# Agenda – Health and Social Care Committee

| Meeting Venue: | For further information contact: |
|---|---|
| **Committee room 5, Tŷ Hywel and video conference via Zoom** | **Helen Finlayson** |
| | Committee Clerk |
| Meeting date: 29 June 2023 | 0300 200 6565 |
| Meeting time: 09.00 | SeneddHealth@senedd.wales |

## Private pre-meeting

(09.00–09.30)

## 1 Introductions, apologies, substitutions and declarations of interest

(09.30)

## 2 Gynaecological cancers: Panel 7

(09.30–10.30) (Pages 1 – 15)

Professor Dyfed Wyn Huws, Director, Wales Cancer Surveillance and Intelligence Unit (WCSIU)

Helen Thomas, Chief Executive, Digital Health and Care Wales

Evidence from Public Health Wales

Research brief

## Break

(10.30–10.45)

## 3 Gynaecological cancers: Panel 8

(10.45–11.45) (Pages 16 – 20)

Natasha Wynne, Senior Policy Manager, Marie Curie

Dr Jo Hayes, Medical Director

Paper 1 – Marie Curie

## 4 Papers to note

(11.45)

4.1 Letter to Health Education and Improvement Wales regarding gynaecological cancers

(Pages 21 - 22)

4.2 Letter from Health Education and Improvement Wales regarding gynaecological cancers

(Pages 23 - 25)

4.3 Letter to the UK Government's Department of Health and Social Care regarding gynaecological cancers

(Pages 26 - 27)

4.4 Letter from the UK Government's Department of Health and Social Care regarding gynaecological cancers

(Pages 28 - 31)

4.5 Letter to Minister for Health and Social Services regarding Dentistry

(Pages 32 - 34)

4.6 Letter from Minister for Health and Social Services and the Deputy Minister for Social Services regarding Hospital Discharge Guidance

(Pages 35 - 42)

4.7 Follow up information from Professor Mark Llewellyn regarding the Evaluation of the Social Services and Wellbeing (Wales) Act 2014

(Pages 43 - 51)

## 5 Motion under Standing Order 17.42 (ix) to resolve to exclude the public for the remainder of the meeting

(11.45)

## 6 Gynaecological cancers: consideration of evidence

(11.45-12.00)

## 7 Forward work programme

(12.00-12.15) (Pages 52 - 71)

Paper 2 - Forward work programme

# Agenda Item 2

Document is Restricted

Gofal a chefnogaeth drwy salwch terfynol
Care and support through terminal illness
Marie Curie

# Health & Social Care Committee: Gynaecological Cancer Inquiry

*January 2023*

Organisation: Marie Curie
Contact details: Bethan Edwards, Senior Policy Manager
Happy for response to be publicly shared? Yes

## Introduction

Improving prevention and treatment of gynaecological cancers is a vital part of ensuring women and those assigned female at birth (AFAB) are living well for longer. However, it is also important to recognise that some gynaecological cancer diagnoses are terminal. Where those diagnoses are terminal, we need to ensure that the best end of life experience possible is achieved, in line with the person's wishes and preferences, and that no disproportionate barriers are facing women and those AFAB when they need end of life care and support. Therefore, we urge the health and social care committee to consider palliative and end of life care (PEOLC) throughout this inquiry and that evidence gathering takes a truly cradle to grave approach.

Research exploring gender inequalities at end of life is still fairly limited, particularly in relation to the situation in the UK and in Wales. As a result, this response is unable to present the specific challenges faced by patients with a terminal gynaecological cancer diagnosis but will put forward the challenges facing women with a terminal illness more generally, many of which will apply to those with terminal gynaecological cancer.

## Context

Research has previously forecast a drastic increase in demand for PEOLC in the next two decades[1]. The Office for National Statistics project that by 2040, there will be an additional 5,000 deaths per year in Wales (from 36,136 in 2021 to 41,000 in 2040-41)[2]. This is partly due to an ageing population and a rise in the number of people living with more than one complex condition.

By 2040, the biggest proportion of those in need of PEOLC is likely to be those over 85 years old, and the leading cause of death is set to be dementia[i,3]. We know that women typically have a longer life expectancy than men, but also live with a greater number of 'years with a disability'[ii].

The above research and projections point towards an increasing number of women in need of PEOLC in the imminent future, and with 546 females dying from gynaecological cancer in 2021 alone[4], it is crucial that the health and social care committee's inquiry includes a focus on women with a terminal diagnosis.

## Challenges faced by women at end of life according to international research

[i] Estimates show that by 2040, dementia deaths will be more than three times higher than the current mortality rate.
[ii] In Wales, life expectancy at birth for males in 2017 to 2019, is 78.5 years old, whereas for females it is 82.3 years. Between 2017 and 2019 in Wales, females lived an average of 22.1 years with a disability, in comparison to males who lived with an average of 17.1 years with a disability.

### *Pain management and symptom burden*

Recent Marie Curie research asked people in Wales what their biggest priority would be when thinking about the end of their life; being pain free was most people's top answer[5]. One of the key pillars of PEOLC is a focus on quality of life and pain management as being pain free enables people to experience a good quality of life for as long as possible. However, research shows that there are factors relating to sex and gender which have led to discrepancies in how some women report symptoms, the pain they experience, and the treatment they receive as they approach end of life.

Evidence shows that women often report more severe daily feelings of pain, nausea, and fatigue[6,7,8], but may also have to report greater symptom distress than men for their pain to be acknowledged[9]. Evidence suggests that this is partly a result of gender bias and women's pain sometimes being underestimated, with healthcare professionals being less likely document symptoms[10]. Research also discusses how women are more likely to have pain attributed to psychological rather than physical needs and to then be prescribed sedatives rather than the appropriate pain relief[11]. The gender bias at play when it comes to how women and men are expected to cope with symptoms can directly affect some women's access to pain management medications, meaning some women may be suffering from unwarranted pain and severe unmet palliative care needs when approaching the end of their life.

Biological differences when it comes to how females and males experience pain and respond to pain management is not a new phenomenon[12], but research now suggests that this could negatively impact women right up until their death. Studies have demonstrated that there are disparities in how the male and female body receives and responds to the main pain relief drug prescribed at end of life - opiates[13]. If women are prescribed opiates with no consideration of how their biology could be impacting the effects of the drug, their quality of life could be disproportionately affected. However, more research is needed here to fully understand how women could be responding to end of life pain management differently to men, to ensure no one is suffering from avoidable pain in their last months, weeks and days of life.

### *End of Life Care Interventions*

PEOLC can be initiated at any point during a patient's journey and can include a range of holistic treatments focusing on psychological, social, and spiritual aspects of care[14]. When it comes to choices around end of life care interventions, the understanding and views of women appear to be affected by social norms and gender bias. While some research shows that terminally ill women tend to be more open, accepting of palliative support, and engaged with their end of life journey[15,16], other studies show that some women are less likely than men to state a preference for end of life care treatments such as chemotherapy, cardiopulmonary resuscitation and artificial feeding[17,18]. The evidenced reasons behind this are not yet substantive and should be fully explored, however such findings do highlight potential inequalities in the way women are approaching, deciding on, and ultimately accessing treatments which could improve their quality of life.

One example of this is how females may not be benefitting from early palliative care (EPC) in the same way as males[19]. EPC is believed to be best practice and is attributed to better

quality of life and lower rates of depression[20,21], but findings have shown that females in some instances report lower quality of life and mood than male counterparts receiving similar treatment[22].

End of life care clinical decisions continue to rely on research and assumed best practice which is majorly based on male biology, neglecting any potential differences in sex and gender. To ensure everyone is able to access the EOLC interventions which will benefit them and enable a better quality of life for longer, more research is needed into how sex and gender impacts on care and treatment decisions.

### *Place of care and death*

We know that over half of all people would prefer to die at home[23], but research suggests that for many women this is often not possible or the case. Social norms have dictated a society where it is women who are the natural caregivers and many even feel it is their duty when it comes to providing care[24]. Nonetheless, many women express fears around feeling like a burden if they themselves need care from family and loved ones[25]. In fact, studies report more women receiving care and support from healthcare professionals and specialists rather than unpaid carers[26].

The fact that women have longer life expectancy and are more likely to outlive their partner (in a heteronormative relationship), reinforces this trend. Additionally, those who have been carers (of which the majority are women), are less likely to want to die at home[27]. This is assumed to be due to a greater understanding of the reality of caring for someone at home.

A wider challenge in supporting women to die at home if this is their preference, is insufficient resources and capacity in health and social care community provision. Recent research projects a substantive increase in demand for care in the community by 2040 in Wales and England, with deaths at home increasing by 88.6%, and deaths in care homes projected to increase by as much as 108%[28]. The insufficient capacity in community provision could also be impacting on women's ability to die at home if this is their preference. Everyone in Wales should be able to die where they wish, if safe and feasible, and more research is needed to understand whether gender norms are currently inhibiting this.

