

# The waiting game

How delays to care during the Covid-19 pandemic have affected people in Kirklees

January 2022

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# **About Healthwatch Kirklees**

Healthwatch Kirklees is an independent champion for people who use health and social care services. We listen to people, especially the most vulnerable, to understand their health and care 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 in the future. We empower and inform people to get the most from their health and social care services.

# **Summary**

Since March 2020 we have had a lot of feedback from the public telling us about delays, difficulties and changes in NHS and social care services, due to the Covid-19 pandemic affecting how these services were run. Healthwatch Kirklees and Healthwatch Calderdale worked collaboratively during 2021 to collect the experiences of people living in Calderdale and Kirklees during the Covid-19 pandemic who had experienced delays to health and social care for non-Covid related conditions since March 2020.

We wanted to get a clear picture of how those delays had been impacting on people's health and wellbeing, and what kind of support they had been able to access. We asked people about the kind of support they would have liked, how effective they had found video and phone appointments, and how they would feel if they were offered NHS treatment further away from home, or at a private hospital (as an NHS patient, if that meant they would be seen sooner).

We also took the opportunity to ask whether people would seek medical help for a serious or worsening condition during the pandemic, if they could change one thing about the NHS what that would be and finally, we asked people to tell us one thing they needed to help improve their health and wellbeing.

We used a number of engagement tools to obtain the feedback in this report, including an online survey (appendix 1), social media, interviews and case studies. Our social media posts for the engagement reached 2,939 people across Kirklees; the channels we used were Facebook, Instagram and Twitter.

Alongside our online survey we used a mixture of social media posts and polls to ask people specific questions from our survey. We also directly messaged community groups to share our survey and provided them with information to provide to their members. Our volunteers shared the survey with their family and friends via WhatsApp.

The online survey collected data between June and August 2021 and in total we received 129 survey responses from service users, their families and carers in Kirklees.

# **Key themes**

A number of key themes were mentioned repeatedly throughout the survey responses and other engagement methods.

- Access to services people reported having difficulties making appointments
  to see GPs face-to-face, not receiving expected follow-up care or diagnostic
  tests in a timely manner and delays in accessing specialist services.
- Communication some people experienced a lack of communication about
  waiting times and next steps for treatment, which led to them feeling
  abandoned or overlooked. Poor communication led to missed opportunities to
  empower people to better manage their own health conditions.
- Quality of care some people highlighted the need for service improvement to support people with psychological and mental health needs, brain injuries and long-term illnesses.
- The impact of delays to care on individuals people reported severe deterioration in their physical, mental and emotional health, with high levels of anxiety and worry amongst people, even more so where people were living with mental health conditions.
- The impact of delays on family members people clearly showed that the delays don't just affect the individual needing care or treatment, but also had a 'knock on' effect to family members as well.
- The importance of support from friends and family over 55% of people reported seeking help from family and friends to help them manage everyday tasks, supporting people physically and mentally, and were there to listen and provide emotional support.
- Travelling further for care most people would travel further or be willing to
  access services at a private hospital (as an NHS patient) if this meant they
  would be seen sooner. However, people had concerns about transportation
  difficulties and caring responsibilities if they had to travel further afield.
- Social Care the key messages about social care during the Covid-19 pandemic
  were that people still needed the same level of support that they had had
  previously, and that if they were awaiting support they needed to be kept
  informed about any delays.

# Survey demographics

#### Service users and representatives of person needing care

- We had a total of 129 responses from service users and representatives of people who wanted to talk to us about the delays to routine care they experience between March 2020 and August 2021.
- Of these, 90 people were service users and the remaining 39 responses were from representatives (family, carer, advocate) of people who had required NHS or social care.

Gender	Number of participants
Female	75
Male	20
Non-binary	1
Prefer not to say	5
Blank	28
Total	129

Figure 1: Gender identity of respondents

#### Age range:

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

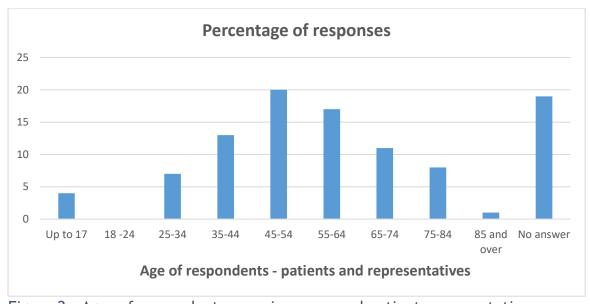


Figure 2: Ages of respondents - service users and patient representatives

### Ethnicity:

• Of all respondents, 67% were white, 7% were Asian and 1% were Black. 7% of respondents preferred not to state their ethnicity and 2% did not answer this question.

#### Religion:

Christianity was the most frequently mentioned religion (40% of respondents).
 26% of respondents stated they had no religion.

Religion	Percentage (%) of respondents
Christianity (all denominations)	40
No religion	26
Other	5
Muslim	3
Prefer not to say	2
Hinduism	2
Blank	22
Total (%)	100

Figure 3: Respondents by religion

#### Disability:

- 36% of respondents stated that they considered themselves to be disabled.
- A further 6% of respondents stated that they had language and/or communication requirements.

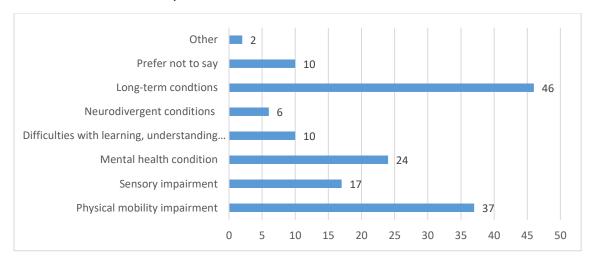


Figure 4: Respondents by disability

#### Carers:

• 23 respondents (18%) stated they were carers, whilst 78 respondents (60%) said they were not carers.

