

The waiting game:

how delays to care

affected people in

Calderdale during the

Covid-19 pandemic

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About Healthwatch Calderdale

Healthwatch Calderdale is an independent champion for people who use health and social care services.

We listen to people, especially the most vulnerable, to understand their experiences and what matters most to them. We influence those who have the power to change services so that they better meet people's needs now and into the future.

We empower and inform people to get the most from their health and social care services.



Summary

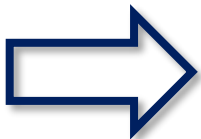
We asked the residents of people living in Calderdale and Kirklees 12 questions about their experiences on delays to care during the Covid-19 pandemic.

In Calderdale, there were 84 responses to the survey which ran between June and September 2021. Not every respondent answered every question.

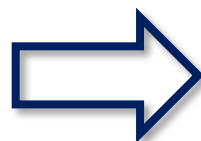
This report looks at people's experiences in the following areas:

- Seeking medical help for health problems;
- Life impact of delays to routine care;
- Support while waiting for care;
- NHS treatments or procedures further away from home;
- Remote appointments via telephone or video;
- Pandemic healthcare changes;
- Improving health and wellbeing.

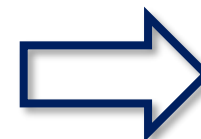
Key Findings



Life impact: 47% (41 people) told us delays to their care had a negative impact on their mental and physical health.



Support while waiting for care: People relied on family and friends (39%, 33 people) and/or medical professionals (39%, 33 people) while they experienced delays to routine care. People told us clear communication about how they would access or receive continuity of care would also have improved their experience and lessened the negative life impact.



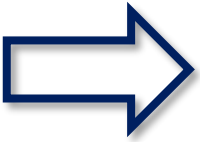
Seeking medical help for their health problems during Covid-19: Only 15 people (18%) stated they were made aware that there would be a delay to their care or treatment during the pandemic (between April and August 2021). 69 people (82%) said that they would definitely seek help for a serious or worsening condition.



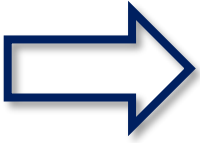
NHS treatments or procedures further away from home: 39% of people (33 people) said they would be willing to travel further away from home for NHS treatment; 37% (31 people) said they did not want to; 24% of respondents (20 people) said they might be prepared to do this.



Remote appointments: People felt that telephone and/or video appointments are suitable for triage or minor ailments and if medical professionals have access to notes and history. Some people said they had concerns about the quality of care they get and felt that appointments over the telephone/video felt rushed or impersonal.



Pandemic healthcare changes: Access to services was listed as the priority of people, with others listing improving services and improving communication as the things they would change. People liked the quietness of waiting rooms and praised the phlebotomy service for improving during the pandemic.



Improving health and wellbeing: Many of the comments in this section related to pain management, pain affecting health and wellbeing and impacting on sleep. People told us an improved way to contact consultants; making online booking easier and allowing greater advanced bookings would have improved their experiences.

Introduction

Healthwatch Kirklees and Healthwatch Calderdale worked collaboratively during 2020 and 2021 to collect the experiences of people living in Calderdale and Kirklees during the Covid-19 outbreak. A few key themes emerged, one of them being delays to care, so we have further explored this issue in this report.

Healthwatch England also engaged with people around their experience of delays to care during the pandemic and published a document explaining what people should expect whilst waiting for care (Healthwatch England, September 2021).

Method

We used a number of engagement tools to obtain the feedback in this report including an online survey, snapshot questions on social media, case studies, social media engagement, and outreach via community groups in Calderdale.

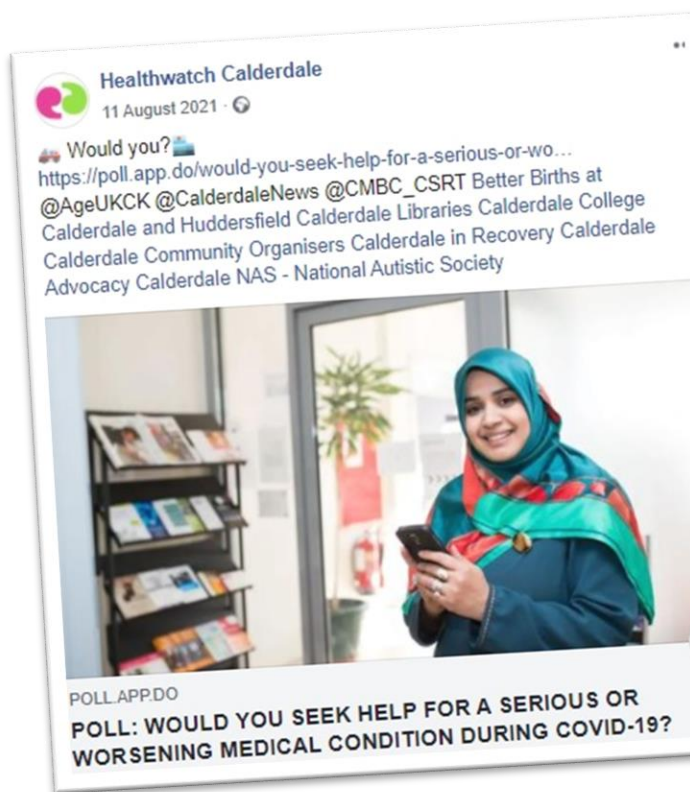
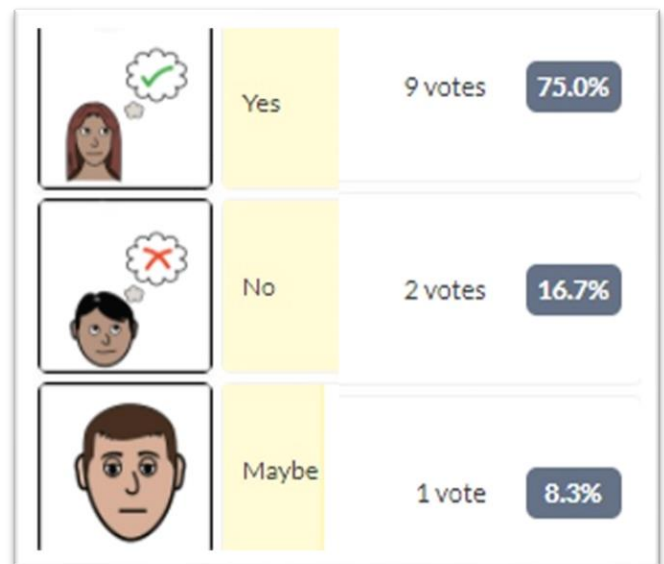


Image shows an example of various quick questions we asked on Facebook as part of our engagement work into delays to care. In this case we asked: **Would you seek help for a serious or worsening medical condition during Covid-19?** The answers were as follows:



Demographic: overview

We had a total of 84 responses to the survey and of these, 59 (70%) people were service users and the remaining 25 (30%) responses were from representatives (family, carer, advocate) of people who had required NHS or social care.

Responses were from: individuals identifying as female (60%, 50); as male (17%, 14); prefer not to say/blank (23%, 20).

The largest response by age category was 45-54 and 54-65 (28% for both). Out of the 84 responses, 65 specified their age.

