

Feeling forgotten?

Hearing from people waiting for NHS care and treatment during the coronavirus pandemic



Accessible formats

This report is also available in Welsh.

If you would like this publication in an alternative format and/or language, please contact us.

You can download it from our website or ask for a copy by contacting our office.

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About the Board and Community Health Councils

The Board of Community Health Councils (the Board) has produced this report on behalf of the 7 Community Health Councils (CHCs) in Wales.

CHCs are the independent watchdog of the National Health Service (NHS) within Wales. CHCs encourage and support people to have a voice in the design and delivery of NHS services.

CHCs work with the NHS, inspection and regulatory bodies. CHCs provide an important link between those who plan and deliver NHS services, those who inspect and regulate it and those who use it.

CHCs hear from the public in many different ways. Before the coronavirus pandemic, CHCs regularly visited NHS services to hear from people while they were receiving care and treatment. CHCs also heard from people at local community events, and through community representatives and groups.

Since the coronavirus pandemic, CHCs have focused on engaging with people in different ways.

This includes surveys, apps, videoconferencing and social media to hear from people directly about their views and experiences of NHS services as well as through community groups.

There are 7 CHCs in Wales. Each one represents the “patient and public” voice in a different part of Wales.

Background & introduction

In 2018 we published our report 'Our lives on hold'¹. The report described the impact on people living in Wales who were waiting a long time for NHS treatment. It identified that when we wrote our report, there had been some recent improvements in the time people had to wait for care and treatment.

The report also called for changes in the way the Welsh Government and the NHS judged how well the NHS was doing – so that the harm that can be caused by inactivity or “waiting too long” for care and treatment was included.

Since then, the coronavirus pandemic has changed everything. In March 2020 the Welsh Government took action to “continue to provide care and support to the most vulnerable people in our communities, whilst also making sure organisations and professionals were supported to prepare local responses to the public health emergency”.

For many people waiting for a diagnosis or treatment following their diagnosis, things were put on hold. As the NHS moved from the initial stages of the emergency, the Welsh Government issued guidance for NHS services on how it should balance the need to continue to respond to COVID-19 at the same time as providing other essential healthcare.

¹ 'Our lives on hold....Impact of NHS waiting time on patients' quality of life is available on our website at the following link
<http://www.wales.nhs.uk/sitesplus/documents/899/Our%20lives%20on%20hold%20-%20ENGLISH%2010.05.20181.pdf>

It was identified that there were 4 types of harm that the NHS needed to focus on and guard against:

Harm from COVID-19 itself	Harm from an overwhelmed NHS and social care system
Harm from a reduction in non COVID-19 activity	Harm from wider societal actions / lockdown

Welsh Government said that essential services² should be maintained at all times throughout the pandemic, and that any backlogs must be urgently addressed.

It said that decisions to re-introduce routine services should be made “when it is safe and appropriate to do so”.

Making decisions about the risks of providing care and treatment during the pandemic involves clinical judgements. CHCs rely on other bodies to provide independent assurance on this.

This report focuses on what it has felt like for many people throughout the pandemic so far. It highlights the things we often heard from people living in Wales about the impact that delays in diagnosis or treatment are having – **in their own words**.

It will not reflect everyone’s experience. We know that people’s individual views and experiences are all different.

Our report doesn’t mean that people across Wales are not supportive of everyone working in the NHS throughout this

² <https://gov.wales/sites/default/files/publications/2020-05/maintaining-essential-healthservices-during-the-covid-19-pandemic-summary-of-services-deemed-essential.pdf>

pandemic – their grateful thanks to healthcare workers continue for everything they have done and are doing.



Our report also picks up on:

- how the NHS response has developed
- what it has done to respond to the things people were worried about early on
- what it is doing now and
- what it can do more of to make it easier for people to understand and manage through these difficult times.



What we did

During the coronavirus pandemic, people across Wales have been able to share their views and experiences of NHS care with us by completing our national surveys.

The feedback we receive through these national surveys 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
- 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.



So that services can respond quickly and appropriately, CHCs share with their health boards what they are hearing from people in their local communities on an on-going basis.

At a national level, the Board and CHCs across Wales meet with the Welsh Government every week to discuss what we are hearing across Wales and the actions needed.



We have heard regularly throughout the pandemic about the impact waiting for care and treatment is having on people and families. This report reflects the things we have heard through our national surveys and local CHC activities.

Who we are hearing from

Here is a snapshot of the people who are sharing their views and experiences of NHS care during the coronavirus pandemic through our national surveys.



We do not always have the same kind of information about the people CHCs are hearing from directly because people do not always tell us everything about themselves when they come to share their experiences and views with us.

We heard from around **1,150** people through our national surveys.

Over **95%** shared their views and experiences in English

Over **three quarters** were women, and over **95%** were cisgender³

The youngest person we heard from was **21** and the oldest was **77**

Around **85%** identified as heterosexual

Around **90%** were White (Welsh, English, Scottish, Northern Irish, British)

Almost **40%** were carers

Almost a **quarter** had a disability or long term health condition

You can find out in our Equality Plan what we are doing to hear from different groups of people so that we can better represent the diversity of the communities we serve. You can find our Equality Plan on our website www.communityhealthcouncils.org.uk

³ Cisgender is a term for people whose gender identity matches their sex assigned at birth

What we heard

In the early stages – postponing routine and planned care

In March, as the coronavirus pandemic started to take hold in Wales as well as the UK and beyond, all of us entered lockdown.

The NHS in Wales took action to respond to the emergency. In order to provide care for the growing number of people with COVID-19 and help stop people catching the virus, the decision was made to postpone all non-urgent NHS care and treatment.

People who were most at risk were asked to shield themselves at home. Urgent NHS appointments with General Practitioners (GPs) started to change quickly and in different ways, firstly by telephone and then videoconferencing.

During these early stages of the pandemic people understood the reasons why planned care, as well as routine care and treatment needed to be postponed.

In the early stages, some people told us they had heard from the NHS and were clear about what would happen.

“I received a letter from the Physiotherapy Outpatient Department telling me about the impact of the situation on my referral.

The letter says they are contacting all physiotherapy patients, and it includes a telephone number for urgent advice about muscle and joint problems. I have found this to be very helpful as I am now clear what is happening.”

