



# Your experiences of surgery waiting lists: improving communication and supporting marginalised communities

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# About Healthwatch

Healthwatch Bristol's statutory duty and remit, which is laid out in the Health and Social Care Act 2012, is to provide a voice for people who use health and adult social care services. We give people an opportunity to have a say, especially those whose voices are marginalised, or have protected characteristics. Where people have poorer health outcomes we refer to these population groups as health inclusion groups. In this report their views have been collated to influence service providers and improve outcomes, by taking public views to the people who make decisions. Healthwatch is committed to promoting equality and diversity and tackling social exclusion in all our activities. We aim to ensure equitable access to our initiatives and projects.

To support people facing surgical backlogs and their equity as peri-operative pathways are transformed, North Bristol NHS Trust (NBT) commissioned Healthwatch Bristol to undertake qualitative research.

The aim was to understand the experiences of patients on NBT waiting lists for elective surgery and surgical investigations. NBT wanted to know what is working and what needs improvement, particularly for patients who have been waiting longer than 6 months.

NBT especially wanted to hear from patients whose experience may be disproportionately impacted by healthcare inequality (their access, experience and quality to services is not equal) NBT identified patient cohorts which included those who are marginalised or seldom heard. It was proposed that Healthwatch would conduct this research by means of a survey, initially, followed by focus group discussions. This took place from December 2023 – March 2024.

## Executive summary

The report findings point to the opportunity for the following changes to support people from inclusion groups who are on a waiting list for surgery.

- Patients articulated their preference for more frequent communication during their wait for surgery.
- Patients felt that in addition to a medical-based pre-operative assessment, consideration should be given to personalised needs assessments of holistic factors (social, financial, housing) in advance of elective surgery.

- Despite a plethora of online sources of health information, patients' responses indicate they want to be directed to evidence-based sources and would like to have links to these in one place.
- Patients used some online "waiting well" resources but also wanted help in their community, in-person support and Social Prescribing.
- The findings of this project make a case for an integrated health and social care approach to pre-rehabilitation across organisational boundaries.
- The Trust to consider an audit of how patients' preferred method of communication is recorded.

## Who took part?

An online survey generated 45 responses. Two thirds identified as female and the rest male. The majority were aged 50 and over.

55% had been awaiting surgery for over 6 months, over half of these for over one year.

Over half of the respondents were from a set of patient data provided by NBT. These were people waiting for elective care and living in Bristol, South Glos or North Somerset's 10% most deprived wards according to the Index of Multiple Deprivation (IMD) [1], or people with protected characteristics including disability, ethnicity, age, neurodiversity, or people with additional communication needs.

'Seldom Heard' groups were targeted by a social media campaign; the groups are listed later in this report. We asked for demographic details from all participants.

Where this was given, ethnicity was 80% White British, 2% Asian British: Indian, 2% Mixed Asian and White, 11% White any other background. 8% requested language translation to participate. 31% declared a disability, 7% described themselves as neurodivergent, 13% said they lived with insufficient financial resources or long-term unemployment. 15% said they had limited family or other social networks.

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<sup>1</sup> Initiatives to maintain the health of patients awaiting surgery and improve post-operative outcomes are referred to as "waiting well" or pre-rehabilitation.

# Survey take aways

## **Communication between the hospital and patients about their waiting status**

68% respondents rated communication from NBT about their waiting times as “poor”, some saying they had received little or no information.

43 of the 45 respondents (95%) said they had not been directed to My Planned Care website [2] where the public can find information about waiting times for their hospital and speciality.

Patients awaiting an elective procedure said they would like to be contacted more frequently about their waiting status.

## **What online information is currently being accessed by patients while awaiting surgery?**

Despite 39 of the 45 respondents having digital access to health information online, this was not the preferred method for all of them. Participants who preferred in-person means of communication included those experiencing social isolation and adverse consequences of prolonged waiting times.

Only 20% said they had been directed to other websites such as the NBT page for patients and carers or the NHS website.

Of those who had been waiting over 40 weeks, 79% said they were unaware of the introduction by NHS England on 31 October 2023 [3] of the possibility of requesting referral to a different provider, if eligible.

## **Impact of waiting on patients’ health, wellbeing and daily activities and what support would help them manage this?**

Over half of respondents stated the condition they were awaiting surgery for was getting worse. They would like personalised, local support to optimise their health before surgery.

While 71% would seek pre-rehabilitation information online, 62% required a mixed approach of printed information, telephone consultations and in-person wellbeing support in their own area. Participants’ comments and case studies (page 19) illustrate the need for not only physical health advice but also support with non-clinical issues which indirectly affect physical, mental and social wellbeing. Several participants anticipated having complicated discharge needs post-operatively and asked for help to put arrangements in place pre-operatively.

# Background

The joint NBT / Healthwatch project ran from December 2023 – March 2024, initially targeting a cohort of people identified by NBT with a survey or options to connect in other ways. This offer was later extended to a wider audience via a poster campaign and social media. The NBT Patient Experience Team and the Patient Access and Inclusion Lead provided data for 464 patients from whom Healthwatch Bristol would invite views.

