



Healthwatch Report to System Oversight and Assurance Group (SOAG) – Paused Treatment

May 2021

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Paused Delayed Treatment/Care – initial findings and themes from local Healthwatch in Bradford, Calderdale, Kirklees, Leeds and Wakefield

Feedback from Healthwatch Leeds

Public Voices: Paused Delayed Treatment/Care

Using our Weekly check-in covid listening programme we have been asking people to tell us about their experience of paused or delayed treatment and care. During May we want to hear from people who have had their treatment/appointment paused or experienced delays to their care for non-covid related conditions over the last year.

The survey has been running for just over one week and we have received feedback from 60 people (11th May 2021). We have also started to gather feedback from organisations supporting people in the community and from other local Healthwatch.

This report summarises the interim key messages that we have heard from the surveys and what other organisations and groups have shared with us so far. The work will continue until the end of May.

What treatments have been paused/delayed

We received comments from 51 respondents about their delayed treatment.

People told us about the lengthy waits they have had and some talk about their missed routine appointments over the last year. Others also told us about appointments that were meant to take place that have just not happened.



“In December 2020, I was tested for diabetes and found to be just over the line for it....I was to be reviewed 2 months later. This never happened.”

“I was supposed to have a scan on my joints to figure out what arthritis I have. This was supposed to be March last 2020 I am still waiting in April 2021.”

“I am being monitored following treatment for Thyroid Cancer. My "next" appointment with the consultant should have been in February 2020. My medication has not been checked since February 2019.”

“Due to have annual check up's in January 2020 & 2021 with my GP but they have not happened!”

“I had a major heart procedure including the fitting of a defibrillator in November 2018 and appointments for consultations and checking was cancelled due to COVID-19. However, everything is now back on track.”

“Broken foot since last October and due to being extremely vulnerable to Covid and having underlying health conditions I'm still waiting for surgery to mend the break as well as other appointments being paused due to Covid.”

“Got a nodule in my Thyroid needs checking to make sure it's not turned into cancer. I also have a device fit for bladder control not seen anybody since

March last year it must be checked regularly to make sure the battery is still working.”

“Had stroke 3.01.21 - follow up support during pandemic was appalling: - struggled to get appointments at GP surgery to deal with my blood pressure and other issues. - GP follow up consultations never happened, - Stroke consultant failed to reply to first contact from my GP surgery regarding my health issues. - Deal in getting appointment with physio.”



Updates and Support

Only 22% of those that responded told us they had been kept updated while they were waiting. Those that had received updates told us these were to let them know they were still on the waiting list or that their appointment had been postponed/cancelled. One person told us they had been given a telephone number to call if their condition worsened.



“Just saying they will be in touch when it’s my turn but could be over 12 week.”

“I was given a telephone number to contact an appropriate staff if my condition worsened.”

“Received a letter to say appointment has been cancelled. Nurse at GP surgery said she would get it reinstated.”

“Had to ring doctors to check if still on wait list.”

“I have had telephone conversations with the midwife but no physical checks & no chance to build a relationship with her.”



What else people told us would help/support them

When asked what would help or support them further the key themes were around being kept updated, getting clear communication and information and not feeling ‘forgotten’. Others talked about practical help to support them, some reassurance and a guarantee that they would get the treatment they needed.



“Just to know what the waiting times are so you have some idea as to what is going on and not feel like you have been lost/forgotten.”

“Could have had some sort of physio to help mobilise round the house instead I had to live downstairs with no bathroom. I could have had shopping support or just even a befriender.”

“To be updated. I have had to chase throughout with GP not offering any other info than to “keep checking.”

“Knowing what is going on and having some idea of a date. It is now well over a year from when I should have had the operation.”

“More communication and understand what is happening. Been waiting over 1 year for this surgery and quality of life is significantly reduced while I wait for it.”

“Some kind of regular contact. I feel I have dropped off their list again”

“A regular update would have helped, all I received was a letter explaining the Op would be delayed due to covid and did I wish to remain on the list for it to be done - to which I replied yes.”



The impact that delayed paused treatment has had on people

People told us about the huge impact of delayed treatments on their lives. The key themes mentioned by the majority of respondents was the impact on their physical and mental health which then impacted on their daily lives. Many people told us about living with the physical pain and discomfort and the constant worry and pain increasing anxiety levels.

Others talked about the impact on their mental health due to the delays or the deterioration in their physical health. Respondents also talked about the impact on their day to day lives including not being able to do things they needed to or enjoyed and the affect on their work and employment.



“It’s left me extremely isolated and physically declining in health due to lack of mobility. My mental health deteriorated dramatically ending up having a breakdown over Christmas which has had further impact on family mental health and being able to do simple daily jobs.”

“I struggle to walk for long periods of time so it has affected how long we are able to go for walks as a family which as a result has had an impact on my weight.”

“Unable to (i) plan for any personal events in the future and (ii) assist my employer to plan for my absence to ensure continuity of cover for my job.”

