healthwatch
Leeds

NHS Long Term Plan

#WhatWouldYouDo?
People from West Yorkshire and Harrogate and Craven share their views
April 2019

what
would you do?
It's your NHS. Have your say.

healthwatch Kirklees
healthwatch Bradford and District
healthwatch Calderdale
healthwatch North Yorkshire
healthwatch Wakefield

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Introduction

In 2018, the government announced that the NHS' budget would be increased by £20 billion a year. The following January, the NHS in England published a 10-year plan for spending this extra money, covering everything from making care better to investing more money in technology.

The plan sets out the areas the NHS wants to make better, including:

- **Improving how the NHS works so that people can get help more easily and closer to home;**
- **Helping more people to stay well;**
- **Making care better;**
- **Investing more money in technology.**

For more information about the NHS Long Term Plan, visit https://www.longtermplan.nhs.uk/

West Yorkshire and Harrogate (WYH) Health Care Partnership were asked to formulate a local plan in response, specifically a 5-year strategy. To ensure this reflected what local people want, our six Healthwatch organisations were commissioned by Healthwatch England to find out local people's views. To do this, we used two surveys and 15 focus groups, engaging with 1806 people in total over a period of two months.

This report sits alongside two reports that the WYH Care Partnership have also completed. One brings together previous information regarding people's thoughts about digitalisation and personalisation; and the other is an engagement and consultation mapping report which sets out the work that has taken place in the six local areas and at a West Yorkshire and Harrogate level.

Key Findings: General survey and focus group

- People told us that the main things they do to keep healthy and well are **exercise and healthy eating**. People wanted support from the NHS and its partners to make it **easier and affordable to keep fit and eat healthily**, as well as more pro-active **support around weight loss**.

- There was a commitment to **self-care** from people who responded to our survey. 9% of people told us that the NHS could help them with this by providing **more information and advice** about healthy lifestyles and how they can better monitor their own health. People were also keen for more prevention of ill health through increased access to **regular general check-ups** as well as screening for specific conditions.

- People want the NHS to provide **easier access to appointments**, mainly with their GP but also with hospitals. Access to appointments was the single most mentioned theme (18% of responses) when people were asked what the NHS could do differently to help them stay healthy and well. The speed with which people could make an appointment was cited as one of the most important things for people when talking to health professionals about their care. People wanted the option of longer appointments, more appointments outside working hours, more appointments available to book online (including same-day appointments) as well as more availability of virtual and telephone appointments.
- **Mental health** was a recurrent theme running throughout responses to many of the questions in the survey. The main findings were:
    - People wanted mental health services to be **more accessible** for people of all ages, with shorter waiting times and easier and quicker assessments.
    - People felt that the **waiting times** for counselling and therapy were far too long, risking a detrimental effect on a person's mental health during the wait.
    - We were told that there needs to be **better emergency support** for people in mental health crisis, and current services are not working well.
    - Mental health services need to be more appropriate and **accessible for people with autism, deaf people and speakers of other languages** who may need an interpreter.
    - There should be more investment in **community support** before people reach crisis point.
    - People want to see more of a focus on prevention of poor mental health through **raising awareness around looking after your mental health** and how to help yourself (e.g.: running mental health first aid courses and general awareness sessions in schools and communities).
    - **Children and young people's mental health services** were highlighted as an area of concern. Respondents said in particular that referral thresholds were too high and waiting lists too long,

and they also cited concerns about the detrimental effects of children having to travel to inpatient units out of area.

- People who were using **digital services** told us that they were mainly booking appointments, ordering repeat prescriptions, finding information and making contact with health professionals. The positives cited for digital services were that they were **convenient and easy to use.** Negatives that were mentioned were that there is not enough access for online patients (e.g.: to appointments or medical records) and that some digital services needed to be **more user-friendly and joined up** with other health and care service systems.
- Whilst the majority of people were in favour of having the option to access the NHS digitally, more than 500 people (41% of respondents) told us about **barriers to using online services**. These included **access to digital technology** (e.g.: not having a suitable device or internet access) and **lack of skills and confidence**. People were concerned that too much dependence on digital technology could create **inequalities** in the system, where particularly older or disabled people and those on low incomes or with language or literacy issues were disadvantaged. Many people were also clear that personal contact was important to them and may be a factor in whether or not they would choose to access the NHS digitally.
- When asked where they would go for an **urgent medical need** (other than A&E or their GP), the majority of respondents told us that they would either call NHS 111 (31%) or attend a minor injuries unit/urgent care centre (22%) or other urgent care provider (31%). A significant number of responses (16%) indicated people weren't sure where to go. There was also **much confusion around the difference between minor injuries units, urgent treatment and walk-in centres**.
- The majority of respondents were satisfied or very satisfied with their experiences of the different **urgent care services** in the last 12 months. The highest rates of dissatisfaction were with out of hours GP services (i.e.: out of hours telephone consultations, home visits, or referral to another GP practice) which had an average dissatisfaction rate of 27%.
- 21% of responses mentioned **education as being crucial to ensuring children and young people live healthy lives** and have the best start in life. This included the NHS and its partners educating parents and carers about making healthy lifestyle choices for their children.

Schools were cited as having a key part to play and people felt that there should be a whole system approach to children's health and wellbeing, and for it not just to be the responsibility of the NHS.

- As well as education, **early support** was an area that people saw as key to children living healthy lives. This included supporting mothers during pregnancy, supporting families with new-born babies, early diagnosis of conditions and support through childhood.
- 22% of people who answered the survey question about **personalised care** were unable to give a definition of it, either because they didn't know, hadn't heard of it or said it wasn't applicable. This figure was higher for BAME communities (37%) and young people aged 15 or under (33%). Those who were able to give a definition understood some of the different elements of it. This included recognising that it is about what matters to individuals and that they are at the centre and a key partner with choice and control over their care. People also mentioned how personalised care looks at the person as a whole and includes physical and mental health, as well as other factors such as housing, family and support networks.
- **Communication** came up throughout the survey responses as key to good personalised care. Primarily people told us they **wanted to be listened to and spoken to as individuals**, as well as **treated with dignity, care, compassion and respect**. Particular communication issues were raised by people with sensory impairments around making information accessible and adhering to the **Accessible Information Standard.**
- When people were asked if they could change one thing about the way the NHS works, the most common response was that people wanted it to be **more efficient**. People wanted to see a change in the structure so that there is less management, more efficient administration systems and more front-line staff who are well trained, supported, and have a good work environment.

Key Findings: Specific Conditions survey

- People with physical conditions are **generally more satisfied** with the initial support they get than people with non-physical conditions (see p.70 for definitions of physical and non-physical conditions).
- People with physical conditions are **more likely to get support** quickly

than people with non-physical conditions.

- People with non-physical conditions are **more likely to find ongoing support** inaccessible and unsatisfactory.
- Having more than one condition often **makes it harder to get initial support**, especially if you have non-physical conditions.
- Ongoing support is most likely to be considered helpful when it involves **reliable, regular person-to-person contact**.
- Respondents feel that ongoing support could be improved if it were made **more reliable and personalised and if it recognised their emotional needs.**
- People with **mental health conditions** are particularly likely to feel their ongoing support is inadequate because they have been given the **wrong diagnosis or therapy**.
- **Cancer services** often provide **effective communication**, whereas mental health and autism services' communications are often felt to be inadequate.
- Most people **get around in their own car** and are **willing to travel slightly longer to see a specialist than to get a diagnosis**.
- At the beginning of the care process, people prize speed over familiarity with health professionals, but once they are in a treatment routine they prefer familiarity over speed.

Next steps

This report will be shared with West Yorkshire and Harrogate Health and Care Partnership. We will work with them to ensure that people's views expressed in this report are taken into account throughout their five-year strategy. We will also share the content of this report with as many other strategic partners as possible in health and care and beyond.

We will share findings with people who took time to share their views and the report will be published on all of the West Yorkshire and Harrogate and Craven local Healthwatch websites, as well as the West Yorkshire and Harrogate Health and Care partnership website.

Each local Healthwatch involved in this piece of work will also be looking at the data for their local area to pull out any local variations and themes.

Response from West Yorkshire and Harrogate Care Partnership

We are delighted that Healthwatch colleagues have reached over 1800 people with the local survey on digitalisation and personalisation, as well as many others for the long-term health conditions national survey. It's also helpful to read further comments gathered on other areas of our health and care work, including the importance of: *'partners working together to make it easier and affordable for people to say fit and eat healthily,* as well as *'more pro-active support around weight loss'*; and concerns around *'better emergency support for people in mental health crisis*' – an area we are working hard to address together.

It's also heartening to hear that as well as the surveys, local Healthwatch colleagues have coordinated over 15 focus group sessions across the area with seldom heard people from different equality groups such as those with mental health conditions; dementia and carers, LGBTQ, disability, faith groups and young people. The voice of carers taking part in the focus groups endorses our programme approach that: *'carers need more support to keep them safe and healthy including regular health checks, respite care and flexible appointments to fit round caring responsibilities'*.

The comments received around quicker appointment times are very helpful. This is a fundamental part of the primary care and urgent and emergency care programmes. For example, Yorkshire Ambulance Service NHS Trust (YAS) had been awarded the contract for NHS 111 telephony, call handling and core clinical advice service (referred to as IUC) in Yorkshire and the Humber. This will see an increase in clinical advice and direct booking; clinical validation for emergency department referrals and managing dental calls for children under five.

We will be sharing this eagerly awaited report with all our priority programme leads and asking for their response on how they intend to make best use of the findings in their work plans.

This engagement report will also be discussed at our leadership meetings, including the Clinical Forum; West Yorkshire Association of Acute Trusts (hospitals working together); The Mental Health, Learning Disability and Autism Collaborative; and Joint Committee of the Nine Clinical Commissioning Groups; as well as the Partnership Board which meets in public in September 2019. Members of all leadership groups are keen to read the report and to act on the findings wherever possible.

Key to all of the above is our next steps. I'm sure colleagues working in Bradford District and Craven; Calderdale, Harrogate, Kirklees, Leeds and

Wakefield will find the report very useful when planning any further engagement work needed at a local level as we will for the West Yorkshire and Harrogate priority programmes. The engagement findings are an important part of developing our Five Year Strategy.

One clear theme worth noting is that people want us to work: *'towards stopping folk getting ill rather than curing illnesses*. This message of preventing ill health, early help and intervention is consistent with the conversations held at the Partnership Board meeting in public in June.

The importance of joining up services for people at a local level in Bradford District and Craven; Calderdale, Harrogate, Kirklees, Leeds and Wakefield will remain at the heart of local and West Yorkshire and Harrogate Plans. All decisions on services are made as locally and as close to people as possible.

With this firmly in view, our Five Year Strategy (which we hope to publish at the end of the year) will describe how the health and social care workforce of over 100,000 in West Yorkshire and Harrogate is changing to meet the current and future needs of the 2.6 million people living across the area – the approach we will take is in line with the recently published 'Interim NHS People Plan'.

Our strategy will recognise the huge contribution community organisations and volunteers make; and the vital role of the 260,000 unpaid carers who care for family and friend's day in day out and whose numbers are more than that of the paid workforce. All significant areas mentioned in this helpful engagement report.

As work on the strategy gets under way, ambition must be joined with realism, transformation and sustainability. Framing the ambition around improving people's health and a new deal with the public offers the best opportunity for the future – having the Healthwatch engagement report to hand will help us develop this further.

People's comments around self-care, communications, and the personalisation agenda will be well received - for example the West Yorkshire Cancer Alliance Focus Group said: *'they wanted communication to be improved between primary and secondary care and time between follow up appointments to be reduced'*.

The wider determinants of health, for example housing, employment and household income are ever present in our Partnership approach and it's helpful that this is an identified theme in the report.

Background

In 2018, the government announced that the NHS budget would be increased by £20bn a year. In January, the NHS in England published an ambitious ten-year plan showing how this extra money will be spent.

The plan sets out the areas the NHS wants to make better, including:

- **Improving how the NHS works so that people can get help more easily and closer to home.** This includes, for example, being able to talk to your doctor on your computer or smart phone; access more services via your GP near to where you live; use other community services which could improve your health; and leave hospital without delay when you are well enough.
- **Helping more people to stay well.** This includes things like helping more people to stay a healthy weight or to stop smoking. It covers helping to tackle air pollution and making sure your health isn't worse because of where you live, the services and treatments available and the amount of money you have.
- **Making care better.** The NHS wants to get even better at looking after people with cancer, mental ill health, dementia, lung and heart diseases and learning disabilities such as autism.
- **Investing more money in technology** so that everyone is able to access services using their phone or computer, and so that health professionals can make better, faster decisions.

The NHS hopes that by spending more money on services in the community, and by making sure that care works as well as possible, it can save money overall and ensure people have all the support they need. For more information about the NHS Long Term Plan, visit https://www.longtermplan.nhs.uk/

Why we did it

West Yorkshire and Harrogate (WYH) Health and Care Partnership were asked to come up with a local plan explaining how the priorities in the NHS Long Term Plan will be delivered in our area, specifically a 5-year strategy. In order to make sure that this plan responds to what local people want, our six local Healthwatch organisations (Leeds, Bradford, Kirklees, Calderdale, Wakefield and North Yorkshire) were commissioned by Healthwatch England to find out local people's views of priorities in the plan. After looking at all the different engagement work that has taken place in our area, the WYH Care Partnership team wanted to hear from different communities and groups who may not ordinarily get their voice heard, or people with the greatest health inequalities. They also identified that it would be great to know more about what digitalisation and personalisation meant to those different communities.

This report sits alongside two reports that the WYH Care Partnership have also completed. One brings together previous information regarding people's thoughts about digitalisation and personalisation; and the other is an engagement and consultation mapping report which sets out the work that has taken place in the six local areas and at a WY&H level.

What we did

This piece of work was completed over 8 weeks, between March and May 2019. We gathered people's views using two surveys and speaking with them at 15 focus groups. The surveys were completed face to face during outreach sessions with different groups and services in the West Yorkshire and Harrogate and Craven area, and were also available online. The online surveys were shared and promoted through all of the West Yorkshire and Harrogate and Craven Healthwatch networks and communication channels as well as those of the West Yorkshire and Harrogate Care Partnership.

There was a focus during both the outreach work and the focus groups on reaching different communities and groups of people who may not ordinarily get their voice heard, and who may also experience the greatest health inequalities. We spoke to people in libraries, community centres, children's centres, bus stations, colleges, Gypsy and Traveller sites, markets, hospitals, local events, GP surgeries, faith establishments, luncheon clubs, youth groups and women's centres. For more information about where we ran the focus groups and did outreach, see Appendices 3 and 4.

The general survey was hosted by Healthwatch Leeds (HWL) and adapted by West Yorkshire and North Yorkshire Healthwatch organisations from a generic Healthwatch England national survey. The revised survey was more relevant to local plans and we made it more user-friendly, accessible and simple to complete. It asked what was important to people when it comes to staying well and accessing health services. Part 1 of this report is structured around the questions from this survey which can be found in Appendix 1.

The second survey was hosted by Healthwatch England and asked what the NHS could do differently or better to help people stay well and provide improved support for people with specific long-term conditions. These included cancer, mental health conditions, heart and lung conditions, learning disabilities, autism, dementia and other long-term conditions such as diabetes and arthritis. Part 2 of this report outlines the findings of this survey and the survey questions can be found in Appendix 2.

Promotional materials for the project were arranged by Healthwatch England and adapted to suit our local needs. They were accompained by Healthwatch England's social media campaign, #whatwouldyoudo.

To ensure we had a good spread of people geographically and in terms of communities of interest, each Healthwatch was asked to identify groups in their local areas. HWL developed the resources and co-ordinated most of the focus groups. The focus groups asked people who wouldn't always have a chance to voice their opinions about their views on digitalisation and personalisation. If a person was unable to attend a focus group or felt uncomfortable in a group setting they had the option of filling in a survey individually. Focus groups lasted no more than an hour each.

Both surveys took around 20-25 minutes to complete. All respondents gave their written consent for Healthwatch and the NHS to use their responses and were reassured about personal details being kept confidential and the content of their answers remaining anonymous.

In total, we engaged with 1806 people. The general survey was completed with 1437 people, 233 completed the Specific Conditions survey and 136 attended the focus groups. To see a breakdown of this by local area, see Appendix 3. Equal opportunities monitoring data for both surveys can be found in Appendices 5 and 6.

It should be noted that there were an additional 47 responses to the Specific Conditions Survey from the Harrogate and Craven (North Yorkshire) area. However, due to timescales in which we received the data for this area we were unable to include the quantitative data in the analysis, although we have included some quotes where appropriate.

