Cyflwynwyd yr ymateb i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar Effaith yr ôl-groniad o ran amseroedd aros ar bobl yng Nghymru sy'n aros am ddiagnosis neu driniaeth

This response was submitted to the Health and Social Care Committee consultation on the impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment

WT 04
Ymateb gan: | Response from: Bwrdd Cynghorau Iechyd Cymuned Cymru | Board of Community Health Councils in Wales

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Board of Community Health Councils in Wales

Inquiry into the impact of the waiting times backlog on people who are waiting for diagnosis or treatment in Wales

Evidence from the Board of Community Health Councils and the 7 CHCs in Wales

CYNGOR IECHYD CYMUNED
COMMUNITY HEALTH COUNCIL
BWRDD CYMRU | WALES BOARD

www.boardchc.wales

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About the Board and Community Health Councils

The Board of Community Health Councils (the Board) is pleased to provide this submission to the Senedd Health and Social Care` Committee's inquiry on behalf of the 7 Community Health Councils (CHCs) in Wales.

CHCs are independent bodies that reflect the views and represent the interests of people living in Wales in their National Health Service (NHS). CHCs encourage and support people to have a voice in the design, planning and delivery of NHS services.

There are 7 CHCs in Wales. Each one is made up of local volunteer members who live in the communities they serve, supported by a small team of paid staff. Each CHC:

- Carries out regular visits to health services to hear from people using the service (and the people providing care) to influence the changes that can make a big difference
- Reaches out more widely to people within local communities to provide information, and to gather views and experiences of NHS services. CHCs use what they hear to check how services are performing overall and to make sure the NHS takes action to make things better where this is needed
- Gets involved with health service managers when they are thinking about making changes to the way services are delivered so that people and communities have their say from the start
- Provides a complaints advocacy service that is free, independent and confidential to help people to raise their concerns about NHS care and treatment.

The Board of CHCs (the Board) exists to support, assist, advise and manage the performance of CHCs. It represents the collective views of CHCs across Wales.

Hearing from people about their NHS care during COVID-19

Since our nation first started living with restrictions in March 2020 because of the coronavirus pandemic, our volunteer members and staff have worked hard to continue to amplify peoples’ voices in their NHS during these extraordinary times – working in new ways aimed at keeping everyone safe.

As the restrictions have changed in response to the levels of risk in our communities, CHCs have been able to reintroduce some face-to-face activity, but this remains very limited. CHC volunteer members and staff continue to miss the vital role face-to-face contact has in hearing about and sharing the views and experiences of people across all communities about their local health services.

CHCs have done whatever they can to enable people to share their views and experiences in lots of different ways. This has included on-line and text as well as more traditional ways including phone and post. CHCs have also developed new ways of hearing from people including on-line focus groups and Facetime chats with people being cared for in our hospitals.

People across Wales have been able to share their views and experiences of the NHS with us by completing our national and local surveys. The direct feedback we receive is only one way in which CHCs hear from people about their NHS services.

CHCs also find out about people’s views and experiences in other ways:

- through enquiries coming into CHC offices
- patient/service user stories being shared with the complaints advocacy service
- contacts with local community networks

- information coming in to us from community representatives and groups
- social media discussions
- monitoring of health board activities and performance.

We know that many of the people who share their views with us through our surveys do so because they have strong feelings about their NHS experience. We often hear very good or very poor experiences. We know that what we hear doesn't reflect everyone's experience.

The most consistent and enduring message we hear from people across Wales is the grateful thanks, support and admiration for health and care workers.

People appreciate that staff have worked tirelessly to keep people safe and provide the best possible care, treatment and support to people in very difficult circumstances.

But it is also true that as the pandemic continues to have such an impact on our NHS services – and the people who deliver and receive those services – we are seeing and hearing more anxiety and frustration. Everyone's resilience is being tested like never before.

We are very grateful to the people who have shared their views and experiences with us. We also want to thank everyone working tirelessly every day so that health and care services can respond to this brutal and unforgiving virus in the best way possible.

Our evidence focuses on what CHCs have heard across Wales about the impact of waiting for NHS care and treatment on peoples' lives, the support available while they are waiting, and the plans and actions being taken by healthcare services to recover from the pandemic.

