should be concerned.

3.2.6. It is for this reason we are particularly concerned that there is little to no reference in current guidance to the importance of food management as a crucial facet of support for many children with medical needs both in the context of emergency and non-emergency chronic conditions. This applies not just in terms of ensuring inclusive and safe meal times but also in other contexts such as cookery lessons or schools trips. A child should not be prevented from accessing a safe hot meal with their peers or taking part fully in school activities because of any perceived inconvenience caused by their requirement for gluten-free food.

3.2.7. We regularly receive enquiries from families of children whose attendance, attainment and overall educational experiences are compromised because of their condition and the lack of guaranteed support from the current framework. It is vital that children are kept safe and healthy whilst they are learning to enable them to achieve their full potential.

3.2.8. Providing such support to children and young people with medical conditions to enable them to participate in all aspects of school life requires a co-ordinated effort. A framework of support for children with medical conditions, agreed between the school and parents to enable children to participate fully in the school day is vital to ensure effective care and learning in the school environment.

3.2.9. We ask the Committee to consider the current situation and question whether there is a need to bring the rights, support and protection provided to children and young people living with coeliac disease in Wales in line with those in England. There is currently a unique and rare opportunity to do this during this Government's legislative programme.

3.3. **Prescriptions for gluten-free staple food**

3.3.1. We welcome the recent statement[2] from the Minister for Health and Social Care, in support of the continued provision of Gluten-free staples on prescription. A strict gluten-free diet is the complete medical treatment for coeliac disease yet gluten-free products can cost 3-4 times as much as gluten-containing equivalents in the shops and can be particularly difficult to access for those rural, more isolated Welsh communities.

3.3.2. The cost of such provision represents just 0.34% [3]of prescription spending in Wales, making it one of the most cost effective treatments for a long term condition in the NHS. We ask the committee to ensure such vital provision is maintained at a time of increased pressure on NHS budgets.

3.4. Consistent standards of care

3.4.1. We would like to draw the committee's attention to the upcoming publication of NICE's updated Quality Standard on Coeliac Disease. We anticipate this will provide welcome and substantive direction on the process for effective diagnosis and treatment of the condition. In particular we welcome a proposed new standard with regards endoscopy waiting times and the importance of health equality challenges associated with accessing gluten-free products for those on low incomes.

[2] Questions to the Cabinet Secretary for Health, Wellbeing and Sport - OAQ(5)0025(HWS)
[3] Prescription cost analysis: Data totals, 2014 (published 18 March 2015) available at http://gov.wales/statistics-and-research/prescriptions-dispensed-community/?lang=en [last accessed 01.09.2015]

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Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Cyfarwyddwyr Gweithredol Therapiau a Gwyddorau Iechyd

Response from: The Executive Directors of Therapies and Health Sciences

2 September 2016

Priorities for Health, Social Care and Sports Committee Executive Directors of Therapies and Health Science consultation response

The Executive Directors of Therapies and Health Science (DoTHS) are pleased to respond to the consultation to inform the key priorities for the next 12 – 18 months.

1. Integration of Health and Social Care services: The DoTHS would support an inquiry looking into the implementation of the Social Services and Well-being Act and other policies on integration of health and social care services.
This would feel like a priority area given the recent implementation of the Act. From our observations, the picture across Wales feels patchy and it is important to understand the barriers that may exist e.g. is it terms and conditions, cultural issues, lack of priority. There are no meaningful targets or whole system indicators to achieve in terms of integrated services as there are for acute services and flow, we would suggest that this be considered.

We are strong advocates of collaborative working and have the only Registered professional group – Occupational Therapy – that is employed in both Health and Social Care and are therefore well- placed to champion integration and its benefits. We believe that integration is vital across all of the public sector to deliver the scale of change required and would request that greater pace is given to this agenda that needs to focus not only on the NHS but with partner public sectors and the third sector. We would suggest that it is important to look at integration across the whole of the public sector, not just integration of service provision, but also integration of policy and priorities to facilitate greater integration. The committee may want to consider metrics as a proxy for integration, such as The National Audit of Intermediate Care 2015 (England) recommendation of a 2 day wait for intermediate care access being a reasonable indicator based on the evidence that patients who wait more than 2 days lose the benefit the service. Something like this would be patient centred, simple to collect, easy to measure and could give a high level indication of improvement in integrated working.

2. Waiting Times: The DoTHS would support an inquiry considering waiting times but recommend that the remit should look at patient outcomes rather than solely tier 1 targets. An interesting from a therapies perspective is that one of the unintended consequence of maintaining waiting time targets is that services are then focussed more toward an assessment than intervention service, and areas where there is strong evidence for intervention intensity eg. Childrens services and frail elderly the focus on

initial assessment may not meet clinical need and best outcomes. Waiting times are a key priority for the NHS and there has been considerable work to focus on improving waiting time. While targets have a role to play, we suggest that this is an opportunity to take a broader view to instigating a system change in the way treatment is delivered to patients and providing the best service we can within the resources available with priorities being based on clinical need. Some of the current key pressure areas outlined are familiar to Therapists and Health care Scientists and we recognise that without some change in waiting time priority services such as diagnostics and therapies will continue to have capacity deficits. It is an imperative that we develop a performance management framework that supports this with attention given to data collection systems and analytical capability and capacity.

3. Primary Care: We would support an inquiry considering primary care to inform the Committee of the pressures for change and the many developments in services across Wales. The DoTHS support the development of clusters to be inclusive or a broader Primary care team beyond the traditional Drs and Nurses. Many of our staff have key roles to perform in delivering sustainable models e.g. physiotherapy first contact practitioners, Psychologically informed care, paramedic practitioners, dietetic advisors. We hope that the enquiry would focus on the contribution of Therapists and Health care Scientists in delivering new models for sustainable community services areas such as musculoskeletal management, Point of care Testing and Dementia care are areas where we have key skills that could be more widely deployed.

4. Efficiency within the NHS and modern management practices: We would support an inquiry considering the efficiency within the NHS. The rise in demand, coupled with constrained financial resources, has made delivering health and care services in the current model increasingly difficult.

5. Neonatal services: Following from the "Bliss baby report 2016: time for change"[i] we would support the Committee considering the recommendations with the report and the issues highlighted to deliver a sustainable model for neonatal services that meet clinical needs and that is provided by a well trained workforce, which should include a requirement to meet the neonatal therapy staffing level standards.

6. Use of antipsychotic medication in care homes: We support the Committee considering the scale of the inappropriate use of antipsychotics to control the behavioural and psychological symptoms of people living with dementia, and if required examine possible solutions. Psychological interventions and management of challenging behaviour through behavioural and communication strategies, education for care home staff, environmental enrichment would be part of the solution and core skills of psychology, Speech and Language therapy and Occupational Therapy.

7. Ambulance Services: The DoTHS would support a short inquiry examining the outcomes of the new Clinical Response Model pilot and consider the Review findings of the CRM pilot that will be published next year.

8. Loneliness and isolation among older people: We would support a short inquiry considering loneliness and isolation for older people but we would recommend that this is extended to include all age groups due to the fact it is an issue that does not only impact on older people. We would like the committee to consider whether this could be linked with the integration theme and then be used as an indicator of wellbeing within intermediate care?

9. Gambling addiction: We would support the inquiry looking at awareness of gambling addiction, the provision of support services, and the steps that could be taken to reduce harm, though think this would be of greater impact for criminal justice than health services.

10. Sport and public health: The DoTHS are strongly supportive of an inquiry considering public health should be a key priority for the Committee and should consider the role and impact of a preventative approach to health services and work to educate the general public about the preventative agenda, as recommended during the Health and Social Care Committee legacy report as well as being a key pillar of Prudent healthcare.

Prevention and early intervention to improve population health is a core skills for many Therapists as well as promoting exercise and sport e.g. Dietitians, Occupational therapists, physiotherapists, podiatrists. WE recognise the benefits of the preventative health care agenda and are also skilled in treatment and maximising peoples potential – so would be strong advocates for this inquiry.

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Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Ymddiriedolaeth Gofalwyr Cymru

Response from: Carers Trust Wales

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Carers Trust

Priorities for the Health, Social Care and Sport Committee

Your name: Kieron Rees

Organisation (if applicable): Carers Trust Wales

email / telephone number: [redacted] / [redacted]

Your address: Carers Trust Wales, 3rd Floor, 33 Cathedral Road, Cardiff, CF11 9HB

About Carers Trust Wales

Carers Trust Wales is part of Carers Trust, a major charity for, with and about carers. We work to improve support, services and recognition for the 370,000 people in Wales living with the challenges of caring, **unpaid**, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

Our Mission is to identify, support and involve Wales' unpaid carers through the provision of action, help and advice.

Together with our locally-based network partners, we provide access to desperately-needed breaks, information and advice, education, training and employment opportunities – working with 20,000 carers a year in Wales. Our network partners benefit from the provision of grants, advice documents and reports to improve carers' services. We give carers and young carers opportunities to speak to someone and make their voices heard, offline via our carers' services and young carers' schemes, and via our online communities.

Our Strategic aims are

1. Championing carers – ensuring their voices heard and carers have a high profile across Wales including in the media, government
2. Delivering services for carers in Wales – researching and promoting solutions for carers across Wales
3. Building partnerships and delivering change – working meaningfully across sectors to reach more carers in all spheres of life
4. A strong Carers Trust Wales network – working closely with our network partners to increase sustainability and impact across Wales

Our Vision is a Caring Wales – where unpaid carers are recognised and able to get the support they need

© Carers Trust

Overview

1. Carers Trust Wales strongly believes that a priority for the Health and Social Care Committee in the coming year should be an inquiry into the needs of carers in Wales and the level of support required. We believe such an inquiry should include a focus on: the provision of replacement care and short breaks, support for carers of people with mental health problems, and support for young and young adult carers.

2. A carer is anyone caring, unpaid, for a friend or family member who without their support would not be able to cope.

3. Wales is a uniquely caring country with the highest proportion of carers in the UK. Carers in Wales are also, on average, caring for more hours a week than carers elsewhere in the UK.

4. Replacement care and short breaks are two of the most frequently raised issues by carers. Carers Trust Wales is calling for the introduction of a Carers Well-being Fund – a national fund to provide breaks and replacement care to carers in Wales. There is a clear moral and economic case for providing such a fund.

5. This fund could be modelled on the Scottish Short Breaks Fund, which has been in place since 2010, but take into account the lessons learned from it.

6. Carers of people with mental health problems, including dementia, face specific and significant barriers. These barriers include getting the information and advice they need, and being meaningfully involved in the treatment of the people they care for. We believe that exploring what can be done to tackle the barriers carers of people with dementia face should be a priority for the committee

7. We agree that loneliness and isolation amongst older people would be a worthwhile priority for the Health and Social Care Committee. Ideally any work on this issue would also explore the role of support services, including support services aimed exclusively at carers, in tackling loneliness and isolation amongst older people. Carers Trust Wales has

a suite of good practice examples from across Wales on this particular issue.

8. Carers Trust Wales would welcome the opportunity to speak to the Health and Social Care Committee on the issues we have discussed in this response.

1. Response

1.1. Carers Trust Wales is calling on the Health, Social Care and Sport Committee to carry out an inquiry into the challenges facing carers in Wales, and the services available to support carers

1.2. A carer is anyone who cares, unpaid, for a friend or family member who would not cope without their support.

1.3. Wales is a uniquely caring country, according to the 2011 census we have the highest proportion of carers in the UK. The 2011 census also found that carers in Wales care for longer on average than carers anywhere else in the UK[1].

1.4. Officially, 12% of the population of Wales provide unpaid care to a friend or family member who would not cope without their support. In reality, this figure is likely to be much higher.

1.5. Among young carers alone, of which there are officially around 12,000 in Wales, research suggests the true figure may be four times higher[2].

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1 http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/articles/2011censusanalysisunpaidcareinenglandandwales2011andcomparisonwith2001/2013-02-15

2 http://www.bbc.co.uk/news/education-11757907

1.6. Carers contribute £8.1billion worth of care in Wales every year, more than the entire Welsh NHS budget and the equivalent of £21,892 per carer every year[3].

2. Replacement Care and Short Breaks

2.1. Replacement care and short breaks play a vital role in protecting the well-being of both carers and those they care for. Similarly, there is a large evidence base that supports the economic case for investing in support for carers – doing so reduces demand upon both health and social service[4]. For example:

2.1.1. One study found that when a person is readmitted to hospital, problems associated with the carer were the reason in 62% of cases[5].

2.1.2. One report found that commissioning for carers could equate to a saving of £4 for every £1 spent[6]

2.1.3. 35% of carers without good support experienced ill health compared to 15% of those with good support

2.1.4. Fewer carers experience mental health problems if they have taken a break since beginning their caring role[7]

2.2. Despite this, services for carers and, in particular, breaks and replacement care have been under significant pressure. This is a direct result of the real terms reductions in local authority budgets. The Carers Trust Wales Network,

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[3] http://www.sociology.leeds.ac.uk/assets/files/research/cuk-valuing-carers-2015-web.pdf

[4] Much of the evidence is collated in our publication 'Investing in Carers, Investing to Save' (2016), https://carers.org/sites/files/carerstrust/media/commissioning_wales_finallo.pdf

[5] Williams, E, Fitton, F (1991) 'Survey of Carers of Elderly Patients Discharged from Hospital', British Journal of General Practice, 41, 105–108.

[6] Conochie, G (2011), Supporting Carers: The Case for Change (The Princess Royal Trust for Carers and Crossroads Care).

[7] Singleton, N, Maung, NA, Cowie, A, Sparks, J, Bumpstead, R, Meltzer, H (2002) Mental Health of Carers (Office of National Statistics, The Stationery Office).

fifteen independently constituted charities across Wales delivering services to carers, have experienced this pressure first hand.

2.3. There have been reductions both in respite services and day centres offered by local authorities – the Welsh Government's figures show a sizeable decline in individuals accessing both these services since 2012[8].

2.4. In the past year, Carers Trust Wales has been calling for the introduction of a national Carer Well-being Fund. The purpose of the fund would be to increase the availability of breaks to carers across Wales, easing pressure on health and social services.

2.5. Such a fund would take into account the lessons of Scotland's Short Breaks Fund which has delivered over £11 million worth of breaks to carers in Scotland since 2010[9].

2.6. A modest annual investment of £1.4 million in Wales would deliver around 53,000 hours of care at home at the new National Living Wage or provide 31,000 days of care at day centres across Wales. Alternatively, the same fund would secure 2,040 weeks of respite. These calculations include the cost of administrating the fund[10].

2.7. Carers Trust Wales believes that the availability of short breaks and replacement care for carers must play a part in the Health and Social Care Committee's work going forward, and should form a key part of any inquiry into carers in Wales

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[8] http://gov.wales/docs/statistics/2015/150902-assessments-social-services-adults-2014-15-en.pdf

[9] http://www.sharedcarescotland.org.uk/publications/short-breaks-fund-round-2-evaluation-report/

[10] Full proposal is available upon request

3. Young and Young Adult Carers

3.1. Young carers (those aged under 18) and young adult carers (those aged 16 to 25) face very specific challenges in maintaining their well-being and receiving the support they need

3.2. The challenges faced by young and young adult carers are varied. Our research with the University of Nottingham[11] found that:

3.2.1. Nearly half of young adult carers (45%) reported having mental health problems
3.2.2. One in four young adult carers said they had been bullied in school as a result of their caring role
3.2.3. young adult carers are four times more likely to drop out of college or university
3.2.4. are more likely to not be in education, employment or training

3.3. Many of the solutions that young and young adult carers need require meanignful coordination and cooperation between health, social care, education and housing. Reaching vulnerable young and young adult carers across Wales requires a joined up, innovative approach that takes into account the breadth of areas that impacts upon their lives.

3.4. Carers Trust Wales would ask that the Health and Social Care Committee ensures that young and young adult carers form a part of any work the committee carries out in regards to carers.

4. Carers of people with mental health problems (including dementia)

4.1. Through our work with services for carers and with carers themselves, we hear frequently that those who care for people with mental health problems experience considerable difficulties in undertaking their caring role. This is often the result of a lack of awareness among professionals and a lack of appropriate information and advice to the carer.

4.2. Research by Carers Trust found that over half of carers of people with dementia said they had not received information about managing medication

[11] www.**ccwales**.org.uk/edrms/157384/

and over half had not been given advice on legal issues[12]

4.3. It is for this reason that Carers Trust developed the Triangle of Care model. The Triangle of Care is a tool that has been used in England to improve carer engagement in acute inpatient and home treatment services[13].

4.4. This model has been well-received in England and is being implemented in a number of hospitals and trusts across the country. There has been interest in implementing it in Wales but capacity has made taking the initial steps difficult. We are still exploring ways to deliver this model, which is evidenced to improve support for carers of people with mental health problems, in Wales.

4.5. We call on the Health and Social Care Committee to explore the particular barriers faced by those caring for people with mental health problems, including:

4.5.1. The lack of appropriate information, including on legal issues and medicine management

4.5.2. The difficulty of ensuring these carers are meaningfully involved in the treatment of the people for whom they care and models that could help tackle this difficulty.

Contact

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[redacted]

[redacted]

[12] http://eprints.whiterose.ac.uk/76737/1/DementiaCarers.pdf

[13] https://professionals.carers.org/working-mental-health-carers/triangle-care-mental-health

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Comisiwn Cydraddoldeb a Hawliau Dynol

Response from: Equality and Human Rights Commission

Is Wales Fairer?

The state of equality and human rights 2015

Comisiwn Cydraddoldeb a Hawliau Dynol | Equality and Human Rights Commission

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Our mandate

Parliament gave the Commission the mandate to challenge discrimination, promote equality of opportunity and to protect and promote human rights.

Our mission

A catalyst for change and improvement on equality and human rights.

This report

This report summarises the evidence for Wales gathered as part of the Commission's five-yearly statutory report on equality and human rights progress in England, Scotland and Wales. Based on the evidence the report identifies the key challenges for Wales.

December 2015

Foreword

We have a duty to report regularly on the extent to which equality and human rights are improving in Britain. This is our report on progress in Wales. It brings together evidence to answer the question as to whether Wales is fairer today than it was when we published our first review five years ago.

We've looked at all of the important areas of life such as health, education, work, justice and individuals' role in society and the changes that have taken place in each of these.

It is important for all of us to understand where inequalities and human rights abuses are happening so that efforts and resources can be focussed where they are most needed.

Evidence suggests that inequality damages the economy and society as a whole. Everyone is affected whether or not we experience discrimination in our daily lives. That's why this review, and the detailed evidence it is based on, is so relevant to all of us in the public, private and third sectors across Wales.

In this report we identify a number of key equality and human rights challenges for Wales. Clarity on these challenges and collaborative action to address them is essential to the prosperity and well-being of everyone living and working in Wales.

We want this report to be a catalyst for change – a means of generating action and partnerships that can eradicate the inequalities and human rights abuses we've identified.

Our aim is that everyone has the opportunity to realise their full potential and to flourish.

We hope that you, and your organisation, will take action to address the challenges we set out here.

We welcome the opportunity to work with you to increase the rate of progress towards a fairer Wales and improve the prospects of future generations.

Ann Beynon
Commissioner for Wales

Kate Bennett
National Director for Wales

Introduction

The Equality Act 2006 placed a duty on the Commission to report regularly on the extent to which equality and human rights are improving in Britain.

In October 2015 we published **Is Britain Fairer?** our report on progress since 2010. In preparing the report, evidence was gathered and analysed across 10 areas: education; standard of living; productive and valued activities; health; life; physical security; legal security; individual, family and social life; identity, expression and self-respect; and participation, influence and voice.

For each of these a detailed evidence paper was published at the same time as **Is Britain Fairer?**. These can be found on our website and include Wales data.

When deciding what to include from the evidence papers we used three criteria:

- the degree to which there has been change over time.
- the extent to which a specific group was affected.
- the scale of impact on life chances.

Is Wales Fairer? provides a short summary of evidence for Wales and, based on this evidence, the key challenges that require action here.

Is Wales Fairer?

In assessing whether Wales is fairer we have found that compared to five years ago:

- There are a few improvements, for example, a reduction in hostility towards lesbian, gay and bisexual people.
- In areas of life such as education and employment significant inequalities remain between different groups of people.
- Young people are significantly worse off in many ways including income, employment, poverty, housing and access to mental health services.

Key challenges

Our analysis has identified seven key challenges that need to be addressed in Wales over the next five years. These are major, entrenched inequalities and human rights abuses that will require substantial efforts of public, private and third-sector organisations and of individuals to reduce them.

We encourage everyone who wants to make Wales a fairer country to respond to the key challenges.

Key challenges summary

1. Close attainment gaps in education.

- Close attainment gaps by raising standards of children receiving Free School Meals, children with Special Educational Needs (SEN), looked-after children and Gypsy and Traveller children.
- Reduce exclusions from school and reduce bullying.

2. Encourage fair recruitment, development and reward in employment.

- Increase the employment rates of young people, disabled people, ethnic minority people and Muslim people.
- Close pay gaps focusing on young people, ethnic minority people and women.

3. Improve living conditions in cohesive communities.

- Reduce poverty especially amongst children, disabled people and ethnic minority people.
- Improve access to care for older people and children.
- Reduce homelessness, especially for people fleeing domestic abuse and people with poor mental health or learning disabilities.

4. Increase access to justice and encourage democratic participation.

- Ensure equal and effective access to civil justice for everyone.
- Improve political and civil participation and increase diversity in public life.

5. Improve access to mental health services and support to people experiencing poor mental health.

- Improve access to mental health services.
- Reduce the rate of suicide especially amongst men.

6. Prevent abuse, neglect and ill-treatment in care and detention.

- Prevent abuse, neglect and ill-treatment of children and older people in hospitals and care homes.
- Protect human rights of people held in detention.

7. Eliminate violence, abuse and harassment in the community.

- Eliminate the incidence of violence, abuse and harassment particularly against women, disabled people, ethnic minority people, Muslim people and lesbian, gay, bisexual and transgender people.

Evidence and data gaps

Is Britain Fairer? is based on an extensive and rigorous process of gathering and analysing evidence across ten key areas of people's lives such as education, health and standard of living. The collection of evidence was done for the whole of Britain including, where available, disaggregated data for Wales, Scotland and England. The core quantitative data we use covers the period 2008 to 2013. This has been supplemented by some more recent quantitative and qualitative evidence.

The Commission sought stakeholder views at round-table discussions and conferences to test and verify findings.

In undertaking this review, it is clear that more comprehensive and better quality evidence is needed to enable us to assess progress.

Sometimes the data is not available at all, and it is often impossible to undertake a more sophisticated assessment of key areas of disadvantage, for example, where people's characteristics intersect.

Some small groups of people such as those aged over the age of 80, transgender people, Gypsies and Travellers, children and young people affected by abuse and exploitation, are often invisible in the data.

The Welsh Government and public authorities in Wales should take steps to improve the evidence collected.

In this report, all evidence cited is for Wales unless otherwise stated. Data has been sourced from **Is Britain Fairer?** and its accompanying reviews of evidence.

Notwithstanding some data gaps, **Is Wales Fairer?** provides a clear, evidence-based assessment of where there has been progress, where we have fallen back and where there has been no change at all.

Context

Changes in equality and human rights in Wales have taken place alongside substantial changes in Wales' population, economy and society. In addition, there have been legislative changes in the UK and Wales.

Economy

The most significant economic events of the period were the recession, subsequent recovery and the associated reductions in public spending.

The UK economy shrank by 2.3% in the final quarter of 2008 during a recession that lasted for about a year. Growth resumed towards the end of 2009 but the recovery was protracted and interrupted by brief periods of decline in 2012. In Wales, the recession was more severe initially than elsewhere in Britain and the recovery has been weaker than in England.

The recession affected employment, with an initial reduction in the number of jobs followed by slow recovery. The recovery was accompanied by shifts in the labour market with an increase in part-time, temporary working, zero hour contracts and self-employment.

The impact of the downturn was a substantial increase in the budget deficit and public sector debt. In 2010, the UK Government pledged to achieve a balanced current budget by 2015-16 and to reduce the public sector net debt.

The UK Government decided to try to achieve these objectives mainly by reducing public spending.

The UK Government's fiscal contraction affected the Welsh Government's budget. Between 2009/10 and 2013/14, total identifiable public expenditure on services in Wales fell in real terms by £822 million, a fall of 2.58% (HM Treasury, 2015).

Society

Wales changed during the period. The population increased by about 66,000 people between 2008 and 2014 because of an excess of births over deaths and in-migration from elsewhere in the UK and overseas.

Other social changes included:

- An ageing population, with median age increasing to 42.1 years in 2014 (the highest in Britain).
- The proportion of the population identifying as White declined between 2001 and 2011, from 97.9% to 95.6%.
- The number of marriages increased and the number of divorces has fallen. Civil partnerships increased and same-sex marriage was introduced.
- More people than ever before said they have no religion.

Political context

There has been a great deal of political change affecting Wales. In the last five years two general elections have brought changes in the UK Government. The 2011 National Assembly for Wales's elections replaced the Labour – Plaid coalition with a Labour minority government. There were European Parliamentary elections, local government elections and elections for Police and Crime Commissioners.

Ministerial responsibility for equality matters in Wales has changed over the period. Following the 2011 National Assembly for Wales' elections, responsibility for equality became part of the portfolio of the Minister for Finance and Leader of the House. It then became the responsibility of three successive Ministers for Communities and Tackling Poverty.

Equality and human rights were the subject of several inquiries by National Assembly for Wales Committees. These included investigations into the future of equality and human rights in Wales, disability harassment, human trafficking, home adaptations, wheelchair availability and the educational outcomes of children from low-income households.

There have been changes in the devolution settlement. In 2011 a referendum granted the Assembly full law-making powers in its areas of responsibility.

A UK Government Commission (the Silk Commission) reported on the Assembly's tax and borrowing powers, with most recommendations being included in the Wales Act 2014.

The Commission then reported on the Assembly's powers, and recommended that a model closer to the reserved powers model already applied to Scotland should be looked at for Wales. This has some implications in respect of equality and human rights. The draft Bill was published in October 2015.

Legislative context

Key UK legislation, such as the Human Rights Act (1998) and the Equality Act (2010), applies in Wales. In the last five years legislation has created new crimes of forced marriage, stalking, and female genital mutilation as well as allowing same-sex marriage.

In Wales, human rights and equality are strengthened by the Government of Wales Act 2006 which stipulates that a provision of an Act of the Assembly is outside the Assembly's legislative competence if it is incompatible with the European Convention on Human Rights, and that Welsh Ministers cannot act incompatibly with these rights.

The Assembly introduced several key pieces of devolved legislation (called 'measures' up to 2012) which included:

- The Rights of Children and Young Persons (Wales) Measure (2011) provides a statutory duty for Welsh Ministers to have due regard to Part 1 of the UN Convention of the Rights of the Child.

- Children and Families (Wales) Measure 2010 provides a legal basis for the Welsh Government's commitment to eradicate child poverty and to reform arrangements for childcare.

- Carers Strategies (Wales) Measure 2010 placed a duty on the Welsh NHS and local authorities to work together to create joint strategies for carers.

- Mental Health (Wales) Measure 2010 extended the provision of mental health advocacy and widened access to mental health services.

More recent legislation with significant equality and human rights elements includes the Social Services and Well-being (Wales) Act 2014, Education (Wales) Act 2014, Housing (Wales) Act 2014 and the Violence against Women, Domestic Abuse and Sexual Violence (Wales) Act 2015.

These economic, political and legislative changes are the context in which to consider whether Wales is fairer compared with five years ago.

Challenge 1: Close attainment gaps in education

Priorities

- **Close attainment gaps by raising standards of children receiving Free School Meals, children with Special Educational Needs (SEN), looked-after children and Gypsy and Traveller children.**
- **Reduce exclusions from school and reduce bullying.**

The proportion of pupils achieving five or more GCSEs at grades A*-C including Maths and English or Welsh has increased from 47% in 2008/09 to 53% in 2012/13. While this is welcome, there has been little reduction in inequalities between different groups and for some groups the gap has widened.

Attainment

There are some children whose attainment of five or more GCSEs at Grades A*-C, including Maths and English or Welsh, remains strikingly low:

• Gypsy/Roma children	13%	2013/14
• looked-after children	17%	2013/14
• children with Special Educational Needs	17%	2012/13
• children eligible for Free School Meals (FSM)	26%	2012/13

Attainment gaps widened between:

- children without SEN and those with SEN

Broadly similar improvements in attainment mean substantial gaps have remained between:

- boys and girls
- pupils eligible for FSM and pupils not eligible for FSM
- ethnic minority pupils and White pupils.

Table 1 Percentage of pupils achieving five GCSEs at Grade A*-C including Maths and English or Welsh, 2008/09 and 2012/13

		2008/09	2012/13	Change (percentage points)
All		47.2	52.7	5.5**
Gender	**Boys**	**43.3**	**48.7**	**5.4****
	Girls	51.3**	57.0**	5.7**
Disability	**Pupils without SEN**	**54.8**	**63.2**	**8.4****
	Pupils with SEN	12.6**	16.8**	4.2**
Socio-economic group	**Pupils Not Eligible for FSM**	**52.0**	**58.5**	**6.5****
	Pupils Eligible for FSM	20.1**	25.8**	5.7**
		2009/11	**2011/13**	
Ethnicity	**White**	**49.2**	**51.6**	**2.4****
	Indian	53.6	60.0**	6.4
	Pakistani / Bangladeshi	47.2	51.2	4.1
	African/Caribbean/Black	37.0**	41.4**	4.4**
	Mixed	49.6	53.6	4.0
	Other	53.8**	56.4**	2.6

Reference groups are emboldened. ** = statistically significant at p < .01 (two-tailed), * = statistically significant at p < .05 (two-tailed). Ethnicity is shown as a comparison of two three-year averages. Data source: Welsh Government (2012), Academic achievement by pupil characteristics 2011, SB27/2012; Welsh Government (2013), Academic achievement by pupil characteristics 2013, SB29/2014; and Welsh Government (2014), Academic achievement and entitlement to free school meals 2013, SB3/2014. | Unweighted base: 2009 (37,607), 2013 (36,617) | IBF reference table: CE1.5

Safety, security and emotional health at school

Between 20% and 50% of pupils in Wales are estimated to have experienced bullying at some point in their school lives (Estyn, 2014). Bullying is a particular risk for:

- pupils with Special Educational Needs
- disabled pupils
- lesbian, gay, bisexual and transgender (LGBT) pupils
- ethnic minority pupils
- pupils from a religious background

Instances of bullying were found to be higher in secondary schools and cyber-bullying remains a concern.

An Estyn report drew attention to wide variations in pupils' experiences of bullying and schools' actions to deal with it. Many schools' strategic equality plans did not 'pay attention to the full range of protected characteristics'. Schools' awareness and understanding of bullying and their policies and procedures was often found to be weak (Estyn, 2014).

Exclusion from school

There is a strong correlation between exclusion from school and low attainment. Overall the proportion of pupils excluded from school in Wales (permanent or fixed term) decreased from 47.6 per 1000 pupils in 2008/09 to 39.3 in 2012/13 (Welsh Government, 2014a).

There has been some reduction in exclusions of boys compared with girls and between pupils eligible for FSM and pupils not eligible, although the gaps between the groups remain large.

In 2013/14 71 children per 1000 eligible for FSM were excluded for five days or less compared with 17 per 1000 of pupils not eligible for FSM (Welsh Government, 2015c).

There have been reductions in the exclusion rate amongst all ethnic groups.

However, while the exclusion rate for pupils without SEN decreased, that for pupils with SEN did not change significantly, so the gap has widened.

Table 2 Exclusions (fixed period or permanent) per 1000 pupils 2008/09 and 2012/13

		2008/09	2012/13	Change
All		47.6	39.3	-8.3**
Gender	**Boys**	**71.3**	**58.9**	**-12.4****
	Girls	23.1**	18.7**	-4.4**
Ethnicity	**White**	**47.0**	**39.2**	**-7.8****
	Asian	24.5**	13.9**	-10.6**
	Black	96.3**	42.8	-53.5**
	Mixed	55.6**	37.7	-17.9**
		2009/10	**2012/13**	
Disability	**Pupils without SEN**	**30.1**	**20.1**	**-10.0****
	Pupils with SEN	98.2**	96.5**	-1.7
	Reference groups are emboldened. ** = statistically significant at p < .01 (two-tailed), * = statistically significant at p < .05 (two-tailed) | Source: Data extracted from Welsh Government (2014), Exclusions from Schools | Unweighted base: Not reported in original data | IBF reference table: CE2.10			

Challenge 2: Encourage fair recruitment, development and reward in employment

Priorities

- **Increase the employment rates of young people, disabled people, ethnic minority people and Muslim people.**
- **Close pay gaps focussing on young people, ethnic minority people and women.**

The recession and recovery have brought little reduction in previous inequalities, and new inequalities have emerged.

There is increasing recognition of human rights violations arising as a result of trafficking including forced labour, servitude and exploitation.

Employment and unemployment[1]

The employment rate was unchanged in 2013 compared to 2008, but the unemployment rate has increased significantly as more people have moved into the jobs market. The effect is that inequalities by gender, disability, ethnicity and socioeconomic group, identified in our How fair is Wales? report 2011, have persisted. Inequalities between young people and other age groups have increased.

For women and men there was no significant change in either employment or unemployment over the period as a whole, so that the long-standing gender gaps remained.

For disabled people, less than half (42%) were in employment in 2013 compared with nearly three-quarters (71%) of non-disabled people. Disabled people's unemployment rate rose, however, to nearly one in eight.

Amongst ethnic minority groups, static employment rates meant that substantial gaps between ethnic minority and White people persisted - 51% compared with 72%. Unemployment for most ethnic groups rose over the period.

[1] Employment rate: the number of people in employment as a percentage of the population.
Unemployment rate: the number of people not currently in a job as a percentage of the 'economically active' population (those who are able and available for work; not those who are not working through sickness, disability or studying.

Similarly, differences in employment between socioeconomic groups have remained unchanged with the lowest employment rates amongst those who have semi-routine and routine occupations (such as van drivers, cleaners and waiters) at 80% in 2013.

Unemployment was higher for nearly all socioeconomic groups compared with the higher professional and managerial group in 2013, as it was in 2008, but there was no change over time.

Young people's employment has decreased markedly while employment rates amongst older age groups increased, creating a substantial gap between younger and older people. At the same time, unemployment amongst 16-24 year olds increased so that they are now more than four times as likely to be unemployed as those aged 35-54.

In Wales in 2008 and 2013 Muslims had the lowest employment rate of any group.

Pay gaps

Over the five years to 2013 average pay in real terms fell for all age groups below age 65.

The gender pay gap narrowed from 20% to 17%. The gap narrowed because men's average pay declined more than women's.

In Wales pay gaps widened for young people, ethnic minorities and people from lower socioeconomic groups compared with some other groups. Young people were the lowest paid of all by 2013, with average earnings of £6.50 an hour compared with 35-44 year olds average pay of £11.20 an hour.

In Britain, White people continued to earn on average 50 pence an hour more than ethnic minorities. In terms of socioeconomic group, pay of those in routine occupations fell the most – by £1.10 an hour to £7 an hour in 2013. There was no decrease in average pay for higher professional and managerial jobs.

Occupational differences

The strong educational performance of girls has not translated into rewards in the workplace with women's employment continuing to be concentrated in low wage sectors.

There was no overall improvement in representation in senior roles. Women and ethnic minority people remain less likely to be in senior roles.

While the proportion of women in senior positions improved in some sectors, such as education, it deteriorated in others such as the NHS and the police.

