

Waiting times for procedures
Research findings
March 2023

1. Introduction and aims

Healthwatch South Tyneside, in our role as the independent local champion for people who use health and social care services, commissioned MMC Research and Marketing Ltd to survey residents of South Tyneside and follow up with a series of focus groups. The aim was to develop an understanding of residents' experiences of waiting times for procedures and how easy or difficult it is to access GP services. The research also set out to evaluate how the legacy of COVID-19 is impacting care (particularly in terms of face to face vs virtual appointments) and to understand how waiting times for different procedures are impacting patients and identify whether other healthcare support is offered in the interim.

There are two reports covering the results of this research project. This report focuses Waiting Time for Procedures. A separate report presents the findings for the research on GP Access/Method of Access.

The insights gathered will be used to feedback to local service providers, ensuring that the needs of the local community are listened to and addressed by GP practices in South Tyneside.

2. Methodology

In order to gather a clear picture of current experiences, a dual quantitative and qualitative methodology was chosen. Firstly, to capture the views and perceptions of a wide audience in a quantitative survey before running qualitative focus groups to explore individual views and experiences in greater depth.

A 10-minute online survey was disseminated in order to reach a wide range of South Tyneside residents. Surveys were completed via an online consumer research panel, a post on the Healthwatch website, shared with select groups on Facebook, and via a QR code on posters in GP surgeries. Participants were offered the opportunity to be entered into a prize draw to win a £50 Amazon voucher as an incentive to take part. The survey was

conducted between 6th September and 3rd November 2022. A total of 181 South Tyneside adult residents took part in the survey.

At the end of the 10-minute online survey, participants were asked if they would be interested in taking part in an online focus group to further explore the topics covered in the survey.

Two focus groups took place focused on waiting times, one in November 2022 and an additional session in January 2023 due to low respondent attendance at the first group. Eleven people in total took part in the focus groups that focused on waiting times.

A note on quantitative analysis and reporting

The results have been analysed statistically and the following points should be kept in mind when interpreting the findings:

- Not all percentages will add up to 100% because of decimal point rounding or multiple-choice questions
- Findings based on small numbers (i.e. <5%) should be interpreted with caution
- Where respondents skipped a question, the base size will not equal the total number of surveys completed
- Where 0% is shown, answers were less than 1%.

3. Context influencing attitudes towards waiting times for procedures

There was a **high level of goodwill** towards the NHS. Participants understand that budgets are stretched and that departments are under-resourced which is impacting on waiting times. However, patience is running out for their need to return to some sort of post-COVID normality.

“It was bad enough during lockdown but now that we’re not in lockdown anymore, I can’t understand why the doctors aren’t operating normally anymore.”

When patients are waiting for procedures, they are likely to have multiple contact touchpoints with reception and appointment booking staff for different departments. Many participants had examples of reception staff lacking in empathy, not listening to

patient's concerns, and even rudeness.

“We do expect it to take a while [to get through on the phone], but then to be greeted with so many hurdles after that. I also expect to be treated with kindness and compassion and empathy, and to be treated like a human being, and I expect that person to treat me with respect because I'm the one who's not okay. Like I'm treating you with respect, but I'm the one who's got whatever issue that may be, whether it's mental or physical or otherwise, to then be treated like crap I think is a massive hurdle. And it kind of makes you go 'Forget it, I'll deal with it myself' and then it just gets worse.”

Positive receptionist contact provides a 'halo' over the rest of the NHS experience and patients are likely to be more understanding if they have a lengthy wait for an appointment, test result or procedure.

There was some evidence in the focus groups that more people are turning to **private healthcare** when faced with long waiting times for procedures. Moving to private healthcare can be expensive but is seen as a worthwhile investment to receive a reliable level of care when needed. Others feel they just can't afford the investment or are unwilling to pay even though they don't feel they receive a good enough service from the NHS.

“I've worked a long time, I've paid National Insurance for a long time, and I worry that as I get older, I'm not going to have that same level of care that has been there in the past. I think if I had known then maybe what I know now, would I have opted for private healthcare? Yes, 100%.”

4. Experiences of waiting times for procedures

Of the patients in the quantitative survey that had experienced recent treatment or were on a waiting list (49 respondents), there was a range of medical issues requiring treatment. General surgery was the most common treatment type, followed by ENT.