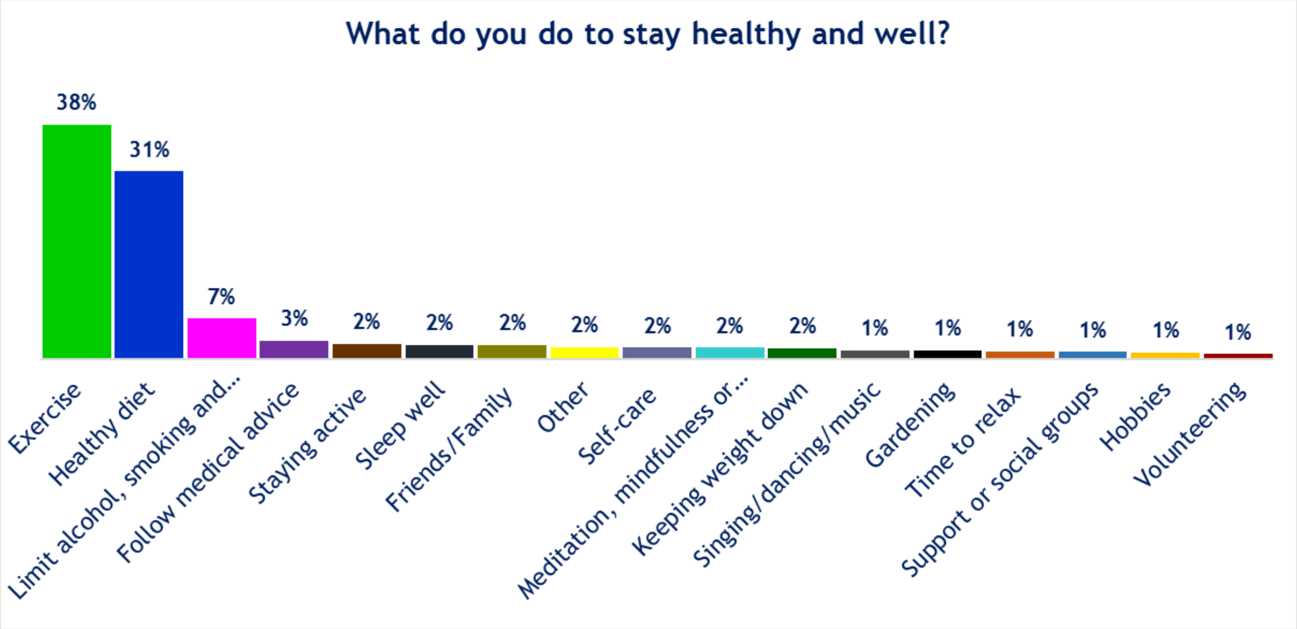
Part 1: Findings - General survey and focus groups

Note about our data

A total of 1437 people completed the general survey and 136 people attended the focus groups. However, it should be noted that not everyone who responded to the survey answered every question and, as a result, the percentages cited under each heading are worked out on the basis of the number of responses to that particular question.

Question 1 asked people to give their permission for us to use their survey responses, and question 2 asked which area people lived in. See Appendix 1 for full details of the questions and Appendix 4 for a breakdown of responses by geographical area.

Q3. Tell us up to three things you already do to stay healthy and well



This question was asked both in the general survey and in all focus groups. In total there were 3972 individual responses from the survey (people were asked to state up to three things each, resulting in multiple responses).

By far the most common answers were doing some form of exercise (38%) and maintaining a healthy diet (31%). Walking, running and going to the gym were the most common forms of exercise mentioned. ‘Following medical advice’ covered taking medication, having regular check-ups and screening, as well as seeking medical advice when needed. The 78 (2%) responses covered under ‘other’ included, amongst other things, accessing alternative or talking therapies and being in work or education.

Spotlight on how different cultural groups stay healthy and well

During a focus group attended by 13 people from a Black Caribbean Elderly group in Bradford District and Craven, members told us how West Indian food has a good variety of grains and pulses which is good for a healthy diet.

They told us about the things they do to stay well: playing dominoes, singing, dancing, painting and laughing. Participants also told us how they liked to reminisce about the past and enjoyed sharing their stories with young people who sometimes visit their group. One person said about attending the social group, “as soon as I get out of my house my pain is over”.

The 11 men who attended a focus group with **South Asian Men in Bradford District and Craven** told us how they walk to the mosque five times a day and how the physical attributes of the five daily prayers contribute significantly to their physical and mental health. Five participants also told us how attending these social group gatherings reduces loneliness and isolation.

15 people from a **Hindu Faith Group in Leeds** told us how they try to eat healthily and have reduced ghee and other fats traditionally used in Indian cooking. They told us how being part of the community and doing things together brings meaning and joy to their lives. One regular volunteer said *“I feel lonely and isolated at home as my children are married and have left home”*.

Q4. What could the NHS and its partners do differently to help you stay healthy and well?

In the survey, we asked people to tell us three things that they thought the NHS and its partners could do to help them stay healthy and well. There were 2416 responses in total encompassing a broad range of ideas which are summarised by theme in the table below. The issue was also addressed in the focus groups.

Theme	More detail	Number of responses
Appointments	• The main issue was around making it easier to get a GP appointment, including having an easier booking system and more appointments available, and being able to see a GP quicker. • Having an option of longer appointments so that people could fully discuss their issues. • More NHS appointments available at evenings and weekends for working people, as well as more access to telephone and online appointments.	441 (18%)
Fitness initiatives	People wanted it to be easier and more affordable to get fit. This included having free or subsidised gym membership, exercise classes and swimming. Many people commented that current gyms and other leisure facilities were not affordable and working with local authorities to reduce gym prices was suggested. Other suggestions were: • Fitness activities such as walking groups and/or gym equipment based at GP surgeries. • Tailored facilities and classes especially for the elderly, disabled and those with complex conditions. • Personalised exercise plans. • GPs prescribing things like exercise classes to patients was also suggested. *"Make it easier to use gyms etc. by making them cheaper and more readily available - don't have to be great big places in leisure centres or with pools - just some pieces of equipment available indoors all year round and locally."*	243 (10%)

	“Whole family health activities - e.g. I can’t go to exercise groups or weight loss classes as I have no childcare for my autistic teenager, would be good to have somewhere we can all go together.”	
Advice on self-care/health promotion	• Information on self-care and healthy lifestyles both in surgeries and online. • Health advice sessions and talks in the community and in schools. *“More awareness for both children and parents of the long-lasting problems from living an unhealthy lifestyle and the benefits of being healthier.”* • Educate people about different conditions and how they can monitor their own health. • Public health campaigns on social media and TV. *“A text/email service to remind you what you can do to stay healthy (perhaps an app that links your appointments and medical records).”*	217 (9%)
Health check-ups/screening	The majority of people who suggested this wanted regular ‘MOT’ type health checks to be routinely and proactively offered, particularly to the elderly. Some mentioned targeting them at younger people (as well as over 40s) and carers. People also mentioned: • Better follow-up after health checks and better sharing of results. • More testing of blood pressure, BMI, heart and lungs. • Younger and older age limits for cancer screening including breast, cervical and bowel cancer. • Having health test drop-ins, more home testing or check-ups by Skype.	175 (7%)

	"Cancer screening compliance in Bradford city is amongst the worst in England especially bowel cancer at 34 per cent compared to a target of 60 percent and a pilot project aimed at faith and community leaders rather than individuals is needed"	
More resources	• This section included more resources and funding generally as well as more doctors, nurses, nurse practitioners and hospital beds. It also included people's wish for there to be more services available, in particular physiotherapy, one to one support, Well Women clinics, health and wellbeing centres, minor injuries, walk in and urgent care centres.	142 (6%)
Mental health	• Make mental services more accessible for people of all ages. • Reduce waiting times. • Have more access and shorter waiting lists for counselling and therapy. • Make mental health services more appropriate for people with autism. • Invest in mental health awareness (e.g. run mental health first aid courses in schools and communities). *"Make it easier for parents of young children to access mental health and wellbeing services for maintenance of their mental health. I've found most services do not provide for parents to take children which makes them very difficult to access whilst breastfeeding a young baby."*	130 (5%)
Support or activity groups or classes	A whole variety of groups and activities were suggested as being helpful. These included men's and women's health, meditation, mindfulness, relaxation, wellbeing, self-help and lifestyle sessions. Targeted groups for specific people such as the elderly, disabled or those with specific health issues (e.g. people who want to lose weight, stop	116 (5%)

	smoking, improve their mental health, etc.) were suggested. The need for more groups in rural areas was mentioned, as well as groups that met outside of normal working hours. *"Have a room at the surgery available to self-help support groups."* *"Have more focus/action groups where patients can get together and share experiences and hints and tips"*	
Healthy eating initiatives	• Make healthy eating more cost effective for those on low incomes (e.g. offering vouchers, lobby government to increase taxes on unhealthy food). It is cheaper and easier to eat badly. • More healthy eating/cooking advice through workshops/taster sessions, leaflets in GP surgeries, on TV and social media. Also more education for children in schools and for parents with small children. • Clearer nutritional information on packaging. • Help with providing personalised diet/meal plans (this could be through an app). *"It's not the NHS itself, but the benefits are not enough to buy fresh food and vegetables all the time"*	113 (5%)
Accessibility	• People wanted services generally to be easier to access when needed. • Improved access for particular groups was also mentioned including those with autism, ADHD and learning disabilities; asylum seekers and refugees; people from BAME backgrounds and LGBTQ groups. • People wanted interpreting support (including BSL) to be more routinely offered and easier to access.	94 (4%)

	• Making information clear and easy to understand was frequently mentioned. *“Make appointment letters understandable instead of NHS speak e.g. my elderly mum doesn't know what 'Endocrinology' means and other terms - this raises anxiety in relation to appointments”*	
Person-centred care	• People said they wanted to be listened to, trusted and taken seriously as experts of their own bodies. • People wanted medical professionals to take a more holistic approach and not see individual symptoms/conditions in isolation. • Carers wanted to be listened to. *“Listen to the needs of carers instead of putting obstacles that hinder the care of our loved ones - so increasing stress to carers.”* *“See the context of people’s lives and help them to connect to what’s around them.”*	82 (3%)
Weight management initiatives	People wanted to see a more positive and proactive approach to weight loss rather than “blaming everything on being overweight”. Things they suggested were: • More advice on healthy diets and help to lose weight, also tailored to specific conditions. • More access to dieticians and ways to monitor weight (e.g. drop-ins, clinics or groups). • Help with diet plans. • Referral to and helping with the costs of slimming clubs for individuals who need it. *“I get told to lose weight but never any support given to do so”*	73 (3%)

Alternatives to medication	• People didn’t just want to be given medication but also other ways of improving their health such as exercise or nutrition. • A lot of people saw social prescribing as a positive and wanted more of this, as well access to other therapies such as talking and alternative therapies to be offered by the NHS. *“Offer more information on nutrition or things you can do to help a condition rather than just medication”*	61 (3%)
Joined up care/continuity of care	• Some people wanted to see the same GP or nurse (suggestions of having a named nurse were made), so that they could develop a relationship and didn’t have to explain their issues again and again. • Some people suggested one point of contact or a specialist centre for all long term conditions, not just some (e.g. Crohn’s nurse). • People wanted specialists and GPs to be better at talking to each other. • Health and social care to work closer together. *“More joined up thinking between departments. E.g.: we have different consultants for each condition with one not being aware of the other.”*	61 (3%)
More focus on prevention	People wanted to see more investment in prevention generally, rather than treatment of conditions which could have been prevented. *“Work towards stopping folk getting ill rather than curing illnesses”*	43 (2%)
Reduce waiting times	This was mainly about making referrals to specialists easier and quicker, but also reducing waiting times specifically for	35 (1%)

	physiotherapy; mental health; ear, nose and throat; and dermatology services. People also mentioned wanting diagnoses to be made quicker.	
Links to local groups	• People felt that knowledge of what is available in local communities could be better and help signpost patients more effectively. • More funding of community groups and centres to provide health-related initiatives, particularly for those on low incomes. • Use volunteers to give advice and support on particular conditions. *"Train more people in community organisations, so that they can help with low level mental and physical health conditions at a fraction of the cost, they also have shorter waiting lists, are easily accessible as they are locally based and have good knowledge about the local population"* *"Have partnership work e.g.: in library or supermarket"* *"Allow NHS staff to visit community groups so they understand how they work"*	34 (1%)
Improve support for long-term conditions	People said they wanted better support generally for long-term conditions. This included: • Regular access to GP and specialist medical professionals with understanding of particular long-term conditions. • Free prescriptions for all those with long-term conditions. *"Make access to medical services easier and quicker if you have long-term health conditions"*	33 (1%)

	“It would be good to be able to have direct contact with my specialists if there is a problem between appointments”	
Communication	Better communication between staff and patients was mentioned. More specifically, people wanted: • To be kept updated about why waiting times are long, or appointments have been cancelled. • Better communication of referral routes and waiting times. • Better use of email, text and social media. For example, appointment notes could be emailed to patients rather than sent by letter.	32 (1%)
Better Systems	This was mainly around having more efficient systems, and less unnecessary paperwork so that professionals can spend more time with patients. • Better organised clinics so that appointments aren’t cancelled at the last minute. • Better use of IT and electronic records. *“To have all trusts having the same computer systems or ones that talk to each other”*	31 (1%)
Transport	• Improve transport links to main hospitals. • Invest in public transport and improve cycle and pedestrian infrastructure (e.g. cycle lanes, etc.) to help combat pollution. • Provide patient transport to GP appointments. • Provide access bus to support groups. • Public transport concessions for all retired people. *“Work with local councils and bus companies, etc. to ensure that people can and do use public transport to get to hospital”*	29 (1%)

Improve support for carers	People felt that carers needed more support to keep them safe and healthy including: • Clarity and choice of options available to them. • Regular health checks. • Respite care. • Flexible appointments to fit round caring responsibilities. • Ensure people get the care they need to reduce burden on carers. *“Support for family/carers’ mental health when one member has long-term health condition”*	27 (1%)
More localised care	• People want to see more services ‘closer to home’ including more specialist hospital services available in community hubs. This is particularly an issue for people with complex health conditions who have to travel to hospital for multiple appointments.	27 (1%)
Prescriptions	• Free or cheaper prescriptions. • Make it easier to order prescriptions online. • Less wastage on prescriptions. *“GPs to be stricter and smarter prescriptions, e.g. addressing concerns with patients, and not ending up with medicine you don't need”*	25 (1%)
NHS dentists	• People want more NHS dental places as there is a current shortage in some areas. • Reduce dental costs for those on low income, as the cost of dental care means that people don’t seek treatment when they need it. *“Extend free dental care to those with incomes below £18,000”*	24 (1%)
Patient responsibility	Some people felt that everyone needs to take more responsibility for their own health and be educated about this. People also felt there should be greater awareness and responsibility taken for not using services	20 (1%)

	unnecessarily. People should be made aware of the costs to and impact on the NHS of not attending appointments, etc. *"There is a lot of information already available, we should help ourselves to find it. Not be wholly dependent on NHS"* *"Educate everybody about when to use the doctor, when to use A&E and when to stay at home and recover"*	
Improve support for elderly	• More things for older people to do to reduce isolation. • More access to home visits and care at home. • More access to information about exercise and exercise classes for older people (also in different formats, not all online). • Regular health checks for older people. • Weekly visits for elderly people living alone.	19 (1%)
Stop privatisation	Stop privatisation and keep the health service free. *"Take out profit motive to optimise resource allocation to focus on health needs."*	14 (1%)
Other	In this section people talked about increased awareness of services available, more compassionate attitudes, better online services and parking at NHS services.	75 (3%)
Total		**2416 (100%)**

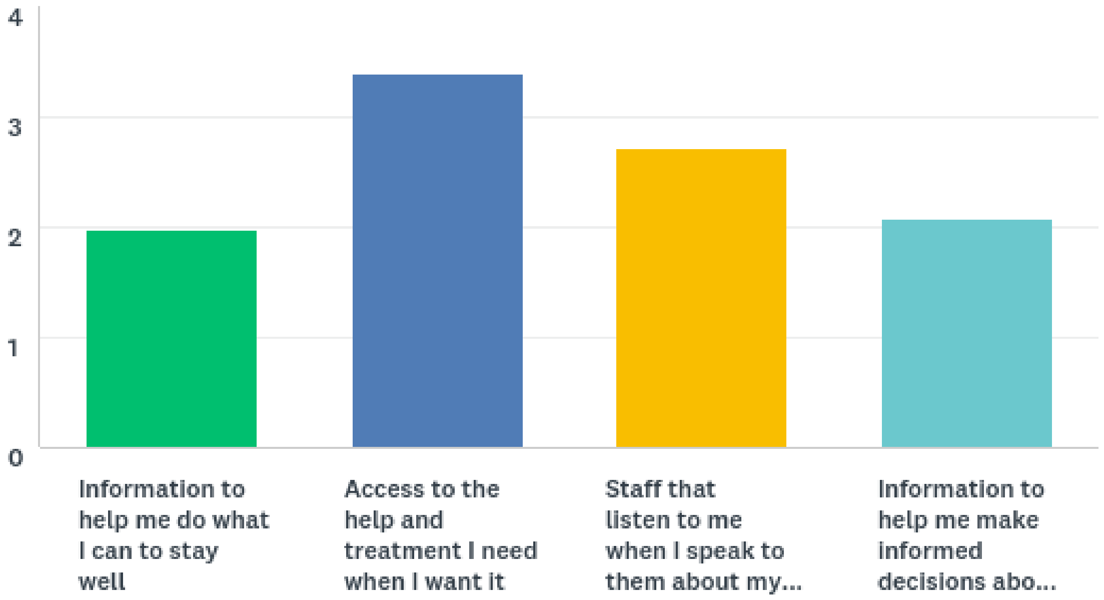
Q5. What is most important to you in relation to health services?