Discrimination at work

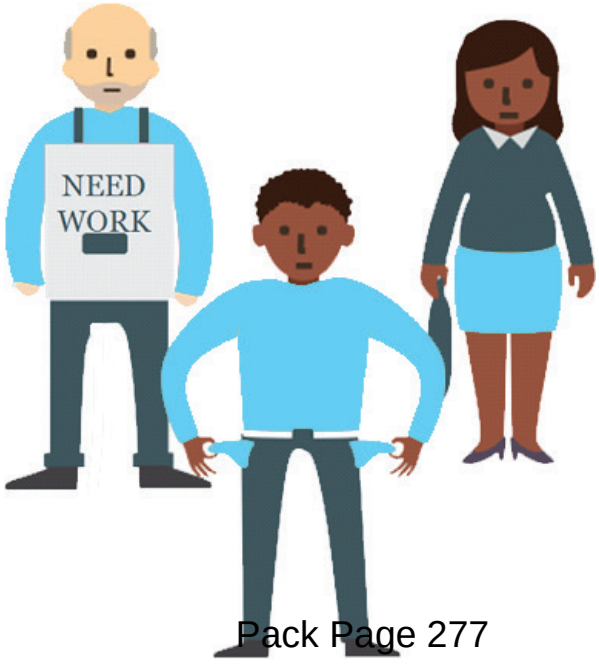
In Britain around one in nine pregnant women or new mothers (11%) were dismissed, made compulsorily redundant or treated so poorly they felt they had to leave their job (Department for Business, Innovation and Skills and Equality and Human Rights Commission, 2015).

Trafficking, forced labour, servitude and exploitation

In Wales, the number of adults, children and young people that were reported to be victims of trafficking almost doubled between 2012 and 2014, up from 34 to 70 reported cases (National Crime Agency, 2015). Most of the people affected were adults and were non-UK nationals. The increase occurred for both genders.

In 2014, one person was convicted of forced or compulsory labour in Newport and in 2015 South Wales Police's Operation Fulcrum identified 13 victims of suspected forced labour.

Concerns remain about missed opportunities to prosecute those involved in trafficking, lack of defence from prosecution for victims vulnerable to slavery, and limitations on escape from slavery for Overseas Domestic Workers.



Challenge 3: Improve living conditions in cohesive communities

Priorities

- **Reduce poverty especially amongst children, disabled people, and ethnic minority people.**
- **Improve access to care for older people and children.**
- **Reduce homelessness, especially amongst people fleeing domestic abuse and people with poor mental health or learning disabilities.**

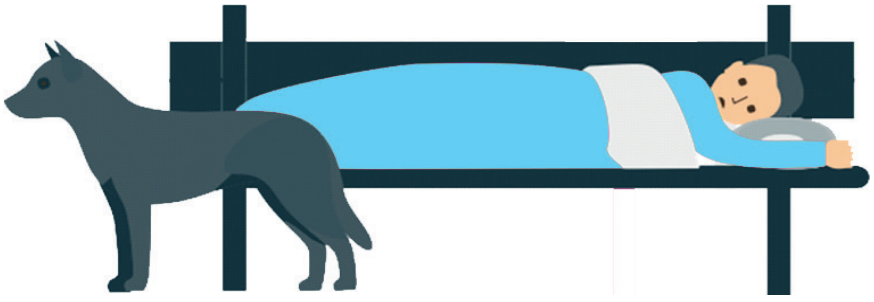
Since 2008 there has been no reduction in inequality in living conditions. Poverty continues to affect some people disproportionately. Access to care continues to be difficult. Homelessness has declined, but some groups of people are more likely to be homeless than others.

Income and poverty

There has been no change in the proportion of people in Wales who live in poverty in 2012/13 compared with 2007/08[2] - nearly one in four (23%) people. There was no statistically significant change in the poverty rate for almost all groups of people. As a result high levels of poverty have persisted for:

- Children - 32% lived in poverty in 2012/13, with even higher rates for children aged 0-4 (42%). Girls (38%) were more likely to be living in poverty than boys (26%).
- Disabled people - 27% in 2012/13.
- Ethnic minorities - 38% in 2012/13.

There was a marked increase in poverty amongst people in some socioeconomic groups. People with routine or semi-routine occupations (such as security guards, receptionists, sales assistants and labourers) were three times as likely to live in poverty in 2012/13 as those with professional and managerial jobs.



[2] Measured as having a household income of less than 60% of the contemporary median, after housing costs.

Welfare reform in 2012 brought numerous changes to social security benefits which are not yet reflected in the data on poverty. Research commissioned by the Welsh Government, and undertaken by the Institute for Fiscal Studies, identified those most affected by the changes as working-age disabled households, non-working households especially those with children, and lone parent households (Phillips, 2014). There were concerns about the impact on women of aspects of Universal Credit, such as one payment of benefit per household or couple. Further changes to benefits were announced in the summer 2015 budget.

Access to care and childcare

The Care and Social Services Inspectorate Wales (CSSIW) has pointed to a year on year drop in the rate of older people being supported to live in care homes from 22.8 per thousand in 2008/09 to 19.8 per thousand in 2013/14. At the same time there was a significant drop in the rate of those supported to live in the community – down from 88.6 to 74.5 per thousand over the same period (CSSIW 2014a).

It is not clear whether the change is the result of a successful strategic shift to preventative services. CSSIW note that little had been done to evaluate the experience of people living without local authority support.

Access to childcare in Wales has increased slightly since 2008/09, with a 2% increase in the total number of childcare places for under eights over the period (CSSIW, 2014a). Provision is patchy: supply in the South Wales valleys and in parts of rural Wales is poor, with Blaenau Gwent having half the number of places per 100 children as in the Vale of Glamorgan or Monmouthshire.

Access to childcare is difficult for parents of disabled children and parents with atypical work patterns. On average childcare for under-two year olds costs £104.32 a week for 25 hours of nursery care and £96.81 a week for 25 hours of childminder care (Rutter, 2015).

In Britain some children in the care system and in custody are allocated placements far from home, making it difficult for them to access friends, relatives and their local support networks (Department for Education, 2014).

Access to housing

A lack of data means that it is not possible to monitor changes in conditions in all types of housing. The proportion of social housing stock meeting the Welsh Housing Quality Standard has increased from 60% in March 2013 to 72% in March 2015 (Welsh Government, 2015d).

There has been a decline in the number of households accepted as homeless by local authorities, although this may reflect administrative changes rather than a decline in the headline numbers (Fitzpatrick et al, 2015).

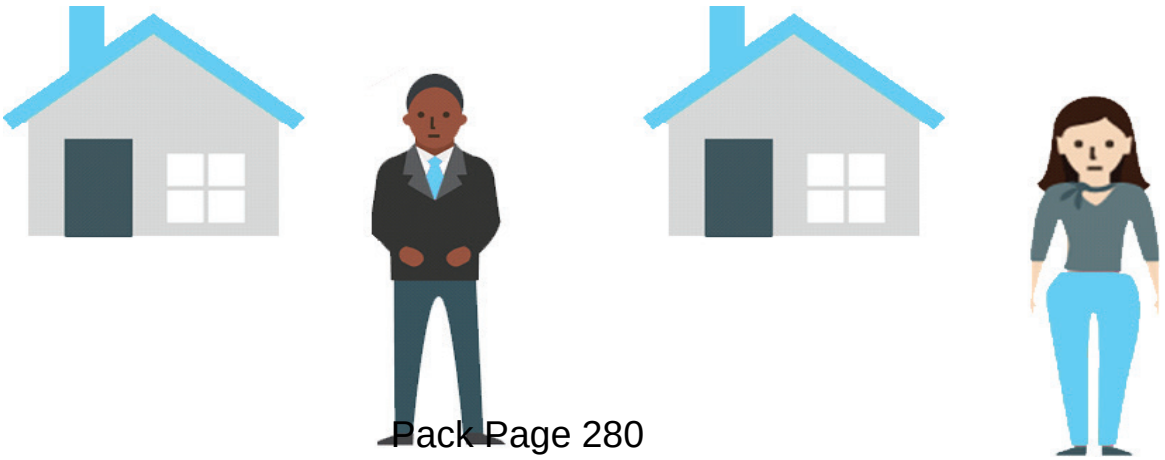
Despite the recent decline, recorded statutory homelessness acceptances in Wales are 70% higher than in England, pro rata to population.

The profile of statutorily homeless households in Wales changed markedly between 2009/10 and 2014/15, with an increase in the number of people fleeing domestic abuse (up 19%) and people with poor mental health or learning disabilities (up 24%) (Fitzpatrick et al, 2015).

In Wales, the number of statutorily homeless youths has fallen, although data for England suggests that young people leaving care are at particular risk of street homelessness.

Access to transport

Access to public and community transport is being affected by reduced funding. In Wales 179 bus routes have been cut, altered or withdrawn since 2010 (Campaign for Better Transport, 2014).



Challenge 4: Increase access to justice and encourage democratic participation

Priorities

- **Ensure equal and effective access to civil justice for everyone.**
- **Improve political and civil participation and increase diversity in public life.**

Reforms to civil legal aid and other reforms affecting access to justice may pose a threat to equal protection and support.

There has been little increase in the diversity of people participating in civil, political and public life.

Access to justice

Major changes to legal aid have occurred through the Legal Aid, Sentencing and Punishment of Offenders Act 2012 (LASPO). LASPO reduced the scope of cases for which civil legal aid is available, excluding the majority of housing, debt, welfare benefits, employment and clinical negligence matters, and made legal aid in private family law cases available only where there is evidence of domestic violence or child protection concerns. The UK Government found that the reforms could have a greater impact on some people with protected characteristics (Ministry of Justice, 2011a).

In July 2013 a two-tiered fee was introduced for claims made to employment tribunals or the Employment Appeals Tribunal, with discrimination claims attracting the higher level of payment. In England and Wales the number of applications to employment tribunals dropped by 81% between January and March 2014, compared with the same period the previous year.

Police stop and search powers continue to have a disproportionate impact on young people, males, Black and Asian people.

Political representation

There is been little evidence of improvement in political representation in the last five years, with women, disabled people, young people, ethnic minorities, religious minorities and lesbian, gay, bisexual and transgender (LGBT) people remaining under-represented at all levels of politics in Wales.

Women's representation in the National Assembly for Wales is the highest of all GB political institutions although women remain a minority at 42% of Assembly Members. The under-representation of women is greater amongst Members of Parliament (23% of the total) and local councillors in Wales - 28% of the total (Expert Group on Diversity in Local Government, 2014).

The closure of Funky Dragon in 2014 means that Wales is now one of the few countries in Europe without a national youth assembly.

Voting at General Elections

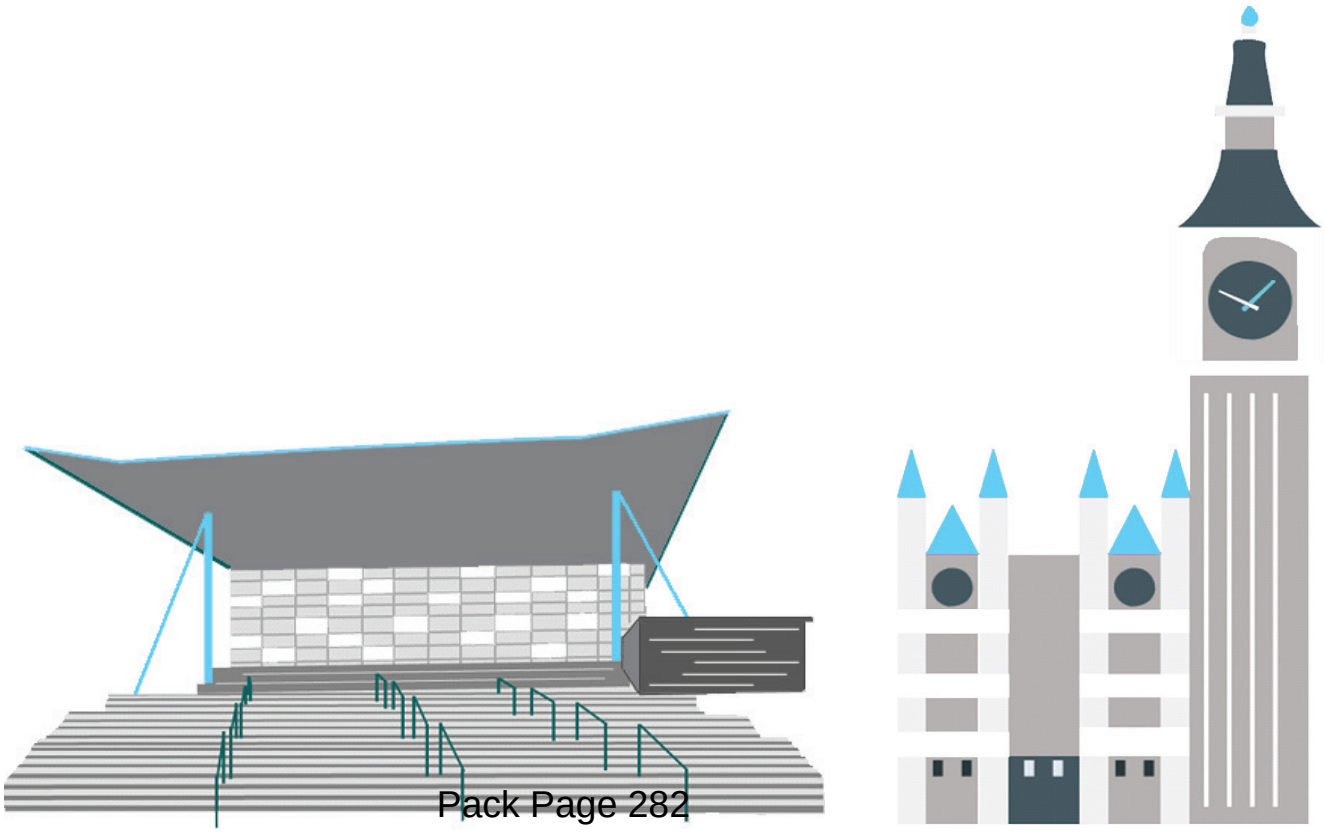
UK evidence suggests that young people, people from some ethnic minorities and people from lower socioeconomic groups were less likely to register to vote than others (Electoral Commission, 2011).

Prisoners in Wales, as in the rest of Britain, remain subject to a blanket ban on voting in elections, which the European Court of Human Rights has found to be in violation of their convention rights.

Wider participation in political activity

In Wales less than one in four people feel that they are able to influence decisions affecting their local area. Older people (aged 75 and over), disabled people and women feel less able to influence decisions than some other groups.

Concerns remain that the right balance between the police facilitating peaceful protest and upholding public order has not yet been achieved, despite changes to police policy in Wales and England (HM Inspectorate of Constabulary, 2012).



Challenge 5: Improve access to mental health services and support people experiencing poor mental health

Priorities

- **Improve access to mental health services.**
- **Reduce the rate of suicide especially amongst men.**

There has been no improvement in access to mental health services. The suicide rate has increased, especially amongst men and middle-aged people.

Access to mental health services

Poor mental health is the most common cause of disability in Britain. The Mental Health (Wales) Measure 2010 aims to ensure appropriate care is in place.

Only a quarter of all those with poor mental health receive treatment (Centre for Economic Performance, 2012). In Wales the number of daily available NHS beds for mental illness fell by 11% between 2010/11 and 2013/14 (Welsh Government, 2015e), while the total number of hospital admissions fell by 5% (Welsh Government, 2014b).

Difficulties accessing Children and Adolescent Mental Health Services (CAMHS) are reported - in 2014 demand for services is said to have increased by 100% over the previous twelve months (National Assembly for Wales, 2014). However public spending on CAMHS has remained static over the period.

There is evidence of continuing problems of capacity and of some children continuing to be hospitalised on adult wards (Health Inspectorate Wales, 2013). It is too early to assess whether the Welsh Government's investment in CAMHS, announced in 2015, will increase access to provision.

Some groups of people in Britain, including transgender people, Gypsies and Travellers, homeless people and migrants have greater difficulty than others accessing health care of all kinds including mental health care (Bishop, 2013; Grove-White, 2014; Royal College of General Practitioners, 2013). Access to mental health care for prisoners in Wales and England is reported to be 'inconsistent' (HM Chief Inspector of Prisons, 2014).

Suicide

In Wales the suicide rate for people aged 15 and over substantially increased between 2008 and 2013, up from 10.7 to 15.6 per 100,000 inhabitants.

While the incidence of suicide has increased for all groups of people, the increase is especially marked for men compared with women (see Table 3).

The suicide rate has increased for certain age groups: it doubled for people aged 55 to 64 and increased by around 60% for those aged 35 to 54. It is also particularly high for middle-aged men (Office for National Statistics, 2015).

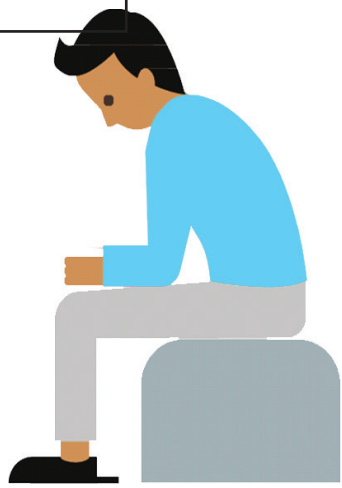
Impact on everyday life

Poor mental health affects many aspects of people's lives. On average, men with poor mental health die 20 years earlier and women die 15 years earlier than the general population (BMA, 2014). People with severe mental illness have an unemployment rate four times that of people with no illness (OECD, 2014).

Table 3 Suicide rate per 100,000 population aged 15 and over, Wales 2008 and 2013

		2008	2013
All		10.7	15.6
Gender	Male	16.1	26.1
	Female	5.5	5.8
Age	15 to 24	8.7	9.0
	25 to 34	14.9	14.9
	35 to 44	13.7	21.8
	45 to 54	12.9	21.4
	55 to 64	8.4	16.8
	65 to 74	6.0#	10.9
	75 and over	7.5#	10.3

treat with caution because of small sample size



Challenge 6: Prevent abuse, neglect and ill-treatment in care and detention

Priorities

- **Prevent the abuse, neglect and ill-treatment of children and older people in hospitals and care homes.**
- **Protect human rights of people held in detention.**

There is no evidence that abuse, neglect and ill-treatment in hospitals, care homes and people held in detention has decreased.

Abuse, neglect and ill-treatment in care

The Care and Social Services Inspectorate Wales (CSSIW) has reported that progress has been made in arrangements to protect vulnerable adults from abuse (CSSIW, 2013). Nevertheless significant concerns remain about the treatment and support provided in some care settings.

Older people

In 2013/14 24% of care and nursing homes for older people did not meet the inspectorate's requirements (CSSIW, 2014a). The Older People's Commissioner has found that older people living in care homes often became institutionalised, did not have their basic health needs met, were unable to access specialist services, and that their emotional needs were not fully recognised (Older People's Commissioner, 2014). CSSIW found that some people were afraid to complain and that advocates sometimes had difficulties making a complaint or referral (CSSIW, 2013).

Operation Jasmine was an investigation by Gwent Police into the deaths of 63 older people in six care homes in south east Wales. After failure to prosecute any of the alleged perpetrators, a Welsh Government-commissioned independent review of the investigation and its aftermath (Flynn, 2015) found extensive ill-treatment and lack of care and was highly critical of many statutory bodies involved.

Younger adults

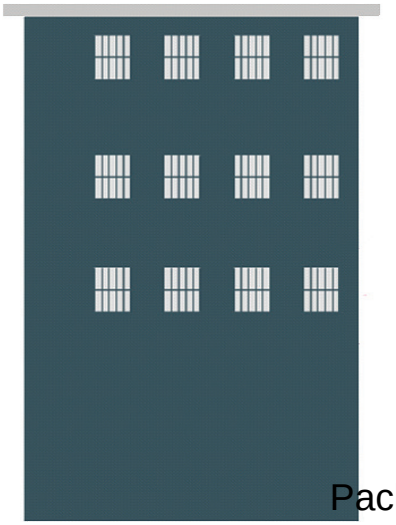
CSSIW reported that services for younger adults had not generated the same levels of concern as older people's services up to 2013/14 (CSSIW, 2014a). It has recently announced a national inspection of care and support for adults with learning disabilities (CSSIW, 2015).

Children

The number of looked-after children has increased from 4,635 in 2008 to 5,765 in 2013 (Welsh Government, 2015f). The majority are placed in foster care although a small number (205 in 2013) were placed in care homes. In 2013 6% of fostering and adoption services, and children's care homes, did not meet the required standards (CSSIW, 2014a). Two major inquiries have highlighted serious issues in relation to historic child sexual abuse and exploitation in Wales: Operation Pallial and Lady Justice Macur's review of the scope of the Waterhouse Inquiry.

Deprivation of Liberty

The Deprivation of Liberty Safeguards (DoLS) are applied to adults who do not have the 'mental capacity' to make decisions for themselves. CSSIW (2014b) and a joint CSSIW / Healthcare Inspectorate Wales review (CSSIW & HIW, 2015) found that although awareness of deprivations of liberty had increased, more needs to be done. They found significant variation between local authorities and health boards.



Restraint

Inspectorates have highlighted the inappropriate use of physical restraint in relation to children in education services. (Estyn & CSSIW, 2011).

Death, abuse, neglect and ill-treatment in detention

In Wales and England the number of self-inflicted deaths in prisons rose from 0.7 per 1,000 prisoners in 2008/09 to 0.9 per 1000 prisoners in 2013/14. The greatest number of cases in 2014 was amongst men aged 30-39.

Gypsies and Travellers are over-represented in Welsh and English prisons and are more likely to experience abuse, physical restraint, self-harm and suicide than other prisoners (HM Inspectorate of Prisons, 2014).

There are serious concerns about the abuse and use of restraint for children in custody. Around one in five children and young people in custody in Wales and England say they have been victimised, with Muslim boys being more likely than non-Muslim boys to report this in 2012/13 (Kennedy, 2013).

There are concerns about the increase in overcrowding and the increase in violence in Welsh and English prisons (HM Inspectorate of Prisons, 2014).

Challenge 7: Eliminate violence, abuse and harassment in the community

Priorities

- **Eliminate the incidence of violence, abuse and harassment particularly against women, disabled people, ethnic minority people, Muslim people and lesbian, gay, bisexual and transgender people.**

There has been no overall reduction in the violence, abuse and harassment experienced by some people but there has been an increase in reporting of incidents to the police and in conviction rates.

Homicide and violent crime

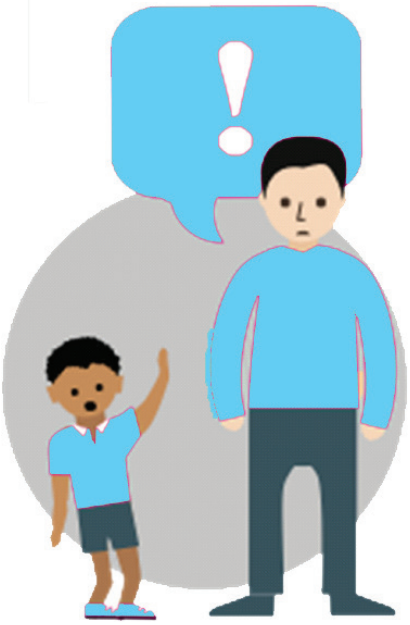
Although homicides have decreased overall in Wales and England, those at greatest risk of homicide remain infants aged under 1. In 2013/14 the homicide rate for infants under 1 was 23.9 per million compared with 10.4 per million for adults aged 16 and over.

There has been no significant change in the rate of violent crime in Wales, with 3% of adults reporting that they had been a victim of a violent crime in 2012/13. Adults under 35 were more likely than older people to be victims of violent crime, as were men compared with women.

The self-reported incidence of violent crime experienced by children aged 10-15 fell between 2009/10 and 2012/13 in Wales and England from 8.5% to 6.1%. However, the gaps between disabled and non-disabled children, boys and girls, ethnic minority and White children, and children with a religion compared with those without, persisted.

Child neglect and abuse

In Wales the number of children on the child protection register has increased from 2,510 in 2008/09 to 3,135 in 2013/14 (CSSIW, 2014a). The main reasons for a child being on the register were neglect (39% of registrations) and emotional abuse (38% of registrations).



Sexual violence

There has been no change in the percentage of people reporting being victims of sexual violence in Wales and England from 2008/09 to 2012/13. There has been an increase in the number of crimes of sexual violence reported to the police. The conviction rate has increased. Young people, women, disabled people and lesbian, gay, bisexual and other people continued to be more likely to report having been a victim of sexual violence in the past 12 months than other groups.

Domestic abuse and forced marriage

Between 2008/09 and 2012/13 in Wales and England the number of self-reported victims of domestic abuse did not change significantly.

The number of domestic violence incidents recorded by the police during the same period, did increase and the number of convictions increased, up by 20%.

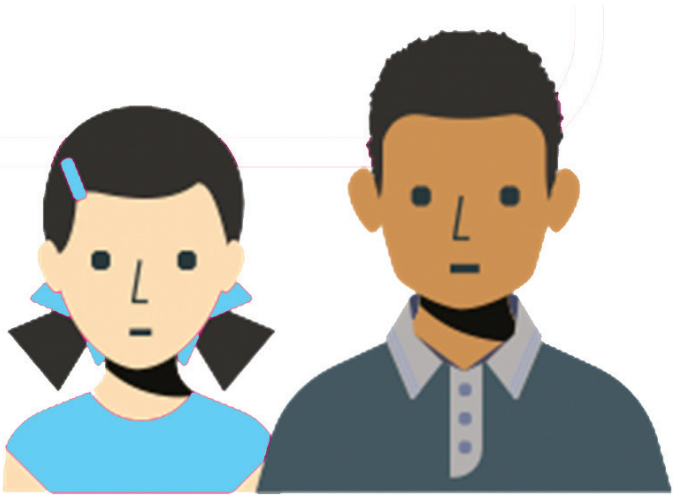
Despite the increase in recording and convictions, an inspection of the police response to domestic abuse in Wales and England in 2013 concluded that the priority afforded to domestic abuse on paper was not translated into reality in 'too many' forces (HMIC, 2014).

The number of referrals from the police to the Crown Prosecution Service (2014) for 'honour'-based offences of violence in Wales and England rose between 2012/13 and 2013/14.

The Violence Against Women, Domestic Abuse and Sexual Violence (Wales) Act 2015 aims to improve the public sector response to domestic abuse, building on the Welsh Government's six year strategy 'The Right to be Safe'. GB legislation has created the new offences of repeated coercive and controlling behaviour, stalking, and new provisions to tackle Female Genital Mutilation.

Of the 1,267 cases of possible forced marriage in the UK in 2014 known to the Forced Marriage Unit (2015), most victims were female (79%) and young (one in five cases involved a victim aged 17 or below). Most cases involved Pakistan, India, Bangladesh or Afghanistan.

However nearly one in four cases was domestic and had no overseas element. The first case under the Forced Marriage (Civil Protection) Act 2007 was heard in Wales in 2015 when a 34 year old man was convicted for making a 25 year old woman marry him under duress.



Hate crime, discrimination, harassment and abuse

In Wales and England there was a decrease in the number of hate crimes reported to, and recorded by, the police between 2008/09 and 2012/13. The number of hate crimes motivated by disability, religion or transgender reported to the police increased.

In Wales, just over three-quarters of the 1,810 hate crimes reported to Welsh police forces in 2012/13 were racially motivated (Home Office, Office for National Statistics and Ministry for Justice, 2013) with Black people being most likely to be the victim. Hate crime motived by sexual orientation was the second most commonly reported hate crime (235 reports), followed by those motivated by disability (135). Hate crime motived by religion accounted for a relatively small number of hate crimes reported to police in Wales (just 39 in 2012/13).

In England and Wales there is a rising incidence of Islamophobic and anti-Semitic hate crime.

The number of convictions for hate crime in Wales and England has increased, with increased convictions occurring for all motivations of the crime.

In Wales, 7% of adults aged 16 and over reported experiencing discrimination, harassment or abuse in the previous 12 months. The incidence of discrimination, harassment or abuse was much higher amongst some groups of people than others.

These experiences were reported by:

- one in five people from an ethnic minority
- one in five people from a religious minority
- one in ten young people
- one in ten disabled people
- one in ten people who have never worked or who are long-term unemployed.

The proportion of British people who believe that 'same sex relations are always wrong' has decreased from 64% in 1987 to 22% in 2012 (NatCen, 2014).

However, British data suggests that LGBT people, and Gypsies, Roma and Travellers experience stigma (Fundamental Rights Agency, 2014; Pew Research Centre, 2014). Disability-related harassment remains a serious problem with significant impact on everyday life, as highlighted by the Pilkington inquiry (IPCC, 2009) and the Commission's Inquiry 'Hidden in Plain Sight' (EHRC, 2011).

Next steps

The challenges we identify in this report will assist in setting priorities for Wales in the coming years.

Elections for the National Assembly for Wales take place in May 2016. Following the elections the new Government will determine its Programme for Government for 2016-2020. There is an opportunity for the Programme for Government to reflect our findings and key challenges.

The Public Sector Equality Duty, and the Specific Duties for Wales, require the Welsh Government and devolved public authorities to set equality objectives for 2016-20. These must be published by April 2016. Publication of this report is timely and will provide evidence to inform Welsh Government and public authorities in identifying priorities and meeting their statutory duties.

This report is intended to be a catalyst for change. The Commission will be working to encourage public, private and third sector organisations to rise to the challenges set out. Partnership work to tackle the challenges in the coming years will improve life chances for people and take us a step closer towards a fairer Wales.

More detailed information

This report sets out headline evidence relating to the key challenges we have identified. If you want to see more detailed information it can be found in the 10 evidence papers published on our website or in the additional references.

Is Britain Fairer? The state of equality and human rights 2015 (http://www.equalityhumanrights.com/sites/default/files/uploads/IBF/Final-reports/revised/EHRC_IBF_MainReport_acc.pdf)

Is Britain Fairer?: Executive summary (http://www.equalityhumanrights.com/sites/default/files/uploads/IBF/Final-reports/revised/IBF-ExeSummary_Eng_acc.pdf)

Evidence papers (http://www.equalityhumanrights.com/about-us/our-work/key-projects/britain-fairer/britain-fairer-supporting-evidence)

Commission in Wales website: http://www.equalityhumanrights.com/about-us/devolved-authorities/commission-wales

or you can contact us on

02920 447710

wales@equalityhumanrights.com

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Most data included in this report is from Is Britain Fairer? and the associated evidence papers.

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Acknowledgements

We would like to thank the Welsh Government and a wide range of organisations and individuals in Wales for their contribution towards this report. We would like to thank Victoria Winckler for writing **Is Wales Fairer?**.

ISBN: 978-1-84206-650-8

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Fferylliaeth Gymunedol Cymru
Response from: Community Pharmacy Wales

Community Pharmacy Wales response to the Health, Social Care and Sport Committee's consultation into the priorities for the Committee during the Fifth Assembly

1 September 2016

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Part 1: Introduction

1. Community Pharmacy Wales (CPW) represents community pharmacy contractors on NHS matters and seeks to ensure that the best possible services, provided by pharmacy contractors in Wales, are available through NHS Wales. It is the body recognised by the Welsh Assembly Government in accordance with *Sections 83 and 85 National Health Service (Wales) Act 2006* as 'representative of persons providing pharmaceutical services'.

2. CPW is the only organisation that represents all 716 community pharmacy contractors in Wales. It works with Government and its agencies, such as local Health Boards, to help protect and develop high quality community pharmacy services and to shape the NHS Community Pharmacy Contractual Framework (CPCF) and its associated regulations.

3. CPW represents a network of of community pharmacies across Wales which provide essential and highly valued health and social care services at the heart of local communities. Community pharmacies operate in almost every community across Wales, including in rural communities, urban deprived areas and large metropolitan centres. It is currently estimated that on an average day the network of community pharmacies across Wales will, between them, deal with more than 50,000 individual patients.

Part 2: Priorities for the Committee

REVISITING THE COMMUNITY PHARMACY REVIEW

4. CPW would encourage the Committee to review and build on the work undertaken by the Health and Social Care Committee in the fourth Assembly through its Inquiry into the contribution of community pharmacy to NHS services in Wales. The inquiry, completed 2012, produced seven recommendations which centred on making more extensive use of community pharmacists and community pharmacies as a health service resource all of which were adopted by Welsh Government. It would useful to understand the extent to which these recommendations have been implemented and the obstacles and reasons for any failure to implement them. Furthermore, the previous Health Committee recommended that its report be revisited at a later date to measure progress.

HEALTH AND SOCIAL CARE WORKFORCE

5. CPW welcomes the intention of the Committee to examine the sustainability of the health and social care workforce and will be submitting evidence. CPW believes community pharmacies have a major

role to play in helping to maintain a sustainable health service going forward. Despite widespread recognition of the massive potential of the community pharmacy network across the political and health professional spectrum, for reasons unknown it remains a hugely under-exploited healthcare asset, with a wide variation in commissioning of community pharmacy services across Wales. Although CPW understands the need for planning care locally, it feels there is a need for the development of core services to be available from every community pharmacies in Wales in order to increase the awareness and confidence of the general public in relation to the full range of community pharmacy based services in order to reduce pressures elsewhere in the primary and secondary care sectors.

6. Community pharmacies could make a significant contribution to releasing GP colleagues to focus on those patients that really do need to be seen by a doctor. For example, community pharmacy based common ailments services and emergency supply services can reduce the pressure on GP practices by releasing the need for these patients to otherwise require appointments. Chronic conditions management services and associated medicines management services can support people to live with a condition which could otherwise result in the requirement of hospital admission and treatment. This will also help to reduce the number of expensive hospital beds and secondary care treatments needed to support an ageing population. An important part of the development of these services would also be a relaunch and re-focus of the under-utilised "batch" prescribing service which forms part of the current community pharmacy contract as the Repeat Dispensing Essential Service. Taken together, these measures could have a significant impact on the GP practice workload.

7. Community pharmacy services could be further transformed by utilising community pharmacist's skills in medication adherence and reducing polypharmacy.

8. The workload of some hospital based services and GP services could also benefit from using the capacity of the community pharmacy network to triage and signpost patients to the most appropriate health care professional. Making community pharmacies the first port of call for patients accessing NHS services would make a massive contribution to the delivery of a prudent healthcare regime.

9. CPW welcomes the integration of health and social care services and would like to seek to understand what opportunities there are for community pharmacies to work closer with social care to support the development of domiciliary care medication support to preserve a patient's independence and allow them to remain in their own home. Community pharmacy services are currently only commissioned through Local Health Boards but local authorities too could benefit from the support that community pharmacy could provide to those in receipt of social services care.

10. CPW has previously developed an enhanced service template in relation to the support that community pharmacies could deliver to care homes as well as working with the Royal Pharmaceutical Society Wales in relation to the production of their policy "Improving medicines use for care home residents". CPW would encourage the Committee to understand what progress has been made in relation to the use of antipsychotic use in care homes and where community pharmacy could support this further.

11. CPW believes that hospital discharge and outpatient services could benefit from the dispensing of related hospital prescriptions in a community pharmacy. This could make a significant contribution to releasing capacity in hospital based pharmacy services as well as leading to significant improvements in releasing hospital beds and in the overall patient experience.

PRIMARY CARE CLUSTERS

12. The Committee might in the future like to look at the development and operation of primary care clusters. CPW understands the importance that primary care clusters have in transforming primary care. CPW would like to see the role of all primary care contractors become an integral part of primary care cluster working. Community pharmacy contractors can significantly support the primary care agenda helping to support the long-term sustainability of primary care by using pharmacists' skills and abilities according to the prudent healthcare principles and releasing capacity in GP practices and in A&E departments. Community pharmacies have the largest daily footfall of all the stakeholders within a primary care cluster and as such should have a significant role to play in relation to supporting the health and wellbeing needs of the local community they serve. However, to date the integration of community pharmacy within the 64 primary care clusters across Wales has been variable and in the majority of cases is unfortunately so far non-existent

PUBLIC HEALTH IN WALES

13. The Committee may be minded to review the delivery of public health services in Wales. Community pharmacies are pivotal to both the delivery of the Public Health agenda nationally in Wales and at local primary care cluster level. The ability of the NHS to cope with future demands on its resources is heavily dependent on the Governments ability to tackle diseases and illnesses related to lifestyle choices. The community pharmacy network arranged as 716 High Street Healthy Living Centres as the channel for organised public health campaigns and offering the full range of services aimed at changing lifestyles and improving public health would make a substantial contribution to achieving existing Government targets.

14. Community pharmacies in the provision of Medicine Use Reviews and other services currently engage with people in discussions relation to their lifestyle, including physical activity. CPW would be interested to understand with the inclusion of sport in the health portfolio how

community pharmacies could be better utilised, potentially in the national exercise referral scheme

Part 3: Conclusion

CPW believes that the Committee could during the current Assembly term :

- Review the progress made in relation to the implementation of the recommendations included into the report produced by the Assembly Health & Social Care Committee in the fourth assembly following its inquiry into the potential contribution of community pharmacy to NHS services;
- Expedite the planned review of health and social care workforce;
- Examine the development, operation and enhancement of primary care clusters;
- Review Public Health services in Wales including the potential contribution of community pharmacy.