- 20% General surgery
- 14% Ear, nose and throat
- 8% Knee replacement
- 8% Cancer treatment
- 6% Hip replacement
- 4% Eye surgery/procedure
- 2% Heart surgery/procedure
- 31% Other (responses include: physiotherapy, ankle operation, varicose veins, thyroid, pain treatment, dermatologist, bariatric, infusions, scans, liver replacement, psychotherapy, hernia and respiratory)
- 20% Prefer not to say

Q14: If you are happy to share this information, please can you tell us which type of treatment or operation you were / are on the waiting list for? Please select all that apply.

Base size: All respondents that have had recent treatment or are on a waiting list (49)

18% of patients requiring treatment or an operation were told they would have it within a month. A further 20% were told to expect a wait of one to six months and 40% were told they would need to wait at least seven months.

- 10%  Less than 2 weeks
 - 8%  3 to 4 weeks
 - 16%  1 to 3 months
 - 4%  4 to 6 months
 - 20%  7 to 11 months
 - 20%  A year or longer
- 20% Don't know*

Q15. Thinking about the waiting list you were/are on for your treatment or operation, how long were you / have you been told the estimated wait time will be?

Base size: All that had treatment in the last year or are on a waiting list for treatment (49)

Patients were split on acceptability of the waiting times they were told to expect, with a third thinking they were reasonable (8% extremely reasonable, 24% reasonable). A further third felt the waiting time was unreasonable (12% extremely unreasonable, 22% unreasonable).



Acceptability is lowest for those waiting longer for their treatment / operation.

Q16. Waiting times of some description are to be expected. Thinking about the estimated waiting time you were / have been given for your treatment or operation, on a scale of 1 to 5, where 1 is 'extremely unreasonable' and 5 is 'extremely reasonable', please can you tell us how reasonable you feel a waiting time of this length is?

Base size: All that had treatment in the last year or are on a waiting list for treatment (49)

Feedback on waiting time experiences in the qualitative focus groups were mixed. Some participants had good experiences, for instance being referred to a physio and offered an appointment the next day. Good communication drives many positive experiences:

“He [consultant] really walked through it and gave the timelines and “if I haven't contacted you by this time, feel free to get in touch and contact my secretary” and things like that. ... me as her daughter knowing that she's got a timeframe and that they're communicating with them made me feel a lot safer about her going into that procedure.”

Others had less positive experiences. The acceptability of the waiting times experienced for referrals/operations etc was dependent on their overall GP experience. Those that felt they were listened to, and could get convenient and timely GP appointments, were more likely to accept a longer wait, as long as they were kept updated. Those with poor general GP experiences were less satisfied with the waiting process.

“I have arthritis in my knee, and I did mention the doctor saying that I'd probably need to have a knee replacement sometime in the future, I said, “But I suppose at the moment the way waiting lists are, there's no point”, and he just shrugged his shoulders. Sometimes the pain is quite hard, but I try to ignore it, if you know what I mean, and try to power through it. I still try and do my exercises and I'm quite an active person. I've learnt to live with it really.”

One participant had to wait at least six months for a first physio appointment for debilitating post-COVID weakness which affected her mental health:

“At the time I was quite down about it, about having post-COVID and really needing some advice and some help. So yeah, it was, it was quite hard at the time.... Mentally, I went through a really difficult phase, something I’ve never really experienced before, so that was quite hard.”