## Ongoing work

For future reference, Marie Curie Cymru is currently carrying out research looking into any potential gender differences in access to their services across Wales; diagnosis and reason for admission are two of the many variables being analysed and may be useful and relevant to the inquiry into gynaecological cancer. Findings are expected to be published in early 2023.

In addition, the Marie Curie Palliative Care Research Centre at Cardiff University are working on developing a PEOLC data dashboard. This is likely to be public in 2023 and will be able to provide data on how patients with gynaecological cancer interacted with end of life care services in their last year of life. Initial research show some interesting insights but are currently unable to be formally published.

If these current pieces of work are of interest to the health and social care committee in gathering evidence for the inquiry, please get in touch with bethan.edwards@mariecurie.org.uk to ask for updates over the coming months.

## Conclusion

Although the above international findings are not specific to terminal gynaecological cancer patients, it is likely that many of the issues discussed are hugely relevant. With the increasing numbers of people reaching older ages, and with complex conditions, it is vital that we are able to provide sex and gender-specific care to women and those AFAB who are approaching the end of their life with terminal gynaecological cancer.

References

[1] Etkind, S., Bone, A. et al, 'How many people will need palliative care in 2040? Past trends, future projections and implications for services', BMC Medicine, 15 (102), 2017
[2] ONS (2022) 2020-based Interim National Population Projections – Wales summary. Principal projection - Wales summary - Office for National Statistics (ons.gov.uk)
[3] Ibid.
[4] ONS, Mortality statistics - malignant neoplasms of female genital organs in Wales (accessed from Nomis, December 2022)
[5] Marie Curie, 2022. Public Attitudes to Death and Dying in Wales.
[6] Ullrich, A. et al., 2019. Exploring the gender dimensions of problems and needs of patients receiving specialist palliative care in a German palliative care unit- the perspectives of patients and healthcare professionals. *BMC Palliative Care*.
[7] Fillingim, R. et al., 2008. Sex, Gender and Pain; a review of recent clinical and experimental findings. *Science Direct*
[8] Husain, A. et al., 2007. Women experience higher levels of fatigue at the end of life: a longitudinal home palliative care study. *PubMed.*
[9] Gott, M., Morgan, T., Williams, L., 2020. Gender and Palliative Care: A Call to Arms. *SAGE Publications*.
[10] Falk, A., et al. 2015. Differences in symptom distress based on gender and palliative care designation among hospitalised patients. *Journal of Nursing Scholarship.*
[11] Schafer G., et al., 2016. Health care providers' judgments in chronic pain: the influence of gender and trustworthiness. *Pain*, 157(8).
[12] Sorge, R. and Totsch, S.K., 2018. Sex differences in pain. *Current Opinion in Physiology*, 6
[13] *Ibid*.
[14] NHS, 2020. What end of life care involves.
[15] Ullrich, A. et al., 2019. Exploring the gender dimensions of problems and needs of patients receiving specialist palliative care in a German palliative care unit- the perspectives of patients and healthcare professionals. *BMC Palliative Care*
[16] Fahad Saeed, M.D. et al., 2018. Preference for Palliative Care in Cancer Patients: Are Men and Women Alike? *Journal of Pain and Symptom Management*, 56(1).
[17] Miesfeldt S, Murray K, Lucas L, et al., 2012. Association of age, gender, and race with intensity of end-of-life care for Medicare beneficiaries with cancer. *Journal of Palliative Medicine*. 15.
[18] Bookwala J, Coppola K, Fagerlin A, et al., 2001. Gender differences in older adults' preferences for life-sustaining medical treatments and end-of-life values. *Death Studies*. 25.
[19]Nipp, R. et al., 2016. Age and gender moderate the impact of early palliative care in metastatic non-small cell lung cancer. *Oncologist*
[20] Fliedner, M., et al., 2019. An early palliative care intervention can be confronting but reassuring: A qualitative study on the experiences of patients with advanced cancer. *Palliative Medicine*, 33(7).
[21] Nipp, R. et al., 2016. Age and gender moderate the impact of early palliative care in metastatic non-small cell lung cancer. *Oncologist*.
[22] *Ibid*.
[23] Hoare, S. et al., 2015. Do Patients Want to Die at Home? A Systematic Review of the UK Literature, Focused on Missing Preferences for Place of Death. *PLOS ONE*, 10(11)
[24] Ullrich, A. et al., 2019. Exploring the gender dimensions of problems and needs of patients receiving specialist palliative care in a German palliative care unit- the perspectives of patients and healthcare professionals. *BMC Palliative Care*
[25] *Ibid*.

[26] *Ibid*.
[27] Gott, M., Morgan, T., Williams, L., 2020. Gender and Palliative Care: A Call to Arms. *SAGE Publications.*
[28] Bone, A., Gomes, B., Etkind, S. et al., 2018. What is the impact of population ageing on the future provision of end-of-life care? Population-based projections of place of death. *Palliative Medicine*, 32(2).

**Y Pwyllgor Iechyd a Gofal Cymdeithasol**
–
**Health and Social Care Committee**

**Senedd Cymru**
Bae Caerdydd, Caerdydd, CF99 1SN
SeneddIechyd@senedd.cymru
senedd.cymru/SeneddIechyd
0300 200 6565
–
**Welsh Parliament**
Cardiff Bay, Cardiff, CF99 1SN
SeneddHealth@senedd.wales
senedd.wales/SeneddHealth
0300 200 6565

Alex Howells
Chief Executive
Health Education and Improvement Wales

17 May 2023

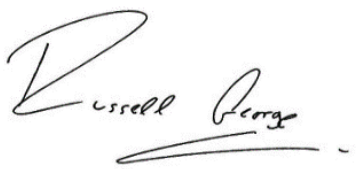
Dear Alex

Inquiry into gynaecological cancers

The Health and Social Care Committee is looking at the experiences of women with symptoms of gynaecological cancer, how they are listened to and treated by healthcare professionals, and how services empower, care for and look after women diagnosed with a gynaecological cancer to ensure their physical, psychological and practical needs are met.

During oral evidence on 27 April 2023 a number of issues were raised in relation to the workforce, and it would assist our inquiry if you were able to provide us with the information in the attached annex. To help inform future evidence sessions, we would be grateful to receive your response by Monday 12 June 2023.

Yours sincerely



Russell George MS
Chair, Health and Social Care Committee

Croesewir gohebiaeth yn Gymraeg neu Saesneg. We welcome correspondence in Welsh or English.

## Annex: Inquiry into gynaecological cancers

During our evidence session on 27 April 2023 as part of our inquiry into gynaecological cancers, a number of issues relating to the workforce were raised. We would welcome further information on the matters listed below. We would be grateful to receive your response by Monday 12 June 2023.

1. The Wales Cancer Improvement Plan says "workforce planning needs to be better, including a greater understanding of the future workforce needs". Could you provide an update on the cancer workforce plan and specifically details of workforce planning in relation to the gynaecological cancer workforce.

2. Data on the number of gynaecological cancer specialist nurses working in NHS Wales. We were also told that there is no supported educational pathways to allow qualified band 5 nurses to develop into cancer specialist nurses. Could you confirm whether that is the case.

3. Data on the number of consultant gynaecological oncologist posts, the number of vacant posts, and relevant number of consultant training posts by health board in Wales.

4. We were told that many clinical nurse specialists are fast approaching retirement age. Has HEIW done any projections on the number of clinical nurse specialists who are likely to retire in the next 5-8 years and who will replace them/ their expertise.

5. What access to training there is for new and experienced nurses to become cancer nurse specialists.

GIG CYMRU NHS WALES
Addysg a Gwella Iechyd Cymru (AaGIC)
Health Education and Improvement Wales (HEIW)

**Addysg a Gwella Iechyd Cymru (AaGIC)**
**Health Education and Improvement Wales (HEIW)**
Tŷ Dysgu, Cefn Coed,
Nantgarw CF15 7QQ
Ffôn | Tel: 03300 585 005
Ebost | Email: heiw@wales.nhs.uk
Gwefan | Web: aagic.gig.cymru / heiw.nhs.wales



Our Ref: JR/cw

Date: 9 June 2023

Russell George MS
Chair
Health & Social Care Committee

Sent by email via SeneddHealth@senedd.wales

Dear Russell

**Inquiry into Gynaecological Cancers**

Thank you for your letter dated 17 May 2023 informing of the workforce related issues raised during the evidence session on 27 April. In our Chief Executive's absence, I have responded to each one in turn.