CPW agree that the content of this response can be made public.

CPW welcomes communication in either English or Welsh.

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Cymdeithas Alzheimer's | Arwain yr ymgyrch yn erbyn dementia

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Cymdeithas Alzheimer's

Response from: Alzheimer's Society

Dr. Dai Lloyd AM,
Health, Social Care & Sport Committee,
National Assembly for Wales,
Cardiff,
CF99 1NA
seneddhealth@assembly.wales

25th August 2016

Dear Dr. Lloyd,

Re: Priorities for the Health, Social Care and Sport Committee

On behalf of Alzheimer's Society in Wales, please find below a response to the proposed priorities for the Health, Social Care & Sport Committee.

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications, National Dementia Helpline, website, and more than 2,000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.

Alzheimer's Society welcomes the Committee's consultation on priorities for the Forward Work Plan. We agree with many of the key priorities, and welcome the direction of travel. We anticipate that the Committee will be monitoring the development of the proposed new Dementia Strategy[1], and we would welcome the opportunity to feed in on that project. Alzheimer's Society particularly welcomes the Committee's interest in the use of antipsychotic medication in care homes and loneliness and isolation among older people, and strongly supports the idea of inquiries on these two extremely important issues.

Use of antipsychotic medication in care homes

Alzheimer's Society is concerned about the over-use and inappropriate use of anti-psychotics in care home settings. Antipsychotic drugs can serve to reduce psychotic experiences such as delusions and hallucinations. However, use of antipsychotics should be limited, due to potential links to serious side effects such as risk of stroke (though there is debate over this in recent evidence[2]), only moderate benefit, and not addressing underlying causes of behavioural and psychological symptoms (BPSD).[3] There is a danger that pharmacological solutions such as antipsychotics are too often used as a first, not a last, resort. Additionally, reviews and reductions of antipsychotics are most effective when nonpharmacological interventions were available to replace antipsychotics.[4] The Older

[1] Welsh Government (2016) *Together for Mental Health Delivery Plan, 2016-19: consultation document*, Wales: Welsh Government.

[2] Howard. R, (2016) Baseline characteristics and treatment-emergent risk factors associated with cerebrovascular event and death with risperidone in dementia patients, *British Journal of Psychiatry*, 209/3.

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People's Commissioner for Wales has said that we must "*ensure that care homes are places of belonging and significance, and that the risks of institutionalisation, often characterised by an inappropriate use of antipsychotics and a failure to recognise the emotional neglect of older people, are eradicated*."[5] The Committee could explore the need to ensure that use of antipsychotics is appropriate.

There is a great deal of excellent work being carried out in Wales regarding improving the use of antipsychotics for people with dementia. This includes research at Swansea University regarding structured scrutiny by nurses[6] which has "*led to improvements in prescribing practice and pain management and greater awareness of adverse side effects*", as well as the STOPP/START toolkit developed by Dr Victor Aziz of the Royal College of Psychiatrists[7], both of which demonstrate interesting routes for further inquiry and best practice development.

Within the National Dementia Vision for Wales, there are commitments to ensure appropriate use of antipsychotic drugs[8]; however, Alzheimer's Society believes an inquiry from the Committee into this issue would help to build the evidence base around their use.

Loneliness and isolation among older people

Loneliness and isolation are a growing concern in Wales. Demographic changes mean that Wales has an increasingly large population of older people (in particular over 80s) and an increasingly older population as a whole – this means that Wales is likely to have an increasingly large population of lonely older people. This is particularly true of older men in Wales, who represent the loneliest cohort of people in the UK.[9] The Older People's Commissioner for Wales has said that loneliness and isolation is a "*modern day epidemic*"[10] in Wales, whilst at a UK level nearly 10% of over-65s see friends or relatives less than once a month.[11]

There are clear links between loneliness and dementia[12]. 39% of people with dementia said they felt lonely, rising to 62% of people with dementia who live on their own. Meanwhile, difficulties in maintaining social relationships and other features of dementia contributed to this with 35% of people with dementia saying they'd lost friends after a diagnosis.

We have found that many of the concerns around isolation and loneliness for people living with dementia and their carers and families are often more pronounced in rural areas. Our

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Cluster-Randomized Controlled Trial by the Well-Being and Health for People With Dementia (WHELD) Program, *American Journal of Psychiatry*, 173(3), pp.252-62.

[5] Older People's Commissioner for Wales (2015) *Response from the Older People's Commissioner for Wales to the National Assembly for Wales, Health and Social Care Committee on the actions taken to implement recommendations made in the Committee's report on residential care for older people and 'A Place to Call Home'*, Cardiff: OPCW, p15.

[6] Swansea University (2015) *Structured scrutiny could reduce drug side effects for people with dementia*, Swansea: Swansea University.

[7] Aziz, V. (2015) *Potentially Inappropriate Medications for older people: the STOPP/START tool*, Cardiff: Royal College of Psychiatrists in Wales.

[8] Alzheimer's Society (2015) *Diagnose or disempower? Receiving a diagnosis of dementia in Wales*, Cardiff: Alzheimer's Society.

[9] WRVS (2012) *Loneliness rife amongst older men*, Cardiff: WRVS.

[10] Care & Repair Cymru (2013) Older People's Commissioner sings Care & Repair praises, Cardiff: Care & Repair Cymru.

[11] Rodrigues, R., Huber, M. & Lamura, G. (eds.) (2012) "Facts and Figures on Healthy Ageing and Long-term Care: Europe and North America", Vienna: *European Centre for Social Welfare Policy and Research*: p35/6.

[12] Alzheimer's Society (2013) *Dementia 2013: the hidden voice of loneliness*, London: Alzheimer's Society.

recently launched project *Dementia in Rural Wales*[13] carried out a series of interviews with people affected by dementia in rural areas of Wales, and it was clear from the responses that the isolation felt by people with dementia and their carers was intensified by rurality. In particular, unpaid carers often face social isolation and a lack of support networks – this is exacerbated in rural areas by distance, lack of public transport and other factors. The broader lack of coverage for support services in rural Wales has a particular impact on dementia, as if people with dementia are not signposted to appropriate services at the time of their diagnosis, there is an increased risk that they will become isolated and at risk of reaching crisis point before they access services.[14] Even when services and support were available, distances and travel times often meant that their usefulness was limited.

Integration of Health and Social Care services

We also welcome the Committee's interest into issues of integration of health and social care. The developing work around integration in Manchester, following the devolution of health and social care, could prove an interesting model to monitor. Alzheimer's Society is playing a role in this process, supporting the "Dementia United" initiative in establishing a five-year improvement plan to make Greater Manchester "the best place in the world" for people with dementia, with input from local government, health and social care organisations, charities, universities, sports clubs, and more.[15]

Sport and public health

Welsh Government recently ran its ACT NOW campaign[16] advising the public on physical activity and how to reduce the risk of developing dementia. Evaluating such campaigns to ensure their effectiveness is critical, and we would be very happy to contribute to an inquiry along these lines.

We look forward to seeing the Committee's final Forward Work Plan, and very much hope to have the opportunity to contribute to any inquiries on the above two issues. If you require any further information, please do not hesitate to contact me.

Yours faithfully,

Dr. Ed Bridges
External Affairs Manager (Wales)
[redacted]

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Ymchwil Canser y DU

Response from: Cancer Research UK

Cancer Research UK submission to consultation on priorities for the Health, Social Care and Sport Committee

September 2016

Cancer Research UK (CR-UK) welcomes the opportunity to input on topics that the Health, Social Care and Sport Committee could explore in the new Assembly term. In summary:

- We welcome the proposed inquiries into primary care and waiting times. Both play an important role in cancer care and our previous research suggests the NHS in Wales could make improvements in both.
- Regarding priorities for the next 12 to 18 months, we suggest the Committee undertake inquiries into diagnostic services and prevention. CR-UK believes both areas require attention if Wales is to achieve the best possible cancer outcomes.
- Inquiries into diagnostics and prevention could yield benefits across a number of disease areas. A range of conditions rely on diagnostic capacity and preventable risk factors, such as smoking and obesity, contribute to a number of diseases including heart disease and diabetes.

1. Inquiry topics identified by the Committee

The Committee's webpage indicates it is considering, among other topics, inquiries into primary care and waiting times. We welcome these proposals for reasons outlined below.

1.1 Primary care

Primary care plays a critical role in effective cancer care: most cancer patients are diagnosed following a referral from their GP.[1] CR-UK's recent report, *Where next for cancer services in Wales?,* found primary care could be operating more effectively in two key respects.[2]

Firstly, evidence suggests poor access to primary care is one of the factors contributing to late cancer diagnoses.[3] Some areas of Wales have particular difficulty attracting primary care staff and this adversely affects access in those places. National data also suggests there is an issue: the 2014-15 National Survey for Wales found that 37% of respondents who had used a GP consultation in the previous 12 months found it 'fairly difficult' (19%) or 'very difficult' (18%) to get a convenient appointment.[4] The figure in the 2013-14 national survey was similar at 38%.[5]

Secondly, how effective GPs in Wales are at identifying cancer symptoms and investigating them needs exploration. GPs have a difficult job in relation to detecting cancer: on average a GP will see only around eight new cancer cases a year.[6] However, there is evidence that GPs in Wales are not consistently adhering to NICE referral guidelines.[7] Findings of the Wales Cancer Patient Experience Survey (WCPES) back this up. Several respondents to the 2013 survey raised concern about the speed at which GPs responded to their symptoms.[8] Relatedly, over one-fifth of respondents indicated that they felt they should have been seen a hospital doctor a 'bit sooner' (12%) or a 'lot sooner' (10%).[9]

Both of these factors can lead to delays in patients receiving a definitive diagnosis. This in turn can negatively affect patients' treatment options and prognoses. We are also aware

that the Welsh Government introduced a new primary care strategy in 2015.[10] Understanding the impact this initiative is having would be valuable. For these reasons, CR-UK would welcome the Committee conducting an inquiry into primary care.

1.2 Waiting times

Waiting time targets play an important role in cancer care. They exist to ensure that patients progress from diagnosis to treatment as quickly as possible.

The Welsh Government maintains two key waiting time targets relating to cancer care. However, the health service is struggling to meet both.

- First, 95% of newly diagnosed cancer patients, referred via the urgent route, should begin treatment within 62 days of referral. This target has not been met since 2008. In the most recent quarter, April to June 2016, nationally 87.3% of patients began treatment within 62 days.[11]
- Second, 98% of cancer patients referred via the non-urgent route should begin treatment within 31 days of the decision to treat. This target was last met in 2014. Performance between April and June 2016 across Wales was 97.5%.[12]

This is a cause for serious concern because it means cancer patients are being delayed in starting treatment.

There is variation in performance against waiting time targets between local health boards (LHBs). For example, in the second quarter of 2016, at Cardiff and Vale LHB 82.4% of patients began treatment within 62 days; at Cwm Taf LHB alternatively over 92% of patients began treatment within 62 days.[13] Similarly, the performance across different cancer types varies. For example, in the second quarter of 2016, 100% of patients with cancer of the brain or central nervous system began treatment within 62 days; alternatively, during the same period only 72.5% of patients with cancer of the lower gastrointestinal area began treatment within the target time.[14]

CR-UK would therefore welcome the Committee exploring waiting time performance. In particular, we would encourage the Committee to investigate the factors that are contributing to performance being below target and why some health boards and cancer specialisms are able to meet performance targets and others are struggling.

In addition, we would welcome the Committee investigating the Welsh Government's intention to introduce a 'single pathway' for cancer patients. We understand this will mean recording waiting times from the point at which cancer is suspected, an aspiration CR-UK welcomes. However, our recent research found progress implementing the single pathway has been slow.[15] We would welcome evidence on what has delayed progress and proposals for how it could be accelerated.

2. Additional themes for inquiry by the Committee

We believe there are two areas which it would be valuable for the Health, Social Care and Sport Committee to investigate in the next 12 to 18 months: diagnostic capacity and prevention. Both are vital if Wales is to achieve world-class cancer outcomes, and could also deliver benefits across a range of disease areas. We consider each in turn below.

2.1 Diagnostic capacity

Early diagnosis has the potential to transform cancer outcomes over the coming years. For example, when bowel cancer is diagnosed at stage one, around 95% of patients survive for at least five years. In contrast, fewer than 10% of those diagnosed at stage four do likewise.[16]

In Wales, early diagnosis was a focus of the Cancer Delivery Plan and some progress has been made in recent years.[17] But there is still further to go: in 2014 around 35% of cancer patients were diagnosed at stage three or four.[18] Achieving consistent early diagnosis relies on patients being able to access diagnostic services so that symptoms can be investigated promptly. Today, however, we believe that diagnostic capacity in Wales is struggling to keep up with demand and thereby contributing to late diagnoses.[19]

We base this analysis on several factors. Firstly, comparing waiting time performance suggests diagnostic delays are a problem. National performance against the 31-day target, which measures from after the point of diagnosis, is below target by a relatively small margin. Alternatively, performance against the 62-day target, which includes the diagnostic phase, is significantly lower. Secondly, expert stakeholders interviewed for our project on cancer services repeatedly identified limited diagnostic capacity – workforce and equipment – as an issue.[20] Thirdly, NICE recommends that GPs should, in certain circumstances, be able to directly refer patients with suspected cancer for investigative tests rather than first referring to a hospital physician.[21] Yet, our project found that GPs' direct access to investigative test was variable across Wales.

Looking ahead, demand for diagnostic services is likely to increase for two key reasons. Firstly, NICE, in a decision CR-UK supports, recently lowered the threshold at which GPs should refer people for investigation in cases of suspected cancer.[22] Secondly, CR-UK projects that the number of cancer cases diagnosed each year in Wales will grow over the coming decade, driven by an ageing population and preventable risk factors.[23] This reinforces the case to think carefully about diagnostic services.

Improving diagnostic capacity would not only benefit cancer patients. A range of conditions rely on investigative tests to achieve a definitive diagnosis. We therefore believe it would be very useful for the Health Committee to explore diagnostic capacity, including workforce and equipment. In particular, we suggest the Committee investigate existing capacity in Wales, the likely trajectory of future demand based on GPs consistently implementing best practice, and the resource needed to meet this demand.

2.2 Prevention

As mentioned above, CR-UK's recent report on cancer services in Wales showed that the number of cases diagnosed each year in Wales is likely to grow over the next decade.[24] This is being driven in part by an ageing population; but preventable risk factors are also playing a role.

Research suggests around four in ten cancer cases are attributable to preventable risk factors.[25] Among a range of factors, smoking and obesity are the most significant. However, rising cancer incidence associated with preventable risk factors is not inevitable: governments are able to influence public behaviour and reduce the prevalence of key risk

behaviours.[26] Doing this will require the Welsh Government to consider the full range of policy levers available to it – and smoking and obesity should be a particular focus.

In 2013-14, 21% of adults in Wales were recorded as smokers – down from 27% around a decade earlier.[27] This is positive, but there is more progress to be made. If current trends are continued, tobacco could lead to over 1.3 million new cases of disease in the UK over the next 20 years. [28] Instead, CR-UK believes a tobacco-free future, where adult smoking prevalence is 5% or less, is the right aspiration.[29]

Obesity, which is the single largest preventable cause of cancer after smoking, is on the rise in Wales.[30] In 2003/04 around 18% of adults were reported to be obese; by 2015 this had reached 24%.[31] CR-UK has shown that current obesity trends could lead to an additional £2.5 billion in direct health and social care costs across the UK by 2035.[32] For this reason, we welcome the Committee identifying sport and public health as a possible topic for inquiry. However, while physical activity has an important role to play in tackling obesity, we think an inquiry into prevention could add value by exploring a wider range of options, such as regulation and product reformulation.

Reducing the prevalence of smoking and obesity would deliver benefits across a number of disease categories. Smoking is associated with heart disease, stroke and chronic obstructive pulmonary disease;[33] obesity is linked to heart disease, diabetes and respiratory problems.[34]

As an ageing population drives demand for healthcare, it is likely that the financial pressure on healthcare services will grow. This reinforces the case for preventative interventions to reduce the prevalence of risk factors likely to cause ill health and incur additional cost. We therefore think the Committee on Health, Social Care and Sport could play a valuable role by exploring and outlining options for ambitious preventative action in Wales.

3. About Cancer Research UK

Cancer Research UK is the world's largest independent cancer charity dedicated to saving lives through research. We support research into all aspects of cancer and this is achieved through the work of 4,000 scientists, doctors and nurses. In 2014/15, we invested £434 million in research, including our £41 million contribution to the Francis Crick Institute. We receive no funding from the Government for our research.

4. Contact details

For more information please contact:

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Or, Leo Ewbank, Policy Adviser, on [redacted] or [redacted].

5. References

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Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Breast Cancer Now
Response from: Breast Cancer Now

Health, Social Care and Sport Committee
National Assembly for Wales
Pierhead Street
Cardiff
CF99 1NA

[redacted]

[redacted]

2 September 2016

To whom it may concern,

Re: Priorities for the Health, Social Care and Sport Committee – response from Breast Cancer Now

Breast Cancer Now welcomes the opportunity to comment on priorities identified for 2016-17 for the Health, Social Care and Sport Committee.

Breast Cancer Now is the UK's largest breast cancer charity, dedicated to funding ground-breaking research into the disease. Our ambition is that, by 2050, everyone who develops breast cancer will live. We are bringing together all those affected by the disease to improve the way we prevent, detect, treat and stop breast cancer. We are committed to working with the NHS and governments across the UK to ensure that breast cancer services are as good as they can be, and that breast cancer patients benefit from advances in research as quickly as possible.

This response focuses on the priorities already identified by the Committee that we believe are particularly relevant to breast cancer patients in Wales, namely, waiting times and sport and public health.

Waiting times

We are pleased to see that the Committee has prioritised waiting times, including cancer waiting times. Breast Cancer Now has long been concerned about the length of time that women presenting to their GP with breast symptoms are waiting to be seen by a specialist following referral by their GP.

Work undertaken by Breast Cancer Now (at the time Breakthrough Breast Cancer) in 2013 and again in 2015 revealed unacceptably long referral waiting times for patients with breast symptoms, as well as significant variation in waiting times between Health Boards.

FOI requests made by Breast Cancer Now in 2015 showed that at one Health Board, patients who were referred urgently with suspected breast cancer could expect to wait, on average, 43 days before being seen by a specialist. For patients referred non-urgently (i.e. where cancer is not

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suspected but investigation is still required), waiting times at some Health Boards could be over 15 weeks[1].

Clearly in these circumstances, diagnosis is not happening rapidly and there is a danger that the delay after referral could have a negative impact on outcomes and survival. There is also the additional issue of the worry and distress caused to patients by having to wait many weeks or months to see a specialist, regardless of the outcome.

While there is a 'Ministerial expectation' that women referred with urgent suspected breast cancer should be seen within 10 working days from the day of referral by their GP – this is not an official Government target and is therefore not reported on publicly.[2]

The lack of public reporting on the 'Ministerial expectation' makes it difficult to scrutinise and measure Health Boards' achievement of this unofficial target. A recent FOI request by the Welsh Liberal Democrats also revealed that at some Health Boards, the majority of those urgently referred are not seen within 10 working days[3].

For patients referred non-urgently there is no such expectation for them to be seen within 10 working days. As already mentioned, they can wait many weeks or even months before being seen by a specialist.

We urge the Committee to conduct an inquiry into the current status of the 'Ministerial expectation' to establish whether this is being routinely met across Wales and if it should be extended to patients referred non-urgently.

The proposed Single Cancer Pathway that has been piloted in Wales fails to address the problems of non-urgent referrals and would not change the current position where a person referred non-urgently could wait many weeks before being seen by a specialist.

It is also important to realise that it is not an insignificant number of patients who will be diagnosed with cancer following a non-urgent referral. Between April 2011 and March 2012 Breast Cancer Now estimate that non-urgent referrals made up around 36% of people diagnosed with breast cancer (excluding those diagnosed through routine breast screening). An answer from First Minister's Questions in September 2015[4] suggested that the number of people diagnosed with breast cancer through the non-urgent route was even higher, with more patients diagnosed through this route than the urgent route.

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[1] We would be happy to provide full details of the FOI responses to the Committee.
[2] *National Standards for Breast Cancer Services*. Welsh Assembly Government, 2005.
[3] http://www.bbc.co.uk/news/uk-wales-35778888
[4] (OAQ(4)0625(HSS)

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We therefore urge the Committee to take any available opportunity to question the First Minister and the Cabinet Secretary for Health, Well-being and Sport on waiting ti[redacted] patients with b[redacted] the progress of the Single Cancer Pathway Pilot and when the interim report from this pilot will be published.

Sport and Public Health

Breast Cancer Now is encouraged to see that the Committee is prioritising sport and public health. In 2012, one of Breast Cancer Now's legacy charities, Breakthrough Breast Cancer, conducted an evidence review around physical activity and breast cancer risk, gaining the consensus of experts regarding the amount and intensity of physical activity required to significantly reduce breast cancer risk. The evidence highlighted that regular physical activity can reduce your risk of developing breast cancer by at least 20 per cent[5]. 'Regular' physical activity refers to undertaking at least 3.5 hours of moderate intensity activity per week, equivalent to 30 minutes or more per day. Nearly 9000 cases of breast cancer could be prevented every year in the UK if all women were regularly physically active[6]. To support this work, Breast Cancer Now has developed a web resource to enable women to track their activity and visually see the risk reducing impact physical activity can have. This web tool is available at http://brisk.breastcancernow.org/.

Another key public health concern which has an impact on breast cancer is alcohol consumption. The results of the Welsh Health Survey[7] revealed that 40% of adults in Wales reported drinking above recommended guidelines on at least one day in the past week, with 24% reporting drinking more than twice the daily guidelines. Regularly drinking any amount of alcohol can increase the risk of developing breast cancer, and that risk increases the more that is regularly drunk. For every 100 women who drink one typical drink per day (two units such as 1 pint of lager or a 175ml glass of wine) there will be an extra two women who develop breast cancer compared with 100 women who do not drink at all.

We hope to see alcohol consumption and physical activity explicitly referred to in the work-plan developed by the Committee and we would welcome a focus on the impact of these factors on the risk of developing cancer, as well as other health issues.

[5] http://breastcancernow.org/sites/default/files/public/physical-activity-and-breast-cancer-risk.pdf

[6] Lee I-M, Shiroma EJ, Lobelo F, Puska P, Blair SN, Katzmarzyk, for the Lancet Physical Activity Series Working Group. Effect of physical inactivity on major non-communicable diseases worldwide: an analysis of burden of disease and life expectancy. The Lancet. Published online 18 July 2012: http://dx.doi.org/10.1016/S0140-6736(12)61031-9

[7] http://gov.wales/statistics-and-research/welsh-health-survey/?lang=en

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Thank you for the opportunity to comment on the Committee's priority areas for the next 12-18 months. If you wish to discuss this further, please do not hesitate to contact me on [redacted] or by email on [redacted].

Yours sincerely,

Sally Greenbrook
Policy Manager

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Breast Cancer Now is the UK's largest breast cancer charity, created by the merger of Breast Cancer Campaign and Breakthrough Breast Cancer.

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Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Cyngor am Bopeth Cymru
Response from: Citizen's Advice Cymru

Response to the National Assembly for Wales' Priorities for the Health, Social Care and Sport Committee August 2016

1.0 Introduction

1.1 Citizens Advice Cymru welcomes the opportunity to help inform the forward work programme of the Health, Social Care and Sport Committee of the National Assembly for Wales during the 5th Assembly, in particular the next 12 to 18 months.

1.2 Citizens Advice Cymru has produced a report titled 'Paying for and accessing social care in Wales: a people's perspective'. The report highlights a number of areas of concern, some of which are being addressed by the introduction of the Social Services and Well-being (Wales) Act 2014 (SSWB Act 2014). However, there are a number of areas that require further attention or ongoing monitoring as outlined below.

1.3 We ask that the committee considers the following as part of its work programme:

- how effective the Information, Assistance and Advice services are at meeting the Information & Advice Quality Framework for Wales (IAQF) requirements and that the information provided is of quality-assured standards;
- review the number of requests for reassessments under the SSWB Act 2014 and consider the need for an appeals process;
- investigate the system of paying for care in Wales;
- review how effective the Welsh Government has been in addressing mental health issues;
- identify and promote best practice in social care;
- keep a watching brief on the implementation of the Well-being of Future Generations Act 2015.

Citizens Advice Cymru forward work programme recommendations

Information and Advice

1.4 We welcome the requirement under the SSWB Act 2014 for local authorities to establish Information, Advice and Assistance (IAA) services. The services are seen as central to the success of the transition to the care and support system under the Social Services and Wellbeing (Wales) Act 2014. Code of practice on Part 2 of the SSWB Act 2014 which covers the IAA services places an emphasis on ensuring the services are accessible, we fully support this. Citizens Advice Cymru believe this should be kept under review to ensure the service remains fully accessible, in particular, for those who are digitally excluded to ensure they do not experience any detriment as a result.

1.5 In addition, IAA services are required to meet national standards for the provision of information and advice as set out in the Information & Advice Quality Framework for Wales (IAQF). We believe the Committee should consider how effective the IAA services are at meeting the IAQF requirements and that the information provided is of a quality-assured standard. Our research showed that people did not know where to go to access information and advice and how best to use the information and advice to help them. Ensuring the IAA services are easy to access and provide quality-assured information and advice will be key to the success of the SSWB Act 2014.

Appeals and Complaints

1.6 Clear and accessible appeals and complaints procedures are essential to ensure information and services meet the needs of the people who use them and identify any problems or issues that need addressing. Unlike the English Care Act 2014, the SSWB Act 2014 does not contain an appeals process, but individuals can request a review or re-assessment of eligibility decisions in certain circumstances. We do not believe this is sufficient nor will it ensure people in need of support get help at the right time.

1.7 Our research shows people are reluctant to appeal a decision or make a complaint about decisions regarding social care services or public services more generally, nor will they be likely to request a reassessment. We believe this could have a negative impact on people's health and well-being.

1.8 The Health and Social Care Committee of the 4th Assembly highlighted the need to closely monitor how the SSWB Act 2014 is implemented. Mark Drakeford, the then Minister for Health and Social Services, committed to evaluate the Act in the Fifth Assembly, focusing on assessment and eligibility to determine whether the objectives are being met. We believe the committee should prioritise this and agree a timeline for review, including the numbers of reassessments requested or carried out.

Paying for care

1.9 A further issue for consideration by the Committee is how residential care is paid for in Wales. This was due to be reformed in April 2016, however, delays to reforms in England and the ongoing reforms to the welfare system resulted in an announcement to delay reforms in Wales. Given the increase in the number of people expected to require care in a residential setting to increase significantly, Citizens Advice Cymru believe the committee should investigate the system of paying for care, using existing evidence to make recommendations to Welsh Government on moving forward with reforms prior to April 2020 when the UK government is expected to introduce changes for England.

Mental Health

1.10 One of the Welsh Government's priorities is to improve the mental health and well-being of people in Wales. The committee should look at how active the Welsh Government has been in addressing this priority and consider what more can be done to ensure services across Wales including social services, financial capability support, domestic abuse provision and victim support are integrated to identify and support those with mental health issues.

1.11 In our response to the Welsh Government consultation on the mental health delivery plan we asked for the delivery plan to be updated to include:

1.12 Clearer cross referencing to the Social Services and Well-being (Wales) Act and the Violence against Women, Domestic Abuse and Sexual Violence (Wales) Act where appropriate, in particular reference to:

- Identifying and supporting victims of domestic abuse during pregnancy and perinatal to promote the best possible start in life
- The new duties on local authorities to assess and support those with social care and wellbeing needs in the secure estate

- The new role of information, advice and assistance services to promote health and wellbeing

1.13 Inclusion of debt and welfare benefits advice, information and support services as a preventative measure and, in light of welfare reform, mitigating the affects on people with mental health problems.

Sharing Good Practice

1.14 During our research we found some examples of good practice, whilst there are some existing forums for sharing good practice we feel more could be done to highlight and share the best examples of both process and practice that improves the provision of social care in Wales and enables practitioners and the public to learn about and share the best experiences and ways of working. The committee could become an advocate for encouraging the sharing of best practice and consider the best ways of promoting these examples across Wales.

Well-being of Future Generations Act

1.15 The Well-being of Future Generations Act national indicators have now been agreed, the scrutiny of the indicators will be crucial in helping shape the national milestones. Of particular importance is the impact of financial capability/inclusion on people's health and well-being. The committee should keep a watching brief on the well-being indicators and scrutinise the Welsh Government's response to them, including the need to revise indicators and implement policy changes where necessary.

Longer-term work programme

1.16 We support the areas outlined in the longer term work programme for the committee, in particular, the integration of health and social care services and primary care, and gambling addiction, including the provision of support services, and the steps that could be taken to reduce harm.

1.17 In recent years gambling has changed beyond recognition, in 2016 it is available 24/7 and viewed as an acceptable form of leisure. In times of austerity vulnerable groups are more likely to turn to risky behaviour as a way to escape their situation or to fund their lifestyle. Newport Citizens Advice offers a Gambling Support Service providing free advice and information for anyone who is worried about gambling. The service is available to those experiencing problems with gambling, family and friends and anyone who may be at risk of developing a problem. We would be happy to discuss this service in more detail should the committee undertake an inquiry into gambling addiction.

About Citizens Advice Cymru

1.18 Citizens Advice is an independent charity covering England and Wales, operating as Citizens Advice Cymru in Wales with offices in Cardiff and Rhyl. There are 19 local Citizens Advice in Wales, all of whom are members of Citizens Advice Cymru, delivering services from over 375 locations.

1.19 The twin aims of the Citizens Advice service are:

- to provide the advice people need for the problems they face
- to improve the policies and practices that affect people's lives.

1.20 The advice provided by the Citizens Advice service is free, independent, quality assured, confidential and impartial, and available to everyone regardless of race, gender, disability, sexual orientation, religion, age or nationality.

1.21 The Citizens Advice Service has responsibilities for consumer representation in Wales as a result of the UK Government's changes to the consumer landscape[1]. Since 1st April 2014 this includes statutory functions and responsibilities to represent post and energy consumers.

For further information or any queries please contact:

Michelle Lewis email: [redacted]
Policy Officer / Rheolwr Polisi
Citizens Advice Cymru / Cyngor ar Bopeth Cymru

[1] On 1st April 2013 responsibility for consumer representation was transferred from Consumer Focus to the Citizens Advice Service (including Citizens Advice Cymru) following the UK Government's review of the consumer landscape. From 1st April 2014 this includes statutory functions and responsibilities to represent post and energy consumers

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Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Ffederasiwn Cenedlaethol Sefydliadau'r Merched
Response from: National Federation of Women's Institute

National Federation of Women's Institutes-Wales

Response to consultation on Priorities for the Health, Social Care and Sport Committee

1.0 Background

1.1 The WI is the largest women's organisation in the UK with some 220,000 members in over 6,300 WIs across England, Wales and the Islands. In Wales, we have about 16,000 members belonging to 600 WIs.

1.2 The WI is an educational, social, non-party political organisation, established to ensure that women are able to take an effective part in their community, make new friends, widen their horizons, and together influence local, national, and international affairs on issues that matter to them.

1.3 When considering key priority areas for the Health, Social Care and Sport Committee during the next 12 to 18 months, Committee members may be interested in the research findings published in *The WI at 100* Report and the resolution *Appropriate care in hospitals for people with dementia* passed by members at the 2016 Annual Meeting.

2.0 The WI at 100 Report – Findings relating to health and wellbeing

2.1 In September 2015, the WI celebrated its centenary. To mark the occasion, The *WI at 100* Report was produced to present the views and opinions of current members as well as highlight key achievements from the organisation's 100-year history. The research reports on WI members' attitudes around 5 key areas including health and wellbeing.

2.2 Looking at our health services, members celebrate the remarkable achievements of the NHS, yet many worry (particularly carers) that health and social care services will not be able to meet their needs as they age. While a clear majority believe that over their lifetime the NHS has got better at meeting the needs of women, they believe that services aimed at improving mental health - a key concern for them - are failing.

2.3 The key findings in relation to health and wellbeing are outlined below:-

- 73% agree the NHS is excellent at caring for those with physical illness
- 17% agree that the NHS is excellent at caring for those with mental or emotional illness
- 70% said they could access healthcare when they needed to, however members in Wales were 10% less likely to report that they were satisfied with health services
- 49% disagree that health and social care services will be able to meet their needs as they get older
- 19% agree that the non-clinical care provided by the NHS is excellent

2.4 The full report can be downloaded from the following link:-
https://www.thewi.org.uk/__data/assets/pdf_file/0009/145854/The-WI-at-100-Final.pdf

3.0 Appropriate care in hospitals for people with dementia

3.1 At the NFWI Annual Meeting in Brighton on 11 June, a resolution was passed calling on the Government and the NHS to provide facilities to enable carers to stay with people with Alzheimer's disease and dementia that have been admitted into hospital.

3.2 One quarter of all hospital beds in the UK are occupied by someone with dementia. Yet, these wards are usually not designed to cater to their dementia-related needs and as a consequence they are not getting the right care. Poor care while in hospital has proven devastating for those with dementia; thirty-three per cent admitted with an unrelated condition will never return to their own homes.

3.3 The WI would like to see a commitment from Local Health Boards to provide 'facilities' that make it easier or more feasible for family carers of those with dementia to stay with their loved one. Providing 'facilities' could mean a hospital offering extended visiting hours for family carers, providing family rooms, or any other practical provision that would enable carers to stay with their loved one for longer periods of time or when it is more convenient for them.

4.0 Further information

4.1 For further information relating to the above response, please contact the NFWI-Wales Office. Tel: [redacted] E-mail: [redacted]

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Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Sefydliad Cenedlaethol Brenhinol Pobl Ddall Cymru
Response from: Royal National Institute of Blind People Cymru

RNIB Cymru Submission to the Health, Social Care and Sport Committee call for priorities for its future work programme

1. RNIB Cymru welcomes this opportunity to contribute to the forward work programme for the new Health, Social Care and Sport Committee.
2. RNIB Cymru is Wales' largest sight loss charity and works on behalf of over 100,000 people in Wales with vision impairment.
3. We provide support, advice and information to people living with sight loss across Wales, as well as campaigning for improvements to services and raising awareness of the issues facing blind and partially sighted people.

4. We acknowledge the progress made by the Health and Social care Committee during the fourth Assembly, but believe that that there are significant challenges for the new Committee to ensure that the level of Health and Social Care in Wales is fit for purpose to meet its long term social priorities within a context of rising costs, increasing demand, and an ageing population.

5. Whilst the previous Committee undertook some important work into specific areas of health, there was not enough emphasis placed on the prevalence of certain conditions. As research suggests that people will be living with a number of health conditions simultaneously in the future, it is crucial to ensure that there is a solid evidence base on which future policies and legislation can be developed.

6. In its submission to the previous Committees legacy report, we highlighted the need for more transparency in the process by which the committee indentifies and develops its inquiry agenda. We believe that Committee needs to be clear on whether its focus is to scrutinise and future-proof Welsh Government policies or to develop an evidence base which will ensure key health, social care and sport issues are fully explored.

7. As with all Assembly Committees the need to be proactive in identifying potential issues for discussion remains extremely important and we welcome this opportunity to highlight areas which we believe need to be prioritised in the Committees future work programme.

8. RNIB Cymru believes that the Committee should undertake an inquiry into eye health in Wales given that over 50% of sight loss is avoidable, yet as many as 1 in 10 people in Wales have never had an eye test.

9. An inquiry into the Welsh Government's Delivery Plan, 'Together for Health: Eye Health Care 2013-2018' and a scrutiny session on Welsh Government's delivery could provide an opportunity to understand and measure the impact of eye conditions and treatment provision across Wales

10. The current Welsh Government plan runs until 2018, and we believe that an inquiry could provide a timely and influential consideration of the current situation early in the new Assembly.