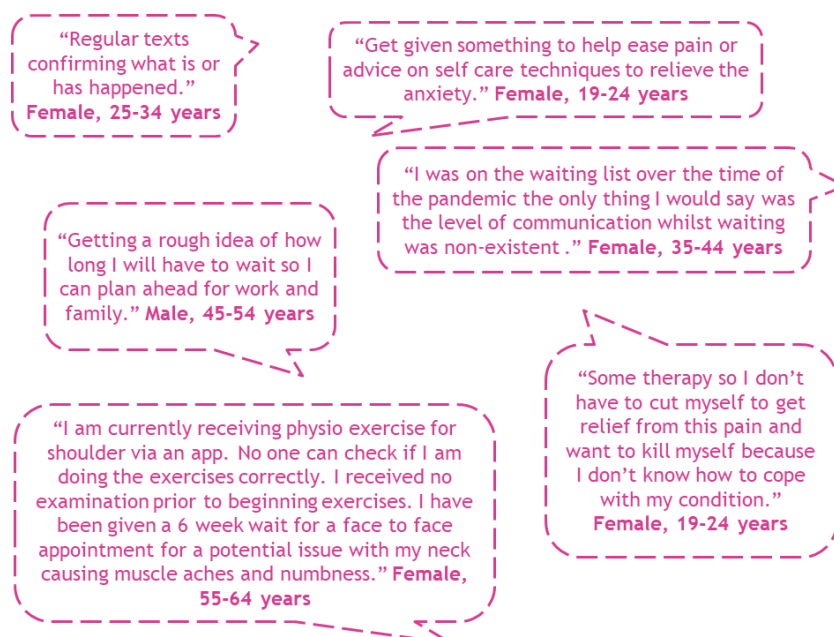
Patients waiting for minor procedures, e.g. steroid injections, often felt like they were assigned the lowest priority even when in significant pain. Waiting times are often undefined/down to individual doctors and the process is not clear to patients. This can make them feel less valued which in turn affects their mental health.

“I was told the doctor hadn’t put out the list yet but if I called back the next week, I might be able to, so I did. I am now on a list, but he hasn’t decided when he’s going to do it again.”

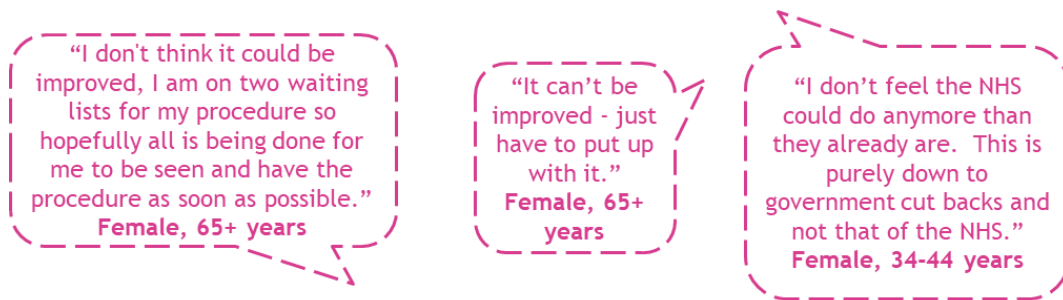
“The receptionist just said they’ll phone me once the list is open. It’s a bit frustrating.”

In the quantitative survey, although some patients were resigned to the length of the wait and felt they were being cared for, others felt abandoned, anxious, and uncertain. They would like more frequent updates on waiting time/treatment plans and more attention while they wait, including better access to interim care/treatment options.

Many patients would like to see changes:



And others were resigned to the wait:



Q18. In what ways, if any, could your experience whilst on the waiting list be improved?
Base size: All that had treatment in the last year or are on a waiting list for treatment (49)

Taking the first step of getting medical help for an issue can be a significant challenge for some patient groups such as some men. Experiencing lengthy waits for appointments and procedures or having tests cancelled can make them less likely to seek medical help in the future.

“It takes a lot for a man to pick up a phone to have a prostate test anyway, so for them to pick up the phone and ask for it, to be told we’re not actually doing them, one...that’s wrong information and two, that- again - is not acceptable when you’re talking about rehabilitation for people’s health. That shouldn’t happen.”

For children, waiting for a diagnosis for neurodivergence-related problems can be especially long, and difficult for the whole family. One parent told the group about her journey with her daughter’s ADHD and autism diagnosis:

“From starting at six, it took three years to sleep clinician, and she's only just been prescribed melatonin because she doesn't produce enough. That's what, five or six years or waiting to get a diagnosis and to get her the medication she needs so that she can function like a normal human being.... Me and my husband nearly split up through sleep deprivation, stress and things like that.”




Similarly to neurodivergence care, mental health care services were raised as having particularly long waits for diagnosis and care. Patients in a mental health crisis usually need urgent support and having to wait months for therapy or to see a psychiatrist is particularly hard. Their crisis may have passed by the time they see anyone, and whilst they might be feeling better, the impact of the earlier crisis on their long-term mental health can be significant.