We asked people which of the following were most important to help them live a healthy life:

- Information to help me do what I can to stay well
- Access to health and treatment I need when I want it
- Staff that listen to me when I speak to them about my concerns
- Information to help me make informed decisions about my health and care

The graph below shows that all of these were important to people, but that access to help and treatment when needed was the most important, followed by staff that listen.

When it comes to health services, what is most important to you, to help you live a healthy life? Score 1-4 with 1 being the most important

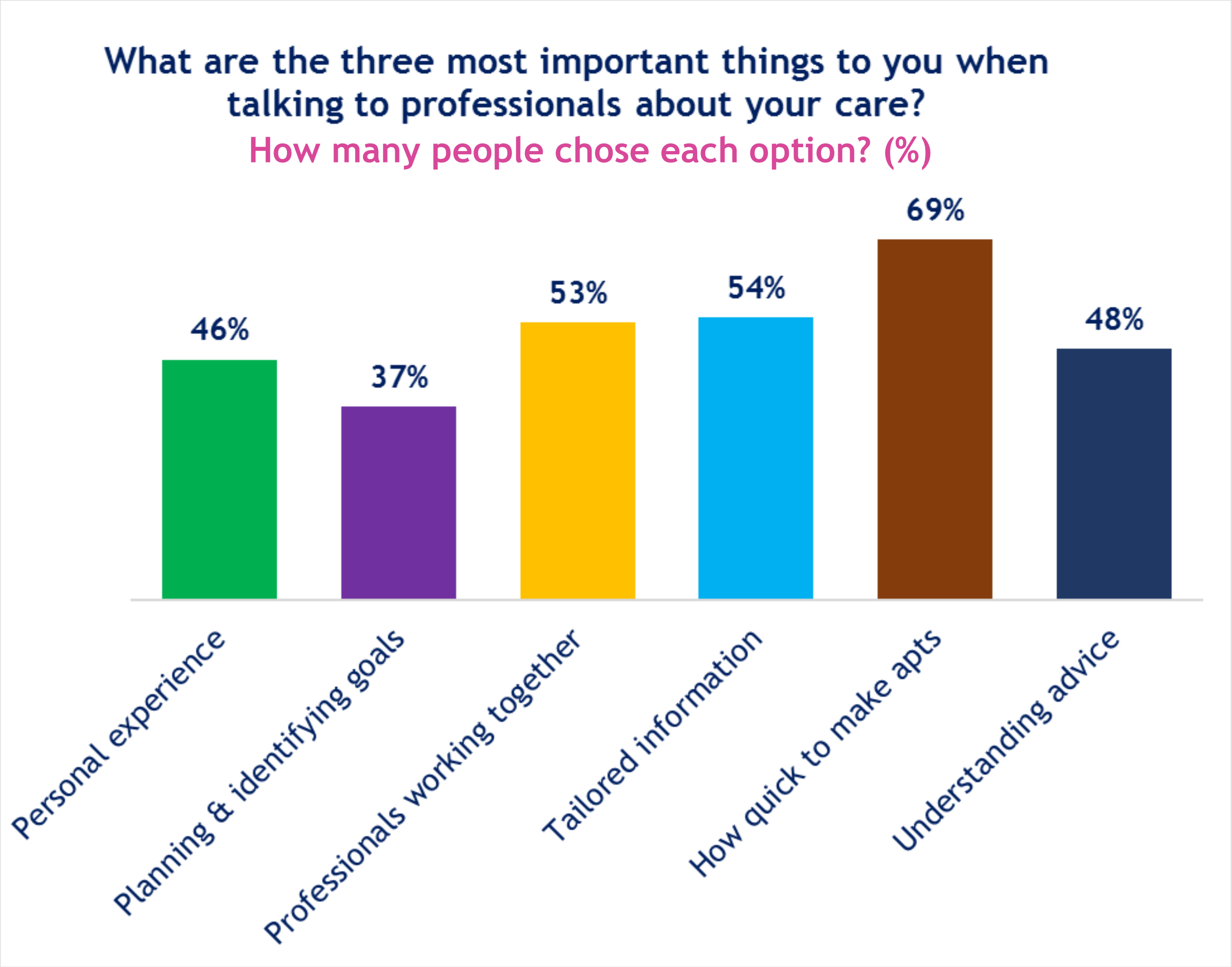


Q6. What are the three most important things to you when talking to health professionals about your care?

1405 people responded to this question. They were given the following options to choose from:

- That my personal experience and expertise is valued and recognised
- That I am involved in planning and identifying my own goals, not just about my healthcare but about my life in general
- For services and professionals to work together and share information in providing care and support
- That the information I receive is tailored to my individual needs
- How quickly I can make an appointment or have chance to talk with them
- That I understand what they are advising me to do and I can go away and be confident that I am doing the right thing

The chart below shows that all of these things were important but that the speed with which people could make an appointment was the most important overall, with 69% (969 people) choosing this option.



People were also given the opportunity to suggest anything else that was important to them when talking to professionals about their care. 320 people made comments, some mentioning more than one issue.

The following themes could be identified from the comments:

Theme	No. of times mentioned in comments
Communication	185
Having more time in appointments	59
Service users' interactions with health professionals being systematically documented	28
Joined-up services	24
Holistic treatment	24
Ease of access to services	20
A culture of openness	11
Disability-related issues	10
Consistently seeing the same professional	10
Other (including interpreting provision, issues faced by carers, prevention and personal responsibility and signposting to other services)	37

Spotlight on Communication

While speed of making appointments was the multiple-choice option cited by the largest number of people (see above), communication was, by a long distance, cited the most frequently in the comments, with nearly 59% of all responses touching on it.

Good communication means different things to different people:

- 79 people said they wanted to feel that they have been listened to.
- For some people, an important part of being listened to is for professionals to take their assessments of their own health and bodies seriously.
- Some emphasised the importance of people being spoken to as individuals.
- Others cited the importance of eye contact and of professionals looking at them rather than a computer screen.
- Some people told us they wanted to be treated respectfully and without any judgements being made about their lifestyle.
- In terms of the level of information patients want to receive, health professionals clearly have a difficult balance to maintain: while a small number of people expressed their dissatisfaction at being "spoken down to", others complained of being spoken to in inaccessible, sometimes specialist terms that they did not understand.

What do the comments tell us about the ideal patient journey?

Here are some of the comments most commonly made by respondents. We have used them to imagine what their ideal appointment journey would be.

Step	Comment	The ideal patient journey
1	*“That the GP has read 'all about me' before I go into the surgery to see them, and if not that, at least the referral from the consultant before I go into the surgery”*	Before the appointment, the professional reads the patient’s notes.
2	*“That they explain things and not use funny words/jargon”* *“Don’t treat me like an idiot”*	When the patient enters the consultation room, the professional introduces him or herself and invites the patient to ask for a clearer explanation if they don’t understand anything during the appointment. The professional understands that different people want to be communicated with in different ways.
3	*“Health professional should listen and make eye contact, not just look at their computer and issue a prescription”* *“That they listen, and are not rushing you out of the door because your 10 minutes are up”*	The professional makes eye contact with the patient and actively listens to their issue, keeping their computer use to a minimum, and giving them the time they need to explain their assessment of their own health.
4	*“A printed copy of agreed care and support plan with timescales”*	Once the appointment is over, the professional documents it. This information is then provided for the patient in hard copy or online, according to patient preference.

Spotlight on carers

7 people told us about how they could be better supported in their role as a carer for a loved one. Here are some of their comments:

“I would like the GP to recognise my role and there seems to be this notion that the community or relative will help, but what about my/our help”

“If you want to use carers/relatives as a resource to save money then look after them too and reward them in different ways so they could keep healthy too”

“Listen to carers, especially because people with mental health issues say that they are fine when the carer is doing a lot for them”

People at a focus groups for older black Caribbean residents of Bradford and people with mental health conditions and their carers in Kirklees said that health professionals should involve carers more, and that they felt ‘invisible’ in their role as carer.

Spotlight on hearing impairments and medical appointments

5 people responded to our survey to tell us how their hearing impairment made it harder for them to interact with health professionals. Some of their suggestions include:

“Understand how difficult it is for patients who wear hearing aids to grasp all that is said”

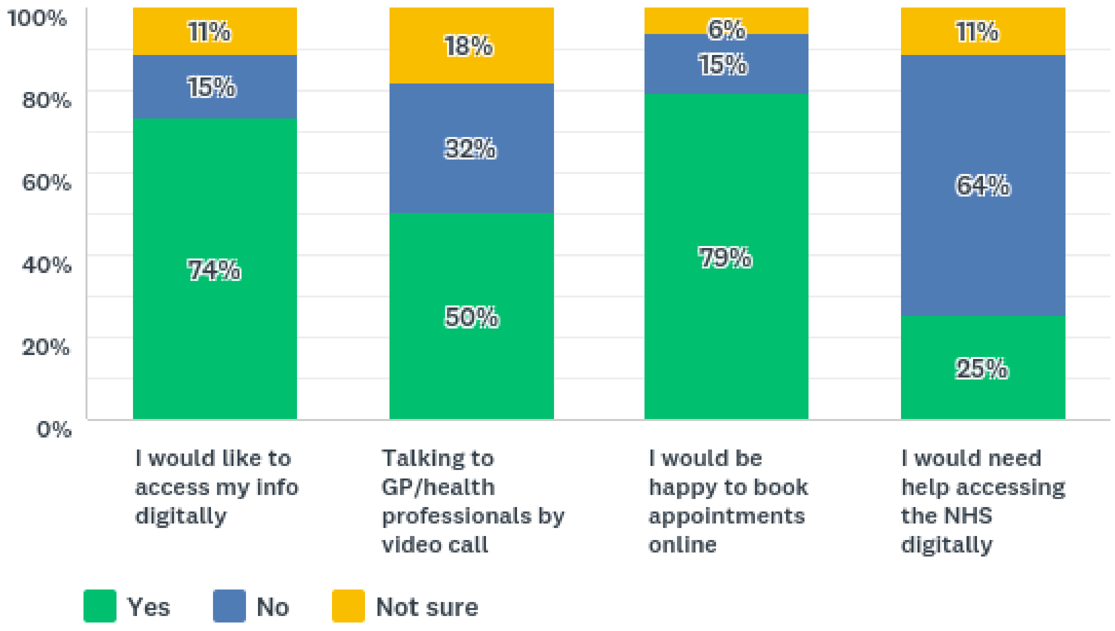
“Make eye contact throughout the appointment! Especially for people who are hard of hearing - elderly people often say they have understood what has been said because they do not wish to appear stupid”

“Have interpreting services for the deaf”

Providing an interpreter was also suggested by attendees at a focus group attended by deaf people in Wakefield. They said health professionals could be clearer about a person’s condition. Some people with impaired hearing know for example that they have a problem with their heart, but do not know what the condition is called.

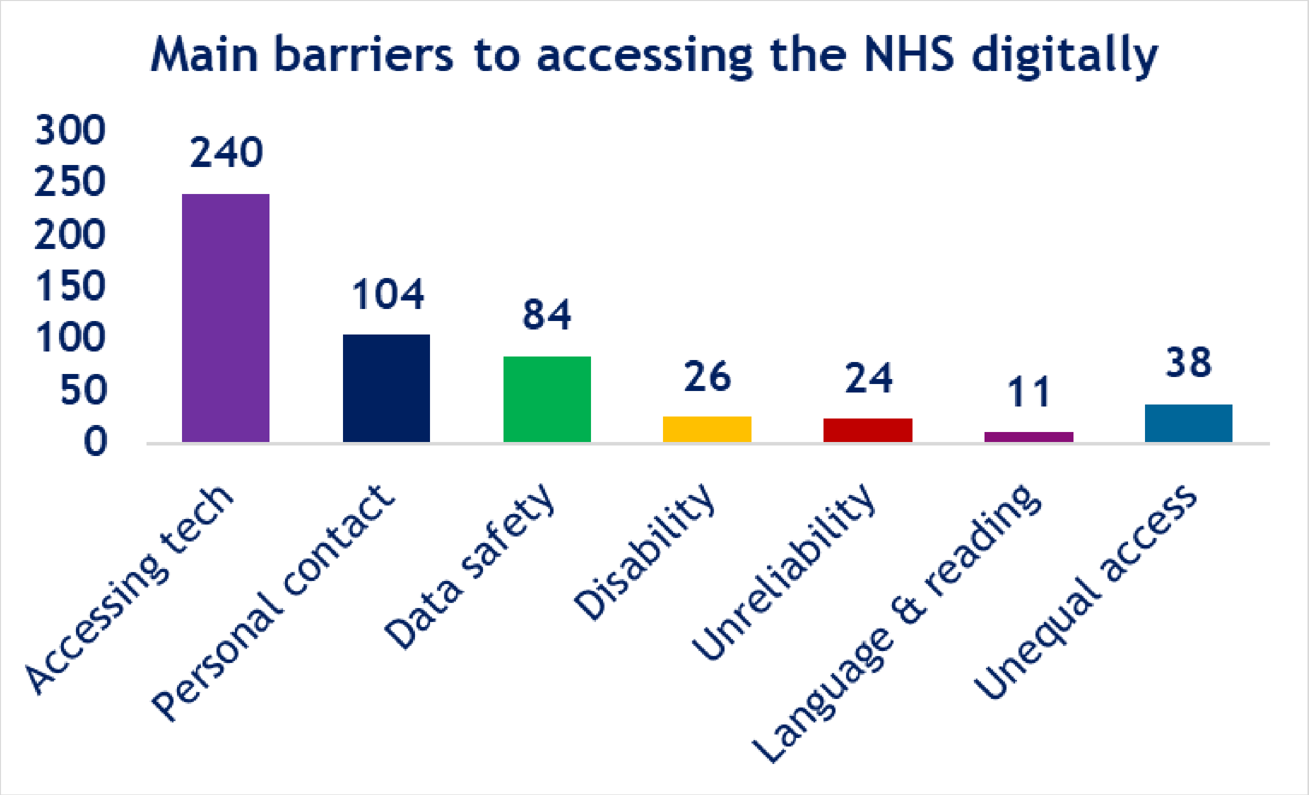
An attendee at a focus group for people with dementia and their carers in Calderdale said they would like the health professional to sit closer so the patient could understand what is being said: *“my father is totally deaf and they talk to him as if he can hear. I think that is totally disrespectful”.*

Q7. The NHS wants to work more digitally, offering more services online such as accessing your health records or having video calls with your GP or health staff.



While a majority of respondents are in favour of accessing the NHS digitally (see chart above), more than 500 people (41% of respondents) told us about why they, or others they know, would not use online services.

The key themes from their answers are detailed below.



Difficulties accessing technology

This was the factor most frequently suggested by respondents. The **240** people who cited this gave several reasons why people might not have the tools or skills to access NHS digital services:

- **Not having a compatible device or internet access:** **102** respondents pointed out that not everyone has a computer, mobile phone or internet access. Some expressed concerns that not all services will be compatible with the mobile devices they rely on to access the internet. Those who do not have home internet or whose home internet is poor (if, for example, they live in a rural area) are obliged to access digital services in public spaces such as libraries. Others may not have their own device and have to use a public computer. They might therefore feel less safe accessing digital health services. *"I would not like to try book an appointment using a PC in a library; not open all the time, not private enough and no good if you are not well."*
- **Lack of skills and confidence:** **94** people viewed a lack of computer skills and digital confidence as a potential barrier to accessing online

Spotlight on Digitalisation Focus Groups

At our 15 focus groups, we took some time to discuss digitalisation. Multiple issues were covered each time, but the table below provides a snapshot of attendees' thoughts and experiences.

