Welsh Parliament
Health and Social Care Committee

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

Engagement Findings

January 2022

In November 2021 the Senedd's Health and Social Care Committee launched an inquiry into the 'Impact of the waiting times backlog on people in Wales who are waiting for diagnosis or treatment'.

The Citizen Engagement Team supported the Committee by facilitating a series of interviews and focus groups with people who are currently, or have previously been, waiting for diagnosis or treatment. This report summarises the Citizen Engagement Team's findings.

Engagement

The Citizen Engagement Team conducted a series of 13 interviews between 4 November and 22 December 2021.

The objective of these in-depth interviews was to gather the views and experiences of people across Wales who have been impacted by the waiting times backlog.

In addition to the 13 interviews, two focus groups were conducted. These were arranged in partnership with Fair Treatment for the Women of Wales (FTWW) which took place on 5 and 6 January 2022 and were attended by Committee members Rhun ap Iorwerth MS and Mike Hedges MS.

Participants

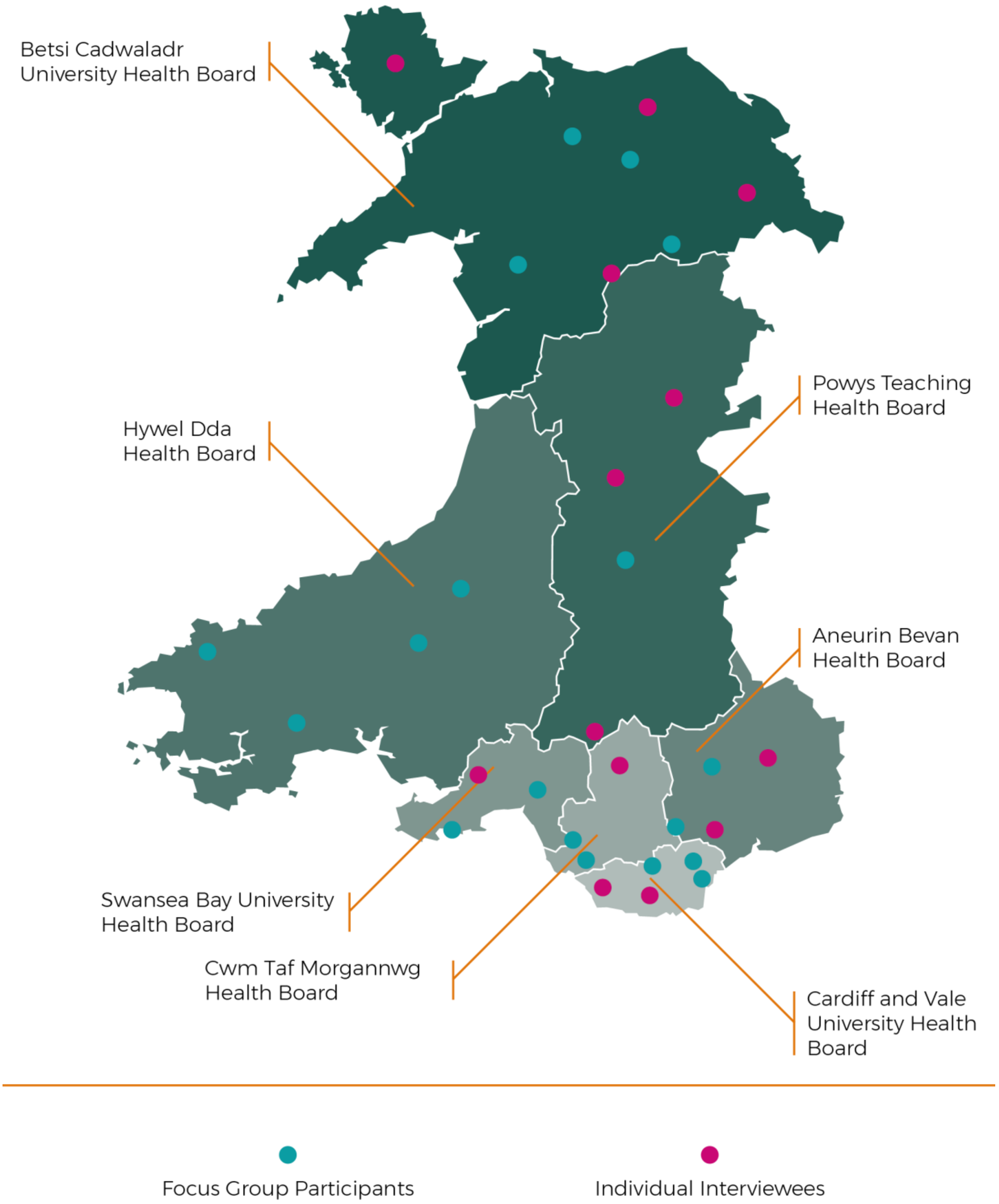
The Citizen Engagement Team worked in partnership with relevant organisations to identify participants and ensure that they received appropriate support and advice throughout. This included some organisations that had identified waiting times as key priorities in their responses to the Health and Social Care Committee's consultation on priorities for the Sixth Senedd. Efforts were made in partnership with relevant organisations to ensure that participants were located across different health boards in Wales and had a fair male/female balance. Ages of participants varied between 23 and 83.

All case studies have been anonymised.

Partner organisations

- Age Cymru
- Carers Wales
- Cymru Versus Arthritis
- Endometriosis UK
- Epilepsy Action Cymru
- Diabetes UK,
- Fair Treatment for the Women of Wales (FTWW)
- Mind Cymru
- MS Society

Location of participants:



Thank you to everyone who contributed to the programme of engagement.

Methodology

Interviews were held over the phone and via Zoom and Microsoft Teams in English. The format of engagement was largely comparable between sessions but varied slightly to meet participants' needs and facilitate organic, qualitative conversations.