Many others were unsure about what would happen to their care and treatment across a wide range of services because no one told them what was happening.

People waiting for a diagnosis or treatment

We heard from some people how a delay in their treatment was something that they understood because the reasons had been explained to them.

“I was due to have a maintenance course of immunotherapy treatment on 25th March. This was cancelled. I was given a full explanation of the reasoning behind this by my urology nurse, and was told that a cystoscopy would be undertaken when it was possible to do so.

I have been very worried, especially when the government was proposing that this lockdown could continue until the end of the year. This morning I received a phone call booking an appointment for me to have the cystoscopyI can't tell you the relief I feel.”



For many people who had been waiting for tests or a diagnosis before the pandemic, a lack of communication about their individual situation didn't help.

“Was referred by GP for Ultrasound weeks prior to the Covid-19 situation - have received no communication whatever regarding the process and if it will go ahead when the situation settles. My understanding is that routine tests will no longer happen such as smear tests. Mine is due in the coming months but not aware of what will happen to those tests that will not occur during this pandemic.”

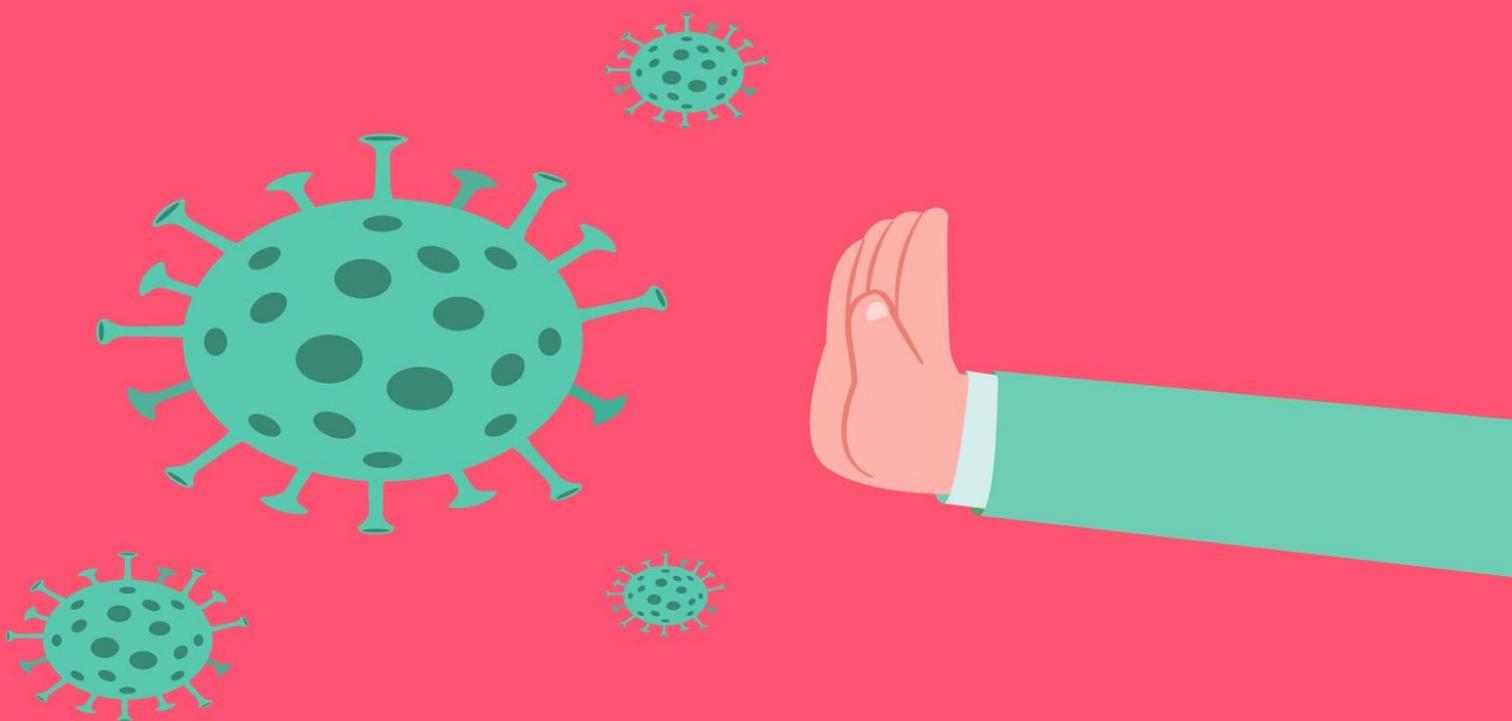


“No result from a blood test over 2 months ago, appointment cancelled due to Covid-19”

People having cancer care

We heard from lots of people about what was happening with cancer care.

"I obviously realise that in the current climate with the added pressures on the Health Board the situation is unprecedented and serious but feel that it must be managed so that possible cancer patients do not have their lives put at risk."



Some people told us how well their treatment was continuing.

“At present in middle of my course of treatment. Nurses have been incredible, kind caring, explaining changes in light of Covid19. They were professional and friendly at all times. They used PPE to keep us safe and measures to ensure we were well enough for treatment e.g. taking temperature in porch of unit.

Always kept updated of changes and asked if it was acceptable and satisfactory for me e.g., change of venue for blood tests. It was busier on one of days I was there but with two units combining it is expected. Everything ran smoothly and cannot praise staff enough. Also change in consultant appointment to telephone appointment which is sensible at this present time.”



Even though the Welsh Government had said that urgent cancer care and treatment would continue, we heard that many people were anxious about delayed results or their on-going cancer care, and the impact on people's condition in the longer term.



“I had a biopsy taken which was sent to the UHB for analyse. My GP advised that it could be skin cancer, since this I have had to attend surgery every other day to have my wound packed and dressed and as it is not healing, my GP upped their request for the results to urgent 4 weeks ago. It has now been 7 weeks since my biopsy was submitted and I am still waiting for the results, this is causing me to feel very stressed about my health condition.”

In some cases, it was not always clear to people why cancer treatment had been cancelled or postponed.

“Firstly I would like to start by saying a big thank you for all the hard work that frontline NHS staff are doing in the fight against the COVID19 Coronavirus pandemic. However I am writing this letter of complaint regarding the treatment of my sister who has recently been diagnosed with a grade 2 breast cancer tumour. She along with many other cancer patients appear to be the forgotten ones by this Health Board in this current crisis.