Focus Group	Example comment
South Asian Men's Group (Bradford District and Craven)	A fear of using computers and learning at an older age represent significant barriers.
Black Caribbean Elderly (Bradford District and Craven)	Internet-related costs are far too expensive – subsidies should be provided.
People with Dementia and their Carers (Calderdale)	Passwords often seem to be faulty and a third of the group prefer face-to-face contact.
Young Volunteers (Calderdale)	All 7 participants are happy to use digital services.
Residents Group for Older People (Calderdale)	Although attendees are prepared to learn how to use digital services, they have no one to teach them.
Parents of Children with Disabilities (Calderdale)	The NHS needs systems that communicate with one another and share data, especially when people are referred out-of-area.
People Living with Mental Health Conditions and their Carers (Kirklees)	Signing up for online services is very difficult and there is a real fear of data breaches.
Hindu Faith Group (Leeds)	GPs should provide translated instructions for people whose first language isn't English.
YouthWatch (Leeds)	Two participants have found mindfulness apps helpful and a good way of saving their own and their doctor's time.
LGBTQ (Leeds)	Most of the attendees work full-time so find online services a handy time-saver.
People with Sight Loss (Leeds)	"There can be a lack of personal connection and digital devices can be too regimented. They offer only check box advice, not advice tailored to me." For more information on what this group had to say, see Spotlight on Sensory impairment and digital services (p.38).
Working Age People (Wakefield)	Attendees said that information-sharing between NHS departments does not work well, so they have had to repeat themselves over and over again. They said this not only wasted NHS time but was potentially dangerous.
Deaf Group (Wakefield)	SystmOne is useful for prescriptions and the sign-in screen at the GP surgery is good – so long as it is working. For more information on what this group had to say, see Spotlight on Sensory impairment and digital services (p.38).
People Living with Mental Health Conditions (North Yorkshire)	Of the 8 participants, 7 said they found online services too stressful to use and 3 reported that living in a rural area made it hard to get a good internet connection.
Cancer Alliance (West Yorkshire)	Attendees said that not enough GPs were offering video calls and that patients who wanted them should be able to get appointment letters, clinical reports and so on digitally.

Spotlight on Digital services: BAME groups

"I don't mind learning but could do with some support"

Just over 25% of people told us that they would need help to access the NHS digitally. This figure was much higher for BAME communities, with a lack of skills and confidence and access to the internet being the main barriers cited. The survey data showed that 42% of BAME respondents said they would need help accessing the NHS digitally, compared to 25% respondents overall.

A Bradford-based South Asian Men's Group said their fear of computers and learning at an older age represented a significant barrier to them.

At our focus group with a Hindu Faith Group in Leeds, people talked about how GP surgeries could run workshops on how to use online services and provide instructions for people whose first language is not English. 3 of the 13 people who came to our focus group with older black Caribbean people living in the Bradford district said they were already using online services, with the remainder claiming they would love to learn – but the cost of internet access was a barrier and should be subsidised.

Preference for Personal Contact

104 people stated that a preference for personal, one-to-one contact might make them or others less likely to access digital services. There was an aversion to "*impersonal*" services and "*machine contact*".

"[It's] too impersonal. I like to communicate with a real person"

"I want to speak to my GP, not a screen"

A number of respondents felt that digital services would be a poor substitute for a person-centred doctor-patient relationship. A few also expressed concern that using digital services would entail them seeing a different health professional every time, instead of building up a rapport with one.

"I have some concerns about how the use of digital changes the culture of the NHS - good bedside manner can already feel like a scant resource - how does reducing one-to-one interaction encourage professionals to respond with compassion?"

Some respondents said they felt that communication was clearer, easier and less stressful in person. This was an area of particular concern for people living with mental illness or learning disabilities.

"[I'm] not sure about video calls – [I] might not remember to ask the right questions that I would perhaps feel more relaxed to ask if the consultation was in person"

"I suffer from Irlens syndrome and dyslexia so my comprehension and understanding of things can sometimes be misunderstood. I prefer a person so I can clarify rather than getting upset that I have misunderstood"

"[Because of my] mental health [I feel] more pressure and fear. I need to talk one-on-one"

A small number of respondents worry that digital services would feel less private.

Respondents sometimes felt digital services could lead to lower quality care. Some felt that health professionals accessed digitally would be able to offer a less holistic service, and potentially miss symptoms which may be more apparent through face-to-face contact.

"So much communication is non-verbal. Lots is lost via video"

"This is not an appropriate way for a healthcare professional to assess and triage patients, nor how they have been trained to do so. If professionals cannot carry out basic assessments such as vital signs it undermines training and knowledge and will ultimately lead to misdiagnosis."

"Digital services break down human contact which can be used to identify issues such as mental illness"

Some queried whether digital services would slow down their access to treatment and a few respondents were concerned that digital channels would lead to a de-professionalisation of NHS care.

"Any need for physical examination would mean another appointment and drawing out the process"

"When it comes to my health I want to see and be seen by a professional"

It is also worth noting that not everyone with tech skills wants to use them to access the NHS.

"I'm young and tech savvy but there is so much to be said for human connection. I have a good relationship with my GP and I want to continue to see her in person"

"Not personal enough, I work on a computer all day at work and the last thing I want in my free time when I am not feeling well is to access technology, coals to Newcastle!"

“I am already having to go online for everything - banking, utilities, booking a holiday, getting information from school about my child's education etc., I would rather speak on the phone or face-to-face to a human about my health”

Some people are happy to access certain services online, but not others. 18 respondents said their level of comfort with digital services depended on what they wanted to do (for example, simply book an appointment rather than have a consultation) or on the type of condition they wanted care for.

“I would prefer to speak to my doctor in person but anything else I don't object to doing digitally”

“If this was for mental health concerns, I would not like to use a digital route. It may reinforce isolation”

“In many situations it is important for a doctor to see and examine a patient, however, there are some situations where a video call would be appropriate (e.g. review of a chronic and currently stable condition)”

Data Safety Concerns

84 people said that data safety concerns would deter them from accessing digital services.

While most respondents cited hacking as their main worry, fears were occasionally expressed about personal information being released accidentally or shared with bodies such as the DWP, or about digital services making service users more vulnerable to scammers.

“I worry about security and being scammed by someone or a site pretending to be the official one”

“The system could get hacked then my information would be exposed”

Concerns around increasingly unequal access to the NHS

38 respondents expressed worries that digitalisation would leave certain sections of the population behind, including some vulnerable groups such as older or homeless people. People who gave this response sometimes commented that digital services should be just one option out of many, rather than being imposed on service users.

“I would not want them if it gave me an unfair advantage over others - I worry digital healthcare will widen inequality”

“Worried that older people cannot always use technology so can be waiting longer to access appointments on telephone as they are already booked by others using technology”

“I would urge you to take in to consideration to the fact that many of today's online systems are only compatible with high end technology such as Apple, Microsoft, Google products etc., which gives an obvious advantage to the more privileged in society, creating further barriers for those most vulnerable.”

“Not EVERYTHING has to be online, and if it is it should be because that is YOUR choice at that time, not because it is forced upon you, as it often is”

Spotlight on Internet access and inequality

Some members of our society currently have less access to the internet than others. They include:

- Older people
- People with low or no income
- The homeless
- People with limited reading or English skills
- People who find computer use daunting due to mental health conditions or learning disabilities or difficulties
- People with sensory impairments
- People with limited movement in their hands (due to arthritis, for example)

People with disabilities were less likely than survey respondents as a whole to want to access all aspects of digital services (61% compared to 71%) and more likely to say they would need assistance to do so (35% compared to 19%). People with mobility or sensory impairments were the least likely to say they were ready to use digital services (55% and 49% respectively).

As a general rule, the older people get, the less likely they are to want to access digital services and the more likely they are to require assistance to do so. 75% of people aged 11 to 24 said they would access digital services; 73% of people aged 25 to 64; and 51% of people aged 65+. 17% of 11 to 24-year-olds said they would need help; 22% of 25 to 64-year-olds; and 38% of people aged 65+.

The attendees at a focus group for older people in Calderdale said that, while they cannot afford a smartphone or computer and currently have no one to show them how to use one, they would be prepared to learn how to use digital services.

Some of the 38 people who expressed concerns about increasingly unequal access to the NHS feared that an increase in digital services would correspond to a decrease in face-to-face services.

“I am concerned that introducing GP video consultations may make it more difficult to see a GP face-to-face”

“Digital should be an enhancement to services not a replacement for it”

A smaller number of people felt that some service users will use their digital skills to advantage themselves over others (in other words, they will *"game the system"*) or that more appointments will be wasted by people booking online."

"It furthers people who don't need to see a GP that day booking appointments they don't need."

"I would be afraid of wasting appointments"

Disability

26 people said their disability was a barrier to accessing digital services, citing, among other conditions, visual and hearing impairments, arthritis, dyslexia, autism and the effects of stroke and brain damage as limiting factors.

Spotlight on sensory impairment and digital services

11 of the people we surveyed told us about how sight loss affected their experience of digital services. 8 of these said their visual impairment influenced their choice not to use digital services; a further 2 noted how the services' font size was too small for them; and 1 respondent said they had been helped by a specialist organisation to get online.

We also held a focus group with 6 people living with sight loss in Leeds. While some found the services easy to use and pointed out that *"fully accessible and multilingual digital services in A&E and GP surgeries can be helpful"*, they also said people with limited sight needed online platforms to be as simple as possible. One person said that *"I fear that this will become a two-tiered service, you will get quicker service if you can access it digitally"*.

Digital services also need to be carefully managed to ensure that they are equally accessible to people with hearing impairments. Three people said that their hearing impairment made them less likely to try digital services, commenting that there would need to be special provision for people with limited hearing if video calls were rolled out (especially bearing in mind that not all deaf people are signers). At a focus group with 7 deaf people in Wakefield, for example, the participants discussed how it can be difficult to rely on text type services for long periods of time.

Lack of trust in IT systems' reliability

24 people said that their belief that digital services are unreliable would make them less likely to access the NHS online.

"I would want to make sure appointments were booked properly"

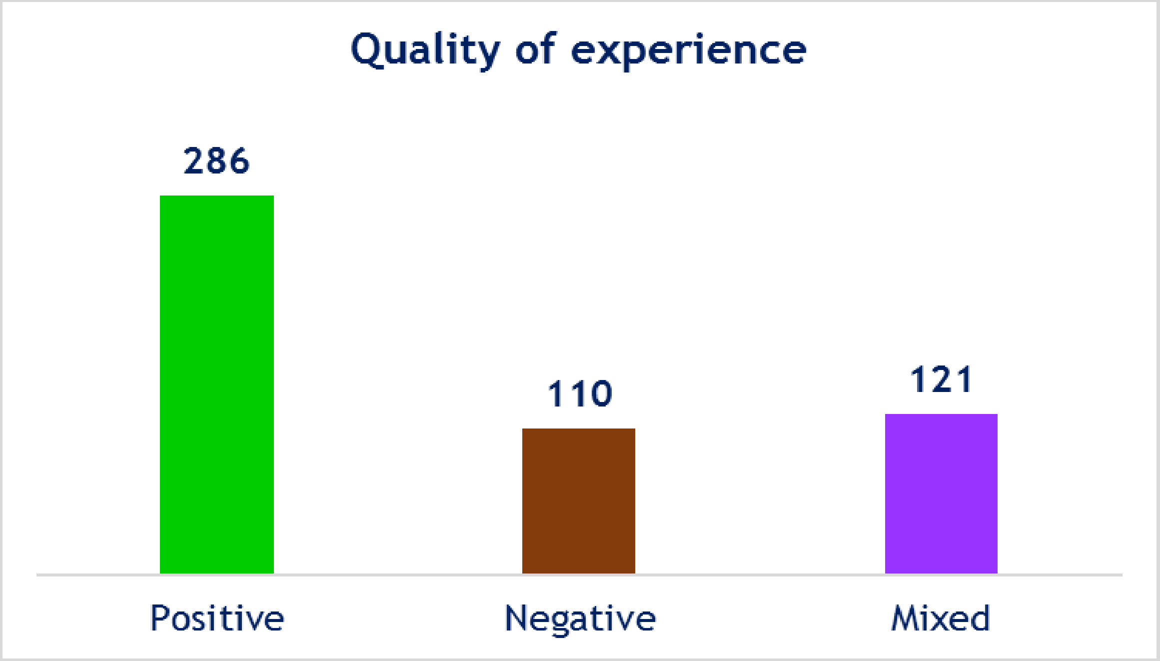
"Most of the time it doesn't work"

Language and Reading Skills

11 people said their lack of English language and literacy skills would make it impossible for them to access online services independently.

Q8: If you are already using NHS digital services, can you tell us about your experiences?

517 people told us about their experience of using NHS digital services. Just over half (55%, 286 people) said they had positive experiences of using digital services, 121 (24%) said they'd had mixed experiences, and 110 (21%) negative experiences.



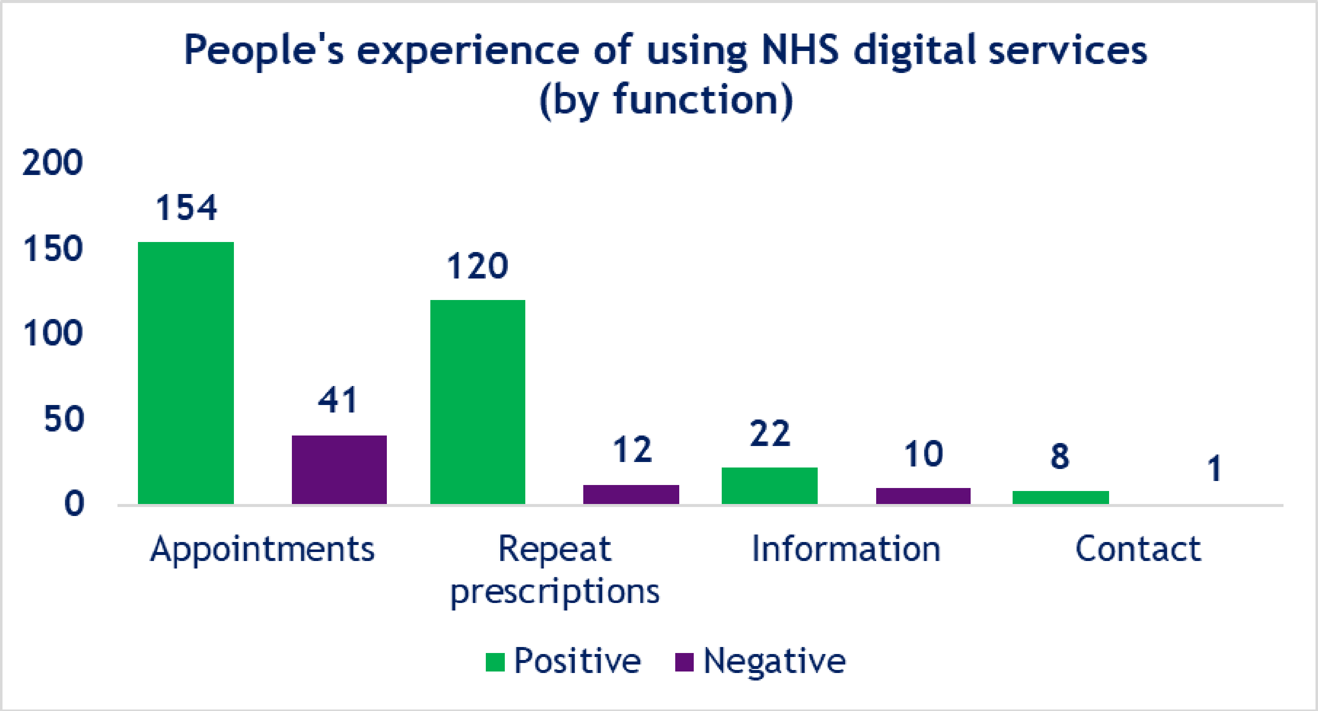
492 (95%) people told us that they use digital services to access services for themselves, whilst 17 said they use them for someone else. 7 people told us that someone uses online services on their behalf and one person said they used online services in a professional capacity.

Of the 17 people who said they used digital services on behalf of someone else, 11 (65%) reported having a mixed or negative experience. This was higher than the corresponding figure reported by direct users (45%). Carers' comments indicated this was because they were more likely to have encountered problems getting the right permissions to access digital services on another person's behalf.