Of those who answered, 59 (70%) said they were white, 2(2%) were Asian and 1 (1%) respondent

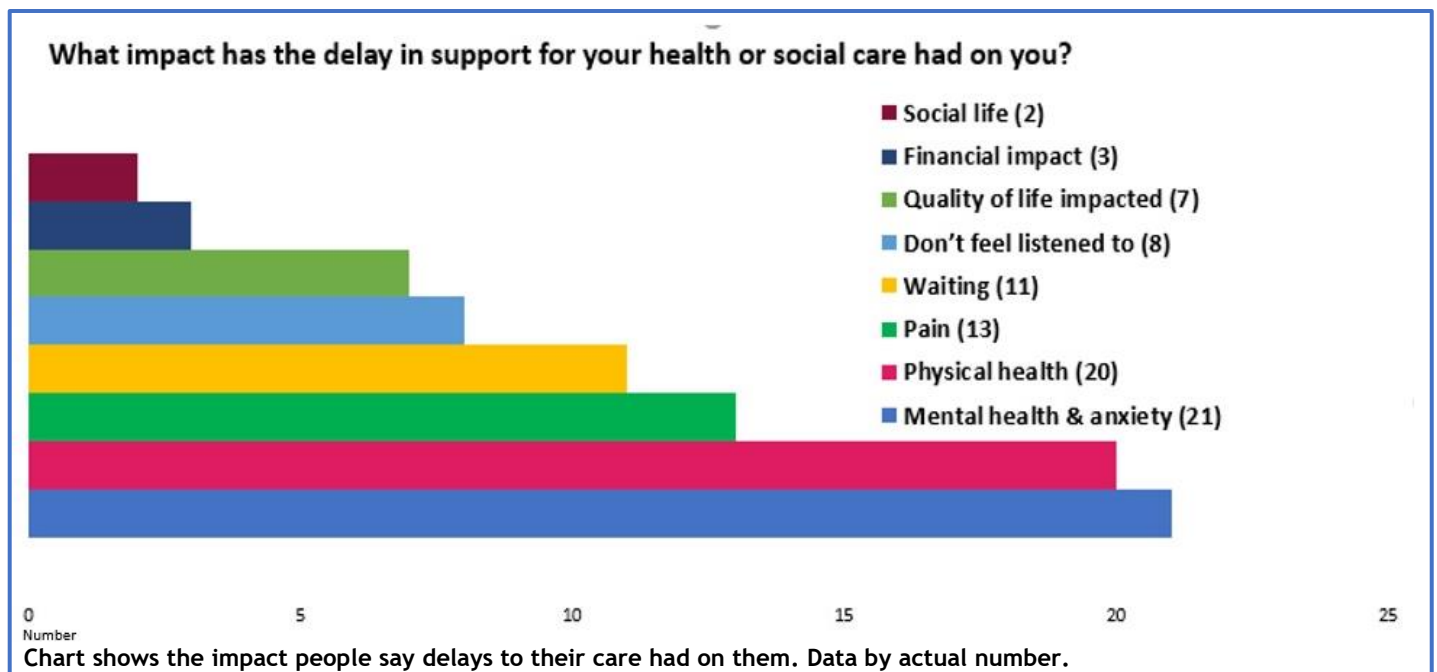
was black. 1(1%) was of mixed or multiple ethnic groups ethnicity, 1 (1%) belonged to other ethnic groups and 1 (1%) respondent preferred not to state their ethnicity. 19 (23%) did not answer this question.

Findings

Life impact of delays to routine care

There were 86 options selected (with some people selecting more than one answer) with every response including at least one negative comment about the impact on physical and mental health people experienced.

The word 'pain' was referenced by people multiple times in the written responses, along with 'mental health' and 'anxiety' - all mentioned negatively.



What could be improved?

Patients felt their symptoms were not taken seriously when trying to book a face to face appointment via any triage system through their GP or NHS 111.

“Profound impact on my mental and physical health... No blood tests done for 18 months.”

“Symptoms began December 2019, wasn't seen for 6 months. Appointment cancelled or consultants didn't turn up due to Covid. I was scared of cancer.”

“I feel like not being able to see a doctor face to face has been bad for my physical health.”

Other comments about named services:

- **Basement Project:** “I attend groups/meetings 5 days a week at the Basement. This not only has had very positive impact on my alcohol addiction but on my mental health also.”

- **GP and Calderdale and Huddersfield NHS Foundation Trust:** “Risk of sepsis and necrosis. Passed from GP to Outpatient, back to GP, waiting for further information - all I need is an ultrasound and hernia surgery. GP accurately diagnosed cause of headaches, waiting for adequate pain management.”

Support whilst waiting for care

We asked about the support people received, specifically:

1. The support people received
2. The kind of support that would have helped people

In terms of support whilst experiencing a delay to their NHS care, most people sought access from family and friends (39%, 33 respondents) or medical professionals (39%, 33 respondents). Types of access comprised of 30% telephone contact, 2% video calls, 2% email, 5% mental health service contact.

A smaller proportion of respondents cited peer support (13%, 11 respondents) charities (6%, 5 participants), and community services (5%, 4 people). Over 14% of respondents (12 individuals) stated that they did not have access to any form of support whilst they waited for their NHS care.

What worked well?

People praised the support received from family and friends.

Peer support was cited as being positive, specifically help from others via apps; the availability of support groups and their response to change was also praised. Groups such as the Basement Project, Diabetes UK and Parkinson’s UK were named as being of great support.

People told us they were receptive of accessing support groups via Zoom video calls, chats and messages, but accessing health care via technology is more divisive, as Page 15 indicates.

What did not work well?

People said not having the ability to ask NHS staff questions easily was a problem; with some asking for extra support for those who wanted to access services but needed help to do so, such as the deaf community and people with learning disabilities.

Providing clear communication about how patients would access or receive continuity of care would also have improved patient experience.

In addition, some comments related to access to information, both for those able to do it themselves and those who need support of others. This could be achieved via improved websites, apps, social media or messages targeted at certain patients.

- People told us improved communication (19 people, 35%) would have improved their experience;
- Support from NHS professionals (15 people, 27%);
- Face to face consultations (10 people, 18%);
- Referrals, pain management and quality of care were also noted.

“My problem is with day to day GP services. They have changed systems for repeat prescriptions without notifying us, impossible to get through on the phone and the recorded message sends you to the website which is a nightmare when trying to access online services. When I eventually managed to access online services it asked me to ring the surgery for the service I required. Feel like going round in circles.”

“Family supported me. Services just stopped, I have multiple conditions and need physio, OT, podiatry, psychology.”

“My daughter spoke as I can't hear.”

Comments about named services:

Parkinsons UK: “Have had to ring Parkinson's U.K. and reach out to support groups on social media for advice.”

“Parkinson's UK Calderdale have been the only people that have given any support with regular phone calls before my brother was admitted to hospital and now ringing at least twice a week for updates.”

Calderdale Royal Infirmary: “The cardiac nurse at Halifax hospital was helpful. But their computer didn't link with my GPs.”

Neurology: Patient told us they received 1 brief call during a time they would normally have 3 or 4 Outpatient appointments.

Pain Clinic services: “A simple phone call the pain clinic managed to do this and were amazing yet other departments just shut.”

Social services: “Not keep changing social workers and leaving my brother in limbo for 30 months.”

Making Space: “The carers group making spaces gave me telephone support and visited. The user group helped with zoom chats and messages.”