“I’ve stopped working full time and gone part time.”

“I am very anxious re having my first baby, no antenatal classes & no visit to the delivery suite at the hospital. I feel fear of the unknown & no idea what will happen when I go into labour in June.”

“I know my condition has worsened. I should have a yearly check up, I got a phone call which was just a tick box exercise.”

“My anxiety is through the roof I’m constantly in discomfort.”

“It’s worried me that my thyroid could have turned into cancer.”

“I am in constant pain in my knees/ body with the added of anxiety of not knowing what is wrong with me.”

“Not able to fully exercise (stop running) or go for longer walks without pain.”



Feedback from Leeds Parkinson’s Group

- The Parkinson’s nurse calls were delayed. They were telephone calls rather than in-person assessments.
- Calls were made when the partner to the individual was not with them.
- One Parkinson’s nurse was available most of the time for questions which individuals appreciated.
- Exercise classes cancelled run by Parkinson’s UK, could have had an impact on service users’ physical health.

Feedback from BHA Skyline Leeds – supporting people with HIV

- The Brotherton and sexual health clinic at Leeds General Infirmary have been very good with providing information and supporting clients since the start of the pandemic. Consultants are available on the phone and clients can discuss any worries and if necessary are invited to the clinic.

The clinic quickly adapted to change and therefore was able to prevent other health complications related to HIV.

- Two pregnant woman with HIV report advised that their midwives have been very difficult to reach and if there has been communication it has not been helpful. For these pregnant women, midwives have been the only person within easy reach as appointments with the GP is near impossible. Not being able to reach them for advice within two to three days has caused them to be anxious and scared.

Feedback from peer stroke and carers support group (Leeds)

- Feedback from people who are needing hip replacement, heart surgery, stroke rehab and support.
- Do not know of anyone receiving any additional support/information to help them while they have been waiting.
- The group are setting up online/telephone peer support for stroke survivors and carers to try and plug the gap.
- A support helpline would help people while waiting for treatment/care.
- The delay/pause has increased isolation.

Feedback from Healthwatch Wakefield

General delays and long waits for follow-up care



“Client had heart surgery in April and still waiting for follow up.” (20 Nov 2020)

“I was due to have surgery 3 weeks after diagnosis but that was in October” (8 April 2021)



Lack of support from health visitors for young families



“My little girl is 16mths and hasn't been seen since the 6-12wk review! I've had no contact from anyone” (15 Jan 2021)



Lack of support while waiting for treatment



“I was referred to Well Women's back in March 2020. The waiting list then, I was told was 6 months, however during the pandemic Well Women's failed to offer ANY kind of support to anyone for nearly 6 months. I am STILL waiting for support from Well Women's a year later....

My mental health continued to decline from March 2020 onwards. I have heard their 6-month waiting list is now 15??”
(1 March 2021)



Feedback from Healthwatch Bradford

- Cancer patient needed a simple blood test at his GP's as he is losing his sight and needed tests to ascertain the cause. Told it was a 2 week wait to see a Practice Nurse.
- Elderly patient needs weekly blood pressure tests, told that the GP would not be offering this service due to Covid restrictions and to buy her own testing machine and take her own readings. The patient felt that she was not able to do this as she gets confused.
- Numerous calls where the patient is accepting of treatment delays, however, there is a recurring theme of wanting to know how long for and frustration at the lack of information re re-scheduling.

Feedback from Healthwatch Kirklees and Calderdale

The themes emerging from Kirklees and Calderdale mirror many of those seen across other Healthwatch. See below for a detailed report and specific examples of what Healthwatch Kirklees and Calderdale have been hearing about paused/delayed treatment/care.

Delayed or paused care Kirklees and Calderdale

In Summer 2020 Healthwatch Kirklees and Healthwatch Calderdale engaged with their local communities about experiences of health and care services during the Covid-19 outbreak. Throughout this engagement, we heard from people in both localities who had experienced delays in their care.

In general, people who responded to our survey told us that the delays they had experienced were attributed to the following services

- GP/practice nurse
- Hospital planned care or outpatient appointments
- Dentistry
- Pharmacy and medication
- Mental health services

Below are some of the comments we received from people in Kirklees and Calderdale.



“I had a long wait for my operation, which was initially fast-tracked. I had a phone call from the consultant at the beginning of lockdown to explain they were postponing and to reassure me, I think. I could have done with another call a few weeks later as I was starting to feel very

anxious.” (Hospital)

“I was able to have consultations on the phone with a nurse and with my GP but Ive been told I need a smear test and my coil replacing which have not yet been offered.” (GP/sexual health)

“Patients who are awaiting hospital appointments should still be monitored by GP and not left drifting indefinitely.” (Hospital)