1. **The Wales Cancer Improvement Plan says, "workforce planning needs to be better, including a greater understanding of the future workforce needs". Could you provide an update on the cancer workforce plan and specifically details of planning in relation to the gynaecological cancer workforce.**

   The National Workforce Implementation Plan (NWIP) produced by Welsh Government recognises the importance of refining our longer-term approach to workforce planning within NHS Wales. There are a number of Strategic Workforce Plans in development as set out in the NWIP including the development of nursing workforce plan which incorporates all nurses working within NHS Wales.

   Specifically on cancer services, we are working with the Wales Cancer Network (WCN) and have developed and tested a pathway workforce planning methodology for Health Boards to use which supports implementation of the Single Cancer Pathway and a guide and resources are now available. We are now focussing on the analysis of data in specific pathway areas including GI, Urology and Lung Cancer which will inform pathway planning and the identification of workforce solutions. As yet, we have not done any specific work in relation to gynaecological cancers, but this is something that we can consider as part of the forward work programme.

2. **Data on the number of gynaecological cancer specialist nurses working in NHS Wales. We were also told that there is no supported educational pathways to allow qualified band 5 nurses to develop into cancer specialist nurses. Could you confirm whether that is the case.**

   Regrettably, our national workforce reporting system, ESR, does not hold information at this level. NHS Wales is exploring opportunities to improve data quality in relation to specific job roles. We are

aware of a recent piece of work conducted by the Wales Cancer Network which attempted to capture data on the size and shape of the specialist workforce through a census. The dataset is not comprehensive, but it does provide a baseline provision and indicates that there are around 22 gynaecological cancer specialist nurses working in Wales currently. Given that one HB has not submitted data to the census, this under-represents the true position.

In terms of educational pathways, this is an area that we have prioritised within our Integrated Medium-Term Plan for 2023/24 and we will be working collaboratively with the Wales Cancer Network over the next two years to develop a competency framework for both nurses and allied health professionals supported with funding by Macmillan. This will include work to understand the future demand and capacity needed across a number of areas including the surgery and oncology cancer nursing workforce areas. Further information on education development is set out in response to point 5 below.

**3. Data on the number of consultant gynaecological oncologist posts, the number of vacant posts, and relevant number of consultant training posts by health board in Wales.**

We do not hold information on the number of consultant gynaecological oncologist posts and vacancies as this information will be held at a Health Board level. We can confirm that there are 77 trainees within the Obstetrics and Gynaecology specialty and a further 12 medical oncology and 27 clinical oncology trainees in Wales.

***4.*** **We were told that many clinical nurse specialists are fast approaching retirement age. Has HEIW done any projections on the number of clinical nurse specialists who are likely to retire *in the next 5-8 years and who will replace them/their expertise.***

The nursing workforce plan that is in development will consider the wider demand and supply side factors and this plan will provide the framework for the consideration of all nursing roles including those working within cancer services. As data on clinical nurse specialists is not specifically recorded within ESR we have not been able to undertake any detailed work on clinical nurse specialists yet. The recent piece of work conducted by the Wales Cancer Network on the data capture on the size and shape of the specialist workforce identified that approximately 44% of the Gynaecology specialist cancer nursing workforce were over the age of 50. However, as part of our work with the Wales Cancer Network we will seek to improve data capture in this area. In addition, within the NWIP there was a specific requirement for HEIW to work with partners to develop a national retention plan for nursing and we anticipate that this will be published in summer 2023.

**5. What access to training there is for new and experiencing nurses to become cancer nurse specialists.**

HEIW supports a range of professionals to develop and extend skills through our postgraduate funding route. Each year, we allocate a sum of £2.5m to Health Boards across Wales which supports registered staff in being able to undertake post-graduate training. A significant proportion of this funding supports individuals to undertake Advanced or Consultant level qualifications.

We have also recently reviewed our Advanced and Consultant level Practice Frameworks and a new Framework for Extended, Advanced and Consultant Level Clinical Practice in Wales is being launched in June 2023. This will provide a more flexible route for individuals to develop within their specialist areas and defines levels of practice, the education required at each level and how employers can provide governance and support to practitioners. Again, working with the Wales Cancer Network, we will ensure that this is aligned with the joint programme of work to be taken forward from 2023/24. In addition, we are finalising a Continuing Professional Development (CPD) Strategy within HEIW and anticipate that this will be published in the summer of 2023.

A Career Pathway, Core Cancer Capabilities in Practice (CiP) and Education Framework for the Nursing and Allied Health Professions Cancer Workforce (the 'Framework') has recently been published as part of a UK wide programme called the Aspirant Cancer Career and Education Development programme (ACCEND). The ACCEND programme aims to provide transformational reform for the career pathways and associated education, training, learning and development opportunities for the nursing and allied health professional cancer workforce. As part of our joint programme of work with the Wales Cancer Network we will map the ACCEND framework against educational resources available with the aim of developing appropriate cancer educational resources in Wales.

I hope you find this information helpful.

Yours sincerely

**JULIE ROGERS**
**DEPUTY CHIEF EXECUTIVE/**
**DIRECTOR OF WORKFORCE & OD**

**Y Pwyllgor Iechyd a Gofal Cymdeithasol**
–
**Health and Social Care Committee**

**Senedd Cymru**
Bae Caerdydd, Caerdydd, CF99 1SN
SeneddIechyd@senedd.cymru
senedd.cymru/SeneddIechyd
0300 200 6565
–
**Welsh Parliament**
Cardiff Bay, Cardiff, CF99 1SN
SeneddHealth@senedd.wales
senedd.wales/SeneddHealth
0300 200 6565

Maria Caulfield MP
Minister for Mental Health and Women's Health Strategy
Minister for Women

17 May 2023

Dear Maria

Inquiry into gynaecological cancers

The Health and Social Care Committee is looking at the experiences of women with symptoms of gynaecological cancer, how they are listened to and treated by healthcare professionals, and how services empower, care for and look after women diagnosed with a gynaecological cancer to ensure their physical, psychological and practical needs are met.

We understand that new funding has been made available by the UK Government to create new women's health hubs, as part of the Women's Health Strategy in England. The hubs should improve access to care for women and girls with menstrual problems, contraception, pelvic pain, menopause etc.

We would be interested in further information in relation to the women's health hubs, in particular:

- whether the hubs are primarily focused on reproductive and sexual health, or if they're seen as a solution to the challenges faced by women accessing gynaecological cancer care too.
- details about what the hubs offer, how a patient can access them, who staffs the hubs and how much they cost to run.
- whether there is any evidence that the hubs are supporting faster diagnosis of gynaecological cancers. Whether any of the women's health hubs have been evaluated.

To help inform future evidence sessions, we would be grateful to receive your response by Monday 12 June 2023.

Yours sincerely

Russell George MS
Chair, Health and Social Care Committee

Croesewir gohebiaeth yn Gymraeg neu Saesneg. We welcome correspondence in Welsh or English.

Agenda Item 4.4

Department of Health & Social Care

*From Maria Caulfield MP*
*Parliamentary Under Secretary of State*
*Department of Health & Social Care*

*39 Victoria Street*
*London*
*SW1H 0EU*

16 June 2023

Dear Mr George,

I hope you are well. I am writing in response to your letter dated 17 May on the Inquiry into gynaecological cancers. I am pleased to update you on our work in this area and provide responses to your questions on women's health hubs. Please find the updates below.

**Ambitions on cancer as part of the Women's Health Strategy for England**

Last Summer, we published the Women's Health Strategy for England, which sets out our 10-year ambitions for boosting the health and wellbeing of women and girls, and for improving how the health and care system listens to all women. We have appointed Professor Dame Lesley Regan as the Women's Health Ambassador for England to work with us to raise awareness of women's health issues, including gynaecological cancers, and to support implementation of the strategy.

In the call for evidence public survey, gynaecological cancers were the seventh most popular topic selected for inclusion in the strategy. Only 14% of respondents felt they had enough information on gynaecological cancers, and this dropped to 5% of respondents aged 16 to 17, and 7% of respondents aged 18 to 19 and 20 to 25. Cancer is a priority chapter in the strategy.

**Current work to improve prevention, diagnosis and care for gynaecological cancers**

Improving the diagnosis and treatment of cancer, including gynaecological cancer, Is a priority for the government and the NHS. One of the core ambitions of the NHS Long Term Plan is to diagnose 75% of cancers at stage 1 or 2 by 2028, and to ensure that by 2028, an additional 55,000 people will survive their cancer for five years or more. The UK also supports the 2020 World Health Organisation global strategy to accelerate the elimination of cervical cancer as a public health problem.