“I do feel like people with a mental health problem, they need to be seen when they're feeling like that, not in three months or six months' time. The waiting list is so long.”

One patient with complex long term mental health problems described how inconsistencies in her care and multiple long waiting lists exacerbated her health issues:

“I feel like sometimes people in the mental health [sector] don't know where to put you, so I was with Life Cycle and then they were like, “no you need to go to community treatment centre” then they're like, “no you need to go hear at the early psychosis intervention” but you're on waiting lists for each different arm of the service while they're trying to figure out where exactly you belong and where exactly you can access health.”

In the quantitative survey, patients on a waiting list strongly agreed the NHS should do more to reduce waiting times. The majority also agreed that the delay to their treatment or operation was causing them stress and anxiety, and they worried their illness or injury would get worse while they waited. Fewer than a third received messages to update them on the waiting time.

	 Agree	 Neutral	 Disagree
I feel the NHS should be doing more to relieve the backlog that was caused by COVID-19 instead of relying on the pandemic to justify delays	71%	12%	12%
The knock-on effects of delaying my treatment on other areas of my life (i.e. being unable to work or exercise) are causing me to feel stress and anxiety	65%	18%	8%
I worry about how much worse my injury or illness might get and/or how much more damage may be caused while I wait for my treatment or operation	63%	20%	12%
The waiting time associated with this treatment or operation is causing me to feel stress and anxiety	59%	14%	22%
The length of the waiting time makes me feel undervalued as a patient	51%	22%	24%
I find appointments relating to my treatment such as the running of further tests reassuring because at least I know things are moving forward	41%	24%	16%
In the period between my referral and my treatment, I feel I have been provided with appropriate levels of support and access to additional healthcare services	35%	22%	39%
I am in a great deal of pain and the waiting time for the treatment or operation doesn't seem to be taken that seriously	35%	18%	29%
I have received messages keeping me updated on the progress of my appointment timing	33%	20%	37%

Q17. Using a scale of 1 to 5, where 1 is 'strongly disagree' and 5 is 'strongly agree', how strongly do you agree or disagree with each of the following statements about the waiting time associated with your treatment or operation? Base size: All that had treatment in the last year or are on a waiting list for treatment (49)

5. Experiences of waiting for test results

Frustrations with waiting times didn't only apply to those waiting for treatment or procedures. The wait for test results can be particularly emotional and difficult if it is longer than expected. Patients are not generally contacted by the GP surgery when their test results come in. They are expected to wait until their next appointment (if they have one booked) or phone themselves to check if the results have arrived.

“I’ve gone to see the GP, I’ve got the tests done, and it’s took that long to get the results, and my life’s been too busy, and blah-de-blah-de-blah, and it’s just dropped by the wayside, and I haven’t got the problem sorted. And six months later, because I didn’t sort it out six months ago, it’s four times as bad and literally you’ve got to do something about it then. It gets to the point where it overtakes your life.”

One participant was shocked to be referred for STD tests:

“On a holiday, I had to avoid those intimate moments with my partner. I never got a phone call back and when I did ring back, the results had come in really the same week I’d had the test and I was never told that it wasn’t that at all and it was simply just an ulcer. ... he felt I was accusing him and then he was accusing me and it was really uncomfortable. I was never given a timeframe, when I did finally ring up and be like, “someone needs to tell me because if it is I need to know what the treatment is, I need to know what the solution is and it’s”, “oh no you’re fine”. I was like, “That would’ve been really good information to have as soon as you had it.”

The wait can heighten anxiety about the outcome of tests, and reception staff are not always sympathetic to this on the phone. Participants complained of feeling like they were being a nuisance when they phoned to check on test results, or feeling ‘invisible’ when results are late coming back and being told there is nothing they can do to chase them.

“For people who are facing results like cancer results or anything like that, being left to just sit there and worry about it, you know, even just a quick message to say, “Sorry your results are not in yet, give another week and we’ll re-contact you,” will put somebody’s mind at rest, because they might be thinking, “ah well, is it bad? Is it bad and that’s why they’re waiting to contact us, because they’re waiting to sort other things?” You know where your mind goes when you’re waiting for stuff like that.”