“I had a routine appointment with the hygienist which I had previously had genuine cause to reschedule the day before. Upon making the alternative appointment they warned me that if I did not attend, I would be struck off the NHS dental practice books as I had left it too late to notify them of my

change of circumstances. My appointment was for a Tuesday and I let them know as soon as I was able on the Monday morning. They do not open Saturdays and Sundays and I was unaware of a problem on the Friday before. My appointment was for the day the government announced that those with underlying health conditions (of which I have) should self-isolate for 12 weeks. This was prior to full lockdown. I felt pressured into attending the appointment, however after speaking to the dental receptionist, she said that if I did not feel comfortable attending, it was my choice and I should not. I needed to seek assurance from her that I would not be struck off because of the cancelled appointment. She said I wouldn't be. I have no written confirmation of that fact. It happened prior to full lockdown and I am assuming I am allowed back when I can. I don't know though." (Dentistry)

"The Diabetic clinic didn't answer the phone line. I didn't get sent an appointment for March as planned - and no contact to say I wasn't getting an appointment either. It's now June and I still haven't had contact to say I'm not getting an appointment." (Community)

"I had severe toothache, could not receive treatment and this impacted on my mental health." (Dentistry)

"Some anxiety and depression due to lack of progress with treatment and confinement." (Hospital)

"Healthwatch Kirklees heard from a man who has recently completed 6 rounds of chemotherapy for blood cancer which have been successful. However, he has been told that the cancer will be with him for life and, in normal circumstances, he would have been called for regular screening and follow up appointments but these are currently

suspended. This is causing worry as he has no way of knowing when he can expect a check-up.” (Hospital)

“I did eventually get my medication but the break in the treatment has been detrimental to my health condition.” (Pharmacy/GP)

“The carer who my loved one relies upon, missed one week.” (Social care)

“I would have liked more up to date and clearer information about where to go. I also would have liked to have been informed about online booking services and potentially how long you MAY have to wait to receive the service.” (GP)

“I received less regular tests and checks from my midwife during pregnancy so far.” (Community)

“My mental health is being made worse as I'm unwell and If I had of had the blood tests, I could have been receiving treatment now, but as it stands, I haven't been able to get the treatment I need.” (GP/Hospital)

“Not having the right pain relief has resulted in having to resort to a stronger dose of Morphine this takes its toll on my family and my mood.” (GP)

“My psychiatric and psychology care has been delayed and feel left to struggle.” (Mental health services)

“I have anxiety and depression (diagnosed clinically prior to Covid-19). I am on medication. I have reviews of medication which was done via telephone.

I felt unsure this was the right thing for me. I feel unsupported in the community.” (Mental health services)



Ongoing contacts

For the past 6 months (since our “experiences of health and social care report during Covid 19” was published) both Healthwatch Kirklees and Calderdale have continued to receive contact from the public in terms of delays to their health or social care. Below is a collection of more recent examples of people’s experiences (which have been anonymised)

April 2021- The patient's wife contacted us to ask if we could help. The patient had been referred to neurology in August 2019 and had four cancelled appointments. The patient's condition has worsened throughout this time and the patient did not know who or where to contact for information. The patient also needed to see a GP for a face-to-face appointment and wasn't getting anywhere. He was struggling to have a telephone call due to being hard of hearing.

March 2021- Family member contacted us in relation to patient & concerns about delays to their treatment at CHFT, delays in being allocated a social worker for dementia & a review of the person's care needs. Patient was admitted to CHFT (Both CRH and HRI) numerous times in Oct & Nov 2020. On Dec 10 patient was allocated a transitional bed & family told she would be assessed for her dementia needs. They were told it would take 6 weeks. After 14 weeks, the patient had not been allocated social worker or assessed. Patient had to be moved to another place as staff at former could not cope with her needs. Family told us that the delays in relation to social care is "excessively long" and they fear the impact on family member is so great it will limit the patient's quality of life going forward.

The family understand it was over Xmas & at time of Covid-19 but feel the delay is unacceptable with little communication.

Follow up

Healthwatch Kirklees and Healthwatch Calderdale are currently working alongside the 'Planned Care' workstream of the West Yorkshire and Harrogate Partnership. Our aim is to engage with the public further around paused or delays to care within our locality to provide live information intermittently and a final report in September 2021. Our engagement will run for three months and provide the planned care workstream with information regarding:

- Patient confidence in contacting health and care services about their delay
- Examples of communication barriers which have led to a delay in care
- How far patients would be willing to travel for planned care and barriers to this
- Willingness of patients waiting for a hospital treatment or procedure, to have this undertaken in a private hospital (paid for NHS) if this meant the patient would receive treatment sooner
- Which services patients are experiencing a delay or paused care
- Types of support people have turned to during their wait for care
- Life impact of the delays to care
- Patients' confidence in how well they can manage their own health
- Patients' confidence in seeking medical help for serious / worsening conditions and what would improve patient confidence.

We would like to suggest that the data and information received, throughout the next three months of our engagement, be used in other workstreams

within the West Yorkshire and Harrogate Partnership and with local stakeholders.

Our experience is that the public do not refer to their own NHS and social care needs in small segments relating to specific services or treatments but rather in an integrated and joined up way.