This project was undertaken in the context of prior and ongoing work by NBT in the aftermath of the COVID-19 pandemic carrying out the NHS England 2022 delivery plan for tackling the backlog of elective care [4]. The delivery plan identified the adverse effects of prolonged waiting on a patient's existing condition and acknowledged this "can also affect other aspects of people's lives...make it harder to maintain independence or continue to work [...] For older people, it can make recovery longer and harder, leading to loss of independence."

This project's findings mirror others that make a case for an integrated care approach. This report highlights the lived experiences of NBT patients awaiting surgery, particularly those at risk from poorer health outcomes. The quality rich data are local examples of those found nationally.

A 2023 King's Fund report on Health Inequalities on NHS Waiting Lists [5] acknowledged there were added implications of longer waits for people already at risk of poorer health outcomes, saying: "Recent analysis highlighted the disparity in waiting times around the country and a correlation with deprivation."

Healthwatch England's report in 2023 [6] demonstrated the impact of delayed treatment. It also was noted that patients **most** likely to be delayed included people with a disability, neurodivergent people, people on lower incomes, ethnic minorities, and LGBTQ+ people.

A similar study in Northeast and North Cumbria Integrated Care Board developed a "waiting well" programme to target some of the most clinically and socially vulnerable patients in those regions. A recent NHS England publication about this programme [7] reported "initially, ... it had a medically driven focus, but the programme revealed patients required support with non-related health issues too, such as financial worries and housing." It was developed with colleagues across the NHS, local councils and the voluntary, community and social enterprise sector (VCSE).

# Methodology

Healthwatch Bristol developed an online questionnaire with NBT to collect qualitative information, while also collecting respondents' comments via telephone interviews and focus group discussion.

A Data Agreement between Healthwatch Bristol and NBT was in line with GDPR regulations and approved by the NBT Caldicott Lead.

NBT supplied names and postal addresses. Letters were carefully composed to be accessible and understood by as many recipients as possible. Content followed the NHS Accessible information Standard [8] and was scanned for readability. Easy Read material was also available. The letter was in English but included a sentence in 10 languages, asking the recipient to contact us if they required translation.

Options for taking part in the survey included: Online (using a QR code in the letter, a link to our website), Email for the project team, Paper or large print copy of the survey, Telephone enquiries were welcomed, a designated telephone number for the project, WhatsApp and text messaging options.

## Survey design

The survey consisted of 18 questions. These invited a mix of multiple-choice answers and free text information boxes for comments.

The survey questions are available on the Healthwatch Bristol website (appendix 1).

Demographic questions were compulsory based on the project's aim to address service experiences based on equality, diversity, and inclusion. A "prefer not to say" choice was included for respondents who did not wish to share all personal information.

A retail voucher was offered as an incentive for respondents willing to take part in an interview or focus group. 17 participants took this option.

## Time frame

The participant letter was posted in the week before Christmas 2023 but had fewer than 20 responses. A second letter was sent in early January.

The project team used other ways to engage NBT waiting list patients with similar health and social factors. A poster campaign was launched in mid-January to promote the survey in 31 GP surgeries within the same IMD post codes as the NBT mailing list. Posters were given to local Social Prescribing networks and offered communications options. Healthwatch BNSSG's Engagement team promoted the survey at public events at Southmead Hospital and South Bristol Community Hospital Urgent Treatment Centre in January 2024.

To boost responses further, targeted social media was used from mid-January 2024, with a focus on inclusion groups on Facebook and using X (formerly Twitter) posts to community groups that serve those populations and the general population of BNSSG. NBT assisted in sharing social media posts within their own contacts and networks and with PALS.

Links and information about the survey were displayed on Healthwatch BNSSG social media, website, newsletter and the engagement hub in The Galleries.

Healthwatch had received no requests for translation after the mailout, but in order to reach out to these communities, we created translations of the survey in four of the most widely spoken foreign languages in Bristol: Polish, Hindi, Somali, Urdu. These were promoted on social media in early February and circulated to community groups serving populations in which these languages are spoken.

## **Survey response**

The survey was completed by 45 respondents in total. Two respondents participated by telephone, due to digital exclusion and visual impairment. Three questionnaires were completed by a third party on behalf of the respondent. Five people used the language translated surveys.

## **Focus group / telephone interviews**

17 respondents from the survey were contacted and of these, 7 consented to take part in focus group discussions in February 2024. Participation was invited in-person, online via Teams and by one-to-one telephone interviews. This enabled participation from those with a disability, who are neurodivergent or digitally excluded. The focus group represented those with long-term physical or mental health conditions, living with limited financial means, with limited family or social networks and long-term unemployed.

## **How could Healthwatch Bristol have improved the survey / methodology?**

Non-English speaking and minority ethnic groups were under-represented among the survey participants. It was noted by a representative of a Bristol community health organisation, Caafi Health, with whom we shared the translated survey, that some of the groups they support can be reluctant to complete surveys or may not recognise their importance. They said "I think it would be a real shame if we do not capture the experience of those communities you mentioned" and offered to share the survey, helping clients to complete it where possible. The approach needs to be unique to each community

Further work is indicated, using mixed methods of research including outreach and direct support through community engagement and drop-in sessions. This could involve partnership with the community organisations who represent harder to reach groups. Healthwatch advises this would necessitate a longer timeframe.