11. There are an estimated 106,000 people with sight loss in Wales. (Access Economics (2009), Future Sight Loss UK 1: the economic impact of partial sight and blindness in the UK adult population, RNIB)

12. It is projected that the number of people with sight loss will double by 2050 (Access Economics (2009), Future Sight Loss UK 1: the economic impact of partial sight and blindness in the UK adult population, RNIB) and so there is a very real need to understand the nature of the challenge and the means of addressing the demands which will be put on health and social services over the medium to short term.

13. RNIB Cymru does recognise that the Welsh Government has placed a higher priority on ophthalmology over the past year or so, but we believe that a clear, thematic review would focus work in the years ahead to ensure the system is robust, fit for purpose and that the relevant reporting and IT systems are in place to monitor patients' journeys through the health service, to ensure that patients receive the relevant, timely and appropriate treatment.

14. In response to the specific topics highlighted in Committees consultation we submit the following comments on relevant headings

i) Integration of Health and Social Care services and

ii) ii) Primary care

15. We note the existing legislative framework and the future requirements for local authorities under the Social Services and Wellbeing (Wales) Act 2014 and the Well-Being of Future Generations (Wales) Act 2015, and consider this to be an

opportune time to look at opportunities for closer integration of health and social care.

16. As existing standards for quality of care are predominantly hospital focused there is a need to consider how these standards can be extended to primary care providers to ensure a seamless quality experience wherever patients enter the service, whether it be from GP surgeries, Pharmacists or Clinics in order to make real progress in reducing the number of avoidable sight loss conditions, whether this is through the delivery of existing legislation or through new legislation.

17. RNIB Cymru welcomes the focus on greater cooperation and partnership in social services provision. We support the Welsh Government's strategic aim of removing fragmentation and delivering integrated support for citizens. Too often blind and partially sighted people experience fragmented care, leaving them isolated and without the help they need to live well with their condition.

18. A key priority of the Welsh Government's Eye Care Plan is to ensure integration of services. Combined with the strengthened legislation included in the Social Services and Wellbeing (Wales) Act, there is a critical opportunity to make a step-change in the integration of health and social care services accessed by people with sight loss. This has the potential to significantly improve both the experiences of services that blind and partially sighted people have, but also their quality of life.

19. One practical example of how links between health and social services can be improved is through Eye Clinic Liaison Officers. Situated in hospital eye clinics, Eye Clinic Liaison Officers (ECLOs) offer both emotional support and practical

help to people at the point of diagnosis with sight loss, including signposting to social services and other statutory and third sector organisations.

20. We also believe that Committee has an important role in ensuring that the Social Services and Wellbeing (Wales) Act, delivers on the stated Welsh Government policy outcomes and addresses any unintended consequences.

21. RNIB Cymru remains concerned about the impact of the eligibility regulations on people with sight loss. Currently, the eligibility assessment relies on a range of preventative services available within the community; yet it is not yet clear what sorts of services these will be and how budget pressures will impact on delivery for example

22. RNIB Cymru is also concerned about the lack of clarity on the future of rehabilitation services for people with visual impairment in Wales, which also makes it difficult to assess the impact of the eligibility regulations on the ground, we believe that Committee will need to ensure that the regulations are subject to regular scrutiny to ensure that they are fit for purpose.

23. RNIB Cymru would like to see health services in Wales deliver excellent services for people with sensory loss. At present there is great commitment from Welsh Government around the area of accessible information, communication and the built environment, with the launch of the All Wales Accessible Healthcare Standards by the Health Minister in 2013; however nearly two years on, the standards have still not been implemented fully.

24. The joint report between Action on Hearing Loss, RNIB Cymru and Sense in December 2014 showed that many people were still experiencing difficulties in accessing information in their preferred format or being able to access instructions on their medicine. (One Year On, the All Wales Standards for communication and information for people with sensory loss, December 2014, RNIB Cymru, Action on Hearing Loss Cymru and Sense Cymru, accessible from the following location: http://www.rnib.org.uk/sites/default/files/One_year_on_report%20-final.docx)

25. The Health and Social Care Committee could take evidence on how these standards could be applied across the health service to inform and improve services for people living with multi-sensory impairment and other age-related conditions.

Waiting Times

26. In the 2014 RNIB Cymru report, 'Real patients coming to real harm' Ophthalmology services in Wales, the conclusions starkly pointed out that patients go blind whilst on waiting lists. The report conservatively estimates that each year in Wales 48 patients are losing their sight due to the length of time spent waiting to be seen in ophthalmology departments, due to a mismatch between demand and capacity – the number of ophthalmology patients is growing however the capacity to treat them is not.

27. An ageing population, more treatment options and an increase in some underlying causes of sight loss, such as diabetes and obesity, have increased demand for ophthalmology appointments. Targets set by the Welsh Government mean that priority is given to the first

appointment which means that patients who need follow up appointments and treatments often have to wait much longer than they should. In that time their sight can deteriorate rapidly without the appropriate treatment.

28. RNIB Cymru believes that everyone in Wales has a right to timely access to high quality specialist care including cataract surgery and NICE approved treatments for degenerative eye conditions.
29. At present the Referral to Treatment Time target (RTT) only focuses on the initial diagnosis and first treatment. There is no target for follow up eye appointments, and therefore the risks to the patient cannot be adequately managed.

30. As most sight loss conditions are degenerative, but also treatable and blindness preventable, a clinically led target is required. We believe that Committee should also consider the impact of intelligent targets which have been designed in consultation with clinicians, to ensure that patients get timely access to safe, efficient and effective service.

Loneliness and isolation among older people

31. Currently 1 in 3 of those over the age of 75 has sight loss and by the age of 90 this rises to 1 in 2 (Access Economics (2009), Future Sight Loss UK 1: the economic impact of partial sight and blindness in the UK adult population, RNIB)

32. Older people with sight loss, particularly those over the age of 75, are often living with up to three or more long term health conditions, making it even more of a challenge to maintain independence, social networks and wellbeing and many need care and support (Tate R, Smeeth L, Evans, J,

Fletcher A, Owen C, Rudnicka A, 2005.) The Prevalence of Visual Impairment in the UK: a review of the literature. RNIB.

33. Sight loss impacts on every aspect of a person's life: their physical and mental health, their ability to live independently, their ability to find or keep a job, their family and social life.

Older people with sight loss are at greater risk of social isolation than the general population, because they experience more difficulty getting out and about, they are also more likely to experience negative outcomes in relation to health, economic wellbeing and social and civic participation (Nazroo J and Zimdars A, 2010). **Social inclusion, social circumstances and the quality of life of visually impaired older people.** Thomas Pocklington Trust

In addition, many older people with sight loss do not regard the use of the internet as an activity that is open to them. (Edwards A, 2012). **Tackling digital exclusion – Older blind and partially sighted people and the internet.** RNIB.

34. There is a higher prevalence of sight loss among people with certain other conditions. In particular, Up to 70 per cent of people who survive a stroke have difficulty seeing or processing visual information (MacDiarmid S, Rowe F, 2007). Interdisciplinary aspects of vision and communication deficits following stroke. British and Irish Orthoptic Journal vol 4, pp21-26.

35. It is estimated that 2.5% of people over 75 years suffer with dementia and sight loss. This figure is likely to be an under-estimate because studies have not accounted for individuals who are considered to be 'untestable'.

36. The degree to which a person with dementia is able to cope will be influenced by their sight loss (Roy Jones and Dr Richard Trigg, 2007), Dementia and serious sight loss, Thomas Pocklington Trust. Occasional paper number 11, February 2007

37. As the population ages, the number of people with both dementia and sight loss will increase. This makes it extremely important to ensure that any discussions on loneliness and isolation also examines the underlying issues of such as the need for appropriate pathways for diagnosing and managing co morbidity and examining the opportunities for future proofed housing, and access to public transport, which all have an effect on confidence and social inclusion.

38. RNIB Cymru support public organisations to deliver improved services for people with sensory loss through our own accredited programme 'Visibly Better'. (Information accessible from the following location: http://www.rnib.org.uk/wales-cymru-how-we-can-help/designing-accessible-housing-and-buildings) This programme highlights actions that organisations should take to ensure their services and environments are fully accessible for people with sensory loss.

39. RNIB Cymru recognises the increasing pressures on budgets across the health sector, but is concerned that health priorities need to take into consideration the fact that as people age, the number of people living with more than one condition increases and means that they require more support from the health service and social care services.

40. It is vital that health and social care services are equipped to deal with people who have more than one condition, in

addition to helping people with sight loss to live independently. If people with sight loss are not supported, the cost of sight loss to the health service will increase significantly over time.

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Colleg Brenhinol Meddygon Caeredin
Response from: Royal College of Physicians of Edinburgh

The National Assembly for Wales

Priorities for the Health, Social Care and Sport Committee

Response from the Royal College of Physicians of Edinburgh

1. The Royal College of Physicians of Edinburgh (RCPE) is an independent clinical standard setting body and professional membership organisation, which continually aims to improve and maintain the quality of patient care. Founded in 1681, we support and educate doctors in the hospital sector throughout the UK and the world with over 12,000 Fellows and Members in 91 countries, covering 30 medical specialties.

2. Physicians are leaders within healthcare teams and engage in difficult discussions about prognosis and treatment options. Our members have identified three key priority areas to inform the health goals of the incoming Welsh Government in 2016. These measures will ensure safe, patient-centred, high quality medical care (1) and improved public health. For more information on any of these issues, please contact us directly: [redacted] or [redacted].

Health and wellbeing

3. The RCPE has worked to improve public health for nearly 350 years and promotes health and wellbeing for all.

4. Obesity: 58% of all adults in Wales are overweight (2) compared to 39% globally (3) and 62% of the UK (4). Prevention is both better for patients and more cost-effective than treatment. However, action is also necessary to assist those who are already overweight or obese. The costs of obesity to both the NHS and patients are high (5), financially and in terms of avoidable suffering. Being overweight increases the chances of developing diabetes, heart disease, cancer and arthritis, and has the potential to lead to reduced mobility, disability and social isolation.

5. It is vital that the public can make informed choices about food. While a balanced diet will help avoid obesity, a poor diet which does not meet recommended dietary requirements and results in overweight/obesity could be described as 'modern malnutrition' (6). Preventative measures such as reduced food portion or pack sizes must be considered along with policies such as the sugary drinks tax.

6. The RCPE supports fully embedding physical activity for health into primary care, secondary care, social care and health education,(7) as well as in the health and social care workforce and workplace. This would include ensuring secondary care staff provide guidance on the recommended minimum levels of physical activity for health, offer brief advice and brief intervention, and signpost to community resources.

7. Alcohol: Problems associated with alcohol continue to be a challenge for the NHS in Wales. We agree with other health organisations that the alcohol industry should have a reduced role in the formulation of alcohol policies to help ensure public health remains the priority. The alcohol industry should be strongly encouraged to contribute to the reduction of alcohol harm by sharing knowledge of sales patterns and marketing influence. The implementation of Minimum Unit Pricing (MUP) remains a priority for the RCPE and we ask the Welsh Government to support this.

8. Tobacco: 20% of adults were active cigarette smokers in 2014 (8). While this figure is gradually falling, we ask the Government to continue to support Stop Smoking Wales and targeted initiatives in order to see further long-term improvements and reduce premature deaths. We also call for a

dementia prevention strategy which recognises that smoking is a major risk factor (9) for developing dementia, and thus would be a crucial part of any prevention work.

9. Mental health: There is a well described link between mental and physical health and wellbeing, (10) and we therefore support extending the integrated and holistic view taken in the Mental Health (Wales) Measure 2010. The Measure is intended to ensure that where mental health services are delivered, they focus more appropriately on people's individual needs. Around 30% of people with a long-term physical health condition also have a mental health problem. The evidence also shows that that people with mental health issues are dying early due to associated physical behaviours and that, for example, stopping smoking improves mental as well as physical health (11). Mental health promotion should be given more prominence with respect to physical health due to the burden of morbidity and reduced life expectancy

10. Inequalities: There are currently significant differences – up to 10 years – in life expectancy between the most affluent and the most deprived areas in Wales (12). Research over the years, from the Black Report (13) to Prof Sir Michael Marmot's Institute of Health Equity, (14) has consistently shown that it is vital that action is taken to improve the social and economic conditions in which people live (15). We therefore call on the Government to pursue policies which will address social determinants of ill health and improve circumstances which lead to poor health or social exclusion, including disability.

11. The RCPE is committed to working with other organisations and professional bodies to embed action on the social determinants of health across the workforce. We ask the Government to support these measures.

12. Overtreatment: Issues such as the overuse of clinical treatments and interventions (16) and the overuse of antibiotics (17) remain high profile and we call for partnership-working between clinicians and the Government to ensure tackling these issues remains a priority and best practice is followed to maintain the efficacy of some of our most clinically valuable medicines.

Workforce planning and training

13. Workforce planning: The RCPE supports increased availability of consultant-delivered care, including at evenings and weekends, where there is potential to improve quality of care for patients with the appropriate staff and services in place. It is essential that an evidence-based approach to extended working is taken, recognising the importance of a multi-professional approach and an appropriately phased implementation. We call on the Government to recognise that this cannot be delivered without additional resource, increased medical staffing, clinical time, and increased support from services such as radiology; pathology and allied health professionals (AHPs).

14. Collaboration is vital between the Government and clinicians to build upon the emerging evidence in this area, such as the findings of the RCPE's expert workshop on extended working. The medical workforce faces a number of challenges and the RCPE recognises the need for safe and sustainable staffing levels throughout the NHS. We need to ensure that we continue to recruit and retain a world class workforce to deliver the best possible patient care (18). The RCPE is committed to working with the Welsh Government and other allied organisations to address issues around recruitment and retention such as consultant vacancies, rota gaps and trainee attrition rates, as a matter of priority. We are also committed to working with partner organisations to promote innovative ways of working in the NHS. The roles of Physician Associates, Advanced Nurse Practitioners and other examples of physician extenders should be further examined to create a workforce fit for the future.

15. Political parties must commit to developing and implementing minimum staffing levels for all professions within hospital settings, based upon best evidence (1), along with improved workforce planning which reassesses the size and structure of the consultant workforce taking account of such changes as the rise of part-time working, extended working, and the needs of an ageing population.

16. The College is committed to promoting the highest clinical standards and implementation of robust, evidence-based medical practice. Standards must be measurable and the associated scrutiny proportionate in order to be effective. Improving patient flow across health and social care remains vital in this regard, both in terms of patient safety and quality improvement (19). Patients must be treated in the right place, and as quickly as possible. This requires the right numbers of staff and mix of skills across health and social care.

17. Training: Excellent training is essential to provide excellent patient care. Doctors in training provide a significant level of core hospital services and care, and are key in identifying concerns in service provision and standards of patient care. Our trainees will become future NHS leaders and the RCPE is committed to supporting them throughout their careers.

18. The RCPE calls for the incoming Government to ensure that: UK wide training standards, as regulated by the GMC, must be met throughout Wales; development of Shape of Training should be conducted in Wales with input from the RCPE and implementation must be appropriately evaluated; medical Royal Colleges need to be able to devise curricula according to patient need, independent of government involvement; training and service are inherently linked and both must be supported in order to deliver high quality patient care. Full adoption of the RCPE's Charter for Medical Training (20) provides this environment.

19. All medical units admitting acutely ill patients must be staffed by doctors in training at registrar level possessing the MRCP (UK) examination, or equivalent Staff, Associate Specialist and Specialty (SAS) grade doctors, working under the direct supervision of consultant staff, all on robust and sustainable rotas. A healthy working environment must also be ensured by, for example, a zero tolerance approach to bullying, harassment or undermining behaviour.

Health and social care

20. Frailty: Current projections suggest that the number of people aged 65 and over will increase in Wales by 50% by 2037 (21) and a significant problem faced by older people is frailty. Frailty is progressive and impacts adversely on life experience (22). We call on the incoming Government to continue exploring new models of approaching patients with frailty which will assist in routinely identifying those living with frailty and signpost them to the most appropriate support, including self-management or care in a community setting.

21. Long-term conditions: Managing patients with long-term or chronic conditions is one of the biggest challenges facing the NHS in Wales and collaboration between health and social care has great potential in this regard. We ask the next Government to actively support primary and secondary care to work effectively in partnership with social care. It is important that, where appropriate, patients are treated in a community setting and are empowered to be active participants in their own care where possible, and that patients fit for hospital discharge can do so without delay.

22. We call on the Government to ensure that consultants and other members of multidisciplinary teams have adequate time for patients with long-term or chronic conditions to promote patients'

understanding of their own care, and for patients to have improved access to specialist nursing care. An important part of providing high quality patient care is ensuring that patients are well informed and have accurate expectations of their treatment and care: effective and compassionate communication with patients will remain a key priority for the RCPE.

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Ymddiriedolaeth Terrence Higgins

Response from: Terrence Higgins Trust

Submission to Health, Social Care and Sport Committee

Priorities for the coming year

Terrence Higgins Trust is the UK's largest HIV and sexual health charity, with over 30 service centres across England, Scotland and Wales. We are a campaigning organisation which advocates on behalf of people living with or affected by HIV or poor sexual health.

We have set out below the areas that we believe the Committee should take up as a matter of urgency.

Access to sexual health services

We would like the Committee to undertake an inquiry looking at the current level of access to sexual health services.

Access to sexual health services across Wales continues to deteriorate. There is currently no statutory sexual health service provision of any kind in Powys. Sexual health prevention and health promotion services have been decommissioned in three Local Health Board's (Betsi, Cwm Taf, Hywel dda) despite these areas being the most deprived. Cwm Taf has the highest rate of teenage pregnancy in Wales and Hywel dda is a rural area with the closest sexual health clinic located 60 miles away in Swansea.

Yet rates of HIV and sexually transmitted infections continue to rise across the country. Over the last two years there has been an increase in reports of new diagnoses of herpes, gonorrhoea, chlamydia and hepatitis B as well as an outbreak of syphilis which is continuing to affect some areas of Wales. 2014 saw the highest ever number of new HIV diagnoses in Wales, affecting both men who have sex with men and heterosexuals. The number of new HIV diagnoses in people aged over 45 continues to rise.

There is a lack of national and local leadership and prioritisation of HIV and sexual health. From 2010 – 2015 the Welsh Government worked towards implementing a National Action Plan on Sexual Health and Wellbeing. This action plan has now come to an end with no new strategy is in place. Action is needed to ensure that a new action plan is drafted as a matter of urgency, that it is written in partnership with communities affected by HIV and sexual health, and that a new action plan addresses the current and emerging issues around HIV and sexual health including access to services, availability of PrEP, and sexualised drug use.

There needs to be clear mechanisms to hold to account those organisations and individuals who are responsible for meeting the sexual health needs of the people of Wales. There are no national indicators holding local health boards to account on the degree to which they

meet local HIV and sexual health needs. Within the national Public Health Outcomes Framework (PHOF) there are no indicators for sexually transmitted infections or HIV. This is in contrast to the PHOF in England that includes indicators on chlamydia detection rates and HIV late diagnosis ensuring transparency on where areas of the country are falling behind in their actions around sexual health.

Policy around HIV should be evidence based. Yet a lack of investment and prioritisation has resulted in poor quality HIV and sexual health surveillance data in Wales - lagging far behind the comprehensive data collected and made publically available in England and Scotland.

HIV and poor sexual health disproportionately affect the most marginalised in our society and directly reflect the inequalities that they face. Sexual health has fallen off the national and local agenda across the country and the inexcusable lack of access to services must be addressed.

Sex and Relationships Education

Our recent report "Shh no talking" included the SRE experiences of over 900 young people, 11% of whom lived in Wales. The report found there was extreme variations in access to, and quality of SRE. However it was clear that young people want SRE – LGBT-inclusive SRE - that answers the many questions they have around sex and relationships.

The report found:

- 1 in 7 young people did not receive any SRE at school at all
- 99% of young people thought age appropriate SRE should be taught in all schools
- Half of young people rated the SRE they received as poor or terrible and only 2% rated it as excellent.
- Only 5% of young people were taught about LGBT sex and relationships yet 97% thought that all SRE should be LGBT-inclusive
- 75% of young people have not learnt about consent.

Evidence has shown pupils with good SRE demonstrate sophisticated personal and social skills, and can confidently and maturely discuss the issues raised in lessons.

SRE can give children and young people the skills and knowledge to:

- Better manage their sexual health

- Be more informed about teenage pregnancy and contraception
- Be informed and supported if they are LGBT, and to challenge and report homophobic bullying
- Be more aware of the unrealistic portrayal of sex in pornography and be safer on the internet
- Identify airbrushing in the media and recognise unrealistic portrayals of the human body
- Be aware of abuse and be empowered to report it if they suffer abuse

Young people need an impartial education on how to address matters such as contraception, STIs, HIV and teenage pregnancy in an age appropriate manner. When young people are equipped with the knowledge they need to make informed decisions, they are more confident in having the relationships they want. International evidence from UNESCO research shows that when taught properly, SRE can delay sexual activity.

Young people across Wales are not getting the SRE they want and need. This needs to urgently change.

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Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: NSPCC Cymru
Response from: NSPCC Wales

NSPCC

CYMRU | WALES

Response to

Inquiry on

Health, Social Care and Sport Committee Priorities

Date: August 2016

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MAE POB PLENTYNDOD WERTH BRWYDRO DROS
EVERY CHILDHOOD IS WORTH FIGHTING FOR

About the NSPCC

We're leading the fight against child abuse in the UK and Channel Islands. We help children who've been abused to rebuild their lives, we protect children at risk, and we find the best ways of preventing child abuse from ever happening.

Abuse ruins childhood, but it can be prevented. That's why we're here. That's what drives all our work, and that's why – as long as there's abuse – we will fight for every childhood.

We help children rebuild their lives, and we find ways to prevent abuse from ruining any more. Learning about what works in the fight against abuse and neglect is central to what we do. We are committed to carrying out research and evaluation to make sure the approaches we're taking are the right ones and we share what we have learnt with partners.

NSPCC Cymru/Wales welcomes the opportunity to contribute to the Health, Social Care and Sport Committee Inquiry on its priorities for the next 12-18 months and its longer term work programme.

We're working to create safer childhoods for every child in Wales and strengthen the delivery of children's rights. We believe that this can be achieved by all partners working to prevent, protect and play a part as together, we can end child abuse.

We have reviewed the areas you are proposing for your longer term work programme and we are concerned that the unique needs of children and young people, and particularly vulnerable children and young people, seem not to feature. As children have no vote and little voice or control, we would strongly recommend you consider undertaking inquiries on issues relevant to children and young people and also ensure that when you are undertaking inquiries for 'people', that a strand of the inquiry focuses on the needs of children and how children's rights are fulfilled or infringed.

NSPCC Cymru/ Wales would like to suggest that the Committee focuses on the following priorities:

1. Monitoring the implementation of the Social Services and Wellbeing (Wales) Act 2014.

NSPCC Cymru/Wales welcomed the coming into force of the Social Services and Wellbeing (Wales) Act 2016 in April 2016. We particularly welcome the focus on **prevention and early intervention** to enhance the wellbeing of people who need care and support.

We believe that influencing factors on an individual's behaviour can be identified and therefore it is possible to **prevent abuse before it occurs**. Issues such as inadequate housing, poor mental health, poverty, domestic abuse, or substance misuse problems are all known risk factors for all forms of abuse and neglect and so we want more attention to be given to **support families facing adversities** and we believe problems should be addressed early. Stressors often occur together and have a cumulative effect- the more of them there are in a family, the greater the risk to the

child.[1] Recent Adverse Childhood Experiences (ACEs)[2] research draws on growing evidence that experiences during childhood can affect health throughout the life course. Findings that adults in Wales who were physically or sexually abused as children or brought up in households where there was domestic violence, alcohol or drug abuse are more likely to adopt health-harming and anti-social behaviours in adult life underlines the importance in effective early interventions. This is likely to pay significant dividends that span learning, health and parenting of the next generation.

This is why we would strongly recommend that the Health, Social Care and Sport Committee **allocates some time in its work programme to monitor the implementation of the Social Services and Wellbeing (Wales) Act 2014.** Possible areas of scrutiny include:

- **Provision of prevention and early intervention services:** The Act requires local authorities to provide preventative services and we would be particularly interested to see the Committee scrutinise the process for planning and provision of preventative services. This will start with the population needs assessment by March 2017 and area plans for prevention and early intervention. As the focus in the Act was on people having a say and more control on the support they require, we would recommend the Committee scrutinises how effectively the needs of children who need care and support are met, and how their voices and views are listened to.

- **Eligibility:** we would be particularly interested to see the Committee scrutinise how the new eligibility criteria for care and support are addressing the issues of "postcode lottery" and access to services, especially for vulnerable children and young people.

- **New duty to report people at risk:** we would like to see the Committee scrutinise how the new duty is being implemented, particularly in relation to children, with a particular focus on the number or referrals, at what stage they occur, and local authorities' response and whether any additional guidance is needed for relevant partners.

We are aware that these suggestions focus primarily on children and some of this scrutiny could be undertaken jointly with the Children, Young

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[2] Public Health Wales (2015) Adverse Childhood Experiences Study

People and Education Committee. We plan to respond to their current inquiry into their priorities and suggest the same points.

We also noted the Minister's statement on monitoring the implementation of the Act last March and suggest that any monitoring undertaken by the Committee could complement that work.

2. A short inquiry into the availability of therapeutic services for children who have suffered abuse and neglect.

We note the Committee's remit in relation to mental health and wellbeing.

The impact of abuse includes mental health problems such as anxiety, depression, substance misuse, eating disorders, self-harm, anger and aggression, sexual symptoms and age inappropriate sexual behaviour.[3] Receiving support can mean the difference between overcoming their trauma, or a life shaped by the horror of their experiences.

Child maltreatment is more common, damaging and diverse than many of us are prepared to recognise. Over 2,900 children in Wales were identified as needing protection from abuse and over 5,600 children were looked after last year[4]. NSPCC has estimated that for every child on a child protection register there are another 8 who have suffered maltreatment but who do not come to the attention of statutory authorities[5]. We also know that some children are 'polyvictims' – the unfortunate targets of many different kinds of victimisation at the hands of a variety of offenders. 'For example, they experience physical and emotional abuse by caregivers, assaults and harassment by peers, sexual victimisations by acquaintances and strangers and are exposed to crime and violence in their communities and neighbourhoods'.[6] 2014 also saw a sharp increase of 26% in the number of recorded sexual offences against children aged under 16[7].

Unfortunately, evidence shows that it can be difficult for children who have experienced abuse and neglect to access support. In 2015, there was a 124% increase in ChildLine counselling sessions relating to mental health and wellbeing that mentioned problems accessing services across

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[6] http://www.unh.edu/ccrc/polyvictimization/

[7] Jutte, S. et al (2015) How safe are our children? London: NSPCC

the UK. This is supported by a survey we have conducted with professionals about the level of support available to children and young people who have experienced abuse. We asked health, education and social care professionals **whether the current provision of therapeutic services is meeting the needs of children for whom the effects of abuse or neglect are a primary concern. 98% of professionals (127) said there are not enough "other "therapeutic services such as counselling, CBT and attachment based therapies.**

Although the Welsh response sample is small, results indicate that the level of service provision is **currently insufficient to meet need.**

Article 39 states of the UNCRC states that the Government 'shall take all appropriate measures to promote physical and psychological recovery….of a child victim of any form of neglect, exploitation or abuse' Children and young people tell us that they have to fight to receive any support following abuse and neglect. The evidence suggest that there is a need to determine exactly **what therapeutic service provision is currently available in Wales for children and young people who have suffered abuse and neglect, and we suggest that this could form the subject of a short inquiry by the Committee.** Such an inquiry would be very timely, in light of the current Together for Children and Young People Programme, and would complement the work which is being undertaken around support for vulnerable families. It would also allow the Committee to scrutinise how the additional funding announced by Welsh Government for talking therapies is being used.

3. NSPCC is a member of the Safeguarding Children in Sport Wales and we support the group's calls for short inquiries into:

3.1 How safe are children in unregulated activities (that sit outside Sport Wales funded recognised partners)?. Unsuitable adults are able to exploit opportunities available in unregulated activities to gain access to children and so we recommend the Committee runs a short inquiry into the safety of Welsh children in unregulated activities. Sport Wales supports key sports bodies to achieve recognised safeguarding standards, but there are still unregulated bodies in the private and voluntary sports sector which we feel should be subject to regulation around safeguarding. This is an area where there are likely to be recommendations which will come out of Baroness Tanni Grey-Thompson's Duty of Care review for sport

https://www.gov.uk/government/consultations/sport-duty-of-care-review-call-for-evidence.

We believe the safeguarding risks are much higher in these environments as they do not come under any regulatory body or scrutiny that recognised National Governing Bodies of Sport or other Sport Wales funded partners do.

We also believe that safeguarding must be embedded within leadership structures and prioritised by all organisations responsible for provision. Accountability for safeguarding needs to be placed at the top of organisations through CEOs, senior management and boards and support advice and guidance prioritised to continuing this work.

3.2 Talented Athletes are the highest category risk group with regards to safeguarding from all the evidence shown, mainly due to their dependence status. Wales exceeded its medal targets in Rio Olympic Games and there is excellent work happening to ensure talented young people exceed their potential. However, some sports manage progression and deselection well and others don't; there is often a fine line between poor practise and safeguarding issues. We would recommend a short inquiry into the safeguarding of our talented athletes to hear the views of national bodies but also athletes themselves. We would recommend that there should be support and guidance available for young people when difficult decisions are made and for a period of time afterwards and that this support should be integrated with mental health services.

We would be pleased to discuss any of the areas we have outlined in our response in further detail if that would be of help to the Committee.

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Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Colegau Cymru

Response from: Colleges Wales

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ColegauCymru / CollegesWales response to Priorities for the Health, Social Care and Sport Commitee

Views on priority areas that should be considered for the next 12-18 months

September 2016

1. ColegauCymru / CollegesWales welcomes the opportunity to submit comments to the Committee for Health, Social Care and Sport in response to the advertised consultation.

2. ColegauCymru / CollegesWales represents the 14[1] further education (FE) colleges and FE institutions in Wales.[2]

3. Since 2014, ColegauCymru / CollegesWales in partnership with Sport Wales has been the lead organisation for Sport and Physical Activity development in the FE sector in Wales. Developments have focused on increasing participation among underrepresented groups, future workforce, collaboration between FE and other NGBs and organisations with similar goals and future proofing systems to build capacity in the sector.

4. Within the FE sector in Wales, ColegauCymru / CollegesWales is currently focusing its work in Sport and Physical activity among the 16-19 age group, there are currently approximately 50,000 students in this age group in full time education in FE colleges in Wales.

In response to the Consultation, ColegauCymru / CollegesWales would like to respond to the point on **Sport and Public Health** specifically:

- **Making Education at all levels a priority** – the current MoU is between PHW and Sport Wales but would be better served including education at the same level. Specific reference to the post 16 sector including FE has often been neglected - for example in some of the recent development work on Physical Literacy.
- **Future Workforce**: Must ensure that the training of the future workforce in FE is given due attention and is linked to short term planning and interventions in primary schools etc. Also that the 16-24 age group is given priority with its cohort including those approaching child bearing age, future parents and future teachers / coaches.
- **Supporting Volunteers:** Opportunities exist to provide better resources for volunteers from FE – 50,000 students potentially doing Welsh Bacc with 30 hours of volunteering required
- **Support change –** if the current model isn't working, increase investment in embedding the WFG Act's 5 ways of working into training for sport and health in the FE sector. This would enable better **Involvement, Collaboration, Integration, Prevention and Long term impact** between FE and other organisations.

[1] The 14 include 10 FE corporations including St David's Catholic College; an FE institution – WEA YMCA Community College Cymru; and The College Merthyr Tydfil, Coleg Sir Gâr and Coleg Ceredigion which are part of university groupings.

[2] In this paper the terms 'FE college' and 'college' are used to cover FE colleges and FE institutions.

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon
Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Gofal Canser Marie Curie
Response from: Marie Curie Cancer Care

Marie Curie response to the Health, Social Care and Sport Committee's longer term forward work programme.

Marie Curie welcomes the opportunity to influence the future work of the new Health, Social Care and Sport Committee.

Introduction

At Marie Curie believes everyone should have the right to the palliative care they need.

Yet we know from our research that, even with all the care and support the NHS and its partners provide, 6,200 people across Wales who need palliative care miss out on it each year because their needs are not recognised and they are not referred on to the right services.[1]

Marie Curie provides a range of services across of Wales, including:

- A nursing service providing hands on care day and night for people at the end of their lives in their own homes.
- A care home support service in west Wales enabling people to avoid being admitted to hospital who are living in supported accommodation.
- A Freephone advice line offering practical advice and support for patients and their loved ones.
- A 30 bed hospice providing in patient clinical care and day services for people across Cardiff and the Vale and beyond.
- A discharge liaison service in Velindre Trust which supports people returning to their own homes.

In providing all of these and the other services across Wales, Marie Curie makes a financial contribution (usually at least a matching one) out of its own charitable funds to augment those provided by NHS commissioning bodies. All of the clinical services in Wales are provided as a result of being commissioned by the NHS in Wales and all of them would be regarded as core services by the public.

Policy and Legislation

Marie Curie would like to draw to the committee's attention the lack of focus on end of life care by the committee's predecessor/s. There has been a considerable amount of focus by the government on end of life care since the publication of the Sugar Review in 2008. For example they published an end of life care delivery plan which is currently in the process of being refreshed. In setting priorities for primary care the previous Minister identified end of life care as one of three key priorities. Each LHB now has a designated EoL Care lead and is obliged to produce and publish its own EoL delivery plan, (something Health Boards in England are not required to do). We have welcomed this however, we have also drawn attention to the lack of specific outcome based assessment of end of life care in Wales.

Marie Curie firmly believes that everyone who needs Palliative Care should have access to it. There are still too many people nearing the end of their lives not getting the palliative care they need[1]. Seven out of 10 carers say people with a terminal illness do not get the care and support they need.

In terms of equity and access the picture is startling. Factors completely unrelated to your illness can also affect how easy it is for you to get the care you need[2]. Access to suitable or appropriate care can be more difficult if you have a disability[3], if you are from a Black or Minority Ethnic background[4] or if you are LGBT[5]. The same is true if you're homeless[6], in prison[7], or you're from a deprived area[8]. This simply must improve.

In advance of the May 2016 elections, Marie Curie launched a manifesto which we encouraged political parties and individual candidates to sign up to.

We stated our desire for the next Welsh Government to:

1. Commit to ensuring everyone who needs palliative care has access to it by the end of the next Assembly (the current one).
2. Take a public health, compassionate communities approach to developing new services for those living with a terminal illness.
3. Commit to a bi-annual survey of bereaved people to provide a fuller picture of end of life care in Wales.

As a starting point an inquiry into the available levels of Palliative Care across wales would be welcome, with a particular focus on equity looking at, but not limited to, the demographics and communities listed above (footnotes 3-8).

NHS England have successfully undertaken three surveys called 'VOICES' which aims to assess the quality of care delivered in the last three months of life[9] by contacting the individual who registered a death. A pilot study taking a broadly similar approach is being undertaken currently in the Cwm Taf LHB area. We would encourage the committee to both study this pilot and the wider survey in England.

We would also be interested in assisting the committee into an inquiry looking at the role of the care home sector in providing end of life care in Wales. As individuals are living longer and longer, many are dying with more complex illnesses and with patients often dying with more than one condition, we are concerned that in the future residential and nursing care homes will be unable to effectively cope with both the demand in terms of numbers but also to provide adequate care.

We very much hope that the Health, Social Care and Sport Committee will consider enquires into these topics.

We will be pleased to continue to work with Committee to help them understand the issues and improve conditions for patients and their families. We would be happy to give evidence either through written or oral means.

Marie Curie
September 2016

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1 On behalf of Marie Curie, Ipsos MORI interviewed a quota sample of 1,067 adults aged 16-75 online who had cared for a family member, friend or neighbour who was, or is, terminally ill in the last three years. This sample was screened from a nationally representative sample of 6,136 online adults aged 16-75 within the UK. Interviews took place between across the UK using i:omnibus, Ipsos MORI's online omnibus between 3 and 29 October 2014. Data are weighted by age, gender, region, working status and social grade to match the profile of the target audience

2 Dixon J. et al. (2015). *Equity in the provision of palliative care in the UK: Review of evidence*. Personal Social Services Research Unit, LSE. March 2015.