What are people using digital services for?

Our findings reveal that people are using digital services for four main functions:

- Booking appointments
- Ordering repeat prescriptions
- Finding information
- Making contact with health professionals



While appointment booking is the most commonly used function, it is not proportionally the most appreciated service.

Function	% negative	Chance of having a positive experience vs a negative experience
Repeat prescriptions	10%	**10** times more likely to have a positive experience
Contact	12.5%	**8** times more likely to have a positive experience
Appointment booking	26.6%	**3.75** times more likely to have a positive experience
Information	45.4%	**2.2** times more likely to have a positive experience

While users are likely to have a good experience of all services, they are most likely to have found ordering a repeat prescription online helpful and least likely to have found information services helpful. However, information services are accessed by a significantly smaller number of people. From the data we were able to collect, it is not possible to discern whether fewer people are using information (and contact) functions because they find them less attractive or because they are simply not offered. There is some evidence that users would like to see more information functions provided (see section below).

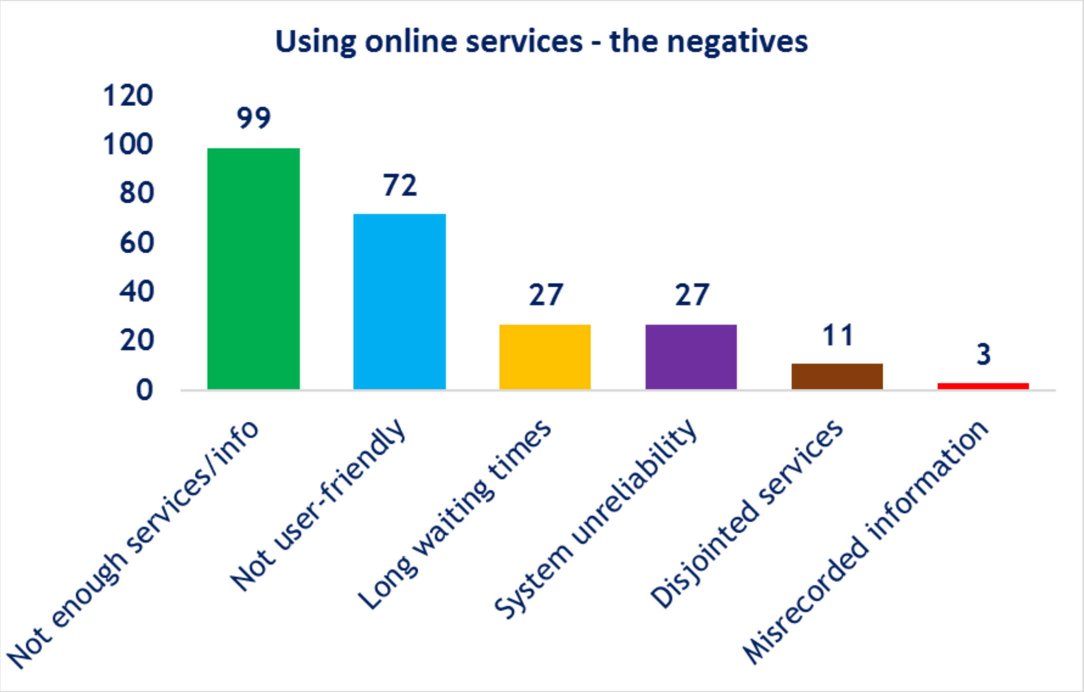
When we compare the frequency with which the function is used against the likeliness of having a bad experience of it, it is clear that more users would see their experience improved by changes to appointment booking functions than to any other area.

What is working well?

The two most commonly cited reasons why people found online services useful were that they were convenient or efficient and that they were easy to use. A smaller proportion said that online services gave them more options or made them feel more informed and in control of their own healthcare. A small number of respondents (fewer than 10) said that their mental health or other condition made it difficult for them to use the phone, for example, so online services improved their access to healthcare.

What doesn't work well?

The most common reasons people gave for not finding online services useful are detailed below.



There are not enough services or information (42%)

This was the most commonly cited problem. Comments reveal that online services simply did not enable them to do the things they wanted to, such as booking appointments (the most frequent issue) or consulting their medical records.

While many appreciated the convenience of an online booking service, they did not feel that it made up for a scarcity of appointments. Some found themselves ultimately contacting their surgery via a standard channel, resulting in online services actually making their experience more long-winded than it otherwise would have been.

“I rarely book appointments online because there are never appointments available”

“Mostly OK except that 'Choose and Book' often shows that no appointments are available, yet a phone call proves otherwise”

“It's OK but you still have to talk to the reception staff”

“Online appointment booking is okay as long as you stay up till midnight when the appointments are updated”

Some have been disappointed with the lack of information and detail they are able to access online.

“I feel you should be able to access all your records as they are all about you”

“It's great but needs to include more things such as test results”

“I have accessed my results, but only results acquired since I was granted access - no historical data to compare”

“Very limited information on my personal records – would have liked more from my medical history and explanation of what results meant”

The services are not user-friendly enough (30%)

Nearly a third of those with negative experiences felt that online services were offputtingly complicated to use or inefficient.

“System online to order prescriptions is a nightmare, if you press the back button, it cancels the order”

“Interface was amateurish and processing slow. Also, staff in hospitals often seem unaware of their own web services, or give contradictory information”

Passwords were a particular issue and some users felt that the initial access authorisation process was excessive, involving going in person to the GP surgery with identification to get passwords reset.

“Annoying log on. Cumbersome usernames and passwords cannot be modified by user”

“I tried to use System Online but I had difficulty logging on and now I have lost that option. Getting a password requires me to go to the GP surgery and I work and cannot get there”

“I only use it occasionally and the system (and thus log in / passwords etc.) seem to be new / different every time”

A very small number of users note that the font size on websites was too small.

Online appointment waiting times are too long (11%)

27 people commented that it was not possible to book urgent ‘on the day’ appointments online and that this would be a welcome option.

“Fine if I want to book an appointment in several weeks’ time (for a meds review etc.) but no use to get an appointment if you are actually unwell.”

System unreliability (11%)

People made comments about online actions not being processed (e.g.: ordering prescriptions which then weren’t actioned), or not getting confirmations when carrying out online activity. There were also comments about problems with websites not working or crashing.

“I book appointments online, but one recently didn't go through. When I went for the appointment, I didn't actually have one, same with prescriptions, I ordered online but when I went to collect it hadn't gone through.”

Services are too disjointed (5%)

People noted that systems in different areas didn’t talk to each other and that they would like to see more joined-up systems.

“Cancer care is started in Bradford and carried out in Leeds and your systems don't talk to each other”

“There are too many different initiatives... SystmOne, Evergreen, NHS app... what about one thing that does everything? Digital is supposed to be convenient... I struggle to know where to go for what and I’m tech savvy.”

Mis-recorded information (1%)

Three people were put off using online services when they saw information about their healthcare had been incorrectly recorded.

Spotlight on mental health conditions and digital services

Some people living with mental health conditions prefer to use online services over others, while others avoid using them altogether.

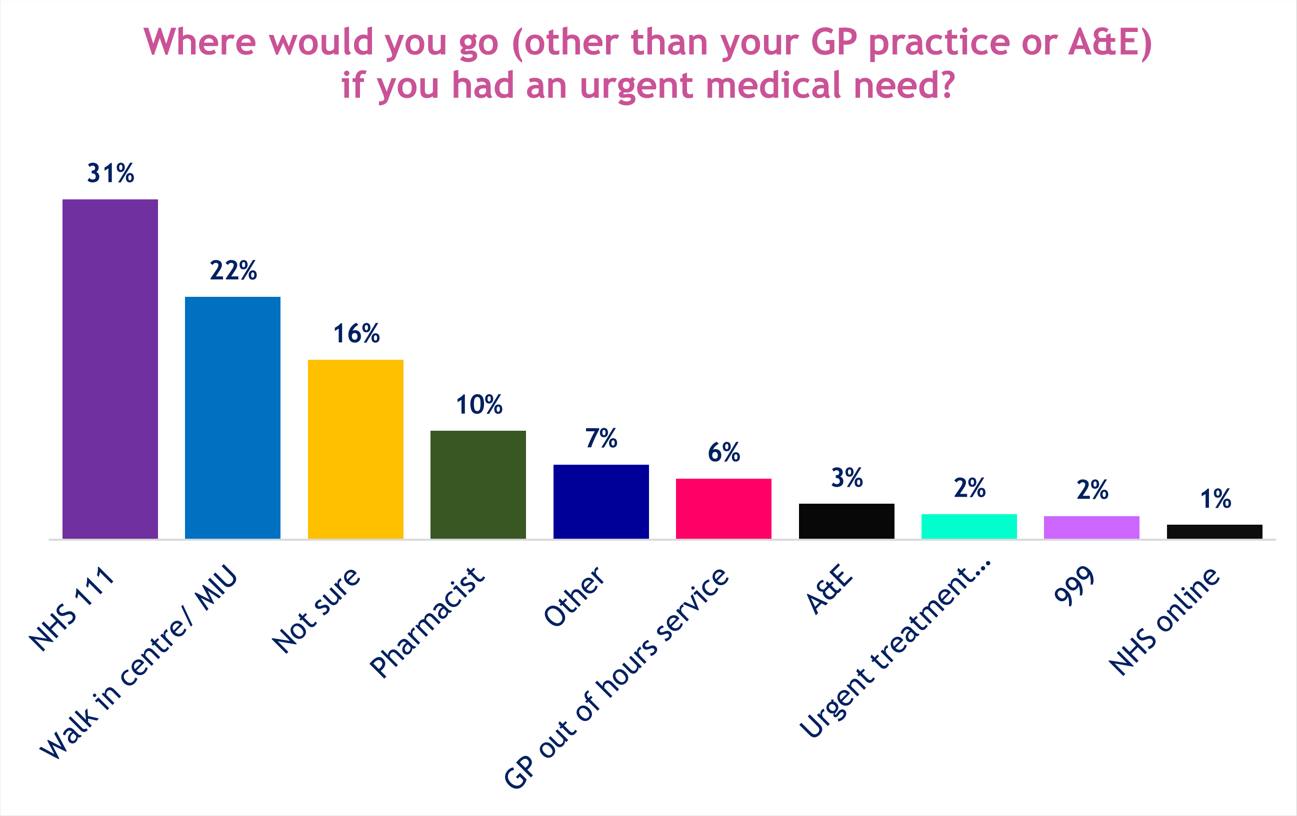
Four people told us that their mental health condition and the *"pressure and fear"* that comes with it made them less likely to access digital services, with one person concerned they might reinforce isolation. On the other hand, two people told us that online services enabled them to avoid the stress and anxiety of talking on the phone or face-to-face.

We held a focus group with 8 people living with mental health conditions in North Yorkshire. Only a quarter of them used online services. The reasons the remaining six give for not accessing healthcare online were as follows:

- They couldn't afford it
- The internet connection in rural areas is poor
- They don't have a smart phone or computer
- Using online services is too stressful
- They prefer face-to-face contact

Q9. Do you know where to go if you have an urgent medical need (when you need urgent help on the same day) other than your GP practice or A&E (which is for emergencies only)? Please tell us where.

Although 1225 people provided a response to this question, many people gave more than one answer as to where they could access urgent care, giving a total of 1741 responses.



NHS 111 Service

This was the most common response, as 535 (31%) of respondents said they would contact the 111 telephone service if they had an urgent medical need. Comments on the service varied, with a just less than half dissatisfied with it. Just over half were either satisfied or very happy. Some people seemed confused between the 101 and 111 telephone number, with some indicating that they knew an NHS helpline existed but hadn't ever called it.

"I rang 111 and they are fabulous! They help a lot and enable you to see a GP if you really need one that day in various locations. It's brilliant!"

"It's difficult to navigate. I have had two dreadful experiences of 111 services where two loved ones could have died had I listened to and not strenuously challenged their advice. It needs more TV and radio advice campaigns."

A common complaint was that many people were still referred to A&E despite trying to avoid going there in the first place.

Walk-in Centres/Minor Injuries Unit

Walk-in centres are mostly located in big cities and are for dealing with urgent problems. These are usually minor illnesses such as small infections, conditions or cuts and sprains. They're run by nurses and people can walk in without an appointment.

Minor Injuries Units (MIUs) can treat less serious injuries and illnesses and can also do x-rays. They can treat cuts, bites, sprains, or minor injuries to bones, muscles or joints.

Almost a quarter (22%, 382 people) of respondents indicated that they knew that walk-in centres and Minor Injury Units were an alternative to A&E. However, it is clear from the comments that much confusion exists around the difference between the two services and what they are called, with people referring to 'MIUs', 'walk-ins', 'drop in centres' or 'drop in clinics' amongst others. Some respondents told us that some of these services occasionally close early due to high demand.

"There are not that many of these walk ins, and they are not always in easy to reach locations or open at convenient times! They seem to be an alternative if you cannot get in to see your GP in the daytime."

Pharmacy

All comments regarding experiences with pharmacies were positive, indicating this was a useful way to access urgent care. 171 people (10%) said that they would access a pharmacy with an urgent medical need.

"I would attend my local pharmacy as they are very knowledgeable and supportive."

NHS online

Only 23 (1%) responses indicated they would use NHS online services. It should be noted however that this figure may be higher if we take into account those people who told us they would '*google*' what to do if they needed urgent treatment, as this might result in them being directed to one of the NHS websites.

"I always refer to NHS Choices to see if there are any local services or walk-in centres and only call 111 if I need to speak to health care professional."

It is evident that some people were confused between NHS Choices and NHS Direct and some people had concerns about the accuracy of some of the information available online.

Urgent Treatment Centres

Urgent Treatment Centres (UTCs) are defined as GP-led, open at least 12 hours a day, every day, offering appointments that can be booked through

111 or through a GP referral, and they are equipped to diagnose and deal with many of the most common ailments people attend A&E for. UTCs also ease the pressure on hospitals, leaving other parts of the system free to treat the most serious cases.

Only 40 (2%) responses indicated they had or would use an Urgent Treatment Centre. Reasons for this varied across West Yorkshire, with some people having heard of them but not knowing where they were located.

"I recently tried to take my mum to St George's Urgent Treatment Centre following a fall - the website said it was open until 11pm. We got there at around 9:30pm and it was closed. We then drove to Burmantofts and our experience was the same. I have little confidence in centres such as this outside of 'office hours' as a result of this experience."

It was apparent from the comments that people are confused by the names of places. For example, St Georges Centre was often referred to as an MIU, UTC and a walk-in centre by people in Leeds.

Other alternative services

Some of the 118 (9%) responses which indicated 'other' are listed below:

- Contact a friend or family member for advice
- Internet search
- Several people carry a care ring or have an emergency button fitted at home
- Contact specialist team or district nurse
- Administer first aid / self-care
- Social prescribers / care navigators
- Dentist, if urgent dental care
- Phone Samaritans or crisis team (mental health)

"How do you know something is urgent? I attended a GP appointment at 4pm was sent away with medication and because of concerns from family I was admitted to hospital 3 hours later with sepsis and fighting for survival - the GP did not think it was urgent!!!"

"I've tried to access alternatives for my child's mental health in a crisis, contacting first response. But ended up being told to call 999 and have her taken by ambulance to A&E which was a horrendous experience for everyone."

A&E / 999

Despite the question asking for alternatives to Accident and Emergency, 56 (3%) still answered that they would go to A&E, mainly due to not knowing where else to go:

"I do not know where out-of-hours services are other than A&E!"

"I'd go to A&E even though I know this isn't appropriate. As far as I am aware there isn't an urgent care centre in Huddersfield?"

This is further confused by the fact that some hospitals' A&E departments have been downgraded, but the minor injuries unit is still based in the hospital. 37 (2%) responses also mentioned calling 999 for an urgent medical need.