A Best Practice Timed Pathway for gynaecological cancers, including cervical cancer, was published by NHS England (NHSE) in March 2023, and Cancer Alliances are now responsible for delivering it. The pathway will support the delivery of a diagnosis or ruling out of cancer within 28 days, in line with the recently introduced Faster Diagnosis Standard. This pathway aims to implement rapid patient triage so they can access the right tests, first time, through the use of appropriately staffed one-stop clinics.

NHSE has also allocated funding to support treatment and pandemic recovery, including £2.3 billion to improve diagnostic care and £1.5 billion through the Targeted Investment Fund to support our wider elective recovery plan. In addition to this, NHSE has also aimed to create a further reduction in cancer waiting times by setting a target for systems to increase cancer treatment capacity by 13% in 2023/24.

The UK National Screening Committee (UK NSC) makes recommendations for all four nations of the UK. Regarding cervical screening, the UK NSC reviewed the evidence on the use of human papillomavirus (HPV) self-sampling as a programme modification within the NHS Cervical Screening Programme in February 2019. The Committee recognised that HPV self-sampling offered a promising test, but that further work was required to ensure its feasibility and value.

The YouScreen project aims to provide evidence on the acceptability of self-testing. GP practices across North Central and North East London were given the opportunity to take part in the YouScreen study offering HPV self-sampling to non-attenders aged 25-64 and those at least 6 months overdue for cervical screening. A separate piece of work, HPValidate, aims to see if self-testing provides the same level of accuracy as an HPV test undertaken by a clinician. These pieces of work will inform a UK NSC recommendation and, if the outcome proves positive, self-sampling could lead to an increase in people being screened for cervical cancer as it will reduce some of the barriers that prevent people from attending.

Human papillomavirus (HPV) is the cause of 99.7% of cervical cancers. The HPV immunisation programme has contributed to a dramatic reduction of HPV infections across the population in England. There has been an 87% reduction in cervical cancers in women who have been vaccinated against HPV when compared to previous generations. Since 2019, HPV immunisation is available to all children, including boys. This supports strong individual protection as well as strengthened population protection as it breaks the chains of transmission.

HPV vaccine coverage decreased during the pandemic and in subsequent years. This was due to school closures and then competing priorities where providers were tasked with delivering COVID-19 and flu vaccines as well as HPV vaccines. Catch-up efforts to make sure that anyone who has missed their HPV immunisation for any reason are underway and amongst those who have previously missed their immunisation, the coverage has gone up. Despite this, uptake remains lower than what we would like to see.

**Women's health hubs**

Expanding women's health hubs across England is a key commitment in the Women's Health Strategy, with an initial aim to see at least one hub within every integrated care system (ICS). We recently announced a £25 million investment over the next two years to accelerate the development of women's health hubs. Women's health hubs aim to improve access and quality of care for services for menstrual problems, contraception, pelvic pain, menopause care and more.

We have commissioned through the National Institute of Health and Care Research (NIHR) the Birmingham, RAND and Cambridge Evaluation Centre to conduct a scoping evaluation of existing women's health hubs. Please see responses to your questions about women's health hubs below, as informed by the interim report of the evaluation. The final report is expected to be published later this year.

1. *Whether the hubs are primarily focused on reproductive and sexual health, or if they're seen as a solution to the challenges faced by women accessing gynaecological cancer care too.*

As far as we are aware, the existing women's health hubs do not offer gynaecological cancer services. Existing hubs provide services for sexual, reproductive and gynaecological health including those for menstrual health conditions such as heavy menstrual bleeding, menopause consultation and treatment, provision of long-acting reversible contraption, and ring pessary fitting and removal. A full list of services currently offered in hubs is available on page 23 of the interim evaluation report.

2. *Details about what the hubs offer, how a patient can access them, who staffs the hubs and how much they cost to run.*

Existing women's health hubs have a variety of delivery models, with some offering open access to women and some available through referral. The interim evaluation report outlines the current workforce within hubs, with GPs with a special interest in women's health as the most common professionals working in hubs, followed by administrators and healthcare assistants. The report highlights the diversity in clinical leadership in hubs, with the most common model being GP led.

We do not have cost figures for the small number of hubs currently in existence. Costs are likely to vary however given the variety in delivery models and services offered. As part of our plans to support the wider roll-out of hubs we are developing a cost-benefit analysis to highlight the expected efficiencies available through implementing hub models.

3. *Whether there is any evidence that the hubs are supporting faster diagnosis of gynaecological cancers. Whether any of the women's health hubs have been evaluated.*

We currently do not have any evidence on if hubs are supporting faster diagnosis of gynaecological cancers. Women may be seen in a women's health hub for menstrual or other problems that could be symptoms of a gynaecological cancer, for example unusual vaginal discharge or bleeding. Women's health hubs should refer into specialist and/or urgent care where required, for example into cancer pathways, in line with recommendations in relevant National Institute for Health and Care Excellence (NICE) guidelines.

I hope this information is helpful

Yours sincerely,

**MARIA CAULFIELD**

**Y Pwyllgor Iechyd a Gofal Cymdeithasol**
–
**Health and Social Care Committee**

**Senedd Cymru**
Bae Caerdydd, Caerdydd, CF99 1SN
SeneddIechyd@senedd.cymru
senedd.cymru/SeneddIechyd
0300 200 6565
–
**Welsh Parliament**
Cardiff Bay, Cardiff, CF99 1SN
SeneddHealth@senedd.wales
senedd.wales/SeneddHealth
0300 200 6565

Eluned Morgan
Minister for Health and Social Services
Welsh Government

16 June 2023

Dear Eluned

## Dentistry

Thank you for your response to the Committee's report on dentistry. We considered your response at our meeting on 14 June 2023, and agreed to write to you ahead of next week's debate on the Committee's report to seek clarification on a number of matters arising from your response. It would be helpful if you could address these points either in your contribution to the debate, or subsequently in writing.

Recommendation 3: The Welsh Government should explore options for a centralised waiting list and report back to the Committee on progress by the end of 2023. As an interim measure, the Welsh Government should ensure every health board establishes a centralised waiting list for its area by the end of 2023.

In your response to recommendation 3, you state that officials are already in discussions with Digital Health and Care Wales (DHCW) to scope a design for an all-Wales dental waiting list. Initial indications are that this can be delivered within the next financial year and finances have been set aside to fund the project. However, in Plenary on 24 May, you said that you hoped that a central data registry will be in place by the end of this year.

1. Can you please clarify when a centralised waiting list will be delivered.

Recommendation 5: The Welsh Government should review the data collection requirements for NHS dentists in order to simplify the process and reduce duplication. This review should be completed by December 2023 and the findings reported back to us no later than March 2024.

In your response to recommendation 5, you say that you will ask the relevant working group to review this recommendation and identify options to minimise administrative burden.

2. Can you please confirm that you will report back to the Committee with the group's findings within the timescales specified in our recommendation?

Recommendation 8: The Welsh Government should ensure that the dental workforce strategy reflects the changing aspirations and the need for a wider skill mix within the workforce and is published as soon as possible. On the basis that the Minister for Health and Social Services expected to receive the draft in December 2022, the final strategy should be published no later than spring 2023.

In your response to recommendation 8, you say that the formal publication of the workforce plan has been delayed until July 2023.

3. Can you please provide further details on the content of the workforce plan and whether it reflects the changing aspirations and the need for a wider skill mix within the workforce as set out in our recommendation?

Recommendation 9. The Welsh Government should bring forward the legislative changes needed to enable dental therapists to have a performer number as a matter of urgency and provide us with a timescale for this.

In your response, you advise that following the announcement by NHS England that Dental Therapists and Hygienists will now be permitted to open and close courses of treatment, there is no longer a need for legislative change at this time, and officials are now preparing communications to health boards to clarify how this change will be operationalised for next financial year.

4. Can you please confirm whether dental therapists no longer need to have a performer number to open and close courses of treatment?

5. Can you also clarify what is meant by 'next financial year', i.e. will the change take effect from April 2024?

Recommendation 14. The Welsh Government should explore options for expanding the Gwen am Byth programme into other residential settings, such as care homes for younger vulnerable people, sheltered housing and extra care housing, and report back on its findings to this Committee by the end of 2023.

Your response states that since receiving the recommendation, you have established that some health boards, via their community dental services, already do engage with these types of services. Furthermore whilst the programme itself is aimed at older people living in care homes the resources are freely available through the Public Health Wales website - Gwên am byth - Public Health Wales (nhs.wales).

6. Can you please provide details of which health boards are being referred to, and of the number and type of settings?

7. Can you also confirm what plans the Welsh Government has to expand the Gwên am Byth programme in the remaining health boards?

It would be helpful if you could address these matters in your response to the debate. If it is not possible for you to cover all of these matters during the debate, we would be grateful if you could respond in writing by 6 July 2023.