Protected groups:

Of all the comments from those with protected characteristics, those with disabilities needed to rely on family and friends, support groups and carers the most.

Quality of care received by people and referrals between 2 NHS organisations had a higher number of negative comments from those who are disabled than those who are not, with them citing communication as the most important factor in assisting them.

Those with a physical mobility impairment spoke about face to face consultation much less, as did those with a mental health condition, indicating these groups would respond more positively to healthcare appointments via telephone or online

Case study: Sam's story



Sam's delay to surgery on her toe has had negative physical and emotional impacts on her health. Due to her toe, problem, Sam has had to change the way she normally walks and this has contributed to a back injury. After picking up a baby and playing with her, Sam felt an instant pain in her back.

She said: "I took an anti-inflammatory pill knowing I needed to reduce the inflammation, however, it had no effect. I couldn't stand, I couldn't sit, I was in tears climbing the stairs to go to the bathroom, I knew after long term back issues I needed stronger painkillers to help me get moving."

At 2.15pm she called NHS 111. At approx. 4.30pm a nurse practitioner called and decided that because of the acute pain she was experiencing, she should be upgraded to speak to a General Practitioner (GP). Sam was assured she would receive a call within two hours, which didn't happen. By 8.30pm Samantha had still received no call back so she went to A&E.

"It shouldn't have been an A&E call and I was extremely embarrassed to take it to that level but I needed pain relief," she added.

Sam was triaged, and given diazepam for the pain. At 12.30am - 10 hours after her initial call - the NHS 111 GP called but she couldn't answer as she was being seen by A&E staff at the time.

"What frustrates me is that NHS 111 may be down as hitting their telephone call return target as 'someone called me back' however being left in extreme pain for so long was awful. I tried to explain on the phone how much pain I was in, but they were clearly in demand 'as it was a bank holiday' and did not have the resources to deal with the demand."

Samantha pays for a chiropractor to help her back pain as she believes there is little chance of help through the NHS for this. She feels she is often left questioning "How do those who can't afford to pay manage?"

"The chiropractor after assessing me worked out my body was leaning to the left as it is compensating for the fact that I am awaiting surgery on my toe on the right foot, I am relying on the left hand side of my body to compensate for my new way of walking, as a consequence of delays for elective surgery it has caused other issues."

82%

of respondents said they would definitely seek help for a serious or worsening missing condition during the pandemic.

What considerations affected people's decisions NOT to seek help for health problems?

All respondents (100%) had tried to access health care services for their condition during the Covid-19 pandemic (March 2020 to August 2021). Sixty-nine people (82%) stated that they would definitely seek help for a serious or worsening condition, 13 people (15%) said they perhaps would seek help and 2 individuals (2%) said they would not.

Eight respondents (9%) were successful in getting help for a medical condition that had developed since March 2020.

We asked people whether or not they were made aware that there would be a delay to their care or treatment during the pandemic between the periods of March to May 2020, June to September 2020, October to December 2020, January to March 2021 and April to August 2021. Only 15 respondents (18%) stated they were made aware that there would be a delay to their care or treatment during the pandemic (between April and August 2021). The figures for the other periods were all lower.

Of those who gave more information about the considerations affecting their decision not to seek medical help (28 people), 12 individuals (43%) told us there was 'no' reason for them not seeking help, followed by:

- Access to services, including access to appointments, or negative experiences of access to services - was given as the most common reason why people did not seek help (10 people, 36%);
- Fear of Covid-19 i.e. fear of getting Covid while visiting a health setting, (4 people, 14%);
- NHS pressures and communication between NHS worker and patient (1 each, totalling 7%).

What worked well?

There were no comments that could be included in this section.

What could have worked better?

Most of the negative comments related to difficulty getting to speak to clinician, mostly GPs, but also physiotherapy and the pain clinic.

"I did seek help but failed to secure the face to face consultation I needed."

"Reluctant to contact health services due to shielding."

"I don't want to put more stress on the NHS than they were already under."

What could have been improved?

- Improving access to services via providing clarity over how best to access suitable appointments i.e. ease of booking online; signposting people to most suitable health worker such as practice nurse instead of a General Practitioner (GP).
- Offering a range of appointment options (in-person, telephone or video appointment), stating a time for the appointment and indicating the duration of telephone/video appointments for people not previously familiar with these types of appointments.
- People told us improved communication between health worker and patients, especially patients with continuing or ongoing care needs, would have improved their experience.

Comments about named services:

Midwife services: “Couldn't get hold of midwife for help had gestational diabetes and sickness.”

VitaMinds: “I referred myself to VitaMinds mental health services. Spoke to other people in same position.”

Mental Health services: “OT (occupational therapist)/care coordinator for Community Mental Health Team (CMHT) has been helpful and visited throughout. Face to face with psychological clinician organised.

“I was re-referred to and received support from SWYP (South West Yorkshire Partnership NHS Foundation Trust) mental health services due, in large part, to social isolation and a lack of familial support.”

NHS treatments or procedures further away from home

We asked whether or not people would be willing to travel further afield to receive NHS treatment sooner and 37% of respondents (31 people) said they did not want to do this; 39% of people (33 people) said they would whilst 24% of respondents (20 people) said they might be prepared to do this.

Of the people who were prepared or who might consider travelling further away from home to receive NHS treatment sooner, we received the following answers with regards to the distance these people would be prepared to travel:

Distance prepared to travel for NHS care to receive treatment sooner	Number of participants	Percentage (%) of participants
Nearest centre	67	80
Up to 5 miles	54	64
Up to 10 miles	49	52
Up to 20 miles	20	24
Up to 30 miles	17	20
Blank	17	20

Figure 1: Willingness of respondents to travel further to receive NHS treatment sooner

It should be noted that a number of respondents left this question unanswered (20%, 17 people).

We also asked respondents who were waiting for a hospital treatment or procedures whether or not they would be willing to have this in a private hospital (paid for by the NHS) if this meant they would receive treatment sooner.

Overall 68% of respondents (57 people) stated they would, 19% (16 respondents) indicated that they would consider this as an option and the remaining 13% (11 people) stated that they did not want the option of treatment/a procedure in a private hospital, as an NHS patient.

Reasons given for not wanting to travel further from home:

- The highest response was transport and problems with travelling (29 people, 35%), followed by 'no issues' (19 people, 23%).
- People told us issues impacting their support network and caring responsibilities (17 responses, 20%) would cause them problems;
- Financial difficulties (of funding further travel) were cited negatively by 8 people (10%).
- There were 11 references (13%) to disability limiting transport options.

The cost of having to get a taxi to and from an appointment further away, which would be met by the patient, was the main concern noted. Those who commented on public transport felt it was not appropriate for their own health concerns, especially if they had to travel back after a procedure.

Some respondents queried whether visitors would be able to visit them, or if their support network would be able to remain with them.

Comments:

"I have no transport without relying on family who lose money whenever they have to be used as taxis."

"The only problem would be childcare whilst I'm away, because I have young children."

"I can't travel due to family dynamics, single parent with no childcare support."

Protected characteristics:

Women had greater transport needs when compared to men (16 women compared with 4 men); and women also cited "problems with travelling" more often (7 women compared with 2 men). They were also the only gender to mention caring responsibilities.

People with a physical or mobility impairment spoke more about travelling and transport but people with other types of disabilities did not and their responses were more aligned with the general data.