She was due to have a mastectomy operation this week, but has just been informed by her nurse that all cancer operations ... have been cancelled this week. I appreciate the need to ensure we have the correct capacity at our hospitals for COVID19 patients, but when I am hearing stories from members of staff about how quiet wards are and how many empty beds there are. It beggars belief that someone has taken the decision to cancel lifesaving cancer operations. In my sister own words “ I feel like a ticking bomb” Is this really how any human being should be made to feel.

The average single mastectomy operation takes 90 minutes in theatre with the patient needing only one nights stay before being discharged the next day. By putting off these kinds of surgery you are increasing the patients risk of the cancer spreading and them then requiring re-assessment resulting in a more complex operation if the cancer has spread to the lymph nodes which results in them using more precious resources.



People with postponed or cancelled operations

Many people had already been waiting a long time for an operation even before the pandemic changed everything. Although they understood the reasons why their operations had been postponed or cancelled, the impact was often devastating.

“Waiting for ovarian dermoid cyst removal. Attended Pre op date in October '19. An op date was given in January which was cancelled and then rearranged for April along with another pre op as previous had expired.

Symptoms have become increasingly difficult to manage leaving me with daily pain, tiredness, altered sensation to my left leg and overall has affected my mental health and wellbeing.

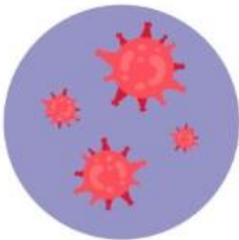
Due to the coronavirus my operation and pre op were cancelled for April. This left me lost, angry and with nowhere to turn to. I went back to my GP in March who organised blood tests and ultrasound scan. A GP rang me to inform me that the cyst had tripled in size and to 'just put a hot water bottle on it and carry on with Codeine'. I ASKED for a copy to be sent to consultant.

I have rang every week for answers. No one will get back to me. Have been told today to 'hang fire' till July for another scan and will only operate if in pain!

“Had my operation cancelled twice after a 2 year wait now spending every day of lockdown in pain with 2 children at home as I'm a single parent”



“My daughter has a brachial cyst in her neck and was due an operation in March. It was cancelled due to the virus and has been steadily growing now to the point she cannot move her neck and she can feel it when swallowing. We are extremely worried that it could burst causing infection likely to be sepsis.”



“My ex wife was due to have a procedure relating to a heart problem but when she arrived she found out from a minor technician that all these procedures where now cancelled. Nobody of note was available to explain.

As a result she has now been sick from work so long that she will soon stop getting paid her full wage and is very stressed and crying a lot. There is no new date for the procedure yet”.

Some people told us that things would have been easier if they had received better advice and information to help them manage while they were waiting.

“As expected and appreciate and understand the cancellation of my Spinal Steroid Injection for pain management. No further information given. Has led to substantial increase in use of Morphine & Fentanyl.

It’s severely impacted my mobility only getting 2 hrs a day out of bed due to excruciating pain. This in turn is impacting my mental health to a very low mood & zero motivation.

But I accept what his happening and just have to ride it out till things change and understand the strains my health trust is under so I'm not complaining. But wish some one had contacted me to discuss how to best manage my severe pain than leaving me fend for myself.

Offered no support whatsoever but understand that pressures are being felt at my hospital so not blaming anyone. It is what it is and am sure I will get my procedure as soon as it's safe to do so.”

People having routine care for life-long conditions

We heard that for some people, their on-going care had continued, although in a different way.

“My on going care for IBD has been brilliant. Any question I have had has been answered by email v quickly by the IBD nurses sometimes within the hour I can't thank them enough...”

“I had my diabetic review from home using video call this is all very new to me and I felt very uncomfortable about it before hand. After I was talked through everything and had the call I was left surprised on how well it worked.”



For many others, in the early stages of the pandemic their routine on-going care simply stopped. Sometimes, people were contacted a little later on with information about what might happen next.

“COPD 23% lung function. All appointments stopped before my appointment at beginning of March for COPD check up. I've just been told they've been cancelled due to Covid 19, which is completely understandable.

I haven't been told if they will resume at any point and again as I am someone who has been shielding since I was ill in January I would not attend and appointment at the hospital anyway. I also was having fortnightly therapy sessions...., which owing to illness either myself or the therapist I haven't been to an appointment since December 2019.

She has rung me recently and stated there is a possibility of resuming our sessions via video link and will contact me when/if that becomes a reality. I haven't heard back from her in about a month so not available yet obviously.”



For others, we heard there was no clear advice and information about the changes or when they might be seen again.

We heard from lots of people who rely on routine **B12 injections**⁴ about their concerns that their treatment was being changed.

“Near the start of the Covid-19 lockdown situation, I received a letter from my GP surgery saying that they were switching IM B12 injections to oral supplements.

This was obviously understandable under the circumstances, although the dose prescribed was 50mcg rather than 1mg which is the quantity recommended by NICE (see attached guidelines).

I queried this at the time and ended up having to buy B12 supplements at the correct level privately, which is an unreasonable expense for a known serious condition which should be covered by the NHS, particularly as I am a medical student myself and therefore not on a high income.”

⁴ **Pernicious anaemia** is an autoimmune condition that affects your stomach. An autoimmune condition **means** your immune system, the body's natural defence system that protects against illness and infection, attacks your body's healthy cells. Most people can be treated with B12 injections or tablets to replace the missing vitamins.

Many people were really worried about changing from injections to oral supplements, as they had been told before this would not be suitable for them.

This made people doubt the advice and knowledge of their healthcare staff, and some people told us they felt their concerns went unheard.

"..... has pernicious anaemia. She relies on B12 injections & was due to have one next week. She told me that her surgery are refusing to give her the injection and have told her she needs to take tablets instead. says WHO advice is that patients should still be having these injections.

.....has suffered with neurological problems in the past and she informs me that this injection is a life-saving injection for her. Her body cannot absorb the tablet orally which is why she must have an injection. She has explained this to the doctor at the surgery to no avail."

"Diagnosed as deficient in B12 in 2016. Have been having 10 week b12 injections and told no oral replacement would work and told how important it was to keep on top. During covid19 my injections have stopped and was advised to supplement with over the counter tablets and I will be ok.