3 Marie Curie Policy and Public Affairs (2014). *The experiences of caring for disabled people at the end of life*. Marie Curie, 2014 *[unpublished]*

4 Calanzani et al (2013). *Palliative and end of life care for Black, Asian and Minority Ethnic groups in the UK: Demographic profile and the current state of palliative and end of life care provision*. June 2013.

5 Fuller et al (2011). *Open to all? Meeting the needs of lesbian, gay, bisexual and trans people nearing the end of life*. National Council for Palliative Care, Consortium of Lesbian, Gay, Bisexual and Transgendered Voluntary and Community Organisations.

6 Davis et al (2011). *Are the homeless dying without access to palliative care?* BMJ 2011;342:d3018.

7 Peacock (2014). *Dying in prison: 'Both sides of the fence' study*. eHospice, 12 June 2014. Online at – http://www.ehospice.com/uk/ArticleView/tabid/10697/ArticleId/10878/language/en-GB/View.aspx

8 Barnet et al (2012). *Epidemiology of multimorbidity and implications for health care, research, and medical education: a cross-sectional study*. The Lancet 2012 Jul 7;380(9836):37-43

9.http://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthcaresystem/bulletins/nationalsurveyofbereavedpeoplevoices/previousReleases

10.http://www.cwmtafuhb.wales.nhs.uk/sitesplus/documents/865/AI%203.2%20Appendix%205%20End%20of%20life%20care%20delivery%20plan%20UHB%2027%20Jan%2020161.pdf (Page 13, paragraph 4)

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Bwrdd Iechyd Prifysgol Caerdydd a'r Fro

Response from: Cardiff and Vale University Health Board

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol Caerdydd a'r Fro
Cardiff and Vale University Health Board

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2 September 2016

Priorities for Health, Social Care and Sports Committee
Cardiff and Vale UHB consultation response

Cardiff and Vale UHB are pleased to respond to the consultation to inform the key priorities for the next 12 – 18 months.

1. Integration of Health and Social Care services: Cardiff and Vale UHB would support an inquiry looking into the implementation of the Social Services and Well-being Act and other policies on integration of health and social care services.

We believe that collaborative working and is vital across all of the public sector to deliver the scale of change required and would request that greater pace is given to this agenda that needs to focus not only on the NHS but with partner public sectors and the third sector. We would suggest that it is important to look at integration across the whole of the public sector, not just integration of service provision, but also integration of policy and priorities to facilitate greater integration. The committee may want to consider metrics as a proxy for integration, such as The National Audit of Intermediate Care 2015 (England) recommendation of a 2 day wait for intermediate care access being a reasonable indicator based on the evidence that patients who wait more than 2 days lose the benefit the service. Something like this would be patient centred, simple to collect, easy to measure and could give a high level indication of improvement in integrated working. The NHS will not be able to meet its challenges without the help of other sectors, especially social services but also those in housing, education, police, fire and criminal justice services.

2. Waiting Times: Cardiff and Vale UHB would support an inquiry considering waiting times but recommend that the remit should look at patient outcomes rather than solely tier 1 targets. Waiting times are a key priority for the NHS and there has been considerable work to focus on improving waiting time. While targets have a role to play, we suggest that this is an opportunity to take a broader view to instigating a system change in the way treatment is delivered to patients and providing the best service we can within the resources available with priorities being based on clinical need. There are examples such as ophthalmology where patients in a follow up cycle may have a greater clinical need that new patients in an RTT phase.

therefore a system that is rebalanced to support clinical priorities and outcomes would be welcomed. We believe that this would help address some of the current key pressure areas outlined, and recognise that without some change in waiting time priority services such as diagnostics and therapies will continue to have capacity deficits. It is an imperative that we develop a performance management framework that supports this with attention given to data collection systems and analytical capability and capacity.

3. Primary Care: We would support an inquiry considering primary care to inform the Committee of the pressures for change and the many developments in services across Wales. Cardiff and Vale UHB aims to provide modern, fit for purpose primary care facilities that support and enables the delivery of safe and sustainable care at or close to home and has a fast growing diverse population with increased requirements for a modern primary care service.

We have well developed Primary Care localities and clusters as well as workstreams to develop a "perfect locality" a multidisciplinary and multi-agency approach to maximise our community assets as part of our Bold Improvement Goal programme. We would welcome the opportunity to raise the issues we are facing, but also articulate the solutions we are developing.

4. Efficiency within the NHS and modern management practices: We would support an inquiry considering the efficiency within the NHS. The rise in demand, coupled with constrained financial resources, has made delivering health and care services in the current model increasingly difficult. Cardiff and vale UHB is committed to working more efficiently in order to rise to the challenges that it faces. However, it has become increasingly clear that traditional methods of savings are unlikely to deliver what is needed in the future. We concur with the NHS confederation analysis of the WAO report[i] and the imperative to be realistic about the current and future costs of health and care services and the need to work with all stakeholders to understand the future resources required to secure the system.

5. Neonatal services: Following from the "Bliss baby report 2016: time for change"[ii] we would support the Committee considering the recommendations with the report and the issues highlighted to deliver a sustainable model for neonatal services that meet clinical needs and that is provided by a well trained workforce.

6. Use of antipsychotic medication in care homes: Cardiff and Vale UHB support the Committee considering the scale of the inappropriate use of antipsychotics to control the behavioural and psychological symptoms of people living with dementia, and if required examine possible solutions.

7. Ambulance Services: Cardiff and Vale UHB would support a short inquiry examining the outcomes of the new Clinical Response Model pilot and consider the Review findings of the CRM pilot that will be published next year.

8. Loneliness and isolation among older people: Cardiff and Vale UHB would support a short inquiry considering loneliness and isolation for older people but we would recommend that this is extended to include all age groups due to the fact it is an issue that does not only impact on older people.

9. Gambling addiction: Cardiff and Vale UHB would support the inquiry looking at awareness of gambling addiction, the provision of support services, and the steps that could be taken to reduce harm.

10. Sport and public health: Cardiff and Vale UHB recommend that an inquiry considering public health should be a key priority for the Committee and should consider the role and impact of a preventative approach to health services and work to educate the general public about the preventative agenda, as recommended during the Health and Social Care Committee legacy report as well as being a key pillar of Prudent healthcare.

Prevention and early intervention to improve population health is a national priority for Cardiff and Vale UHB as we all recognise that it is key to improving the health and well-being of the whole population, while helping to manage demand on secondary care. In common with the rest of Wales we face a significant number of public health challenges, including high levels of obesity, drinking above the guidelines, smoking and poor levels of physical activity. The impact of such behaviours on our health is resulting in significant demand being placed on the health service. The Committee could consider the role and impact of a preventative approach to health services, and work to educate the general public about the preventative agenda and this key element of the Prudent health care agenda and future sustainability of health services.

[i] From Rhetoric to Reality – NHS Wales in 10 years' time: Socio-economic Deprivation and Health

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Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Sefydliad Safonau Masnach
Response from: Trading Standards Institute

Robyn Ellison
Policy Officer
Chartered Trading Standards Institute
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Basildon, Essex, SS15 6TH
Telephone: [redacted]
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Dear sir/madam,

Priorities for the Health, Social Care and Sport Committee

The Chartered Trading Standards Institute (CTSI) and Wales Heads of Trading Standards (WHoTS) welcome the opportunity to make suggestions on the Welsh Assembly for Wales' Health, Social Care and Sports Committee's Foreword Work Program for the coming year. Together we are calling for increased partnership working between local authority trading standards and adult social care teams. We would welcome an investigation by the committee into best practice in this area to help combat issues of loneliness and financial scamming among the elderly in society.

CTSI and WHoTS are particularly pleased to see that the committee is already considering 'loneliness and isolation among older people' as a potential long term priority. The Institute believes this is an incredibly important issue which needs to be rigorously investigated. However, we also feel there is scope to expand this priority beyond simply 'understanding and raising awareness of the health and wellbeing implications of loneliness and isolation for older people'. Loneliness and isolation are issues that directly contribute to the issue of scamming which can have devastating effects, both psychologically and financially, for victims.

There is clear evidence that loneliness is linked with deterioration in health. Around a million (10%) older people are termed 'chronically lonely' at any given time in the UK. This seriously increases their risk of suffering mental and physical illness. Loneliness also puts individuals at greater risk of cognitive decline which is a key factor that contributes to an individual becoming a victim of a scam. Furthermore, victims of scams are often lonely and engage with a scammer more readily than other people because of their natural need for human interaction. In addition to the personal suffering caused, loneliness is heaping pressure on various local authority and health services, as it is often the tipping point for referrals to adult social care and cause for a significant number of GP visits.

On average scam victims are aged 74, and those that are identified by trading standards are frequently found to be lonely and socially isolated. Feeling lonely rather than being alone is associated with an increased risk of clinical dementia in later life. Dementia is another factor that makes people more vulnerable to scams.

The impact of scamming on an individual can often extend far beyond financial loss to include physical risks, loss of their homes, depression, and even contemplated, attempted, or actual suicide. One victim known to trading standards admitted to a family member how much money they had lost to scams and suffered physical abuse as a result.

A victim's trust in his or her own judgement and trust in others is often shattered. They may have hesitated to tell family members, friends, or colleagues about their victimisation for fear of criticism. Family members and

business associates may even have been financially exploited at the victim's urging, resulting in increased feelings of guilt and blame.

A National Trading Standards Doorstep Crime Project was completed in 2014/15 and its report included a victim impact survey which highlighted four significant details in relation to health harms:

- On a scale of 1 to 10, with 10 being the worst affect, 50% rated the effect of the crime on them as between 6 and 10.
- 23% said it had affected their health.
- 38% said it had resulted in them having reduced confidence generally.
- 26% said it had left them feeling down or depressed.

Trading standards in Wales

Trading standards services in Wales have a responsibility to keep safe vulnerable adults from financial and other forms of abuse. This duty of care was reinforced by the Social Services and Well-being (Wales) Act 2014. WhoTS, alongside local authority trading standards services across Wales, are active in the prevention of scams (particularly aimed at older and vulnerable people) and also in the investigation and prosecution of rogue traders who commit frauds such as doorstep crime. Notably, WHoTS has made 'Safeguarding Vulnerable Consumers' one of its five strategic priorities for 2016.

WHoTS is also actively engaged in regional and national programmes such as Scams Awareness Month and the Wales Against Scams Partnership (WASP). Each local authority carries its own strategies to assist vulnerable consumers which often includes visits to scams victims; support of cold calling control zones; and rapid response to incidents. One authority, Carmarthenshire, was recently 'highly commended' at the Municipal Journal Awards for Innovation in Partnership for its Financial Exploitation Safeguarding Scheme, a multi-agency scheme to protect vulnerable people against scams, fraud and repeat exploitation.

The Welsh Government provides the funding that allows local authorities to support trading standards services and has created a statutory responsibility in relation to the provision of care and support for the vulnerable. Trading standards plays a key role in the delivery of the safeguarding responsibilities of local authorities and further contributes to the Welsh Government's overall Safeguarding Policy objectives.

1. WHOTS therefore calls on Welsh Government to formally recognise; challenge; and hold to account the work of trading standards –
2. The Welsh Government and Local Authorities need to be assured trading standards are up to the task of safeguarding the vulnerable. Therefore, trading standards should be set a stern challenge by the Welsh Government to demonstrate its contribution to their overall Safeguarding Policy objectives.
3. Targets should be set by the committee around putting the individual and their needs at the centre of their care, increasing preventative services, measuring the success of care and support, the number of individuals involved in the design and delivery of the services they need, and partnership working with other agencies.

Finally, to reiterate, CTSI and WHoTS are calling for increased partnership working between local authority trading standards and adult social care teams and is looking to the committee to investigate best practice for how to take this forward.

This response was compiled in partnership with CTSI's Lead Officers for Vulnerability and the WHoTS executive team. If you have any questions regarding the issues raised within this response or would like any further information or case studies please contact [redacted] and the team will be happy to assist.

Yours faithfully,

Robyn Ellison

Policy Officer, CTSI

About CTSI

CTSI is a professional membership association founded in 1881. It represents trading standards officers and associated personnel working in the UK and also overseas – in the business and consumer sectors as well as in local and central government. The Institute aims to promote and protect the success of a modern vibrant economy and to safeguard the health, safety and wellbeing of citizens by empowering consumers, encouraging honest business, and targeting rogue traders.

Additional resources:

The work of Trading Standards professionals has seen many criminals brought to book; examples include:

- Torfaen TS: a builder was ordered to pay £10,000 compensation after using a woman's life savings to build a potentially dangerous and sub-standard conservatory. He was also sentenced to a 2 year community order
- Rhondda Cynon Taff TS: a man who ran an unauthorised PPI Claim Back Scheme jailed for 4 years after defrauding 1,500 people out of £170,000
- Neath Port Talbot TS: a director of a Green Deal Scheme company has been jailed for 6 months for misleading older and vulnerable consumers; another officer of the company was given a community order

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Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Cymorth Cymru
Response from: Help Wales

Consultation: Priorities for the Health, Social Care and Sport Committee

Consultation response

Cymorth Cymru welcomes the opportunity to reply to the Health, Social Care and Sport Committee, regarding forthcoming priorities. The committee oversees a broad variety of areas that are of great importance to our organisation and to our sector, some of which are outlined below.

Our response will be presented under a number of headings indicating what our organisation and those which we represent believe to be the greatest priorities for the Health, Social Care and Sport Committee.

The impact of the National Living Wage on care providers

The National Living Wage for those over 25 was implemented in April 2016. The impact of the National Living Wage on care providers causes a number of issues. The combination of legal challenges creating the need for sleep-in top-ups and a higher National Living Wage has resulted in acute pressures for the care sector. For Learning Disability providers alone, costs rose by an average of £1.71 per hour in April 2016. Both these changes have required providers to increase their care staff salary budgets from between £60,000 and £1,054,000 per annum with effect from April 2016. This will then need to increase by a further 5% year on year until 2019/20.

We appreciate that immediate crisis this year has been avoided but the threats are still very real as time passes. We believe that the most effective way to combat this is for the committee to look into radical new ways of commissioning which are less bureaucratic and more focused on results and less on price. It also requires an acknowledgment that costs have risen and a commitment of resources to meet that shortfall.

The sustainability and importance of workforce being recognised

People working in a 'frontline workforce' such as care and social work often feel undervalued. It is a priority to recognise the importance of, and protect the value of, the workforce. Workforce should be recognised through regular and relevant training; supported opportunities for career progression; regulated working hours with sufficient breaks, and a clean and safe working environment. Also, through a parity of esteem between all forms of care work and other

professions, particularly when it comes to practice improvement and engagement with the workforce. The lack of value placed on the care profession often leads to a high turnover of team members, resulting in an under-skilled and under-enthused 'temporary workforce' that has little time to deliver relationship-centred support. This can have a tremendous negative impact on the quality of service received by the individuals accessing support services.

A workforce which feels valued is vital for delivering a robust service, which is more important than ever considering the volume of care work and social support that is currently being delivered by the third sector. Often it is people within the frontline workforce who most understand the needs of the client. We believe it is crucial to not squander this knowledge by losing undervalued team members to other professions.

The Social Services and Wellbeing (Wales) Act that came into force in April 2016 plans to give carers an equal right to be assessed for support, as part of the Care Council's vision of making sure that we have a workforce that feels valued and recognised[i]. The changes in this Act are one example of an attempt to support and value a workforce. It should be a priority of the committee to look into how the Welsh Government is prioritising policies and practice that help support the values of the Act, looking into ways of promoting the importance of a good working environment as outlined above and raising the profile of and respect for the profession.

The way the Housing Act, the Violence Against Women Act and the Social Services and Wellbeing Act are being implemented can only benefit from a collaborative approach – and the longer-term lack of join-up with housing needs to be addressed

Our members deal with a range of issues as part of their daily work and hold a lot of knowledge on these issues. We believe that this knowledge should be recognised and valued as we move towards a more collaborative way of working. We appreciate that housing is starting to be acknowledged more widely – but as work continues to integrate health and social care more closely, we cannot lose sight of the need to keep housing involved. For example, quality housing inevitably leads to better health outcomes. In addition, social services and the health sector often struggle with changing services or a lack of a single contact. Often housing is somewhat more stable and so should be involved much more. We believe it should be a priority for the committee to consider how housing is involved and included in areas of public health and social services.

The Violence Against Women, Domestic Abuse and Sexual Violence (Wales) Act 2015, The Social Services and Wellbeing (Wales) 2014 Act and the Housing (Wales) Act 2014 all place prevention at the forefront. We are concerned that across Wales the implementation of these three Acts is not always joined up as an approach. There is a real opportunity to ensure that services work more closely together than at any previous point in time in Wales – and so we would hope that the

committee can consider how local authorities are implementing these three Acts in a joined-up way, so we can avoid duplication and inefficiency in the future.

Linked to this point is the need to shepherd through the Wellbeing of Future Generations (Wales) Act in a focused and practical way. This Act could represent one of the first overarching ways of coordinating services. Traditionally, departments as varied as education and health, for example, have not worked together as well as they could. With the Future Generations, work streams could be aligned to objectives under that Act. This relies on the implementation of the Act being relentlessly practical, with indicators that are both broad and achievable. We would recommend that the committee considers how the Future Generations work is being taken forward and what, if any, impact it could have on service collaboration and joint working.

The synergy between prudent healthcare[ii], Can and Can only, and wider community-led initiatives

We recognise the value of the practical intentions for all three of these approaches as outlined below.

Prudent Healthcare is healthcare that fits the needs and circumstances of patients and avoids wasteful care. It is the difference between GPs offering prescribed medication to deal with the immediate symptoms of a problem and in looking for the appropriate solution. We believe that one way, for example, that prudent healthcare can be met is through a GP offering 'social prescriptions' such as sensible service signposting, benefits advice and similar. We believe in the preventative power of prudent healthcare and its main objective of offering the most appropriate care, not the cheapest.

Prudent healthcare as an idea will stand or fall by the way in which public services work well together and so we feel that one of the priorities for this committee should be to consider how this idea works alongside other sectors and services. For example, with the *"Can and Can Only"* principle within the Social Services & Wellbeing (Wales) Act.

"Can and Can Only" aims to reduce the number of people on care and support plans by creating more opportunities for accessing preventative services. By seeing what care the family and the individual can provide for themselves and then offering support for the gaps which cannot be met, we believe the value of the model is that it enables the individual to live within a more person-focused and fulfilling network of care as opposed to being fit into a pre-structured care package. This meshes closely with the aims of *prudent healthcare* and it will work best when services are working together to deliver services and new approaches.

Community led initiatives need to be considered alongside the above approaches. It is community initiatives which will enable people to remain independent for longer, to take part in activities such

as sport and volunteering. Without community activity being led locally, both prudent healthcare and “can and can only” are bound to fail.

The next step we feel for the committee, is to look at ways to integrate these ways of working with each other – in a broad and flexible way. However the committee should also consider the third sector organisations which are already utilising these three initiatives, the successes of these organisations and how this is being negatively affected by the commissioning process.

Commissioning

Commissioning and retendering have thrown up many obstacles in the last year for organisations providing services in the third sector, making good practice increasingly difficult. We wish to see a system that revolutionises the relationship between commissioner and provider that has:

- A partnership approach, and not an “enforcement” approach – i.e, commissioners work with providers to establish a service that is affordable within current budgets, rather than being forced to commission services that are not sustainable, and then having to enforce strict terms when things go wrong;
- An honest approach that takes into account the costs of delivering services. The consultation document talks a great deal about what should be ended, what should be added, or what is best practice, but unfortunately does not talk a great deal about the funding for that. Naturally, none of our provider members would wish to use zero-hour contracts or to pay the minimum wage, but many are forced to do so by contracts.
- Clear guidance from Welsh Government that local authorities can be flexible in commissioning, and can take risks, enabling providers to seek innovative solutions that can ultimately save money.

We would ask the committee to look into new, less time consuming, more dynamic ways of commissioning to cut down the bureaucracy of the current commissioning system.

The voice of people being supported by services being heard

The positive experience and outcomes of people accessing organisations providing services should be at the centre of every service. There needs to be a recognition that it is extremely difficult to gather this experience without resources. It should be a priority of the committee to look at savings and cuts to management budgets, to see how this is affecting the ability of services to actively engage with people using services.

Conclusion

Wales has the ability to move to a highly integrated nation. The recent Acts by Welsh Government give frameworks through which services can be better joined up. The opportunity will be lost,

however, without clear direction on how to ensure the implementation of the various Acts *supports* integrated working. The Committee has a significant window of opportunity to inquire into the progress and to ensure these opportunities are not lost.

At Cymorth Cymru we are already working to raise awareness of these opportunities and would be happy to assist in any way we can.

ENDS

[i] Care Council for Wales' response to the requirements for action in the Older People Commissioner's Review: A Place to call Home? Page 4, paragraph 1.15
http://www.olderpeoplewales.com/Libraries/4_Residential_Care_Review_SB/CCW_OPC_Report_-_Care_Council_Response_08_07_2015.sflb.ashx

[ii] http://www.prudenthealthcare.org.uk/

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BMA

Cymru Wales

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Cymeithas Feddygol Prydain Cymru

Response from: BMA Cymru Wales

Prif weithredwr/Chief executive:
Keith Ward

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Registered as a Company limited by Guarantee. Registered No. 8848 England.
Registered office: BMA House, Tavistock Square, London, WC1H 9JP.
Listed as a Trade Union under the Trade Union and Labour Relations Act 1974.

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BMA

PRIORITIES FOR THE HEALTH, SOCIAL CARE AND SPORT COMMITTEE

Consultation by the National Assembly for Wales Health, Social Care and Sport Committee

Response from BMA Cymru Wales

2 September 2016

INTRODUCTION

BMA Cymru Wales is pleased to provide a response to the Health, Social Care and Sport Committee's call for suggestions as to what the priorities of the Committee should be during the Fifth Assembly.

The British Medical Association (BMA) is an independent professional association and trade union representing doctors and medical students from all branches of medicine all over the UK and supporting them to deliver the highest standards of patient care. We have a membership of over 160,000, which continues to grow every year. BMA Cymru Wales represents over 7,500 members in Wales from every branch of the medical profession.

RESPONSE

We would broadly agree that the areas the Committee has identified in its initial discussions, as possible areas for consideration, are all valid and important.

We do feel however that, for at least some of them, a significant amount of work has already been undertaken in considering these subject areas – and as part of that, in collecting views and evidence from key stakeholders. This volume of work, we would argue, has not however been matched by action or tangible change – resulting in an abundance of reports, recommendations and strategies but very little action or change visible 'at the front line'. This is especially the case on the subject of the NHS Wales workforce, and primary care – our evidence on these subjects will not differ widely from that given to other inquiries and consultations on these subjects conducted over the last few years, albeit our areas of concern may have deteriorated further in that time.

Our main observation in relation to this is that we are in danger of being in a state of perpetual evidence gathering, and that organisations will begin to suffer from consultation fatigue. Further, on many subject areas (GP workforce being one of them) there is a broad consensus on what needs to be done to improve on the status quo.

Whilst understanding that the Committee's role is to hold the Welsh Government to account and to examine legislation, we would urge the Committee to look at such subjects from a new perspective. Such an approach could be, for instance, to follow up on the reports and recommendations of previous inquiries – for instance the 2015 GP workforce inquiry by the previous Health and Social Care Committee (HSCC), but also on its own inquiries going forward. It would be a useful exercise to examine how many of the recommendations have been taken forward, and which ones the Committee feels are still valid – whether or not they were accepted by Welsh Government at the time of original publication. Examining the impact of any changes that have previously been introduced, and whether or not they have achieved the desired impact, including in terms of population outcomes, should also be undertaken as a first step before any new actions are considered.

It would therefore be worthwhile for the Committee to examine progress on recommendations that have previously been put forward and agreed in other external inquiries and reviews – such as the recent NHS Wales Workforce Review chaired by David Jenkins and progress against the commitments in the Welsh Government's workforce plan for primary care, '*A Planned Primary Care Workforce for Wales*'. We make this suggestion with the issue in mind that recruitment and retention are currently the key challenges for the NHS in Wales.

Below, we offer comments on the subject areas identified by the committee:

- ***Integration of Health and Social Care services*** – BMA Cymru Wales holds that collaborative cultures with shared values, good professional relationships and effective leadership are essential if integration is to get off the ground. As confirmed by doctors in our surveys, these elements are also vital to securing what should be the key measures of success of efforts to integrate – improved clinical outcomes and better patient experiences. Therefore the individual must be the organising principle for any changes. They key role that is played by the GP practice should also be considered.

  We do not believe that the full integration of health and social care (structures, budgets and staff) is absolutely necessary to produce genuine joint working and more coordinated care. We believe that coordination is best achieved by creating long-term stability across the NHS and local authorities and allowing integrated care to become a priority, not by further reorganisation. The Committee might therefore focus on good information sharing, and facilitating effective professional relationships across disciplines and organisations. It is often the case that frontline staff across organisations are hindered in working together as effectively as they might by organisational requirements, so it could also be helpful to look at how such barriers to integration can be addressed.

  The Committee might also wish to consider the inter-relationship between social care and health care provision and how an inadequacy of social care provision can lead to health services being overwhelmed. There is currently considerable variability of social care provision across Wales, with services having been substantially reduced in some localities, and this is leading to an increase in both avoidable hospital admissions and incidences of delayed discharge. To underpin the Welsh Government's often stated intention of delivering more health services within community settings, it might therefore be worth considering if enough is being done, and enough resource being provided, to support independent living and effective implementation of the Social Services and Well-being (Wales) Act 2014.

  Further information on our views on this subject area can be found within our evidence to the NHS Wales Workforce inquiry – here.

- ***Waiting Times*** – The focus of this work seems to be placed on finding solutions to the current pressures of meeting waiting time targets. This area would also offer the opportunity to look at the appropriateness of some targets, and consider where organisational or financial targets might better be replaced by clinically derived or outcome focused measures, including looking at whether some targets may inadvertently distort clinical priorities (e.g. prioritising first appointments with a consultant at the expense of follow-up appointments) and the merits of moving to a model that is better able to take on board the clinical needs of individual patients. The extent to which individual targets add value needs to be properly considered, including

whether or not they simply divert a proportion of activity towards ensuring they are met rather than towards improving care.

- ***Primary Care*** – This is an obvious priority area to consider and one where we have a wealth of expertise and policy to offer. The key areas to look at, we suggest, are: workforce (recruitment and retention, including GP training); workload pressures (including how the Welsh Government can address this to better support practices); finances into primary care (including looking at how a continual erosion in the proportion of NHS funding in Wales going to general practice can be addressed, and ensuring that when work is transferred from secondary to primary care this is matched by an appropriate transfer of resources); clusters and how they are both operating and delivering; and infrastructure (such as IT systems). It is worth noting that when looking at such areas, the whole practice team needs to be considered.

  The Committee might also wish to consider the extent to which progress is being made against the relevant recommendations of the report published earlier this year by the Organisation for Economic Cooperation and Development (OECD)[1] which compared the performance of the different health care systems in the UK. This could include looking at what action is being taken by the Welsh Government and local health boards to advance the OECD recommendations which called for primary care to be put 'front and centre', including by reserving a seat on every health board for a GP. Such action might help ensure that health boards have access to greater knowledge about what support they can provide in order to assist GP practices.

  As we have touched upon above, we think it is important that any work undertaken in this area should take account of how previous work by the former HSCC and existing Welsh Government strategies are being taken forward, rather than seeking to simply look at these aspects afresh.

  Further information on our views and suggestions in this area can be found in our strategy document for general practice, here, and our response to the HSCC inquiry into the GP workforce, here.

- ***Efficiency within the NHS and modern management practices*** – we would be wary of looking at this with a sole objective of identifying efficiency savings or suggesting other cost cutting measures. However, looking at instilling organisational learning and sharing of best practices would be extremely valuable – as well as looking at the appropriate use of resources as set out in the BMJ's 'too much medicine' work, for instance. This work could also consider whether we have the right balance between non-clinical and clinical management, including looking at the merits of better empowering effective clinical leadership. The inquiry could also be expanded to take on board many of the suggestions we previously put forward in our response last year to the Welsh Government's Green Paper, '*Our Health, Our Health Service*', here. These include looking at the culture within the NHS in Wales, to ensure that staff feel able to raise patient safety concerns knowing that these will not be ignored, and that they can raise such concerns without fear that they will suffer bullying, harassment or other adverse consequences as a result.

[1] *OECD Reviews of Health Care Quality: United Kingdom 2016. Raising Standards.* OECD (2016). Available at: http://www.oecd.org/unitedkingdom/oecd-reviews-of-health-care-quality-united-kingdom-2016-9789264239487-en.htm

- ***Neonatal services***; ***Use of antipsychotic medication in care homes; Ambulance Services –*** We would support these topics being looked at by the Committee as a follow-up to the previous work and consideration of them, and would be interested to have sight of any progress made. We are particularly interested in ongoing concerns about staffing and the sustainability of neonatal services in Wales.

- ***Loneliness and isolation amongst older people –*** whilst this is not an area where BMA Cymru Wales could make a comprehensive contribution we nonetheless recognise the significance of loneliness and isolation and its impact on health and wellbeing. A wider review of healthy aging in Wales might allow for consideration of an array of pertinent issues relating to physical and mental health and wellbeing of older people in Wales.

- ***Gambling addiction –*** this is an important area which we consider should be treated alongside measures for other addictions such as for smoking, alcohol, and substance abuse for instance. Gambling addiction is associated with a number of health problems and for health and social care professionals can be hard to detect.

- ***Sport and Public Health –*** obesity is a major public health concern. Sport and exercise may have a part to play in addressing the obesity epidemic, but they are only one element and need to be considered alongside other important factors such as high energy food promotion. We believe that this topic requires further thought, as currently as it is written it appears 'tagged on' just because sport is now within the committee's portfolio. We do, however, believe that looking at how our growing obesity epidemic can be more effectively tackled is an important topic for the Committee to consider. The recently publicised criticisms of the UK Government's strategy for childhood obesity might offer an opportunity for Wales to take a lead on this issue, albeit within those powers that are exercisable by the National Assembly. On the subject of sport, the committee could seek to capitalise on the momentum, enthusiasm and interest generated at the international level (from Euro 2016 and the Rio Olympics for instance) to look at a range of areas seeking to build exercise and healthy living into individuals everyday routines – for instance, how easy it is to access sporting activities and groups/classes, opportunities to exercise or to undertake leisure pursuits across Wales, options and access to active travel, for all age groups and abilities.

Below we offer suggestions for other topics which the committee might consider:

- ***Data collection –*** There are many areas where there is a paucity of data available compared to that available in England, including in relation to the NHS workforce in Wales. This might be an area the Committee would therefore wish to look into. Another area of concern is the current lack of collection and publication of meaningful data on workforce vacancies, with such data not having been routinely published in Wales since 2011. We have significant concerns that this hinders effective workforce planning. When data has been obtained since 2011 on vacancies amongst hospital consultants through the use of Freedom of Information (FoI) Act requests, the responses, despite showing worryingly high vacancy rates, would appear to significantly under-represent the true situation owing to the use by some health boards and trusts of what we would consider to be a flawed definition which means vacancies are only counted as such when an active process is underway to fill them. There is also a lack of consistency between health boards and trusts regarding how vacancy data is recorded, possibly as a result of it not being routinely published. The FoI responses also revealed that a variety of definitions of a vacancy are

currently in use.

- ***Occupational health/staff wellbeing –*** The Committee might wish to look into the current level of provision of occupational health services for NHS staff. Although it has recently been agreed that these services can be extended to cover primary care, something we fully support, we have concerns regarding how well resourced the current provisions is. We are aware, for instance, that a number of health boards have unfilled posts for occupational health consultants.

- ***Deprivation, inequalities and health –*** Recognising that education can be a major determinant of social wellbeing and health, this could include working with other relevant Assembly Committees to look at what action needs to be taken to improve the levels of literacy and numeracy in Wales, with a specific focus on health literacy.[2]

- ***Child health –*** The Committee might consider looking specifically at the topic of child health. The BMA's Board of Science has published a number of relevant reports which might guide the Committee's consideration of this topic including '*Growing up in the UK - ensuring a healthy future for our children*' in 2013, and '*Food for thought: promoting healthy diets among children and young people*' in 2015. The Committee might also which to look at following up on the inquiry undertaken in 2013 into childhood obesity by the Assembly's former Children and Young People Committee.

- **End of life care –** Throughout 2015, the BMA undertook a major project seeking views from our members and the public on their experiences, views and perceptions on end-of-life care and some aspects of physician-assisted dying. We found that there is significant variability in the type and quality of services provided, both within and between geographical areas, and also, sometimes, between conditions. We published the final report in three volumes; it makes recommendations for governments; for providers of education and training; for doctors; and for healthcare providers. All of the reports and more information about the project can be found at: www.bma.org.uk/endoflifecare.

[2] Health literacy can be defined as 'the personal characteristics and social resources needed for individuals and communities to access, understand, appraise and use information and services to make decisions about health.' (WHO, 2015).

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Cymdeithas Fferyllol Frenhinol

Response from: Royal Pharmaceutical Society

Patron: Her Majesty The Queen Chief Executive: Helen Gordon Member Enquiries T 0845 257 2570 E support@rpharms.com

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Health, Social Care and Sport Committee
National Assembly for Wales
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31st August 2016

Dear Sir / Madam

Priorities for the Health, Social Care and Sport Committee

The Royal Pharmaceutical Society (RPS) Wales welcomes the opportunity to respond to the consultation into the priorities for the Health, Social Care and Sport Committee in the 5th Assembly.

Over the next 12 to 18 months we consider that the following should be a priority for the committee:

1. Long term and chronic conditions management

With a growing and ageing demographic in Wales, the demands on the NHS from long term and chronic conditions is projected to increase by around 181,000 or 32 per cent between 2010 and 2026[1]. As well as affecting an individual's health, there can be associated wider social and economic challenges for the individual along with implications for family members, who may be providing care for a loved one.

People with a long term condition (LTC) are twice as likely to be admitted to hospital as a patient without such a condition[2]. This indicates a failure to effectively manage LTCs in the community and closer to people's homes. Not only is this distressing for the patients but puts unnecessary and avoidable pressure on secondary care resources.

The development of 64 cluster networks, provides new opportunities to think differently about how health and social care is delivered. Ensuring increased multidisciplinary working along with effective sharing of information and resources between healthcare professionals within clusters will help to maximise the access to and the quality of primary care to deliver improved local health and wellbeing therefore contributing to a reduction in health inequalities.

[1] Welsh Government, Local Authority Population Projections for Wales, 2011-based Variant Projections (SDR 165/2013), 2013

[2] Wales Audit Office. 2014. The Management of Chronic Conditions in Wales – An Update.

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The RPS strongly believes that better utilisation of the clinical expertise of the pharmacist will have a positive impact on care and outcomes for patients with LTCs. The diverse skills within the whole pharmacy team can support people throughout their whole care journey, from maintaining good health through to intensive coaching and medicines advice. Full utilisation of the pharmacy workforce will enable resources to be used more efficiently to deliver the standard and level of care that patients deserve. Pharmacists can work in partnership with healthcare colleagues and can make an immediate difference, for example by freeing up the time of GPs to manage more complex or demanding cases.

As it is predicted that the cohort of people with chronic conditions will increase significantly in the future, we recommend a review of the services available to support people with chronic conditions, ensuring they are fit for purpose now and in the future in Wales.

2. Enabling better communication by utilising IT

Harnessing the benefits of new technologies must be a priority for NHS Wales to help transform healthcare delivery in all settings. We believe the use of IT to enable appropriate access for health and social care professionals to a single patient record is critical and is one key area where a quicker pace of transformation is needed.

Each healthcare professional will record important information about a patient's care on separate records. Currently, as these records are not joined-up or integrated, they cannot be accessed by other healthcare professionals. We advocate that a single patient record would overcome the current barriers and delays to health care that result from poor information exchange between professions. A single accessible record would importantly enable more informed and safer health decisions to be made by practitioners and patients at the point of care.

RPS Wales recommends that one single patient health record is necessary where all essential information is stored for the individual. All registered health and social care professionals involved in the patient journey must have appropriate access to the patient health record with the patient or their designated carer's explicit consent.