Those accessing benefits spoke much more about transport and problems with travelling (14, 70%). Only 1 person accessing benefits said there would be "no" problems. We had 5 out of 6 responses noting caring responsibilities.

Remote appointments

We asked about video and telephone medical appointments and whether or not people had problems with these. The highest response by recipients was "none" with 15 comments.

There is a lack of clarity on what people meant when selecting 'none' - some people interpreted it as they do not want any appointment by video or telephone, while others said they have no problems with it.

Thereafter, people raised concerns about:

- Quality of care they got when having a health appointment via telephone and video (11 people, 15%).
- Difficulties with technology (9 people, 13%);
- Inequalities and face-to-face preferences were raised (7 people each, 10%).

Where inequalities were raised, some related to digital concerns and the inability or struggle some patients may face with video and telephone appointments, while some feel the inequalities relate to communities or people with certain conditions, such as those with learning disabilities, autism or those with hearing loss, who may be impacted the greatest.

What worked well?

Patients felt that telephone or video appointments are suitable for triage or minor ailments if medical professionals have access to notes and history.

One patient told us: “I would be ok with either. Not ideal but I can explain clearly if the practitioner has my records.”

Other patients described telephone/video appointments as “fab”, “absolutely brilliant” and said they are better for triage.

What did not work well?

Patients told us NHS staff appeared to lack empathy in telephone/video appointments; they felt information was harder to gauge and they lacked a personal touch.

Others have said they have had an unknown clinician call them instead of a known practitioner.

What could be improved?

Patients told us that giving an approximate time for the appointment, even within an hour, would be useful with one respondent saying: “I have a job and cannot speak to doctor whilst at work. Doctors need to be more user friendly and have proper appointment times for phone appointments just as if you would if you were visiting the surgery.”

One patient asked if the clinician calling would have access to previous medical records and would have familiarised themselves with a patient’s history before calling. This is something that can be clarified by improved communication between the health worker and the patient.

“Many things cannot be dealt with over these methods, e.g. with mental health many people can ‘hold it together’ on a call, but face to face the true extent of their problems are likely to emerge.”

“It is difficult when working to set whole afternoons aside for an appointment that may take place within a three-hour window.”

“Phone works but video fails as the system there using is not fit for purpose.”

Protected characteristics:

Women had greater quality of care concerns than men, and they also cited difficulties with technology as issues with appointments via video and telephone.

Those with a disability spoke much less about diagnosis and face to face appointments. They also spoke more about inequalities.

Pandemic healthcare changes

If you could change one thing about the NHS what would it be?

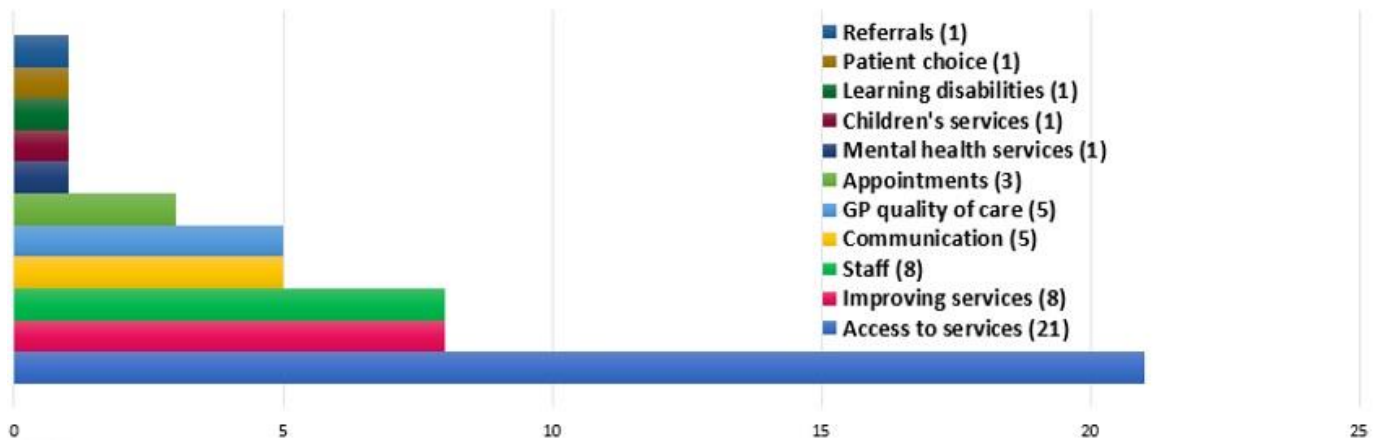


Chart shows the options suggested by people about future changes to the NHS. Data by actual number.

Comments:

Most comments relate to improving access to staff within GPs and services offered at local surgeries, including allowing patients to decide if they are comfortable with telephone/online appointments when booking the appointment.

The majority of respondents (63%, 53 people) said they did not want to keep any of the changes to their NHS and social care that had come about since Covid -19. Seventeen percent (17%, 14 people) indicated that if the choice were theirs they would be willing to keep some of these changes and 20% (17 people) said they may be happy to retain some of the changes.

Similar to most of the other questions, access to services (40%, 13 people) is one of the most talked about themes, mostly negatively. Thereafter:

- Comments about telephone appointments (31%, 10 people);
- Appointments in general (28%, 9 people).

What worked well?

A number of patients praised the **phlebotomy service**, welcoming the quicker turn around for a blood test and saying it was a more efficient service.

Another patient said their **cervical screening** appointment was quicker due to no other patients waiting.

Another patient said the **waiting rooms** were quieter, which they preferred.

One patient praised **E-consult** at their GP surgery, saying *“this is useful in getting complex information to my GP without having to rely on a third person.”*

What could have worked better?

Patients said there could be improvements in ordering prescriptions over the telephone and online.

One patient with a disability tells us they now have to visit the surgery in person to post a request in a letter box. This patient was shielding and found that an unacceptable change in service.

Protected characteristics:

Women spoke much more about not wanting to keep anything from the COVID period. They also spoke much more about telephone appointments being suitable for minor ailments and queries.

Improving health and wellbeing

What is one thing you need to improve your health and wellbeing?

