



Elective Care Recovery - Mood of the Public

July 2021

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About Healthwatch and Healthwatch Together (HWT)

Healthwatch was established in April 2013 as part of the implementation of the Health and Social Care Act 2012.

Healthwatch England acts as the national consumer champion for all local Healthwatch organisations, enabling and supporting individual Healthwatch to bring important issues to the attention of decisions makers nationally.

A key role of each individual Healthwatch is to champion the views of people who use health and care services in their area, seeking to ensure that people's experiences inform the improvement of services. Healthwatch is constantly listening, recording, and reporting on the views of local people on a wide range of health and care issues, ensuring that people are able to express their views and have a voice in improving their local health and care services.

Healthwatch Together (HWT) consists of Healthwatch Cumbria, Healthwatch Lancashire, Healthwatch Blackpool and Healthwatch Blackburn with Darwen, working in collaboration together. It operates over the whole footprint of the Lancashire and South Cumbria Health and Care Partnership.

INTRODUCTION

During the Coronavirus pandemic and subsequent lockdown that began in March 2020, many routine and elective surgeries and procedures were postponed in England. As a result, there are a backlog of patients waiting for appointments.

The Lancashire and South Cumbria Integrated Health and Care Partnership found that many patients, when contacted and offered an appointment or consultation, were reluctant to attend the hospital. However, the findings from the series of HWT reports on people's experience of the pandemic, suggests that there may have been some changes to how people feel now, as opposed to earlier in the pandemic. It was decided that it would be beneficial to get a better understanding of this as part of the modelling process so that attitudes towards changes of situations and circumstances can be addressed, to help patient flow and outcomes.

The In-Hospital Cell is currently shaping and modelling recovery taking account of the requirements for delivering services in line with COVID-19 guidance and by using the Clinical Prioritisation process, but it has been agreed that more insight is needed to better understand the "mood" of the public to be ready to respond to invitations to come in for elective care.

Specifically, the Elective Care Recovery Group (ECRG) is focused on getting people on waiting lists into hospital for agreed procedures and operations, and on how to deal with growing numbers of people arriving on the waiting lists due to delayed identification of need and continued capacity restrictions.

For those who had been on a list for elective care prior to the pandemic, the experience of this may have impacted them in a variety of ways which could in turn impact on the planning and modelling process. It is known that in recent months to bring people into hospital have involved up to eight phone calls to identify one patient who was willing to come in for their operation. Greater understanding of the factors likely to be involved will help to shape thinking, planning and efficiency.

The conclusions of the survey will provide intelligence to:

1. Inform the modelling and Clinical Prioritisation processes.
2. Inform communication and engagement activity to help address fears and anxieties.
3. Inform the booking process to shape reassurance and support activity.
4. Inform pre and post operation community-based support system.
5. Improve patient flow and outcomes.

METHODOLOGY

Research Design

The survey was designed to help gain an understanding of how acceptable a change in a healthcare situation would be if it meant a reduction in waiting time and gather the general mood that the public has towards the waiting list situation based on personal experience. To do this, the survey was split into two distinct sections, the first part was scenario questions, and the second part was a short questionnaire.

The scenario section was made up of 5 hypothetical situations that consist of a change in the process and respondents had to state if they would find such changes acceptable. If changes were not acceptable, respondents were asked if anything would help them accommodate the change. The hypothetical situations consisted of a change of:

- Hospital
- Doctor
- Private hospital
- Doctor and hospital
- Doctor and to a private hospital

The survey questions section is a compilation of 19 questions, to gauge the attitudes and opinions of the general public based on their own personal experiences of being involved in the waiting list situation. Questions were asked about what would prevent respondents from having an appointment, what the reasonable amount of time to travel for treatment would be, and questions which provided the opportunity for respondents to share their worries about their situation. Additionally, in the survey, there was an option for respondents to leave contact details to be interviewed by Healthwatch regarding their experience as a case study.

The full set of questions that were asked in the survey can be found in appendix A.

Survey Participants

In total, there were 65 respondents to this project's survey.

This project aimed to get patients living in the Lancashire and South Cumbria area who are either waiting for, or who have recently had an appointment or consultation for elective surgery, as well as members of the general public from the area.

Participants were obtained through the Lancashire and South Cumbria Health and Care Partnership sharing the survey with five trusts, these trusts were:

- Blackpool Teaching Hospitals NHS Foundation Trust
- East Lancashire Hospitals NHS Trust
- Lancashire Teaching Hospitals NHS Foundation Trust
- University Hospitals of Morecambe Bay NHS Foundation Trust
- Lancashire and South Cumbria NHS Foundation Trust

Data Collection

The 'Mood of the Public' survey went live on the 29th March 2021 and ran until the 21st May 2021.

The Lancashire and South Cumbria Health and Care Partnership shared the survey with five trusts, by using a letter from Healthwatch which invited people to respond. Each trust randomly selected 200 patients from their own waiting lists to send letters too, and thus a total of 1000 letters were sent out. There was then a reminder letter sent out midway through the response period to recirculate the link to further encourage potential participants from the waiting lists to respond.

The Lancashire and South Cumbria Health and Care Partnership also promoted the survey through using their networks and social media. Healthwatch Together further promoted the survey with the wider public by posting the link on their websites and social media sites.

Case study participants

In the survey, there was an option for respondents to leave contact details to be interviewed by Healthwatch regarding their experience as a case study. 18 respondents left their contact details as part of their survey response.

These 18 respondents were contacted with the intention to organise a time to do a case study. 4 of the 18 respondents agreed to do a case study. 2 further individuals agreed to take part in a case study, they were identified to fit the criteria to take part in the project. Therefore, in total there were 6 case studies completed.

These case studies were done throughout June 2021 and the start of July 2021.

Response rate

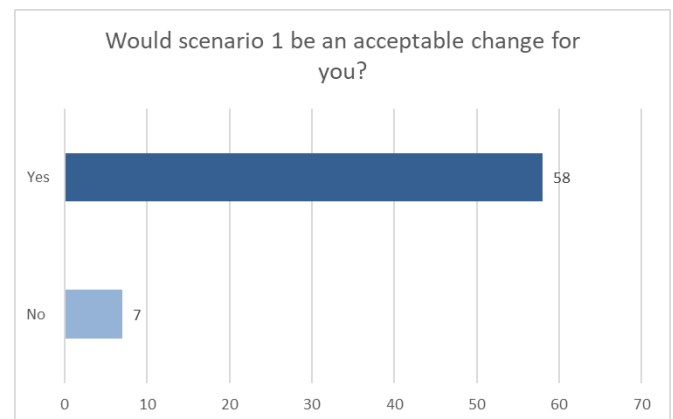
The response to this project survey was low. The anticipated number of responses was much higher than the total number that were received. There has been evidence throughout the Covid pandemic of survey fatigue, with both Healthwatch and other organisations noticing a decline in survey responses as a general trend. However, despite the low response rate the responses gained have been useful in terms of a having a good geographical representation as well as providing good quality information.

SECTION 1: SCENARIO QUESTIONS

Scenario 1 - Change of hospital

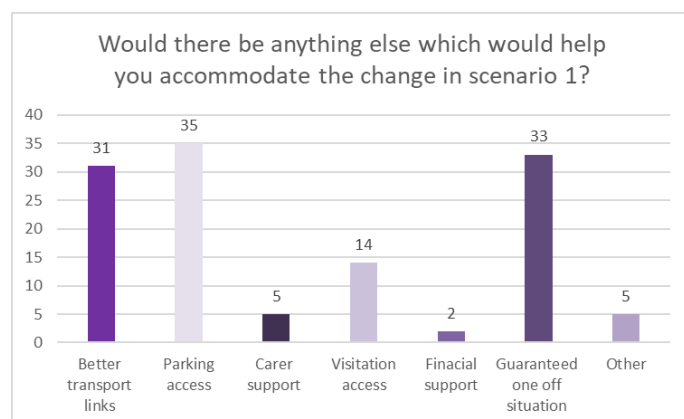
Scenario: Mariam has been waiting for an operation on her knee; she usually sees a consultant, Dr Ferreira, at Burnley General Hospital. She receives a call from Jane, who is an NHS worker. Jane tells Mariam that she can choose between staying on the waiting list for another four months to have her operation with Dr Ferreira at Burnley General, or she can have the operation with Dr Ferreira at Royal Preston Hospital in three weeks.

In the scenario being described the patient is being offered the opportunity to go to a different hospital with the same doctor for their operation, in return for less time on the waiting list. **89% of survey respondents deemed this alteration acceptable**, suggesting that the majority would agree to a change in hospital if it meant a reduction in waiting time, if this were a situation that was offered to them.



The survey respondents were asked if they would agree to this change, what would help the individual in adjusting to this new situation. A short list of suggestions was given as well as the opportunity to state anything else that would help accommodate a change of hospital, the respondents were told to tick all that applied to them. The top three were:

1. 61% parking access
2. 58% guaranteed one off situation (meaning that they would not have to do the same for any follow up appointments)
3. 54% better transport links (the ease of getting there and back)



Other suggestions made by the respondents included:

- Being given at least 3 days' notice prior to the change so that they would be able to put sufficient plans in place.