This goes against all information the GP has told me for the past 4 years. This has increased my anxiety alone and generally leaving me doubting the advice given me now or in the past."

For people living with **life-long conditions** like **diabetes**, we heard worries that the lack of regular monitoring and annual check ups is leading to bigger problems. We heard that some people felt abandoned.

"they must not forget people with long term conditions. We are being abandoned."

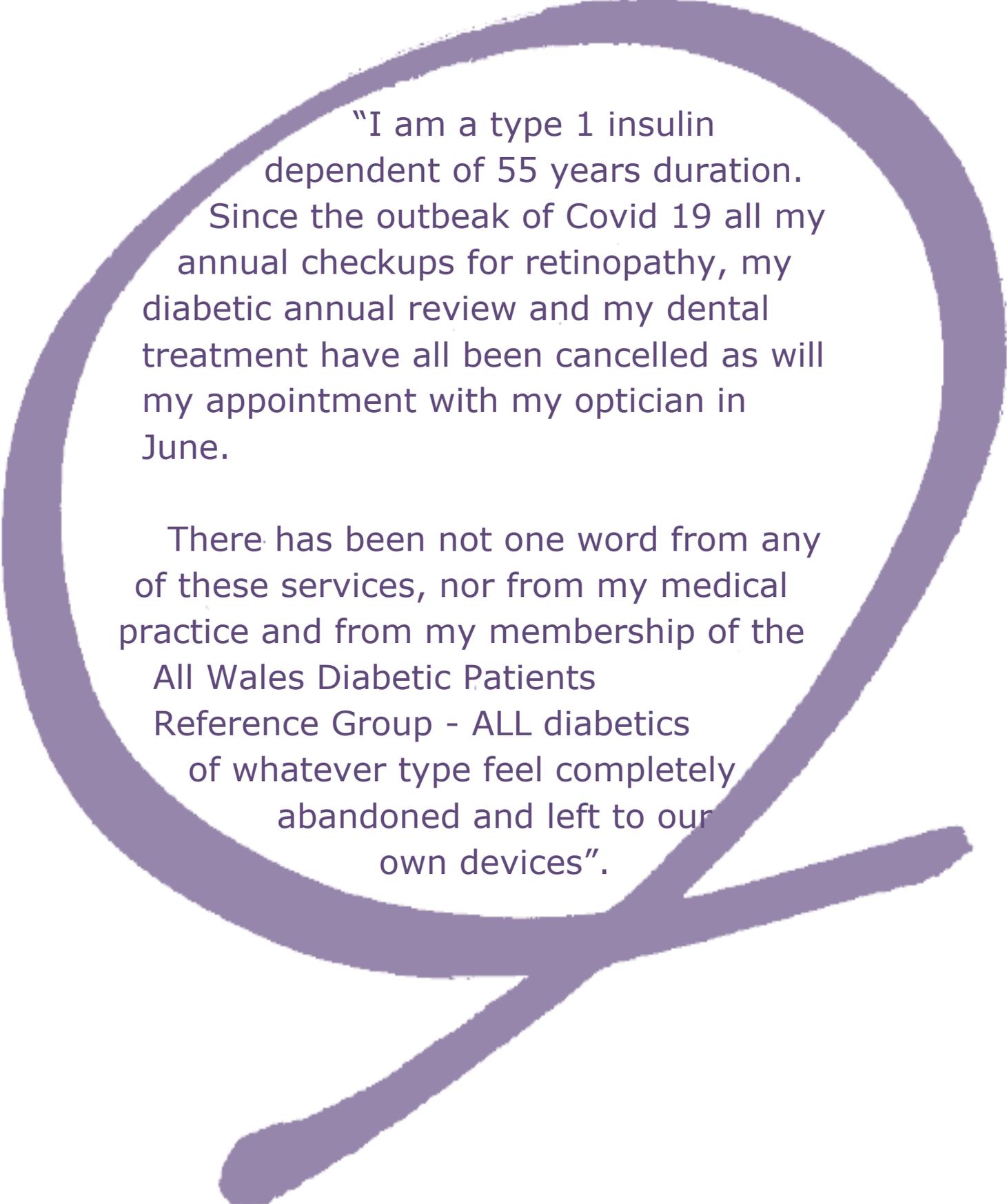
"....letter to say all services postponed until further notice. Referred by podiatry about pressure area on foot and for potential review of footwear and caliper.

Also need to have shoes and caliper serviced regularly so as not to end up in position where I have nothing to wear and all appliance are in factory at the same time."

"My concern is that nothing routinely has been done, example 1 - my husband has not seen a diabetic nurse since last September, normally it used to be every 6 months, he has rang but the clinics were closed.

3 weeks ago I rang again, as he was due for annual checkup, they came and took a blood sample, shortly after a diabetic nurse rang and said she would put him in touch with a community diabetic nurse, she came last week and informed them he was having far too much insulin (cut intake by 10 units).

This is the first check in over 12 months and feels he could have died."



“I am a type 1 insulin dependent of 55 years duration. Since the outbreak of Covid 19 all my annual checkups for retinopathy, my diabetic annual review and my dental treatment have all been cancelled as will my appointment with my optician in June.

There has been not one word from any of these services, nor from my medical practice and from my membership of the All Wales Diabetic Patients Reference Group - ALL diabetics of whatever type feel completely abandoned and left to our own devices”.

We heard that for some people, making decisions about whether to attend NHS places for check-ups would have been easier if they had better information.

“I take my 90 year old mother for 6 - 8 weekly checks and injections at clinic. My mother chose not to attend her next appointment as she is in a vulnerable category for Covid19.

She was contacted to see whether she still wanted the check but after discussion with me decided not to go ahead with the appointment. What would have been useful is more information regarding how this may impact her vision and to have a discussion in order to weigh the risks to make an informed decision.

Instead we were simply asked about the appointment. We hope we’ve made the right decision to protect her general health. But we simply don’t know whether we’ve jeopardised her visual (and therefore her independence) health. More information would have been useful.”



People needing follow up appointments after earlier care or treatment

We heard from some people that they were able to have great follow up care even though this was done in a different way.

“Reason for the appointment was a blood test, which I need every 3 months following prostate cancer. Attending the surgery was different under present circumstances but the staff were careful and thorough. I also had an appointment for my Zoladex implant – again all went well, under present restrictions.”