Yours sincerely

Russell George MS
Chair, Health and Social Care Committee

Croesewir gohebiaeth yn Gymraeg neu Saesneg. We welcome correspondence in Welsh or English.

**Eluned Morgan AS/MS**
**Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol**
**Minister for Health and Social Services**

**Julie Morgan AS/MS**
**Y Dirprwy Weinidog Gwasanaethau Cymdeithasol**
**Deputy Minister for Social Services**

Agenda Item 4.6

Llywodraeth Cymru
Welsh Government

Russell George MS
Chair
Health and Social Care Committee
Welsh Parliament,
Cardiff Bay,
Cardiff,
CF99 1SN

15 June 2023

Dear Russell,

Thank you for your letter of 21 April regarding our updated hospital discharge guidance. We are pleased to provide the following updates on the status and publication of the guidance set out in your letter.

**Hospital Discharge Guidance**
Work is currently ongoing to develop updated guidance for hospital discharge that will replace the extant available guidance *COVID-19 Hospital Discharge Service Requirements (Wales).* The revised guidance is being developed jointly by health and social care teams to review and update the existing guidance, ensuring that we are strengthening links to other guidance being prepared in this area under the Six Goals of Urgent and Emergency Care programme of work. The updated guidance will heavily reflect the latest patient pathway processes such as Discharge to Recover then Assess (D2RA), SAFER and Red to Green.

Another key aspect of the guidance will be to ensure that the latest update reflects the current position in terms of Infection Prevention and Control (IP&C) practices. The health and social care environment has changed significantly in the wake of the covid pandemic and since the extant guidance was published. Therefore we want to ensure that the guidance now takes account of the latest available information and support of discharge practices in respect of covid, as well as other respiratory viruses. This will keep the discharge guidance in line with other IP&C guidance which are taking a similar approach that broadens their focus beyond just a covid response.

In addition to this we are also using this opportunity to explore potential to expand our guidance so that we have more relevant content relating to social services, to the patient, their families and unpaid carers. While the core audience for the updated discharge guidance will be for staff and

Canolfan Cyswllt Cyntaf / First Point of Contact Centre:
0300 0604400
Gohebiaeth.Julie.Morgan@llyw.cymru
Correspondence.Julie.Morgan@gov.wales

Bae Caerdydd • Cardiff Bay
Caerdydd • Cardiff
CF99 1SN

professionals working in health and social care, there will likely be situations where an individual, who is moving towards discharge, may require social care support that they didn't previously receive, either on a permanent or temporary basis. The updated guidance will have information for staff that can either be directly provided to the individual/family/unpaid carers, or can signpost them towards supporting organisations. Work is being taken forward with organisations such as the Carers Trust, Care and Repair Cymru, the Older People's Commissioner's Office and British Red Cross to ensure we include relevant useful information, guidance and support that could be conveyed to support the patient.

The work to finalise this guidance is progressing and we expect to publish the bilingual guidance in August. We will, of course, provide a copy as soon as the guidance is available.

**Trusted Assessor**

Guidance to support the use of the Trusted Assessor function has been developed and shared with local authorities and health boards on 21 December 2022. A copy of this guidance has been attached as requested.

The Trusted Assessor guidance is also being supported with an online toolkit that will include information guidance modules, a competency matrix and some case examples to further support the sector in implemented trusted assessor roles or functions. The first two information modules of the online toolkit and the guidance are due to be uploaded to the 6 Goals of Urgent and Emergency Care website in the coming weeks. This activity is led by a small working group comprising representation from across social care and health, HEIW, Social Care Wales, NHS Delivery Unit and Welsh Government. This will ensure that partners are enabled to embed and extend existing arrangements to deliver trusted assessor roles.

**Reluctant Discharge**

Updated guidance on reluctant discharge has now been drafted and is in the process of being finalised ready for publication. The development of this guidance has been led by NHS Delivery Unit teams in collaboration with health and social care teams. The content has been considered by legal teams to ensure appropriate sign off and to ensure that it is aligned with appropriate practices. We will shortly be circulating the guidance to Health Boards and publishing so that it is fully available for teams and staff to access in the coming weeks. A copy of this guidance will be shared with you as soon as finalised.

We trust that this information has responded to your request and we will share both the reluctant discharge guidance and overarching hospital discharge guidance in due course.

Yours sincerely

**Eluned Morgan AS/MS**
Y Gweinidog Iechyd a Gwasanaethau Cymdeithasol
Minister for Health and Social Services

**Julie Morgan AS/MS**
Y Dirprwy Weinidog Gwasanaethau Cymdeithasol
Deputy Minister for Social Services

# Trusted Assessor Role Guidance

## 1. Purpose

One of the priority actions for creating additional community capacity is to support efficiencies in the system. This includes the development of Guidance on a 'once for Wales' basis to assist in addressing issues that cause delays at key points in the pathway.

Where organisations "trust" in others to undertake assessment on their behalf and they are confident that assessors are sufficiently skilled, the Trusted Assessor role can be useful in a variety of situations to reduce duplication of effort and provide more timely access to assessment services.

One potential barrier to the timely transfer to a more appropriate care setting or to access alternative services is the time taken for referral to onward teams for assessment or services. This can add cumulative unnecessary days to an in-patient stay, causing potential harm to the person involved and also limiting the available capacity for those in need of acute care services.

There appears to be significant opportunity across Wales to consider the Trusted Assessor role to support a more efficient and timely service response. An information request across all HBs undertaken in June 2022 indicated only two health boards were actively progressing Trusted Assessor roles. This is despite a requirement by Welsh Government in the COVID-19 related Discharge Guidance that hospital discharge teams should:

> *Where Trusted Assessor relationships and arrangements are not already in place, rapidly work with the discharge team to implement these rules and processes*

This document sets out the key requirements of a trusted assessor role as identified in key national policy and practice guidance. Regional partners are encouraged to use this to support active consideration of the added value of a Trusted Assessor role; if Trusted Assessor roles are already in place, partners are asked to consider whether additional value can be added through any of the principles outlined in this document.

Examples of roles developed under the Trusted Assessor requirements are also included in order to ensure good practice can be widely shared and accessed.

## 2. National Policy and Practice Guidance

The term 'trusted assessor' is used in two national documents in Wales:

1. Trusted Assessor is referred to as one of the building blocks and one of the seven key principles in *Home First.*
2. The **WG COVID-19 Discharge Requirements**[1] also refers to the role of Trusted Assessor. This requirement is expected to be confirmed in the anticipated updated WG Discharge Requirements.

### a) The *Home First* requirements and definition

[1] COVID-19 Hospital Discharge Service Requirements (Wales) Published April 2020

*A trusted assessment involves a trusted assessor – someone acting on behalf of and with the permission of multiple organisations – carrying out an assessment of health and/or social care needs in a variety of health or social care settings.*

Trusted assessors can come from any agency and should have direct access to services and equipment. Use of the model has grown in Wales, but to varying degrees in different regions. The experience of the COVID-19 pandemic has expedited use of the trusted assessor model, with some areas reporting positive results.

The model must always:

- Be undertaken within professional competencies.
- Protect patient safety.
- Have clear boundaries.
- Be designed around achieving the best outcomes for the individual, not as a mechanism for filling service gaps.

**b) The WG COVID-19 Discharge Guidance Requirements**

This requires that hospital discharge teams should:

- Act as a key problem-solving contact between hospital and community teams.
- Where not already in place, train discharge staff (potentially those who no longer have to undertake CHC assessments) to operate 'Trusted Assessments' for patients in hospital from care homes, so they can return to their care home promptly, and support all care homes with these new discharge arrangements.
- Where Trusted Assessor relationships and arrangements are not already in place, rapidly work with the discharge team to implement these rules and processes.

*(The WG COVID-19 Discharge Guidance Requirements are current at the time of drafting this paper. However updated WG Discharge Guidance is expected to follow which it is anticipated will maintain the requirement for the development of Trusted Assessor Roles)*

## 3. The Trusted Assessor Role: Key Principles:

Both sets of guidance referred to above do not describe any single role as the Trusted Assessor. Instead, it refers to a **function** that could be undertaken on behalf of others where that has been identified and agreed and the requirements set out above regarding competencies, boundaries and outcomes are met.

The role could be **within** an organisation, for example between different departments or professional groups within a health board or operate **across** organisational and/or sectoral boundaries.

Trusted assessment schemes **do not remove or replace statutory responsibilities**. It is essential that those who are placing their trust in others to undertake assessment on their behalf are confident that the risks, costs and local market are sufficiently understood, and that assessors are sufficiently skilled.