However, 11% of the survey respondents stated that they would find this suggested change unacceptable. When asked why they would not agree to this change, the majority of responses stated that the change in hospital would result in them having travel issues.

“I live on my own and might have trouble getting there and back.”

“If the travel was paid for and arrange then yes but if not, no. Would be more cost on travelling.”

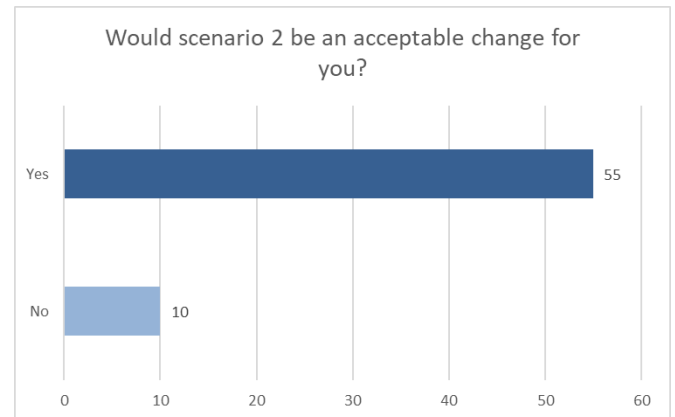
“Too far to travel.”

“I want my care close to home.”

Scenario 2 - Change of doctor

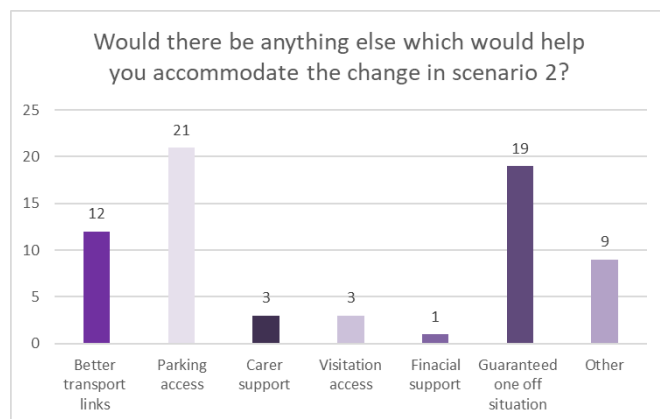
Scenario: Martin has been waiting for a procedure on his sinuses for six months; he usually sees a consultant, Dr Abbas, at Royal Preston Hospital. He receives a call from Jane, who is an NHS worker. Jane tells Martin that he can have an appointment to see a different consultant at Royal Preston Hospital next week, or wait another three months to see Dr Abbas.

In the scenario being described the patient is being offered the opportunity to go to see a different doctor at the same hospital for their procedure, in return for less time on the waiting list. **85% of survey respondents deemed this alteration acceptable**, suggesting that the majority would agree to a change of doctor if it meant a reduction in waiting time, if this were a situation that was offered to them.



The survey respondents were asked if they would agree to this change, what would help the individual in adjusting to this new situation. A short list of suggestions was given as well as the opportunity to state anything else that would help accommodate a change of hospital, the respondents were told to tick all that applied to them. The top three were:

1. 51% parking access
2. 46% guaranteed one off situation (meaning that they would not have to do the same for any follow up appointments)
3. 29% better transport links (the ease of getting there and back)



Other suggestions made by the respondents included:

- Guarantee to continue to see this new doctor afterwards for any follow up care
- Reassurance that the proposed treatment to be carried out would be the same regardless of which consultants were seen
- Reassurance that this change would not result in a reduction in quality of care
- The new doctor would be given a full handover of the patient's medical history/ records from the patients regular doctor

“Would need reassurance that any proposed treatment to be carried out would be the same irrespective of which consultants were seen.”

“That the new doctor was given a full handover of my past history with my normal one so I don’t need to explain everything that’s gone on again.”

“Reassurance that this change in consultant isn’t to the detriment of my procedure and I won’t suffer as a result of it.”

However, 15% of the survey respondents stated that they would find this suggested change unacceptable. When asked why they would not agree to this change, respondents shared that they would want a relationship with the doctor that is doing the procedure due to a lack of trust with an unknown/unfamiliar consultant. Others stated that they would want to remain with the same doctor as they want to be able to guarantee a continuity in the quality of care they would be set to receive.

“Sometimes with complex history changing clinician is stressful and not helpful to an overall care pathway.”

“Quality of doctors varies greatly.”

“Doctors rarely read their notes...they skim read and then make crucial decisions.”

“Continuity of care with same consultant.”

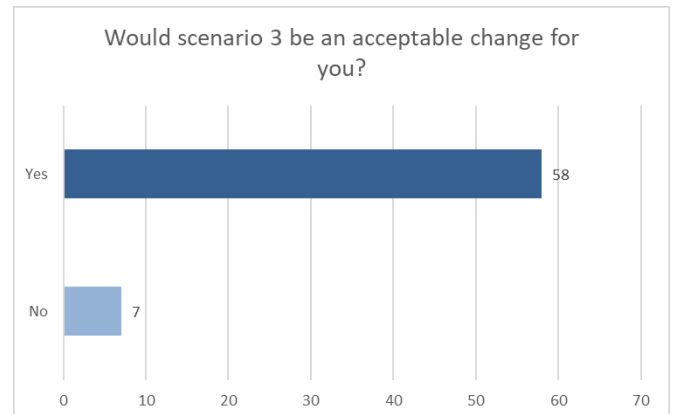
“Would prefer to remain under the care of the same person, for continuity.”

“I need to have a relationship with someone who is carrying out a life changing procedure on me.”

Scenario 3 - Change to private hospital

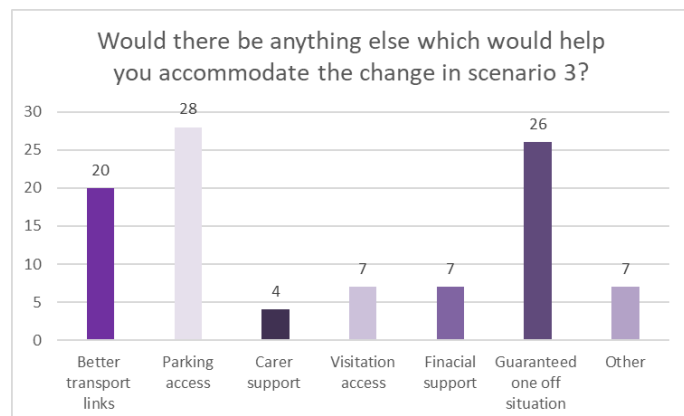
Scenario: Adam has been waiting for an operation on his hand for three months; he usually sees a consultant, Dr Smith, at Royal Blackburn Hospital. He receives a call from David, who is an NHS worker. David tells Adam that he can choose between staying on the waiting list for another five months to see Dr Smith at Royal Blackburn Hospital, or he can see Dr Smith at Blackpool Spire private hospital in six weeks.

In the scenario being described the patient is being offered the opportunity to go to a private hospital with the same doctor for their operation, in return for less time on the waiting list. **89% of survey respondents deemed this alteration acceptable**, suggesting that the majority would agree to a change to a private hospital if it meant a reduction in waiting time, if this were a situation that was offered to them.



The survey respondents were asked if they would agree to this change, what would help the individual in adjusting to this new situation. A short list of suggestions was given as well as the opportunity to state anything else that would help accommodate a change of hospital, the respondents were told to tick all that applied to them. The top three were:

1. 61% parking access
2. 56.5% guaranteed one off situation (meaning that they would not have to do the same for any follow up appointments)
3. 43.5% better transport links (the ease of getting there and back)



Other suggestions made by the respondents included:

- Guarantee that the treatment is still under the NHS with no additional costs

However, 11% of the survey respondents stated that they would find this suggested change unacceptable. When asked why they would not agree to this change, respondents shared that they are against the idea of privatising the NHS in anyway or any potential move in that direction. Others mentioned that the move to a private hospital is also a change of location which would make the distance to travel too far for them.

“This allows for back door privatisation of the NHS.”

“Keep the NHS public! Stop giving bits to the private sector.”

“Public NHS money should not go to private, profit making companies. Invest public money in the NHS.”

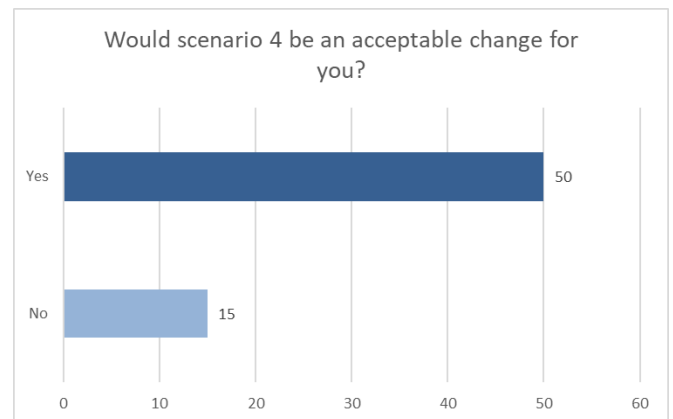
“Distance to the changed appointment hospital.”