“The care during the pandemic has been amazing. The team have kept in regular contact via email / text messages / phone calls with any updates & have been offering Zoom meeting & virtual clinic appointments which have worked really well. They have even set up a virtual leisure centre which I've found so helpful during lockdown & shielding in order to maintain my lung health. Home spirometers were provided to be able to monitor my lung function at home. When I've had to visit the clinic for blood tests the staff have been really reassuring, wearing full PPE with robust procedures in place. I have been able to maintain access to all my medication that comes from the hospital & the Nurses were even bringing this to my car to prevent me having to enter the hospital.

The hospital has dedicated 2 parking spaces to CF patients which are by an entrance that's very near to the clinic, when I've needed to visit. Couldn't have asked for better care during a challenging time!”

For lots of people, we heard they had not had any follow up contact or appointments after the care or treatment they had received before the lockdown. This was a big worry for them.

“my mum has chronic lymphocytic leukaemia and was due an appointment in April to check her bloods as they are climbing again. Obviously appointment was cancelled due to COVID like all other outpatient appointments but we don't know what happens next. No one has been in touch”.

“I had no follow up sessions for my hip replacement in February because they were cancelled.”

For some people this was limiting what they do in their daily lives, as well as affecting their families and loved ones. For others, it was threatening their recovery.

“Had to receive A&E care in May following which I was admitted to Cardiology. Care I received in Emergency department and on ward was excellent. However follow up care by GP was extremely difficult to access and resulted in several more visits to A&S for care reviews.”



"I have been seeing a Dermatologist..... since January. I was prescribed Isotretinoin for acne. This includes blood and pregnancy tests each month. My March blood test was cancelled and so was my appointment with the Dermatologist in March due to Covid-19.

I was told I would be contacted but wasn't. After a week of ringing his secretary, I had to send a photo of my negative pregnancy test. I was then sent a prescription by post. Today I tried to email for another prescription only to be told it is only prescribed for 4 months.

I am very disappointed about this as I was told by my consultant it would be for 6 months. My skin is not better yet and I have suffered side effects since taking the tablets.

I have now just been left in the middle of treatment with no contact or follow up appointment. I had been waiting for about 8 months to see the Dermatologist and feel it has been a waste of time. I've just been left. Very disappointed."

“I am worried about my eye care. I have had some laser treatment that stopped me from being able to drive for a bit. Then all of this started and I think I have not had an appointment when I should have.

I am the only driver in the house, my wife is disabled and we are not shielding. We are only in our fifties but we can't see our grandchildren now and we are worried about driving in the future if my sight gets damaged.

My wife is also a recently diagnosed diabetic. This whole situation has made us realise how vulnerable we are and more scared about how we will go shopping or get to our appointments or see our grandchildren again.

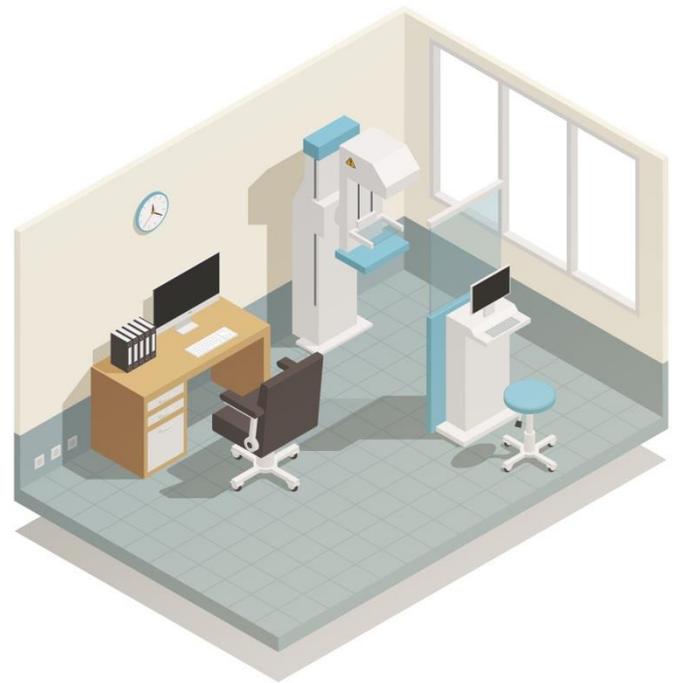
This is very depressing for us and makes our children worried too. I don't know when I will get another appointment or if I should risk going to it.”

“I was given an appointment the same day after feeling suicidal in Jan 2020 at I was offered advice and sent home with a referral to the community team. Who I am yet to hear from it is now May 2020. There has been no follow up what so ever”.

People waiting for screening services

In the early stages of lockdown most screening services were suspended, although some urgent screening services continued. People were told that if they had any symptoms they should contact their GP without delay.

People were not always clear what they should do at this time. For some people, the messages from different parts of the NHS were not the same.

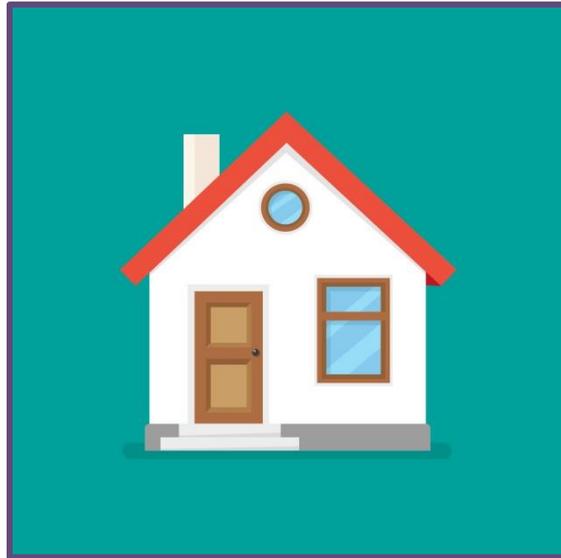


For others, not knowing when things might start again and how the NHS would deal with the backlog worried them.

For people who were due screening appointments following earlier treatment, the delays meant they felt even more anxious.

“We are being told that we shouldn't miss serious issues, and screening etc. But it seems we cannot go to the surgery, so how does that work? People need to know what is available for them.