It is imperative that there is a clear and rapid route for challenge, escalation and resolution of problems or issues raised by any parties involved in the trusted assessment scheme. Any disputes should be resolved as soon as possible and within a locally agreed timescale.

There should be a clear projection of the number and types of assessments that might be suitable for a trusted assessment function, the impact this should have on improving flow throughout the system.

Taking the national policy and guidance requirements into account, the Trusted Assessor role would be expected to reflect the following key principles:

- Added value and person focused. Joined up / integrated working across health, social care and third sector to improve service users' experience and outcomes.
- Agreed, streamlined processes and pathways avoiding repeat assessments between professional groups & partners; focused on patient safety, preventing delays in handover to other teams / settings.
- Having clear boundaries and operating within professional competencies.[2]
- Explicit agreements between partners, with governance arrangements (Memorandum of Understanding or partnership agreement) in place e.g. for making financial commitments on behalf of one or more partners.
- Supported by Information governance agreements, with access to partner computer operating systems to support recording and other process.
- Autonomy and accountability for commissioning / providing equipment and other services on behalf of the partners to support the next stage of the persons care pathway.
- Be able on behalf of partners to support temporary increases to existing services pending a review.
- Identify and implement outcome measures that would capture the effectiveness of the Trusted Assessor role, designed around achieving the best outcomes for the individual, not as a mechanism for filling service gaps.

## 4. Examples of Trusted Assessor Roles

Simple examples of where a Trusted Assessor function may improve timeliness and efficiency that have been provided in Wales are:

- Occupational Therapists, Physiotherapists and Nurses carrying out initial proportionate assessment to commission short-term care at home. This example involves health board staff completing the local authority assessment for commencement of care and completion of the required documentation, populating the local authority computer system for recording of information in the persons record. The local authority then accepts this assessment, and the commissioning of services for the individual, and undertakes the review at an appropriate or agreed period of time, adding to the person's existing record.
- For individuals not known previously the trusted assessor "creates" and populates the persons individual new record.
- For individuals with existing services the trusted assessor would, based on their proportionate assessment, be able to temporarily increase previously commissioned services for a specified period of time pending a review.
- Following the proportionate assessment the trusted assessor could commission short term step down to recover opportunities either in identified beds in care homes or extra care or in a community bedded step down to recover facility.
- A similar approach is used to commence full Community Response Team interventions.
- Community Response Team nurses have undergone local authority training to undertake the Trusted Assessor role regarding medication assessments. This was initially implemented due to staff sickness / absence which was impacting upon timely discharge of patients requiring a medication assessment.

[2] A competency profile for the trusted assessor should be agreed by all participating organisations.

- Internal HB arrangements which allow Band 4 OT and Physiotherapy technician staff to carry out independent low-level interventions with Community Response Team patients, rather than the registered member of staff being involved first. This is overseen by a competency structure and regular staff supervision by the registered staff.

- Streamlining the process for accessing reablement support via an assessment undertaken by the referring setting.

- Third sector organisations such as Care and Repair assessing for and ordering equipment as part of a commissioned agreement with support for staff competency training.

The **benefits** of the Trusted Assessor role include:

- Reduced duplication of effort and of tasks (cost avoidance, increasing value).
- Smooth out the referral interface.
- Reduces inappropriate referrals.
- Provides a single assessment of person's needs.
- Is both criteria and competency based.

**Appendix 1: Trusted assessment implementation checklist:**

*(adapted from NHS England, LGA & ADASS "Developing trusted assessment schemes: essential elements, July 2017)*

**Consider the strength and maturity of relationships and trust between local health and social care commissioners and providers, and agree any steps to be taken to support improved trust and relationships as part of plans to develop and implement a trusted assessment service.**

 Shared ownership of risk requires positive, trusting relationships across health and social care systems and between commissioner and provider organisations.

 In many areas there will be a provider forum of some sort, including social value fora. This is likely to be an excellent place to start discussions and involve independent sector providers in coming to a viable solution from the outset. Where there is no local provider forum, local systems may wish to seek out potential willing participants among care home and home care providers via local commissioners, national associations or the Care Inspectorate Wales (CIW).

**Bring all stakeholders together to begin the co-design process:**

 For the assessment and the assessor to be trusted, all stakeholders need to be involved in designing and developing the role and the agreed process/procedures.

**Establish a set of common/shared objectives for the trusted assessment service:**

 This should include a description of the target population, and all participating organisations should commit to the objectives of the scheme, with shared responsibility for their achievement.

**Ensure there is an end-to-end process for patient and carer involvement:**

 Trusted assessment is ultimately a tool to support better patient and carer experience and outcomes. Patients and carers should be involved in the design of the service and ongoing review.

**Agree what kinds of assessment will be included in the service:**

 The term ‘assessment’ is used for a variety of assessments, so to avoid confusion and help with compliance each local system should state exactly what assessments are included in the local scheme, examples may include:

- ✓ Transfer back to an existing support package including home care or care in a care home.
- ✓ Transfer to an interim support package, e.g. reablement or D2RA.
- ✓ Establishing step down to recover placements.
- ✓ Assessments for (social) care & support [including support for unpaid carers to maintain caring role].
- ✓ Assessments for equipment, aids or adaptations e.g. OT TA model re: home adaptations.

**Co-design a streamlined process end to end:**

 Review the process from end to end to identify any delays and their causes. Scrutinise all paperwork and remove duplication. If possible, agree a generic assessment process for multiple services and purposes.

 Systems should also look at the whole patient journey rather than only one particular point of assessment.

**Agree who can be a trusted assessor:**

 Consider if it is essential that the service requires a social worker, clinician or a therapist to carry out the assessment. It is likely that in the majority of cases this will not be the case and a wider staff group can be considered for the role. A clear competency framework will be essential. For example assessments for equipment, aids and adaptations may be undertaken by housing / housing support providers and /or third sector service such as Care & Repair, British Red Cross.

**Agree competencies and put in place training requirements:**

 You will need either to have an agreed competency framework that potential assessors can be measured against and/or a training programme to bring assessors up to the required competency, including an understanding of local care home and home care service provision. Encouraging assessors to work alongside, and familiarise themselves with, the home care and care home providers that are parties to the scheme is likely to aid the development of the required trust. **Systems need to assure themselves that anyone acting in a trusted assessor role is occupationally competent.**

 Once competencies and knowledge requirements for a trusted assessor have been agreed, these can be checked against existing role profiles to identify gaps. This will inform any training plan.

**Build clear frameworks and a feedback loop/hotline into the model:**

 A good service will take a person-centred approach and support each person to achieve the outcomes they wish. This may mean working in new and different ways, and may sometimes involve taking risks – for example, trying to get someone home from hospital even if they are very frail. The trusted assessor needs to be supported by a clear risk-taking framework, agreed by all the partners involved in the service. This will be done in discussion with the patient and their family, with clear contingency plans for any identified risks.

 If the service on whose behalf the trusted assessor is working believes an assessment is inaccurate, they must have a quick and easy route to discuss and resolve the concerns. This could involve, for example, a hotline to another more experienced colleague or manager with an agreement to find alternative or additional support when needed.

 Establish an open/transparent problem/dispute resolution process, agreed by all parties involved in the scheme.

**Build evaluation into the start of the process:**

Agree metrics to be used to monitor how the service is operating and its impact:

Such as, what percentage of those going home would be expected to be assessed by a trusted assessment service? What proportion of these should have no ongoing support? When will this be hospital or service wide? What percentage of discharges or admissions will have a trusted assessment?

 What effect should this have on delayed transfers of care and length of stay? Is patient feedback positive? Is professional feedback positive?

**Agree where the service can be put in place quickly:**

 Establishing trust between organisations and individuals can take time so start small with one ward or service and gradually roll out further but do have a clear timeline for further rollout into other services or settings.

**Feedback to the Health and Social Care, and Public Accounts and Public Administration Committees - 25 May 2023**

At the meeting you agreed to provide the following:

- Your views on how well you think assessments for care and support are currently working and whether improvements are needed in this area; and
- The evaluation identified problems with multi-agency working – what were the main barriers you found, what actions are you calling for and why.

In addition, we would welcome your views on the effectiveness of the Act's eligibility criteria/regulations and whether they are fit for purpose.

## ASSESSMENTS FOR CARE AND SUPPORT

### Overview

From qualitative evidence (from service users and carers and the workforce) across the IMPACT Evaluation Study, there is a mixed picture of how assessment processes are working, and as well, some intelligence of where improvements might be made.

Whilst there are positive views on the framework for assessments and the inherent co-productive processes, and examples were given of supportive outcomes, there were also views from people who use services and carers of negative and disempowering experiences.