“Too far to travel.”

Scenario 4 - Change of doctor and hospital

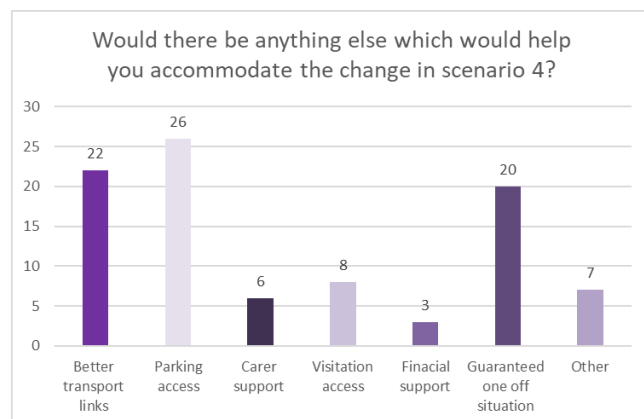
Scenario: Leah has been waiting for an operation on her back for eight months; she usually sees a consultant, Dr Johnson, at Lancaster Royal Infirmary. She receives a call from David, who is an NHS worker. David tells Leah that she can choose between waiting another four months to see Dr Johnson at Lancaster Royal Infirmary, or she can see a different consultant in three weeks at Burnley General Hospital.

In the scenario being described the patient is being offered the opportunity to go to see a different doctor at a different hospital for their operation, in return for less time on the waiting list. **77% of survey respondents deemed this alteration acceptable**, suggesting that the majority would agree to a change of doctor and hospital if it meant a reduction in waiting time, if this were a situation that was offered to them.



The survey respondents were asked if they would agree to this change, what would help the individual in adjusting to this new situation. A short list of suggestions was given as well as the opportunity to state anything else that would help accommodate a change of hospital, the respondents were told to tick all that applied to them. The top three were:

1. 67% parking access
2. 56% better transport links (ease of getting there and back)
3. 51% guaranteed one off situation (meaning that they would not have to do the same for any follow up appointments)



Other suggestions made by the respondents included:

- Guarantee to continue to see this new doctor afterwards for any follow up care
- Reassurance that these changes would not result in a reduction in quality of care

However, 23% of the survey respondents stated that they would find this suggested change unacceptable. When asked why they would not agree to this change, respondents shared concerns about not knowing the doctor, issues with the travelling distance, and worries about medical records not being read or shared. It was indicated that multiple alterations to the original plan would be too much of a change.

“I’d want to meet the person operating on my back.”

“Travelling too far.”

“Too much change. I would need to have confidence in the consultant or the hospital. Two unknowns is too much change.”

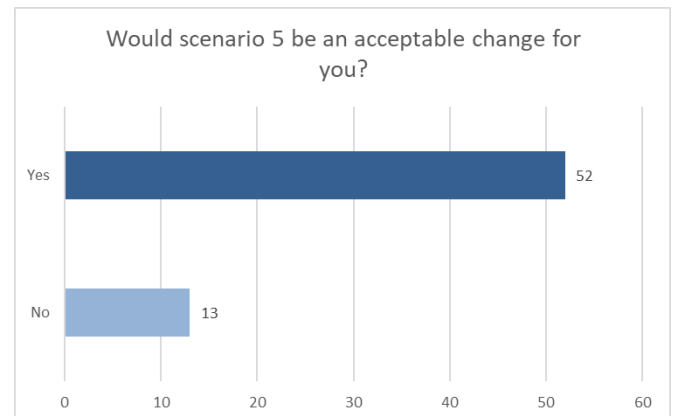
“Being a different hospital and different consultant, I would be nervous about everyone having the correct medical records.”

“Confidence - does the new doctor understand the condition and the procedure? What if the new doctor changes their mind and decide the procedure is not to be done despite the patient suffering and potentially not benefiting?”

Scenario 5 - Change of doctor and to a private hospital

Scenario: Jakub has been waiting for an operation on his foot for four months; he usually sees a consultant, Dr Smith, at Royal Blackburn Hospital. He receives a call from Jane, who is an NHS worker. Jane tells Jakub that he can choose between waiting another four months to see Dr Smith at Royal Blackburn Hospital, or he can see a different consultant at Blackpool Spire private hospital in five weeks.

In the scenario being described the patient is being offered the opportunity to go to see a different doctor at a private hospital for their operation, in return for less time on the waiting list. **80% of survey respondents deemed this alteration acceptable**, suggesting that the majority would agree to a change of doctor and to a private hospital if it meant a reduction in waiting time, if this were a situation that was offered to them.

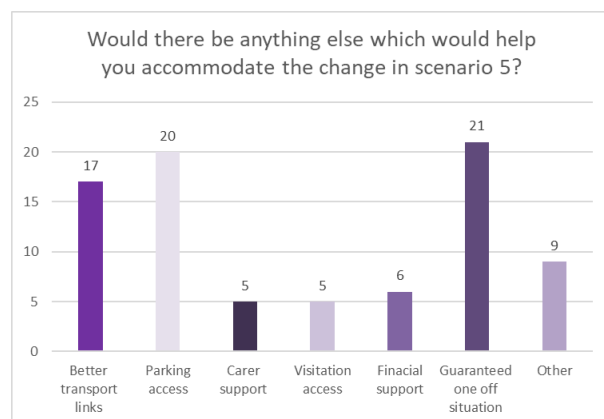


The survey respondents were asked if they would agree to this change, what would help the individual in adjusting to this new situation. A short list of suggestions was given as well as the opportunity to state anything else that would help accommodate a change of hospital, the respondents were told to tick all that applied to them. The top three were:

1. 52.5% guaranteed one off situation (meaning that they would not have to do the same for any follow up appointments)
2. 50% parking access
3. 42.5% better transport links (the ease of getting there and back)

Other suggestions made by the respondents included:

- Guarantee to continue to see this new doctor afterwards for any follow up care
- Reassurance of effective communication of medical records (including scans and plans)
- Guarantee that the treatment is still under the NHS and no additional costs



However, 20% of the survey respondents stated that they would find this suggested change unacceptable. When asked why they would not agree to this change, respondents stated that they desired consistency, sharing worries with having an unknown doctor and medical records being effectively communicated. Another issue respondents voiced with this change option was that some were strongly against private care (or anything close too).

“I don’t want a different doctor as the quality of doctors vary greatly. I don’t want to attend a private hospital as this will encourage privatisation of the NHS.”

“Continuity is paramount for patient care. Sometimes medical records/notes aren’t correct.”

“NHS money should not go to private, profit making companies. Too much change and too many unknowns, I need to build up trust and confidence in the hospital or medical team.”

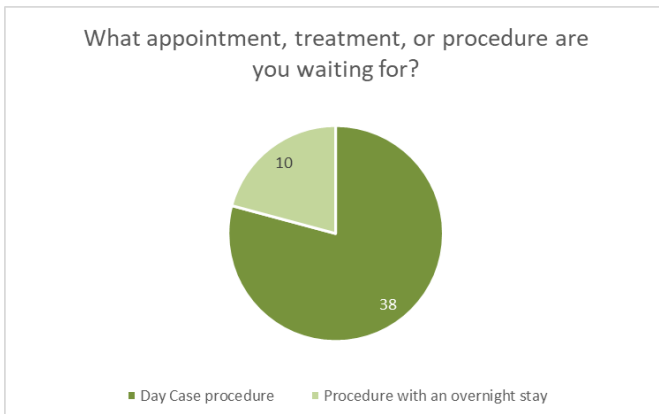
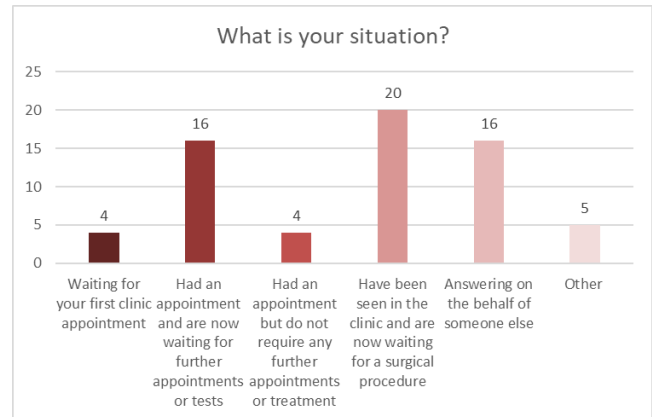
SECTION 2: SURVEY QUESTIONS

Respondents' situation

The questionnaire section of the survey included questions which allowed a clearer picture to be gained of the individual experiences of the respondents. This included asking respondents to share details about the procedure they have been waiting for, how long they have been waiting and how they are planning to travel to their appointments.

What is your situation?

It was determined that 7% of respondents were waiting for their first clinic appointment at the time of responding. 29% had an appointment and were waiting for further appointments or tests, while 7% had an appointment but did not require any further appointments or treatment. The highest percentage of respondents (36%) had been seen in the clinic and are now waiting for a surgical procedure. The rest of respondents, were either answering on the behalf of someone else (11%) or stated other situations (5%) including not currently receiving or waiting for hospital care.



