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 33
Ymateb gan: | Response from: Age Cymru

Consultation response

Senedd Cymru: Health and Social Care Committee

Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment

Introduction

Age Cymru welcomes the Health and Social Care Committee's inquiry into waiting times. We live in an ageing society and population projections suggest this trend will increase with more and more older people living with ill health. With the current crisis in health care, health inequalities can reasonably be expected to widen and through the pandemic there has been a marked deterioration in older people's physical and mental health.

The ongoing reduction in elective treatment is disproportionately felt by older people. Older people are greater users of elective hospital care than younger age groups. Whilst life expectancies have increased, the length of time that people remain in good health has not. Men and women in Wales are living on average 16.9 years and 20.2 years respectively – or around a fifth of their life – in poor health:

- 45% of people aged 60-74 are living with a long-term condition, illness, or disability and only 34% of this age group say they are not limited by a long-term condition. 24% of this age group are limited a lot by health issues.
- For those aged 75 and older this increases to 49% living with a long-term condition, illness, or disability and 35% of this age group are limited a lot by health issues.[1]
- Surgery and treatment for musculoskeletal (MSK) conditions have been affected more than many other areas of treatment during the pandemic as these are treatments that cannot be delivered digitally or remotely. These conditions can have adverse effects on mental health. 33.9% of people aged over 50 UK wide with MSK conditions have persistent anxiety issues and 22% have a persistent depression problem. Mental health also has an impact on a person's ability to deal with an MSK problem.[2]
- A global study showed that 59.8% of people aged 65–74 are living with an MSK condition, which rises to 62.6% for 75–84-year-olds and falls to 60% for those aged 85+.[3]

If additional efforts in Wales are made to reduce the backlog in treatment, the above statistics can in time change.

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[1] Older People's commissioner - State of the Nation report 2021 https://www.olderpeoplewales.com/en/reviews/sotn.aspx

[2] Public Health England. (2019). *Musculoskeletal Health: applying All Our Health*. Available at: https://www.gov.uk/government/publications/musculoskeletal-health-applying-all-our-health/musculoskeletal-health-applying-all-our-health.

[3] Global Burden of Disease Collaborative Network. Global Burden of Disease Study 2019 (GBD 2019) Results. Institute for Health Metrics and Evaluation (IHME), Seattle, 2020.

We wish to clearly state that older people have told us that when they have accessed treatment (elective and emergency), the majority have praised the treatment and care from health staff and are appreciative of the efforts of the Welsh NHS to provide a service in such difficult circumstances. However, many older people have told us of significant issues with delays in planned care that are heart breaking, many of which pre-date the pandemic. Waking up in pain after a broken night's sleep, being in pain all day, and going to sleep still in pain not knowing when treatment will be available has a profound effect on people. Not knowing what exercise can be done safely means many won't be taking the steps that are possible to help themselves maintain physical and mental health and prevent a downward spiral. Many people are not aware that safe exercise can help reduce pain levels whilst people await treatment. Not knowing how the correct diet can improve their health and so increase positive outcomes post-treatment also contributes to reduced physical and mental health.

Common circumstances like living alone or having multiple conditions can also make managing a condition and preparing for surgery more complex.[4] One person told us:

> *'Health appointments have been diabolical. I've not seen rheumatologist for a year nor had treatment. I've waited over a year for orthopaedics appointment that had been cancelled numerous times. Many other appointments cancelled & postponed. A terrible impact on my worsening health conditions. Hindering my mobility. Too many services are limited or negligible. Most only offering emergency provision.'*

Another person spoke of concerns for their mother from delays:

> *'My Mum has a serious health condition and tried to get an appointment to see a consultant in October. Her appointments have been continually cancelled or just non-existent […] I am very concerned about her health and believe she is at risk of dying. The appointment is only for a consultation, so if she requires a procedure (very likely if she survives that long) my concern is this could be delayed for at least a year.'*

The repeated cancellations of appointments not only cause concern and mental distress for the patient but can often affect others. Families and carers make arrangements including time away from paid work and then have to rearrange this again and again, as well as delays meaning caring roles are required for longer than necessary.