One participant mentioned that it felt disrespectful to be told to “keep phoning” for test results that weren’t back yet when she was busy with work and every phone call takes a long time to get through. Another was made to feel like they were wasting the GP receptionist’s time when chasing test results.

“I’ve called up asking for the results and I’ve almost got the vibe that someone is irritated at me for not taking the silence as an answer. As if that was an answer at all.”

This concept of 'no news is good news' when waiting for test results is difficult for patients to deal with, particularly those that are already feeling anxious about their health. There was a perception that diagnostic services are not working hard enough to get test results to patients, even if they are good results.

"It's left to clinicians to deliver results and what typically happens is letters are left in the consultant's tray, secretaries don't have time to get it out and whilst it's good news for the patients, because cancer hasn't been found, they don't know that. It's the not knowing and even the family and the carers that are with these patients, it's just traumatic and everybody goes to Dr Google and then scares themselves mad."

They asked for a better system of communicating when test results had arrived, e.g. SMS messages.

"Bring some more volunteers in, there's loads of people wanting volunteering experience in the NHS, loads. I work with loads of them, that's part of my job, is managing a team of volunteers for the NHS. There's so many people, just send me a text."

6. Support and communication whilst experiencing waiting times

Experiences differed in terms of the support patients are offered whilst waiting for treatment. Most patients weren't offered any support, alternative therapies or updated whilst they waited, and felt abandoned.

“There was no “this is happening or that’s happening or we’re trying to do this or that”. There was no communication there and it became quite unbearable to live with. Not only was I affecting my physical health, my mental health was suffering because I was worried about if anything was going to get worse. I was worried that it wouldn’t happen, they wouldn’t fix it.”

Some were more positive about their wait, especially if their medical issue didn't particularly impact their day-to-day life.

“They offered me all sorts of different routes to try while I waited. I can’t really criticise them from that perspective.”

The common thread linking all experiences was the importance of communication. Unless it is a particularly urgent, or a painful problem, patients are willing to wait for treatment as long as they are kept up to date. Communication needs to include:

- The updated likely waiting time
- Any additional test results/implications (rather than not receiving any test results until all investigations are completed)
- Solutions to reduce pain/symptoms while waiting. e.g. physio exercises, dietary advice, painkillers, complementary therapies.

“To me, the method of communication is irrelevant as long as the communication happens. As long as there is a system in place that people know about and that people are regularly updated, that’s really the only important factor.”

Patients that feel they are not being looked after or kept up to date are more likely to give up and put up with symptoms/pain and may be less likely to seek help from GPs in the future until a condition becomes unmanageable.

Patients that do feel they are being kept up to date feel involved and more positive about their medical treatment.

“So all through the process of getting her diagnosed [with autism], it was emails backwards and forwards, letters with appointments, face to face appointments. It was great. It was absolutely brilliant. I cannot fault them at all. I felt involved. It was like I was involved in my daughter’s treatment.”

“I got a letter from my doctor and from the Sunderland eye infirmary within about two weeks saying we’ve got our referral, unfortunately I’m not an urgent case. They’ve got no appointments, they’re prioritising appointments to get through waiting lists. Was very clear, I thought the letter was really good and it did reassure me that actually it hadn’t just gone into somebody’s pile.”

The clarity and ease of understanding of test results was also raised as an area for improvement. When patients are often waiting longer than expected for test results, feeling that they don’t understand the results or implications can compound feelings of frustration and being let down.

“After waiting a long time to get an appointment for tests, anything I did get after the test to say what they found, was weeks later and using a bunch of jargon that I didn’t understand. For example, what hinted that it was chronic appendicitis, they said, “there’s uncertain significant inflammation of the appendix”. What does that mean?”

This need for better communication was universally acknowledged across all of the medical departments and health needs that were raised in the focus groups. Whilst patients appreciate that test results and medical reports need to be written in enough detail to be useful to medical practitioners, they would like to see an additional summary or way of communicating information that is aimed at the patients themselves, in plain English, who may have very little health knowledge.

“I think in terms of communication, what’s really important is it needs to be looked at through the health literacy lens. Within South Tyneside, we know that health literacy is a massive problem. Something like one in six adults across the country can’t understand information that’s given to them by health professionals.”