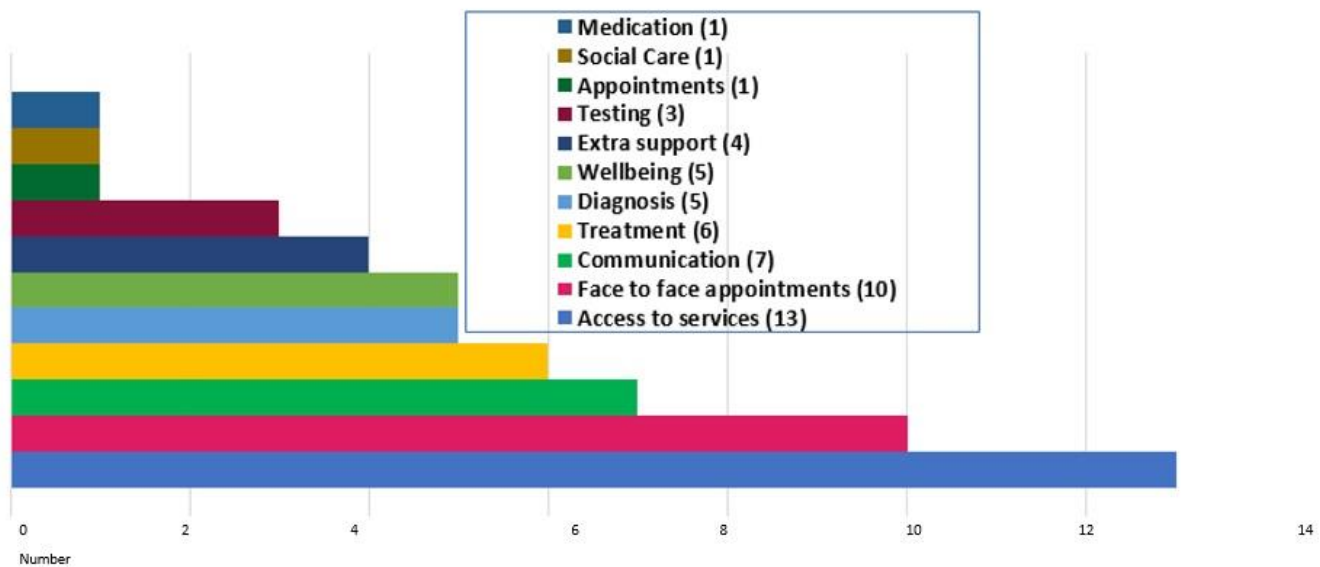


Chart shows the ideas suggested by people they say would improve their health and wellbeing. Data by actual number.

What could be improved?

Many of the comments in this section related to pain management, pain affecting health and wellbeing and impacting on sleep.

Patients told us an improved way to contact consultants; making online booking easier and allowing greater advanced bookings would have improved their experiences.

Comments about named services:

Calderdale CCG: “...Investing in psychological services and not applying a sticking plaster such as IAPT [Improved Access to Psychological Therapies] or vita minds, who cannot provide therapy other than generic CBT/EMDR [Cognitive Behaviour Therapy / Eye Movement and Desensitisation and Reprocessing] etc.”

Social care: “Wasn’t even informed that social worker number 3 was no longer dealing with case so had to wait again for another to be assigned. This is our experience over 5 years not just during the pandemic. Many people and services are using the pandemic to cover their incompetence.”

“Social services being available and not putting obstacles in the way. My brother was in respite

for 13 months before the pandemic and should have been found suitable accommodation before then. Now after 30 months he's only got out of respite care because he's in hospital. His social workers still ignoring my calls and emails, so no contact since before he was hospitalised. Disgusted with the care system in Calderdale and it needs to be put right before any other person goes through what we have had to endure."

Protected characteristics:

Those with a mental health condition and those with a physical or mobility impairment spoke much more about communication than those who just identified as having a disability or other disabilities. They both made 5 comments.

Those over 60 spoke much more about face to face appointments than those under 38.

Here are some comments about other services:

"Integrate dentists into the NHS."

"Consultants working together - across specialisms in order to treat the patient in a more holistic way."

"Better and more services for disabled people with Parkinson's. Having more than one nurse in the whole of Calderdale would be beneficial."

"More choice for patients who are pre-diabetic and type 2."

"Visiting rights for people with learning disabilities when in hospital."

Equality: headline findings

Age:

People aged 35-55 were more likely than other respondents to share experiences about delays to care if they had an existing medical condition.

Half of the respondents in this age range (who had a delay to their care) had tried to access GP services and were very dissatisfied about their care experience, this group have been supported by friends and family and peer support groups during waiting periods rather than medical professionals.

People aged over 65 years were more likely to highlight to us that they had the following existing conditions than any other demographic group:

- Diabetes
- Chronic kidney disease
- Cancer
- Cardiovascular conditions
- Respiratory conditions

The majority of this group had tried to access GP services but had also had difficulties accessing podiatry and dental services and were extremely dissatisfied with their experience. During

waiting periods people over the age of 65 were relying on telephone calls from medical professionals and from friends/family for support.

People aged 65 plus did not want to travel further than 10 miles to access treatment even if they could be seen sooner.

Gender:

Those who identified as male were more likely than those who described themselves as female to express a preference for keeping the changes to health and social care, which have taken place since Covid-19 began and they were also more willing to accept treatment in a private healthcare setting, as an NHS patient.

Disabilities:

Respondents who highlighted that they had a physical or sensory disability indicated that they would prefer to access their nearest centre rather than travel to access care sooner.

Those with autism or mental ill health indicated that they were much less willing than the general survey population to want to keep the changes to health and social care brought about by Covid-19. Those with a long term condition were more likely to say they wanted to keep these changes.

People who indicated that they had a diabetes condition were more likely to seek support from GP, A&E and hospital outpatient appointments in June - September 2020. They were somewhat dissatisfied with their experiences and had relied upon family/friends, telephone calls from medical professionals and peer to peer support during this time.

Respondents who identified that they had a cancer condition indicated that they had tried to seek medical support throughout March - May 2020 via GPs and hospital outpatient appointments. They were also somewhat dissatisfied with their experiences and had been dependent upon friends/family, telephone calls from medical professionals and peers for support during this time. All people in this group said they would be willing to have treatment in a private hospital paid for by the NHS, if they could have their treatment sooner.

Respondents who identified that they required pain management for their conditions were more likely to tell us that they would like to keep some of the changes to NHS and social care than any other cohort.

Deprivation:

Respondents who identified that they received benefits told us that they would prefer to access their closest centre for care and treatment.

Carers:

This group of respondents are more willing than the general survey population to have their NHS treatment in a private hospital if this meant they could have the treatment sooner.

Treatment for a new condition:

People who indicated that they were able to seek support for a new medical condition told us that they had been able to access the following services; GP, Podiatry, A&E, hospital inpatient and hospital outpatient appointments but were somewhat dissatisfied with their experience. A quarter of these people indicated that they had not accessed any support during this time.

Additional data

We took the opportunity to ask people how satisfied people felt overall towards their experience of NHS services during the Covid 19 pandemic and how confident people felt about managing their own health and wellbeing during this challenging time. The results are below:

Level of satisfaction people felt about their experience of NHS services during the Covid 19 pandemic



Overall people felt dissatisfied towards their experience of NHS healthcare during Covid-19.

How confident people feel about managing their own health and wellbeing during the Covid 19 pandemic



On a scale of 1-5 (1 being low and 5 being high) we found that the general survey population confidence was 3.02.

This number decreased slightly for women (2.91) and increased for men (3.29).

Conclusion

The pressure on services in the health and care sector during the Covid-19 pandemic has led to unprecedented delays to planned and routine care and treatment. A report published in January 2022 by the Health and Social Care Committee states that “tackling the wider backlog caused by the pandemic is a major and ‘unquantifiable’ challenge” (Health & Social Care Committee, Jan 2022). Plans to address the 5.8 million patients currently on a waiting list for planned procedures are once again hanging in the balance as pressure on emergency services continues.

It almost feels like the task is too huge to contemplate tackling, particularly while the system remains under such pressure. However, there are changes and improvements that could be made that would make a huge difference to the experience of people waiting for care. Our engagement highlights the physical and mental impact when care and treatment are delayed;

not knowing how long the wait will be, how best to manage pain, and how to access support can all make people feel frustrated and lost in the system.