The following questions were used to prompt interviewees:

- What help have you received from the NHS to help you manage your condition and pain related to it while you waited for treatment?
- What type of support were you offered, such as referral to the third sector, physiotherapists, occupational therapy, prescription or over-the-counter medication, mental health support?
- Have you been able to access this support?
- Have you had to access GP or A&E services for support for the condition you are awaiting treatment for?
- How easy has it been to access information on how to manage the pain and symptoms?
- What communication have you received from the hospital and clinician?
- Have you been able to easily access information about where you are on the waiting list?
- Have you or are you considering private healthcare?
- What are your concerns and how do you think your experience could be improved?

Summary of findings

Each interviewee raised specific issues relating to their own circumstances. However, a number of key themes emerged across the interviews, and across different health boards and medical conditions. Quotations relevant to these themes can be seen in the individual case studies.

Key themes included:

- Participants were consistent in the view that **communication** problems had been exacerbated due to Covid-19.

- Participants noted key **inequalities** that affected their ability to receive care. This included geographical inequalities and financial inequalities.

- Multiple participants indicated a **lack of NHS support** to help manage their conditions, including pain management support and mental health support.

- Participants indicated several examples of problems with regard to **referrals** to neighbouring health boards and also cross-border referrals .

- Several participants have either explored the possibilities or had **private treatment** due to the length of waiting times

- Participants brought up wider **systematic issues** within the NHS which played a role in longer waiting times, including poor health board collaboration.

- Participants noted that early **misdiagnosis and lack of knowledge** within the NHS of certain conditions, caused much longer waiting times and poorer experiences for patients.

- Participants noted that there was a reliance on **third sector organisations** to provide the support for patients on waiting lists that should be provided by the NHS

Case Studies

Participant A

Age: 82
Sex: Female
Health Board: Cwm Taf Morgannwg University Health Board

Key themes:

- Quality of life being affected
- Frustration leading to exploring options for private treatment
- Poor communication during Covid-19

Background:

Participant A noted that as an active older person, the impact of being on a waiting list has affected their confidence and quality of life. An issue affecting her eyes developed in 2017, after a routine visit to her opticians identified that she was slowly developing cataracts.

"I am a very active pensioner, I like to have my independence, I used to drive down to see my daughter and now it's just not possible. I do still drive but driving in the dark or in bad weather is now a big safety risk for me and others. Reading is very difficult; I can't make out numbers and I have found myself just not going out as much as I used to. I have to rely more on friends and family – I have lost my independence."

Participant A explained that a referral was initially made to the NHS in the winter of 2019 and that no follow-up correspondence was received.

"I did have an initial letter in 2020 to confirm that I was on the waiting list... since then, nothing … it's a shambles really."

Participant A is clear that she believes Covid-19 may have had a detrimental impact on the quality of service she received, in particular relating to communications.

"I had no contact since January 2020 from the NHS. I have tried to chase them up on 3 separate occasions; the phone kept ringing. 6 weeks ago, I finally managed to speak to someone. I was told the waiting time was 27 months from time of referral. I am now waiting for next steps, I am not holding my breath."

Participant A explained how the situation has got to such a point where going private had now become a real option, despite the financial difficulties that would present. She did not feel that waiting a further 27 months was an option.

"The only way I could do it (go private) is potentially going and dipping into my savings. I have a small NHS pension having worked with the NHS all of my life. It's a bit disappointing than when you need something you can't get it after giving your whole life to the NHS."

Conclusions:

Whilst acknowledging the impact of Covid-19, Participant A was extremely frustrated with the lack of communication from the health board. She pointed out that she was extremely proactive and that she knew of others with similar issues that are going unnoticed.

"Communication doesn't have to be over-bearing. It's not asking for much, even if we were given an update once every 6 months, even once a year! It would make you feel that you haven't been forgotten about."

Participant B

Age: 79
Sex: Male
Health Board: Betsi Cadwaladr University Health Board

Key Themes:

- Poor communications
- Frustration and pain led to seeking private treatment
- Lack of advice and support from health board about pain management
- Difficulties around cross-border referrals

Background:
Participant B previously underwent surgery in 2016 for a hip replacement at which point he was advised by the surgeon that he would need to replace the other hip soon. This initial surgery took place in England, and he stated that everything ran smoothly from the initial referral to the surgery itself. According to Participant B his experience changed in 2018 when his other hip started to cause issues.

> *"It was 2018 when I started having pain in my left knee. After X-rays showed nothing, the GP said it could be the left hip which wasn't a huge surprise. I was prescribed painkillers and sent to a musculoskeletal clinic. This was a complete and utter waste of time, and I was sent back to the GP utterly pissed off. I asked them why I simply couldn't see the same surgeon as I did in 2016 over the border and was told that ''Gobowen (Hospital) is a dirty word as far as Betsi Cadwaladr is concerned'."*

Participant B notes that things did not get any easier over the next 12 months. Multiple trips back and forth between the GP and physio took place before he was diagnosed as having a clear issue with the hip and referred to a consultant in August 2019.

> *"After referral in August 2019, I didn't hear anything for the rest of the year. Eventually after chasing and chasing, I managed to make sense that I was on a waiting list. Finally had a call from a knee surgeon at the start of 2020 who told me nothing was wrong with my knee but my hip was in a bad state. This was something I already knew years ago! By this point I was in excruciating pain, walking with a stick and my quality of life had decreased dramatically. I was told then - even after the confusion around my diagnosis – that the NHS waiting list was 3 years and rising. I had no option then but to go private."*

Participant B had private surgery in 2021 and stated that he made this decision as a result of huge frustration, the deterioration of his quality of life and the prospect of another 3 years of waiting.

Conclusions:

"There desperately needs to be better communications, a phone call, a questionnaire. Some people might not suffer so much and others have issues that really negatively affect their life. There is just no contact from the health board. The GP knew I was paying for private physio and encouraged me to continue down that path: 'Lord knows when you'll get dealt with here'. The fact that you are on a list with 3 years plus is one thing but the non communication is infuriating. I could do nothing else. I felt left by the wayside, and I am one of the fortunate ones."

Participant C

Age: 21
Sex: Female
Health Board: Betsi Cadwaladr University Health Board

Key Themes:

- Poor communication between health board and patient
- Poor internal communication between therapists and doctors
- Negative impact of Covid-19 on Mental Health Services
- Lack of support from health board in suggesting different services available, for example the third sector.