#### Pregnancy:

Zero respondents were pregnant or had given birth in the last six months.

## Benefit recipients:

- 26% of 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.
- 70% stated that they did not receive the above listed benefits and 4% of participants preferred not to answer this question.

# **Findings**

# Delays to routine care during Covid-19

At the start of the pandemic (March-May 2020), more people (22%) said that they were informed or became aware that there would be a delay to their care or treatment. Since then, smaller proportions of respondents reported being informed or aware in this regard: June to September 2020 (12%), October to December 2020 (0%), January to March 2021 (18%), April to August 2021(17%).

The service to which most respondents reported a delay to their care was hospital outpatients. Some respondents experienced a delay to their care across multiple services. Other services at which people experienced delays to care are listed in the table below:

Service	Percentage (%) of respondents who experienced delays to their care
Hospital outpatient	40
Dental	12
Hospital inpatient	10
General practitioner (GP)	8
Hospital Accident and Emergency department	8
Mental health services	7
Podiatry	5
Other	5
Home adaptations	4
Residential care/nursing home	2

Figure 5: Delays to care by service

# Life impact of routine care delay

When asked what the life impact was of the delay in support, many people stated the impacts were both physical and mental, and that they didn't just affect the individual but also had a 'knock on' effect to family members as well.

People reported severe deteriorations in their mental and emotional health, with high levels of anxiety and worry amongst people, even more so where people were living with mental health conditions.

'High level of anxiety at the length of time to diagnosis which is still ongoing'

'I am more anxious as a result of delaying going for further treatment about the issue, in case it is a symptom of cancer.'

'Made me seriously consider suicide'.

For some people the lack of regular ongoing care has led to a decline in their physical health and abilities, along with increased infections.

'Lack of regular neurophysiology appointment had an impact on my overall physical condition. Increase in number of falls and decrease in physical ability due to lockdown situation and less access to services.'

'My worsening thyroid disease with tracheal obstruction is still yet undiagnosed. The symptoms are impacting my physical health (breathing, energy, swallowing and talking'.

There was also some concern about the possible long-term effects of not having medication properly monitored and adjusted.

'My daughter has not had her thyroid medication changed in over a year, she is 3 years old she is displaying significant changes to her behaviour which are consistent with her dosage no longer being correct...I am worried about permanent/lasting damage as a result.'

One comment suggested the delay to care may have been a contributing factor to a loss of life.

'Delay in being referred maybe was a major factor in eventual fatality - patient died 1 week after being admitted to Pinderfields'

We also heard how the delays had led to reduced mobility and isolation.

'Increased pain, with deterioration in mobility and weight gain while waiting to have hospital procedure. Unable to access GP when condition worsened until unable to walk.'

Delays to routine care had also had an adverse effect on people's employment, finances, education, and family planning.

'My pain and movement is getting worse each week, it'll soon be the case I have to give up work altogether and how do I survive without a wage?'

'Dental treatment, which was abandoned part way through in March 2020, was only re-started 2 months ago. Delay and decay caused loss of a big molar and 2 crowns @ £300+ paid from our old age pensions.'

'This has made my sons mental health even worse. He was nearly permanently excluded from his mainstream school... '

'This [delay to care] has impacted me as I want to have my fibroids removed and plan for a baby as I am not getting any younger.'

# Case study - Mary's story



Mary has coeliac disease, osteoporosis and arthritis. She requires a special diet due to her health problems as she cannot eat foods that contain milk or gluten. She struggled to get essential foods at the beginning of the pandemic as she said people were buying all the milk, flour and bread that were specific to her dietary needs. As shelves became empty and food in short supply, she tried stocking up as much as possible but only has a small freezer.

Mary doesn't have transport of her own and sometimes struggles to get on the Access Bus as this is often booked up. She has to take two buses to go to the store that sells the specialist milk that is suitable for her needs.

Mary told us she would have liked access to see a specialist at a Coeliac Clinic at a hospital so they could give advice, weigh her and support her during this time "As far as I am aware there is no outpatient specialist or hospital clinic in Kirklees." She described the delays during the pandemic. "I haven't been able to see a dietician face to face or be weighed and don't know when I will be able to go back to seeing them in person, it's been phone calls only". She spoke of a lack of local dieticians and expressed concerns about her heath due to the difficulties experienced "we seem short of dieticians in this area as they seem to come and go and don't stay, when I have spoken to one they are very good and give me enough time, don't rush me but I wasn't able to see the dietician face to face for her to weigh me and I do think I have lost weight." Seeing a dietician face to face had other benefits for Mary too, as previously she was given samples of specialist food products to try that were suited to her dietary needs.

Mary is entitled to four free hours of home care support per week but felt that during lockdown it would have been really helpful if she had been given additional free hours with a carer who had access to a car and who could help with isolation, jobs around the home and shopping as friends and family were unable to visit.

# Seeking medical help from GPs and hospitals during Covid-19

Of the respondents 97% had tried to access health care services for their condition during the Covid-19 pandemic (March 2020 to August 2021), and 85% stated that they would seek help for a serious or worsening missing condition during the pandemic.

There were a number of considerations that affected people's decisions as to whether or not to seek medical help. Some people mentioned that they would be prepared to seek medical help in the pandemic if their condition deteriorated, became life-threatening, if they experienced increasing pain, developed additional symptoms, or if their health began to negatively impact their daily life. Others mentioned that they were concerned about the risk of catching Covid-19 when accessing medical care. A number of people also talked about the need to be well when caring for others.