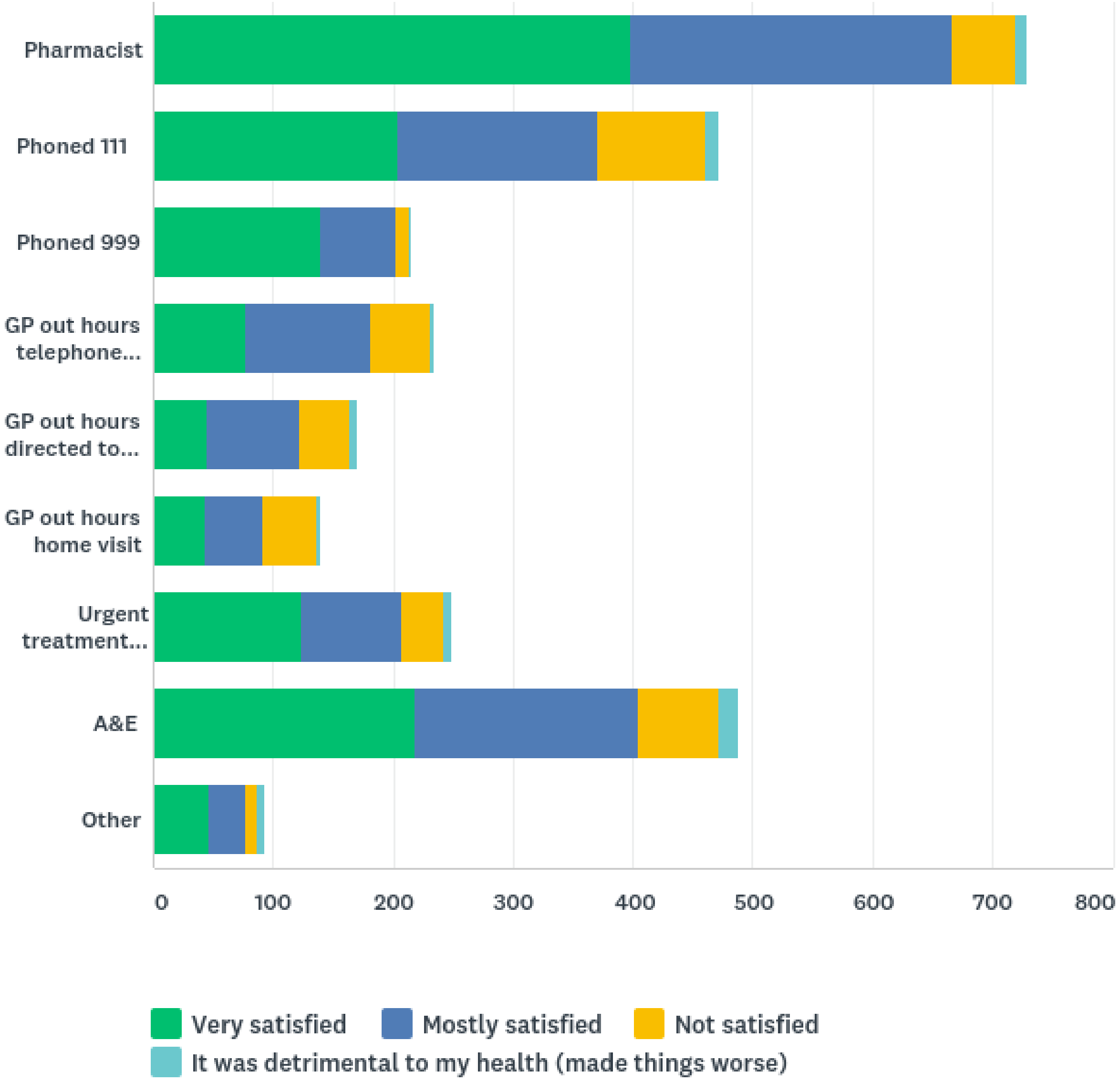
Don't know

A significant number of responses (16%) indicated people weren't sure where to go. This figure was significantly higher amongst respondents from BAME communities (27%), those aged 80+ (31%) and people with a physical and mobility impairment (26%). Many seemed to be confused, with people mentioning changes where they live which adds to the confusion.

"I know there used to be a walk-in centre in the Light, which was very good, but this has closed. I wouldn't know where else to go other than my GP or A&E (which I try to avoid using)."

"As I don't get ill very often, I don't really know how things work anymore."

Q10. In the last 12 months have you accessed any of the following services for an urgent medical need? Please rate how it was.



A total of 1017 people responded to this question.

Pharmacy

729 (72%) people who responded to this question said they used pharmacies for their urgent care need. There was a high satisfaction rate amongst these people, with 667 (92%) saying they were either very satisfied or mostly satisfied.

"I have an excellent pharmacist who I can speak to at any time for reassurance regarding my medication and my sons."

Accident and Emergency (A&E)

Approximately 489 (48%) of people said they attended A&E for an urgent medical need, of which 83% were very satisfied or mostly satisfied.

However, it should be noted that the reason some people said they were using A&E was because they were unable access other appropriate services.

“People continue to use A&E services because they can’t see their GPs in a timely manner. 111 often direct you to A&E! The hospitals are burdened with non-urgent medical cases. Primary care needs to address this gap urgently.”

NHS 111

473 people (47%) used the 111 telephone service if they had an urgent care need. 371 (78%) of those were very satisfied or mostly satisfied. A significant percentage were either not satisfied with this service (19%) or felt that it made things worse (3%). Some people commented that NHS 111 were too quick to send an ambulance.

“I personally didn't find 111 helpful...I felt their response was to send an ambulance...even though I was confident I could get to A&E in the car.”

Urgent treatment centre

249 respondents (24%) attended an urgent treatment centre, of which 208 (84%) were very satisfied or mostly satisfied with the service received. Among those not satisfied, a common complaint was that they felt that they had attended the correct place but then ended having up having to go to A&E for various reasons.

“I attended an urgent treatment centre then was told to go A&E - this meant we were further down the queue.”

“I called 111 and requested a call-back from a doctor. I explained my daughter was ill, and that I’m the main carer for my disabled son and I don’t drive. My request was refused, and I was advised go to an out of hours/urgent care centre. When I got there, it was closed! My daughter had a chest infection and the temperature that night was below freezing - we had to wait outside for a return taxi in the cold.”

“They need more doctors. I have waited nearly 3.5 hours so far today. Went to an urgent medical centre and waited but no one available to do my X-rays so had to come to A&E.”

Telephoned 999

94% of the 216 people who told us they called 999 were either very satisfied or mostly satisfied.

GP out-of-hours services

234 people reported using GP out-of-hours telephone consultation services, 139 people used GP out-of-hours home visits, and 170 had been redirected to another GP out of hours.

Although the majority of people were satisfied with their experiences of out-of-hours GP services, these were also the services with the highest rates of dissatisfaction.

49 (22%) of the 234 people who reported the out-of-hours telephone consultation said they were either dissatisfied (21%) or that it was detrimental to their health (1%).

42 (25%) of the 170 who reported having been directed to another GP practice also said they were not satisfied, whilst of the 139 people who said they'd had a home visit from their GP, 45 (32%) were not satisfied and 2 people (1%) indicated it was detrimental to their health.

Little explanation was given as to why people gave these ratings apart from a few comments about difficulties in accessing GPs and making appointments, as well as being directed to out-of-hours practices which were too far away.

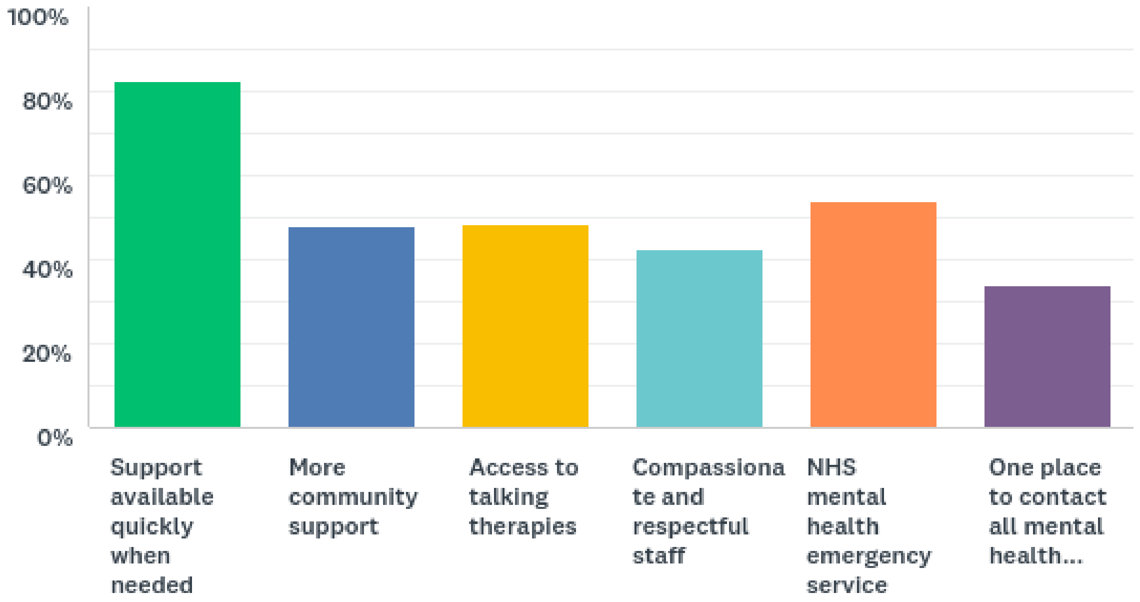
"I tried getting hold of out-of-hours doctor as I needed a home visit via the 111 service but due to my complex health needs 111 were not able to arrange a home visit. I only wanted advice about something, but they decided I needed an ambulance, paramedics then decided I needed A&E. I was not happy I wanted to stay in my home. After 5 hours I was allowed home, I had an infection."

Other services accessed for urgent medical needs

93 (9%) people told us they had used 'other services' when experiencing an urgent medical need. Most commonly mentioned were mental health services and walk-ins. Other services mentioned were: 111 online, an advanced nurse practitioner at the local health centre, sit and waits to see a GP, Boots the Chemist hearing centre, the clinical assessment team, the district nursing team via the Hub, the emergency dentist, the emergency breast clinic, the maternity assessment centre, the medical assessment unit, the oncology 24 hour helpline, One You dietary advice, the optician and the sexual health clinic.

“My GP service offers walk in appointments for emergencies every morning, which is fantastic.”

Q11. What three things do you think are the most important to improve support for people’s mental health?



1375 people answered this question. They were given the option to choose up to three answers. Many people commented that they thought that all of the options were important, which reflects the fairly equal spread of responses. Below are some of the reasons why people chose each option.

Support to be available quickly when needed

This was rated as important by 82% of people who answered this question. The main comments in relation to this were that waiting lists for services are too long and that initial assessments need to be easier and quicker. People explained how this often had a detrimental impact on their health and that there needed to be flexibility or a change in the criteria for receiving help.

“If you don't meet the threshold or fit in the category, you can expect to be shunted from place to place whilst your health deteriorates. This has to stop.”

“I have personal experience (through work) of supporting clients who were told they were too unwell for primary mental health care, yet classed not unwell enough for secondary mental health care services. This meant they bounced around in circles becoming more unwell and frustrated. This needs resolving.”

Other comments included the need for:

- Better communication following assessment both with the service user and with other professionals.
- The option to do assessments face-to-face rather than over the phone.
- More information and support for the individual following assessment so that they are clear what the next stage will be.

An NHS mental health emergency support service available 24 hours a day, seven days a week

People talked about the need for 24/7 mental health emergency support, with 54% of respondents mentioning this as an important issue. Some people were critical of current mental health crisis services, saying that they didn't receive the help they felt they needed and that A&E often wasn't well set up for people experiencing a mental health crisis. People commented how having a 'mental health A&E' would enable the right environment to be provided as currently many A&Es don't have a quiet room for people in crisis.

"A&E is not appropriate and can have a detrimental effect on mental health"

Whilst a lot of the respondents thought that around-the-clock support would be beneficial, especially for those in crisis, there was a recognition that the NHS in its current guise may not be able to provide that (without further funding and restructuring).

"In an ideal world mental health support would be available 24/7 (as mental health doesn't just slot into office hours) however I don't believe it is the sole responsibility of the NHS; it should be a partnership between the community and the health services."

People raised the issue of how the time-limited nature of interventions with little follow-up support was often a contributing factor in a crisis.

"I feel like I am going to be completely unsupported until I am next in crisis, at which point I will be assigned to a CMHT until I am no longer at risk and then discharged with no further support again. The mental health services are completely unprepared for our current levels of mental ill health, and with rising levels of poverty, and mental illness, it is only going to get harder to get adequate support."

Access to talking therapies e.g. counselling or Improving Access to Psychological Therapy (IAPT)

48% of people talked about the importance of good counselling and therapy services. The majority of comments relating to this were critical of the long waiting times for counselling/talking therapies (these are frequently over 6 months in most areas), with concerns that these would contribute to deteriorations in mental health.

"Waiting lists for counselling are extremely long, a family member waited over 18 months which is totally unacceptable for someone struggling with mental health issues."

"My husband has been waiting over 6 months now and is still waiting to have 1-2-1 counselling for a mental health issue, has been assessed and been put on list, still waiting. This is not good enough."

There were some comments relating to a lack of talking therapy for people whose first language is not English, and that there was a need for more accessible services.

"Have interpreting services for counselling and IAPT - people with language differences are not offered these services because it costs the NHS too much for interpreting."

Other comments related to people's experiences of not even being offered talking therapies and simply being prescribed medication. Some also talked about an over-reliance on cognitive behavioural therapy (CBT) in general and more specifically CBT delivered online, which is not appropriate for everyone.

"The online therapies and CBT are no good for people who are already overwhelmed."

More community support, e.g. local drop-ins where you can talk to people about how you are feeling

Almost half of those who responded (48%) felt that there was a need for more community support. This support should come from community mental health services, but there should also be a recognition of the important role of community groups and schools in helping prevent people facing potential crises in the future.

"A lot of mental health could be improved with access to excellent local community support (via VCFS sector), social prescribing and nipping it in the bud before it becomes a bigger issue."

One professional pointed out that useful monitoring data could be gathered from community services to identify causes and therefore invest in prevention.

"As a professional who regularly encounters people in need of mental health intervention, I would like to see more community support available, and for monitoring of these services to identify any patterns which may be the cause of mental health problems… For example, many of the people I work with suffer with increased mental health problems due to lack of income and difficulty accessing the benefit system, therefore it is my opinion if funding was made available for more free and independent money/benefits advice there would be a significant decrease in mental health crises."

One person talked about the importance of having different ways to access support:

"I believe a text or email service for people wanting to reach out for help with their mental health would be beneficial to people who find a telephone call or appointment with a GP daunting."

Compassionate and respectful staff

Having compassionate and respectful staff was highlighted as important by 42% of respondents. People told us that, in their experience, staff weren't always compassionate and respectful. They described how it can take them a lot to ask for help only to then feel like they're not being taken seriously. They explain that this can make things worse.

"I once had a very bad experience with an NHS mental health professional who was very brusque with me. I was extremely vulnerable at the time due to being at my lowest point during chemotherapy and this lady suggested I should try harder to pull myself together because this approach worked with a friend. She decided I didn't have a mental health issue even though I felt suicidal at the time."

There were also a number of comments relating to the need for more investment in staff, specifically having more staff with better pay and conditions.

One place to contact all mental health services

Having one place to contact for support was rated as one of the top 3 things that were important by 34% of people. It was apparent from the comments that people did not always know where to turn for help with their mental health.

Although the general feeling was that there wasn't enough mental health provision overall, people also thought that it would be beneficial if there was one contact point that was easily accessible (including on evenings and weekends). However, people noted it would need to be properly funded and staffed to enable this to happen. People wanted such a service to provide quick and professional advice, information and signposting and, where appropriate, referral to organisations that could help.

"One big team split by area with clearly defined roles, clearly defined types of support they give, would be good. Also, an advice line where non-urgent queries can be directed to a trained professional who can properly advise patients, their friends and families with general mental health guidance - no matter who the call is about or what information the caller is willing to give."

Other Themes

Several other themes came out of people's comments on this question:

Children and Young People

Children's mental health services, in particular CAMHS, consistently came in for criticism across the region. This was mainly regarding waiting times, high referral criteria, staffing and treatment.

"My son has dyspraxia and was referred to CAMHS for cognitive behavioural therapy to treat his anxiety, a short assessment over the phone indicated that he was appropriate for a "stress reduction" group session, this was completely inappropriate. This decision was very difficult to challenge and actually added to his stress levels."

"I took a teenager to a CAMHS appointment and was shocked at the leading questions that the professional used. I was particularly shocked as it took so long to get the appointment, I thought they would be experts."

"Bradford CAMHS [Child and adolescent mental health] is understaffed and there are children being lost in the system including my son. This service should be seen as the gateway to adult services. My son felt abandoned by them at least 3 times in 7 years, he does not have a lot of hope for the adult services because of this and neither do I."

Concerns were raised about the damaging effects of having to travel out of area for inpatient care, resulting in children and young people being isolated from their friends, family and community.