The breadth and depth of the distress caused by delays cannot be overstated. This needs to be seen in the context of the wider impact of the coronavirus pandemic on older people. In our survey of older people's experiences of the most recent lockdown last year we asked older people what they had found challenging. 37% said they had found loneliness a challenge and 51% said their emotional health had been impacted. 35% said their physical health has been impacted. These are all

[4] Independent Age 2021 Patiently Waiting – this report is specific to England but the issues are similar in Wales. https://www.independentage.org/policy-and-research/patiently-waiting

increases from our earlier survey undertaken in the first lockdown, demonstrating the incremental effects of lockdown and lack of access to services.

The impact of longer waiting lists on older people and their loved ones is profound and felt in every aspect of a person's life. For many, a life waiting for surgery or other treatment is a life on hold. Impacts include:

- Worsening and severe pain
- Poorer physical health
- Lost mobility
- Weight gain
- Loss of sleep
- Loss of independence
- Poorer mental health
- Increased loneliness and isolation
- Reduced financial security through being forced to seek private healthcare

One person commented that the impact was:

> '*Difficult, needed cataract surgery since last year, still no appointments available, eyesight is now a danger to me*.'

Others with sight loss told us how they can no longer go out unaccompanied, demonstrating the loss of independence that could be avoided with reduced waiting lists. Many older people rely on unpaid carers for support whilst they await treatment and through lockdown many respondents to our survey told us that they have provided significantly more care than before the pandemic started. Nearly 23% of respondents said that they had taken on additional caring responsibilities during the pandemic. Additional caring responsibilities sometimes related to the loss of usual care services such as domiciliary care, with reduced hours of care available due to staff shortages in care services, day centres and respite services. For others these related to those they care for needing to shield, meaning friends and families taking over shopping and similar support tasks. Some unpaid carers have told us how they have injured themselves by providing personal care when other services have not been available and so required treatment through health services themselves – which contributes to additional pressures on the Welsh NHS as they now required treatment themselves.

> *'Because of lockdown and understandably Covid priorities, access to medical support and information has been restricted to 'essential' minimal. The usual rehab programmes have not occurred. As the carer I have relied mainly on internet for information. Whilst very grateful for excellent surgery and hospital treatment for my husband, the feeling of 'going it largely alone' has been quite stressful. Follow up scans and cardio - specialist checks are on hold.' -* Female carer, 70-74, Isle of Anglesey.

1. **The services in place for people who are waiting for diagnostics and treatment, particularly pain management support.**

It is our perception from what older people have told us that there are differences across Wales on the availability of services for people that are waiting for diagnostics and treatment, as well as inconsistencies in who is offered a service. Common themes of feedback we have had from older people is that they received little or no communication relating to the condition they are awaiting treatment for; how long they are likely to be waiting; and in some cases, no communication is received at all to confirm that they are even on waiting lists for treatment. Hope needs to be restored for older people that they are not being side-lined and that health services are doing all they can to address the backlog.

Where communication is not happening, people are left in limbo with no information on how to self-care. With some services having moved during the pandemic, many people are unsure who and where to contact to see what is happening with their treatment, which can result in additional pressures on GP services as a known point of contact.

It's not just the patients waiting that are affected by delays – it's also unpaid carers who have taken on so much more care, and whose health is affected by additional responsibilities. This can have a knock-on effect in waiting times as they are more likely to suffer from worsened health as a result. It is therefore vital that health records are joined up to reduce the patient's need to negotiate complex booking systems. Systems should record where a patient is also a carer, or has a carer, to ensure that messages get through to all concerned.

Each health board in Wales has pain specialist services, though the services offered through each board may vary. Many pain specialist services offer medical interventions and self-management courses, but these are not routinely offered to all people that would benefit from them. Different people with different conditions will be benefit from different approaches: some can effectively be supported via digital approaches; others will require face to face treatment; others will benefit more from peer support groups to help them cope and manage their symptoms. Each health board should offer a range of approaches to address the needs of all patients. Social prescribing needs to be made available via GP services and other health settings to provide people with improved opportunities to wait well.

Communication

Older people have told us that they feel abandoned waiting for diagnosis and treatment, and some have not even had written confirmation that they have even been put on a waiting list.

Older people are likely to deteriorate more quickly than younger people whilst waiting for treatment[5] and as a result may not be medically fit for surgery by the time they reach the top of the list. A study by Independent Age found that 71% of older people

[5] Independent Age 2021, Patiently Waiting: Older people's experiences of waiting for surgery https://www.independentage.org/policy-and-research/patiently-waiting

waiting for treatment said their health had become worse during the pandemic compared to 49% that were not waiting for treatment.[6] Such deconditioning needs to be overcome through proactive efforts of health services.