Several people said that they didn't want to put additional pressure on the NHS, and whilst this could be seen as positive in terms of reducing the burden on the NHS, it may not have always been beneficial for the individuals concerned. Some of these people felt that overburdening NHS hospital services could be avoided where there was good access to GPs, pharmacies and community care.

'Not wanting to overload the NHS but equally our GP practice was really approachable so we felt we could still get help and like the online and phone options'

There were several positive comments with regard to seeking and receiving help for health problems during Covid-19:

- ".. Our GPs have been brilliant..." 'The district nurses have been wonderful'
- 'I was able to get audiology appointment when lockdown restrictions lifted, so now have new hearing aids.'

# **Accessing support during Covid-19**

In terms of support whilst experiencing a delay to their NHS care, most people sought access from family and friends (55.81%) or medical professionals (42% in total comprising 32% telephone contact, 2% video calls, 3% email, mental health service contact 5%).

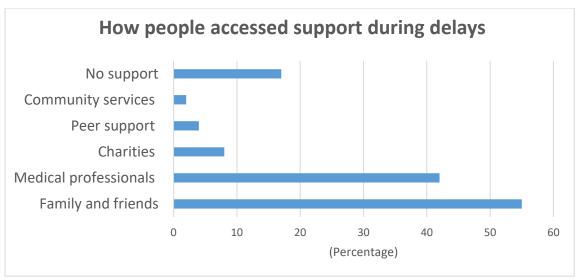


Figure 6: How people accessed support when waiting for care or treatment

Smaller proportions of respondents found support in charities (8%), peer support (4%) and community services (2%). Over 17% of respondents stated that they did not have access to any form of support whilst they waited for their NHS care. Some people accessed a range of the above listed forms of support.

In addition, people talked about the importance of communication (16%), obtaining medical appointments (7%), and access to services (6%).

Friends and family were the biggest providers of support for people who were in need of or waiting for medical care. They provided help with everyday tasks, supported people physically and mentally, and were there to listen to people and to help them talk through their issues.

'Family have had to help with everyday tasks because of delays in diagnosis and treatment'

'My friends have been a lifesaver. They've supported me physically and mentally.

There was however another side to using friends and family members for support. Respondents stated that it can be exhausting for those providing the support, and can lead to these people taking on a huge amount of work, potentially meaning that they have to make sacrifices and give up a lot of things in their own lives.

'As his wife I have been his carer, dressing, helping with personal care, and due to his lack of mobility doing all of the household tasks that would be normally shared. I've got long Covid and I'm knackered!'

'My partner does his best to support me. At times this has been difficult. He shielded with me for the first three months of the pandemic, and has had to be extremely careful and vigilant since. He finds some of it difficult due to lack of information/understanding.'

'Daughter has retired early to support with care for wife.'

Another aspect is that some people might not have family around who could help them. One person told us that their only family was overseas so, even though they had zoom calls, they wouldn't be able to get any practical help or support from them.

People talked positively about the support they gained from having phone contact with specialist nurses, Advanced Nurse Practitioners (ANP), and physiotherapists, as well as having video meetings with consultants and GPs.

'Telephone contact with ANP from GP surgery, and nurses'

'District nurses visit weekly to change catheters.'

'Phone calls from our physiotherapist to check if we were ok, if we had any issues she could help with. Letting us know that she is there if we need her (for medical needs).'

Whilst some people received reliable regular support, others report having to chase professionals to find out what was happening regarding their care.

'Emails with Secretary's in CHFT to find out what's going on with outpatients appointments.'

# **Desired support**

The key types of support that people highlighted, which would have helped them during delays to routine care were:

- Improved access to services (31%)
- Better communication (24%)
- Good quality of care (12%)

These are discussed in greater detail in the section below.

# Access to healthcare in the pandemic

Overall, people felt generally dissatisfied about their experience of NHS healthcare during the Covid-19 pandemic. Most people gave feedback about not being able to access health care when they needed medical help. Better access to health and social care services would have improved people's experience during the pandemic. In many cases this feedback referred to their GP. For some people this meant they had been unable to make medical appointments:

"...I couldn't get a GP appointment so didn't try

'My doctor's surgery was closed. Received message to say if I had Covid symptoms phone NHS number. Could not make appointment to see doctor.'

'Pharmacy help has been wonderful however GP help has been non-existent poor and unavailable '

In one case this could have contributed to a loss of life:

'Put off by GP reception. Lack of test results. Only when conditions seriously worsened did GP get involved and only by phone. Referred to hospital and kept in, death a week later!!'

For others the feedback was around the lack of face to face appointments or what was referred to as service suspension:

'Unable to get face to face appointment'

'Several of the services I use were suspended'

Some people mentioned that the lack of access to a GP may mean that they would consider attending Accident and Emergency (A&E) instead, even though they did not really want to have to resort to this option:

'GPs no longer see people you have to go to A&E for any medical support right now'

'I have various chronic health conditions and don't want to end up in A&E'

There was concern that people weren't able to access specialist support in a timely manner, and that they were having to wait too long for the results of diagnostic tests.

'GP was excellent, but having to wait 7 months for initial telephone consultation with neurologist due to limited neurology service'

"...actual follow up after scan results received. I had to call Surgery after 2 months of waiting to hear from them. Thankfully this was not a life threatening scan.

A number of responses highlighted some real challenges people had experienced when seeking medical help for themselves or a loved one. The patients involved had experienced increased pain and suffering as a result of these difficulties.

'Incontinence nurse required earlier in my condition. I was unable to urinate for 6 months before I was offered support.'

'Trying to get my husband's hip replacement escalated due to the pain, has been a battle.'

In some cases, people had used considerable personal resources to fund private healthcare.