7. Conclusions and recommendations

In summary, although some participants were content with their experience of waiting times and waiting experience for NHS services, the majority felt that their needs are not currently met in terms of waiting times and communication.

The emotional impact of long waiting times for procedures can be significant and casts a shadow over expectations and perceptions of the whole NHS. Patients can become resigned to not getting quick treatment, referrals or reassurance, which means they are more likely to delay getting medical attention next time they need it until their symptoms are much worse.

There are a number of ways to improve the patient experience given the constraints on appointment availability and treatment waiting times:

1. Improve receptionist/care navigator training to include more empathy towards patients and a higher level of customer service even when phone lines are busy, and staff are under pressure.
2. Improve support available whilst waiting for referrals and treatment. This will help with mental health (not feeling abandoned at a time of high anxiety) and physical health (e.g. guidance on access to pain relief and alternatives such as home-physio and complementary therapies). Patients would benefit from more practical support whilst on waiting lists including: self-help strategies (whether around mental health, wellbeing, diet, or practical exercises) and complementary therapies available (e.g. talking therapy, homeopathy, acupuncture etc).
3. Communicate more with those experiencing waiting times for procedures. Patients waiting for procedures often feel forgotten. They would greatly value more updates on their position/likely time on the waiting list. Any regular communication, even if it is simply to confirm there has been no change in the wait time, would help make patients feel they are being cared for.
4. Set expectations for communicating to patients while they are waiting for test results, referrals and treatment. Especially when waiting times are long, patients would

benefit from regular updates to reassure them during their waiting time experience and offer any additional support while they wait.

5. Ensure all patient communications are written in easy-to-understand plain English with a minimum level of technical health language.

When patients feel involved in their own care and feel the NHS is invested in their personal wellbeing through communicating effectively and regularly, they are more likely to stay in a positive mindset and also be more accepting of longer waiting times and other challenges accessing a physical and mental health services.

8. Appendix: Respondent profiling from quantitative survey

Respondent profile

This section of the report details the demographic breakdown of the 181 individuals who completed the survey.

Before continuing with the questionnaire, respondents were first asked to confirm they lived in South Tyneside and were registered with a local GP (selected from a list). The survey ended if they lived outside of the area or were not registered with a GP from the list. In order to qualify for the survey, participants also had to confirm that they had had a GP appointment at least once in the last two years. This is to ensure all participants could share recent experiences of South Tyneside GP practices.

Gender

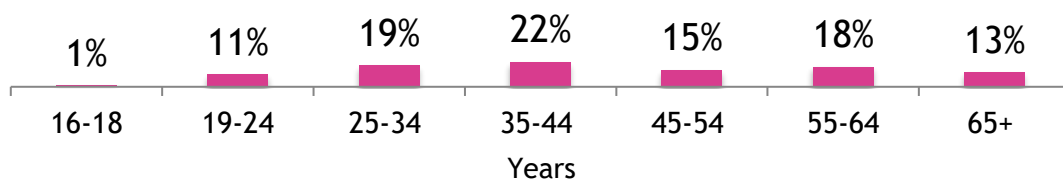
As a consequence of a primarily online methodology, where sample demographics were allowed to fall out naturally, a higher percentage of females (77%) participated in the survey, with males making up 22% of the sample. Two participants (1%) selected 'prefer not to say'. No participants selected 'prefer to self-describe'.



Q20: Please select your gender.
Base size: All respondents (181)

Age

Participants from all age groups completed the survey. Approximately a third were aged 16-34, just over a third were aged 35-54, and another third were aged 55 or over. Again, respondents were given the opportunity to select 'prefer not to say', and one person selected this option.



Q2: Please select the age band which applies to you.

Base size: All respondents (181)

Ethnicity

93% of those who took part in the survey were white: English/Welsh/Scottish/Northern Irish/British. 6% of participants identified with non-white ethnic groups.