# Survey findings

## Demography

There were 45 respondents, over half the respondents were from NBT's shared mailing list with postcodes selected by NBT, the rest recruited via social media and poster campaigns. Female: 69% Male: 31%, 78% were aged 50 and over with 8% aged 80 or over.

80% white British /English / Northern Irish / Scottish /Welsh, 2 % Asian British: Indian, 2% Mixed: Asian and White, 11% Any other White background (4% preferred not to say)

11% of people requested a survey with a language translation, these either used the translated survey or had help from a third party / family member to complete it in English. 32% of people in the study declared a disability and 55% said they had a long-term health condition, 7% said they were neurodivergent, 13% described themselves as lacking financial resources or were long-term unemployed, 16% said they had limited family and social networks.

## How many people are waiting for six months & how many over a year?

While 37% of respondents had recently been added to a list within the previous six months, 55% had been waiting for over six months and included 14 patients who had been on a waiting list for over a year. Only two people had an operation cancellation.

## Type of operation / surgical investigation

One third were awaiting orthopaedic surgery, most of these being joint replacements. The others were under the care of a variety of specialities including gynaecology, urology, gastroenterology. 3 respondents were waiting for surgical investigations. 2 were awaiting elective surgery for skin cancer, presumed to be non-urgent but one commented "been told [it is] slow growing but how do I know that?" (Female, 65 – 79)

## Knowing their waiting time status (if known / stated) and whether this had been extended.

29% of respondents said their waiting time had been extended.

35% had not been advised of an initial estimate so were unsure if it had been extended.

"Surely confirmation of inclusion on the list would not be too much to ask?"  
(Female, 80+, awaiting Gynaecological surgery)

Some were not sure if they had been added to the list or were still on it:

“I have not received any information [...] to let me know how long roughly and reassure me I’m still on waiting list.” (Female, 18 – 24, awaiting knee surgery)

Of those who were aware of an extension, most understood the reason:

One commented that her expected wait had been “extended due to a miscommunication.” She had understood she was already on the list for a hip replacement but at another consultation 3 months later was advised that she had not yet been added. “I was then put on the list.” (Female, 25 – 49, awaiting hip replacement)

Another had been advised that “I’m now told I am the lowest priority” and that the estimated 3 – 6 months’ wait for would now be in the region of 9 months.’ (Female, 25 – 49, awaiting arthroscopy and labral repair)

However, some could not find out the reason for the delay: in summer 2023, having been given an estimated waiting time of 2 months, one respondent was still waiting in February 2024. A forthcoming telephone consultation in March 2024 had been cancelled with no new date.

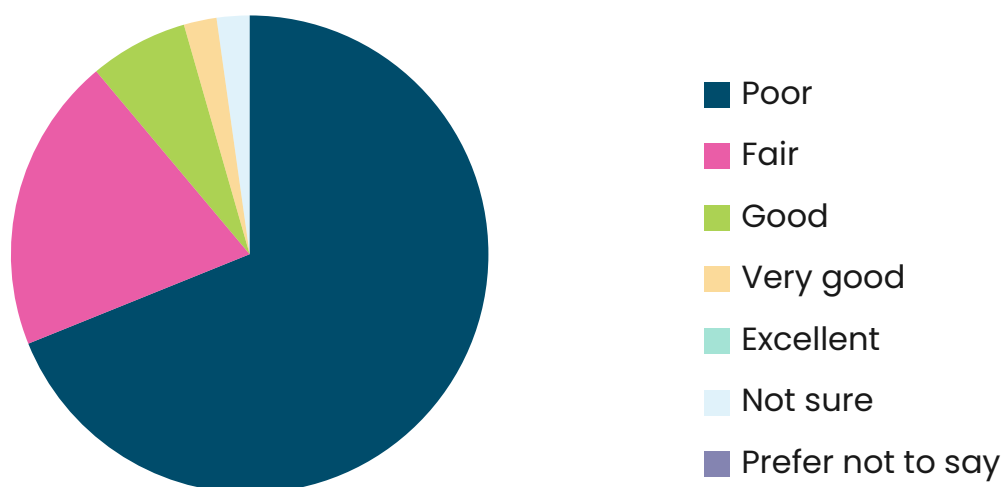
“I keep on phoning but no joy at all.” (Male, 65– 79, awaiting laser treatment of prostate).

### **Of those who had waited more than 40 weeks / nine months, how many were aware that they may be eligible to have their operation sooner at a different hospital?**

Only three of the 14 respondents who had been waiting over a year were aware that from October 2023, as part of the NHS England Elective Recovery Plan, they would have a choice or could submit a request to move provider (Patient Initiated Request or PIDMAS).

Only those who are eligible were contacted by the NHS when this was introduced last year. This could suggest that some of our respondents were ineligible. One mentioned she was under the care of a specific team and needed to plan well in advance for her recovery and understood it was inadvisable to be treated at a different hospital. She said accepting a short-notice cancellation would be “a nightmare” for her (female, 50 – 64, awaiting back surgery for over one year).