Also my smear test has been put back months, and I'm sure the situation is the same for thousands of others.....”



“Having a pain in my breast radiating to my underarm and down to my elbow I became concerned. After a month I phoned the breast screening and was given an appointment. However the virus struck and it was cancelled /postponed.

Concerned I phoned for a GP appointment but was told they were not seeing anybody in surgery but the Dr was making phone consultations. In order to get a phone consultation I had to detail my problem to the receptionist for her to consult with the doctor as to if he would make the call.

**However she returned to the call to inform Dr said no need for an appointment just take paracetamol!!!!!!!
End of March, condition remains!”**

"I was told after my last cervical screening test (February 2019) that I should have another test in 1 year. I telephoned to arrange but was told that their allocation of appointments were all taken and to phone back in a few weeks.

It is difficult enough as it is to try and time these appointments around time of month and also childcare so I did not expect that (+ the fact that it takes a lot of courage to go arrange and go to these appointments in the first place anyway!).

By the time I was able to try again to make an appointment, we were in lockdown due to Covid-19. It is constantly at the back of mind that something may have changed since my last smear test. My mum had Cervical cancer at the age of 29."

"My daughter who is 28 was diagnosed with bowel cancer in Feb 19, she was due to have an MRI scan in April but it was cancelled, this is causing anxiety for us all as a family, we would like to know when routine screening will resume?"

Lockdown easing and the re-introduction of NHS services

In June, the lockdown restrictions started to ease. People were able to meet outside as long as they kept socially distanced, and families and others were able to create support bubbles. Shops selling non essential goods could trade again and places to eat also began to re-open.

Shielding ended for many people, although not for people who were at most risk from the virus.

More NHS services started to be re-introduced across Wales. This included screening services, as well as some eye care and dental services.

Many services were provided in different ways, using technology.

As the lockdown restrictions eased, we heard from people who were frustrated that they were still waiting and couldn't get the care they needed, even though they had heard that their services had re-started.

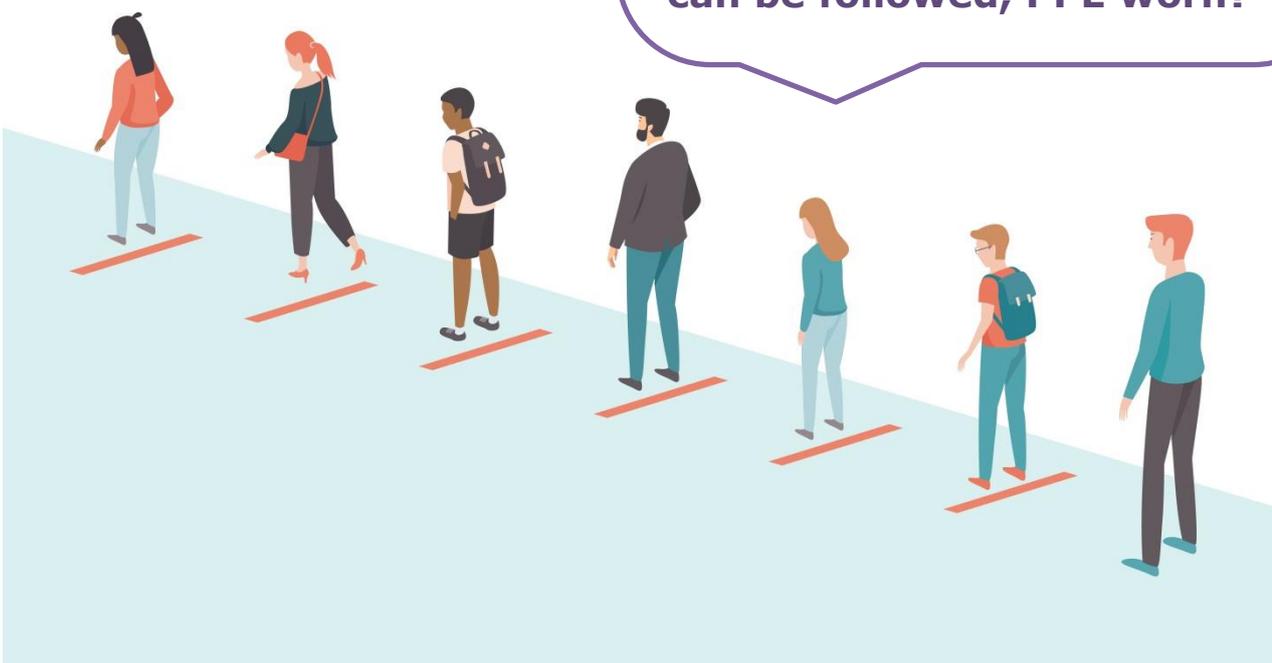
"My husband's scan was cancelled and not rescheduled for 4 months. During this time, he had no face to face appointments with his consultant or any doctors at all - the cancer is back and has travelled to the lymph nodes in his neck. Had proper care been provided this could have been detected much earlier. I kept listening to the Health Minister say that the NHS was open for business.....I for one would say it wasn't".

“My GPs are still not doing cortisone injections. I am 63 years of age still working full time. I have worked every day through this virus but my knees are now so bad due to not being able to receive my cortisone injections I don't know how much longer I can go on for....”

Lots of people felt that some NHS services were slow to re-open compared to other NHS services or wider services in the community, and didn't understand why this was happening.

“Please resume normal health care for all, use social distancing and PPE, like everyone else has to. This is not fair.”

“I needed to see the Dr regarding eczema, but seems too difficult not things are done over the phone rather than face to face. Other medical places are open, I don't know why the GPs still aren't when social distancing can be followed, PPE worn?”



“IVF treatment has been cancelled. Despite the HFEA and Government announcing that it can resume the WFI have still not even applied to reopen.

The updates have been limited and I have heard from other people going through the same. No timeline is being given and when you are battling infertility it’s incredibly stressful. The impact that the delays are having on my mental health is substantial.

No support has been offered and it’s been very mixed messages on social media. I understand that the health boards are delaying it but it needs to resume now. Other NHS clinics are open and have restarted seeing patients but WFI seem to be incredibly slow and are dragging their feet.”

When some services re-opened they were provided differently. Some people told us they wanted that to help them feel safe.