Ethnic Group	
	White
93%	English/Welsh/Scottish/Northern Irish/British
1%	Irish
-	- Gypsy or Irish Traveller
1%	Any other white background
	Mixed/Multiple Ethnic Groups
-	- White and Black Caribbean
-	- White and Black African
1%	White and Asian
1%	Any other Mixed/Multiple ethnic background
	Asian/Asian British
-	- Indian
-	- Pakistani
1%	Bangladeshi
1%	Chinese
-	- Any other Asian background
	Black/ African/Caribbean/Black British
1%	African
-	- Caribbean
-	- Any other Black/African/Caribbean background
	Other ethnic group
-	- Arab
1%	Any other ethnic group
1%	Prefer not to say

Q22: Which of the following best describes your ethnic group or background?

Base size: All respondents (181)

Health problems or disabilities

A total of 47% of respondents said their day-to-day activities were limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months, with 22% saying their activities are limited a lot and 25% saying their activities are limited a little.



Q23. Are your day-to-day activities limited because of a health problem or disability which has lasted, or is expected to last, at least 12 months?

Base size: All respondents (181)

Caring responsibilities

Around a quarter of respondents were carers and regularly looked after another person. 76% of respondents had no caring responsibilities.



Q24. Are you a carer? By this we mean that you regularly look after someone to help them with their daily life because they're ill, disabled, or can't manage without your support.

Base size: All respondents (181)

Children in the household

Nearly two-thirds of respondents had no children under the age of 18 living in the household. 34% of households included one or two children.



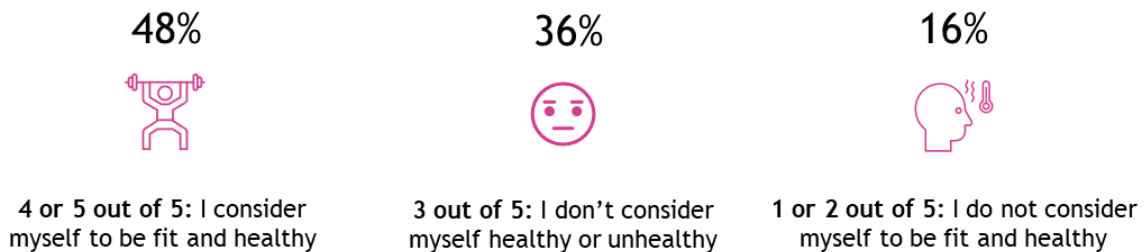
Q21. How many children under the age of 18 live in your household?

Base size: All respondents (181)

Health status and diagnosis

Current health profile

Just under half of respondents said they consider themselves to be fit and healthy. Of the remainder, 16% did not consider themselves to be fit and healthy.



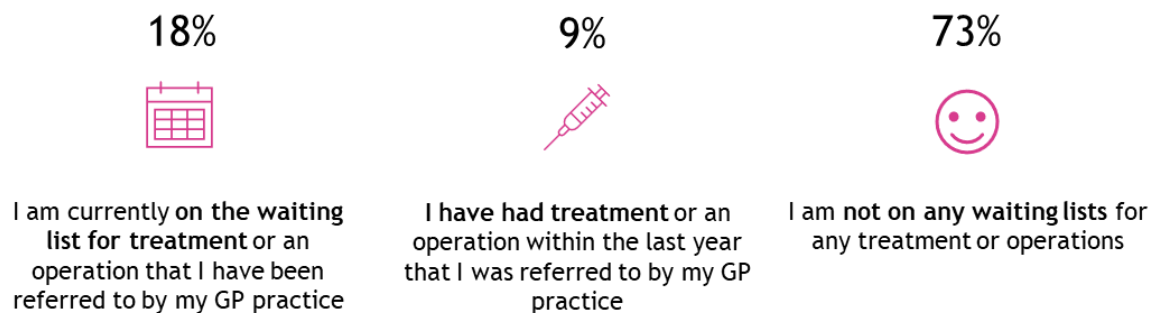
Those that consider themselves healthier see their GPs less often than unhealthy participants

Q3: On a scale of 1 to 5, where 1 is 'strongly disagree' and 5 is 'strongly agree', to what extent do you agree or disagree with the following statement? I consider myself to be a fit and healthy person

Base size: All respondents (181)

Medical treatment

Just over a quarter (27%) have either had treatment recently or are on the waiting list for treatment or an operation.



Q13: Please can you now tell us which of the following statements best applies to you? By treatment or operation, we mean procedures such as a knee or hip replacement or cancer treatment.

Base size: All respondents (181)