## How did respondents rate communication from the hospital while waiting?



While a third of respondents rated communication fair to very good the majority, 69% rated communication once on the waiting list as “poor”.

When asked why, some said it was because they had received little or no information.

“Good communication from orthopaedics but communications about waiting list poor.” (Female, 50 – 64, awaiting spinal surgery)

“Gynaecology (department) are good.., you do get a letter within a couple of weeks which is a reflection of what has been gone through, but it doesn’t give you anything about the wait [...], the systems in place are very poor.” (Female, 25–49, awaiting laparoscopy)

### Respondents’ comments revealed frustration at not receiving frequent updates

“Communication now and again would be good.” (Female, age 50 – 64, awaiting knee replacement for more than one year)

“It would be nice if contact was made to see how things are to reassess my situation.” (Male, age 65 – 79, awaiting back surgery for 4 – 6 months)

“They haven’t unless I have messaged them first. Any communication would be better than none” (Female, age not given, awaiting posterior repair for 4 – 6 months.)

“You are told you’ve been put on the list, then there’s nothing [...] there needs to be some form of communication throughout that waiting period. Just that you’ve not been forgotten.” (Female, 65 – 79, awaiting hip replacement for 4 – 6 months.)

“I would like them to ring me often to see where I stand for my operation.” (Male, 50 – 64, awaiting carpal tunnel surgery for more than one year)

## **How were patients informed they were on the waiting list for surgery?**

40% of patients hadn’t yet received any communication about the waiting list. Others said:

- 36% received a letter
- 4% received an email
- 17% received a phone call

One participant had found out by using the NHS App’s new waiting times feature introduced in January 2024.

**Some patients initiated contact themselves but had little information about who to contact:**

“It’s not always easy to find [...] I’ve just found the surgeons’ secretaries off the internet.”

“Then you get someone annoyed with you for calling because they’re the wrong people [...] It’s not easy to find stuff because you’re not signposted to the right place. You shouldn’t be having to do that when you’re in pain.”

“My daughter contacted them on my behalf” (80+ age group, declared disability, visually impaired).

## **Preferences for communications**

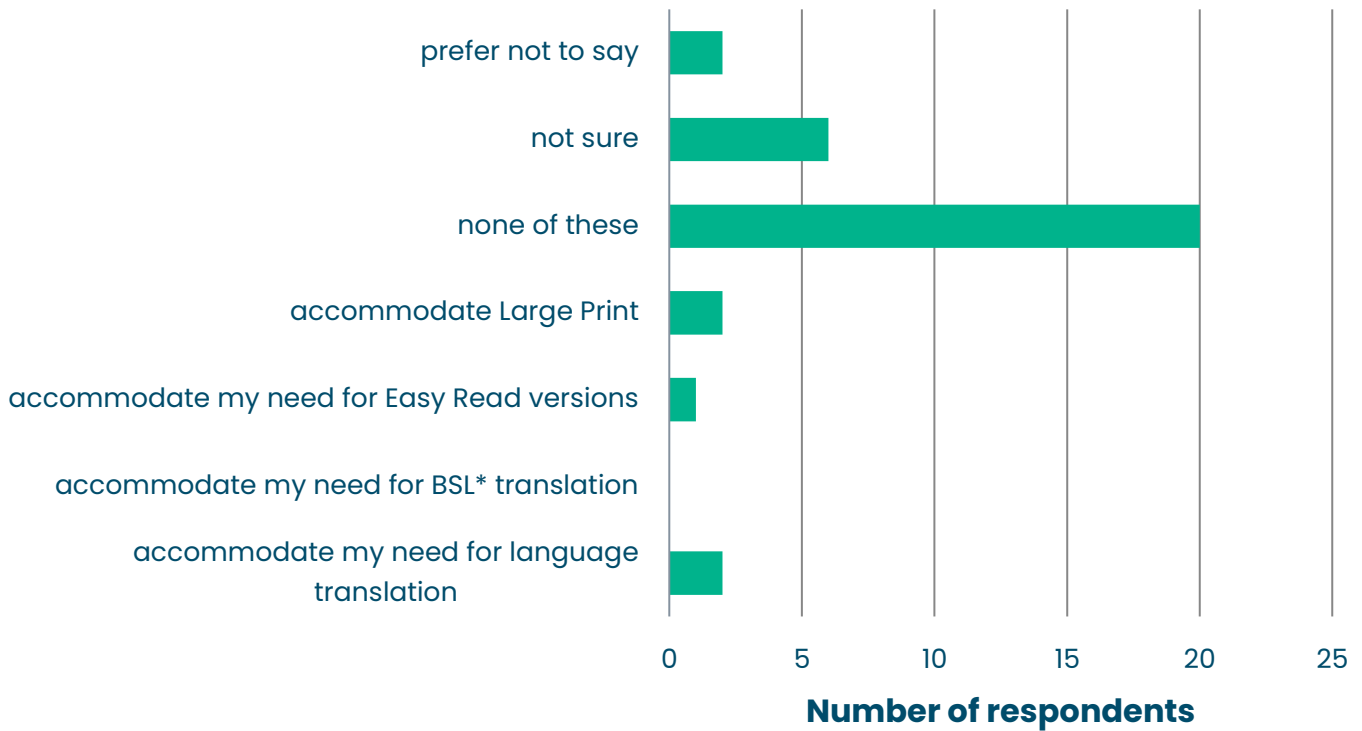
50% of respondents said they were happy with the method of communication. The other half who answered “unhappy” included those who had had none at all.