Access to the patient health record will allow pharmacists to make more informed clinical decisions, in partnership with patients and other health and social care professionals, about the pharmaceutical care that patients receive. It will support improvement in the treatment of individual patients and help the NHS to maximise the value of the significant investment it makes in medicines.

3. Mental health and reducing the inappropriate use of antipsychotic medication

People with mental health needs must be able to access support and treatment in a timely way and with dignity, just as a person presenting with physical health needs would be. Appropriate use of medicines to support the patients with mental health needs is essential. The RPS is concerned by reports of inappropriate use of medicines, for example unjustified use of antipsychotic medications in individuals with dementia.

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There are 850,000 people living with dementia in the UK and this is forecast to increase to over a million by 2025[3]. Often dementia begins with short-term memory loss and can lead to changes in the way people think, speak and do things. Antipsychotic medicines are used for some types of mental distress or disorders. There are increased risks of harm from prescribing these medicines in patients with dementia and they are often inappropriately prescribed to alleviate the symptoms of Behavioral and psychological symptoms of dementia (BPSD). Only one antipsychotic medicine is licensed for treatment of BPSD in certain circumstances in the UK.

Multidisciplinary team input including the utilisation of a clinical pharmacist would benefit patients through the elimination of potentially inappropriate prescribing and optimising patient care.

4. Care for older people including care homes and domiciliary provision

All individuals living in a care home must feel safe, supported and encouraged to maintain as much independence as possible. There is a great deal of good care and support available to individuals living in care homes and inspiring examples of current good working practice across Wales. These are acknowledged in RPS Wales' recent policy document, Improving Medicines Use for Care Home Residents, and it is important that we can learn from these good examples. Recent reports however have revealed pockets of poor standards and unacceptable practice which need urgent attention.

Care home residents, as well as older people living in their own homes, may be less likely to have direct contact with a pharmacist or a GP themselves. It is critical that those individuals should still expect to receive primary care services including information on their medicines (addressing polypharmacy). The same principle applies for access to other services such as the influenza vaccine or advice on giving up smoking.

There is evidence that unintentional changes to medications are occurring during transfer of care when a patient moves from one care setting to another. These discrepancies have the potential to cause harm. Better communication and appropriate sharing of information will help to assure safe and effective transfers of care and minimise the risk of medicine related harm.

RPS Wales' recommendations for improving the use of medicines for care home residents can be accessed at;
http://www.rpharms.com/wales-pdfs/improving-medicines-use-for-care-home-residents-(wales).pdf
This policy addresses issues highlighted by a number of recent reports, in particular those raised by the independent voice and champion for older people across Wales, the Older Peoples Commissioner for Wales in the report A Place to Call Home.

[3] Alzheimer's Society. 2015. Statistics. Available at: https://www.alzheimers.org.uk/statistics. (Last Accessed: January 19 2016)

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I trust this helps to outline the issues we believe are important and require further exploration by the Committee.

RPS Wales look forward to working with the new Health, Social Care and Sports Committee on these and many other issues over the next 5years. Please do not hesitate to get in touch if you require any further information.

Yours sincerely

Suzanne Scott-Thomas, Chair, Welsh Pharmacy Board

The Royal Pharmaceutical Society (RPS) is the professional body for pharmacists in Great Britain. We represent all sectors of pharmacy in Great Britain and we lead and support the development of the pharmacy profession including the advancement of science, practice, education and knowledge in pharmacy. In addition, we promote the profession's policies and views to a range of external stakeholders in a number of different forums.

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Cymdeithas Seicolegol Prydain

Response from: The British Psychological Society

The British Psychological Society
Promoting excellence in psychology

National Assembly for Wales
Health, Social Care and Sport Committee
Consultation on the Forward Work Programme

The British Psychological Society Wales welcomes the opportunity to comment on the Forward Work Programme of the Health, Social Care and Sport Committee.

Areas identified by the Committee

The BPS welcomes the areas the Committee has identified that may be included in its longer-term work programme. In particular, the BPS supports the following:

- Waiting Times

The BPS agrees with the identification of this as an area for the Committee to examine. The inclusion of mental health services in this inquiry is most welcome and the BPS would also hope to see the Committee use this inquiry to examine outcomes alongside a focus on high waiting times and pressures in the system.

- Use of anti-psychotic medication in care homes

The BPS strongly agrees with the identification of this area for the Committee to examine. The use of anti-psychotic medication for those with dementia is an issue that demands urgent attention. The BPS very much welcomes the Committee's intent to examine this area and the solutions that exist to reduce the use of this medication.

- Sport and Public Health

The BPS agrees this is an area that requires scrutiny. The BPS would also like to see a distinct focus on behaviour change and what behaviour change techniques can be deployed to promote and sustain increased levels of participation in sport and physical activity.

Additional areas to consider

In addition to the areas identified by the Committee, the BPS would also like the Committee to examine the following areas:

- Dementia

The BPS would like to see a broader inquiry on dementia as a follow-up to the inquiry on the use of anti-psychotic medication in care homes. This wider inquiry could focus on:

- Access to timely psychological assessment
- The involvement of people with dementia in their care planning
- The level of involvement of family and carers in care planning
- The level of ongoing psychological support available to those with dementia, their families and carers

- Obesity

As a follow-up to the Committee's examination of sport and public health, the BPS would like to see an inquiry on obesity more broadly and the psychological interventions that can be deployed to address the challenges of overweight and obesity and the long-term sustainability of interventions.

- Suicide and self-harm prevention

The BPS would welcome an inquiry into suicide and self-harm prevention. The suicide rate in Wales is rising, particularly among certain age and gender cohorts and the reasons for this and actions to address them should be examined in greater detail.

- Prevention approach in public health

The BPS would also welcome an inquiry examining the prevention approach in public health. This would explore risky health behaviours as well as sub-optimal condition management by those with long term health conditions. The inquiry could consider approaches that exist to reduce risky health behaviours and improve condition management and how they can be brought to scale quickly and efficiently.

- Brain injury and neuro-disabilities in the criminal justice system

The BPS would welcome an inquiry into the prevalence of brain injury and neuro-disabilities among those who come into contact with the criminal justice system or who are in prison. The inquiry would also consider the health screening and rehabilitation approaches that can be deployed to improve offender outcomes.

Further Information

The British Psychological Society in Wales would be pleased to provide the relevant evidence base to support and expand upon the areas identified above. The BPS would also be pleased to identify lead academics and practitioners from across its membership to further advise on these priorities and how they may be implemented. Please contact Tanja Siggs – [redacted]

About the British Psychological Society in Wales

The British Psychological Society, incorporated by Royal Charter, is the learned and professional body for psychologists in the United Kingdom. We are a registered charity with a total membership of over 53,000. The Society has over 2000 members in Wales.

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Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Gofal Arthritis
Response from: Arthritis Care

Health, Social Care and Sport Committee
Forward Work Programme – submission from Arthritis Care Wales
2 September 2016

GOFAL ARTHRITIS
ARTHRITIS CARE

Introduction

This submission is in response to the Health, Social Care and Sport Committee (HSSSC) request for external organisations to help inform its Forward Work Programme.

We would like to recommend that the HSSSC look at arthritis related health care issues in Wales and opportunities to reduce the impact of the condition on individuals, families, communities and the wider economy.

Arthritis – a 21st century health care priority for Wales

> *With Wales's ageing population and the rise in obesity levels, the prevalence of arthritis is set to grow. It is estimated that 2010 prevalence levels will increase by 50% by 2030[1].*

Arthritis can strike at any age. An estimated 480,000 people in Wales live with the condition, 10 million across the UK. Living with arthritis can mean experiencing pain day in, day out. It can mean waking to pain in the morning and falling asleep in pain at night. Arthritis can impact on all aspects of a person's life – from being able to perform activities of daily living that we otherwise take for granted, such as getting dressed or making a cup of tea, to family and social life as well as employment.

Pain is not visible; therefore, arthritis is often a hidden condition.

The tremendous impact of arthritis isn't restricted to individuals and their families. Arthritis is a leading cause of disability and work absence in Wales and has a huge impact on the NHS, social services and the wider economy. Musculoskeletal conditions account for 30% of GP consultations[2] and 42% of reported cases of work-related ill health[3].

> *'It's the forgotten condition that no one thinks is important. It affects everything. It's exhausting, depressing and makes you feel angry and frustrated. It robs you of the life you thought you were going to have, the one you planned with your family… You can't do what you want, when you want, it's unpredictable. Life has to be adapted and constantly changed. It becomes important not to look back at what is lost and make an effort every day to look forward and think positively.'*
>
> Arthritis Care survey respondee

Arthritis key facts

- Arthritis can strike at any age. An estimated 15,000 children live with arthritis in the UK[4].

[1] http://www.publications.parliament.uk/pa/ld201213/ldselect/ldpublic/140/140.pdf
[2] Musculoskeletal Services Framework. Department of Health (2006)
[3] Health and Safety Executive (2013/4). Health and Safety Statistics. Annual Report for Great Britain. http://www.hse.gov.uk/statistics/overall/hssh1314.pdf?ebull=stats/oct=14&cr03
[4] Sacks J et al. (2007). Prevalence of and annual ambulatory health care visits for pediatric arthritis and other rheumatologic conditions in the United States in 2001-2004. Arthritis Rheum 2007; 57(8):1439-45.

- The condition is a leading cause of pain, disability and work loss with 480,000 people living with the condition in Wales.
- There are over 200 types of arthritis, including osteoarthritis, rheumatoid arthritis, ankylosing spondylitis, Lupus and Gout.
- Arthritis conditions vary widely, but many share common symptoms such as pain, inflammation and joint stiffness. These symptoms often impact on mobility and dexterity. Many types of arthritis also cause significant fatigue.
- Arthritis can have an impact on all aspects of a person's life – from day to day activities and access to independence to family and social life to work life.
- A recent survey from Arthritis Care found that 44% of people waited over a year to seek help for arthritis.
- In a recent survey, 71% of people with osteoarthritis stated that they are in constant pain. 87% were concerned about maintaining their independence in the future due to their condition.

Arthritis – the challenges

We have highlighted below a number of the current health policy and service challenges impacting on people with arthritis in Wales.

Prevention
Arthritis is not unavoidable. Increasing physical activity and maintaining a healthy body weight can impact on a person's chances of developing a musculoskeletal condition. The numbers of people living with arthritis is set to increase, however future prevalence can be influenced by policies and behaviour now. Increasing physical exercise and keeping a healthy body weight can significantly reduce the chances of an individual developing osteoarthritis – the most common form of arthritis. For those already living with arthritis, exercise and achieving a good body weight can reduce the impact of the condition at every stage of the disease. Obese people are more than twice as likely to develop knee osteoarthritis than those of normal body weight[5].

> *More than two out of three knee replacements and one in four hip replacements in middle-aged women in the UK are attributable to obesity*[6]

Arthritis Care believes that public health initiatives that work to increase activity and participation in exercise and sport should be a priority for the Fifth Assembly. In addition, we believe there is scope to further highlight the link between exercise and healthy body weight and healthy bones and joints in the future. That message is needed as a primary prevention approach for the wider population to tackle future prevalence levels of arthritis and as secondary prevention for people already with arthritis to limit its impact. We need a robust public health approach to musculoskeletal health in Wales.

Orthopaedic services
We believe it is vital that current waiting times for elective orthopaedic services in Wales are reduced. We believe this should be one of the highest health priorities of the Fifth Assembly. Longer waiting times for a joint replacement can have a devastating impact on an individual, their quality of

[5] Blagojevic M et al. (2010). Risk factors for onset of osteoarthritis of the knee in older adults: a systematic review and meta-analysis. Osteoarthritis Cartilage 18 (1):24-33.
[6] Liu B et al. (2007) Relationship of height, weight and body mass index to the risk of hip and knee replacements in middle aged women. Rheumatology (Oxford) 46(5): 861-867

life and life circumstances. An estimated 91% of primary hip replacements and 97% of primary knee replacements are due to osteoarthritis.[7]

Rheumatology services

For people with a suspected inflammatory arthritis such as rheumatoid arthritis, early referral and assessment by rheumatology services is vital in reducing the impact of the condition long term. However, many people are experiencing waiting times that fall outside established standards. The British Society for Rheumatology's Clinical Audit of Rheumatology Services in England and Wales in 2016 found that compliance with relevant NICE Quality Standard 2[8] – ability to see patients in rheumatology within 3 weeks of referral was at 22% in Wales[9] (down from 28% in 2015[10]). Those Wales figures are lower than any region of England.

Paediatric rheumatology – services for children with arthritis

Despite its population size, Wales does not have a dedicated multidisciplinary paediatric rheumatology service. With the lack of current provision, many children are travelling to hospitals in England to access services. Arthritis can have a significant impact on many aspects of a child's life, including continuity in education and social and peer group integration. Minimising the impact of arthritis is vital for a child's development. We believe that the population size of South Wales requires the establishment of a dedicated multidisciplinary paediatric rheumatology service.

Promoting supported self-management

Arthritis Care has been at the forefront of the movement to promote supported self-management for people with chronic long term medical conditions. Self-management support enables people to better manage their health condition on a day to day basis – it can take the form of referrals to third sector services, mentoring, peer support, access to publications, helplines, training and signposting. Examples of self-management activities include taking up exercise, improving diet, losing weight, goal setting and using techniques to manage pain. People with arthritis can play a pivotal role in managing their condition and stopping it from managing them. Despite this, many people with arthritis are not aware of the difference they can make in managing their condition and many people are not referred to services such as those provided by Arthritis Care.

Many people with arthritis are coping with the daily pain of arthritis with pain killers alone when so much more can be done to limit the impact of the condition. People with arthritis should be supported to be fully involved in their health care and should be offered a personalised care plan, yet too often people go without such plans.

> *'24% of those with a limiting long-term illness said they had a personal care plan. 88% of those who had a personal care plan agreed that it helped them take care of their health and well-being'*[11]

[7] National Joint Registry for England, Wales and Northern Ireland (2014), 11th Annual Report
[8] https://www.nice.org.uk/guidance/cg79
[9] http://www.rheumatology.org.uk/resources/audits/annual_report/second_annual_report.aspx
[10] http://www.rheumatology.org.uk/includes/documents/cm_docs/2016/b/bsr_hqip_report.pdf
[11] National Survey for Wales April 2014 – March 2016. Published Feb 2016. http://gov.wales/docs/statistics/2015/150914-national-survey-wales-2014-15-headline-results-revised-en.pdf

Policy Issues for the Fifth Assembly

A decade ago, Arthritis Care led a successful campaign for the Welsh Government to develop Europe's first national arthritis strategy[12]. The government in England followed Wales' lead and developed its own musculoskeletal strategy. Subsequently, a national Clinical Director for Musculoskeletal Services in England was recruited to drive up standards and promote good practice. No similar role exists in NHS Wales.

Despite Wales' lead a decade ago, there is still much work required to improve health care services for people with arthritis in Wales. Since the strategy, guidelines have been developed by NICE to inform best practices in health care for people with many forms of arthritis including the most common forms, Osteoarthritis[13] and Rheumatoid Arthritis[14]. Additional Standards of Care have been developed by ARMA[15]. Arthritis Care has been calling for the Welsh Government to develop an updated Action Plan to improve arthritis and musculoskeletal health care services in Wales informed by recent standards and guidelines and that fits with the current NHS structure and policy context. Recent Health Ministers have stated that work to align its Arthritis Directives with Prudent Healthcare will be undertaken by officials[16]. We are keen to see this work taken forward as soon as possible.

Arthritis Care wishes to work constructively with all stakeholders to drive forward health care standards for people with arthritis in Wales. To support the development of an updated action plan, we are currently working to establish a new Arthritis Alliance Cymru, with key stakeholders from across Wales, including representatives from key health professional groups and voluntary organisations.

About Arthritis Care Wales

We are the leading voluntary organisation working with and for people with arthritis in Wales. People with arthritis are at the heart of our work: they form our membership, are involved in all of our activities and direct what we do. We believe that people with arthritis are entitled to receive the best possible treatment and support, and to have their voice heard in decisions affecting their health and well-being.

Our central aim is to help people get their lives back, increasing their independence and improving their health and wellbeing. We do so through a range of services via helplines, including 'The Source' for young people; online forums; award winning publications; community information points; campaigning; peer support and local groups. We have most recently launched a 'Get Active for Arthritis' project in North Wales.

[12] Service Development and Commissioning Directives, Arthritis and Chronic Musculoskeletal Conditions, 2007 http://gov.wales/docs/dhss/publications/130902arthritisen.pdf
[13] https://www.nice.org.uk/guidance/qs87
[14] https://www.nice.org.uk/guidance/qs33
[15] http://arma.uk.net/resources/standards-of-care/
[16] WAQ70019, WAQ70021, WAQ70022, WAQ70023. WAQ70325, WAQ70325.

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Fforwm Gofal Cymru

Response from: Care Forum Wales

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Consultation response –
Priorities for Health, Social Care & Sport Committee

Care Forum Wales welcomes the opportunity to help identify the key priorities and issues facing the Health and Social Care Sector. We are a membership organisation for Health and Social Care Providers in Wales representing over 450.

We particularly welcome the inquiry on Health and Social Care workforce to which we will be providing a separate response, but in broad terms, we will be highlighting:

- The effect of commissioning practice on the terms and conditions of the workforce;
- Appropriate pay and terms and conditions and career structure and in particular how to increase them when around 70% of direct costs relate to staffing and income is dependent on public funding;
- improving NHS commissioning of pre-placement training for nurses within the independent sector;
- reducing the impact of nurse shortages through delegation of nursing tasks in appropriate circumstances;
- improved access to training for social care workers aged over 25.

There are wider challenges faced by the health and social care sector that we would like to see covered in the Committee's forward work programme, although some of these could perhaps be incorporated into the proposed inquiry into the integration of health and social care, were it to take a partnership-based approach and include services commissioned and not just directly provided by the statutory sector:

- the demographic challenges to be met by health and social care provision;
- commissioning and inspection to meet the ideas and values of the Social Services and Wellbeing Act (Wales) and the working of Regional Partnership Boards

We would also expect the committee to consider secondary legislation to be issued under the Regulation and Inspection of Social Care (Wales) Act, which could have a significant effect on the health and social care sector dependent on the changes made.

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As regards the additional proposed inquiries, we would offer the following thoughts on those aspects that most affect our members:

- Primary care – the inquiry should ensure that residents in care homes have equal access to primary care services with other citizens, as highlighted by the Older People's Commissioner and promised by the previous Health Minister.

- Efficiency within the NHS – independent providers can provide care to keep people out of hospital either in care homes or in their own home and can be used as step up / step down / re-ablement facilities. In order to work most efficiently providers need to be recognised as partners. We would also like to see more innovative work such as using care homes as community assets to deliver clinics etc. where premises are not available and using down-time between busy home care periods to provide additional services such as falls prevention.

- Over prescription of anti-psychotic medication – we would suggest that the focus of the inquiry needs to be on when anti-psychotic medication is necessary and what other solutions there are for dealing with behaviour that challenges. We would be happy to share experiences from the sector in implementing such approaches.

- Ambulance Services – we could provide information on the factors leading to ambulance call outs by care homes and suggestions about how to reduce the number.

- Loneliness and isolation – we could offer information on the role of the care sector in combatting this in terms of both the role of care homes, including for example as day centres and the provision of support with care at home visits. The success of Monmouthshire County Council's Raglan Project shows that wider social wellbeing outcomes can be met through more imaginative use of resources but also require a change in the approach to commissioning.

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Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Bwrdd Cynghori Coleg Brenhinol yr Anesthetyddion yng Nghymru
Response from: Royal College of Anaesthetists Advisory Board

Response from the Royal College of Anaesthetist's(RCoA) Advisory Board in Wales / National Specialist Advisory Committee (NSAG) to the Consultation on the Priorities for the Health, Social Care and Sport Committee of the National Assembly for Wales

1. A request for responses was sent to all the committee members of the Anaesthetic NSAG / RCoA's Advisory Board in Wales to disseminate in their departments /groups and to report back to the vice-chair by 21 August 2016.
2. It is disappointing that this consultation had to take place over the summer holidays in order to meet the deadline of 2 September 2016. As a consequence we have received a small amount of responses.
3. Responses can be divided into: Maternity services & The South Wales Plan, Funding & Privatisation, Recruitment&Retention of qualified staff and The Health of our Patient Population.
4. A significant amount of resource had gone into the South Wales Programme (SWP)during the fourth assembly, with very little to show for it. The uncertainty created by the SWP is still detrimental to many. The delays caused by this process have got the potential to put our patient's health and wellbeing at risk. Without clear guidance and financial support it is impossible for health boards to prepare and be ready to provide patients with the care they may need.
5. Similarly in North Wales there has been a catalogue of reviews of a variety of services from which no discernible change has ever occurred. The fear & political risks associated with any major change just appears to overwhelm & the cry for world class services on everybody's doorstep becomes too loud. The situation with 3 DGH`s across North Wales is almost certainly 1 that would not be considered if commencing from a "blank canvas" position. Therefore a long term view is required to ultimately achieve a sustainable position.
6. An area of particular concern for the Obstetric Anaesthetist in Cardiff is the increase in their patient population, excluding the reconfiguration and problems of the SWP. They are frequently in the situation where there are not enough beds to accommodate women in labour. There also still remains a significant burden on our Obstetric and Neonatal colleagues due to the lack of neonatal cots.
7. Following the vote to leave the European Union there is a fear that cuts are going to be made to Heath care and reassurance is sought that at the very least there will be no real term decrease in per capita spending. With this in mind concerns have also been raised about privatisation of the NHS.
8. With regards to sustainability of the NHS the suggestion was made that a system approach may need to be adopted to achieve higher levels of efficiency and reliability. This includes the much wider use of protocols, guidelines, algorithms and

computer programmes. The suggestion is that these can be delivered by staff with less training and therefore be more effective.

9. We appreciate that the main focus at present is on recruiting in primary care. Our problem in secondary and tertiary care does not only include medical personnel. We have problems recruiting nurses, midwives and operating department practitioners (ODP's). It is therefore felt that there should be more focus on incentives to recruit and retain all forms of staff in Wales.
10. There is a feeling that with limited resource more focus should be placed on patient's life style related issues and healthy living. All patients should be encouraged to drink within moderation, eat healthy and not to smoke; it is felt to be unfair to impose blanket punitive measures and that it would be better to target individual access to heath care provision. Simplified labelling of food content will enable more people to understand what they are eating and may encourage healthier eating.

Dr A.D. Theron

Vice Chair Royal College of Anaesthetists Advisory Board in Wales/ NSAG

August 2016

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Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Coleg Brenhinol y Seicatryddion
Response from: Royal College of Psychiatrists

Royal College of Psychiatrists in Wales

Consultation Response

DATE:	**5 September 2016**
RESPONSE OF:	**THE ROYAL COLLEGE OF PSYCHIATRISTS in WALES**
RESPONSE TO:	**The Health, Social Care and Sport Committee Future Programme for the Fifth Assembly**

The Royal College of Psychiatrists is the professional medical body responsible for supporting psychiatrists throughout their careers, from training through to retirement, and in setting and raising standards of psychiatry in the United Kingdom.

The College aims to improve the outcomes of people with mental illness, and the mental health of individuals, their families and communities. In order to achieve this, the College sets standards and promotes excellence in psychiatry; leads, represents and supports psychiatrists; improves the scientific understanding of mental illness; works with and advocates for patients, carers and their organisations. Nationally and internationally, the College has a vital role in representing the expertise of the psychiatric profession to governments and other agencies.

RCPsych in Wales is an arm of the Central College, representing over 550 Consultant and Trainee Psychiatrists working in Wales.

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Dr. Dai Lloyd AM,
Health, Social Care & Sport Committee,
National Assembly for Wales,
Cardiff,
CF99 1NA

5 September 2016

Dear Dr Lloyd, AM

Re: The Health, Social Care and Sport Committee Future Programme for the Fifth Assembly

Thank you for giving us the opportunity to comment on the Committee's proposed forward work plan for 2016-2017.

We are pleased that the Committee has prioritised areas that directly relate to mental illness, specifically work on gambling addiction, isolation and loneliness in the elderly, and the use of antipsychotic medication in care homes. The College in Wales considers these as high priority areas and we therefore strongly support the Committee including these in their forward work programme.

The other areas proposed are also important and commendable. If any of these are to be included in the forward work programme, we would strongly suggest that the work include a mental health aspect. Mental health and physical health are inextricably linked.

We provide detailed comments overleaf.

Yours Sincerely,

Professor Keith Lloyd

Chair, Royal College of Psychiatrists

Integration of health and social care services

This is a very important area for the College and other health and social care organisations, and it is one which all political parties have pledged to address. Plaid and Labour have begun to conduct a parliamentary style review into integration of health and social care. It is unclear to us at this point what shape this Review will take or how it would tie in to work of the Committee.

If the Committee were to proceed with this piece of work, it would have to be clear on what it means by 'integration'. Would it include integration within health and social care; for example between primary, secondary and tertiary services? Being clear on the definition could narrow the scope of what is potentially a large-scale project.

Mental health services rely on multidisciplinary working and as such can be seen as the forefront of integration. We use the Whole Systems Approach in planning and delivering care, in hospitals but largely in the community, to achieve patient-centred care. Mental Health service models involve multi-disciplinary teams covering a range of services in social services, education, and health and the level of success of the service provided is often dependent on how well it is integrated.

A model that is structured on integration can still be broken if it is not supported by individuals. It is therefore important not to just look at policies and legislation but to focus on cultural environments than enable integration.

Waiting Times

Waiting times are generally longer in Wales than in other UK countries so we believe that the Committee should examine this issue to understand why this is the case. RCPsych in Wales is particularly concerned around waiting times for psychiatric appointments in CMHTs and the availability of psychological therapies, timely ASD diagnoses, and appropriate referrals to CAMHS.

It is important that the Committee focuses on quality of care alongside the length of waiting times and how or if Welsh Government is meeting its targets.

Efficiency within the NHS and modern management practices

We questions whether this could form part of the forward work programme of the Assembly's Public Accounts Committee.

Although not directly connected, the HSCS Committee could scrutinise the success of Welsh Government's Prudent Healthcare agenda of co-production, treating those with greatest need first, do only what is necessary, and reduce inappropriate variation.

Neonatal services

We question whether it would seem sensible for the current CYPE Committee to undertake this review.

Use of antipsychotic medication in care homes

RCPsych in Wales has called for a cycle of national and a local audits of prescribing antipsychotics in care homes to patients with dementia to improve clinical practice. We have worked closely with the Commissioner on this issue and we are in partnership with

the Royal Pharmaceutical Society in Wales, campaigning for an end to routine prescribing and a reduction in the time and dosage where antipsychotics are required.

The use of antipsychotics results in a number of side effects, such as drowsiness, nausea and constipation. The longer term use of antipsychotics increases the risk of fatal conditions such as stroke.

The College would ask the Committee to focus on the use of *inappropriate* prescribing of antipsychotics. This fits into the Government's Prudent Healthcare Agenda.

Ambulance Services

We welcome the new clinical model for measuring Ambulance services with a focus on quality and not just the speed of delivery. If the Committee were to examine this area, we would like it to focus on ambulance responses to those patients with dementia. We worry that the ambulance services may be reluctant to transfer patients who lack capacity to A&E, hospital wards or care homes. Section 6 of the Mental Capacity Act states that they are allowed to do so, including the use of appropriate force. There are also concerns that sometimes section 135 of Mental Health Act is used inappropriately to transfer those patients without capacity

Loneliness and isolation among older people

According to Age Concern Cymru, 75,000 over-65s in Wales describe themselves as 'always or often lonely', equating to nearly half of the elderly population. The Committee is right to consider this area for further investigation as studies show that isolation and loneliness have a significant impact on a person's health and wellbeing. Recent studies have shown loneliness to have twice the health impact as obesity, and can cause premature death in older people by up to 14%.[1]

If the Committee were to examine this area, we would like it to look at the connection between isolation and alcohol misuse. In recent years, we have seen an increase in the number of elderly people drinking above 'safe limits' (20% in men and 10% in women). Boredom, isolation, loneliness, bereavement, retirement, depression are psychosocial factors that are associated with the onset of alcohol misuse. If the Committee decides to look further into the area of loneliness and isolation in the elderly, we would suggest including the growing trend of elderly people and excessive drinking.

Gambling addiction

We are very pleased to see that this issue has made the list of Committee proposals. There needs to be a better understanding of problem gambling and more funding in treating those who suffer with this addiction. People with gambling problems will only seek help when they reach the point of crisis, or if they are seeking help for alcohol or drug addictions. Most will go untreated.

Given the ease of gambling in today's culture, we are unprepared to treat those who are predisposed to problem gambling. The repercussions of problem gambling are serious for the individual and their families. We must treat problem gambling as any other addiction and begin to tackle the stigma attached to it.

[1] Presentation by John Cacioppo, Professor of Psychology at the University of Chicago to the American Association for the Advancement of Science (February 2014).

We must also makes steps to understand the seriousness and scale of the problem. There is a lack of data on the prevalence of problem gambling. The gambling industry is the main provider of treatments for those with serious addiction and they do not divulge the scale of the problem. It is unclear how many are affected or in need of treatment. There is only one NHS Treatment service for gamblers, which is part funded by the Responsible Gambling Authority.

A Committee inquiry into gambling may begin to address these issues. There has, to date, been only one debate in the Assembly around gambling and we feel much more attention needs to be given to this area.

Sport and public health

It is clear that regular exercise improves a person's health and wellbeing. The Committee needs to examine why, despite overwhelming evidence, we are still struggling as a nation to become healthier.

We also know that a number of factors play a part, such as disability, physical and/or mental illness, chronic pain, and so on. For example, a recent international study into psychosis and activity shows that men with psychosis are twice as likely as those without the illness to miss global activity targets. The reasons for this are often due to impairments associated with the illness, such as depression, chronic pain, cognitive impairments and mobility problems.[2] For many with a learning disability it is often a case of access.

Also, those less likely to exercise are females, the elderly, and those in deprived areas. For some, physical activity is not seen as a priority or there isn't enough time for exercise.

Promotional messages must be tailored to address a variety of groups and these messages must be appropriately targeted. We must avoid developing a single message that is designed to address the population as a whole.

RCPsych in Wales would like to recommend other areas which the Committee may wish to examine either now or during the Assembly's 5th term:

Learning Disabilities and healthcare provision

People with learning disabilities are often predisposed to certain physical and mental illnesses. There is a much higher prevalence of a range of diagnosed psychiatric disorder in people with a learning disability compared with those without. They are also more likely to experience health inequalities and suffer from poor physical health. Once in the healthcare system, many will face barriers to receiving good care, such as difficulties in communication, diagnostic overshadowing, challenging behaviour, attitudes among professionals, and poorly developed links between specialist learning disability and general hospital services.

There is no baseline audit on learning disabilities in Wales. Professor Dame Sue Bailey, a world renowned Child Forensic Psychiatrist, past president of the Royal College of Psychiatrists and current President of the Academy of Medical Royal Colleges, said at the Faculty meeting in Wales, "Having a baseline audit puts you on the map; it says that you actually matter".

[2] http://schizophreniabulletin.oxfordjournals.org/content/early/2016/08/19/schbul.sbw111.abstract

The Committee could look in to specific issues around the Learning Disability Strategy for Wales (1983) and why this has been updated only piecemeal over the years, despite a shift from treatments in institutional settings to community-based services.

Eating Disorders and Disordered Eating

The current level of service provision for people with eating disorders is inadequate and cannot appropriately address the psychiatric and psychological needs of the population.

Eating disorders are on the increase in the population and expansion of Welsh universities brings at risk population of young adults creating additional pressures on eating disorder services and CMHTs.

Patients with the most severe cases who require hospitalisation are transferred out of area to the NHS and increasingly to private clinics in Bristol, Marlborough, or London where they can stay for up to one year. Teams have to deal with multiple care providers and lack of continuation of care. As a result of commissioning services for local populations in England, Welsh patients have to wait for beds for up to several months.

Tragically, those most likely to be affected by eating disorders are young adults. There is a common misconception that, because many are young girls, the disorder is brought on through vanity. The reality is that most people with an eating disorder have psychiatric co-morbidity such as complex trauma, personality disorder, depression, or anxiety and are using their eating disorder as a means to control the only aspect of their lives, namely what they eat.

A patient is identified as having a need for treatment dependent on their Body Mass Index (BMI), not if he or she has a mental illness resulting in an eating disorder.

Wales remains the only country in the UK, where patients with severe eating disorders are seen by general psychiatrists and by multiple teams with resulting lack of medical leadership. We feel that a dedicated service providing a seamless care for inpatients and outpatients is needed in Wales and that Welsh patients should be treated locally in a dedicated in patient unit.

Disordered Eating is common in the elderly, in particular with those suffering from dementia or those with co-morbidities, including those who have difficulty in swallowing. Their diet and nutrition is severely impacted. (This could also form part of an examination into Dementia, which we outline below.)

Out of Area Placements

There are a large number of people in Wales who must be placed out of area to receive the treatment they need.

People receiving treatment for mental health conditions are often placed out of area where they can be seen by specialists. Almost all patients with eating disorders are treated in England; for young adults this leads to loss of support from peers and families and educational underperforming. Patients with gender dysphoria are all referred to London; lack of funding for local services results in excess spent and waits of over a year. Patients requiring specialist inpatient learning disability services are also often transferred out of area when beds are available. There are no prisons for women in Wales. Prisoners have

the highest proportion of mental health conditions compared with most other populations. Again, this group of people rely on treatment from English services.

We would suggest that the Committee look into the human and financial costs.

Primary Care Mental Health Support

The College believes that more focus should be placed on prevention and early intervention where possible and primary care should be equipped to deliver this. The Mental Health (Wales) Measure was passed recently to better support primary care mental health provision; however, a report by Gofal shows that patient satisfaction has not improved since the law was implemented. A survey of GPs conducted by Wales and Mental Health in Primary Care (WaMH in PC) showed that 50% of respondents said that they are spending 20% of their workload on helping people with mental health issues. This group felt that there should be a rebalancing of priorities within the Local Primary Mental Health Support Services (LPMHSS) to provide better support to the primary care workforce.

The Health Committee held an inquiry on the post-legislative scrutiny of the Mental Health (Wales) Measure and we understand that there are no plans to undertake another review.

Dementia

Welsh Government is currently developing Wales' first Dementia Strategy for Wales as outlined by the *Together for Mental Health Delivery Plan*. The Strategy will be published by the end of 2016. The Committee could examine the progress of the Strategy in due course.

We feel the Committee could look specifically at early onset dementia. To date, there are no services that are able to best treat this cohort of people. The patient is often inappropriately referred to Old Age services. We feel a national assessment, diagnostic and supported service for Wales is needed.

It is important to note that depression accounts for 40% of Old Age Psychiatry workload. It is highly prevalent in early onset dementia patients where frequently a diagnosis of dementia can trigger depression. We would ask the committee to look at the level of training in identifying and treating depression in patients with dementia. This aspect could also be included in work on isolation and loneliness in the elderly.

Gender dysphoria

According to the Gender Variance Report (2009)[3] there is a continuing increase in cases presenting with gender dysphoria as a result of increasing public acceptance and overcoming stigma associated with the condition. Welsh patients with gender dysphoria have no local service provision. Expert assessment and treatments such as hormone therapy are well established and relatively inexpensive and could easily be provided in Wales.

Currently treatments for Gender Dysphoria are only provided in London and Welsh patients must endure lengthy waits. If you take into account the long wait for routine psychiatric assessments in CMHTs, followed by a long wait for assessment out of area, often patients will wait for two years with their lives on hold. This again is often a problem affecting

[3] Reed, Bernard. et. al. (2009) Gender Variance in the UK: Prevalence, Incidence, Growth and Geographic Distribution. Gires.

young adults and leads to unnecessary suffering and occupational underperformance of this vulnerable group.

The Committee could consider the benefits of having a local gender clinic in Wales.

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Cyfadran Iechyd y Cyhoedd

Response from: Faculty of Public Health

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UK Faculty of Public Health response to the National Assembly for Wales' Consultation on Priorities for the Health, Social Care and Sport Committee

About the UK Faculty of Public Health
The UK Faculty of Public Health (FPH) is the standard setting body for specialists in public health in the UK. FPH is the professional home for close to 4,000 professionals working in public health. Our members come from a range of professional backgrounds (including clinical, academic and policy) and are employed in a variety of settings, usually working at a strategic or specialist level.