Our engagement shows that very few people (18%) were told that there would be a delay to their care or treatment. Providing people with clear, regular updates about their care and giving information on the support available to them could help people to understand why their care is delayed, what will happen next and to have places to turn for support when needed. NHS England produced a guide to help services provide good communication to patients who are waiting for care (NHS England, May 2021) but, as our engagement shows, it is questionable whether this guidance is being implemented effectively.

Healthwatch England notes that waiting lists are inevitable, it's how we manage them that matters (Healthwatch England, Nov 2021). They emphasise again how good communication, providing more support services, and making structural changes such as “dedicated funding for discharge processes to help get people out of hospital faster and with the right recuperation support, freeing up beds for new patients” could help to make a big difference to people's experience.

One concern with how waiting lists are talked about is that people could feel like they don't want to add to the problem by seeking help with a new or worsening condition, as they may feel like this would further burden the NHS. It's reassuring to see that 82% of people we engaged with would seek help if they needed it; this actually helps to lessen the demand on NHS services in the long-run as preventative, early intervention is preferable to treating serious conditions which have been left undiagnosed and untreated. Being able to access appointments with GPs and community-based services is crucial to help people seek an assessment, care, treatment and support before things develop or worsen and our engagement highlights that access to such services has been problematic during the pandemic.

We know that delays to care and cancellations are likely to be with us for a long time so our recommendations are based around the best way to plan for this and how services could provide good quality information and support for people who are waiting for care or treatment.

Recommendations

Information and Support

Hospital Trusts	To look at how Trusts/relevant NHS providers provide patients with updates or information on expected waiting times.
Hospital Trusts	We would ask hospital Trusts to advise Healthwatch Calderdale if - and how - they follow guidance from Healthwatch England on What to expect when waiting for care Healthwatch And if - and how - they follow guidance from NHS England in their document on Good communication with patients who are waiting for care This is so we can better understand, explain to our clients and advise on improvements.
All NHS and social care providers	Signpost to suitable support groups and highlight services which accept self-referrals such as Improved Access to Psychological Therapies (IAPT) .
GPs	Improve awareness of social prescribing by utilising resources currently available, but widely not known.

Referrals

All relevant NHS providers	Consider allowing self-referral to services patients already known to such as physiotherapy, to ease the pressure on GPs.
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Appointments

All relevant NHS providers, but specifically GPs	Improve access by offering a range of appointment options (in-person, telephone or video appointment), bearing in mind the needs of those who may be digitally excluded.
GPs	Provide an explanation to people if they are being signposted to a more suitable but new / different health worker than expected (i.e. nurse rather than GP) for their needs during triage or booking process.
All relevant NHS providers	Consider giving patients a potential timeframe for telephone/video calls (within 1 hour).
All relevant NHS and social care providers	Consider needs for those who want to access services but need support to do so, such as the deaf community and people with learning disabilities, in keeping with Equality Act guidelines.

Communication

GPs	GPs websites/social media/text messaging to be utilised to keep people well informed and regularly updated.
GPs	Improved empathy with patients when making appointments/triaging so patients understand their interactions with the call handler, do not feel dismissed or blocked from seeing a doctor but instead see it as a means to get them to the most appropriate professional, which may not necessarily be a doctor.

References

Healthwatch England, September 2021 [online] “What to expect when waiting for care”. Available from: [What to expect when waiting for care | Healthwatch](#)

Health & Social Care Committee Report, January 2022 [online] “Clearing the backlog caused by the pandemic”. Available from: [Omicron and emergency care crisis could derail plans to tackle backlog, warn MPs - Committees - UK Parliament](#)

Healthwatch England, November 2021 [online]. “Waiting lists are inevitable, it’s how we manage them that matters”. Available from: [Waiting lists are inevitable. It's how we manage them that matters. | Healthwatch](#)

NHS England, May 2021 [online] “Good communication with patients waiting for care”. Available from: [Briefing template \(england.nhs.uk\)](#)

Acknowledgements

Thank you to everyone in Calderdale who contributed to this engagement and to our volunteer and Trustee, Lisa, who has helped us to check through the content.

Appendices

Appendix 1: Methodology

To gather a full understanding of the experience of delays to routine care between March 2020 and the end of August 2021, Healthwatch Calderdale used a range of different engagement approaches to collect feedback from members of the public.

The approaches used were:

Experience survey:

We developed a survey to help us understand how delays to routine care are impacting patients. The survey asked questions the topics listed below about individuals' experiences. Respondents could choose to answer questions most relevant to them/their needs and choose not to answer some questions.

The survey was widely promoted across the Calderdale area. It was publicised on social media through tailored targeted marketing campaigns. This has encouraged diverse and under-represented groups to complete the survey.

An equality monitoring form was also conducted as part of the survey. This ensured the data we gathered as representative a sample as was possible of the views from the public and identified any inequalities to access or delivery of care.

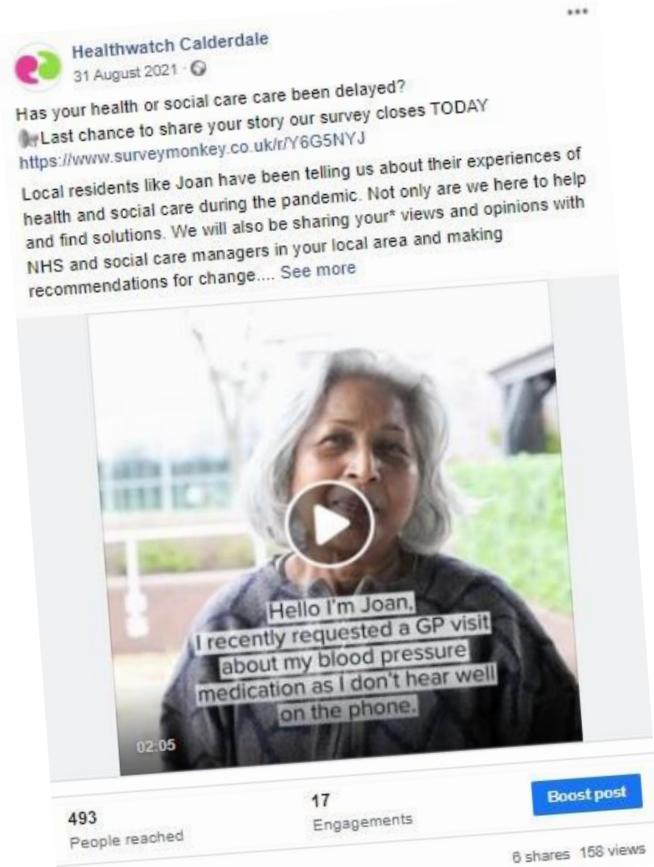
In this piece of work, we found people were not as responsive as usual in terms of completing our online survey. The Covid-19 pandemic resulted in a general surge engagement activity, whilst at the same time restricting the way in which the data could be collected and this led to a rise in survey-based engagement. We feel that this increase has contributed to 'survey fatigue' and could explain why it was more difficult than usual to collect data in this way.

Social media:

Alongside our online survey we used a mixture of social media posts to ask people specific questions from our survey. Our Social media posts for the engagement reached 961 people across Calderdale.

The mediums we used were Facebook, Instagram and Twitter. We also directly messaged community groups to share our survey and provide them with information to provide to their members. Our volunteers shared the survey with their family and friends via WhatsApp.

Image shows example of a Facebook post, which includes explanation of engagement, link to survey and video which explained our project.