There was an identified need for reduction in assessment related to bureaucracy, for time to have and co-produce respectful 'what matters conversations', more promotion (and in simpler ways) of the availability of assessments for care and support, and greater focus on continuity of care and relationship focused practice. Issues were also raised about portability of assessments across local authorities and the need for improvements including timely communication and information sharing between local authorities.

This evidence is from the following study reports:

- Llewellyn M., Verity F., Wallace S. and Tetlow S. (2022) *Expectations and Experiences: Service User and Carer perspectives on the Social Services and Well-being (Wales) Act*. Cardiff. Welsh Government, GSR report number 16/2022. (Qualitative findings from 170 people; carers and people who use social services).
- *The Expectations and Experiences of Black, Asian and Minority Ethnic Service users and carers Report* (2022), an account of qualitative research
- Llewellyn M., Verity F., Wallace S. and Tetlow S. (2021) *Evaluation of the Social Services and Well-being (Wales) Act 2014: Process Evaluation.* Cardiff. Welsh Government, GSR report number 2/2021.
- Andrews N., Calder G., Blanluet N. and Baker R. (2023) *Co-production: Research to support the Final Report of the Evaluation of the Social Services and Well-being (Wales) Act 2014.* Cardiff. Welsh Government, GSR report number 38/2023.

Expectations and Experiences Service User and Carer perspectives on the Social Services and Well-being (Wales) Act (gov.wales)

#### *Assessment Processes*

Perspectives and experiences of the process of assessments are discussed in Section 3.10-3.15, and Section 3.44 of the *Expectations and Experiences of Service Users and Carers* Report.

### Key messages

- There are positive accounts where assessments are described as supportive, acknowledging, and empowering, and negative and frustrating experiences where assessment processes are seen by some as overly about completing 'forms and paperwork', disempowering, judgemental and hard to access. (See Section 3.10-3.15).
- There are also stories of people having to repeat assessments because social workers had moved on and with a new worker the process started again. This raises issues about how continuity of care is being implemented. (See Section 3.44)
- There were also experiences of assessments not translating into any timely practical support as outlined in Section 3.22 of the report.

- Suggestions for improvement by the people we spoke with included a closer link between assessment processes and well-being outcomes, more emphasis on relationship-based practices, stronger continuity of care and less focus on the technical tasks of paperwork.

***Knowledge of the Act***

The need for knowledge about entitlements and the means to access assessments for care and support is a theme discussed in Sections 3.2-3.9 of the above report.

**Key messages**

- Some study participants found it hard to locate and access this information and if they did locate it, to make sense of it. They speak of the language describing entitlements under the Act being complicated, general, and unclear. From their perspectives, this was a barrier to engagement in the assessment processes and understanding entitlements under the Act.

***Interpretations of the Act***

**Key messages**

- Examples were given of inconsistencies between local authorities in the way that they interpreted the requirements and duties of the Act and how it was applied, leading to service users and carers pointing out variation in the processes of care and support between different authorities in Wales.
- For example, carers gave examples of the process for carers assessments being different in different parts of Wales. (See Section 3.35)

Evaluation of the Social Services and Well-being (Wales) Act 2014: expectations and experiences of Black, Asian and Minority Ethnic service users and carers | GOV.WALES

Drawing on the findings of qualitative research with 10 Black, Asian and Minority Ethnic older people, the following key messages were identified:

- The difficulties in accessing care and support, including assessments.
- Feeling let down by the care system and disconnect between expectations and what happened in practice.
- Having to 'battle' to be heard and receive care and support.
- Lack of responses to care needs.
- Impact of racial stereotyping on care and support.

Evaluation of the Implementation of the Social Services and Well-being (Wales) Act: process evaluation (gov.wales)

Assessments are discussed under Chapter 6 in the pre COVID-19 Evaluation report (2021, p.46-52).

**Key messages**

- Overall, and 'on balance' from the perspective of the workforce members interviewed pre COVID-19, the assessment processes were working well. Some participants noted examples of empowering outcomes as a result.
- The focus on strengths and asset-based conversations were positively noted. What matters conversations were viewed as a 'return to good practice' (2021, p.50)
- The focus on less risk aversion in assessments was noted as positive (2021, p. 49).
- There was also a view that the assessment processes require more time which can hard to realise with a system under pressures.

- There was a view expressed that the assessment forms and paperwork needed to be less complicated, and also that there are systems issues across local authorities which impede the 'portability of assessments. (2012, p. 50).
- Some participants spoke about carers 'not accessing carers' assessments' (2021, p.48).
- Tensions were discussed between voice and control when needing to facilitate/undertake challenging conversations e.g., safeguarding 2021, p.49).

Co-production: research to support the final report of the evaluation of the Social Services and Well-being (Wales) Act 2014 | GOV.WALES

**Key messages**

- Co-production is a key aspect of the undertaking of assessments.
- The IMPACT co-production study found that:

  *'…the value of participation, and what makes it work well, were often expressed in terms of principles and virtues, such as respect and inclusion and good listening' (2023, p.23).*

  Conversely, as the report author's state where there were experiences where *'…a lack of participation were articulated in terms of feeling marginalised, discriminated against, or being 'done to' rather than respected'. (2023, p.24)*
- Some perspectives that co-production is ambiguous with implications for what it means in practice. (2023, p.15)
- 'Organisational rigidity' has a bearing on how co-production happens. (2023, p.16) and power dynamics and hierarchies.
- When it works well the process is as important as the outcome.

From Act to Impact? Final Report of the Evaluation of the Social Services and Well-being (Wales) Act 2014 (gov.wales)

In closing, the 'test' questions posed in the final report have a relevance to the question around assessments for care and support, directly Qs1-4, which sit under Strategic Intention 1:

**Strategic Intention 1: Providing help and support to people to assess their needs and organise and secure the care and support services they require**

What needs to be done to ensure there is improvement in the:

1. delivery of social care such that it reinforces compassionate, relationship centred forms of care and support services?

2. way that assessments for social care support are undertaken, when, and by whom so that they are better able to deliver the best possible well-being outcomes for individuals and carers?

3. sufficiency, appropriateness and sustainability of funding so that everyone who has needs as defined by the Act can be supported and cared for?

4. workforce recruitment and retention, to ensure workforce quality, sufficiency and sustainability?

## MULTI-AGENCY WORKING

This is an issue which appears in a number of the documents in the study, and in the response we identify the key points that are of note in response to the question.

Evaluation of the Social Services and Well-being (Wales) Act 2014 Literature Review (gov.wales)

Key messages from the literature review are:

- Terms are often used interchangeably but have common characteristics and success factors.
- Building equal relationships with common language and purpose, culture (trust, honesty, reciprocity), managing expectations, permissions and processes are key although can be resource (including time) intensive.
- Working together across agencies is challenging but it provides opportunity to problem solve by sharing each other's knowledge and skills, so benefitting individuals, families, and communities.
- There is a gap in the multi-agency literature on the views and experiences of the individual, but especially family and carers and the workforce as the literature focusses mainly on care organisations, policy, and governance.
- Integrated care has mainly focussed on health service delivery until recent years where it is now moving towards health and social care integration.
- Not one study has sought to identify the success factors of a country's workforce working towards multiagency working.

Evaluation of the Implementation of the Social Services and Well-being (Wales) Act: process evaluation (gov.wales)

Key messages from the pre-COVID process evaluation, examining workforces perspectives on the implementation of the Act were broken down into two sections – strategic and operational multi-agency working relationships:

**Strategic relationships with partners**

Findings were that:

- Boards and structures have been a key aspect enabling the formalising and strengthening of partnerships between social care, health, and other agencies
- Regional Safeguarding Boards were especially viewed as positive developments to enable regional working
- Work is required to continue to develop the structure of RPBs, and to improve relationships between the RPB and the PSB
- The size of the region presents challenges to in-depth discussions about health and social care integration
- Applying 'a one size fits all' regional approach is problematic in responding to sub-regional and locality issues

**Operational relationships with partners**

Findings were that:

- The importance of leadership to initiate and sustain change is clear
- There is great value placed on positive, reciprocal working relationships with partners

- The Act is a driver and lever for developing partnerships with health
- The Act has, to an extent, enabled the integration of social care and health to develop in respect of collaborative regional approaches, commitment and buy-in from leaders, integrated working spaces, mutual respect and trust, and consistent messages to both organisations
- Time and resource are required to build effective partnerships
- The voluntary sector is an excellent partner on the whole, but concerns over capacity, funding and sustainability persist
- Competing 'cultures' of different organisations – especially social care and health – need to be further reconciled

Expectations and Experiences Service User and Carer perspectives on the Social Services and Well-being (Wales) Act (gov.wales)

There is a chapter in the 'Expectations and Experiences' report about the service user and carer experience of multi-agency working (Chapter 4, pp.59-70) which concluded that:

- Overall, there was a shared perspective on the importance of agencies not only working well together with each other, but also with the people in receipt of care and support.
- Yet, across the interviews and focus groups, there were frequent experiences of a lack of effective multi-agency working within and between LAs, and between different sectors. In particular, poor multi-agency working practices between social services and health featured heavily in the accounts of participants.
- Further, despite a significant value placed on third sector support, it was felt these services are not fully recognised by statutory services, which is especially problematic given that there were a number of positive examples of third sector support cited by participants.
- As demonstrated in this chapter, an absence of effective multi-agency working in the provision of care and support was the norm rather than the exception for the service users and carers we heard from.
- Their evidence focused on issues of variation like disparities of care and support between LAs and other agencies, differing interpretations of the Act, and delayed information sharing. Ineffective working, communication and information sharing between and within LAs, and between and within sectors, were all identified as issues to the detriment of service users and carers. For example, disruptions to the continuity of care when moving between LAs, and repeating information and experiences to multiple professionals, leading to feelings of frustration and distress.
- Whilst there were few positive experiences of multi-agency working, aspects seen as supporting effective multi-agency working included the introduction of dedicated transition workers for those moving between children and adult services, and single point of access teams.