'I have an injury, I've had to pay for private physio, which led to a private MRI scan (£400), which has confirmed an injury that needs an operation. Despite this I simply cannot get an appointment with a GP.'

'Private physiotherapist of a specific activity and private magnetic resonance imaging (MRI) scan'

Some patients felt that their needs or health conditions weren't being taken seriously enough by health professionals.

- "... someone actually caring about my concerns. Very unheard and fobbed off".
- "...to be actually seen if I felt it was necessary, I know my own body and I know if I need help."

'immediate help to start to get to the problems I still had after having had Covid in March 2020, I lost my 21-year-old daughter to this and in all honesty I felt like I had been left to die.'

# Case study - Jack's story

"He was given a big horrible diagnosis and just left to get on with it"

Jack was diagnosed with prostate cancer just before the COVID-19 pandemic. His family wanted to share his experience with us "he was given blood test results and leaflets with a list of support services and dates for groups but these were all cancelled because of the pandemic". The family spoke about their concerns with regards to communication and ongoing support. "Jack was also offered an appointment for 6 months' time but we felt this was just too far away and asked for a 3-month appointment instead", "I think the information we were given at the time about his condition was very limited and he's had very little support since". Jack has more recently had a telephone appointment with the consultant and a magnetic resonance imaging (MRI) pelvic scan but they don't know when he will get his results as there has been no follow up appointment given. They told us "communication seems lapse [sic] and limited, I have to chase things up on his behalf, I shouldn't have to, it's terrible"

The family described how Jack has been through a lot of worry and stress as he was left with a lot of questions he would like to have asked and had them answered as the weeks progressed following his diagnosis. "when you get this type of diagnosis you should be offered more support from someone who will sit down with you, talk and guide you through the stages and explain things more thoroughly" They also said they would have liked Jack to have had the opportunity to talk through his diagnosis on a one-to-one basis, ideally face to face, with a professional who had indepth knowledge of and was trained in supporting someone emotionally following a diagnosis of prostate Cancer, but this wasn't offered as an option. "I think he would have been able to deal with it better if he'd had more emotional support in the beginning from the hospital staff or being able to see someone face to face after he had been given the diagnosis but these were all cancelled." The family believes that getting no emotional support has negatively affected Jack's mental health and how he is coping with everyday matters.

The key things that people wanted to see were shorter waiting times, making it easier and quicker to get GP appointments (either face-to-face, on the phone or online whichever is preferred by the patient), out of hours access to GPs and blood tests (i.e. not simply 9am to 5pm five days a week), better access to specialist services, and less diagnosis over the phone.

'Better access to specialist doctors, not everything can be cured by GP.'

'GPs working hours, not everyone is able to get time off to see one between 9-5'

"... start a 6-day service in every area, primary and secondary healthcare."

'Hospitals need earlier blood test appointments'

'That GP's see patents rather than diagnose over the phone or as in my case leave it too late as the damage is done.'

#### Communication

Some comments about communication related to better joint working between different NHS services.

'I would like to see more communication and joint working within the different areas and services within the NHS so that treatment is more transparent and clear'

'Better communication between health professionals, GP acting on information more appropriately and timely'

A number of people commented on communication, suggesting poor communication overall and lack of information, with male respondents commenting more about wanting easier and quicker access to information provision.

People also asked for better communication around waiting times, more reassurance and advice when care is delayed, and for easier access to information in a way that patients wish to receive it.

'More transparency on wait times, process and being able to track my progress through the system'

'Ensure hospitals can treat patients referred without long delays (my GP not willing to refer me due to long waiting lists at hospitals'.

'Sending waiting list letters, if it can't be posted due to Covid send it electronically via NHS login and provide a reception telephone number for the service you have been referred to for any questions. As left having to ring various numbers by looking on NHS website etc.'

Additionally, people would have liked to be updated regularly especially with regards to dentists, GPs and consultants, with a focus on receiving updated

information relating to routine and ongoing treatment and support. This would help to make sure they did not feel abandoned or overlooked by services.

'Some indication of next steps, where else support could be accessed'

Things that might have improved these situations could have been:

'People being straight. A one stop person who could navigate the system'

'Access to where he was in the system, info on how long the delay could be, alternate treatments, better support from consultants'

One person mentioned that their consultant had explained there would be quite a long wait for the necessary surgery, but said they appreciated the consultant's honesty about it.

"...seen in February 2020 and told I needed a colonoscopy...I had it in September, and received a call from the consultant in October. He discussed the findings with me ... there was something that needs removing, it wasn't very urgent. He said he could list me for surgery and that it would be quite a wait, which I said didn't bother me. I appreciated his honesty..."

Clearer communication about whether or not GP surgeries were open, or when they would open would have been helpful, along with easier and quicker access to GP appointments, especially face-to-face consultations.

People also mentioned that improved communication between GP practices and patients would be useful, as would more accessible help for people dealing with injuries, chronic health conditions, or those awaiting operations.

'Check in calls, at least talking through treatment options instead of avoiding the subject all together'

"...communication from the hospital with a guide of waiting time for an appointment would be helpful. This would have guided me and my GP as to whether my appointment should be escalated further."

'An email address to send queries to the GP and consultant for non-urgent queries (e.g. can I book a steroid injection, my joints are flaring what can I do/take to reduce pain and swelling as current meds aren't working etc.). Much easier and more beneficial than losing an hour at a time on the phone before it cuts you off!'

With better communication in place, patients felt they would have been able to manage their own care better, and they wouldn't have had the feeling of being left in limbo unsure about the status of their care.