Appendix 2: Survey demographics

Service users and representatives of person needing care

We had a total of 84 responses from services users and representatives of people who wanted to talk to us about the delays to routine care that they experience between March 2020 and August 2021. Of these, 59 (70%) people were service users and the remaining 25 (30%) responses were from representatives (family, carer, advocate) of people who had required NHS or social care.

The gender identity of respondents was as follows:

Gender	Number of participants	Percentage of participants
Female	50	60%
Male	14	17%
Non-binary	0	0%
Prefer not to say	1	1%
Blank	19	22%
Total	84	100%

Figure 2: Gender identity of respondents - service users and patient representatives

In terms of age range, of the 65 participants who responded to this question, they were in the following groups:

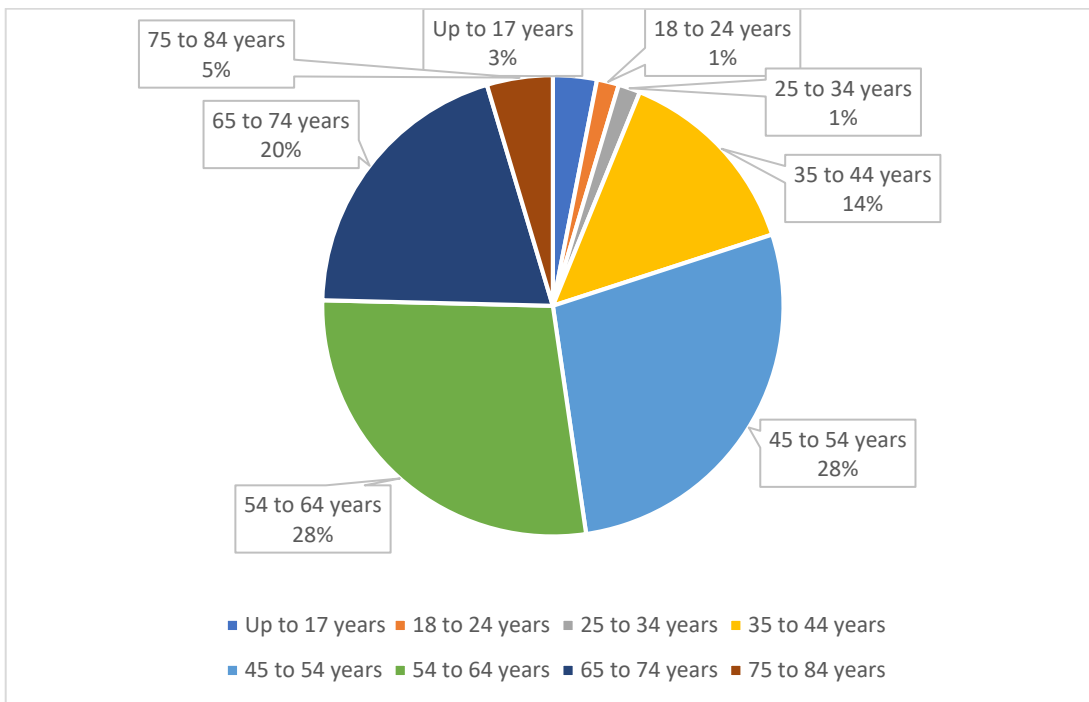


Figure 3: Ages of respondents - service users and patient representatives

Only a small number of the survey respondents (4%) were children or young people (aged up to 24).

The services to which most respondents reported a delay to their care was General Practitioner (GP) and hospital outpatients. Some respondents experienced a delay to their care across multiple services. The services at which people experienced delays to care are listed in the table below:

Service	Number of respondents who experienced delays to their care	Percentage (%) of respondents who experienced delays to their care
General practitioner	50	47%
Podiatry	8	7%
Dental	10	9%
Mental health services	6	6%
Hospital Accident and Emergency	4	4%
Hospital inpatient	3	3%
Hospital outpatient	22	21%
Home adaptations	1	0%
Home care	3	3%
Total	107	100

Figure 4: Delays to care by service

Of all respondents, 59 (70%) were white, 2 (2%) were Asian and 1 (1%) was black. 1 (1%) was of mixed or multiple ethnic groups, 1 (1%) belonged to other ethnic groups and 1 (1%) respondent preferred not to state their ethnicity. 19 (23%) did not answer this question. These figures are rounded to the nearest whole.

As far as religion was concerned, Christianity was the most frequently mentioned religion (33% of respondents). 27% of respondents stated they had no religion. Figures are rounded to the nearest whole.

Religion	Number of respondents	Percentage (%) of respondents
Christianity	28	33%
No religion	23	27%
Other	5	6%
Muslim	2	2%
Prefer not to say	5	6%
Blank	21	25%
Total (%)	84	99%

Figure 5: Respondents by religion

In terms of disability, 33% of respondents stated they considered themselves to be disabled. A number of participants had multiple disabilities. The most commonly cited disability was long term condition.

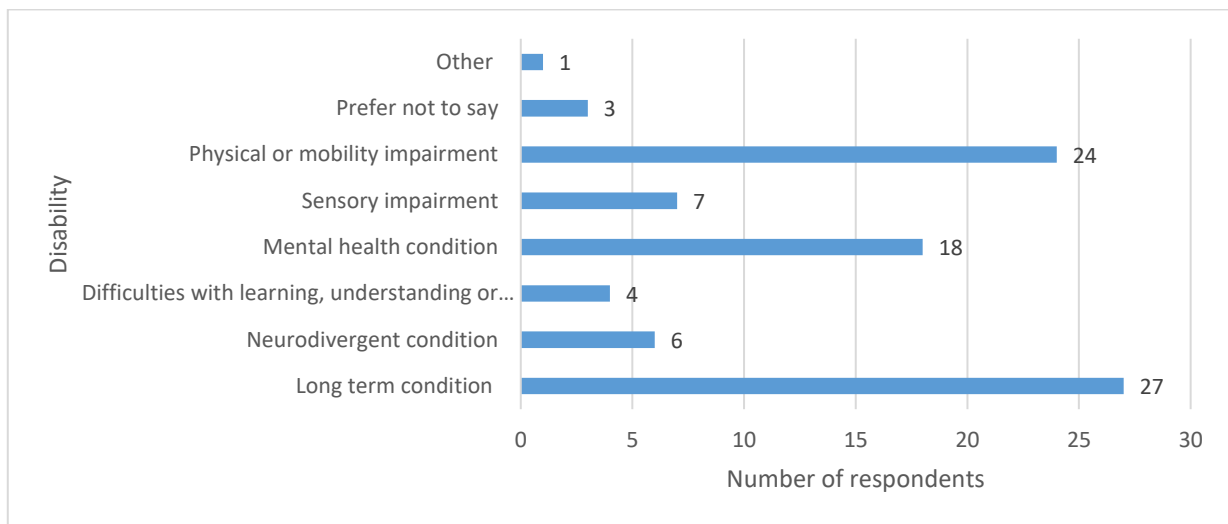


Figure 5: Number of respondents by disability

A further 7 (8%) of respondents stated that they had language and/or communication requirements.

With regard to carers, 17 (20%) of respondents stated they were carers, whilst 47 (56%) said they were not carers. Nineteen (19) people did not answer this question (23%) and one participant (0%) preferred not to say.