"NHSE funding for tier 4 inpatient care out of area should be redirected to local support in the community. I have spoken to several families with

experience of their children being admitted to out of area inpatient care. In every case their child was traumatised and further damaged by the environment and separation from their families."

Services better tailored to specific needs

There was a call for mental health services to be better tailored to individual needs, in particular for people with autism or hearing impairments. Others called for more support for drug users with mental health issues.

"Mental health support is inadequate. When you make contact with IAPT, you might get offered 6 CBT (telephone) appointments. As mentioned above, I'm deaf and this is a non-starter for me. I was offered an alternative of face to face, however when I actually attended, I was told we could only work on one issue. This again was not helpful and felt as though the service had shut down its offer of help before it started."

"Autistic children with mental health issues are not treated because there are no trained staff that can adapt existing treatments to meet their needs."

More joined up services

Some people felt that there needed to be better communication between staff from different agencies and that as a result of poor communication they sometimes fell 'between the gaps' or faced numerous different assessments.

"I have had a lot of issues in trying to get proper help for my 42-year-old daughter with serious mental health issues…. Lack of communication between services. Long waiting times for proper treatment. The feeling of being 'fobbed off' as you are referred to another service."

"Her GP offering a predominantly walk-in based service meant that each time she was experiencing symptoms (essentially chronic vomiting resulting from anxiety and other underlying mental health issues) she had to explain the issue to someone different who would often come to a different conclusion to the last person she'd seen or sometimes be outright dismissive."

"Our current provision involves a huge, poorly understood and disjointed service with isolated pockets of brilliance. It needs much better IT systems that work across multiple care providers and share data to ensure joined up care."

Staff training

A lot of the comments related to better training for all staff working in health and care, not just mental health professionals. This included better training to spot mental health issues and signpost or refer, with the aim of making services more accessible.

It was felt that mental health staff would also benefit from continuous professional development, especially around things that they might not specialise in.

"Better understanding of an individual's needs - e.g.- how someone with severe anxiety finds it hard to attend clinics, drop ins and would do better with initial home support"

"There are many psychology graduates every year in the UK, most will have studied mental health as part of their degree and are accredited by the British Psychological Society. The clinical structure which we currently operate within means that many positions within the mental health sector are largely limited to only those with nursing degrees. Nurses are valuable and are stretched but we have a large psychology graduate resource which is not being used."

GPs came in for some criticism, with people saying that they are often too quick to prescribe medication. People wanted GPs to have more knowledge of what other help was available so that they can better refer to other sources of support.

"I suffer with my nerves and I have only ever been given tablets and that is not really what I want. I want to be helped to get better. GPs need to be more understanding and refer you to services. I don't know where else to go. I am stuck."

Prevention

There was a general feeling that more needs to be done to prevent mental ill health where possible.

"Community and public health programmes to improve people's mental health and support people whose mental health is failing but is not yet an acute episode."

People told us that they felt the public should be made more aware by staff and services of what help is out there, including the third sector, but also the importance of self-care in maintaining good mental health.

“NHS direct involvement with all local community groups to teach all leaders how to identify possible red flags and where to direct people.”

People felt that there was a need to improve perceptions around mental health so it is recognised as being no different from other illnesses. Mental health first aid courses in communities were suggested as one possible way to help with this.

“Ways to reduce the stigma in families that may not be aware about the detrimental effects it can have on individuals i.e. community classes with translations in different languages”

Carers and families

Several people commented that it was particularly important to remember that families and carers of people with mental health issues need support too. This includes children of people with mental health issues.

“The carer is put under a great deal of pressure during this time, which can make them unwell themselves… The carer must be looked after too as their health is paramount in helping the sufferer to keep going when things get tough.”

Other carers or family members noted how they often don’t feel as involved as they would like to in the care of the person they look after and that they want more information shared between carers and staff.

Q12. What could the NHS do to make sure children and young people have the best start in life and to live healthy lives?

1006 people (70% of all respondents) answered this question. The main themes arising from answers were as follows.

Education and information for parents and children

209 (21%) responses mentioned education as being crucial to ensuring children and young people live healthy lives. This included educating parents and carers about making healthy lifestyle choices for their children, for example by making sure their children have a balanced diet and do regular physical exercise. People also highlighted the importance of educating children from a young age in nurseries and schools about living a healthy life.

“Ensure children are taught about health and staying healthy all the way through their education. Public health and use of social media has big role to play in getting healthier lifestyle message out.”

Many people commented that it was important for the whole family to get involved in activities, in order to ensure motivation and encouragement continues at home.

“Provide useful guidelines to parents and implement strong messages through interventions about the critical nature of families all collectively following healthy routines. Also, provide more family-orientated sessions in the community to involve all ages and educate all ages with better tips”

Advice and support from the NHS

130 people (13%) suggested that the NHS should provide non-judgemental support and enable good access to advice and information for parents and carers according to their needs.

114 (11%) respondents felt that that it was important for support and services to be available during the early stages of a child’s life. This included supporting mothers during pregnancy; supporting families with new-born babies; early diagnosis of conditions; and support through childhood. Some people also said that more health visitors should be available for families and in schools.

“Give parents access to support/advice in early years. These years are a crucial time and support is being cut back at every level, from a reduction in the amount of visits you have from a midwife and health visitor to lack of access to early years health professionals in places like Children's Centres which have closed. We talk constantly of early intervention and prevention yet services do the exact opposite of providing this valuable support.”

22 people (2%) mentioned Sure Start centres as a model that worked well for supporting children to have the best start in life and wanted to see these kinds of services reinstated for both parents and children.

“Sure Starts were brilliant. There really needs to be something like that.”

Spotlight on parents of children with disabilities

Parents of disabled children attending a focus group in Calderdale wanted to see the services that are already in place working properly - wheelchair services were mentioned as a key issue. *"Nothing seems to work"* was a phrase that was heard in this focus group, as well as frustration expressed at being passed from pillar to post.

People suggested providing a flowchart detailing where they need to go with regard to managing care for someone with a disability. People said that they often found out about a service or useful NHS contact by word-of-mouth.

They want young people to move to adult services with an automatic referral. At the moment they require a GP referral and if this is not done, the young person is at risk of dropping out of services unintentionally.

They want to see diagnosis times improved so that people do not have to wait many years. They would also like improved access to assessments for people with learning disabilities and other conditions, as having a learning disability can sometimes make it hard to follow the usual assessment route.

Integrated services and the role of schools

A number of people agreed that there should be a whole-system approach to children's health and wellbeing, and that it is not just the responsibility of the NHS. They felt that services should be provided in partnership with local authorities, voluntary and community organisations, schools and nurseries.

Some people spoke about more promotion of healthy lifestyles in school, educating schools about providing healthy school meals, bringing back cooking sessions for children and making health and wellbeing a compulsory subject.

40 people (4%) suggested that schools should proactively provide regular physical and mental health checks through school nurses.

Some people said that more help was needed for vulnerable children who lived in poverty and those from disadvantaged backgrounds, and that the NHS should reach out to those who don't attend school.

Children and young people's mental health

68 people (7%) mentioned the importance of looking after children and young people's mental health. They felt that there is a real need for mental health education and support to be available in school. People wanted to see the NHS working with primary and secondary schools to raise awareness and understanding of mental health, as well as providing more regular mental health checks in addition to those currently done for physical health.

Spotlight on young people and mental health

Young people from a focus group held with YouthWatch Leeds talked about how they thought more mental health services should be open during the night and on weekends. They wanted the NHS to provide better information on where to get mental health support, and suggested it should offer more well-being and mindfulness support. They thought school assemblies, lessons and websites that address young people's mental and physical health should be widely available.

Some people suggested teaching children and teens practical skills such as mindfulness meditation and other relaxation techniques to look after their mental health.

People mentioned the importance of support for parents' mental health, in particular new parents, as their mental health has a huge impact on their children's health and wellbeing.

16 people (2%) spoke about under-resourcing and long waiting times in Child and Adolescent Mental Health (CAMHS). They felt that young people require quicker access to mental health services.

"Treat children and young people with respect, make services easier to access, reduce waiting times."

They also mentioned the need to invest in community services.

"There needs to be more funding for community and children's centres and for young people to have better access to mental health services"

Q13. What is your understanding of personalisation?

1042 people responded to this question. Out of these, 223 (22%) were unable to answer, either because they didn't know, hadn't heard of it or said it wasn’t applicable. This figure was higher for BAME communities (37%) and young people aged 15 or under (33%). Our data suggests that people with disabilities weren’t any more or less likely than people with disabilities to understand the term.

About the individual

Over half of the respondents (543, 52%) understood personalised care to be about the individual, what matters to them and that the person is at the centre and a key partner in all aspects of their care. Some people said that it requires having a care plan or package in place that is tailored to meet the specific needs of the individual. They also understood that it is not a one-size-fits-all approach, that it looks at the person as a whole and includes physical and mental health, as well as other factors such as housing, family and support networks.

“I am in an equal partnership when there are decisions to be made and health professionals LISTEN to what I have to say.”

“The whole person looked at in a joined-up way with all services they are accessing, physically and mentally supporting the individual.”

“Personalised care requires the individual to be fully involved in all discussions regarding care planning and the care plan meets the individual's needs as far as possible. It is not a one-size-fits-all.”

Values and principles

109 respondents (11%) spoke about some of the values and principles that underpin the delivery of personalised care and said it was about the individuals having choice and control over their care. People mentioned that when receiving care they should be listened to and treated with dignity, care, compassion and respect.

“Giving people more control over their healthcare”

“Suited to individual needs of individual, consistent, respectful with dignity”

Working together

65 people (6%) said they thought personalised care was a whole-system approach and a partnership between staff, the person receiving care and anyone who cares for that person. The importance of having one professional to oversee and review a person’s care was important in providing continuity and effective personalised care.

“A care plan which is set up by all involved in my care, including myself,

and/or caregivers, which acknowledges my own personal needs and wishes, provided in ways that work for my circumstances and needs."

"When there is some continuity in being able to see the same professional through your care journey."

Other

Various other interpretations of personalised care were given, including:

- 44 people (4%) thought that personalised care was about an individual taking responsibility of their own care and looking after themselves.
- 43 (4%) thought it was care delivered in a person's home or in a care home.
- 15 (1%) thought it was about professionals having joined-up access to all of an individual's medical records.

Q14. If you could change one thing about the way the NHS works, what would you change?

1154 people responded to this question through our online survey. There was significant overlap with the responses to question 4.

Improve the efficiency of the NHS

330 people (29%) said they wanted the NHS to become more efficient.

153 people (13%) said they thought there was a need to change the staffing structure so that there is less management, admin support is streamlined and there are more front-line staff such as doctors and nurses.

"I would stop the continuous reorganisations and have less managers and more staff working on the coal face"

14 people (1%) spoke about the impact bureaucracy had on the system and that they wanted the NHS to get rid of unnecessary paperwork and checks.

"So much red tape and expensive bureaucracy. Which leads to not enough money and resources available for the real part of NHS - doctors and nurses."

48 people (4%) said they felt the NHS should improve collaborative working with social care and voluntary organisations to provide integrated care for patients.

58 people (5%) said that they thought communications should be improved between different departments and areas of health care. For example, 14

people said they would like patients' medical records to be shared more effectively.

"Joined up thinking about the whole person so that if a person is referred to a lot of different professionals they are seen quickly. So I am not having to wait months to get a diagnosis and treatment."

Spotlight on cancer treatment

The West Yorkshire Cancer alliance focus group said they wanted communication to be improved between primary and secondary care and time between follow-up appointments to be reduced.

Funding and resources

180 people (15%) said funding is the one thing they wanted the NHS to improve on. 95 people (8%) said they wanted more funding generally to be invested in the NHS.

106 people (9%) specifically said they thought more resources should go to front-line health professionals to provide better support and training and a better working environment for them. People from the working-age population focus group in Wakefield and the West Yorkshire Cancer Alliance group said they wanted the NHS to provide better care for its staff.

"The NHS needs to "walk the walk" by exemplifying good health and well-being in its management of staff. There is much evidence to show that shift patterns are detrimental to health, well-being and family life. Instead of flogging the front-line staff with poor contracts and bad management practices – recent figures show that 160,000 nurses have left the NHS in eight years because of poor work/life balance – put people before money."

Appointments

161 people (14%) said they wanted the NHS to improve their access to appointments, in particular GP appointments (103, or 9% of all responses). The issues raised echoed the responses to question 4, including making it easier and quicker to book an appointment and having more appointments outside working hours. Issues were also raised around people wanting longer GP appointments and their preference for seeing the same GP.

Spotlight on LGBTQ

Some people in the survey mentioned how they felt receptionists at GP practices were “gatekeeping” appointments. In a LGBTQ group focus group in Leeds, people said they wanted the NHS to review whether the reception staff should ask triage questions to determine whether the patients should have an appointment.

Reduce waiting times

149 people (13%) wanted the NHS to reduce waiting times for treatment and offer quicker access to services.

Spotlight on Mental Health

A focus group for people with mental health conditions in North Yorkshire expressed that it was especially important for people with specific and multiple conditions to have easy access to GP appointments and also to be able to see the same doctor each time. They also talked about the importance of reducing the time it took to get a diagnosis so that they can access appropriate treatment.

Communication, language support and the Accessible Information Standard

68 people (6%) wanted the NHS to improve its communication. 10 people wanted their communication needs to be better met (e.g. by providing information in an accessible format and providing more language support).

“The NHS should hold accessible information for all patients on one system that can be utilised by GPs, patient transport and any referral that you’re made so they understand whether you require transportation, a different format of appointment letter and whether you need assistance through the clinic. I feel this would change the way the NHS works completely and stop people being confused over letters and missed appointments.”

Spotlight on Sensory Impairments and Communication

A focus group for people with sight loss in Leeds said they wanted the Accessible Information Standard to be implemented more widely as there are still many services in the NHS that are not adhering to it since it became law.

Both deaf and sight loss groups (i.e.: the focus group for people with sight loss in Leeds) asked for better staff training in regards to sensory impairment and other long term conditions.

Spotlight on Language Support

A focus group with a Hindu faith group in Leeds said they wanted the NHS to provide a Level 3 interpreting service so that people could understand and manage their health conditions fully.

Other

- 50 people said they wanted to see more patient-centred services that would suit individual needs and treat people more holistically.
- 35 people wanted easier access to and better mental health services.
- 31 people wanted to introduce penalties for unattended appointments and unnecessary use of services to make people more responsible for using the NHS.
- 29 people said they were happy with NHS services and required no changes.
- 28 people said they wanted to stop privatisation in the NHS. This view was echoed by three of the focus groups, attended by a total of 24 people.
- 27 people wanted improvements in A&E services, particularly around waiting times.
- 12 people wanted better information-sharing between agencies and with patients.
- 11 people wanted improvements in elderly care.
- 6 people wanted to see more NHS dentists available.
- 3 people wanted a quicker response time from ambulances.
- 3 people wanted to see improvements in autism services.

Part 2: Findings - Specific Conditions Survey

Note about our data

Not everyone who responded to the survey answered every question. Where people have not answered or indicated that they didn't know, these responses have not formed part of the total percentage.

Our data does not tell us when each respondent was diagnosed; as a result, it is likely that some received treatment several years, if not decades, ago.

Analysis has revealed that many respondents view their care as a single experience rather than a process with discrete stages (initial diagnosis, post-diagnosis treatment, ongoing support). As a result, we have sometimes amalgamated responses from several questions into a single section of the report.

A total of 280 people completed the specific condition survey. 47 of these responses were from people in the Harrogate and Craven (North Yorkshire) area but due the data being received later than anticipated, timescales meant we were unable to include the quantitative elements from this area in the analysis, although we have included some quotes from respondents where appropriate.