One of the concluding statements of the report also reflected this:

| Statement | Comment |
|---|---|
| *There was absolutely no warning ahead of hospital discharge. We were kept out of the multi-disciplinary team meeting where all of the key decisions were taken.* | Multi-agency working is an area that was identified as especially problematic. The feeling of being on the outside when a multi-agency meeting is happening and important decisions are being taken is a symptom of sub-optimal working relationships. The Act requires that people are at the heart of the decisions about them, but there is distance to travel before this is consistently achieved. |

Multi-agency working Research to support the Final Report of the Evaluation of the Social Services and Well-being (Wales) Act 2014 (gov.wales)

There is an entire report focused on multi-agency working which was produced as part of the study. There is considerable detail in the document, but turning to 'next steps' for multi-agency working in the Welsh health and social care system, the authors identified six issues as a basis for further discussion on how the effectiveness of multi-agency working can be improved:

1. **Performance measures, outcomes and evaluation information need to be more robust to inform decision making**. At present, the development of effective outcome measures is an ongoing issue. Determination of effective methods at an organisational level needs to be coupled with consideration of how agencies can adopt measures on the basis of joint accountability.
2. **Multi-agency and cross-border processes should be clear to individuals, their families and carers**. Navigating the health and social care "system" is difficult for people seeking access to care and support. It is made more difficult when that care and support is provided by more than one agency.
3. **Further guidance on how to achieve sector-leading multi-agency working should be produced**. This should be developed for use by Regional Partnership Boards and agencies, and include a multi-agency 'checklist' of critical success factors that are considered most important with most impact, thereby facilitating a sense-check of where they are in relation to achieving excellence.
4. **A community of practice across Wales should be established to share ideas and solutions for challenges encountered.** The development of communities of practice for other purposes, such as achieving implementation of the national models of care being supported through the Regional Integration Fund, should be extended to include fulfilment of the Act's aspirations for improved multi-agency working, alongside the other principles.
5. **A champion for multi-agency working should be identified within each Regional Partnership Board across all population groups.** This should be undertaken with the Commissioners for Older People, and Children and Young People.
6. **Mandatory refresher training on the Act should be provided for all operational and strategic partners, in a multi-agency setting, together.** In addition, mandatory training on multi-agency working should be provided through inter-professional education (IPE) and through higher education and further education professional programmes in health and social care.

From Act to Impact? Final Report of the Evaluation of the Social Services and Well-being (Wales) Act 2014 (gov.wales)

In closing, it is worth pointing to the 'test' questions posed in the final report – many of the 19 have a relevance to the question around multi-agency working, but in particular Q18 and Q19, which sit under Strategic Intention 7:

> **Strategic Intention 7: Achieving integration of local government services and between local authorities and their partners, particularly the NHS, to achieve better outcomes for individuals, carers and communities**
>
> What needs to be done to ensure there is improvement in:
>
> 18. multi-agency working and practice (including safeguarding), and in the practices of remote and distant working for some forms of interaction?
>
> 19. technological solutions that enable people to live independently, especially in a post-pandemic context of system pressures and workforce shortages?

**ELIGIBILITY CRITERIA/REGULATIONS**

There is limited evidence within the study on the effectiveness of the Act's eligibility criteria / regulations and whether they are fit for purpose. The following excerpts provide some insights in this regard, but do not provide sufficient evidence for us to make a determination as to whether they are fit for purpose.

Evaluation of the Implementation of the Social Services and Well-being (Wales) Act: process evaluation (gov.wales)

New approaches which embodied the emphasis on strengths- and asset-based assessment under the Act in understanding people's eligible need around well-being were evident

Paragraph 6.2

There was an overall approach described by many which embodied the new emphasis on strengths- and asset-based assessment under the Act in understanding people's eligible need around well-being, and an honest reflection that at the time of implementation there were (ultimately unfounded) worries about this leading to 'flood gates' opening.

> *…having those strengths based conversations with them [citizens] is almost like planting a seed I guess, allowing that person time to think about what you've said and what the impact is on them and promoting trust and confidence (Operational Manager, LA, Locality 2) There was an anxiety, I think, as there is with all aspects of change around 'what's that going to mean for me'? Are we going to open the flood gates of loads of things all coming in through the front door because everybody is going to be asking for an assessment and they have to have one […] That didn't actually bear out in reality (Senior Manager, Regional, Locality 4)*

Paragraph 6.32

Key to outcomes-focused working was the judgement of practitioners which has received a challenge in respect of linking outcomes to eligible need:

> *[T]he staff are having to have uncomfortable conversations and I think for staff to be able to do that well, they need to be well supported, they need to be confident in their ability and clear in what the expectation is on them really isn't it. (Operational Manager, LA, Locality 2)*

Expectations and Experiences Service User and Carer perspectives on the Social Services and Well-being (Wales) Act (gov.wales)

Paragraph 3.13

In contrast, some participants expressed their frustration that assessments felt like a 'tick box' exercise with the priority being the completion of forms and paperwork. There were experiences recounted where carers had not been able to gain an assessment, despite being eligible and wanting one. This was the case for the two carers below, as seen in extracts from their interviews:

> *…the Act specifically says that you know, carers have a right to an assessment and that assessment should be, is carried out by law to ensure that carers have the same outcomes and treatment that the person that they care for has. I think what has happened is the Act and the actual carers assessment has become, uh, disfranchised. It's become just a loose thing that happens, that possibly happens, when you become a carer (Carer, South West Wales, Male).*

*I mean just to give you an example, under the Act we are legally entitled to a Carer's needs Assessment and let me tell you my experience of carers needs assessment and I can tell you a great deal of other people, you can't get them ok (Carer, South East Wales, Adult).*

Paragraph 3.21

Some respondents had opposing interpretations to social service staff on what they were eligible to receive under the Act. The first excerpt below illustrates this point through an experience of direct payments, where the offer from the social service department contrasted with the respondent's own wishes for the provision of support as noted in the excerpts below:

*I think the way that social services interpret the Act is very, very different to how an individual would interpret it. They're often using it to shut things down rather than open them up because their argument is 'ok you could find a personal assistant for £12.66 an hour therefore that is a reasonable direct payment to give you', whereas I'm saying 'a) I can't find one and b) I don't want one'. So it was easier for them to then contract the agency themselves and pay them directly which closes the whole thing down (Carer, South West Wales, Female, Adult).*

*…they're [LAs] just not doing what you know, those things that they say that they are supposed to do. They're just not doing it (Service User and Carer, South West Wales, Female, Older person).*

*I think to be honest it is since lockdown everybody is using excuses […]. … there's so many more excuses used about COVID as a reason not to do things now and that's in all aspects of disabilities full stop (Service User and Carer, South West Wales, Female)*

Paragraph 3.53

Experiences were relayed where participants perceived that the social services managers were making care and support decisions based on the money available, not the assessment process:

*…the social workers don't decide on you know what support you get, the managers do. I think it just depends on how much money they've got in the budget at that particular time you know and basically whether you're eligible in inverted commas or not (Carer, South East Wales, Adult).*

*As far as we know this request was turned down by a panel of middle/senior managers. To date, we have not been formally informed of this decision. This to me suggests that our views and wishes, as a family, in respect of the type of care and support we need are listened to at a ground roots level. Unfortunately these views can be overridden further up the decision making chain. These decisions and the reasons behind them are seldom communicated to the service users. These are factors that I believe are contrary to the aims of what is on the whole a good and empowering Act (Carer).*

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