Waiting for care and treatment

CHCs have heard continually from people across Wales about the impact of waiting for care and treatment on their day to day lives, the lives of those they care about, and their concerns about the future.

In November 2020, we published our report 'Feeling Forgotten?[1]' that set out the key things CHCs had been hearing throughout the different stages of the pandemic from people affected by delays in care and treatment.

Since then, we have continued to see the reintroduction of planned care in Wales, along with the development of plans to deal with the backlog in a range of ways.

But the recovery in Wales so far has been slower than anyone would want.

CHCs have heard how reduced capacity because of COVID safe practices, lower resilience levels amongst healthcare staff, increased sickness, and staff shortages in many parts of the health and social care system has further affected the ability of the NHS to provide pre pandemic levels of planned care.

As well as this, we know that many people who were not able to or did not feel safe enough to see their GP earlier in the pandemic have now been seeking help.

This means that more people are now waiting for diagnosis or treatment, and in some cases their need for care and treatment is greater because their condition is worse than it might have been if they had been seen earlier.

In recent months, as we have moved towards winter, CHCs have heard in some areas that planned care has had to be temporarily

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[1] Feeling forgotten? Hearing from people waiting for NHS care and treatment during the coronavirus pandemic, published in November 2020. You can access the report at the following link https://boardchc.nhs.wales/files/what-weve-heard-from-you/feeling-forgotten-waiting-for-care-and-treatment-during-the-coronavirus-pandemic/

suspended or reduced again in response to pressures in other parts of the health and care system.

The publication by the Welsh Government about the overall numbers of people waiting for care and treatment in Wales continues to show the stark reality of the situation.

The scale of the challenges facing health and care services is unprecedented - as they tackle the harm caused by the coronavirus pandemic as well as the long standing challenges facing many parts of the health and care system even before then.

The effects on people of waiting too long for diagnosis or treatment

The services we are hearing most often about from people waiting or affected by delays in diagnosis and/or treatment across Wales are:

- orthopaedics
- eye care
- dental care
- mental health, including child and adolescent mental health services (CAMHS)
- cancer care.

We also hear from lots of people living with life long conditions like diabetes whose ability to manage their condition and stay as healthy as possible is being affected by delays in routine checks and treatment.

Looking beyond the ever increasing numbers, the often heart-breaking and devastating impact on many people whose care and treatment has been delayed because of the pandemic is clear.

The impact on each person and those who care for and about them is different, with people describing a range of things affecting their day to day lives while they wait.

What's also clear is that the extent of this impact will often depend on a person's wider social circumstances, and not simply their clinical condition which defines their place on a waiting list.

For example, those who are in the most vulnerable situations may not be confident to or able to advocate for themselves. They may not be able to describe a deterioration in their own condition in the way that others might, and COVID restrictions has made it harder for others to advocate for them.

Some may not feel able to ask for or follow up with health services about their own condition in the way that others might in order to get themselves help and support.

What we hear most about when people tell us the impact of waiting on their lives includes their:

- overall life chances
- ability to work
- mobility and related issues such as weight gain
- confidence, independence and isolation
- quality of life
- ability to care for others
- relationships with loved ones and level of involvement in family/social life
- resilience and ability to live with chronic pain
- overall mental health and wellbeing.

For example, lots of people have told us they worry about the longer term effects of their children not being able to access routine NHS appointments to help keep their teeth healthy.

Many people have shared their worries and concerns about the impact on their whole family of waiting a long time for assessment and treatment for their child's psychological needs, eg., in areas such as eating disorders.

CAMHS services were stretched and unable to meet the demand in Wales before the pandemic, so the ability of the service to support more children and young people needing help is harder.

For adults who may have more severe and enduring mental health condition, waiting for a diagnosis from mental health services that were often struggling before the pandemic has been even harder.

For many people who work, the anxiety of not being able to do as much at work, not knowing how long they may be off work or whether they will be able to keep their job at all is a major worry. They worry about the financial and social impact on them and their loved ones.

Many older people have shared with us how conditions that are often referred to as 'coming with age' are limiting their day to day lives. The waiting lists for orthopaedic surgery and eye care treatment are big areas of worry.