Background:

Participant C first contacted the NHS while she was in school, and her experience has been varied over the intervening years with the Covid-19 pandemic having an impact on NHS Mental Health waiting times and services.

'" I didn't know what mental health was. I felt very quiet and regressed. My parents noticed this and put me into CAMHS (Child and Adolescent Mental Health Services) at 15 before I transferred to Adult Services. I found the initial stage hard, learning about what mental health was at a tough time for me with school."

Participant C has seen a huge change in the service over the last few years as she transitioned from CAMHS to Adult Services. She stated how her situation has gone from bad to worse over the last 10 years and points to possible systemic issues and poor communication playing a part in this.

"I hardly see my mental health therapists anymore. I get no communication, only the odd letter about blood tests. I used to have weekly therapy support and then it disappeared and went non-existent. I feel sorry for anyone coming into this system during the last 2 years.

Communication has been dreadful in the last few years; I was introduced to different therapy and emotional support when I was younger and in all honesty, I couldn't fault them. Now it feels very different. Covid has had a huge impact on Mental Health services – you are the one doing the chasing all the time. I just feel like garbage!

The health board needs to sort out their working system. The communication between therapists and doctors seems horrendous – you end up getting promised referrals and then nothing happens. You end up thinking – why are they lying to you?"

Participant C mentioned the benefits of having strong support from Mind Cymru but that she had to research any external support herself and never got any referral or suggestions from the health board.

"I read up on Mind and only realised then that there are people like me – Mind is keeping me busy and positive. I have been supported by Mind for 3 years and the support of the third sector is so important.

They fill a role that the NHS isn't. With the NHS you are the one chasing, calling, trying to make an appointment, trying to help yourself and then just waiting… weeks… months… years… for a response."

In July 2021, Participant C received a letter from the NHS to explain that she had been discharged from the NHS Mental Health services they were already accessing without any specific reason given.

"I opened the letter, and I am still shocked today. I couldn't get an answer why they had discharged me. I thought I was just garbage – I really felt low.

My Mental Health that I have struggled with for a decade went downhill, it was an awful feeling.

After that letter, I had to consider going private – my parents saw it in my face that I was broken and disappointed. I have been looking at private clinics, got to the point of no return with the NHS."

Conclusions:

"The NHS staff work hard; we know this but we desperately need more expertise, we need more therapists. Communication both internally and to patients needs improvement. Covid hasn't helped but it was an issue before that as well."

Participant D:

Age: 65
Sex: Female
Health Board: Swansea Bay University Health Board

Key themes:

- Misdiagnosis and mis-referrals.
- Poor communication from health board around waiting list times.
- Lack of support from NHS to manage situation.
- Poor mental health and deteriorating quality of life due to waiting.
- Forced to seek private treatment abroad.

Background:

Participant D had a history of surgeries before being sent to a hip consultation in 2017. She notes that 4 years of misdiagnosis and poor communication with the health board led to an extreme deterioration in her quality of life, poor mental health and ultimately left her feeling like she had no option but to travel abroad to seek private surgery.

"My 2017 consultancy was very dismissive. The diagnosis and the X-ray didn't match the pain. Eventually the NHS suggested an injection into my hip which didn't work. I went back and forth between referrals to the spinal team, then back to the hip consultant. It was July 2021 that I final saw a hip consultant and was put on a list."

By July 2020 Participant D was in a lot of pain, walking with two sticks and totally deflated. She mentions that in the years leading up to 2021, the support she received from the NHS was minimal with the focus being on rest, and the lack of support led her to visiting a private physio which improved her movements.

"I know there was a long waiting list, but it wasn't until September 2021 that I was put on one. No-one had even mentioned waiting lists to me until this point, but I knew they

were long by conversations I had with friends. I was told then that the waiting time at that point was 3 years… most likely 5. It was at this point, (and I don't cry easily) that I burst into tears. I am 65 and can barely walk no so what am I going to be like by the time I get an operation.

The feeling I got then was that they were happy to leave me for 3 years and just let me rot away in the corner."

By this point Participant D had started doing some research about private hip replacements. In the UK, she had seen quotes of £15-17k for two days of hospital care and no aftercare which was beyond her financial capabilities, so she started looking for options abroad.

"I saw an advertisement…it looked incredible. I did my own research including joining an online support group and talked to someone local wo had it done and was very happy with the experience.

In my meeting with the doctor he asked, 'have you thought about going private'. I explained that I had but UK was too expensive and said I had looked abroad. After finding out where – his reaction was 'I have been there – If I were you, I would explore that opportunity'. It could be years and years before you get seen here.

I eventually booked, and stayed there for a fortnight to recover as well. Including flights, insurance, rehab and hotel for me and my husband it was £8k, that included a couple of G and Ts. Half the price of just the surgery in the UK.

I feel and look 10 years younger – I felt a grey shadow of myself with all the pain and the waiting. My Mental health was in a terrible place. Why can't the NHS pay or part fund people to go abroad? It makes no sense that for £10k cheaper I can travel abroad, get the procedure done and recuperate than I can get it done in the UK."

Conclusions:

"I am frustrated. Communication was awful – there could be some easy comms in place to keep people updated, and maybe suggest some places for help, third sector orgs or support groups. I am used to communicating with people in my professional life. I just didn't get anywhere when I tried. You felt dumped and for some people that is going to be a big problem. You gradually and gradually sink a little bit lower each time, left in utter limbo."

Participant E

Age: 83
Sex: Male
Health Board: Powys Teaching Health Board

Key Themes:

- Lack of communication and updates from NHS
- Covid-19 a clear distraction for NHS
- Waiting times leading to poor quality of life
- Significant impact on mental health
- Inequality around access of private surgery

Background:

Participant E first started having problems with his hip in 2018 before he was quickly referred to a consultant by his GP. He was put on a waiting list in the early part of 2019 and whilst he was not told any specifics around the time he might be waiting, from his own research he realised it would not be imminent.