“[I’d be] happy to receive a phone call or letter” but selected the negative response because “I’ve not been sent anything. That’s why I’m frustrated as I don’t know if they still got me on list [...] and a rough idea how long I’ll be waiting”.

## Alternative (non-standard) communication preferences

We asked how communications sent out from NBT could be improved to be inclusive of those who need alternative forms of communication. This included people with a visual impairment, neurodivergent people, and people with a learning disability. The question was responded to by several of the focus group and interview respondents.

### How could communication sent by the hospital be easier for you to understand or receive?



4% of respondents asked for language translation of hospital communications, 2% asked for Easy Read and 4% Large Format. None of our respondents asked for British Sign (BSL\*) Language translation.

Comments from people who said 'none of the above' included one person who asked for "standardised letters so you don't have to call the admin staff to try and decipher what it means."

10% of people we spoke to requested some or all methods of communication via a third party such as an advocate, relative or caregiver. Their surveys, completed by family said:

"Mum is hard of hearing." Another mentioned that they had "completed on behalf of my severely disabled [adult] son"

A respondent who used the Polish translation of the survey stated she had received no information at all. Had she received any, she would have preferred a letter and needs language translation.

## Digital access to health information

87% of the 45 respondents told us they would be able to access health information by digital methods (phone, tablet, computer) but only 71% said they would choose to use this method for receiving health information over others.

Those who were digitally excluded, having no email address or computer at home, preferred communication from the hospital by phone or letter.

## Other methods of health information

Respondents had received health information about their operation by other means during their wait. 20% had leaflets, 46% had in-person consultation with doctor, nurse or other health professional. 8.8% had telephone consultation with doctor, nurse or other health professional. 35% of participants received none of the above. 2% of people volunteered information that they had accessed the waiting list section in the NHS App.

## Impact of waiting on health and wellbeing: respondents' needs and how they changed while waiting for any operation

### While you have been waiting has anything happened to your health or wellbeing?



While waiting, many respondents reported their condition had got worse (60%), condition improved (4%), they developed a different physical condition or one got worse (33%), they developed a mental health condition or one got worse (18%), they had work or income related impacts (4%). Many patients felt they missed out socially (47%), and almost a third experienced loneliness or isolation (31%), others felt that they experienced unhealthy consequences, such as becoming inactive (33%).

Respondents also talked of living with chronic pain, increased time off work, and sleep problems.

**“It's momentous, living in a world of pain, unable to pursue my interests and living like a hermit. Even standing and showering are difficult.”**  
(female, 65– 79, awaiting orthopaedic surgery for more than one year)

Of the respondents who said that the condition they were awaiting surgery for had become worse, 12 had needed to consult their GP to help manage their condition. Two had attended Accident and Emergency requiring urgent care.

29% reported an extension to their waiting time. Two had experienced a cancellation of their operation.

The focus group discussions and patient comments in the survey found many people taking charge of their lives but they were experiencing adverse effects of prolonged waiting despite their efforts to remain well:

“I am very much a pro-active person [...] with preventative stuff.” “Nobody's given me any advice on what to do and what not to do to stop it getting worse (but now) my life has become unbearable. My house is a mess. My social life is non-existent. I watch far too much television. Because I have major sleep issues and exhaustion.” (Female, 65-79, awaiting hip replacement, telephone interview)

“My condition hasn't worsened but it has continued - and it impacts on my ability to go to work when at its worst. I haven't lost my job but I have had increased time off work.” (Female, 25 – 49, awaiting hysterectomy, survey respondent.)

## **Information and support required by patients on waiting lists for elective surgery.**

We asked respondents if they received all the support and information they needed in relation to their operation: **29% said yes, 71% said no.**