Social prescribing needs to be embedded in all primary care services across Wales to allow people to wait well for treatment. Efforts need to be made by health services to ensure that all patients on lists for treatment are contacted to see what would benefit them whilst they await treatment. We detail further in (4) below more on improved communications with patients.

Pain management services should be offered to them where needed and information on other support services that can help should be offered routinely. These will include pain self-management tools and techniques, peer support groups (that can also assist with reducing loneliness and isolation), suitable exercise groups (again that can help overcome loneliness and isolation), as well as dietary advice.

Staff should be trained in the needs of older people and how to communicate with them. Relevant information also needs cascading to carers and there should be a formal pathway for this that also considers how to identify carers and the information and support they need.

2. Access to psychological therapies and emotional support for those who may be experiencing anxiety or distress as a result of long waiting times.

The clear link between people being in persistent pain and increased poor mental health is now more recognised than previously. Being in constant pain also contributes to increased loneliness and isolation.

People need access and signposting as appropriate to physical activity support and resources, peer support, self-management information, support for pain management and their mental health, as well as assessments for aids and adaptations. Some of this support can be successfully delivered through the third sector but the situation is patchy across Wales in terms of access and length of time that projects are in place. Wider services that patients can be referred to are often provided through short term funding, particularly for third sector services.

When such support is only provided though short term funding it does not allow services to develop to their potential and so do not always allow the best possible outcomes for people. Attracting, training and retaining staff is difficult when funding is only provided year on year. Further, getting information out into communities on the availability of such support takes time and efforts. It also takes time to build up confidence in the community that it is a good service, which is difficult in the short term. Where such support exists Health Boards and Primary Care need to be proactively signposting to these services: social prescribing is key to this but at present this is not happening across all of Wales.

[6] Independent Age 2021, Patiently Waiting: Older people's experiences of waiting for surgery https://www.independentage.org/policy-and-research/patiently-waiting

It would be helpful to have a strategic lead at national level to help drive change and improvements and to share emerging best practice on how to support people on the longer waiting lists.

3. **The contribution the third sector can make in providing peer support and information to patients waiting on an NHS waiting list**

The impact of support from the third sector can be huge in allowing people to 'wait well' whilst waiting for treatment and for their later recovery stage. It is vital that we work across sectors and ensure that older patients have access to services that can help them and that systems are in place to refer people awaiting treatment onto support that can help them whilst they wait.

Many older people would not know where to go to get help and with many older people not being digitally literate, so it's vital that social prescribing becomes embedded in practise and that signposting is part of referral pathways whilst people await treatment.

Peer support shouldn't be seen as an 'add on' – it is part of the holistic approach that is needed to allow people to wait well and to also assist with improving outcomes after treatment. Older people have told us that they have become aware of such support 'by accident' and not through routine care pathways. When they do have such support, they find it highly beneficial as it not only reduces loneliness but also opens up avenues to others with lived experience of their conditions who can help them live more healthily. It also provides emotional support from people who do not need to explain how their condition affects them as they are all in similar situations. Such support groups should be available in all areas of Wales and funded on a longer term and sustainable basis.

4. **The effectiveness of messaging and engagement with the public about the demands on the service and the importance of seeking care promptly**

22 responses to our winter lockdown survey in 2021 clearly stated that they had consciously avoided accessing health care. The main reasons were that older people did not wish to burden health services unnecessarily; that they had tried to access GP services but had 'given up;' or that they were concerned about catching the virus in waiting rooms. As such we are concerned that many older people may not have yet to come forward and that current waiting times statistics are do not accurately represent the full volume of demand, and that these delays may mean that it is too late to help older people by the time they feel more confident and able to access health care. People are often unaware that even where waiting lists exist that there are other interventions that can support them to not deteriorate whilst they await treatment.

<u>Engagement with the general public</u>

We are aware of the efforts that Welsh Government and the Welsh NHS have taken to engage with the general public to say that health services are open, and that people should come forward for diagnosis and treatment, as well as where to go to

get the right help at the right time, and these initiatives are welcomed. In practical terms it will take time for such messaging to be received and fully understood by people across Wales.

To increase the effectiveness of such efforts it would be helpful if specific initiatives were targeted at deprived areas where health inequalities are likely to be higher, and towards specific groups of people that are known to be at risk of poorer health; and towards those that are less likely to come forward for help. Targeted work via sites such as community centres, lunch clubs and groups that such people engage with could increase confidence of the messaging sent.