"I didn't hear anything until 2020 – the consultant called me in and said:
'I can offer a steroid injection, but if I do and you take it then your place in the queue will be rock bottom as the health board will deem it as you have been seen to'. I was told that it wouldn't cure the problem but could alleviate the pain. I had no other constructive piece of advice from the NHS during this period'

Early in 2021 I was called by the hospital and again asked if I would like a steroid injection. I noted what I told the surgeon that I didn't want to be put in the back of the queue. A couple of days later, I received another call which said I had now been moved from the routine list to the urgent list. I thought 'that's progress'. Later in the year, I had 2 further appointments and thought things were moving on as they were taking an active interest."

Participant E notes that he heard no more from the NHS following these appointments, even after chasing up on two separate occasions. He now feels that his condition has deteriorated, and pain increased which has led to a much poorer quality of life, poor mental health and an overall lack of confidence.

"I have to say that since Christmas, my hopes and aspirations have taken a nosedive. I know my condition has deteriorated, I now have to walk across the house with a walking stick. The pain is constant and getting to the point where even making a cup of tea is a physical and mental effort.

It might sound melodramatic, but I am 83 now and in two years time I will be 85 – I don't think I want to go on as I am. I am on my own, I am weary of it all – if I reach 85 and nothing will have been done then I don't know if I will be able to go on. I have lost my confidence to go out of the door.

It's not just a physical problem that I have, it's a mental one as well. I'm taking a step back from everything. I'm in here and the world is out there, and I get angry with myself, I get cross with the situation as it stands."

Conclusions:

"During Covid the communications have been non-existent, nothing at all – I have made 1 or 2 approaches to the surgery to see if I could make sense of it, but they are not prepared to tell me anything.

If someone could give me an idea of a date, then I could look forward to it. If nothing happens in 2 years, then I am just going to give up'.

I have thought about going private, but the cost is so prohibitive, £14-15k – I don't have that money. It's a nice thought but not realistic, it's just an unfair system, just not viable."

Participant F

Age: 40
Sex: Female
Health Board: Aneurin Bevan University Health Board

Key themes:

- Long waiting lists at a crucial development stage
- Poor diagnosis from NHS specialists leading to longer waiting times
- Mental health impact on carers of people on waiting lists
- Covid-19 having a negative effect on communications although pre-pandemic communication was also poor.

Background:

Participant F is a carer for their 5-year-old. Her child has had extensive stomach issues since birth with the lack of diagnosis an issue. Alongside the stomach concerns her son was also on a waiting list for an ear, nose and throat specialist appointment and been diagnosed as autistic.

"Things came to a head in 2019/2020 – when he went to nursery and it transpired he was spending most of his time there lying on his stomach. He was just miserable. Around that point we realised there was a major problem with his stomach. We were already under a paediatrician, being investigated for global delay/sleep problems and for ENT problems

The doctors were very poor – they had no idea what to do with him and having different 'treatments' didn't work. The guidance from our paediatrician was sketchy at best.

I thought the communication was poor leading up to Covid; we would get some calls and the odd face-to-face interaction. Covid meant things just got so much worse. The only reason we had any comms was because I would have been ringing them up and shaking them like a tree. I am a second gen carer so I know you have to chase appointments."

Participant F also explained their worries that long waiting times for a referral to an ear, nose and throat specialist during such a crucial development stage of life could have had a negative impact on their son's development.

"I feel it's wasted time. 2 years of vital time between 2 and 4 and we were just on a waiting list. We were 2 years on the ENT waiting list before we finally got the appointment (after a cancelled one due to Covid). We found out that he was going deaf on one side, and this was then affecting his speech. If we had known this two years ago, we could have done something different about it."

As well as obvious issues for her son, the impact his health and the relationship with the NHS had on the carer and family has been difficult.

"It's been intense – watching him in pain is hard work. Not feeling like I was being taken seriously earlier makes me angry. It felt like they were kicking the can down the road. It's negatively affected our quality of life – it's mentally and physically exhausting."

Conclusions:

"With better diagnosis it feels like waiting times could improve in some areas. Until we figure it out it takes longer and longer to get to the solution.

We are still in touch with NHS as my child has multiple issues. Whilst it's wonderful that he finally seems to be getting better, the lack of diagnosis two years ago is frustrating – so it's a conflicted feeling of elation."

Participant G

Age: 40
Sex: Female
Health Board: Powys Teaching Health Board

Key themes:

- Mental health of carer and family
- Terrible cross-border communication
- Inequalities of access in Wales
- Lack of specialists and knowledge within the health board
- Poor support from NHS for managing the conditions and accessing support
- Positive support from third sector

Background:

Participant G is a carer for her son who has chronic health problems. Participant G notes that her child's health issues over the last 15 years, coupled with negative experiences with the health board has caused huge pressures on the entire family.

Since October 2021 the child has been moved to a specialist unit in England, which means that Participant G travels 120 miles whilst sharing caring responsibilities with her partner.

"We were admitted to Telford Princess Royal Hospital on the 22nd of September where my child was presenting a slight jaundice and an increasing itch.

This escalated during the 3 weeks in Telford, where he scratched the skin off his feet, he was toxic yellow, very confused and he had an internal bleed and was dying in front of our eyes.

He went into kidney failure due to the liver and length of time he had to wait, 11 weeks!

His paediatrician and his team were literally fighting to get a bed for my son on a specialised liver unit, they are general paediatric unit and not able to save my son.

It took three weeks until we finally arrived at QE Birmingham where we were told he was very poorly, he wouldn't be going home and that he needed a liver transplant.

On the 11th of December he had his life saving liver transplant. On the 25th of December he had surgery as he had a blockage and needed corrective surgery."

Participant G highlights the that access to specialist services is dependent on where you live in Wales.

"Living rurally means we have never been offered the choice in Wales. We were told, 'oh well what do you expect us to do, pick up the hospital and move it to you?' Geographically we are not in a good place to be in."

Another key message coming from Participant G is the impact this had on the family, with support coming not from the NHS or the Welsh Government but from the third sector, with 'Carers Wales' in particular providing invaluable support. She specifies the PTSD the entire family have experienced and the decline in her own mental health.