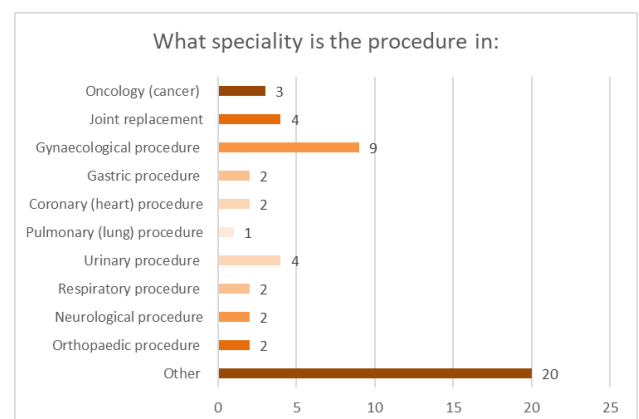
What appointment, treatment or procedure are you waiting for?

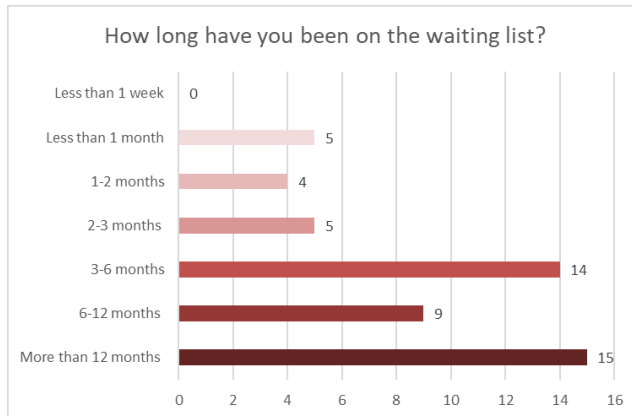
79% of respondents were waiting for a Day Case procedure. The other 21% were waiting for a procedure with an overnight stay.

What speciality is your procedure in:

The respondents were waiting for a range of procedures in a variety of specialities. The most common speciality that respondents had a procedure in that they were on the waiting list for was gynaecology, with 17% of respondents. The specialists and procedures that were listed under 'other' by respondents, included (but was not limited too):

- Audiology
- Ophthalmology
- Hand surgery





How long have you been on the waiting list?

Roughly, 3 in 10 respondents (29%) revealed that they have been on the waiting list for over 12 months, and the majority of respondents have been on the list more than 3 months. Whilst no one had been on the waiting list less than a week. However, most respondents, with 54% (28 respondents), shared that they had been on the waiting list less than 6 months, with 18% of these

respondents (those who have been on the waiting list less than 6 months) disclosing that they had been on the waiting list less than a month.

“Maybe longer ... a mix up with my address meant a missed appointment.”

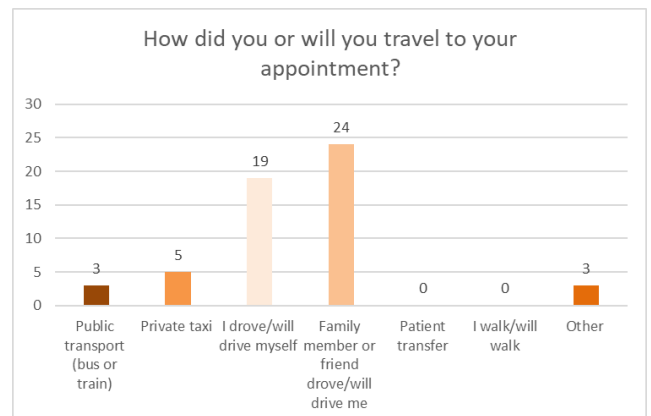
“So pleased with East Lancashire for admitting my daughter for surgery within 2 weeks of having severe episodes of pain.”

“Was told 16 week in December 2019. 16 months wait in the end ... yet patients I knew had hip replacements over the period within 7 months...”

“But been having the problem for over a year.”

How do you or will you travel to your appointment?

When the respondents were asked about how they get to their appointments, it was made clear that respondents often ask a family member or friend to drive them (with 44% of respondents stating that this was the case). But it was also fairly common (35%) for respondents to drive themselves. Some respondents shared that they have been having or are due to have virtual appointments/assessments, which has removed the need to travel to appointments.

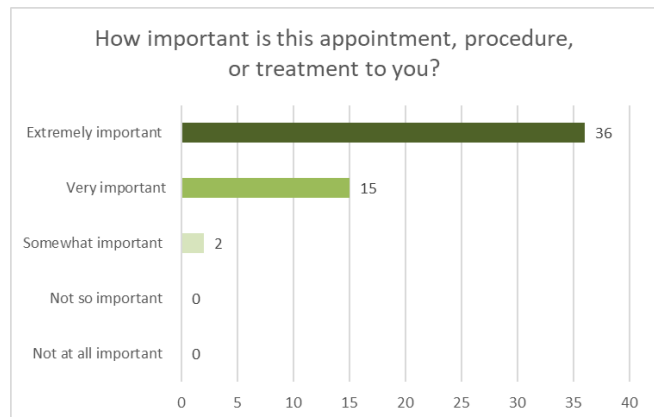


Importance and prevention

Respondents were asked about how important it was to them to have their appointment, procedure, or treatment, and if there would be any reason that would prevent them from having it.

How important is this appointment, procedure, or treatment to you?

The majority of respondents shared that the appointment, procedure or treatment that they have been on the waiting list for is extremely important to them. None of the respondents said that their appointment, procedure or treatment is not at all important or not so important. The respondents who gave some more insight into their situations revealed that it is important to them because they are currently living in pain and have a strong desire to get on track to try and fix this.



What would prevent you from having an appointment, procedure, or treatment?

Respondents shared some reasons that would prevent them from having their appointment, procedure, or treatment, but an overwhelming number of responses stated that nothing would prevent them. This indicates that the main reason respondents have not had their appointment, procedure, or treatment done is because they are having to wait due to the waiting list situation.

- 17 respondents stated that nothing would prevent them
- 5 respondents mentioned that travelling and distance from the hospital could be an issue that would prevent them
- 4 respondents shared that their appointments have been cancelled (not by them)
- 4 respondents revealed that Covid-19 or illness would prevent them
- 3 respondents said that a change of doctor would prevent them
- 1 respondent indicated that work commitments might cause them to prevent
- 1 respondent shared that a lack of trust of/in anyone in the process would prevent them

“Nothing, I need it doing.”

“Nothing (other than death!) It is very important to keep appointments.”

“I live on my own in Blackpool so require to be quite close to access where the surgery is to be performed.”

“Travel too far from home, public transport is not reliable.”

“If the clinic cancels it.”

“The clinics have been stopped completely due to Covid.”

“High rates of Covid in the area.”

“Only if I was ill.”

“Change of doctor that I don’t know or trust.”

“Nothing, my only concern would be how useful an appointment with a different consultant would be who isn’t familiar with you/your health.”

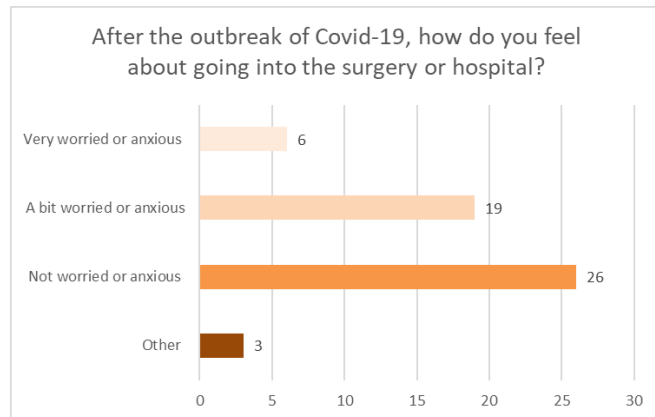
“A lack of trust in anyone in the process.”

Covid-19 related feelings and concerns

Respondents were asked about their levels of anxiety and worry as a result of the outbreak of Covid-19 and if they had any specific worries, referring to going into the surgery or hospital.

After the outbreak of Covid-19, how do you feel about going into the surgery or hospital?

48% of respondents were 'not worried or anxious', while 35% of respondents were 'a bit worried or anxious', but 11% of respondents shared that they were feeling 'very worried or anxious' about going into the surgery or hospital.

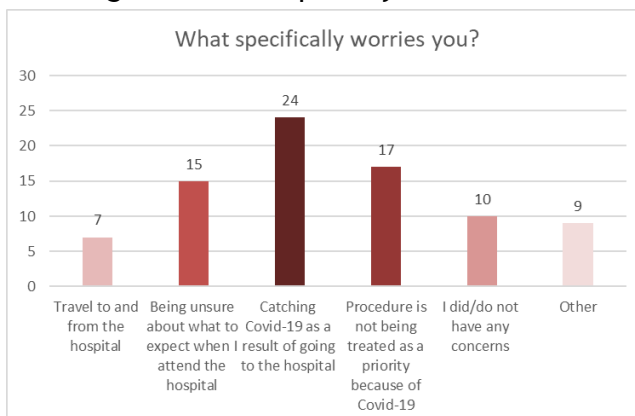


“It was a concern but in so much pain and limited mobility I would have taken the risk especially after vaccine.”