For many people, the debilitating and life changing impact of living with pain and limited mobility, or losing your eyesight has such a significant effect on things like their mental health and wellbeing, their independence, and their ability to care for a loved one who may also have health needs.

Some people are waiting for diagnosis and treatment for conditions that are worrying and urgent, such as cardiac and cancer care. The stress and impact of this is usually reduced by quick access to treatment, but we know people have been waiting longer than usual.

For some people, they worry that they will die without ever getting the treatment they need.

CHCs are hearing more and more from people that because they don't have enough money they don't have any choice but to wait on a waiting list (either for themselves or a family member) – even though clinical staff may have told them that if they could pay they would be able to be treated within weeks, often by the same surgeon.

As well as increasing the sense of unfairness, some people have told us they feel guilty about being unable financially to help a loved one get treated earlier by paying for private healthcare.

We’ve heard from others that they have gone into debt to fund private healthcare for themselves or someone they care about.

Support for people, their carers and their families while waiting for treatment

The people we’ve heard from have identified a range of things that are important to support them while they are waiting for treatment:

- **Keep me informed and updated about my care and treatment**

  Lots of people have told us how important it is that they are kept informed and updated whilst they wait for treatment.

  Understanding the impact of the wait on their condition, knowing how long they can expect to wait before treatment and being kept updated of changes while they are waiting helps people plan to make the changes and adjustments they may need to make while they are waiting.

  People tell us that having a clear idea of when they may get treatment helps them to cope and manage the anxiety that comes with uncertainty.

  Knowing and talking about their condition and treatment with healthcare staff and loved ones makes a big difference to people and helps them to feel more in control of their own lives.

NHS bodies across Wales are doing things to help achieve this more consistently. This includes things like:

- Sending updates more often to people on waiting lists providing information on estimated waiting times, and giving details of how to access further advice, services and support
- Introducing family liaison officers/single contact point to support discussions between service users, healthcare staff and loved ones
- Developing an NHS app that will help people see for themselves where they are on the waiting list, as well as access other relevant and up to date information.

While these actions are positive, more work is needed so people are routinely kept informed and updated, and there is an equitable approach in place wherever they live in Wales.

At the moment we are still hearing too often from too many people how much ringing around they or someone who cares for them has to do before they get the advice and information they need.

For those people who may be hesitant about bothering the NHS at this time, or who may not be confident to do so, then they may continue to wait, increasing the risk of them feeling abandoned and forgotten.

▪ Support me to manage my condition and stay as healthy as possible (physically and mentally) while waiting for treatment - in the way that best meets all my needs

People want to feel they have some control over their lives and their condition while they are waiting for treatment. They also want to be involved in their care and treatment options, so they can make the best decisions for them (and often those they care about) with healthcare professionals.

Restrictions on visiting and attending healthcare appointments because of COVID-19 is making it more difficult for people to talk about their care and treatment options together with healthcare staff and the people who care for and about them at the same time.

People need access to the right package of advice, support and range of therapies to meet their individual needs, provided in a way that best meets their own circumstances. This includes things like:

- Appropriate pain management, including medication
- Access to advice, help and support relating to their particular condition
- Psychological and emotional support to help deal with the anxiety and depression that may result from waiting
- Appropriate therapies to help minimise or stop the deterioration of their condition
- Support in dealing with the consequences of waiting for treatment, eg., help to lose the weight that they may have put on because of limited mobility, etc.

Getting access to pain management clinics is currently a problem for many people, with long waits to be seen.

Even then, people often hesitate about using medication to help because they are worried about becoming overly reliant on it, or because they are worried about the physical impact long term use of medication may have.

Taking the time to talk about the options and what may work best makes all the difference to people.

There is already lots of online and in person advice and support already available – often provided by the third sector – but finding out about what's available and how to access it depends on good signposting.

Front line healthcare staff are often not fully aware of what's available locally and online. The 111 service is developing its ability to effectively signpost people to the right service and support, but there is still work to do so that this is consistently available and effective.

Online support is often available for people but navigating a way through it is a real challenge. People without IT skills, access to a device or connectivity in their area are at a particular disadvantage in terms of getting these self-help options.