As a considerable proportion of older people are digitally excluded it is important that information is available in other ways rather than just via social media and websites. Messaging should be clear that, though there are delays due to the pressures on the NHS, support through health services can help people wait well and prevent further loss of health in the meantime.

For people who have not yet come forward with their conditions it's important that public messages are clear that services are open, though access may be different now to 'traditional' methods. As not all people are comfortable with digital access or confident that remote consultations are helpful, it would be helpful for public messaging to include case studies to help drive such messaging home. These should include how delivering services differently can speed up access to support and free up time for the NHS to see more people and so reduce waiting lists. Messaging should also be clear that though there are delays in getting full treatment, there is a lot that services are able to do in the meantime to allow them to wait well.

Taking the example of physiotherapy, a blended approach of face to face and remote treatment can be highly effective at reducing the time people take to recover from an injury. At first glance people may not be confident in telephone appointments for this. Whilst remote appointments will not be suitable for all people needing physiotherapy treatment, and some will need face to face support both to ensure that diagnosis is correct and to overcome confidence issues that they are doing the right thing, for those with digital access information and links to videos can be emailed to the person to allow them to learn exercises that will allow them to recover. Remote appointments free up physiotherapists time, allowing more people to be assessed and treated earlier.

Engagement with those on waiting lists

For those on waiting lists, communication should begin early and not be a 'one off,' but rather ongoing contact from a health professional to ensure that the person waiting for treatment's condition has not deteriorated or changed in other ways. It is important that people no longer feel that they must fend for themselves whilst awaiting treatment and that things can be done to allow them to wait well.

All health boards should develop a holistic package of communication, signposting and support. This should include:

- expected time frame for treatment

- What other services are available
- Who to contact if circumstances change
- access to information and support on how to maintain existing levels of health whilst they wait. This can contribute to improved outcomes for patients post treatment as it reduces deterioration over time.

5. The extent to which inequalities exist in the elective backlog, with deprived areas facing disproportionately large waiting lists per head of population compared to least deprived areas.

Age Cymru have little information from older people that is broken down to this geographical detail that would indicate where health inequalities lie. However, as it is known that musculoskeletal conditions, which disproportionately affect older people, are more prevalent in poorer communities it seems likely that there will be longer waiting lists in those areas.

Older people have told us that they have sought private treatment because of increasing waiting lists. Some older people have told us that they have paid privately and travelled abroad for operations. We are concerned that the pandemic has added strength to the creation of a two-tier system: those that can pay for treatment can access this privately and get back to their lives free of pain, illness or with improved sight, whereas poorer older people have reduced independence and quality of life whilst waiting for treatment that they are not sure will ever happen.

Older people are usually living on a fixed income and so where they do pay for treatment this can come from savings that can not be replaced.

6. Plans to fully restore planned NHS care in Wales.

Hospital treatment services were of major concern to many respondents to our survey. The additional funding announced by this Senedd to address waiting lists will assist greatly but in practical terms, reducing waiting times will take time to achieve. As such, solutions need to be found in the short term, as well as looking at changes to practice that can reduce the time from diagnosis to treatment and recovery in the longer term.

Welsh NHS needs to prioritise building additional capacity for elective surgery immediately. This needs to be upscaled from pre-pandemic levels as waiting lists were already growing.

It is also vital to develop additional wrap around support for those currently waiting for treatment to overcome some of the negative effects of delays and assist with preventing more serious interventions. It is vital that those waiting for diagnosis and treatment have access to information and advice on safe exercise, healthy eating and pain management techniques for expected conditions that can be improved in these ways. This will help slow down any worsening of conditions and to reduce some of the symptoms of their conditions whilst they await treatment. These ‘pre-habilitation services’ should be available at GP surgeries and health centres via a ‘First Contact practitioner’ type role as these are sites that people turn to first. Patients awaiting confirmation of diagnosis and treatment should have ongoing

access to support that could be a combination of telephone, face to face and digital technologies according to which have been evidenced to produce the best outcomes for people.

Consideration needs to be given on where surgical procedures take place in the longer term. Though it is preferable to have treatment available close to home, this may not be practical for all treatments, so consideration needs to be given on which treatments are available more locally and which are centralised. For example, ‘once in a lifetime’ treatments may mean travelling further than other treatments that are needed more frequently. Hospital transport should be available to patients especially in cases where they are required to travel further afield for treatment.