Healthwatch England in "What to expect when waiting for care" (September 2021), makes a number of suggestions for healthcare staff when they are contacting people who are waiting for care which could help improve communication, such as:

• Providing personalised information for patients not just generic responses

- Using clear and accessible language in all communications
- Communicating with patients in the way that they prefer
- Being transparent and open around delays and cancellations

# Quality of care

People wanted to be treated with compassion, to feel cared about, and to receive the regular, good quality care and support they needed.

'Regular support from GP practice would have been helpful instead of being told they couldn't do anything when I asked for advice'

'District nurse for leg dressings daily when needed instead of once per week'

'Stroke nurse or anyone who could explain issues. Doctors giving the impression they don't believe what I told them.'

One person gave an example where a poor quality of care had left them with a much poorer long-term outcome.

'I initially attended A&E on the day of the injury. Whilst an X-ray was done, and I was told there was no fracture, I didn't actually see a doctor. The receptionist and nurse were both abrupt and rude. The MRI scan has identified loose fragments of bone/cartilage that need removed. Why was this not identified or a referral given. I have been in pain and largely immobile for a year now, and may well be for the foreseeable future.'

The comments about staff fell broadly into two themes. The first was around a wish for professionals to be more compassionate, caring, and empathetic with improved listening skills.

'For staff working within it to have compassion and empathy, very few do, and many are judgemental, particularly concerning addiction issues.'

'That medical professionals would actually listen to us as patients. That they would have empathy and compassion... That receptionists would stop trying to stop you having an appointment and would just make one for you without them quibbling and questioning all the time.'

The second theme concerned staff being more valued and better paid.

'Staff are overworked; they need more support for their well-being...'

There were also comments suggesting an improved NHS in the future should have more specialist nurses, and for nurses to have improved training.

'More specialist nurses for long term/incurable illnesses'

'Better treatment of staff, to improve retention of staff and encourage people to train.'

# Service improvement

Responses showed that people wanted more investment and support for psychological and mental health, for people with brain injuries, and for those with long-term illnesses.

"...Psychological health to be treated to the same standard as physical health."

'Put money into children's mental health. It's well known that Child and Adolescent Mental Health Services (CAMHS) is not fit for purpose.'

'More support for brain injury persons' 'Prioritise the long term ill...'

There was the suggestion that patients could be taught how to help themselves instead of having to rely on doctors or physiotherapists.

'Teaching patients how to help themselves instead of relying on seeing a doctor monthly for physio.'

There were also a number of comments about stopping the privatisation of services.

'Stop further privatisation of the NHS and the constant reorganisation!! Stop handing services over to private companies and give adequate funding to the NHS so that they can recruit all the medical staff they need.'

# NHS treatments or procedures further away from home

When asked whether or not they would be willing to travel further afield to receive NHS treatment sooner, 29% of respondents said they did not want to do this, 51% of people said they would, whilst 20% of respondents said they might be prepared to do this.

Of the people who were prepared to 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	Percentage (%) of participants
Nearest centre	86
Up to 5 miles	66
Up 10 miles	52
Up to 20 miles	37
Up to 30 miles	25
Blank/no response given	14

Figure 7: Willingness of respondents to travel further to receive NHS treatment sooner

Many respondents had no specific concerns or difficulties with receiving treatment or procedures further from their home.

'As long as I was getting the help I needed I would be okay'

'I would overcome any administrative difficulties to get my ankle fixed'.

But the effect on some people's health and wellbeing, and the length of time spent apart from family support were factors that could have a negative impact. Some people commented on possible difficulties with isolation, especially when friends and family might not be able to visit due to the extra distance to travel.

'Difficulties would be isolation, not having any friends or family visiting'

'It would be more challenging for my family to visit which would be an important part of, not only my recovery, but also their mental wellbeing.'

'No visitors, most of my family and friend do not drive. it took a friend a 2 hours' journey, each way, on public transport to visit her mum in Halifax hospital from where she lived in Huddersfield and that was before Covid'

A significant number of people also highlighted transport in their response, citing a variety of concerns such as finances, logistics with some people living in more rural settings, inability to drive and reliance on public transport.

- "...please do not send me somewhere miles away that is inaccessible by bus."
- 'I do not have transport and I am on benefits I can't afford taxis'
- 'I have no car, disabled, can't walk far and have no money. I need treatment HERE'

Others suggested that with no practical support, having health issues or a disability would also make it difficult and uncomfortable to travel longer distances. Some people felt very strongly that they should be seen locally.

'Neither my husband or myself are very well at present. Travelling is difficult. If and when his chemo etc. finishes he will be the fittest and he is the driver. Then I would be able to receive treatment further away'.

'Mobility and pain make travelling by public transport troublesome'

'I would refuse to be treated further away from home.'

We also asked respondents who were waiting for a hospital treatment or procedure 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 your treatment sooner. 91% of respondents stated they would, 6% indicated that they would consider this as an option and the remaining 3% stated that they did not want the option of treatment/a procedure in a private hospital, paid for by the NHS.

# Remote technology: electronic, video and telephone consultations

When asked whether or not people would experience barriers to video and telephone appointments, some people stated they would not, and indeed some welcomed telephone and video appointments finding them useful and an alternative way for them to gain access to help and support.

- 'Video conference meetings and phone calls. Very good in fact think my daughter preferred this method of contact.'
- "... I have had telephone consultation with doctors during Covid and I think it is great whilst you are on the phone to them, they can send a link to you so you can upload 5 images of your health condition and send it".

Others suggested that these methods of having an appointment were only appropriate in certain situations only, for example when obtaining blood test results or for general routine appointments.

Seven people raised their concerns questioning how appropriate it is to diagnose patients over the phone or video, and the effect of not receiving a physical examination was also highlighted.

'If only I could have seen my doctor, how can you explain a lump and pain over the phone?'