Sometimes people can only access support services if they are referred by a GP or other healthcare professional and that can mean more delay.

Health boards across Wales are using the additional funds made available to them to further develop and introducing new arrangements to help support the increased demand from people for support as more of us wait longer for treatment whilst the waiting times backlog is being cleared.

These include things like:

A wellness improvement service in Cwm Taf Morgannwg University Health Board area. This is an online and face to face programme running over a 9 month period that includes pain management and other lifestyle choices like smoking cessation and alcohol awareness.

People will agree goals with wellness coordinators and once reached, will receive vouchers that can be redeemed in local shops.

A pre-habilitation programme in Betsi Cadwaladr University Health Board through the introduction of Well-being Hubs.

A psychological wellbeing practitioner (PWP) service within GP practices in Aneurin Bevan University Health Board area.

This service will offer appropriate assessment 'at the front door' wherever possible. The aim is to offer a range of support options including self-learning and referring on to the primary care mental health support service, etc.

It's really important that these and similar developments are introduced at pace so people can get the help they so desperately need as soon as possible. Feedback from users of these services needs to be gathered routinely so that people using these new services share what works well and what might need to be changed.

This learning should be shared more widely within and across health board boundaries.

Too often CHCs see 'pilot projects' working well but then not being extended out quickly so others benefit – or not staying in place even when they were valued because the initial funding has ended.

As well as new developments, there is an opportunity to strengthen and extend already established arrangements. For example, some health boards employ staff in care co-ordinator roles. These are often long established in mental health or integrated care services.

They can be very helpful in stopping people feel isolated from their own care through regular and personalised contact and support. It helps people feel their care is being actively managed. This means they don't feel pressure to have to chase progress themselves.

The use of care coordinators is inconsistent. The kind of support offered to people is different between the different sorts of care pathways they follow.

It's important this kind of help is offered more consistently.

Support me to deal with the other things I worry about because of my condition

For many people, the impact of waiting for treatment doesn’t only affect their health but how they and their families are able to live their lives. Being limited or unable to work often causes significant financial worry. Being unable to care for children or other family members without support often creates longer term challenges.

Health services need to work effectively with social services and the third sector so that people are aware of and able to access the full range of services available to them – through support for roles like ‘community connectors’ for example.

Signposting between websites is often still limited, making it harder for people to find the full range of services available.

Support for carers and families

CHCs often hear people who need treatment worrying about the impact this will have on the people they care about – and who care for them.

Many people worry that their loved ones will ‘carry the burden’ of looking after them, providing the bulk of the care and support they need without themselves getting the advice, support and respite they need, when they need it.

Unpaid carers are often unaware of the support available to them, and healthcare services are not always aware that someone is playing a vital carer role – this was clear during the vaccination roll out when carers were often not contacted and had to identify themselves to healthcare services.

In recent months, as the pressures on health and care services have risen again and continue to rise, the reliance on carers has increased.

It’s vital that health services continue to build a clearer picture of who carers are, the part they play in someone’s care and treatment, and the support they need to enable them to play this vital role.

Support for people with life-long conditions

Throughout the pandemic we’ve heard from lots of people living with long term health conditions about the impact of the pandemic on their condition, and on their overall wellbeing.

In the earlier stages of the pandemic, lots and lots of people shared their fears, and in many cases experience of worsening health as they were not getting regular access to the routine check-ups and the care and treatment they need to help them more confidently manage their condition and its wider effects.

The development of more services being available in pharmacies has helped ease the situation for many, and as things got better overall and the NHS was able to reintroduce more routine services, we generally heard less from people about this.

With the increasing strain on GP services, we are hearing more from people who are struggling to get a routine appointment in their GP practice. Sometimes this is because the booking arrangements are the same for urgent and routine appointments.

This often means everyone has to telephone from 8am in the morning and by the time the person is able to get through all the appointments have gone.

Some people who were finding access easier through e-consult and AskmyGP are also now finding it more difficult as GP practices are often restricting or suspending access to these services because of capacity challenges.

The very recent extension of the vaccination roll out arrangement in response to the Omicron variant of COVID-19 will cause concern again that GP practices may again suspend their routine appointments to help deliver the booster programme.