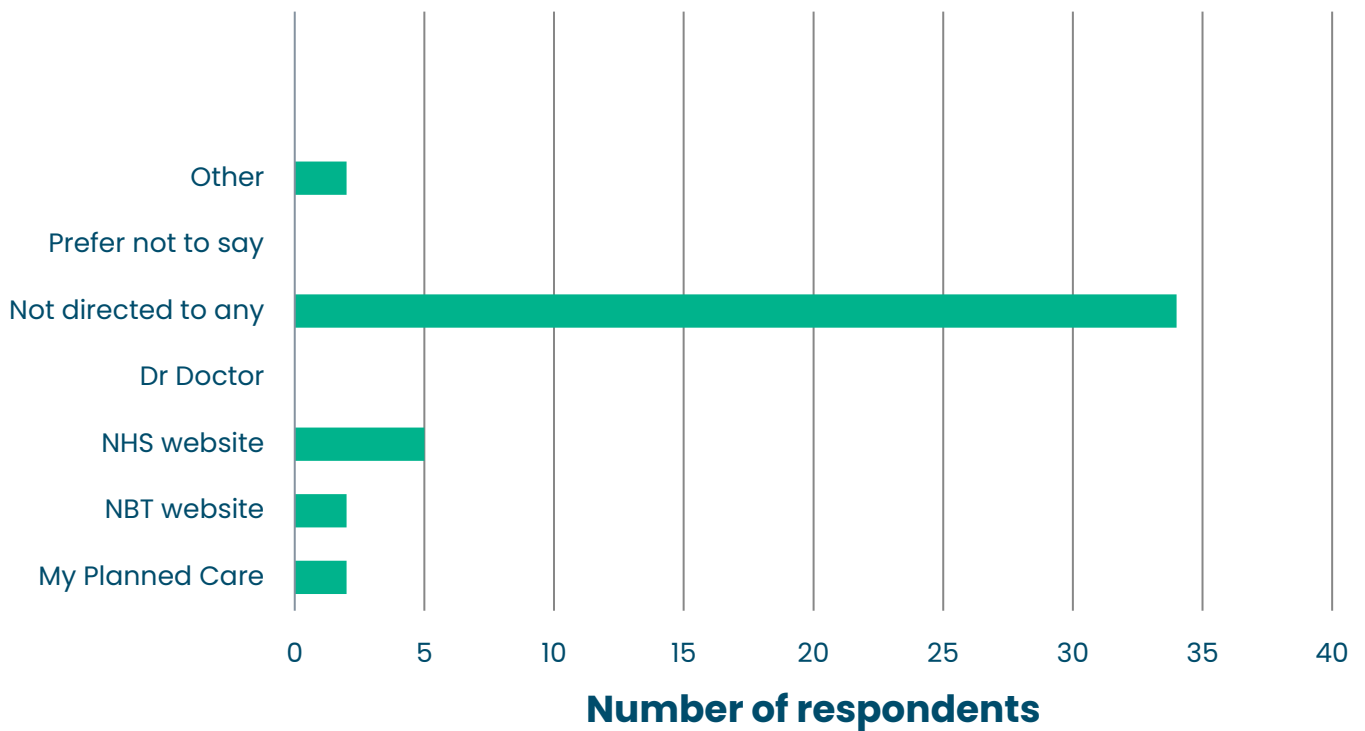
One patient said information they have had about the surgery is; “Very vague, would have liked more detail of how they would do it, what choices I have etc.” (female, 50 – 64, awaiting shoulder replacement, no estimated waiting time given)

38% of respondents said they would like help preparing for their recovery, 29% wanted help with an ongoing health problem, and 27% to prepare physically for the operation. In the section 'none of the above' respondents mentioned pain management and help to manage their home.

Only 20% of people while waiting had been directed to either My Planned Care, NBT Information for Patients and Carers, or the NHS website.

2 people said that they had used the NHS App for this.

### Have you been directed to any of these websites for information while waiting?





## We asked what help they want and how patients wish to access health information in preparation before surgery?

While the majority had access to health information online, those who expressed a preference for in-person methods (telephone consultations and wellbeing support in their own areas) had also declared social isolation, loneliness and had experienced unhealthy consequences of prolonged waiting time.

	Online website	Leaflets	By telephone	Wellbeing support in your local area	Prefer not to say	Other (please specify)
Help to prepare physically for my operation	7	7	2	3	0	0
Help to prepare mentally for my operation	6	1	3	16	0	0
Help to manage an ongoing health problem	10	5	4	4	0	0
Help to prepare for my recovery	11	8	3	5	0	0
Help from my local community	2	1	2	1	0	0
Help from others going through something similar	2	1	2	2	0	0

Respondents told us:

“She needs pain management, physio to prevent muscle loss, someone to physically see her. She gets conflicting info from various health professionals [...] disabled, mental health has declined since knee was injured” (Female, 80+, awaiting knee replacement. Visually impaired, does not use digital methods of communication, survey completed by relative on her behalf)

“Help in the home. Walking is painful. I find it hard to tidy up or concentrate to attend to paperwork” (Female 25 – 49, awaiting hip replacement, declared disability and neurodivergent, limited family and social networks)

**One focus group participant suggested: “Maybe a [group] meeting with others on same time frame for operations. Just for coffee and to talk over issues with someone. Occupational [therapy] etc.”**

“I have taken control of my weight privately, not via the NHS. I was told there was no provision for help with weight loss so I pay [BMI 42].” (Female, 25 – 49, awaiting hip replacement, declared disability, long-term health condition, limited family and social networks)

“Face to face”(Female, 50 – 64, long term health condition, limited family and social network, awaiting hemicolectomy)

### **Planning complex discharge arrangements in advance**

Several participants voiced concerns about wanting to plan their discharge arrangements before the surgery, rather than post-operatively.

“Rehabilitation, what I should be doing?” (female, 65 – 79, awaiting spinal surgery)

**“I think knowing how you’re going to be [afterwards]. At the moment, all you’ll hear is that you’ll be out of bed same day. It’s going to affect me more because of the problems of getting in [the front steps] and the stairs. That needs to be sorted out before the operation, not when I’m in hospital blocking a bed because I can’t get into my house.”**

“Mentally I’m very stressed.....I’m really, really frightened of coming out (of hospital) because of medication, shopping, and things like that. I don’t have any family support. Friends my age have got issues of their own.”