Carer	Number of respondent	Percentage (%) of respondents
Yes	17	20%
No	47	56%
Prefer not to say	1	0%
Blank	19	23%
Total (%)	84	100

Figure 7: Percentage of carers among respondents

Of the respondents, just one (1%) was pregnant or had given birth in the last six months.

In terms of benefits, 26 (31%) respondents stated that they were receiving one of the following types of benefits:

- Universal Credit
- Housing benefit
- Income Support
- Pension Credit Guarantee Credit Element
- Child Tax Credit
- Incapacity Benefit/Employment Support Allowance
- Free School Meals
- Working Tax Credit

Council Tax Benefit

Fifty-seven (68%) stated that they did not receive the above listed benefits and 1% of participants preferred not to answer this question. These numbers are rounded to the nearest round figure.

Appendix 3: Survey

Have you had to wait a long time to access NHS and social care services?

This survey asks you about the type of health or social care delay you have experienced, how this has impacted you, and what you'd like to see improved.

It takes around 10 minutes to complete and is completely anonymous.

Your feedback helps us to inform health and social care managers in your local area of what you need. For every piece of information shared we are able to shape NHS and social care to work better, for you and your loved ones.

Thank you

The survey will close on 30th August 2021

Section 1

The impact of Covid-19

It is important we understand how Covid-19 has changed the way we access services and how what we learn from this experience can shape a better service in the future. Please tell us a little bit about yourself and share with us your views and stories.

1. Which area do you live in?

Calderdale

Kirklees

2. Are you....?

Select your answer

3. Have you tried to access health or care services for your condition, during the Covid-19 pandemic?

4. Is there a reason you did not seek medical help for your health problems during Covid-19?

5. Would you seek help for a serious or worsening medical condition during Covid-19?

6. Please tell us what considerations affect your decision to seek help?

Section 2

Your Delay

Please tell us about the delays you've experienced, and how it's impacted you.

7. Do you have any of the following conditions (please tick all that apply)?

- Diabetes and related complications
- Chronic kidney disease
- Liver disease
- Cancer
- Pain management
- Cardiovascular disease (CVD) - also called heart and circulatory disease for example high blood pressure, stroke and vascular dementia, coronary heart disease
- Respiratory disease Chronic respiratory diseases/diseases of the airways/lungs such as chronic obstructive pulmonary disease (COPD), asthma, occupational lung diseases and pulmonary hypertension
- Planned orthopaedic surgery for example joint replacements

8. Is this a new or existing condition?

- New
- Existing
- I do not have any conditions

9. Were you successful in getting medical help or social support for this NEW condition?

- Yes
- No

10. When were you informed or when did you become aware that there would be a delay to your care or treatment? (tick all that apply)

- March - May 2020
- June - September 2020
- October - December - 2020
- January - March 2021
- April - Current 2021
- Unsure
- N/A

11. Which NHS or care services did this apply to? (tick all that apply)

- General Practitioner (GP)
- Podiatry
- Dentist
- Mental health service
- Hospital accident and emergency (A & E)
- Hospital inpatient (overnight stay)
- Hospital outpatient (hospital attendance without overnight stay)
- Residential care/ Nursing home
- Home care services
- Home adaptations

12. What impact has the delay in support for your health or social care had on you? (This could include the impact on your emotional and physical health, your family, your work, or other aspects of your life.)

13. How did you feel about your experience of NHS health care during Covid-19?

Very satisfied
 Somewhat satisfied
 Neither satisfied nor dissatisfied
 Somewhat dissatisfied
 Very dissatisfied

I felt...

14. What could have improved your NHS health care experience during Covid-19?

Section 3

Managing your care

We'd like to understand more about the ways in which people in our community have managed their care during the pandemic. Please tell us a bit more about any alternative services or approaches that have helped you through this difficult time.

15. Did you receive any of the following during the delay to your diagnosis or treatment: (please tick all that apply.)

- Support from family or friends
- Telephone calls from medical professionals
- Video calls from medical professionals
- Emails from medical professionals
- Support from a charity
- Support from community services
- Support from mental health services

Support from people in similar circumstances (peer support, support groups)

No support

16. Please tell us a bit more about the support you received.

17. What other kinds of support would have helped you during your delay to diagnosis or treatment?

18. How would you rate the confidence you have in managing your own health and wellbeing?

.

19. What is one thing you need to improve your health and wellbeing?

20. If you could change one thing about the NHS what would it be?

Section 4

Solutions for the future

As plans and decisions are made in to what the future of the NHS and social care services look like, we'd love to know your thoughts on some of the options being discussed by commissioners and decision makers. We will feed your views back to them.

21. If it was possible would you be willing to travel further afield to receive treatment sooner?

Yes

No

Maybe

22. How far would you be willing to travel for treatment?

I only wish to attend my nearest centre for treatment

Up to 5 miles

Up to 10 miles

Up to 20 miles

Up to 30 miles

Any distance

23. If you are waiting for a hospital treatment or procedure, would you be willing to have this in a private hospital (paid for by the NHS) if this meant you would receive your treatment sooner?

Yes

No

Maybe

24. Would there be any difficulties for you, if you were receiving NHS treatments or procedures further away from home?

For example, transport, possibility of visitors whilst you are in hospital etc.?

25.Video and telephone appointments will continue to be used for safety, convenience and efficiency during Covid-19. Please tell us if you have problems with video or phone appointments, and why?

26.There have been many changes to NHS and social care since Covid-19 began, are there any changes to your routine care you would like to keep?

Yes

No

Maybe

Section 5

Demographic

The following additional 10 questions are optional but they truly help us to understand our community better and shape our approach to suit you best. Your time completing this section is appreciated.

28.What is your age in years?

29.What is your ethnic group?

Select your answer

30.What is your gender identity?

Select your answer

31.What is your religion or belief?

Select your answer

32.Do you consider yourself to be disabled?

Yes

No

33.If you have any of the following conditions, please tick all that apply.

Physical or mobility impairment (such as using a wheelchair to get around and / or difficulty using your arms)

Sensory impairment (such as being blind/partially sighted or deaf/hard of hearing)

Mental health condition (such as depression or schizophrenia)

Difficulties with learning understanding, concentrating or memory (such as Down's syndrome, stroke or head injury)

Neurodivergent conditions (such as autism, ADHD, dyslexia etc.)

Long term condition (such as cancer, HIV, diabetes, chronic heart disease or epilepsy)

Prefer not to say

34.Do you have any language and/or communication requirements?

For example, do you require an interpreter? Do you have additional communication requirements due to a disability (such as autism) or illness (such as dementia or stroke)?

Yes

No

35.Are you a carer?

Carers are those who provide unpaid care for relatives or friends who are ill, frail, have a disability or who have mental health or substance misuse issues. This care could be provided 24/7, or just for a few hours a week.

Yes

No

Prefer not to say

36.Are you pregnant or have you given birth in the last six months?

Yes

No

Prefer not to say

37.Do you or anyone you live with receive any of these types of benefits?*

Universal Credit, Housing benefit, Income Support, Pension Credit - Guarantee Credit Element, Child Tax Credit, Incapacity Benefit/Employment Support Allowance, Free School Meals, Working Tax Credit, Council Tax Benefit.

*** We are asking this question to help us understand if being on a lower income affects experiences of health and care services*

Yes

No

Prefer not to say

38.Where did you hear about this survey?

Twitter

Facebook

Instagram

Newsletter

Friends and family

Kirklees Libraries