Engaging with the public

Letting people know what's happening with their health service nationally and locally is key to people's understanding of what this might mean for them and their healthcare needs. Messaging from England risks confusing the picture.

CHCs across Wales are seeing messaging locally and nationally has been clear and often stark about the immediate pressures facing the NHS overall and the challenges we face as we go through the winter period.

It's important that these messages are properly co-ordinated and consistent, so that people can make a clear link between what's happening in the NHS and what this means for their care and treatment.

Since the pandemic, CHCs have seen NHS bodies extend their use of social media to update people quickly in response to immediate issues and pressures. They are also increasingly using this media to address rumours and misinformation that can cause real worry for many people.

The relative informality and speed in which messages can be put out to the public through this media can be both helpful and unhelpful.

CHCs have seen, for example, healthcare providers setting out clearly and thoroughly the scale of the pressures facing their service, what this means in terms of accessing healthcare differently, and why first point of contact staff may be asking more detail about their health than they would have done before the pandemic.

CHCs have also seen messaging from healthcare providers that has caused much more concern amongst patients because of their content or tone.

Importantly, for people who may not be active on social media, or who may not access information digitally, we have seen some health boards develop creative and innovative ways to update, inform and engage with people in their local communities.

Aneurin Bevan University Health Board has introduced a 6 month community engagement programme. It has arranged a road show bus.

This will transport healthcare leaders and officers to local communities, towns and events to speak to people face to face, to hear people's feedback, deliver key healthcare messages and also encourage recruitment opportunities in health and social care settings.

Whatever the messaging, it's important that it matches peoples lived experience.

Picking up information on the GP telephone line asking you to use the website using AskMyGP or e-Consult only to find that the service is not available leads to anxiety and frustration. Variation across GP surgeries about the digital options they offer also makes it difficult for patients to know what's available for them.

For lots of people, the easing of restrictions in wider society creates an expectation that health services can open up at the same time and in the same way. It hasn't always been clear enough to people why, for example, there are more risks in opening up a GP waiting area in the same way that someone can sit down with people in a pub or restaurant.

When messaging clearly and consistently tells people how important it is that they should seek help quickly if they are feeling unwell or are worried about symptoms, it’s important that people can get that help when they need it.

The current pressures on the health and social care system is having a massive impact on urgent and emergency care.

For many people having difficulties in getting a GP appointment or getting through to the 111 service, we hear that people have simply given up, or gone instead to the place they know will be open, which is usually the emergency department (often to be sent back again to try to get to see someone in their GP practice).

We have also heard from some people that they have been directed to the emergency department by their GP surgery because of its capacity challenges – only to be ‘told off’ for attending the emergency department by hospital staff.

CHCs have seen positive developments in helping people get the care they need quickly from other services instead of their usual place. People often like these new arrangements and are positive about the care they receive in these new ways.

The extended options within pharmacies, including for example the minor ailments service, works well when people know about it, but the messaging and awareness about what is available and where remains patchy, despite the efforts of healthcare services.

As healthcare services continue to adapt and change to recover from the impact of the pandemic and tackle the longer term challenges that were already present in the NHS before the pandemic, it’s vital that we do this together.

Our health and care services for the future must be designed and developed with people and communities – and not done to them. People in Wales care so passionately about their health and care services and the people who deliver those services – they must have their say in how their services are delivered.

People understand that during the pandemic things needed to change quickly and this meant it was not possible to engage and consult people in the usual way. But designing sustainable services for the future is different – this must be done together, through continuous engagement and public consultation whenever this is appropriate.

Health service plans to recover from Covid-19

The NHS Wales Recovery Plan sets out in clear and broad terms the approach needed to recover from the coronavirus pandemic. In general terms its approach responds to the things CHCs heard were important to people across Wales – but within a likely timeframe that recognises the scale of the challenge but is longer than anyone wants to see.

People don't just want things to get back to where they were before the pandemic – waiting times were too long for too many people then.

People want to see the things that have worked well for them during the pandemic continue and be further developed in the future. This includes things like digital healthcare (including the development of digital records that help and support 'joined up' health and care provision), and health and care partners (including the 3rd sector) working effectively together within local communities, etc.