“Royal Preston Hospital has a terrible reputation for Covid infection rates acquired in hospital.”

What specifically worries you?

Respondents were asked a follow up question about their concerns following the Covid-19 outbreak concerning their procedure/treatment. It was highlighted that the two biggest areas of concern for respondents was (46% were worried about) catching Covid-19 as a result of going into the hospital and (33% were concerned) that their procedure is not being treated as a priority because of Covid-19. Whilst 19% of respondents stated that they



did not have any concerns. Some 'other' areas of concern shared by respondents included parking issues, putting family members at risk and not having anyone able to look after them at home afterwards.

“Obviously sick people are at the hospital so maybe at more of a risk than staying home.”

“Hand washing facilities, wearing a mask.”

“My health deteriorated over this time

because surgery was not prioritised.”

“My condition had got a lot worse since all clinics stopped, I can't get my treatment.”

“Can't park anywhere without costing a fortune!”

“Being able to have someone with me at home post procedure due to Covid restrictions.”

“Putting loved ones/others at risks of catching COVID as I will need help to get home. Or if caught it I could take it back to the family home.”

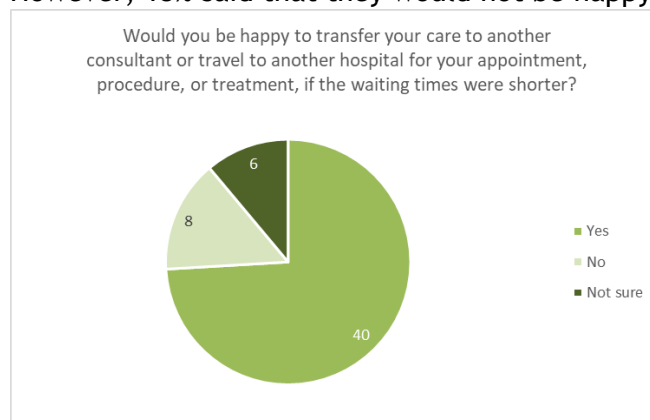
Feelings towards the options for shorter waiting times

Respondents were asked about if they would be happy to transfer their care to another consultant or travel to another hospital if waiting times were shorter, and if they responded that they would not be happy they were asked why this was the case. Then respondents were asked about if they would travel to another hospital but still being seen by their existing consultant if it meant a shorter waiting time, with a follow up question to determine what respondents feel is a reasonable time to travel.

Would you be happy to transfer your care to another consultant or travel to another hospital for your appointment, procedure, or treatment, if the waiting times were shorter?

74% of respondents stated that they would be happy to transfer their care to another consultant or travel to another hospital if it meant the waiting times were shorter.

However, 15% said that they would not be happy with this suggestion and 11% shared that they were not sure.



they were not sure.

“I would prefer to know something of the consultant before the appointment/ procedure.”

“As long as the care was at the same level and consultant abilities.”

“I am currently waiting to be seen at spire as I have waited over 12 months on Blackpool hospitals list.”

“As long as clear records and communication of tests so far. I was only discharge 6 months prior to re referral. So had hoped for continuity.”

“I would go in a heartbeat if they’d let me change.”

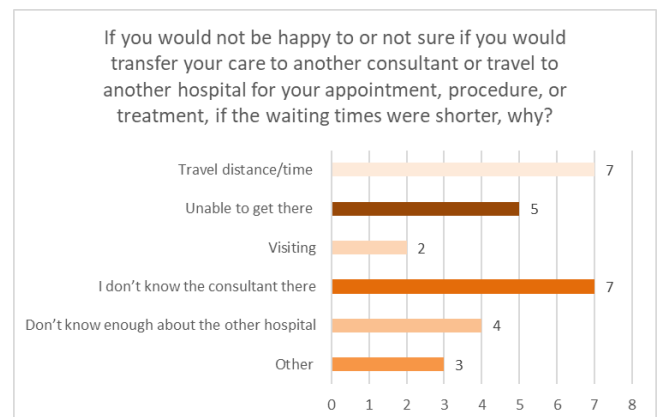
“I have stated I would accept the next available slot with any surgeon. Waiting list staff have been working very hard to get me listed.”

“If there was free transport there and back when I needed it.”

“Only to a different hospital. I would not change doctor.”

“Would change hospital but not consultant.”

A follow-on question was posed to those who responded with ‘no’ or ‘not sure’, asking why they would not be happy with the proposed situation if offered to them or why they were not sure they would be happy with it. 50% of respondents stated that travel time and distance was a reason they would not be happy, 50% of respondents shared that they would have an issue with not knowing the consultant. ‘Other’ reasons given by respondents included cost, one respondent revealed that *“cost is a barrier”* as they *“don’t earn a lot”*.



Would you travel to another hospital for your appointment, procedure, or treatment, if their waiting times were shorter and you were seen by your existing consultant?

83% of respondents claimed that they would travel to another hospital if they were to be seen by their existing consultant. But 8% of respondents stated that they would not agree to this suggestion, while 9% said that they were not sure if they would agree.

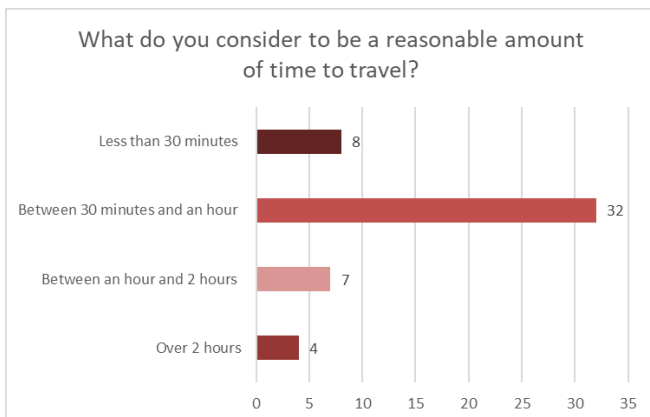
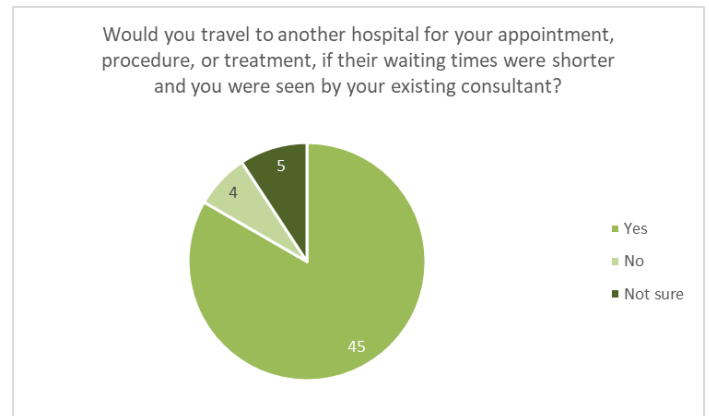
“It helps you get waiting lists down and me by getting the care I need to more on, faster.”

“Anything to shorten the time waiting is a plus.”

“Still the travelling.”

“I don’t want to travel.”

“Depends on the distance, parking, ease of access.”



A follow-on question was asked to determine the length of time respondents would consider to be a reasonable amount of time to travel to another hospital if they would still be seen by their existing consultant. The majority of respondents (63%) believe that between 30 minutes and an hour is a reasonable amount of time to travel. 15% of respondents claimed that less of 30 minutes would be reasonable, whilst 22% of respondents said that they would travel over an hour.

“It depends on the procedure needed and how well/ill the patient is.”

“I travelled all the way from Cumbria to Kent & Oxford for MH so anything shorter than that is more convenient.”

“I don’t really care as long as the fix me.”

“Restrictions on overnight stays haven’t helped.”

“Depends if it’s by public transport or car.”

“Patients should be able to access local care.”

“This travel time is ok for a planned appointment or procedure, not for unplanned care.”

Anything else:

Is there anything else you would like to tell us about your experience?

There were only 17 responses to this question. However, from the comments that were made by respondents it is evident that there is an issue with communication between the trusts and their patients especially those on the waiting lists. The following is a selection of the responses that were left:

“Covid has made us all realise how valuable our NHS is.”

“It’s quite ridiculous how long this is taking.”

“Communication between doctors and hospitals hasn’t been great over COVID and I got pregnant after waiting over a year on the waiting list and instead of having my procedure once I’d had the baby they are making me wait the whole time again, therefore could be ages until I actually get my op! Also cancelled my appointment 4 times in a row.”

“Had my pre op over 7 weeks ago and still not been given a surgery appointment.”

“Abysmal communication from the hospital in spite of my many phone calls to so many depts, numbers and messages left, over a year, no one returned a call until a personal letter was sent and a further email to complaints. It was like psychological torture, week after week, month after month, and year after year ... shocking when any information or explanation would have helped so much. Never in my life have I felt so isolated and helpless.”