'I had problems that needed to be seen, not described over the phone and not possible to show on video call'

Twenty-two people told us how the use of remote technology was affecting the quality of care they received. They described feelings of not being listened too, rushed on the call, and feeling confused, and shared concerns about the lack of availability of someone to monitor changes to their health and wellbeing.

Some people felt telephone appointments were not always a suitable alternative to being seen in person, and a number of other issues regarding telephone and video appointments were also flagged up, including system and information technology issues, poor reception, call and picture quality issues, or the lack of equipment capable of receiving video calls.

'It is not always clear what the doctor/Health adviser has said'

'Sometimes the connection isn't good, it breaks up. Any pictures you may send might not be clear and might not show the problem clearly '.

'I don't have a phone capable of video calls'

"...sending photos to GPs via their systems was confusing

Some patients didn't feel comfortable with, or didn't trust the use of digital technology for medical appointments, and this covered all ages. Therefore, it cannot automatically be assumed that all young people have access and are happy to use remote technology.

'Don't like appearing on camera'

The use of auditory information only in telephone calls can result in communication problems, notably miscommunication, and some people experience problems with processing auditory information, so they can find it difficult to make sense of spoken information alone.

'They make me feel rushed. I struggle to take the information in when it's not face to face. Also, I don't ask as many questions because my head isn't in the same place as if I had travelled to the appointment and was there in the appointment room'.

'I don't feel info on the phone is always understood by either participant. Things can be missed, especially visual clues to underlying health issue'

A lack of visual prompts in remote consultations could lead to what one person felt was possible 'guesswork'.

'Diagnosis for children seemed like they were guessing the illness'

'Phone calls weren't enough. You felt GPs were guessing at your condition.'

Confidentiality issues were also an issue for some people.

'lack of confidentiality as no private space to make the call/chat.'

Cancellations were mentioned as a problem, as sometimes planned remote appointments did not always go ahead.

'Video and Telephone appointments are not always convenient as I work and an actual time the GP will call cannot be confirmed like an actual face to face appointment and on a couple of occasions I haven't had a call back at all!'

'Often cancelled on the day or at last minute'

Also, some people felt that remote appointments were simply not suitable for certain situations:

'A GP can't listen to my heart or lungs over the Internet only a face to face can do this effectively.'

Some respondents preferred face to face appointments, with some suggesting that this should be offered when it was their preferred option.

'Telephone consultation doesn't give the same solution as in person conversation with a doctor.'

'They are not age appropriate for children; children need to be seen in person'.

'The only problem with telephone appointments is that you can't be seen. A video call is better than that, but still nowhere near as good as face to face.'

Others stated that telephone appointments were not helpful, and that they were based more on GPs rather than patients' needs, and may lead to inappropriate treatments.

'I've never met my specialist nurse in person, I feel as though this is contributing to my treatments not being appropriate and pains being misdiagnosed'

'Sometimes telephone appointments are useful but should be according to patient need not GP need'

Being unable to access a face-to-face appointment left some people with concerns about the length, accuracy and quality of their appointment. Other people raised concerns about only being able to discuss one issue via phone and e-consultations\*, and that remote appointments may not be effective for undiagnosed conditions.

'Phone appointments have been helpful somewhat but I have also required to be seen physically which then takes up 2 appointment times - one for the phone consultation and one for the in-person consultation. '

'They rely on e-consult which only works for one issue and not multiple or undiagnosed conditions'.

'Not always the best for diagnosis, a lot of conditions need face to face appointments'

(\*eConsult is the first online consultation service to be integrated with the NHS App. It makes form-based remote consultations available at around a quarter of practices in England. Patients can use this forms-based service to request GP advice without the need to book an appointment or contact their practice face-to-face or by telephone: <a href="https://econsult.net/nhs-patients/how-to-use-econsult">https://econsult.net/nhs-patients/how-to-use-econsult</a>)

### What could make things better?

People felt a video appointment was better than a telephone call as the patient was able to see the medical professional and vice versa; however not everyone was offered this as an option. Although telephone consultations were offered to the majority of people who responded, the option of a video appointment was not readily available to all, as some GP practices were not offering this service. Had this been an option some people may not have had to go on and access further help and support, as they could have had a more effective consultation in the first place.

'I have not been able to access video appointments due to my surgery not offering them'

'Less hesitancy for Face-to-face and better video appointment access, as this could've been beneficial if offered'

An improvement to the system would be for organisations to offer both telephone and video calls as remote options and also ensuring people have the option of a face to face consultation.

'Having no face to face appointments available despite describing the problem to the receptionist is appalling. Not being able to book non-urgent

appointments is difficult for routine checks, it's awful having to ring daily to secure a telephone appointment to ask the Dr to please see you in person'

# Pandemic health care changes

A majority of respondents said they did not want to keep any of the changes to their NHS and social care that had come about since the Covid -19 pandemic.

Some highlighted the difficulties they had faced, suggesting they had seen no improvements, and had had little or no help when trying to access services or get appointments to see someone in person. Some felt they had experienced a decline in the quality of care they received, and others felt that remote consultations were not always effective and could lead to misdiagnosis.

- '1 hour and 40 minutes one time ringing doctors. Very bad for poorly people'
- 'I don't see any changes that benefit children's mental health'
- 'They misdiagnosed as well as missed vital presentations on parts of my body more than three or four times by not using video or in person appointments.'

There were some positive comments as well, as some people highlighted that despite a difficult situation they had been able to seek some support, with several commenting on how useful telephone consultations were for them, particularly when it was a routine enquiry or for obtaining results. Many wanted this to continue, but there was also significant emphasis placed on being able to see a GP in person if that was a preferred option.