"We needed better communication with me and better communication between hospital and GP. More help needs to be available to manage the condition and additional signposting to services that may be able to offer help."

Conclusions:

"The dynamics of where we live in good old Powys, no man's land in regard to health and services means we have such an inequality of services.

My son nearly died and the trauma of this has and will never leave us. My son has PTSD and it has been suggested by a psychologist I'm showing signs of trauma. We are three months into our hospital stay, my husband and myself share care at his bedside, travelling 120 miles back and forth to the hospital. It's financially a strain for both of us on the sick on reduced pay. It's an emotional rollercoaster.

I am concerned that my child's condition will get worse, his pain condition worsens, he will have a longer recovery time and condition will become permanent due to the damage caused by not having treatment in a timely manner.

NHS management need to be accountable and politicians need to be accountable for a system that takes our money and pays their wages but is not delivering the service. People are dying and someone needs to answer for this."

Participant H

Age: 58
Sex: Male
Health Board: Betsi Cadwaladr University Health Board

Key themes:

- Poor communication
- Impact of Covid-19 on communication
- Seeking private treatment

Background:

Participant H is a chemically induced diabetic due to having had bowel cancer three times. Whilst the diabetes was initially under control with medication following a referral within the health board, he states that things got progressively worse. One of the main issues was the impact that diabetes was having on the participant's sight.

"In 2017 I detected there was a problem with my glasses, so I got monitored every 6 months instead of 12. A consultant said I needed to start a period of treatment involving an injection into one eye and laser treatment on the other. It was January 2019 when I had the first ones, then lockdown started. I had another injection and no treatment on the left eye. Usual comms went down, 6 months later, no contact, no response. I eventually got back in touch with an appointment clerk in early 2021, only to be told I had missed an appointment, which was never the case..."

Participant H explained how there was a marked dip in communication once Covid-19 arrived and caused additional stress to the health board.

"Everything seemed to stop dead – the missed appointment with a letter that never existed, I never received it, first I knew of it was when I phoned up to check a whole three months after this so-called missed appointment.

After that last eye injection, it was like I didn't exist anymore, there was no guidance on how long I would have to wait.

If I hadn't gone private by going to the optometrist then we would be having a different conversation"

Conclusions:

"It did feel like a perfect storm. I have sympathy with the NHS with the conditions they were working in. I am probably more easy-going as I have such admiration for the NHS, but simple things like improving patient communications would help the experience so much'

I am also under oral health dental hospital in Liverpool and the way I get treated over the border has been totally different, the communication there has been immaculate and video calls have been great."

Participant I

Age: 49
Sex: Female
Health Board: Aneurin Bevan University Health Board

Key Issues emerging:

- Covid-19 affecting communication
- Lack of signposting to support
- Need for regular checks for key conditions
- Poor support in diagnosis stage
- Positive support from the third sector

Background:

Participant I was first diagnosed with type 2 diabetes 7 years ago where she recalls the poor support she received initially. Participant I notes that a lack of support is consistent in her experience, with a dip in communication during Covid-19 being very apparent leading to crucial appointments being cancelled.

"The nature of diabetes is that it gets worse – it's a progressive condition. It can attack nerve endings, in ears/eyes/fingers/toes. It is important that regular checks take place. During the pandemic everything stopped and diabetic specialist nurses were deployed to the front line, nothing there for you. You could try to ring, and the phone just kept ringing and ringing, you felt abandoned. There was no communication.

Care is now mostly through hospital, but annual check is at the doctor and is supposed to be once a year minimum, it's regularly cancelled."

Participant I also notes that the NHS's lack of knowledge and support when dealing with diabetes symptoms is a clear issue and leads to people having to find out their own answers online.

"More support in the NHS would stop this from happening. I had a 6-month review and that was it. I should have been referred to the eye screening service and an education course, they would need to do a foot check, but it was not explained properly, and it was a big concern for me.

I came across Diabetes UK and started a local group in Newport. The checks were really poor and some of the comments from the group were staggered about the poor service they were getting and the poor checks (not even taking shoes off for foot checks).

I find that I was doing the job of the GP and health board to support people with diabetes in the area. I went to tell all the GP practices I was there for support via Diabetes UK – please use us to signpost people but only 1 GP took it up."

Conclusions:

"I think the retinopathy service needs to be looked at. It can happen so quickly that it creeps up on you and not having regular checks is a massive issue. If it gets caught early enough then it can be treated. In my opinion eye service and eye screening is a huge issue.

Psychological support needs to be improved for diabetes care as well. They do it so well with care plans for other conditions and issues – but so poor with this condition. Over last 8 months my dad has been diagnosed with cancer – and the service from the cancer team has been incredible – so it's not all bad.

People are fed up with waiting – and pick up information that might be wrong and scare monger off Google. How do you put a measure on somebody's quality of life?"

Participant J

Age: 34
Sex: Female
Health Board: Powys Teaching Health Board

Key Themes:

- Lack of general NHS knowledge around endometriosis
- Good support from endometriosis nurse
- Covid-19 impact on communication
- Inequalities of geography

Background:

Participant J was diagnosed with endometriosis recently but believes that she has actually had endometriosis for 17 years. Following initial surgery in May 2019 she was referred to a specialist in Cardiff.

"I sort of knew I had this since 14 but not diagnosed 'til I was 31. I read an article in the Western Mail which showed the symptoms. I went back with this article and the GP agreed and referred me to a gynaecologist…first time I have ever been referred.

So, I had an initial operation in May 2019, and it was then I was referred to Cardiff because that's where the endometriosis specialists are because I have pretty severe endometriosis. I was told, then there would be a bit of a wait, and that was obviously pre-Covid."

Participant J is clear that they believed there was clear lack of knowledge from her GP and the wider NHS around endometriosis, and it was not until her first meeting with the endometriosis nurse that she managed to get some information which helped.

"In January I had an appointment with my endo nurse – this is where I got some really good suggestions as to how to manage the pain, something that GPs etc in the past have never even mentioned. I learnt more from this half hour with the endo nurse than with 17 years' worth of GPs. In that appointment I was put on a surgery list, then told it was a potential 2 year wait, I was just happy to be on the list."