The UK Faculty of Public Health FPH is a joint faculty of the three Royal Colleges of Public Health Physicians of the United Kingdom (London, Edinburgh and Glasgow). In addition, FPH advocates on key public health issues and provides practical information and guidance for public health professionals, aiming to advance the health of the population through three key areas of work: health promotion, health protection and healthcare improvement.

FPH welcomes this opportunity to respond to the National Assembly for Wales' Consultation on Priorities for the Health, Social Care and Sport Committee. At the outset, FPH is pleased to endorse the response to this consultation submitted by Public Health Wales.

FPH is encouraged by the broad range of areas the Committee wishes to consider, and, in particular, welcomes the attention given to the integration of health and social care services, to waiting times and to primary care. We also support the recognition given to gambling addiction, often insufficiently addressed, and support the proposal to undertake an inquiry looking at awareness of gambling addiction, the provision of support services, and the steps that could be taken to reduce harm.

However, we commend to you the 12-ambitions outlined within FPH's manifesto for public health, *Start Well, Live Better*[1]. This document is the culmination of an extensive consultation with our members about the top public health priorities for government and local action. These we feel would strengthen the Welsh proposals.

The scale of the obesity epidemic, the cost to our society of cheap alcohol, and the continued dangers from tobacco are major public health threats that need legislative and regulatory interventions – especially to protect children and young people. The interventions which are needed are of the kind that only the Government can implement.

We believe there should be a firm commitment to upstream legislative action to ensure health is at the heart of all national and local government policy formulation – thereby reducing health inequalities by taking action across all social and economic determinants of health. The Faculty of Public Health strongly advocates that a framework for health in all policies should form a central pillar of public health policy, ensuring strong cross-sectoral collaborative links may be made and a strategic national approach adopted, supported by local initiatives.

Accordingly, the Faculty of Public Health places a firm emphasis on the introduction of a statutory duty on Ministers to consider the health impact of all policies which will be of practical utility in improving health outcomes and reducing health inequalities. This will ensure that public health is at the heart of wide ranging departmental portfolios and central to policy formulation, e.g. in relation to the economy, transport, town planning, housing and the environment, early years, mental health and wellbeing and education (including adult education).

We note that the Healthy Schools initiative is still available across Wales and this could be used as existing infrastructure to tackle childhood obesity. There is also a further opportunity to use the Childhood Measurement Programme as an opportunity to promote local opportunities for physical activity to each family. A bespoke response with nearest parks, play spaces, open space and local clubs is possible from the Local Development Plan and Local Authority work on mapping activity options.

[1] http://www.fph.org.uk/uploads/FPH_14056_FPH%20Manifesto%20FINAL%20low-res.pdf

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Improved cycling and walking routes is another area that should be a priority and some of the work the Health Improvement Group have recently done on cycling and walking could be used in this response too. This is a win-win for climate change and building activity back into people's lives.

FPH further notes that the Welsh Policies of Wellbeing of Future Generations and Social Services and Wellbeing (Wales) Act need to be used as effective levers by Public Health to get the most from them.

Results from the first Welsh Adverse Childhood Experience (ACE) study show that suffering four or more harmful experiences in childhood increases the chances of high-risk drinking in adulthood by four times, being a smoker by six times and being involved in violence in the last year by around 14 times. FPH supports and highlights the ongoing work in this area.

Public Health Wales (PHW) has recently produced key actions to make a difference document (attached with this response) and if all of these things were being done systematically this would have an impact. FPH is keen to support PHW in the wide implementation of these key programmes.

The issue of antipsychotics use in people with dementia is being tackled at the local level in each area. FPH would welcome greater focus and strengthening on this area.

Waiting times continue to be an issue, as they are across the UK, and FPH stresses the importance of return on investment and value for money of prevention. To that end, we urge the Committee to read our response to the Health Select Committee inquiry on Public health post-2013 - structures, organisation, funding and delivery http://bit.ly/28WgY0z, and case study in relation to healthcare public health http://bit.ly/2b8nRsw.

FPH identifies evidence based measures that will have a direct impact on physical activity and health, including the reinstatement of at least two hours per week of physical activity in schools and investment in public and active transport.

However, of equal importance, FPH also identifies indirect measures and upstream legislative action that will be critical to reducing rates of cardiovascular and non-communicable disease, e.g. stopping the marketing of foods high in sugar, fat and salt before the 9pm watershed on TV and tightening of online marketing restrictions; and the introduction of a 20% duty (per litre) on sugar sweetened beverages. FPH is pleased to attach our new Manifesto alongside this submission.

FPH is committed to working with the Welsh government, Public Health Wales, NHS Wales, local government and stakeholders across the field to develop strong evidence based public health policies to improve and protect people's health and wellbeing. FPH is concerned that at present we are, as the Health Select Committee suggests, "losing the fight and simply encouraging a 'normalisation' of obesity." Current voluntary mechanisms to address physical activity are "distracting from prevention and early intervention," – necessary in order to address the current 'obesogenic' environment.

If you require any further information, please contact Mark Weiss, Senior Policy Officer for the UK Faculty of Public Health - markweiss@fph.org.uk, 0203 696 1479.

Yours sincerely,

Professor John Middleton
President
UK Faculty of Public Health

Appendices:

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FPH has published expert resources on a range of issues connected to the relationship between physical activity and health that demonstrate the importance of an integrated approach to improving people's health, and make recommendations for action to tackle the issues they address.
These position and briefing statements can be found at the following links, and summaries of the recommendations are presented within this response

- The built environment and physical activity briefing statement (pdf)
- The built environment position statement (pdf)
- Food marketing to children (pdf)
- Obesity (pdf) and
- Transport and health position statement (pdf)
- Transport and health briefing statement (pdf)
- Sugar sweetened beverages (pdf)
- Alcohol (pdf)

We furthermore draw the Committee's attention to the comprehensive evidence reviews and published guidance on 'what works' undertaken by NICE, and to the wealth of information known about the impact of obesity and of physical activity on health.

For evidence on physical activity, please refer to the HSE 2012 report chapters on this:
www.hscic.gov.uk/catalogue/PUB13218/HSE2012-Ch3-Phys-act-child.pdf and
www.hscic.gov.uk/catalogue/PUB13218/HSE2012-Ch2-Phys-act-adults.pdf

For evidence on obesity, please see the HSE 2013 report chapters on this:
www.hscic.gov.uk/catalogue/PUB16076/HSE2013-Ch10-Adult-anth-meas.pdf and
www.hscic.gov.uk/catalogue/PUB16076/HSE2013-Ch11-Child-BMI.pdf

In terms of causation & prevention of non-communicable disease, poor diet is more powerful than tobacco, alcohol & smoking combined. [2]Thus, FPH recommends food policy as an area that the Committee may wish to prioritise. Achieving weight control in healthy populations requires work at legislative, policy, and environmental level, with individual interventions, while important, nonetheless not the focus of activity.

FPH emphasises that one of the most important messages is the strong evidence that weight loss programmes do not achieve useful long-term weight loss, as most recently demonstrated by the new Systematic Review commissioned by NICE [3]and discussed in a recent BMJ blog[4] and highlighted by Sarah Boseley in her book *The Shape We Are In*.

FPH notes that for cardiovascular disease prevention, there is clear evidence that the Mediterranean diet, even just a handful of nuts and or liberal consumption of olive oil, is effective[5], and could lead to a rapid 30% reduction in deaths & non-fatal events. Furthermore, this demonstrates that a healthy diet is more powerful than statins.

Finally, within this response, we stress that mental health problems have increasingly been shown to precede, and be important in the recovery from, physical health problems. It is important that this – and the parity of esteem between physical and mental health – is considered by the Health Committee.

Appendix 1 – The Built Environment and Physical Activity:
FPH makes the following recommendations in relation to the built environment and physical activity:

- Physical activity has an important impact on physical and mental health and wellbeing – in particular for children and young people, their educational attainment and future life chances;

[2] Global Burden of Metabolic Risk Factors for Chronic Diseases Collaboration.Lancet Diabetes Endocrinol. 2014 Aug;2(8):634-47. doi: 10.1016/S2213-8587(14)70102-0. Epub 2014 May 16. Cardiovascular disease, chronic kidney disease, and diabetes mortality burden of cardiometabolic risk factors from 1980 to 2010: a comparative risk assessment.
[3] University of Oxford, Weight regain after behavioural weight management programmes
[4] BMJ – Spending Money on Weight Management Services
[5] New England Journal of Medicine, Primary Prevention of Cardiovascular Disease with a Mediterranean Diet

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- It can reduce their risk of chronic conditions in later life such as coronary heart disease, type 2 diabetes, mental health problems and obesity;
- Strong cross-sectoral relationships are needed, including with councillors, planning, regeneration and transport teams in the local authority, local employers and clinical commissioning groups
- Public health must be considered in local plans and strategies including the Local Development Framework, Supplementary Planning Guidance and Sustainable Communities Strategy
- Ensure that built environment and planning are considered in the Joint Strategic Needs Assessment and Health and Wellbeing strategy
- Public health input must be factored in at the earliest stages of planning proposals, and the potential health impacts of proposals must be assessed
- Non mainstream sports that are popular with boys should be promoted such as skateboarding, surfing, free running and martial arts for those who are not interested in team games.
- The recommendations of the FPH Position Statement on Transport must be followed to deliver measures that achieve a shift away from cars in favour of walking, cycling and public transport.

Appendix 2 – Food Marketing to Children

FPH makes the following recommendations in relation to food marketing to children:

- What is defined as high fat, sugar salt (HFSS) foods and drinks must be clearly communicated
- Schools, early years settings, youth, leisure and other settings 'where children gather' must be supported to:
    - discuss the reasons why children need to be protected from the marketing of HFSS foods and drinks
    - develop local food policies so that they are free from all forms of marketing of foods high in saturated fats, transfatty acids, free sugars or salt
- Services commissioned by the NHS and local authorities must not have any marketing of foods that are high in saturated fats, transfatty acids, free sugars or salt, by including this in service specifications
- Stakeholders must be influenced to ensure cultural and sporting activities in the local areas are free from marketing of foods high in saturated fats, transfatty acids, free sugars or salt.
- Enforcement agencies such as environmental health officers and other partners must work together to monitor these actions and explore further opportunities
- Awareness raising and education of the wider public health workforce about the impact of food advertising to children, and the wide range of forms food marketing can take must be made
- Local media can help to advocate the messages

Appendix 3 – Obesity

It is critical to ensure that the right emphasis is placed on prevention, and to that end, the Faculty of Public Health make the following recommendations:

- For Government to consider fiscal and regulatory policies
- Local Directors of Public Health and Health Boards should act as strong advocates for the most effective evidence-based interventions
- Joint strategic needs assessments should reflect the obesity burden in populations
- Health Boards should consider the guidance produced by the National Institute for Health and Care Excellence on obesity, active travel, physical activity and other relevant guidance, and how the guidance should be implemented locally
- Free water must be available in all children's environments, including schools, parks, playgrounds, sports stadia and cinemas
- A ban on all junk food (high in saturated fat, salt or refined sugars) and sugary drink marketing to children must be implemented
- Schools (including academies) and early years environments should abide by the nutritional standards of the Children's Food Trust and the School Food Plan
- Active encouragement of breastfeeding should be made by national and local government
- Policies to increase active travel (cycling and walking), such as lower speed limits, changes to road design, designated cycle routes and cycle storage should be implemented

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- Schools should encourage active travel through policies such as walking – buses, bike storage and cycle training
- All planning permission decisions should take the impact on health into consideration, including through the use of Health Impact Assessments
- Reformulation will also be necessary, to substantially reduce the added sugars hidden in junk food and sugary drinks (Mandatory reformulation consistently works better than voluntary reformulation)
- To inform consumers, we need legislation requiring all manufacturers to adopt the consistent food nutritional labelling system

We draw attention the report by the Academy of Medical Royal Colleges, "*Measuring Up – the medical profession's prescription to the obesity crisis*", which sets out a range of practical recommendations that we would urge the Government to adopt as part of a strategy on the most effective and coherent way to tackle obesity, as set out below:

1. **Education and training programmes for healthcare professionals:** Royal Colleges, Faculties and other professional clinical bodies should promote targeted education and training programmes within the next two years for healthcare professionals in both primary and secondary care to ensure 'making every contact count' becomes a reality, particularly for those who have most influence on patient behaviour

2. **Weight management services:** The departments of health in the four nations should together invest at least £100m in each of the next three financial years to extend and increase provision of weight management services across the country, to mirror the provision of smoking cessation services. This should include both early intervention programmes and, greater provision for severe and complicated obesity, including bariatric surgery. Adjustments could then be made to the Quality and Outcomes Framework, providing incentives for GPs to refer patients to such services

3. **Nutritional standards for food in hospitals:** Food-based standards in line with those put in place for schools in England in 2006 should be introduced in all UK hospitals in the next 18 months. Commissioners should work with a delivery agent similar to the Children's Food Trust to put these measures into place

4. **Increasing support for new parents:** The current expansion of the health visitor workforce in England should be accompanied by 'skilling up' the wider early years workforce to deliver basic food preparation skills to new mothers and fathers, and to guide appropriate food choices which will ensure nutritionally balanced meals, encourage breastfeeding and use existing guidance in the Personal Child Health Record as a tool to support this.

5. **Nutritional standards in schools:** The existing mandatory food- and nutrient-based standards in England should be applied to all schools including free schools and academies. This should be accompanied by a new statutory requirement on all schools to provide food skills, including cooking, and growing – alongside a sound theoretical understanding of the long-term effects of food on health and the environment from the 2014/15 academic year

6. **Fast food outlets near schools:** Public Health England should, in its first 18 months of operation, undertake an audit of local authority licensing and catering arrangements with the intention of developing formal recommendations on reducing the proximity of fast food outlets to schools, colleges, leisure centres and other places where children gather

7. **Junk food advertising:** A ban on advertising of foods high in saturated fats, sugar and salt before 9pm, and an agreement from commercial broadcasters that they will not allow these foods to be advertised on internet 'on-demand' services.

8. **Sugary drinks tax:** For an initial one year, a duty should be piloted on all sugary soft drinks, increasing the price by at least 20%. This would be an experimental measure, looking at price elasticity, substitution effects, and to what extent it impacts upon consumption patterns and producer/retailer responses

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9. **Food labelling:** Major food manufacturers and supermarkets should agree in the next year a unified system of traffic light food labelling (to be based on percentage of calories for men, women, children and adolescents) and visible calorie indicators for restaurants, especially fast food outlets

10. **The built environment:** Public Health England should provide guidance to Directors of Public Health in working with Local Authorities to encourage active travel and protect or increase green spaces to make the healthy option the easy option. In all four nations, local authority planning decisions should be subject to a mandatory health impact assessment, which would evaluate their potential impact upon the populations' health.

We also draw attention to the 2013 report, *Action on Obesity* by the Royal College of Physicians, which found that the response of the NHS to obesity is patchy at best. The Faculty of Public Health supports the RCP's recommendation that multi-disciplinary weight management clinics be made available to cover severe and complex obesity.

The London Healthy Schools programme is doing an important job of ensuring the Children's Food Trust nutritional standards are met in London's schools which mean that schools meet the FPH's position. The Healthy Schools programme should be continued.

Appendix 4 – Transfats

FPH remains deeply concerned by the substantial on-going health risks presented by IPTFAs. We strongly recommend that these hazards should be controlled through proportionate and cost-saving legislative measures for which there are international precedents, including the Austrian, Danish, Icelandic, Swedish and Swiss models.

Transfats are a poisoner of people and a creator of obesity and therefore likely to negatively impact on active lifestyles – with the impacts felt more acutely among the poorest and most vulnerable societal groups.

As demonstrated by the Hierarchy of Effectiveness, "upstream" interventions, (such as legislation) will usually have bigger population benefits than piecemeal local and "downstream" interventions. Hence the NICE guidance on the Prevention of Cardiovascular Disease in Populations (2010), which calls for the "elimination of IPTFAs for human consumption"[6].

FPH is therefore concerned by the likely marginal impact of the current approach, voluntary Responsibility Deal (RD) interventions trying to tackle the harms caused by a substance declared toxic in 2009 by the WHO[7], and described as a "significant health hazard" by NICE in 2010[8]. The absence of robust evaluation mechanisms to assess the progress of the RD is a further concern.

We are also that the Government simply view Transfats as "within current UK recommendations",[9] thus implying that IPTFAs can therefore be ignored. This is wrong for two reasons. Firstly, there is no safe minimum level of IPTFAs. Secondly, even if population average levels are considered acceptable, this ignores important strong socio-economic and demographic gradients – particularly among young, deprived and ethnic minority sub-groups.

It is absolutely critical that all societal groups are protected and the social determinants of health and health inequalities are robustly factored into Government policy on IPTFAs. Yet the most recent Low Income Diet & Nutrition Survey (LIDN) in 2007 indicated that the most deprived 2.5% of the UK population consume over 2.6% of their dietary energy intake from IPTFAs[10]. This group is likely to include a substantial and disproportionate number of deprived children, young people and ethnic minority groups, thus compounding existing health inequalities already suffered by these groups.

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[6] NICE, *Public Health Guidance 25: Prevention of Cardiovascular Disease*, June 2010 <http://www.nice.org.uk/nicemedia/live/13024/49273/49273.pdf>, P.10 (Accessed 24 May 2013)

[7] WHO *Scientific Update on trans fatty acids (TFA)* European Journal of Clinical Nutrition, Volume 63, (Supplement 2), May 2009

[8] NICE, *Public Health Guidance 25: Prevention of Cardiovascular Disease*, June 2010 <http://www.nice.org.uk/nicemedia/live/13024/49273/49273.pdf>, P.10 (Accessed 24 May 2013)

[9] Department of Health, Woodeson, Liz, *Artificial Trans Fats: Briefing Note*, 17 December 2012

[10] Food Standards Agency, *Low Income Diet and Nutrition Survey*, 2007, <http://www.food.gov.uk/multimedia/pdfs/lidnssummary.pdf> (accessed 24 May 2013)

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FPH urges the Government to consider again building on the successful international precedents, and implementing the effective, proportionate and cost-saving legislative mechanisms available to address this critical health issue.

Appendix 5 – Transport and Health
FPH makes the following recommendations in relation to transport and health:

- Local MPs and councillors should implement policies which will deliver a shift away from cars in favour of walking, cycling and public transport
- Local authority transport planning teams should identify ways of working stakeholders to deliver a shift away from cars in favour of walking, cycling and public transport
- NHS travel plans should be developed and implemented which deliver a shift away from cars in favour of walking, cycling and public transport
- Good practice, including reducing the need to travel, should be disseminated nationally and locally
- The potential health impacts (including effects on inequalities) of local and regional transport policies and major transport projects must be assessed
- Local authority planners must work collaboratively with other key partners on new residential developments to ensure that the most convenient, sustainable, active and affordable option for short journey stages will be walking and cycling, and for longer journey stages cycling and public transport
- Work should be undertaken by healthcare providers to promote active travel as a convenient and sustainable means of maintaining good health and recovering from illness
- In England, use Health and Wellbeing Boards and local health and wellbeing strategies should include and promote public health and active travel, as well as influence planning and transport policies
- Activity to integrate public health considerations into the design, delivery, adaption and maintenance of the built environment should be undertaken.

Appendix 6 – The relationship between mental health and wellbeing and physical health
At the outset, FPH draws attention to the Royal College of Psychiatrists resource, *Physical Activity and Mental Health*[11] which underscores the strong and positive relationship between physical activity and mental health. Some general principles are set out as follows:

- Physical activity promotes mental health and wellbeing and prevents mental illness
- Fruit and vegetables consumption is very likely to promote mental health and wellbeing too [12]
- Mental health and wellbeing are important for developing and maintaining healthy lifestyles because they support agency, autonomy and motivation
- Mental health and wellbeing is important in the prevention of a range of chronic illnesses and in preventing premature mortality

Mental health is vital to public health; mental wellbeing is profoundly important to quality of life and the capacity to cope with life's ups and downs. It is protective against physical illness, social inequalities and unhealthy lifestyles. There are now a large number of evidence-based approaches to promoting mental wellbeing and preventing mental illness, and these are growing daily. FPH draws attention to our own resource on mental health and wellbeing, which contains many relevant and useful tools to empower individuals and communities: http://www.fph.org.uk/better_mental_health_for_all

We can empower individuals and use community assets to enable them to improve their own health by building on the recommendations of the Marmot review in understanding and building on the growing body of evidence which builds resilience, reduces material inequality and supports the development of social, cultural, community – and individual capital http://www.instituteofhealthequity.org/projects/fair-society-healthy-lives-the-marmot-review

[11] RCPsych, Physical Activity and Mental Health http://www.rcpsych.ac.uk/healthadvice/treatmentswellbeing/physicalactivity.aspx
[12] See for example Saverio Stranges, Preshila Chandimali Samaraweera, Frances Taggart, Ngianga-Bakwin Kandala, Sarah Stewart-Brown Major health-related behaviours and mental well-being in the general population: the Health Survey for England BMJ Open 2014;4:e005878 doi:10.1136/bmjopen-2014-005878 and the quoted refs

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Evidence that there is a strong relationship between mental and physical health has been accumulating over the last few decades. This challenges firmly held attitudes and beliefs in both health care and public health about the mind-body dichotomy [13] [14] in which mental and physical health are seen as separate. Further progress on the physical aspects of public health is likely to depend on changing these attitudes and beliefs, and the development of new interventions and programmes which take this evidence into account.

Mental health problems have increasingly been shown to precede, and be important in the recovery from, physical health problems. For example, the Whitehall Study showed that emotional health, especially negative affect – a general tendency to report 'distress, discomfort, dissatisfaction, and feelings of hopelessness' – predicts the onset of heart disease and recovery from infarcts independently of other risk factors.[15]

Psychological distress is also a risk factor for stroke.[16] For people with a diagnosis of severe mental illness such as depression, the risk of physical illness is high: 46% of people with a mental health problem have a long-term physical health problem such as coronary heart disease or COPD. [17]

Mental illness also increases the risk of cancer,[18] musculoskeletal problems like back pain [19] and psychosomatic problems like irritable bowel [20] and possibly a range of other diseases.[21] Death rates are also higher in people with mental illness compared to people without mental illness, especially deaths from cardiovascular, respiratory and infectious diseases. [22]

Diagnosis of neurotic disorder (mental illness that falls short of psychosis) in general practice increases mortality over the next 11 years by 70% and a self-report of depression in population studies increases mortality by 50%. [23] People with psychotic disorders die on average 25 years earlier than the general population. [24]

People with physical health problems, especially chronic diseases, are at increased risk of poor mental health, particularly depression and anxiety – around 30% of people with a long-term physical health condition also have a mental health problem. [25]In some cases, depression appears to result from specific biological effects of chronic illness.

Examples of this relationship include links between depression and central nervous system disorders such as Parkinson's disease, cerebrovascular disease, or multiple sclerosis, as well as endocrine disorders, such as hypothyroidism.

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In other cases, the association between depression and chronic illness appears to be mediated by behavioural mechanisms, the limitations on activity imposed by the chronic illness leading to gradual withdrawal from rewarding activities.[26] Mental health problems can also increase the overall burden of illness in patients with chronic medical conditions, including the need for healthcare services.

For example, compared with those without depression, medical outpatients with depressive symptoms experienced decrements in quality of life [27] and had almost twice as many days of restricted activity or missed work because of illness.[28] Compliance with treatment for physical health conditions can also be an issue, with depression increasing the risk of non-compliance with treatment recommendations three fold. [29]

Mental health problems associated with physical illness can increase healthcare costs by more than 45% according to some international studies, which, if applied to NHS expenditure could mean that £8-13 billion of long-term physical health care costs are due to poor mental health. [30]

Treatments for mental illness such as anti-psychotic medications have been shown to increase the risk of physical ill-health. [31]More recent evidence has shown that despite the high risk of physical ill-health, people with mental health problems have less access to preventative and early interventions for physical illness including coronary angioplasty [32], [33] and may suffer discrimination in healthcare systems. [34]

The unhealthy lifestyles and behaviours which plague the public's health – smoking, excess alcohol consumption, misuse of illicit drugs, consumption of, sugary foods and over-eating in general – are used because they are effective in managing stress. For example, eating carbohydrates increases serotonin levels, which may boost mood.[35] People find it very difficult to stop these behaviours because they can be addictive.

Other factors like social norms, availability, price and legality also play a role and provide important opportunities for regulation, but a key reason most people find it difficult to change their lifestyle is because the lifestyle assuages emotional distress.

- Almost 50% of all tobacco is now smoked by people with mental illness [36]
- Obesity is more prevalent among people with mental illness [37]
- Alcohol and drug misuse are commonly associated with mental illness [38]

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- Mental health problems in childhood predict the adoption of unhealthy lifestyles in adolescence. [39]

Healthy foods, particularly it would seem fruit and vegetable consumption up to eight portions a day, [40] [41] can positively affect mental as well as physical health. Levels of physical activity can also impact on mental wellbeing in terms of mood, stress, self-esteem, anxiety, dementia and depression. [42]Current NICE guidance recommends the use of structured physical activity in the treatment of depression. [43]

Emerging evidence suggests that improving mental wellbeing can contribute substantially to improving physical health, reducing morbidity and mortality. [44] [45] [46] [47] [48] For example, a meta-analysis found that positive mental well-being including positive affect (eg. positive mood, joy, happiness, vigor, energy) and positive trait-like dispositions (eg. life satisfaction, hopefulness, optimism, sense of humor) were significantly associated with reduced cardiovascular mortality in healthy populations, and with reduced death rates in patients with renal failure and with HIV (human immunodeficiency virus) infection. [49]

An association between positive affective traits and lower morbidity, decreased symptoms and pain has also been demonstrated. [50]Other studies have also shown that mental wellbeing can extend survival in cancer and renal disease. [51] [52]

Conversely, negative affective styles such as anxiety and hostility have been shown to predict increased risk for illness and mortality. [53] [54] Thus, public mental health interventions to promote mental wellbeing can work in conjunction with other public health interventions focused on behaviour change and risk factor reduction to improve physical health.

Social wellbeing – distinct from but interlinked with, and often incorporated into definitions of, mental wellbeing – can also affect physical health and is relevant here. A seminal study from 1979 found that relationships with others – partners, family and friends and to a lesser extent more formal social groups – reduced the risk of mortality. [55]More recent work reinforces the impact of the social context on health. [56]For

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example, a study in Wales showed that neighbourhood social capital is linked to the health of individuals within that neighbourhood. [57]

At present services are provided to address mental health issues independently from services to address unhealthy lifestyles, and although lifestyle interventions are increasingly informed by psychological insights, they do not aim to promote mental health and wellbeing as an important part of the treatment package. Lifestyle change programmes could be more successful if they focused as much on mental health as they did on lifestyles and the interplay between the two. [58]

Good evidence exists for a range of public mental health interventions across the lifecourse that could be commissioned to promote mental wellbeing, encourage a healthy lifestyle and prevent chronic disease and mental illness. [59]

Robust evidence of effectiveness exists for public mental health interventions aimed to give children a good start in life. This is also an opportune time to intervene as 75% of mental illness starts before the age of 25 years [60] and many health risk behaviours such as smoking and substance misuse start in childhood, having a long-lasting adverse effect.

Interventions include a wide range of options to help people 'live well', promote mental health, and prevent the adoption of health risk behaviours, such as targeted approaches for smokers with mental disorder or physical activity programmes for those with depression.

Evidence-based interventions include physical activity to improve mental functioning, reduce mental illness, decrease social isolation and improve wellbeing in older peoplethe elderly, [61]and addressing physical disabilities including hearing loss to improve quality of life and reduced social isolation. [62] [63]

Resources on the relationship between physical and mental health:

- Improving physical and mental health website jointly established by the Royal College of Psychiatrists and the Royal College of General Practitioners;
- Physical Health Project by Rethink.
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Appendix 7 – Alcohol

FPH underscores the contribution of alcohol-derived calories to the alcohol-obesity relation, and notes the clear positive association between alcohol calories and obesity, and that alcohol calories are likely to be a significant contributor to the rise in obesity.[64]

Accordingly, FPH has called for health warnings to be printed on alcohol labelling to give people more information about the risks of drinking. There is evidence that such a move would increase people's knowledge about the potential harm alcohol can cause. It would also make it easier for people to understand the need for minimum pricing per unit of alcohol, which FPH supports.

These health warnings would help educate the public and give them key information before they decide to buy a can or bottle of alcohol. The evidence linking alcohol to over 60 medical conditions is unarguable, so we need factual, not sensational, warnings to help the public understand the risks. People don't realise that drink is associated with a whole range of health harms and has potential long-term implications.

The Faculty of Public Health is a member of the Alcohol Health Alliance UK, and strongly supports the introduction of a minimum unit price per unit. This policy powerfully addresses the growing burden of alcohol harm including liver disease, dementia, violence and accidental injury.

FPH also advocates that licensing authorities must be empowered to tackle alcohol-related harm by controlling total availability for alcohol in their jurisdiction; and that all alcohol advertising and sponsorship should be prohibited. In the short term, alcohol advertising should only be permitted in newspapers and other adult press. Its content should be limited to factual information about brand, provenance and product strength.

Finally, FPH notes that predispositions to addictions, e.g. alcohol and tobacco, are likely to reduce the likelihood of physical activity.

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Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Tŷ Hafan
Response from: Tŷ Hafan

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30 August 2016

Ms Sarah Beasley
Clerk
Health, Social Care and Sports Committee
National Assembly for Wales
Cardiff Bay
CF99 1NA

Dear Sarah

Priorities for the Health, Social Care & Sport Committee

We would like to highlight how together we can make an affordable step change in quality of life for children and families needing paediatric palliative care.

It was a pleasure this week to be able to host Dr Lloyd for a visit and Tŷ Hafan will need no introduction to your committee. Members may however be surprised that as we celebrate 18 years in 2017, we are on a daily basis supporting 260 families at and our work now starts before children are born. It means 22% of the families work with come to us with a child less that 4 months old and 20% of our families receive sibling support and parental support for 5 years or more; adjusting to the loss of a child whilst you have a life to make never truly gets easier. Our community services provide play support, music and complimentary therapies at the hospice and at home. Ty Hafan provides medical, nursing and social support in the Hospice. More and more children, with the benefit of palliative paediatric care throughout life, will live into early adulthood, transitioning into adult services. Having jointly recruited with Cardiff and Vale UHB a full time paediatric palliative care consultant we are ambitious to work with the Deanery to work together to further develop the Paediatric palliative care consultant workforce in Wales.

In 2015, Tŷ Hafan in conjunction with the Wales Institute for Health and Social Care (WIHSC) published a major report '*Palliative care for children and young people in Wales: meeting future needs'*. Mark Drakeford led the official launch. Despite the combined current capacity of Tŷ Hafan and Tŷ Gobaith, and excellent partnerships with our health boards means there is not enough paediatric palliative care capacity to meet the need in Wales. The work initiated recently by Veronica Snow to ensure children with life limiting illness are explicity included in blue light ambulance priorities in Wales is exciting. This is gap it is an unintended one. When we first set such priorities children receiving paediatric palliative care did not need these services, now they do.

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30 August 2016

Ms Sarah Beasley
Health, Social Care and Sports Committee
National Assembly for Wales
Cardiff Bay CF99 1NA

We can only do what we do at Tŷ Hafan because of the tremendous commitment and generosity of the Welsh people. They give more than £3 million to fund the care we deliver every year, adding substantial value to the historic government investment in Tŷ Hafan of just over £200,000. In raising these funds we encourage people across Wales to get fit for Tŷ Hafan. We are a major partner when it comes to sports and health. Over 7,000 people have registered with us to undertake major fitness challenges for Tŷ Hafan using wearables to track their progress. In a new partnership with "Give a Penny" our fundraisers will be able to track steps and challenges to walk a kilometer or a 5k rainbow run as a family, ensuring we make a difference to health and fitness and as well as inspiring support for Tŷ Hafan.

Wales is exceptional in the UK in that our government recognizes the need for paediatric palliative care. However, palliative care policy has, never the less for understandable reasons been largely focused on adult services. We believe that needs to change now and we have been working closely with the Welsh Government to explain why. Having the opportunity for Dr Dai Lloyd to see for himself what we are currently providing was a pleasure and it was gratifying that he felt that we have significantly developed the service provision in the time he has known us and the positive impact that makes. During the visit I discussed with Dr Lloyd the need for the voice of children to be heard. I am sure you would agree that this is an issue that transcends party politics and on behalf of Tŷ Hafan, we would be extremely keen for the Committee to consider looking into paediatric palliative care in Wales.

We would also be very happy to engage more broadly with the committee on issues that affect the health of children more widely, including long term conditions and public health.

I look forward to working with you over the Fifth Assembly.

Yours sincerely

Kate Phipps
Chief Executive

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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Plant yng Nghymru

Response from: Children in Wales

Consultation response - Priorities for the National Assembly for Wales Health Social Services and Sport Committee

Introduction

Children in Wales is the national umbrella organisation in Wales for children and young people's issues, bringing organisations and individuals from all disciplines and sectors together. One of our core aims is to make the United Nations Convention on the Rights of the Child (UNCRC) a reality in Wales. Children in Wales campaigns for sustainable quality services for all children and young people, with special attention for children in need and works to ensure children and young people have a voice in issues that affect them.

For further information on the work of Children in Wales, please see www.childreninwales.org.uk and www.youngwales.wales

Our Response

Children in Wales welcomes the opportunity to aid the Committee with its planning by sharing our views on some of the areas the Committee has already identified for inclusion in its longer term programme.

United Nations Convention on the Rights of the Child (UNCRC)

On the 3 June 2016, the United Nations Committee on the Rights of the Child issued a series of Concluding Observations to the UK and devolved governments which set out ways in which they can better meet their obligations in respect of implementing the UNCRC. The UN Committee made a number of Recommendations in respect of **Health and Health Services, Mental Health, Adolescent Health** and **Nutrition** (pp14-17). The Committee was particularly concerned at the inequality in access to health services and inequity of health outcomes in respect of vulnerable and marginalised groups.

We would suggest that the Committee give due regard to these Concluding Observations when initiating all enquiries which encompass the physical, mental and public health and well-being of all children and young people in Wales.

1) Integration of Health and Social Care Services

Part 9 of the Social Services and Well Being (Wales) Act 2014 sets out the duties placed on local authorities to make arrangements to promote cooperation with relevant partners to improve the outcomes for people (including children and young people) with care and support needs. Cooperation, integration and partnership are key cornerstones of the Act, alongside ensuring that recipients of services have a voice and control. The previous Welsh Government also provided revenue funding to

improve care coordination between social services, health, housing, education and the third and independent sector.

Children in Wales would welcome the Committee looking at the progress made to date on the integration of health and social care services, and links with community based services, and to assess the impact of Welsh Government policies and legislation to date.

For disabled children and young people, we would suggest that the following issues are considered as part of this inquiry:-

1.1 Definition of a Health and Social Care Need

Members of Children in Wales from both the health and social care sector who work with disabled children and young people tell us that there are ongoing discussions between professionals around what constitutes a health need or a social care need and therefore who should provide and resource support. This sometimes means that disabled children and their families do not receive support until this matter is resolved which is of some concern.

1.2 Transition to adulthood for disabled young people

An omission from The Social Services and Well-being (Wales) Act 2014 is the absence of provisions which detail local authority responsibilities to both disabled children and their carers when a young person is in transition to adulthood. The Act does not appear to repeal the duty to consider the transition needs of children with Special Educational Needs Statements under the Education Act 1996. This means that the duties under the Disabled Persons (Services, Consultation and Representation) Act 1986 sections 5 and 6 remain – namely the duty when the child is 14, that the relevant social services officer be contacted with a view to a social care assessment of the young person's needs being undertaken – so that services are in place when educational provision ceases.

The Act is for 'people' and therefore the local authority is responsible for disabled people from 'cradle to grave'. The reality is that different departments and social services teams, who have different budgets and local criteria, will often be responsible for disabled children from those responsible for disabled adults. We have some concern that Transition problems will continue to occur as frequently as they did under the previous legislation.