“Screening appointment had to be cancelled March and still waiting for screening call (Breast)- Ophthalmology appointment had to be rearranged for August..... Make assurances that "business as usual" is safe - get the message out sooner and use the technology now available via video and phone”.

“Proper PPE and safety can and should be in place for dentists to carry out these treatments safely, so that patients can receive the level of care they deserve and that the NHS promises to provide.”

We heard from others who felt that not being able to see healthcare staff face to face, or having to travel further to see their healthcare staff when services were reintroduced made things more difficult.

“People with long term conditions need regular face to face monitoring, especially as consultant appointments are now by phone. You need someone to actually see you. I had physio and 8 week post op all done by phone.

It is impossible to measure degrees of movement without physically seeing someone. I have had to choose my specially made shoes over the phone, not ideal.”





“During the Coronavirus emergency my local surgery....has been closed. Every 10 weeks I receive a B12 injection, but at the beginning of the closure I was told my treatment was being suspended.

When it was eventually implemented I had to travel..... (having to catch 2 buses and a considerable walk - EACH WAY). I arrived at the stated time but was told I was half hour late (which I definitely was not) and had to go back home and come back in 2 days time again having to catch 2 buses each way and when you are not feeling well becomes exhaustive.

I contacted the Practice Manager regarding the reopening of the ... surgery but felt I was brushed off with the reply stating the reopening was under consideration for sometime in the future and to look at their website - which does not really tell you anything regarding the reopening”.

Some people were relieved they didn't have to visit NHS premises but worried whether things would be missed if they were not seen face to face.

"My diabetes care has mostly been phone based apart from blood tests. I have been a bit concerned that the usual hands on aspects have been missed I.e. Checking blood pressure, weight and foot care. I am still anxious about visiting the surgery but not sure what is worse."

For lots of people facing continued delays, not knowing why or when their care might restart was particularly frustrating.

"Whilst I understand that covid resulted in staff being relocated to work in covid wards I am left concerned that essential equipment and therapy stopped and has still not resumed. Patients have no idea when it will resume and in what form. Being offered a video call is no substitute for hands on help and therapy.

I would like to see a route map to get back to hands on therapy as it is not sufficient to say that it is no longer possible and Covid is likely to be with us all for years. The fear is that everything else will also stop until it is eradicated.

That cannot be acceptable..... communicate with users for the plan for their treatment/therapy/service to resume and in what period, what it will look like."

"..been waiting for an appointment since last October to see consultant about my knees had one letter to say they would contact me before lockdown Feb 2020, heard nothing contacted them to be told I was on a waiting list and it would be at least 6 months went into lockdown

- have heard nothing, contacted them last week and was told they are still not seeing anyone I am now practically house bound being unable to walk any distance and in constant pain. Language used in letters need to be clear as to when I will be seen and any delay communicated with further dates."

"Communication, I understand why operations can't happen but keep me informed. The CMHT have no excuse really, all I need to do is speak to someone, the delay is bordering on cruel".

"Communication is key to help patients cope, i.e. reassurance that they remain on waiting lists and even if not known it would be great to know an approximation of when you may be seen or have treatment would make the wait a lot more bearable."



“Consultants and their teams should get in touch with people to explain why their illness isn’t important anymore. I’ve gone from having appointments every month to nearly 3 months without a single one.

My disease might be causing a lot more damage because it’s not being monitored when we know it is active. Also information on who to contact should you become unwell because I certainly don’t want to go to A&E as I’m in the shielding group... except I didn’t even get that letter until May!”

During this time local health boards started to provide more general information about what was happening. This was found on their websites and in communities, explaining how local services were being provided during the pandemic, and when they were planning to re-introduce services.

Some local health boards are better than others letting people know what’s happening with their own care and with services more generally, including what the plans are moving forward.

As we moved into summer, when people started to be much more active in their communities and things were starting to feel as if they were getting back to some kind of normal, people started to get more frustrated that services seemed to be slow to restart.

Urgent care was being provided. NHS services were being re-introduced. Health boards were having to arrange services in different ways to separate patients receiving COVID care and those receiving non COVID care. However, many people didn’t know this was happening in their area.

People shared their worries that more and more people would become sick or get sicker with non COVID illnesses the longer it took to reintroduce services. Lots of people did not know what was happening with the field hospitals and whether these could be used to make a difference.

“Use one hospital for non covid cases and one for covid cases so some planned operations could take place”

“The health service has not maintained its care of non covid patients and seems reluctant to restart.....Making services available again e.g.. checks in chronic conditions”

“I can understand operations were cancelled at the start but as soon as covid was under control all urgent ops should go ahead like other area, in particular children”

“It seems as though all other conditions, mine included (rheumatoid arthritis) have taken a back seat to the pandemic. More people are going to suffer because of lack of being able to get an appointment or treatment for non covid illnesses.

I suffer with rheumatoid arthritis and have not been able to see my rheumatologist or gp since March. I've been in pain and have been told to wait until the pandemic is over. I have a friend who was due to start therapy for trauma. I have another friend waiting for a cancer referral.”

People facing cancellations and further delays

Some people told us their appointments that had been arranged during lockdown were cancelled at short notice. This caused real difficulties for them and their families.

"I received a date for an operation so promptly self isolated, took Covid test etc. On the morning of the operation the ward rung asking me if I was ready to go in earlier which I was. Just as I was about to leave the house the surgeon rang and said the operation was cancelled due to a lack of staff.

I was told to continue to self isolate which I have done so. We are now 2 weeks on and despite ringing twice, still have no rescheduled date for my operation.

This means myself and three teenagers have already self isolated for 1 month for no apparent reason. We have no symptoms, are not shielding and have no date. As you can imagine my teenagers are not too pleased with this. When I ring or email and ask they say it's up to the surgeon who does lists when it's rescheduled.

I read online that in England it must be rescheduled within 28 days. The lady told me this wasn't the case in Wales, but it seems ludicrous to just leave people in isolation for no reason and just have people hanging on.

The fracture has had a huge impact on my life as I was super active before and it also means that I can't work.

....."

People were even more concerned about cancellations if they didn't know why the cancellation had happened, or when they didn't feel the information they got was helpful.

"Be honest with your communication. If you have to cancel an appt, don't send out generic letters which don't apply during a ... pandemic."