Participant J noted that the impact of Covid-19 on both the communication and service she received was immediate.

"2 months later Covid hit, and everything was cancelled I wasn't worrying too much about that initially. I had no update, the only news I would get was in a Facebook group I was part of – word of mouth from others who had some discussion with the hospital. In April I rang Cardiff and was told there was no surgery until at least 2020.

Eventually I got a follow-up call later in the year from a nurse – I was on Prostap injections and the side effects were very bad. I was supposed to be taking them until my operation but now there was no end date I had to go to the GP.

I rang the hospital again in January 2021. They didn't have much of an idea but was given an indicator that I was in the top 40 in the list out of 200 plus and should hear soon. Nothing again so rang again in April and was told everything was shut again"

Conclusions:

"Up to Covid I found comms quite good to be fair, I don't like to bother people – I tended to email asking a few questions and I would get a reply. The endo nurse email was very useful – having a direct contact made a huge difference I think without those direct contacts I would be in limbo.

Before my official diagnosis I was being tested for everything. I feel there's a real knowledge gap here around endometriosis. Felt like I was the expert not the health professional…

I definitely encountered some inequalities around geography. I think people need to know their pathways, what is the referral map? Where do I go? Are waiting times big? Should I be chasing things up?"

Participant K

Age: 28
Sex: Female
Health Board: Cardiff and Vale University Health Board

Key themes :

- Lack of support from NHS to manage condition
- Lack of knowledge of endometriosis
- Effect on family
- Positive support from third sector

Background:

Participant K was initially diagnosed with endometriosis at 17 years old and mentions that it was only due to her mother advocating on her behalf at this age, that she was diagnosed this early, which she finds lucky in that regard. She spoke in-depth about the struggles she faced when trying to escalate the issue within the NHS.

"I've got an NHS appointment next week with the endometriosis specialist in Cardiff. But I had to pay to see this same specialist in private last year as a one-off thing. This was because I'd been telling my general NHS gynaecologist for 10 years about my bowel symptoms and it was just brushed off as IBS. So, I paid, and the specialist told my gynaecologist that I really needed a scan, which then diagnosed the endometriosis on my bowel. So, the specialist put me on his NHS list – I looked into doing the next part privately, but it was too expensive. The specialist has suggested I'd need surgery, but the waiting list is 6 and half years long."

Participant K is adamant that whilst Covid-19 has had a big impact on some recent communications and waiting times, there are deeper rooted issues around poor NHS support for people with endometriosis.

"When I spoke to the practice manager about pain management it didn't go down well. They don't understand. The practice manager said, "my friend has endometriosis and they've had a hysterectomy" and I explained that this procedure isn't a cure, just because you know someone else is OK with it, people manage pain and health issues in different ways. They just said that they were doing everything they can for me. I was understanding but I said maybe they could give me a little bit more support. I've asked the support for my mental health and again, their answer is just tablets.

I'm on quite a lot of strong painkillers at the moment, so I take Tramadol, Oramorph, and Co-codamol when needed. It's not the best option for me because I have a 4-year-old daughter to look after.

I understand that medical staff's hands are tied because there is no cure but in terms of support, I don't really get a lot, and it's been quite difficult."

Conclusions:

"In England they have a women's physiotherapist. it'd be great if there was one of these in Wales. I've never been offered that type of support.

If it wasn't for the endometriosis nurse in Cardiff that you can self-refer to, I wouldn't have had this appointment next week so soon.

It's people like them [endometriosis nurse] that are a middle ground for patients like me so I can speak to them when I need to, and they can help me out and tell me what to say to the doctors or give me advice on what to do next. It's definitely a massive help. We've got someone that understands our condition directly.

I think the GPs need a better understanding of the condition because they're always the first point of contact for anything. and I think if they did, they wouldn't be so dismissive.

I try my best and I feel so lucky to have such a supportive partner and family who really do understand. But I still feel a lot of guilt, I often wonder if I could be a better parent for her because I can't go to the park with her. I can't take her out on walks and things because I'm in so much pain majority of the time. I just feel that she misses out on things that she shouldn't be missing out on."

Participant L

Age: 72
Sex: Female
Health Board: Betsi Cadwaladr University Health Board.

Key themes:

- Covid-19 causing communication issues and extending waiting times
- Having to access private treatment
- Positive third sector support
- Lack of support from NHS

Background:

Participant L uffers from solitary sclerosis, a rare and progressive condition that can cause an individual to develop progressive motor impairment which is attributable to a single lesion.

Whilst she described her symptoms as 'not being desperately bad at all' she explained how she had developed a limp and has issues with her balance.

Prior to the pandemic the participant took part in a month-long clinical trial for fampridine – a drug used to improve walking speeds for individuals diagnosed with multiple sclerosis and solitary sclerosis. Fampridine was initially brought to her attention through the MS Society, an organisation she engages with regularly. She subsequently spoke to her consultant, based in Chester, who explained that it was not approved by the NHS in England, but was approved in Wales. A referral was made to Glan Clwyd Hospital, and she subsequently participated in a clinical trial.

She explained that having been part of the trial, she felt, along with her consultant and her husband, that there was a marked improvement in her walking ability and speed. As such, her consultant considered that she would benefit from taking fampridine. However, due to the length of time it was taking for her to be prescribed the medication, which she attributed to delays caused by the pandemic, she decided to pay privately for the medication. She has been in touch with her MP and her MS about these issues, and described the process of getting the medication as *"awfully long."*

Conclusions:

Participant L explained that whilst she concedes that her condition is progressive in nature, she does feel as though her health would be better if the pandemic had not happened and she was able to have had earlier access to fampridine. She explained that the process of trying to get the medication has caused her to feel anxious *"all the time"* and that her confidence has been affected.

The participant explained that it has been an extremely long process in order to be prescribed fampridine and said that she sometimes feels that the pandemic is being used as an excuse for the delays. She also expressed some frustration that she only found out about fampridine from members of her MS Society group, and it had not been raised with her by her consultant.