Recommendation

Children in Wales therefore recommends that the committee consider the above two issue as part of an overall inquiry around the impact of Welsh Government policies and legislation on integration of health and social care services.

1.3 Children and Young People's Continuing Care

Continuing care packages provide long term care and support to children and young people who are disabled or otherwise in need of support. The packages can include care provided by both health and social services professionals. Managers of local authority disabled children's team in Wales have informed Children in Wales that although many of the children they work with have complex health care needs which the social workers believe would meet the eligibility criteria for continuing care funding, very few are assessed by health as meeting the required criteria when the decision support tool is completed. This in effect means that many children and their families are at the centre of a dispute over who pays for the required support and may not be receiving the care to which they are entitled.

Recommendation

Children in Wales recommends that the Children and Young People's Continuing Care Guidance is reviewed with a particular focus on whether the decision support tool needs to be replaced with a summary of need as has been proposed by The All Wales Children's Community Nurse Forum Subgroup for children and young people's continuing care. (Further information can be provided on request)

2) Neonatal services

The Committee's previous inquiry noted clear improvements in some areas whilst concluding that further progress was still required in a number of important areas, including addressing the shortfall in medical and nursing staff and the effective distribution and utilisation of cots. Children in Wales would support a follow up review of the previous recommendations.

3) Sport and public health

Children in Wales would welcome the Committee examining the potential health benefits of sport and the role of NHS Wales in promoting sport and physical activity generally to tackle obesity. The Consultation document makes reference to the rise in the level of adult obesity evidenced by the Wales Health Survey 2015. The Committee will be aware that the previous Children and Young People Committee published their report following an inquiry into childhood obesity in Wales. We would suggest that progress in taking forward the Recommendations from this report is also included as part of any inquiry.

The Committee could also include reference to the growing calls, and support amongst some previous Assembly members, for a 'Sugar tax' with the potential for the Welsh Government to introduce a levy on sugary drinks. Only last month, children and young people called for there to be a sugar tax on fizzy drinks as a means of helping to prevent tooth decay and some diseases, such as diabetes.

We would also support the Committee examining the relationship between health and access to sports facilities, which would include participation in sport activities, including by children, young people and groups with protected characteristics. The previous Communities and Local Governmnet Committee undertook an inquiry into participation levels in sport which took evidence from health professionals and made a series of recommendations, some of which should be reviewed through a further inquiry.

Rising levels of obesity can have a big impact on the health of children and young people with their parents needing additional support to manage healthy lifestyles. This would include advice around healthy eating and exercise. One initiative which provides this is the Welsh Government Families First programme which highlights a range of support services under the healthy lifestyles package that could benefit all children and young people in Wales. Unfortunately this and other programmes that work with obese children and young people are not widely known.

Other issues

4) Child Health

Children in Wales would support a specific inquiry focused on child health, with an emphasis on preventative action and giving children the best start in life; addressing harmful behaviours, reducing instances of mental health problems and promoting healthy behaviours. With the status of the National Service Framework for Children, Young People and Maternity Services in Wales remaining unclear (to our knowledge the All Wales Posture and Mobility Partnership Board is the only body that provides regular reports on how the wheelchair service is performing against the key actions) a new focus on child health is required.

The Royal College for Paediatrics and Child Health Wales (RCPCH) have published a report entitled "Child health matters: A vision for 2016 in Wales - rcpch"

This identified five ways in which children's health outcomes can be improved. These are:-

1 Preventing children and young people from becoming unwell, acting early and intervening at the right time

2 Tackling child health inequalities

3 Reducing the number of child deaths

4 Involving children and young people in decision making

5 Delivering effective healthcare for children and young people

Recommendation

Children in Wales supports the RCPCH report and recommends that:-

1) The status of the National Service Framework for Children Health and Maternity Services in Wales is clarified

2) A renewed focus is given to child health and a rights based, outcome focused health delivery plan for children and young people is developed

Participation and engagement in health services

The UN Committee on the Rights of the Child made a recommendation that '*children are not only heard but also listened to and their views given due weight by all professionals working with children'.* As part of any inquiry which the NAfW Committee chooses to conduct, it is imperative that the issue of participation and engagement of all children and young people on all decision making matters which concern them is considered and included.

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Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Leonard Cheshire Disability
Response from: Leonard Cheshire Disability

Health, Social Care and Sport Committee
National Assembly for Wales
Pierhead Street
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CF99 1NA

1 September 2016

Dear Health, Social Care and Sport Committee,

Thank you for the opportunity to contribute to your consultation on priority issues for the Committee to consider during the 5th Assembly.

About Leonard Cheshire Disability

Leonard Cheshire Disability is the UK's leading charity supporting disabled people. We work for a society in which every person is equally valued.

We believe that disabled people should have the freedom to live their lives the way they choose, with the opportunity and support to live independently, contribute economically and participate fully in society.

Leonard Cheshire Disability provides a range of care and support services including residential care, supported living, homecare, day services and specialist care for adults with acquired brain injuries. This includes seven residential care services in Wales.

We also campaign to make care fair for everyone who needs it, including seeking an end to flying 15-minute care visits and sustainable long-term funding for social care.

Committee practices in the Fifth Assembly

Leonard Cheshire Disability welcomes the opportunity to engage with the Committee in this way. We have set out in the submission below a range of issues that we would recommend the committee examines over the course of its work.

In addition, and more importantly, we would urge the Committee to actively seek to include and engage with disabled people throughout its work. Whether the Committee is examining the integration of health and social services, or examining the health benefits of sport, it is important that the voices of disabled people are heard. In practical terms, we would be very happy to assist the Committee in taking this work forward, including supporting the committee to gather evidence from people who use our services.

Choice and control

The Committee has identified that a potential inquiry for it to undertake would be an examination of the integration of health and social care. We would welcome such an inquiry, but would recommend the committee reconstitutes it by looking at the inquiry from the perspective of a person receiving such care.

In May 2016, Leonard Cheshire Disability conducted a series of focus groups and in-depth interviews with disabled people across Wales in partnership with an independent qualitative research agency. One of the key findings from the research was the range of participants who expressed concerns to us that they still lacked control over their care.

Access to social care

Some participants felt that they lacked clear "signposts" to the services that were available to them. One participant with multiple sclerosis commented that "if you don't know the system, you get nothing: you get lost." They recommended that there should be "clearer pathways as to what you can access in the community." In separate discussions two participants with differing conditions (arthritis and diabetes) advocated that "there should be signposting to services in GP surgeries."

There was also a discussion about how much more difficult it is to get a social worker and support following discharge from hospital if you are working aged. One participant, who suffers with severe Arthritis, commented that:

> "you watch the hospital staff go from bed to bed of the elderly on the ward telling them what care has been organised for when they go home and I lie there being ignored – it is assumed as I'm in my late twenties that I can cope without formal care."

Another participant talked about her feeling of abandonment by the social care system. She described how she after 6 weeks in hospital:

> ”I felt safe on the ward as I was being continuously checked and monitored, someone was helping me with physio and keeping me as active as was possible and then all of a sudden I was discharged and sent home to nothing.”

Personalisation

Others felt that the care they received was not sufficiently individualised, to recognise different people’s needs. We believe this can be rectified by commissioners providing funding for staff to take the time to read through individual care plans.

One participant with diabetes commented that: “there is a one size fits all approach to assessment and identifying equipment.” Another participant with Pompey Disease said that:

> “you can get wheelchairs, but there is no flexibility about wheelchair types. If you want an electric wheelchair you have to fund raise for that, I can’t use a self-propelling chair so if I didn’t buy my own I would have no freedom at all.”

Most participants felt that equipment provided to them was the cheapest and most basic available, rather than what was actually going to provide them with the most assistance, freedom and help to get on with their lives.

Support for unpaid carers

Support for families, friends and other informal carers was also a key issue in the research we conducted.

Many people with unmet care needs told us that they rely on informal care to get by. Others talked about the importance of friends and family for their holistic wellbeing, saying that they felt depressed, exhausted and inclined to stop engaging with the world altogether. However, they also reported that the provision of care created stress and tension on their relationships. Participants felt that the current social care system has not been sufficiently developed to support informal carers. One participant with fibromyalgia and arthritis commented that:

> "Your family are trying to manage their life as well as your life. The stress it puts on your family is extreme- you have to depend on others and you don't want to."

Other participants talked about the impact of their disability on others- about how their friends felt "guilty." One participant suffering with psychosis said that "some relationships were not the same anymore as people interact differently with me since I've been ill."

There was a general feeling of frustration that the system does not support informal carers and/or help with discussing your care needs with family and friends. There was also an overwhelming sense that not enough information about how to access support and advice was readily available. One participant with arthritis, diabetes and a heart condition commented that 'if the information or support is out there I don't know how to find it and my family haven't been able to find it.'

It was suggested that information about services available to help friends and family support needed to be provided on many platforms, including online information; signposting and referral services being easily available via a general practitioner; and guidance booklets being given out at the point of diagnosis.

Taking a holistic approach to social care

A number of participants also suggested that insufficient consideration was given to the holistic needs of people receiving care. They said that a person was not looked at as a "whole package." One said that the biggest negative impacts of their disability wasn't the disability itself, but the way it affected their day to day life, stopping them from ever going away, having a social life or any 'respite.' The participant suffering with psychosis commented that sometimes a person didn't need 'care' per se, but simply someone:

> "to help me go out. I don't go out on my own… it would be nice to have someone neutral who could come out with me, someone who doesn't see the disability, they see me."

Another participant with multiple sclerosis suggested that newly disabled people should be given support in breaking the news of their disability to friends and family. They advocated that there should be help in putting complex medical diagnosis into a plain language form, to explain "to my kids why Mummy sometimes can't play anymore."

The National Living Wage

Leonard Cheshire Disability welcomes the introduction of the National Living Wage.

However, we are concerned about the challenges faced by the social care sector in finding the additional funds needed to meet wage increases at a time when local authority commissioners are squeezing care budgets and asking providers to do the same or more for less.

Across the UK, the social care sector is currently under significant financial pressure. Social care has seen funding reductions of £4.6 billion in real terms over the past five years, with further reductions of £0.5bn to come in 2015/16.[1] As a result of these severe funding pressures, most providers' fee levels are remaining static (and decreasing in real terms). This means that many providers now receive fees from local authorities which do not reflect the true cost of supporting people.

Sustainable funding for social care

We believe that over the next five years funding for social care will need to 'follow the legislation.' The Social Services and Wellbeing Act's person centred policies come at a time when social care across the UK is facing unprecedented financial challenges, with many providers receiving which don't reflect the true cost of supporting people. We believe funding has to be there to turn positive ideas into best practice. To ensure a sustainable care market, providing quality support for disabled people, facilitating them in fulfilling their potential, and living the lives that they choose.

We believe a more sustainable approach to funding would be to provide funding over five year terms. We would welcome the committee looking at the way in which commissioning for care is undertaken and see whether longer funder cycles may help improve efficiency and delivery of services.

We also believe that there are innovative solutions which could potentially be found in the 3rd sector to help statutory services better deliver their duties, and reduce wider budget pressures. For example, some of Leonard Cheshire's residential care homes in Wales include hydrotherapy pools and other equipment for delivering physiotherapy. At the moment, these are used exclusively by our residents. But, potentially, funding solutions could

[1] ADASS, Budget Survey, 2015.

be reached whereby they were used by a broader range of care recipients, relieving pressures on LHBs.

Issues impacting young disabled people

Leonard Cheshire Disability recently facilitated a group of disabled young people in visiting the National Assembly for Wales. During their visit, the young people suggested a number of other issues which the Committee might wish to consider. These included:

(a) Review of wheelchair services and funding

Disabled people talked about how getting access to the 'right' wheelchair has been challenging and raised concerns about ongoing maintenance and upkeep of their wheelchairs and access to services. People were clear about the need for improved funding for wheelchairs so that they can access chairs fit for their individual needs.

(b) Funding issues around social care

Various participants:

- had experienced lengthy delays in receiving social care funding (from application, to decision, to money received) and said that the process is too complicated and lengthy.
- hoped that the Social Services and Wellbeing Act would result in improvements related to social care funding, and asked that post-legislative scrutiny be conducted on the implementation of the Act.
- were concerned that there was not enough funding for 'social' hours (care packages meet basic physical needs but not enough funding is provided to enable people to experience social activities)
- were concerned about staff shortages (in that there was not enough funding to provide enough care staff to have prolonged interactions with care recipients)

Access to services for disabled people

Various participants spoke about the difficulties they have experienced in accessing services and finding community based programmes, particularly 'social' activities. Disabled people also told us that more needs to be done

to make accessing services easier, including awareness raising that programmes and services exist.

Yours sincerely,
Rhian

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Leonard Cheshire Disability
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Ymchwiliad i'r Adolygiad Blaenoriaethau ar gyfer y Pwyllgor Iechyd, Gofal Cymdeithasol a Chwaraeon

Inquiry into the Priorities for the Health, Social Care and Sport Committee

Ymateb gan: Coleg Brenhinol y Llawfeddygon

Response from: Royal College of Surgeons

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Priorities for the Health, Social Care and Sport Committee

Consultation Response
The Royal College of Surgeons

Leighton Veale
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M: [redacted]
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The Royal College of Surgeons (RCS) is a professional body that sets the highest standards for surgical practice and training in order to deliver safe and high quality patient care.

We welcome the opportunity to respond to this consultation and we would be pleased to appear before the Committee on any of these issues.

We outline below three key areas we believe the Committee should focus attention on during this Assembly term.

Improving access to services

Waiting times for elective surgery has long been a major challenge facing the Welsh NHS.
Elective waiting times

The current Welsh Government target is for at least 95 per cent of patients to have waited less than 26 weeks from referral to treatment, with 100 per cent treated within 36 weeks.
Figures for 2016 showed that by the end of May the equivalent of 370,000 patients (86%) in Wales waited less than 26 weeks despite the Welsh Government's target of 95% of patients meeting this figure. This is compared to 83.8% of patients within the target for the same month last year.

Waiting times in Wales are starting to move in the right direction and this is welcome. However, the Government's target of 95% of patients being treated within 26 weeks is still being missed by a significant margin. The 26 and 36 week planned treatment targets have not been met since September 2011.

Use of waiting times as a standard can be criticised but they are useful as a measurement of performance.

The NHS in Wales is facing increasing demand and is treating more people than ever before. In 2000/01, 275,000 elective inpatient and day cases and a total of 586,000 inpatient and day cases were seen. In 2011/12, 362,000 elective inpatient and day cases and a total of 723,000 inpatient and day cases were seen. A 2015 report by the Wales Audit Office into waiting times for elective treatment found that: "financial pressures have been a contributing factor to the decline in performance against waiting times targets". Such monetary pressures likely result in lower staffing and consultant levels in Wales with comparable parts of the UK.

Wales lost nearly half of its beds between 1999/2000 and 2013/14.

This reduction in bed numbers coupled with an increase in patient demand is a fundamental factor which has not been addressed. Until this discrepancy is resolved the Welsh NHS will continue to underperform. At present many patients present to emergency departments, not because they require hospital treatment but because they are frail and have nowhere else to go.

Other patients who have received inpatient therapy cannot be discharged because there are no facilities in the community to care for them.

We believe that the single biggest improvement in waiting times and capacity overall would be achieved by increasing capacity for frail people in the community.

Critical Care Bed capacity

A July 2014 report for Welsh Government showed that Wales has the lowest number of critical care beds in Europe. The analysis shows that Wales has 3.2 critical care beds per 100,000 people, compared to 4 in England and the European average of 11. The report also identifies that the number of critical care beds has fallen by four across Wales since 1999, with most units routinely operating above the recommended 75 per cent occupancy rate. Another factor is the inappropriate use of critical care beds as a result of delayed discharge, inappropriate admission or a shortage of staff.

Delayed access to and premature discharge from critical care have been identified as important risk factors for post-operative death, as has delayed admission to critical care. Further information on this can be read here: http://www.bmj.com/content/316/7148/1853 Routine admission to critical care after high risk surgery reduces complication rates and subsequent admissions to intensive care. This ultimately saves money through shortened hospital stay and reduced use of ICUs, which currently cost the NHS around £88 million per year.

We believe bed capacity, particularly critical care bed capacity, needs urgent consideration and we would urge the Welsh Government to consider how to increase bed capacity and use existing capacity more effectively.

In England, the number of available and occupied critical care beds is published publicly on a monthly basis. We would like to see similar data published in Wales.

Data and outcomes

Greater transparency in the health service in Wales would improve governance and drive up performance and allow us to make judgements about the quality of patient care in Wales.

As with many parts of the NHS across the UK, data collection in Wales has been historically poor, particularly for outcomes data. There are a variety of reasons for this, but in Wales outcomes and recording activity in particular have historically not been well resourced.

In Wales there is no routine publication of data on how many operations are cancelled and whether the cancellation is for a clinical or non-clinical reason. Data collection is fundamental to

increased efficiency and performance. This is recognised by NHS Wales in the collection of Hospital Episode Statistics, and by all specialty associations across surgery many of which have registries and national audit projects. In 2013 the Welsh Government undertook to work towards publishing surgical outcomes on a unit level; the RCS strongly supports this initiative. The RCS has the expertise to work with the Welsh NHS on this project.

Healthcare Inspectorate Wales

There has been criticism of HIW in the past from the medical profession and the Welsh Government indicated it would like to see 'full formal independence from government' for HIW. Legislation has been promised during this Assembly term and we support this.

The College supports the Welsh Government's position that HIW should be an independent body distinct from government. At present HIW is unfunded and understaffed. While proportionate regulation will not solve the problems facing the NHS alone, there urgently needs to be a clear inspection system providing external challenge to the NHS to help raise standards and reassure the public about the quality of services. HIW adequately funded could lead this system.

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Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: Iechyd Cyhoeddus Cymru
Response from: Public Health Wales

National Assembly for Wales – Health, Social Care and Sport Committee Consultation 2016

1. Public Health Wales believes that the Health, Social Care and Sport Committee has a significant opportunity to place a spotlight on pressing challenges and evidence based solutions regarding improving health and well-being in Wales. In addition to areas already identified for long term focus by the committee, such as sport and public health, gambling addiction, loneliness and isolation among older people, Primary Care, our submission highlights other areas the Committee could consider as part of their work.

2. Public health challenges and priorities

Wales faces significant challenges to improving health and well-being including:

- Tackling inequity in health – we know that there is a substantial and unacceptable gap in health and well-being between people living the most and least deprived areas of Wales
- Improving early years experiences – life before birth and during early childhood shapes health and experiences of inequalities in later life and therefore needs to be a topic of focus
- Improving mental well-being – poor mental well-being impacts on physical health and social inequalities and is a fundamental component of good health
- Shifting to a partnership model of prevention – our current system cannot continue to meet increasing demand and is not financially sustainable. Partnerships with individuals, communities and between public services and different sectors should help to deliver a better focus on prevention
- Improving healthcare outcomes - further improvements could be made through focusing on quality of care, patient safety, innovation, sharing and implementing good practice.

3. Public Health Wales' strategic priorities have been identified as means by which we can contribute to addressing these issues and include adopting a multi agency systems approach; working across sectors to improve the future health and well-being of children; supporting primary and community care services to improve the

public's health; supporting the NHS to improve outcomes for people using services; and continuously improving the quality, safety and effectiveness of the services we deliver.

4. The Well-being of Future Generations (Wales) Act provides a legislative framework and driver for adopting a more radical and transformational approach to the way we work. More specifically, the Committee has an opportunity to use the Act as a lens through which it undertakes it scrutiny function, thereby facilitating the embedding of the Act.

5. Investing in sustainable health and well-being

Public Health Wales has published a report "*Making a Difference: Investing in Sustainable Health and Well-being for the People of Wales*", which draws together expert opinion and research evidence on effective and sustainable solutions that are worth investing in to optimise health in Wales. The report highlights how removing the causes of poor health and inequalities saves lives, money and improves mental, physical and social well-being. Prevention has both short and long term benefits for not just the health system, but also for communities, society and the economy.

6. The report identifies three priority areas, which are enabled by legislation and approaches such as the Well-being of Future Generations Act, Prudent Healthcare principles and a systems working approach of building partnerships and synergies across sectors and stakeholders. The priority areas are:

a. Building resilience across the life-course and setting

Specific areas for action include:

- Ensuring a good start in life for all
- Promoting mental well-being and preventing mental ill health
- Preventing violence and abuse

b. Addressing harmful behaviours and protecting health

Specific areas for action include:

- Reducing smoking prevalence
- Reducing prevalence of alcohol misuse

- Promoting physical activity
- Promoting healthy diet and preventing obesity
- Protection from disease and early identification

c. Addressing wider economic, social and environmental determinants of health

Specific areas for action include:

- Reducing economic and social inequalities and mitigating austerity
- Ensuring safe and health promoting natural and built environment

7. There are already examples of partnership working to address the priorities identified. The United in Improving Health initiative, which includes representatives from the NHS, Local Authorities, Welsh Government, the Police, Third Sector, academia and local services, has identified the first 1000 days of life as a priority for action, with the aim of improving outcomes and reducing inequalities through realigning existing local and national resources.

8. Public Health Wales is using the findings from the report to further shape its strategic priorities for 2016-17. The report has been shared with partner organisations, with the aim of supporting the implementation of the Wellbeing of Future Generations Act.

9. The Committee may wish to consider the report when identifying areas for focus of its work.

10. Adverse Childhood Experiences

To date, Public Health Wales has published two reports which examine the prevalence of adverse childhood experiences and their impact on health and well-being across the life course. Adverse childhood experiences include abuse and neglect of children, as well as growing up in households where children are routinely exposed to issues such as domestic violence or individuals with alcohol use problems.

11. The first report links these experiences with health harming behaviours in the Welsh adult population and the second examines the impact on mental well-being. A third report, examining the use of health, social care services and premature mortality will be published later in 2016. Children with greater exposure to adverse childhood experiences are more likely to develop health harming and antisocial

behaviours e.g. being a high risk drinker, smoking tobacco, committing violence or being incarcerated, as well as reporting worse mental well-being.

12. The reports provide compelling evidence about the need to prevent adverse childhood experiences, to not only benefit those children, but also future generations in Wales. Preventing such experiences is also likely to reduce pressures and costs on the NHS and improve outcomes for the health, social, criminal justice and educational systems.

13. Recognising the importance tackling Adverse Childhood Experiences, Public Health Wales is translating the findings into practice. For example, the '*Early Intervention and Prevention: breaking the generational cycle of crime*' project aims to increase early intervention, prompt and positive action by ensuring that the police and partners have the right knowledge, skills and support in place so that they are able to identify and respond appropriately and effectively to early indicators of harm and vulnerability through the lens of Adverse Childhood Experiences.

14. Public Health Wales recommends the Committee consider how these findings could be used to inform its work programme.

15. Broader determinants of health and well-being

Tackling the wider determinants of health is pivotal to achieving the types of improvement in health and well-being – and the reduction in health inequalities – that are required in Wales. However, while National Assembly Committees facilitate discussion and action around a broad range of public health issues, we are concerned that the specific focus of each may not encompass a review of overarching problems facing the Welsh population. Such issues include housing-related matters (covering home safety, carbon monoxide, falls prevention, poor housing conditions), climate change mitigation and adaptation, outdoor air quality and other built and physical environment concerns such as sustainable design and planning for healthy communities and road traffic crashes and casualties.

16. Such public health priorities pose significant challenges as they require multi-faceted solutions that can only be achieved through

multi-agency and multi-disciplinary collaborative action. There is a concern that these matters do not fall under one Committee, but rather straddle them all, with the associated risk that they may not receive the required attention. We would advocate that National Assembly Committees consider these overarching priorities

17. Other areas of focus

Specific areas we would recommend the Committee focus on, over the forthcoming term include:

- Immunisation and vaccine preventable diseases. For example, expanding the children's influenza programme is expected to impact on reducing morbidity and mortality at all ages and associated NHS winter pressures due to influenza because children are 'super-spreaders'; Improving uptake of immunisation among school children, particularly aimed at preventing meningococcal disease and eliminating measles; Implementation of human papillomavirus (HPV) vaccination for men who have sex with men through sexual health clinics in Wales; Introduction of universal hepatitis B vaccination to the infant schedule (subject to UK procurement of a cost effective vaccine).
- The use of real-time genomic diagnostics in the community. This is likely to have a significant impact in providing fast and accurate diagnostics for infectious disease e.g. for disease surveillance or responding to disease outbreaks.
- Ensuring that Welsh Language and culture is a consideration in the services we provide to the public.

18. About Public Health Wales

PHW is an independent NHS body that has four statutory functions. These are to:

- provide and manage a range of public health, health protection, healthcare improvement, health advisory, child protection and microbiological laboratory services and services relating to the surveillance, prevention and control of communicable diseases;
- develop and maintain arrangements for making information about matters related to the protection and improvement of health in Wales available to the public; to undertake and commission research into such matters and to contribute to the provision and development of training in such matters;

- undertake the systematic collection, analysis and dissemination of information about the health of the people of Wales in particular - including cancer incidence, mortality and survival; and prevalence of congenital anomalies; and
- provide, manage, monitor, evaluate and conduct research into screening of health conditions and screening of health related matters.

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Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: The Delivery Unit
Response from: The Delivery Unit

Health Social Care and Sports Committee Consultation

Priorities for the Health, Social Care and Sports Committee.

The Delivery Unit welcomes the opportunity to provide a response to the Committee's priorities for the Fifth Assembly and in particular its programmes during the next 12- 18 months.

The Delivery Unit (DU) is responsible for the functions of assurance, improvement of performance and supporting delivery within the NHS. In order to achieve this it works in partnership with statutory and non-statutory health and social care agencies.

The work and priorities of the Health Social Care and Sport Committee are therefore of significant interest to the DU.

The areas that the committee has identified from its informal discussions are all highly relevant to improving the quality and efficiency of health and social care services.

Of these the DU would see the following as particular priorities likely to have a broad impact on patients given the universal nature of the service areas involved:

- Integration of Health and Social Care services
    - Particular focus could be paid to joint commissioning arrangements and the development of intermediate care services and their potential to avoid unnecessary admissions and facilitate timely discharge. It would be helpful to focus not only on local developments but on the scale and pace of development in response to demand together with mechanisms to measure outcomes for individuals and communities.
    - Specific scrutiny could also be given to arrangements for the provision of care in other settings such as care homes and extra care schemes designed to promote independent living and care in non-hospital settings. The development of such resources is dependent on longer term planning between Health and local authority social services and housing departments.
- Efficiency within the NHS and modern management practices
    - This issue is related to that of integration between health and social care and the development of intermediate care approaches. These initiatives can assist efficiency, improving flow through hospitals in scheduled and unscheduled care reducing delays in transfer within the system, reducing cancellations in scheduled care and thus reducing waiting times.
- Waiting Times
    - As stated above the scrutiny of waiting times should not be viewed in isolation from the issues of integration and efficiency due to the interconnectedness of these challenges.
- Primary care
    - Primary care is also integral to improving efficiency. Scrutiny could include not only improving the manner in which primary care attends to its core business but to the role clusters can play in enhancing coordinated

multidisciplinary working in physical and mental health. This could include the development of virtual wards in community settings.

- The Ambulance Service
    - As in a number of the priority areas the scrutiny of the ambulance service needs to be addressed with other priorities in mind including the relationship of the management of ambulance services to unscheduled care and flow within hospital settings most notably within Emergency Departments and assessment units.
- Sport and Public Health
    - Consideration of access to sport, but perhaps more importantly encouraging and enabling people to be more active, is a vital part of improving both physical and mental health. The findings from studies such as the Caerphilly cohort study can inform the impact that physical activity and other related lifestyle changes can have on; improved health and quality of life, reduced health and social care demand and reductions in premature mortality.

A number of the committee priorities are more specific to particular sections of the population. These are also helpful priorities addressing the potential to provide the best start in life for children in Wales and focussing upon the challenges of Wales' ageing population. These have the potential to improving health at a population level and reduce the potential growth in demand for health and social care services in the future.

The following priorities are therefore also supported:

- Neonatal services
- Loneliness and isolation among older people
    - As with initiatives to enhance access to sport and broader physical activity tackling loneliness and isolation not only improves quality of life and mental and physical health but can also impact on premature death. Recent studies have demonstrated that loneliness and isolation can have an equal impact upon health to smoking 15 cigarettes per day (Holt-Lunstad, 2010). It is not therefore merely a social intervention but has significant health benefits.
- Use of antipsychotic medication in care homes
    - This is an important aspect of the management of people with cognitive impairment and dementia more specifically. A number of initiatives to reduce inappropriate prescribing in hospital and other care settings have been introduced in recent years. Maintaining scrutiny of the degree to which these initiatives are impacting upon clinical practice and the development of alternative strategies to manage behaviours that challenge is important particularly given the increasing prevalence of dementia as the population ages.

The DU supports the priorities already considered but would urge that scrutiny of the individual priorities is connected and that it considers the pace and scale of change.

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Inquiry into the Priorities for the Health, Social Care and Sport Committee
Ymateb gan: CLlLC
Response from: WLGA

Priorities for the Health, Social Care and Sport Committee

September 2016

WLGA • CLlLC

Introduction

1. The Welsh Local Government Association (WLGA) represents the 22 local authorities in Wales, and the three national park authorities and three fire and rescue authorities are associate members.

2. It seeks to provide representation to local authorities within an emerging policy framework that satisfies the key priorities of our members and delivers a broad range of services that add value to Welsh Local Government and the communities they serve.

3. In advance of the National Assembly for Wales elections in 2016 the WLGA published its Manifesto which identifies the key priorities where we believe the Welsh Government can help councils deliver on national outcomes and prioritise services that matter most to the communities of Wales. These include:
   - Commit to fully cost and fund any new Welsh Government initiatives or legislation.
   - Properly commit to multiyear financial settlements so councils can plan more effectively and support the Welsh Government's longer-term 'Future Generations' ambitions.
   - Urgently reform the increasingly outdated finance formula which underpins funding to properly reflect deprivation, sparsity and the challenges of the future.
   - Keep social care within local government as set out in the Social Services and Well-being (Wales) Act 2014.
   - Establish a new Preventative Integrated Care Fund for Wales funded through the potential Barnett consequential from the £8bn annual NHS investment in England.
   - Transfer Public Health Wales function and its funding into local government.
   - Ensure greater democratic oversight of the NHS through locating the powers of Community Health Councils (CHCs) within local government.
   - Switch investment into preventative services such as social care, economic development, transport, housing, libraries, leisure and environmental health. These services increase people's wellbeing

and keep people out of care in hospitals, that is both expensive and can lead to people losing control over their lives.

4. The WLGA welcomes the opportunity to help inform the Committee's Forward Work Programme and we have identified a number of key priority areas we believe should be considered both over the next 12 to 18 months and in the longer term work programme. The priorities set out in our manifesto are an important starting point as these will help local authorities respond to local challenges and needs and contribute to the delivery of national ambitions and outcomes. More importantly they will help local councils deliver on the priorities of their own local communities. The consultation outlines a number of areas that the Committee may wish to include in the longer term work programme and we would support the priority areas of integration of health and social care services; primary care and in particular how local government are involved in the planning of services; and a focus on loneliness and isolation among older people.

Key Priority Areas

Impact of legislation

5. Under the previous Government we saw the introduction of two major pieces of social care legislation – the Social Services and Well-being (Wales) Act and the Regulation and Inspection of Social Care (Wales) Act. In addition, we saw legislation being passed that the health and social care sector will need to consider and link with, such as the Well-being of Future Generations (Wales) Act and the Housing (Wales) Act. There was also consultation undertaken on other potential pieces of legislation in relation to health and social care in the form of the NHS Green Paper: Our Health, Our Health Service.

6. It will be important that the Committee monitors the implementation and impact of these pieces of legislation, the linkages between them and any new legislation or changes made following the Green Paper.

7. The Social Services and Well-being (Wales) Act will have a significant impact as it is implemented over the next few years, transforming the way social services are delivered and changing the way citizens needs are assessed. One of the key elements of the Act is around greater

partnership working and integration of services and it will be important to exam the role of all partner organisations in relation to delivery of the Act, ensuring that they are aware of their responsibilities and carry these out to ensure compliance.

8. Key to the successful delivery of the ambition for the future and improving quality is through a workforce which is sustainable, competent, confident, valued and capable of delivering personalised and flexible services which meet changing demands and delivering improved outcomes for people and communities. It will be essential that any examination of the legislation picks up on the progress that is being made to support the workforce and we welcome the fact that the Committee has already announced an inquiry into the sustainability of the health and social care workforce.

Increasing Demand and Demographic Challenges

9. The increasing demand for services and demographic changes at a time of austerity has been well documented and whilst the Act looks to support greater partnership working and integration of services we need to look at how best this can be achieved in light of some of the challenges that we are currently facing. In addition to the demographic changes there are a range of other issues that have increased demand for services such as the Cheshire West judgement which has resulted in a 17-fold increase in Deprivation of Liberty Safeguards (DoLS) cases in Wales, the resettlement of Syrian Refugees and potential increases in numbers of Unaccompanied Asylum Seeking Children (UASC). Recently there has been a significant focus on improving outcomes for looked after children and it will be key to ensure that the Committee is sighted on these issues as well as the Children, Young People and Education Committee.

10. The Social Services and Well-being Act does provide future direction for how services can and should be delivered, but we need to ensure that both the time and resources to support its proper implementation are provided.

11. The pressures being faced have increased the importance of providing preventative activity and services aimed at early intervention (with the intention of holding off more costly and potentially intrusive

interventions at a later stage). We all agree with the benefits of early intervention and prevention in the first case, in terms of better life experiences and well-being for individuals and families, as well as reduced costs for public services, particularly in the longer term. But such services are at significant risk should local government be required to shoulder the burden of any further cuts. Local government shares the view of the importance of preventative council services and appreciate these make a vital contribution to reducing pressure on other public services in Wales, such as the NHS. However, reduced budgets have placed increasing pressure on the availability of preventative services, most of which are non-statutory. While new models of service have been established in many authorities, it is likely that any further cuts will continue to see a decline in some community services that promote well-being.

12. An examination of the role of preventative services and how best they can be provided and supported would be beneficial.

Integration of Health and Social Care

13. In Wales, significant progress has been made through partnership working in terms of enacting the Social Services and Wellbeing Act 2014, and in the introduction of factors such as an intermediate care fund (ICF). This progress has been significant, however we have also seen the policy developments and investments that have taken place in England which point to an ambitious agenda. For example, Greater Manchester's proposals for a combined health and social care budget will see a £6bn pooled budget between the NHS and local government. It will be important that the work of the Committee ties in with the Parliamentary Review into the long-term future of Health and Social Care in Wales announced by the First Minister, but we believe that an inquiry looking at the progress made to date; and assessing the impact of Welsh Government policies and legislation on integration of health and social care services should be one of the priorities for the Committee.

14. One of the key issues for the new Welsh Government will be how to shift the priorities from hospitals to prevention and public health. It has been the WLGA's policy that the latter function should be located in local government as is the case in England.

Health and Social Care Funding

15. In 2012 the Institute for Fiscal Studies report on local government expenditure in Wales showed that, until 2009-10, spend had been increasing in real terms by around 5% each year. This kept pace with inflation and service pressures. From 2009-10, spend has been reducing in real terms, but if expenditure had kept pace with general inflation, it would now be over £7bn. The resulting gap of £720m represents a conservative estimate of the cuts and efficiency savings achieved so far by local government. From April, councils in Wales face budget pressures of just over £200m due to inflation, demography and unavoidable financial pressures, e.g. the introduction of the single tier pension. It is likely that by 2019-20 there will be a cumulative budget shortfall of around £800m. The submission by WLGA and ADSS Cymru to Welsh Government on Social Services budget pressures last year indicated that social services departments in Wales faced unavoidable cost and demand pressures that will increase from £68m in 2016/17 to £234m by 2019/20. Clearly the ability to absorb any additional costs is virtually non-existent.

16. There have also been significant concerns raised over the fragility of the residential and domiciliary care sectors across Wales. There are a series of factors that have increased or will further increase the costs of providing care services, including:
    - National Living Wage
    - Sleeping in judgement
    - Pension changes
    - Travel costs
    - Impact of HMRC changes

17. We believe that an examination of the future funding of social care in Wales in order to ensure the future sustainability of the sector is needed and should be one of the key priorities for the Committee.

For further information please contact:

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