"I think keeping peopled informed as to what is happening would be good instead of giving appointments and the cancellation with no explanation."

Many people still hadn't heard anything at all about when they might have an appointment. For people who were still waiting for appointments since lockdown started, we heard how this was making more and more of a difference to their lives, both physically and mentally.

"I suffer with menorrhagia and suspected endometriosis. I have been put on numerous medications and nothing has stopped the pain. I get fobbed off each time I speak to a doctor, and I have been waiting for my referral to come back from the hospital since May 2020. My pain is getting worse. Nobody is taking me seriously"



“Since being referred 6 months ago by my GP to MCAS, I still have not been seen. I live in constant debilitating excruciating pain despite strong painkillers. My pain is increasing daily and limits capabilities greatly.”

“My father has been waiting for a cat scan since March to see the cause of bowel obstruction. He is struggling physically and emotionally the wait.

My mother in law has been waiting over a year to see a geriatrician with Parkinson symptoms and now is deteriorating because of dementia symptoms with the shaking. Her appointments have been cancelled twice due to Covid.”

People with worries about further delays leading up to winter

As we moved towards the autumn, we started to hear more concerns that people waiting for services may have to wait even longer if they have to be stopped again during winter.

“Currently waiting for 2 urgent orthopaedic surgeries and am concerned that they may keep being postponed over the winter meaning not only months more in pain while waiting but also more long term damage being done in the meantime.....”

“As a full-time carer, who is asthmatic and awaiting a cardio referral, I do feel anxious about the winter. We're still awaiting appointments that have been delayed due to Covid-19. We're hoping we'll get seen before we hit the winter period.”

“I had a hip replacement beginning of this year and was due another 12/14 weeks later. Due to Covid I'm still waiting, I am very concerned about this I have been on sick from work for a year ready. I need to get this sorted before another break out and the usual winter illnesses.....A quick hip replacement so I can work and look after elderly parents”



Dealing with the backlog and planning for the future

As the pandemic continued to affect NHS care and treatment across Wales, people's concerns grew about the size of the backlog being created.

People worry that the NHS was struggling before, and want to know more about how it will catch up in the future. People want to be involved in planning for the future.

"I can't see them catching up with the backlog unless plans are put in place. Inevitably, people will die of other illnesses, because the system was struggling before. It would be nice to see what plans are afoot to catch up with other health issues".

"I understand we are in a very difficult time, but in my professional opinion the surgery and other services offered by the Health Authority have been reduced by too much and you should be using your influence to encourage more face to face activity or we will find ourselves in another health pandemic caused by the backlog of undiagnosed illnesses during the current COVID-19 pandemic in the next 1 - 5 years."

"Liaise better with individual citizens, voluntary and council services to ensure solution are always co-produced and everyone is involved in planning, delivery and evaluation of our health service".

Reintroducing services at different times

CHCs know that there are differences across Wales in the way that services are being re-introduced.

We know that sometimes, this variation is because NHS staff may be unable to do their usual work because

they are needed more elsewhere or because of their own personal situation. It may be because NHS premises are not available to provide services in a safe way, or there may be other reasons.



If a certain kind of operation or treatment can be restarted in one area of Wales (or England), it doesn't make sense to people that it isn't available in another area, or if it takes much longer for people to be seen in one area than another.

People will feel this is unfair if no one explains the reason for this, and what is being done to make things better.

It is important that the different NHS bodies in Wales work together to make sure that decisions about restarting services get the balance right when thinking about the impact on people of waiting for treatment.

In November 2020, the Welsh Government started letting people know again about the numbers of people waiting for NHS care and treatment in Wales.

This will help make it easier for everyone to see where there are differences, to find out more and let people know why

there are differences, and to take action to make things fairer where this is needed.

Learning from what we heard



"I'm worried that the NHS is currently a Covid service."

Throughout the pandemic, CHCs have heard the grateful thanks from people in Wales for everything health and care staff have done and continue to do to care for people when they are ill. We hope the feedback people have shared helps NHS staff and others to recognise and value what has worked well for people so far.

We also heard the heartbreaking and devastating impact on many people whose care and treatment has been delayed because of the pandemic. We heard the worries people have about becoming ill in the future because vital early detection has not always been possible.

We heard the difference it makes to people when they know and understand what is happening with their care and treatment, and where they can go to get further advice and support. This makes any delay easier to manage.

When this doesn't happen, people get more anxious and concerned – particularly if they don't know the reasons why or when they might be seen. They worry about being forgotten in the system, and often don't want to bother the NHS to find out at such a busy time.

NHS bodies in Wales need to respond to the worries people have shared with us by making sure:

- healthcare staff keep in regular touch with people waiting for care and treatment. This will help them know what is happening, how long they might need to wait, the reasons for the delay and what the delay might mean for them in the longer term
- people waiting for care and treatment know how to get advice and support while they are waiting
- healthcare staff involve people in discussions about the benefits and risks of treatment during the pandemic. This will help people feel involved in the decisions being made and that they have control over their own lives through shared decision making
- they explain clearly and simply when changes need to be made to the way services are provided during the pandemic, and what this means for people attending for care and treatment
- they provide up to date, clear and simple information about how local NHS services have changed during the pandemic, and what the plans are to reintroduce services
- they reach more people who may not be able to find things out by looking on-line. Not everyone has or is able to use a smartphone, tablet or computer. Accessible, up to date information should also be shared in other ways through community networks and groups.





The **Welsh Government** needs to make sure:

- healthcare services in Wales get things right in balancing the harm caused by or as a result of the coronavirus pandemic
- all NHS services for people living in Wales are reintroduced as soon as it is safe to do so, taking action to identify and address any unnecessary differences across Wales.

People living in Wales know and understand there are big challenges facing the NHS in the years ahead as it tackles the harm caused by the coronavirus pandemic. It will be as important as ever that it does so by involving people in developing its plans and designing its services for the future.

Thanks

We thank everyone who took the time to share their views and experiences with us about their healthcare services and to share their ideas.

We thank the healthcare staff who are working so hard to care for people and their loved ones during the pandemic.

We hope the feedback people have taken time to share influences healthcare services to recognise and value what they do well – and take action where they need to as quickly as they can to make things better.

Feedback

We'd love to hear what you think about this publication, and any suggestions about how we could have improved it, so we can use this to make our future work better.



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