Participant M

Age: 38
Sex: Female
Health Board: Cardiff and Vale University Health Board.

Key themes:

- Lack of mental health support
- Lack of knowledge of condition in the NHS
- Poor support from NHS and referrals regularly refused
- Issues around cross health board treatment
- Breaches of NICE (National Institute for Health and Care Excellence) guidance
- Positive support from third sector

Background:

Participant M has had a long and complex history with endometriosis which has a big impact on her adult life. During her interview she highlights the lack of support she has had from the NHS during the entire period.

"My medical history for endometriosis is complex. My diagnosis came 23 years after my symptoms started. I have absolutely no doubt that had I been diagnosed properly the first time I wouldn't have other health conditions

I've been suicidal before, due to my illness and due to endometriosis. I don't want to go down that route again. This is one of the reasons I have gone privately. I felt penalized for going private. When I asked the general gynaecologist if I could have a referral to the endometriosis nurse who's in our health board was told "no" because if I go private, I'm not allowed to have any access to NHS help."

Participant M is clear that both internal and external communications have been a huge problem for her and led to key decisions and appointments taking longer to happen.

"I need to see a specialist which I think is quite difficult. I saw a rheumatologist in September (2021) about my pain. She wrote a letter to my GP. When I contacted my GP, probably a month ago, to ask what was happening, they hadn't received a letter. I was surprised, I had received a letter, but they said "we've had nothing here. The letter hasn't arrived."
It is such bullshit! I got sent the letter! I had the letter in my hand! I've learned from my 23 years of hell to ask to be copied into every correspondence.

This happens all the time whatever doctor surgery it is. My specialist jokes that it's "the NHS shredding service""

Participant M is clear that Covid-19 has had a big bearing on waiting times over the last few years. This in turn has led to extremely frustrating experiences with refused referrals another key issue.

"Waiting times feel like they have been compounded since the pandemic. Being a disabled person during the pandemic has been very difficult, and the media bombard me with the message that I don't matter. If I died of Covid tomorrow, I'd be labelled as someone with underlying health conditions"

Participant M also states how important the support of Fair Treatment for the Women of Wales (FTWW) has been during this period, not only for herself but for its 1,500 members who she communicates with regularly. She recalls that after a particularly challenging NHS appointment how the group's support and advice helped her in that difficult period.

> *“It's a place to be proactive and find out where to access different support. I've always said that FTWW saved my life, and I am not exaggerating that. I found them when I came out of my final NHS appointment before I got diagnosed with endo. After a very brutal internal examination by a male consultant who I still don’t think should have done so because he was incredibly rude to me.*
>
> *The first thing I did say when I could speak was say “I've had enough. I'm going to kill myself” and my partner pulled me through that. To this day I am surprised that I was allowed to walk out of there in that state. There was no real attempt to actually comfort me or to say “what do you want us to do? How can we make this better?” The attitude was that I was completely wasting their time.”*

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Conclusions:

> *“In England you have the power of choice. You can ask to be referred to a specialist that is good at certain types of diagnosis even if they are miles away. But in Wales the block funding system means health boards have to refer you and use a ‘transfer’ system to ensure health boards aren’t ‘out of pocket’ for taking on too any patients outside of their area. This means you live in a postcode lottery because you can be refused a referral due to lack of funding.*
>
> *I have questioned my own sanity at times. I ask myself am I really that bad. The diagnostic delay is so long in Wales, the longest wait of all the home nations, where you could be waiting an average of nine years.*
>
> *I was not offered mental health support until I got diagnosed with ME. And then the only reason I was offered it was because it was part of the NICE guidelines at the time.*
>
> *I am incredibly critical of my experiences of the NHS. I've been in the media talking about it. But the reason I do it is because I love the NHS and I want it to be better funded. I want it to thrive. I want it to offer the services that patients actually need.”*

Focus groups

Focus Group 1
Number of participants: 12
Theme: Endometriosis and Adenomyosis

Focus Group 2
Number of participants: 10

Theme: Women's Health waiting times

Summary:

Two focus groups were facilitated on 5 and 6 of January in partnership with Fair Treatment for the Women of Wales (FTWW). Discussions focused on issues impacting women's health in Wales. Rhun ap Iorwerth MS attended the focus group on 5 January and Mike Hedges MS attended the focus group on 6 January.

Key Themes:

- **Early advice and initial diagnosis of Endometriosis very poor**

Several participants commented on the poor early advice given by GPs, which had led to their condition not being properly diagnosed.

"Early advice, as in other cases were very poor. I was pushed on the pill, which actually just masked my endometriosis. Pain during smear tests is what pushed me to get diagnosed properly. 2016 was the first time a health professional asked me about the pain"

"Every time I move health board I have to prove myself every single time, it's exhausting. The Head of Gynaecology told me, 'I don't believe in Endo, there is no need for them to have surgery space'. I was told last week that there is 7.5 years of backlog which is horrific"

"Endometriosis is not a rare health condition, it has a 1 in ten ratio like diabetes. There are few specialists and a system that doesn't let us access them, it's nothing short of a disgrace"

- **Very long waiting times**

All participants noted that waiting times for women's health services are worse than they have been in a long time, with the added frustration of finding it very difficult to find out how long they actually are, with many only discovering the true details from support groups online.

"My follow up appointment with my current gynaecologist has needed to be pushed back due to the sheer amount of people waiting to be seen on an urgent basis"

"Waiting lists were up the creek before Covid – now hearing they are 5, 6, 7 years"

'Waiting lists to pandemic was huge. Now there is just no explanation – you have to constantly advocate for yourself; it's exhausting to bang your head on a brick wall"

"I was on a waiting list for a follow up neurology appointment. Had a letter that said due to length of time since I was last seen, was told I couldn't have another appointment. Luckily I know the system and rang the right people to explain I was still bleeding and needed treatment. I was eventually out back on the waiting list, and there was at least a 12 months appointment. They can't take people off a waiting list just because they have been waiting a long time!"

- **Women not being listened to or taken seriously leading to condition not being treated in a timely manner**

A constant theme across both focus groups was participants noting that women were not being taken seriously when approaching the NHS. Participants commented on the frustration when dealing with the NHS, with several mentioning an apparent 'gender bias'.