“It was not possible at re referral to be referred back to original consultant. Had I been aware of that I would have accepted an earlier appointment at another hospital.”

“Very disappointed that us people with long term conditions have had our treatment stopped, and condition had deteriorated as a result.”

“When my procedure was cancelled, I was not given an interim hospital appointment to receive my pain injections. No one seemed able to help me whilst I waited for a new procedure date. I had to ring around myself and sort out appointments. If I hadn’t have done that I would not have been seen. If I hadn’t have done that I would have been waiting even longer for my procedure because that clinic appointment made them aware of how badly I was doing. I felt forgotten.”

“Not happy with the time I have been waiting, I’m in so much pain, but it’s not classed as urgent.”

“It’s been disgraceful, with extremely poor communication. No updates have had to chase every single appointment.”

“Communication has been extremely poor.”

“I have Asperger’s, and the lack of clarity on when things are happening causes me stress. I don’t always feel confident calling.”

Entire survey evaluation

Summary of the results

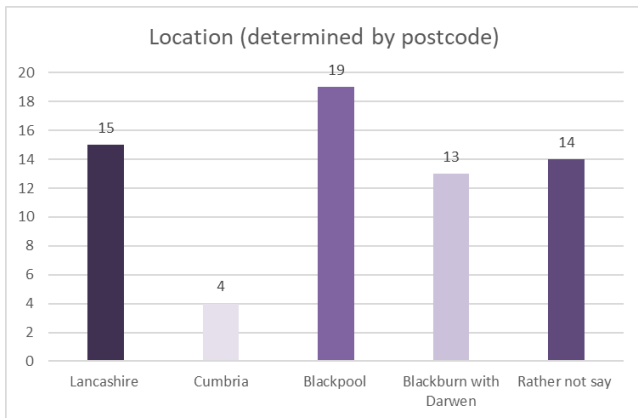
The following are the finding highlights from the survey as a whole (both the scenario questions and the questionnaires).

- Respondents would rather change hospital (to either a private or non-private hospital) than change their consultant/doctor
- Patients are worried about the continuity of their care if they changed doctor (would want medical records up to date and shared between appropriate consultants)
- Multiple changes are less acceptable than a single change
- Many respondents would agree to any changes to get treatment/waiting times reduced
- A commonly shared specific worry of respondents was that their procedure is not being treated as a priority because of Covid-19
- Most of respondents have been on the waiting list for over 3 months (73%), with 29% of the total number of respondents have being the list for more than a year
- The majority consider that between 30 minutes and an hour is a reasonable amount of time to travel
- Communication has been a common issue during the pandemic

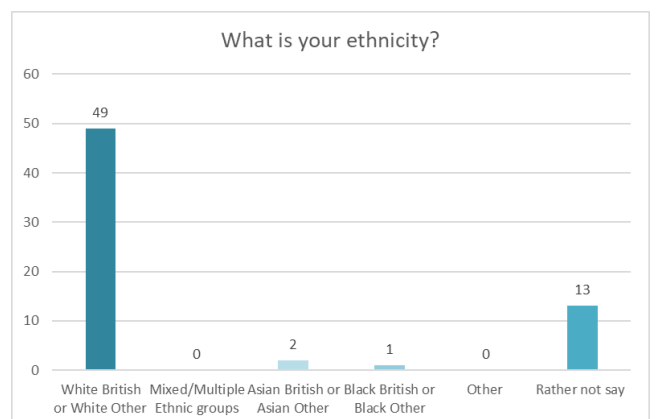
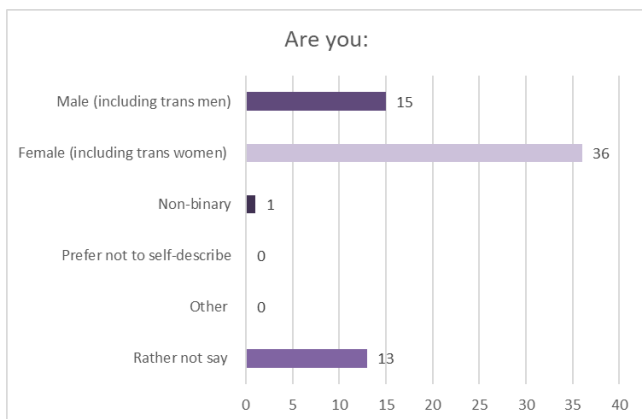
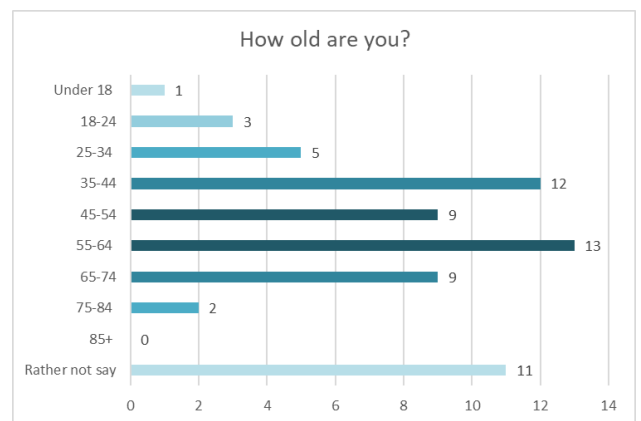
These results contributed to helping design the contents and the structure of the case studies.

Demographics of the respondents

The demographics of the survey respondents are represented by the graphs below. The highest proportion of respondents were from Blackpool (determined by the first half of the respondent's postcode). The majority of the respondents were older than 45 (with the highest percentage of respondents aged between 55 to 64), identified as a female and are White British or White Other.



Location (determined by postcode):
 Lancashire - 23%
 Cumbria - 6%
 Blackpool - 29%
 Blackburn with Darwen - 20%
 Rather not say - 22%



SECTION 3: CASE STUDIES

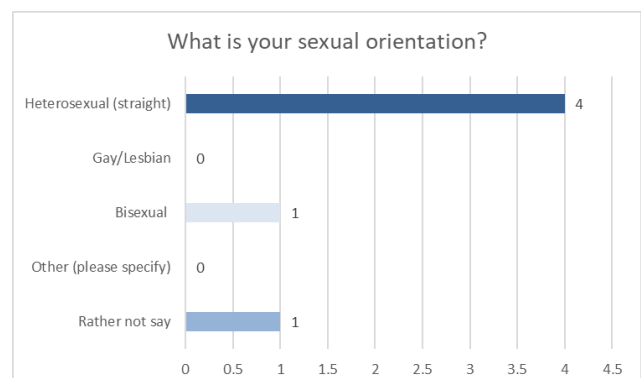
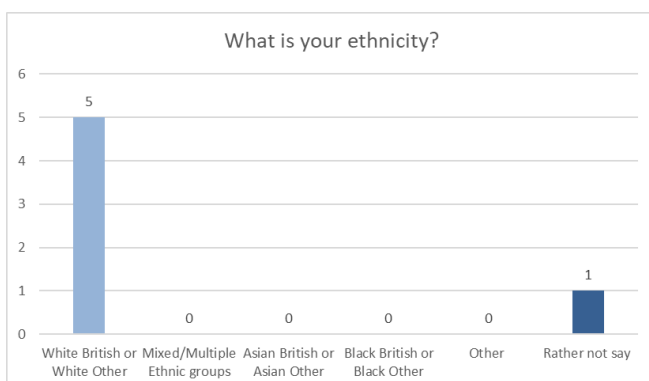
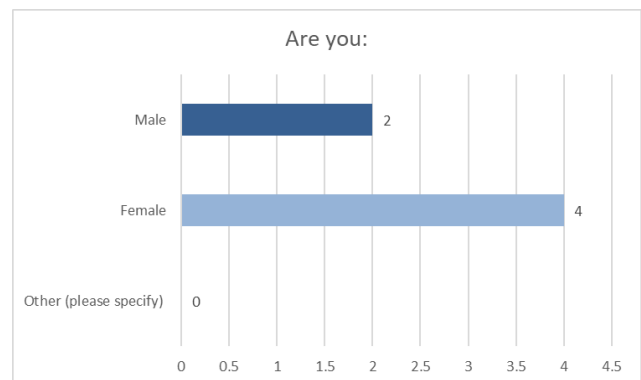
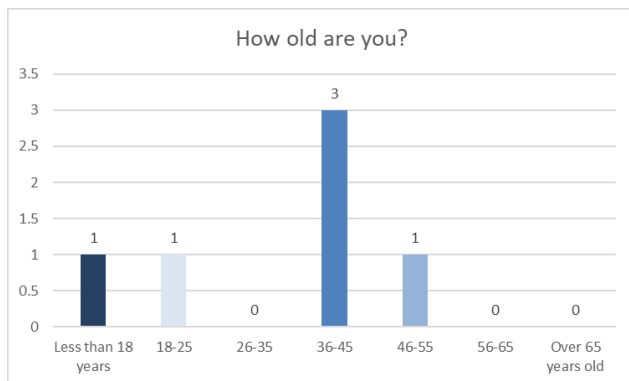
There was a total of 6 case studies completed.