## Getting other support

18% experienced worsening mental health during their wait and asked for support not only with physical pre-rehabilitation but also to mentally prepare for their surgery:

**“I find I am in a lot of pain now, can’t do things I used to do, getting depressed from it all.” (Male, 50 – 64, awaiting elbow surgery for carpal tunnel syndrome, requested help to mentally prepare for surgery)**

Another focus group participant saw the benefit of support groups: “The mental health side of it, the loneliness, am I going to be able to fund the roof over my head, how do I keep working with this pain? All of that stuff [...] is bad for your physical health as well.” She added “When you hear other people’s stories, it gives you hope [and] you can actually talk about other things [...] that remind you that you are a real person. That you are not your pain, you are not your condition.” (female, 25 – 49, chronic pain, awaiting laparoscopy)

45% of participants said they are missing out socially with nearly a third said they were feeling socially isolated and lonely due to the impact of waiting.

For those living alone, some said that information and instructions online or by leaflet can be difficult to follow. Unsupervised physiotherapy and exercise raised concerns about “not doing it right.”

One socially isolated respondent expressed an interest in art and painting.

# Case studies

Names have been changed to preserve patient anonymity.

## 1: Diane



Female, aged between 50 – 64. Diane had been awaiting spinal surgery for over a year.

She has autism spectrum disorder and a long-term health condition. She has limited family and social networks and describes herself as living in poverty.

Diane's additional needs have been flagged by the hospital and she said that she has an "autism passport" in her medical records, designed to communicate her needs to doctors, nurses and other health professionals.



Her surgery was due in January 2023. At a pre-operative assessment a month before, she was given new information about the details of her operation that scared her, causing her to cancel at short notice.

At a subsequent appointment having had time to process the pre-operative information that had scared her, she asked to be put back on the list. She finally had a chance to discuss it with her Consultant in September 2023 and received confirmation that she was back on the list in November 2023, almost a year after her pre-operative assessment.

Diane can understand correspondence on her own but likes to take a friend or her social worker with her to appointments. Diane said at one of her appointments she had to point out that her autism passport was out of sight at the back of her notes, so thinks her needs had not been pre-empted in advance of her appointment.

## 2: Ali

Female, aged between 65 – 79. Ali had been awaiting a hip replacement for 4 – 6 months. She was recently advised that the wait will be a further 6 months.

She had been experiencing painful, stiff legs, groin pain and difficulty walking for which she was seeing a physiotherapist. She had an X-ray but did not hear anything for several months. She said the doctors initially did not think she needed a hip operation. She said “[I’m]very proactive with my health, with food, with my exercises”.

Regarding methods of communication, Ali says “I detest the computer, I lose things. I can’t find things. My eyesight is poor.” She prefers letters as she says her memory retention is poor too. “I can take some information in, a bit at a time and then I can scribble notes by the side as I’m reading it, as questions arise for me.”

Ali lives on her own and would like help to move house. “I need to downsize because it’s just too much.” She has a disability, is neurodivergent, has chronic fatigue and an underactive thyroid. Exhaustion had caused her to miss hospital appointments on occasion. She is visually impaired due to cataracts.

Ali receives social care Personal Independence Payments helping her pay for practical support each week: “it’s a lifeline for doing paperwork and sorting out phone bills and costs”

She would like someone to come and discuss her peri-operative support because she is terrified. “I mean, I can hardly cope now with a stick, my place is a mess, I can’t get on top of bills.....How am I going to manage if I have a hip operation and am on crutches?”

### 3: Cheryl



Female, aged between 65 – 79 has long-term conditions including Rheumatoid Arthritis and is registered disabled. She has had two knee replacements. Awaiting hip replacement surgery for 6 months, advised the wait could be 18 months. .

Has access to a computer and is digitally confident. She received verbal confirmation that she was added to the waiting List. She stated a preference for Large Print format but has had no letter.



She says she would appreciate “just some communication, that you’ve not been forgotten. You get automated reminders of appointments now. If they can do that, there’s no reason they can’t keep you updated on your whereabouts on the waiting list.” She feels unable to plan ahead.

She has noticed discrepancies in information from different service providers, “only slight differences, but enough to make you question what it is you’re doing.” Despite being able to access digital information, she did not like online physiotherapy exercises. “The exercise wasn’t anything I didn’t already know.” But Cheryl still wants to know she was “doing it right.”

Cheryl experiences dizzy spells which have caused 3 serious falls. She does not feel safe to exercise on her own at home and has had to cancel her gym membership of 30 years. Her pain worsened, causing her to become less active despite her efforts: “I was able to manage through two knee ops, working out in the pool was a great help to my recovery. I had got to a point where I could do aqua classes easily and was able to walk unaided.

Then in 2022, I developed severe pain [and] I finally [in 2023] got an X-ray which confirmed my right hip was severely affected.” The impact of her condition worsening while waiting contributed to loneliness and isolation and losing the health benefits of the gym.

She knows from previous experience that she will need to adapt her home post-operatively. She is worried of, “blocking a bed because I will not be able to access my house or go upstairs after the operation.” as the assessment isn’t until after the surgery .