"I was told that it's all in your head, 'there is nothing wrong with you' – at 17 I went privately and was diagnosed with Stage 4"

"I think there is a gender pain bias there as well – my husband got support to manage pain straight away, I was batted away and told to take paracetamol"

"My GP said it was all in my head"

"Women are not being listened to…I can walk in and list my symptoms and get totally ignored"

"I believe the more common poignant theme is the simple issue of women not being listened to, and therefore not being able to access appropriate healthcare to treat their conditions in a timely fashion"

- **Referrals between health boards and across border extremely poor**

Many participants were critical of the referral system in Wales, with several commenting on the barriers that they had faced.

"There seems to be a culture in Wales of not referring people to specialists out of areas but people want to be treated by a specialist, this reluctance in Wales to refer to other

health boards or over the border is poor, there is no respect for the people that make referrals and they just get disregarded."

"Out of Health board cases get sent back all the time, the communication is a mess. I run a group and the stories are consistent, Swansea Bay Health Board comms is awful, nothing is being done. The situation was dire before this but now…I am worried about everyone who has to deal with this medical trauma"

"I was not doing well, and I know in Bristol that they were getting people in the same day. There was a lack of joined up services but all the health board said was 'we haven't had a meeting about that yet'. We need a women's service that deals with the issues that women face."

- **Lack of support from NHS in key areas such as mental health**

A theme that kept appearing was the lack of support given by the NHS to participants' mental health. Many commented on the overwhelming mental toll their experiences had on them.

"I am 28, my ovaries, womb, bowel out, this disease has taken everything and I had no support from the NHS. No Mental health support, physio, pelvic flooring…I could go on and on"

"I went to commit suicide due to endo, I lost my job, nearly lost my family – it's such a painful condition it has to be shared"

"There is inequality of access in Wales and a clear lack of Mental Health Support – experiences will have huge strain mentally as well as physically"

- **Third sector providing essential support that is currently not happening within the NHS.**

Whilst participants were critical of the support they received from the NHS, they were keen to emphasise the positive experiences they had with third sector organisations, with several participants noting that they filled a gap the NHS weren't providing.

"FTWW and Endometriosis UK forums keep you sane – it feels they are doing the job of the NHS when it comes to providing support'

“Support again was poor, Powys women have to go over the border and are being let down. You have to be an expert yourself, if it wasn’t for support of FTWW then I don’t know what I would do and I dread to think where some of us might be.”

- **Many participants having to seek private treatment**

Several of the participants noted that, due to the issues they faced with getting support from the NHS, they felt that they were left with no option other than to seek private treatment, which often caused them additional financial burdens.

“In the end with help from my dad I had to pay 10.5k for a private surgery, if it would have been left then god knows what would happen, my large bowel could have perforated and could have killed me. Delays of months and years, I am beyond frustrated for the system, I had to pay money for a hospital in England. It worries me what the state of the NHS will be with endometriosis in Wales, we are behind as it is now, where will we be?”

“I took out a personal loan for private surgery and stage 4 endometriosis was found. I was left a bit high and dry then as I couldn’t afford further treatment. We are still paying off the loan now and due to misdiagnosis initially we are actually looking at negligence.”

“I had a breast cancer scare that ended in me going private. After initial diagnosis I rang them back after 2 weeks, unfortunately I was told there was a backlog of 4 weeks due to Covid, after 4 weeks I rang back and was told now 6-8 weeks…this was untenable. It wore down my mind and mental health, 2 weeks is long enough with a cancer scare , especially as the prognosis gets worse and worse. I eventually spoke to a manager who said it was now 12 weeks, the time just kept increasing. My husband put his foot down and said we were going private”

- **Lack of knowledge around women’s health in NHS**

Many of the participants felt that there was real lack of knowledge of women’s health issues within the NHS in Wales.

“I know more about my condition than my GP or any gynaecologist I’ve seen in Wales. I'm made to feel like a drug seeker when requesting more pain relief, or even when I say its not touching the sides. How many people that are passing out and vomiting in pain actually want the drugs? We don't. We want a normal life, we'd rather be without pain, so why make us feel like crap for asking for it?”

“I would sum up my experience, that consulting with any medical professional I have felt like the most knowledgeable person in the room about my condition. There are no specialists in Wales who oversee my care”

- **Lack of specialists in Wales**

Participants frequently mentioned the importance of being seen by a specialist at the right time, and the frustrations of not being given that option when speaking to a GP.

“I have been referred for 20 years, but didn’t know a specialist even existed since I spoke to other people, no mention of this from NHS over the years and I just assumed I was under the best care.

“Every time I move health board I have to prove myself every single time. I went from Swansea Vale Health Board and The Doctor told me there was nothing else he could do to me , he wouldn’t refer me to another health board. I had to fight and fight in the end to be seen in Cardiff by a specialists. Being seen by a specialist at the right time is crucial and there just aren’t enough in Wales”

There is a real lack of awareness around specialities…it’s quite telling that my GP was at a loss where to refer me due to a lack of specialism, I feel for people that just can’t afford private care. There needs to be an overhaul of the system, if England has centre of excellencies, why in Wales are we being denied that support. You are left feeling you are not worthy of care, left all alone and your entire life is affected”

- **Communication getting worse during Covid-19**

Several participants noted that communication during Covid-19 had been extremely poor. However there was a constant message that communication pre-pandemic was also disappointing.

“Appointments have fallen off the radar due to Covid, I was waiting on a dermatologist, haven’t heard for them over two years. I run a support group of 60 people in the same boat, no one has heard anything – they are like the dying of the dinosaurs – they have gone extinct recently. If you are diagnosed with a rare auto immune rheumatic disease in Wales it’s an impossible situation, there is a complete lack of recognition that these illnesses are serious enough to warrant specialist care.”

“The staff work very hard and it is hard to be critical during a pandemic, but the majority of my healthcare has been poor prior to the pandemic. Communication between Consultants and with patients and GP lets the system down at every turn”