It was decided that there would be some case studies done after the survey closed to get a further insight into some individuals personal experience of being on the waiting list. The case studies were designed and contextually based on the information gained from the survey results. The case studies were split into four sections:

- **Background** - This was a discussion about the participants story and personal experience of being on the waiting list.
- **Communication** - Poor communication was highlighted as an issue raised by several survey respondents; thus, the case studies were asked specifically about their thoughts and opinions on the communication they received whilst on the waiting list.
- **Waiting lists** - This part of the case study discussed possible options for changes that could be made to reduce waiting list times and how the participants feel about these options.
- **Additional notes** - This section allowed participants to share anything else about their experience or any other thoughts relating to this topic.

The demographics of the 6 participants:

The participants were from a range of areas, including Blackpool, Kendal, Lancaster (the other 3 participants did not disclose). The rest of the demographics of the case study participants are represented by the graphs below. The majority of respondents were aged between 36 and 45, identified as female, heterosexual, and are White British or White Other.



Background

The case study participants had a range of different medical situations and thus, shared experiences that in many ways are vastly different from each other. No one was on the waiting list for the same medical problem or procedure, with participants sharing that they had been/were waiting on:

- A colonoscopy
- An endoscopy
- For a dental extraction
- For a social prescriber
- Because of respiratory issues
- Because of bladder issues

1 participant mentioned that they have been seen and are now no longer on the waiting list, however, the other 5 individuals indicated that they are still waiting for their appointment/treatment or have continued to be on the list for further appointments/treatment. Waiting times were mixed for participants:

- 2 participants indicated that they have been waiting 6 months or less
- 2 participants shared that they have been/were on the waiting list more than 6 months but less than a year
- 2 participants stated that they have been waiting for over a year

All participants gave an overview of the situation they were in whilst on the waiting lists. It was made evident that all the participants have been living with their medical issues for a significant period of time, with some sharing that the procedure they need is linked to long term conditions they already have, whilst others mention that they are needing procedures or appointments to determine the root cause of the problems they have been experiencing for a long time (sometimes years).

It was evident from the conversations with the participants that there is a general understanding that it can take a while to be seen once placed on a waiting list and there was a recognition of the impact that the Covid pandemic has had on healthcare and specifically waiting lists. However, the length of time on the waiting lists did cause frustration and annoyance, as well as concern and worry about their own medical situation as it is not being investigated or fixed whilst they are on the waiting list and in some cases their conditions are getting worse the longer they wait. Thus, there was a strong desire by participants to have waiting lists shortened and waiting times reduced.

Communication

The survey responses highlighted communication as an issue for many who were on waiting lists, this was reinforced as an issue from the case studies. Participants shared that they received no updates and got limited contact (if any) during the time they were/have been on the waiting list. The case studies gave an insight of being made aware of appointments, participants being forced to chase it up themselves, the difficulty in accessing information, the negativity participants faced from some medical professionals and the preference of communication methods.

One participant was first made aware of being on the waiting list for a procedure after receiving a cancellation letter. They had not even been informed that they had been

referred prior to this letter. This cancellation letter made the participant feel uninvolved and not in control of their condition/treatment as they felt that decisions were being made without them being in the loop. This participant also shared that they have been contacted since (approximately 6 months later) to be asked if they would like to remain on the waiting list. They were then asked to provide a sample to determine where on the waiting list they will be placed/moved.

4 participants explicitly stated that they have had to chase up their doctors/hospitals for updates themselves. One participant said that they were made to feel bad after ringing up about their appointment after months on the waiting list, and as a result they haven't contacted the doctors/hospital again since. Other participants commented on the speed of replies being very slow and how the information they did receive was often very limited, essentially making participants feel that they were pleading for information. Furthermore, it was stated by a participant that the answering machine they were getting through too when trying to chase up appointments was giving out incorrect information which meant that leaving a message was not possible. The same participant mentioned that it should be recorded when participants contact the NHS and not solely when the NHS have contacted the patients. It was made evident from the conversations that the participants would have really benefited and liked a follow up call/message to inform patients that they are still on the list.

Participants declared that it is often very difficult to access information from the NHS, this included gaining access to information in their own medical records. A participant described the process as stressful and a frustrating process. As they felt that several hoops had to be jumped through. It was claimed that information does not get effectively shared between different hospitals/doctors, often forcing patients to start the process of accessing information again if they change doctors/hospitals/trusts.

Some participants also shared some negative experiences they had with health professionals, and how the poor communication that occurred contributed to these negative experiences. A participant was made to feel bad about contacting the doctors whilst on the waiting list, and they had only contacted the doctors as they had not received any updates and they haven't contact them again after this bad experience. Another participant shared their negative experience of dealing with medical professionals, the participant mentioned that it feels patronising when professionals constantly focus on their weight when they go to the doctors with a medical issue, which is made worse when they are forced to repeatedly explain their situation to multiple people. They said that this makes them feel unheard.

It was indicated by participants that they wanted some form of written communication from the hospital. One participant mentioned that they liked receiving a physical copy, such as a letter, detailing information about their appointments, whilst others shared that digital communications would be the most effective way to receive information, such as email. Other participants stated that a text would be a sufficient form of communication throughout the process as a way to feel included and ensure patients that they have not been forgotten about. A participant thought that receiving a follow up text around the 3-month mark would be ideal. The same participant suggested that a national campaign from the NHS to say that patients on the waiting list have not been forgotten about, could have been beneficial.

Waiting lists

There was a shared desire amongst participants to have the waiting times reduced, even though it was acknowledged by some participants that the Covid pandemic has had an impact on the current length of waiting times. However, 2 participants claimed that they would accept any change if it meant a reduction in waiting times, including going anywhere or being seen by anyone to get treatment and answers to their medical problems. Alternatively, one participant shared that they would prefer to have no changes made but did not rule out committing to changes absolutely if necessary.

Participants mentioned that they would travel further to go to a different hospital if it meant a reduction in the waiting times as long as it is not extreme distances. One participant mentioned that they would be happy to travel up to 25 miles, but they admitted that they would potentially travel even further as a one-off situation if they already had a good relationship with the doctor. Another participant mentioned they would be willing to travel up to an hour to get the procedure they needed, but that would mean that their parents would have to take time off work to do this so it would not be ideal. It was indicated from the conversations that the participants tend to go to the hospital that is closest to them due to convenience. Thus, some participants shared that if the offer was made to go to a different hospital they would do, however, this would not be ideal. On the other hand, a participant said that they would not change hospitals as they know and trust the hospital they are currently scheduled at.

The option of a different doctor was considered by the case study participants. It was mentioned that having a good relationship with their doctor was important to many participants. Whilst it was highlighted by others that they do not currently know which doctor would be doing their procedure and thus they would most likely accept a change of doctor.

Participants mentioned that the willingness to make changes depends on specific personal factors. This included for one participant, if they felt that their treatment was being restricted or rationed in any way, they would oppose accepting any changes. It was also indicated that the severity of the problem or urgency of the need for the procedure to be done would affect the willingness to accept changes. It was mentioned by a participant that they had a long term condition which their procedure (that they are on the waiting list for) is linked to. Thus, they know the level of pain (and with what medication) they can live with and without and how long for, as they have been in a similar situation previously. Therefore, they said that they would wait longer for consistency. However, if the procedure became more urgent, or if it was a potentially life or death situation they would be far more flexible in accepting changes. Another participant stated that they would have to take their disability into consideration when making changes and would hope the doctors/hospital would do too.

Additional notes

4 participants did not have anything else to add, nor wanted to shared anything else about their experience relating to this topic. However, 2 participants made some extra comments.

One participant expressed that they would like to have a face-to-face appointment, but they stressed that they feel that they need to be more cautious now than earlier on in the pandemic. This is because they feel that people are reaching the point of having had

enough and combined with the restrictions easing that this results in an increased risk. Thus, the participant feels the need to be cautious especially in the hotspot areas, stating that they would feel a lot of anxiety about going to an appointment in a hotspot area.

Another participant shared that they had another procedure done (a septoplasty of their nose) which they were allowed to pick and book to have this done at a private hospital. The participant said that having this choice was amazing.

Summary

There was a total of 6 case studies completed and they all gave a deeper and invaluable insight into people's opinions and experience of the waiting list situation. The following have been identified as key findings from the conversations that were done:

- Participants have been forced to chase up appointments themselves
- It would benefit people if they received an update throughout the waiting process (this would also make them feel like they have not been forgotten about)
- The majority of participants would prefer to receive updates and be communicated in a written digital format
- The flexibility to accept changes can depend on the severity of their condition and/or the urgency in the need to have a procedure done at the time (thus flexibility can potentially be subject to change)
- Most participants (though not all) are willing to consider a change in hospital or doctor if it meant a reduction in waiting time
- Time/distance of travel was indicated to be a significant factor on deciding to accept a change of hospital (if the time/distance to travel is too extreme the option to change would be rejected)

CONCLUSION

This project aimed to gain an understanding of how acceptable a change in a healthcare situation would be if it meant a reduction in waiting times. As well as gather the general mood of the public towards the waiting list situation based on personal experience.