She would welcome local face-to-face wellbeing support: “maybe a meeting with others in the same situation [...] for coffee and to talk over issues with someone, occupational therapy.”

# Considerations for NBT

1. Implement the five NHS England Elective Care 2023/24 core requirements [9] as priority, particularly the following:

**“Patients waiting for in-patient procedures should be contacted by their provider at least every 3 months.”**

**“Patients identified as having risk factors for poor perioperative or surgical outcomes should receive proactive, personalised support to optimise their health before surgery.”**

These core principles recommend that communications include **setting out clear steps to manage expectations of what will happen next with an estimate of likely and honest timescales. Patients require mechanisms to get back in touch.**

2. **Consider an audit of how and where patients’ preferred means of communication are flagged for practitioners.** The Healthwatch “Your Care, Your Way campaign” 2022 [10] offers guidance on how Trusts may facilitate the delivery of the NHS Accessible Information Standard. This recommends that patients ‘information and communication needs ‘must be identified at registration or upon first contact with the service.’
3. **Patients awaiting surgery would like to be directed to various evidence-based, recommended sources with links to these in one place.** It is hoped the new, integrated BNSSG webpages will be included.
4. **Online support should complement, but not replace, the role of community, in-person support, Social Prescribing and personalised needs assessment.** Include effective use of the online “waiting well” resources and proposed pre-rehabilitation App being developed by NHS England Transformation Directorate [11].
5. **Patients would benefit from being referred to a comprehensive pre-rehabilitation / waiting well programme that crosses organisational boundaries.** Patients who need an integrated health and social care approach could be identified by means of an additional, pre-operative social needs assessment. This would be in addition to established medical pre-operative assessment. Patients asked for support with holistic factors (social, financial, housing, discharge arrangements) in advance of elective surgery.

# Acknowledgements

Healthwatch would like to thank NBT and all those who participated in this study and shared their personal experiences.

Bristol Transcription and Translation Services for translating the survey and transcribing the recorded Focus Group Interviews.

Thinklusive for creating an accessible Easy Read leaflet for Focus Group participants.

Caafi Health.

Babskie Spotkania, Bristol.

And the many others who helped promote this project:



# Responses

**Maria Kane, Joint Chief Executive of North Bristol NHS Trust and University Hospitals Bristol and Weston NHS Foundation Trust.**

We are pleased to receive Healthwatch Bristol's report looking at patient experience whilst waiting for elective surgery in our hospital. We approached Healthwatch to undertake this piece of work as we wanted to enhance our understanding of the experiences of patients on a waiting list, particularly from marginalised backgrounds or those with protected characteristics.

The findings in this report reflect several key challenges that our patients face whilst waiting for surgery. Whilst these are not completely surprising, the responses and identified themes do undoubtedly provide a richer insight than we've previously seen and will help focus our attention on specific improvement actions that will make a meaningful impact.

We are pleased to report that work is already underway against several of the recommendations made in this report.

For example, the recommendations encourage us to contact patients waiting for in-patient procedures at least every 3 months. We have an established administrative process in place to contact patients to ensure they still require and want surgery and are moving towards ensuring this is completed every 3 months, in a way that is accessible for the patient.

The recommendations also suggest that patients would benefit from being referred to a comprehensive pre-rehabilitation / waiting well programme that crosses organisational boundaries. We are planning to introduce a patient screening questionnaire to develop a pre-operative management plan for patients whilst they wait for surgery. Patients will complete this questionnaire at the time of listing for surgery and this will support proactive management of patient pre-operative pathways. A pilot for Orthopaedic in-patients is planned to commence from mid-April onwards.

We are part of a system-wide Peri-operative Pathway Steering Group and Health Inequalities Steering Group where we will be sharing this report and working through the recommendations. In addition, we have identified reducing health inequalities as one of our Trust's Quality Priorities for 2024/25 and have our own internal Health Inequalities programme and Accessible Information Standards Steering Group which will help us oversee progress against each of these recommendations.

# Responses

Dr Seema Srivastava MBE, Deputy Medical Director, University Hospitals Bristol and Weston NHS Foundation Trust and Consultant Medicine for Older People, Front Door Frailty and Peri-Operative Medicine, North Bristol NHS Trust.

Waiting Well is a key Quality Objective for UHBW. We used insights from our Health Matters Waiting Well public engagement event in October 2022 to build on our Waiting Well group, with patient representation to help guide our focus and approach. Our efforts have been invested in improving the quality of information on our 'Preparing for your appointment or procedure' webpage, the introduction of our DrDoctor Patient Portal, improving the availability of waiting times information available on the My Planned Care website, and participation with the NHS England roll out of the e-Meet and Greet feature on the NHS App to provide patients with confirmation that their referral has been received by the hospital. We continue to listen to our patients and community partners, with a strong focus on Health Inequalities and Waiting Well.

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# Appendices

## Appendix 1: survey questions

## Appendix 2: Listing of social media posts

## Appendix 3: Easy Read leaflet

View or download appendices 1-3: [www.healthwatchbristol.co.uk/patient-experiences-elective-surgery-march-2024](https://www.healthwatchbristol.co.uk/patient-experiences-elective-surgery-march-2024)

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