People don't want a 'one size fits all' approach – health and care services must be delivered flexibly, in a way that meets peoples' individual needs. This must include the right balance between face to face and digital activity.

The challenge facing health services across our local communities in Wales – when health and social care staff at all levels are exhausted (planners, managers and front line staff) is balancing the 'crisis management' needed to deliver health services in the here and now with designing and developing sustainable health and care services for the future.

In the short term, CHCs are seeing health boards look to deal with the waiting times backlog in their areas in lots of different ways. These include, for example:

- Funding independent healthcare and out of area providers to provide treatment for NHS patients
  Health boards are agreeing contracts for their population to get things like joint replacements and cataract operations in other places.

- Validation or risk stratification
  Health boards are reviewing patients waiting for appointments to check and prioritise where people are on the list based on their clinical condition and whether they have said they still need treatment

- Doing things better
  Health boards are looking at better ways of doing things. They are looking to use tools like 'Releasing time to care' which aims to improve processes and free up capacity, and 'Getting it right first time[2]' which looks at reviewing services by focusing on data and clinical knowledge to see how things are done and how they can be done better.

- Managing demand in different ways
  Health boards are trying out things like:

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[2] Find out more at the following link Getting It Right First Time - GIRFT

  - hospital consultants offering advice and guidance to GPs to help them provide patient care directly without the need to refer them to someone else
  - Patient initiated follow ups (PIFU) – placing responsibility with a patient to decide whether they need a follow up clinic appointment (within strict guidelines)
  - Virtual clinics – to reduce the number of people attending hospital sites and carrying out extra clinical activity without placing additional demand on outpatient areas
  - Clinical assessment service – review of referrals from GPs to see whether adding someone on a waiting list is the best way of meeting someone's care and treatment needs
  - Shifting services from hospitals to community settings, eg., supporting imaging carried out in community optometrists for virtual review by hospital staff, and extending the management of some patients by community optometrists.

- Redesigning hospital spaces to separate planned care from urgent care

  Health boards are changing things around within or between hospitals so that some planned care can still take place because it is operating separately from emergency care.

- Introducing new diagnostic equipment and looking at the joint delivery of services, eg., on a regional basis.

When developing these arrangements, it's important that health boards look beyond the numbers and think about what they mean for the people on waiting lists.

For example, offering quicker treatment further away is no good if someone can't get there easily, or if it means a longer absence from work/their caring responsibilities which they can't afford.

Health boards also need to think about and understand the impact on patients living "outside" of their population boundaries but who equally depend on, and are affected by the waiting times backlog.

In the longer term, detailed service design and delivery plans must learn from ours (and others) approaches and experiences during the pandemic. They must be developed by health and care planners working together within communities, regionally and across Wales.

They must avoid any postcode lottery for health and care services, and focus on delivering equitably for people living in all parts of Wales in a way that places equal value on physical and mental health services, and health and social care provision.

They must get the balance and focus right between treating us when we are ill to helping us to stay healthy.

They must better understand and tackle – once and for all - the health inequalities that have been so devastatingly demonstrated throughout the pandemic – and where the causes are wide ranging and extend way beyond healthcare.

Further evidence

As well as the areas covered in this evidence, CHCs have published reports that include what they have heard about the impact of the waiting times backlog on people in Wales:

- **Have you got a dentist?** Hywel Dda CHC, April 2021

  https://hywelddachc.nhs.wales/files/reports/have-you-got-a-dentist/

- **Every mind matters** Hywel Dda CHC, September 2021

  https://hywelddachc.nhs.wales/files/reports/every-mind-matters-report/

- **Mental health of young people during COVID-19**, Powys CHC, September 2021

  https://powyschc.nhs.wales/files/report-library/report-young-people-mh-survey-september2021/

- **Is my life worth living?** Lived experiences of patients waiting in pain for elective orthopaedic surgery, Swansea Bay CHC, September 2021

  https://swanseabaychc.nhs.wales/what-we-have-to-say/report-library/sb-chc-thematic-reports-2021/orthopaedic-report-september-2021-pdf/

www.boardchc.wales