- 'I think the telephone service by doctors and submitting your photos of health condition is great and think it should continue'
- 'My remote reviews for my pacemaker from Calderdale cardiology have been excellent, they are a phenomenal team'
- 'The testing's i.e. scans and bloods etc. need to be in hospital but for some appointments to discuss details if things are good ok by phone if more detail and discussion needed face to face'.

When asked 'if you could change one thing about the NHS what would it be?' the most common answers were improvements in access to services, improving quality of care, and communication.

# Improving health and wellbeing

When asked what the one thing was that people needed in order to improve their health and wellbeing, the overarching theme was access to services, with the majority of people requesting additional support particularly for people with ongoing health and wellbeing needs.

They described a need for a better service from their GP with access to regular help and support put in place within a reasonable timescale.

- 'Being able to see a medical professional in a timely manner'
- 'Timely diagnosis and treatment'
- 'More support with managing the condition.'
- 'Regular contact from a healthcare professional or social worker to see if I'm coping'

Some people spoke of wanting improved access to support regarding their mental health, whilst others suggested that doctors should be more proactive in terms of suggesting tests, getting tests results, and helping patients to obtaining diagnoses.

- 'A diagnosis so that I actually know what my condition is, instead of having to second guess and rely on painkillers!!'
- 'I need tests for my conditions. Tests they never do. I beg for years, they do them, they come back positive and I yet again diagnose myself. 10 conditions all diagnosed by myself first, years before the doctor!!'

We asked respondents how they rated their confidence in managing their own health and wellbeing. On a scale of 1-5 (with 1 being low and 5 being high) we found that the general survey population confidence was 3.15. This number rose slightly for women (3.25) and decreased for men (2.83).

# Protected groups and equalities

The responses from people with protected characteristics were similar to those of the general population, with many comments focusing on access to services, health and well-being, and safety concerns, but there were a number of specific responses that highlight equality-related issues.

### Issues affecting people with disabilities and long term health conditions

People with disabilities made more comments about continuity and quality of care, and communication was very important to those with long-term health conditions. Also, a lack of adequate communication and support by health professionals when waiting for urgent surgery was referred to:

- 'The continuation for priority health care. Everyone was put to one side regardless of their diagnosis or prognosis'.
- 'The need for urgent surgery. Initially told 6/10 week wait. Still waiting at 16 weeks. Contacted departments who all have different answers, examples were; your consultant is going on holiday for a month, she doesn't even have a list. Try going to A&E it'll be quicker. You could try privately.'

The need for ongoing support and difficulties accessing health services, professionals and additional condition specific support for their health and

wellbeing was also highlighted. This would suggest there is a need for a more 'tailor made approach' to monitor people's health and well-being needs, and that of the people they care for.

'I used to feel more confident about managing my health and wellbeing, and due to Covid and the factors I have described I have lost quite a bit of confidence in how to maintain my wellbeing in relation to the lung disease'

'Reliable continued monitoring of my heart and lung conditions, monitoring how my medication is or is not working'.

'Support in assisting my disabled children'.

Responses also highlighted the importance of having a range of support, both online and from peer support groups, and people who were accessing benefits make more comments about struggling to get support from charities.

'Brain injury support group. Platform 1 charity mental health support counselling'

'Also support from my WhatsApp Meditation group'

'The best support has been from my online support group.'

'Alzheimer's organisation could have kept in touch.'

'Admiral nurse could have given support.'

'More support from non-profit voluntary organisation'

### Issues affecting different age groups

Adults over 60 had a stronger preference for seeing a GP for a face to face consultation, while younger people particularly those under the age of 25 years expressed a greater preference for retaining telephone and digital consultations.

'I find it easier talking face to face with people and then they can also see how my ability to walk has changed and is affecting me'

'Being able to see a Doctor face to face as some things can't be seen clearly. Being asked to take a photo of a possible cancer in a place that is hard to reach is ludicrous. Especially when asked can no one else take the photo for you, I live on my own, so no'.

'Video-conferencing. Autistic daughter seems to engage more and prefer this.'

'My GP surgery uses e-consults and I'm always happy to have a phone call rather than a face to face appointment. I am confident that if it was necessary, I'd be invited in for a face to face assessment. Getting documents electronically has been really helpful, such as sick notes and pathology request forms.'

People over 60 also spoke about issues with quality of care and waiting times.

'Neurology have offered and then cancelled 5 face to face visits despite involving PALS at Huddersfield Royal Infirmary'

'Informing as to why my appointment keeps getting cancelled, I've not been told once why it has needed to be rearranged so many times.'

#### Issues affecting minority ethnic groups

A couple of ethnic minority community members highlighted specific health conditions when raising safety concerns.

'My child is immunosuppressive'

'TIA, angina, lbbb (left bundle branch block - cardiac), thromboembolism, heart failure (cost £4,000 to date for private treatment).'

There were also some comments from British Indians that highlighted possible language issues.

'Better communication with me about the end to end process and what is happening along the way. I have no idea who has said what and what next.'

### Issues affecting unpaid carers

There were a number of responses from carers highlighting health and well-being issues, as they had to look after their own health and well-being as well as dealing with the conditions of people they care for.

One carer of a vulnerable person didn't want to go to hospital because of fear of Covid, as they feared that they could pass the virus on to the person they care for.

'I do not feel comfortable yet going to hospital due to the risks associated with any treatment and catching Covid or a variant strain that are highly transmittable at the moment as I am a carer for vulnerable person'

# Issues affecting more than one protected group:

#### Digital technology, video and phone appointments

The majority of comments came from people with disabilities or long term health conditions, including some from minority ethnic groups, suggesting that there are additional complications for people who do not have English as their first language.