To do this a survey was developed (consisting of scenario questions and a short questionnaire) and sent out to 5 separate trusts. This survey received 65 responses. An additional 6 case studies were done to give a further insight and a more personally specific insight into the waiting list situation. It was concluded that there was a strong desire for waiting times to reduce, with many of those who participated in this project being willing to accept any change to achieve this. However, a change of hospital was preferred to a change in doctor. It was also highlighted that there is a common problem of poor communication between the trusts and the patients on the waiting lists.

All the results to the survey and the case studies have been analysed and presented in this report.

Finally, a huge thank you to all those individuals who took the time to fill out the survey and/or participated in a case study, to provide their invaluable feedback.

Recommendations

The following recommendations have been made:

1. Explore different methods of engaging with the public

To increase the number of respondents and to try and combat survey fatigue, it is essential to explore other methods of engagement with the public.

2. Additional work to gain further insight into under-represented communities

Respondents demographical feedback from both the survey and the case studies evidenced that there were some groups, including the BAME and low IMD communities, that have been under-represented in this project. This is likely to be a result of the project being aimed widely at the general population, and thus more specific insight work is required.

3. Give individuals the option to change hospital and/or doctor if they are on the waiting list when this option is available

This would give people the option to change if they felt that this would suit them and their need, and in turn it would help reduce the amount of time people are on the waiting lists. The amount of change offered should be kept to a single change.

4. Ensure that medical records are up to date and are shared between appropriate consultants

This would mean that patients would not need to repeat themselves less when seeing a new doctor and consequently reduce the worry that the process would start again if a patient was sent to a new doctor.

5. Help patients understand that their appointment/treatment/procedure is still a priority

Patients are worried that their appointment/treatment/procedure is not a priority because of the Covid pandemic, it needs to be communicated to patients that this is not the case.

6. Send out updates to those on the waiting lists about the progress of the waiting lists

This would reduce the need for patients to chase up appointments and it would make those on the waiting lists feel more included in the process and ensure them that they have not been forgotten about.

7. Improve communication between the trusts and waiting list patients

This was highlighted as an area that needs significant improvement by respondents. Patients have admitted to often feeling forgotten about while being on the waiting lists.

APPENDIX A: Mood of the Public survey

This survey aims to assess if people would prefer to change the place they are due to be treated and potentially be seen by NHS providers further away, if it resulted in being seen quicker. There are two parts to this survey, the first part is a series of scenario-based questions and the second part is a short questionnaire.

All responses are anonymous.

Part 1: Scenario questions

The following questions will determine your feelings on a particular scenario which is described. There are 5 scenarios, with each scenario being a different permutation of care situation which could occur.

SCENARIO 1 (change of hospital): Mariam has been waiting for an operation on her knee; she usually sees a consultant, Dr Ferreira, at Burnley General Hospital. She receives a call from Jane, who is an NHS worker. Jane tells Mariam that she can choose between staying on the waiting list for another four months to have her operation with Dr Ferreira at Burnley General, or she can have the operation with Dr Ferreira at Royal Preston Hospital in three weeks.

1. Would this be an acceptable change for you? Yes/No
2. If no, why would you not agree to this change?
3. If yes, would there be anything else which would help you accommodate this change? (Tick all that apply to you)
 - Better transport links (ease of getting there and back)
 - Parking access
 - Carer support (for child/elderly relative/other)
 - Visitation access
 - Financial support
 - Guaranteed one off situation (i.e. would not have to do the same for follow up appointments)
 - Other (please specify)

SCENARIO 2 (change of doctor): Martin has been waiting for a procedure on his sinuses for six months; he usually sees a consultant, Dr Abbas, at Royal Preston Hospital. He receives a call from Jane, who is an NHS worker. Jane tells Martin that he can have an appointment to see a different consultant at Royal Preston Hospital next week, or wait another three months to see Dr Abbas.

4. Would this be an acceptable change for you? Yes/No
5. If no, why would you not agree to this change?
6. If yes, would there be anything else which help you accommodate this change? (Tick all that apply to you)
 - Better transport links (ease of getting there and back)
 - Parking access
 - Carer support (for child/elderly relative/other)
 - Visitation access

- Financial support
- Guaranteed one off situation (i.e. would not have to do the same for follow up appointments)
- Other (please specify)

SCENARIO 3 (change to private hospital): Adam has been waiting for an operation on his hand for three months; he usually sees a consultant, Dr Smith, at Royal Blackburn Hospital. He receives a call from David, who is an NHS worker. David tells Adam that he can choose between staying on the waiting list for another five months to see Dr Smith at Royal Blackburn Hospital, or he can see Dr Smith at Blackpool Spire private hospital in six weeks.

7. Would this be an acceptable change for you? Yes/No

8. If no, why would you not agree to this change?

9. If yes, would there be anything else which help you accommodate this change? (Tick all that apply to you)

- Better transport links (ease of getting there and back)
- Parking access
- Carer support (for child/elderly relative/other)
- Visitation access
- Financial support
- Guaranteed one off situation (i.e. would not have to do the same for follow up appointments)
- Other (please specify)

SCENARIO 4 (change of doctor and hospital): Leah has been waiting for an operation on her back for eight months; she usually sees a consultant, Dr Johnson, at Lancaster Royal Infirmary. She receives a call from David, who is an NHS worker. David tells Leah that she can choose between waiting another four months to see Dr Johnson at Lancaster Royal Infirmary, or she can see a different consultant in three weeks at Burnley General Hospital.

10. Would this be an acceptable change for you? Yes/No

11. If no, why would you not agree to this change?

12. If yes, would there be anything else which help you accommodate this change? (Tick all that apply to you)

- Better transport links (ease of getting there and back)
- Parking access
- Carer support (for child/elderly relative/other)
- Visitation access
- Financial support
- Guaranteed one off situation (i.e. would not have to do the same for follow up appointments)
- Other (please specify)

SCENARIO 5 (change of doctor and to a private hospital): Jakub has been waiting for an operation on his foot for four months; he usually sees a consultant, Dr Smith, at Royal Blackburn Hospital. He receives a call from Jane, who is an NHS worker. Jane tells Jakub

that he can choose between waiting another four months to see Dr Smith at Royal Blackburn Hospital, or he can see a different consultant at Blackpool Spire private hospital in five weeks.

13. Would this be an acceptable change for you? Yes/No

14. If no, why would you not agree to this change?

15. If yes, would there be anything else which help you accommodate this change? (Tick all that apply to you)

- Better transport links (ease of getting there and back)
- Parking access
- Carer support (for child/elderly relative/other)
- Visitation access
- Financial support
- Guaranteed one off situation (i.e. would not have to do the same for follow up appointments)
- Other (please specify)

Part 2: Short questionnaire

16. What is your situation?

- Waiting for your first clinic appointment
- Had an appointment and are now waiting for further appointments or tests
- Had an appointment but do not require any further appointments or treatment
- Have been seen in the clinic and are now waiting for a surgical procedure
- Answering on the behalf of someone else
- Other (please specify)

17. How important is this appointment, procedure, or treatment to you? Please answer even if you have already had your appointment/procedure.

- Extremely important
- Very important
- Somewhat important
- Not so important
- Not at all important

18. What would prevent you from having an appointment, procedure, or treatment? Please answer even if you have already had your appointment/procedure.

19. How did you or will you travel to your appointment?

20. After the outbreak of Covid-19, how do you feel about going into the surgery or hospital? Please answer even if you have already had your appointment.

- Very worried or anxious
- A bit worried or anxious
- Not worried or anxious
- Other (please specify)

21. What specifically worries you? Please answer even if you have already had your appointment. (Please tick all that apply)

- Travel to and from the hospital
- Being unsure about what to expect when I attend the hospital
- Catching Covid-19 as a result of going to the hospital
- Procedure is not being treated as a priority because of Covid-19
- I did/do not have any concerns
- Other (please specify)

22. What appointment, treatment or procedure are you waiting for? Please answer even if you have already had your appointment/procedure. Day Case procedure/ Procedure with an overnight stay

23. What speciality is the procedure in:

24. How long have you been on the waiting list? Please answer even if you have already had your appointment/procedure.

25. Would you be happy to transfer your care to another consultant or travel to another hospital for your appointment, procedure, or treatment, if the waiting times were shorter? Yes/No/Not sure

26. If you answered no or not sure for question 25, why? (Please tick all that apply)

- Travel distance/time
- Unable to get there
- Visiting
- I don't know the consultant there
- Don't know enough about the other hospital
- Other (please specify)

27. Would you travel to another hospital for your appointment, procedure, or treatment, if their waiting times were shorter and you were seen by your existing consultant? Yes/No/Not sure

28. If so, what do you consider to be a reasonable amount of time to travel?

29. Is there anything else you would like to tell us about your experience?

30. What is the first half of your postcode?

31. How old are you?

32. Are you:

- Male (including trans men)
- Female (including trans women)
- Non-binary
- Prefer not to self describe
- Prefer not to say
- Other (please specify)

33. What is your ethnicity?

34. If you would be interested in helping us shape these services, by potentially being interviewed by Healthwatch regarding your experience as a case study, please leave your email address. This is optional.