'I suffer from a severe anxiety disorder. Video calls are not possible'

'Hard of hearing so difficult to hear properly on the phone and video'

'Not fit for me (mentally, emotionally, physically)'

'Sometimes limited English makes conversations difficult'

Finance and age were also factors for some people, with a significant number over the age of 60 having issues with understanding, accessing and using appropriate technology. 8 people highlighted difficulties with digital technology and 11 people with digital access.

'Trying to get an appointment by phoning the surgery is a big problem because it uses up credit'.

'It is difficult to get your point across via telephone I do not have technology'

### Travelling further for NHS care

People with a long term health conditions and disabilities, and unpaid carers expressed difficulties with this.

There were also a higher proportion of comments from women who would find it difficult to travel further afield due to their caring responsibilities, with respondents under 25 speaking more of caring responsibilities than those over 60.

'Care of wife. She is unable to function without 24 support'

'Yes, my daughter is autistic and would require me to take her and be with her. If its further away it might require more planning to ensure this could happen.'

'Commitment and responsibilities for the rest of the family e.g. other siblings, young children'.

'With me having children at schools it would then have to be in school hours as well'

#### Feedback about Social Care

Although we asked about both health and social care, most people gave us feedback on healthcare and there was very little feedback about social care.

There were a few mentions of people getting support from charities and social services:

'The Royal Voluntary Service (RVS) helped us, family, friends and neighbours brought us food and essentials to the doorstep.'

'Forget Me Not delivered some toys and food for the children'

'Disabled children social care team support'

'I was contacted by Navigation to Care who helped me as well'

Several people wanted services to go back to how they were pre-pandemic, as while they felt that the services had not been ideal then, they were preferred to those currently being delivered.

'Although lots of activities have taken place at my home to keep me entertained. I still wish to return to my usual day services and see my friends'.

There were also some comments from people who needed better ongoing support from social care, such as continued home help support, and progress updates for people who were waiting to have home adaptations.

'To not have our home help pulled.'

'Affected our whole family as I have 3 neurodivergent children and all home help was pulled, we are still on waiting lists for support and have heard nothing...'

'Kirklees Council agreed to do adaptations Oct 2020, but we're still waiting for a plan 9 months after applying.'

'Regular contact from accessible homes team to tell me what's happening and how long it will be for work to commence.'

# 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, 'Clearing the backlog caused by the pandemic', 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" 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.

While the task feels nearly impossible there are some changes and improvements that could be made that would make a huge difference to the experience of people waiting for care. Our engagement has flagged up some of the current barriers for people seeking medical help, outlines the kind of support they have received or would like to have received during delays, and explains the impact that delays to support have had on them.

We have also received feedback on people's experiences of having remote appointments and consultations, and on particular difficulties that people might have if they were asked to receive NHS treatment further away from home. Both of these issues have specific implications for people with protected characteristics.

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.

A 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 important that people are encouraged to seek help if they need it, as this 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	We would ask hospital Trusts to advise Healthwatch Kirklees 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
GP practices	Provide improved information and support for people dealing with injuries, long term health conditions, disabilities or those awaiting operations, by promoting self-referral to services such as Connect Health for physiotherapy / pain management, Improve Access to Psychological Therapies (IAPT) and Kirklees Wellness Service.
	Ensure those waiting for care and treatment are given opportunity to speak to a social prescriber who can provide information and signposting to a range of support available in the community.

# **Appointments**

GP practices	Improve access to GP practices by offering more
	flexibility with appointments, offering face to face,
	telephone and video consultations to suit the needs

	and preferences of patients, allowing extended or additional appointments when more than one issue needs to be discussed, and prioritising face to face communication for people who are digitally excluded.
All health service providers	Give patients a timeframe for telephone/video calls (within 1 hour) so that they can be available and in a space where they can talk confidentially, refer to notes, or make a recording of the discussion if they wish to. Allow time for patients to ask questions, and offer to provide a brief written note of any important points, such as referrals being made, changes to medication etc.

# Communication

	1
Social care	People expect to get the same level of support that they had before the pandemic. If this is not possible then services need to make sure that they keep people properly informed about any changes or delays to services, explain the reasons for changes or delays and, if possible, when they can expect the support to be delivered. They should do this using the service users preferred form(s) of communication, and also give them the details of a named person they can contact if they need more information
GP practices	GP practice websites need to be kept up to date with information about what services are available, and how and when people can access services.  Social media and text messaging can also be used to keep people well informed and regularly updated.
GP practices	When making appointments or triaging patients, call handlers should treat patients with empathy and compassion so that they don't feel their concerns are being dismissed, or that they are being blocked from seeing a doctor. Explain clearly if it is more appropriate for them to see a different medical professional.
All health and social care providers	Make communication more effective by ensuring that all contact details are up to date in people's records, and recording whether they have any specific communication needs or preferences, such as requiring language support if English is not their

first language, or preferring to receive information
in writing so they have time to process it. This
should be flagged up in their records so that all
staff are made aware of it, and staff should know
how to cater for these communication needs so that
there are no barriers to accessing services.

# References

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# Acknowledgements

Thank you to everyone in Kirklees who contributed to this engagement. We'd also like to thank our wonderful volunteers who shared and contributed to this piece of work.

# **Appendix: 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

pulmonary disease (COPD), astrima, occupational lung diseases and pulmonary hypertension
Planned orthopaedic surgery for example joint replacements
8.Is this a new or existing condition?
New
Exisitng
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?

VerySomewhatNeither satisfied norSomewhatVerysatisfiedsatisfieddissatisfieddissatisfied

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)?
For example, do you require an interpreter? Do you have additional communication requirements due to a
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)?
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
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
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
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.
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
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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?
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

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

Tay Renefit

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

Yes

Prefer not to say

38.Where did you hear about this survey?
Twitter
Facebook
Instagram
No. contests on
Newsletter
Friends and family