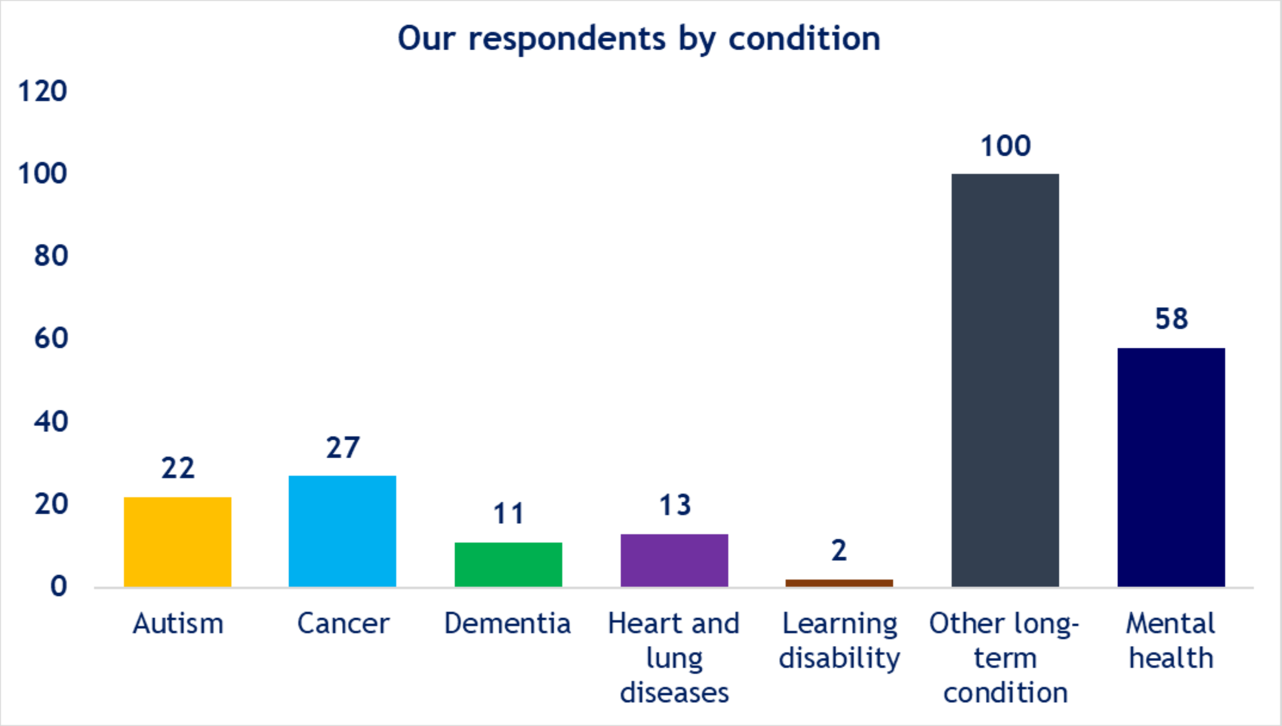
Terminology

For the purposes of this report, cancer; heart and lung conditions; and other long-term conditions will be referred to as "**physical conditions**". We will use the term "**non-physical conditions**" to refer to mental health conditions, dementia, autism and learning disabilities.

We have tried to reflect respondents' own understanding of NHS terminology as accurately as possible. As such, we use the term "**ongoing support**" to refer to all post-diagnosis treatment services or professionals, such as physiotherapists, specialist nurses and consultants. The term "**specialist**" refers only to consultants.

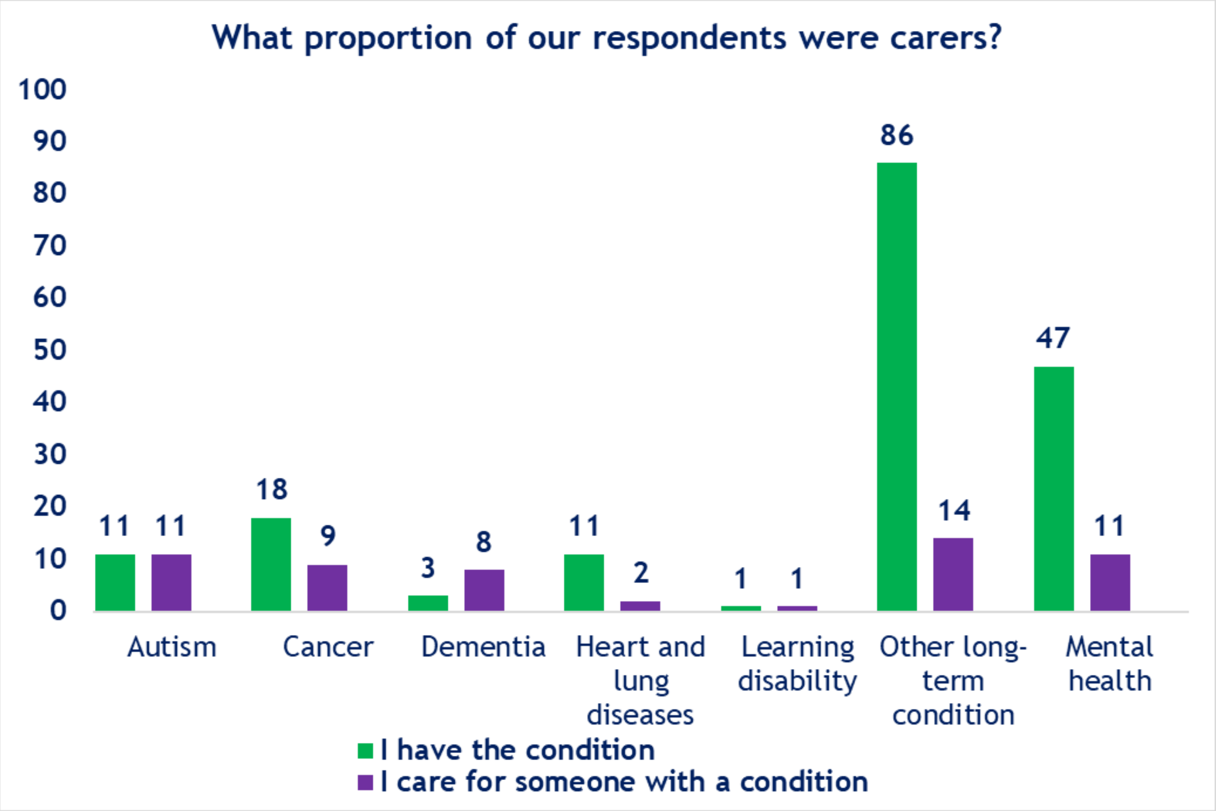
Section 1: About our respondents

Q1: What condition do you have experience of?

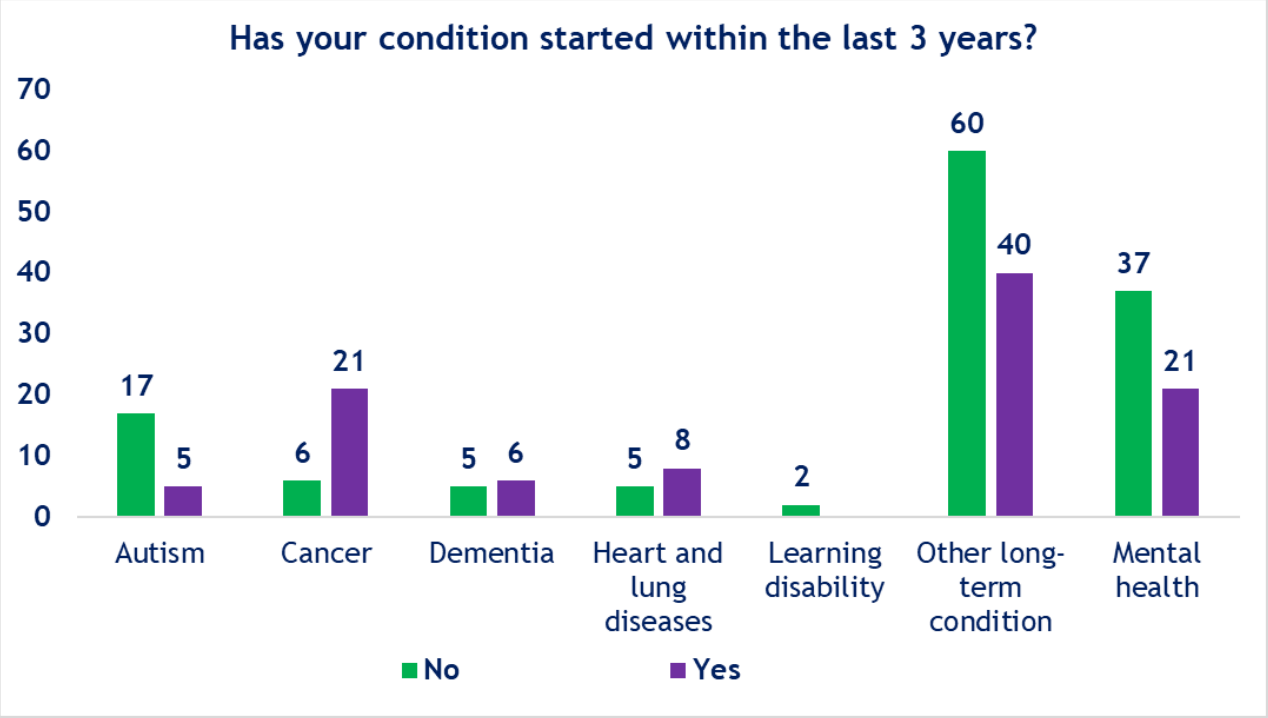


Q2: Do you have this condition, or do you care for someone who has it?

Most of our respondents were speaking on behalf of themselves. However, in the case of autism and dementia, carers made up at least half of our respondents.



Q3: How long have you had your condition for?



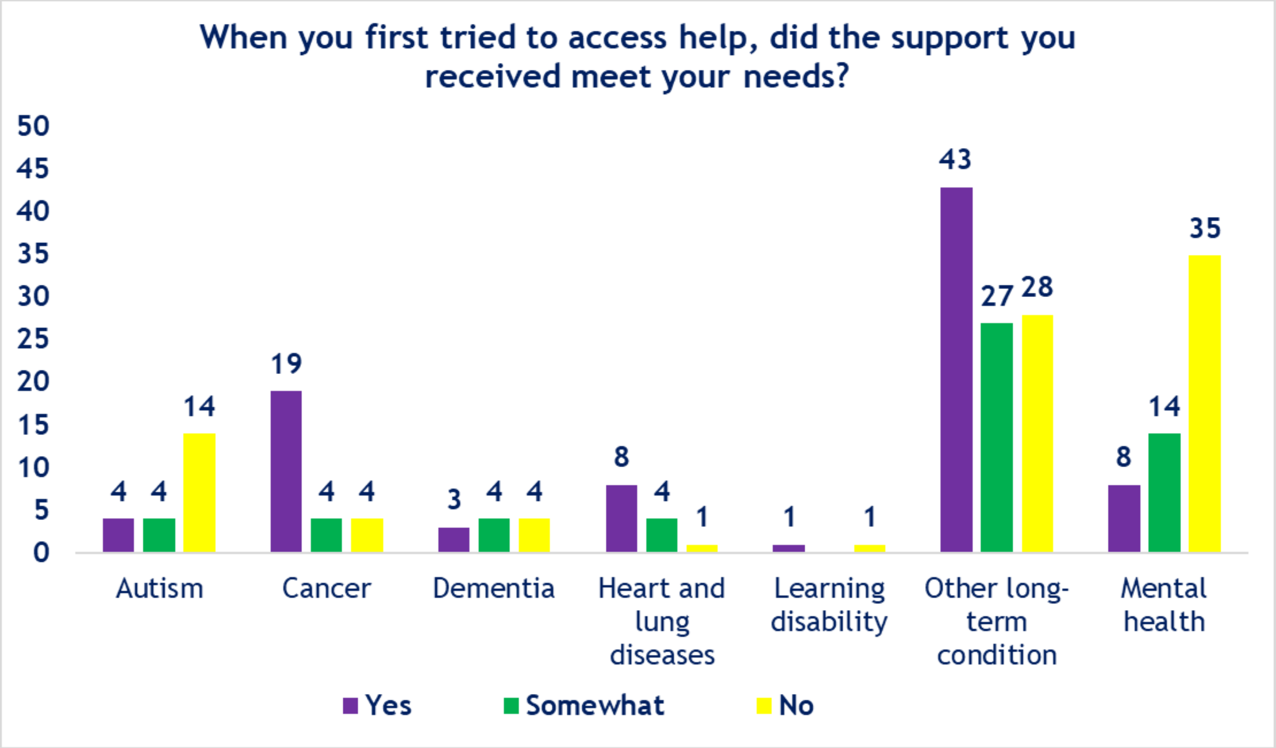
Most respondents with cancer, heart and lung conditions and dementia said they had been living with their condition for less than three years.

Conversely, most people with autism, learning disabilities, mental ill health and other long-term health complaints said they had been living with their condition for more than three years. (Note that in the case of life-long condition autism, we suspect that respondents interpreted this question as meaning “Were you diagnosed in the last three years?”.)

Section 2: Accessing initial support

On the whole, people living with physical conditions reported a more positive experience of getting help and support than people with non-physical conditions.

Q4: When you first tried to access help, did the support you received meet your needs?



76% (105 out of 138) of people with a physical condition found that the initial support they received met their needs fully or partially.

41% (38 out of 92) of people with a non-physical condition found that the initial support they received met their needs fully or partially. People with experience of dementia are more likely to be satisfied than those living with mental health conditions or autism, with 64% (7 out of 11) saying their needs were at least partially met.

Q5: How could initial support have been improved?

Although people with physical conditions were more likely to have a better experience of getting initial support than people with non-physical conditions, we found evidence that people in both categories felt care fell short in two ways.

Firstly, people reported long waits, inefficient services and being left to cope alone in the meantime.

“It took a lot of time and appointments with different doctors and 2 A&E visits and being referred to physio (unnecessarily) before eventually getting a diagnosis. My cancer referral went missing resulting in a long

wait even though I rang to chase it up […] GP surgeries and hospitals should work together more effectively” (cancer)

People living with autism or mental health conditions often mentioned the distress they experienced while waiting for diagnosis or assessment.

“Getting a diagnosis took over 4 years and there was no support available during that period” (autism)

“Lots of support is only available once you get a diagnosis, nobody helps you by explaining what you need to go through to get one, the waiting list is 3 years” (autism)

“When depression or anxiety is bad we need to access psychology immediately. Joining a waiting list of months for just a basic CBT therapist is useless. And when a psychologist is needed waiting 2 years as I am is a disgrace” (mental health)

Secondly, people felt there was a lack of knowledge among non-specialist health professionals, particularly GPs and regarding autism and other long-term health conditions.

“It took 2 years to get a diagnosis. GPs need more understanding of hypothyroidism” (other long-term)

“I tried to access help and support from my son's GP. I was told ‘we just deal with physical health’” (autism)

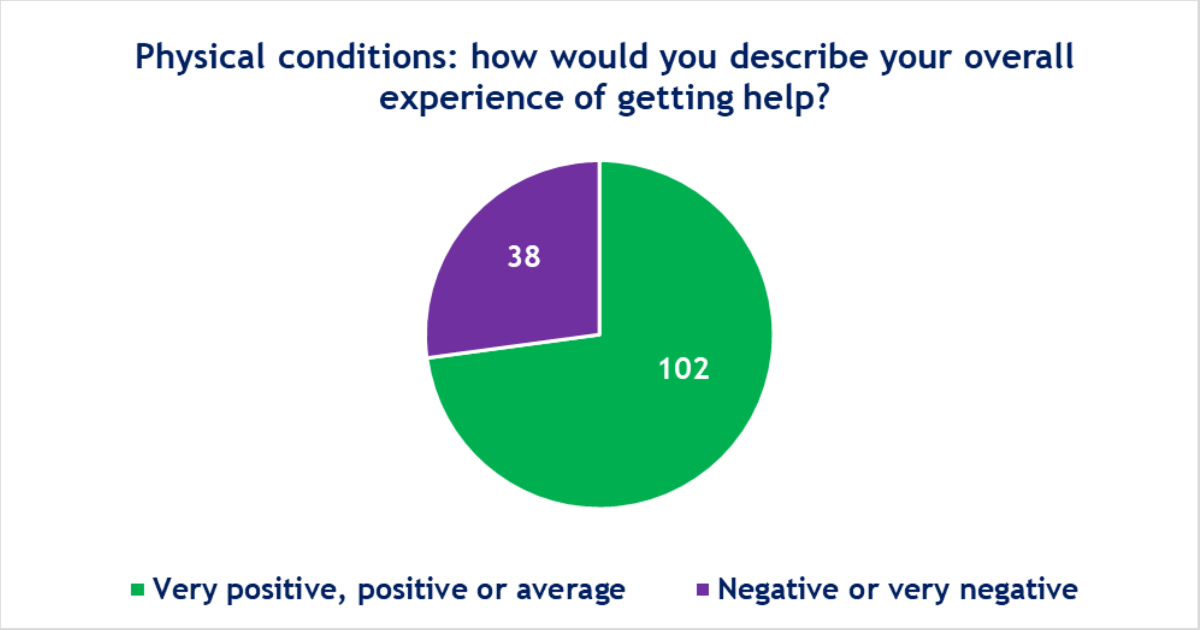
“The health visitor was not trained in understanding the symptoms of autism and completely overlooked them” (autism)

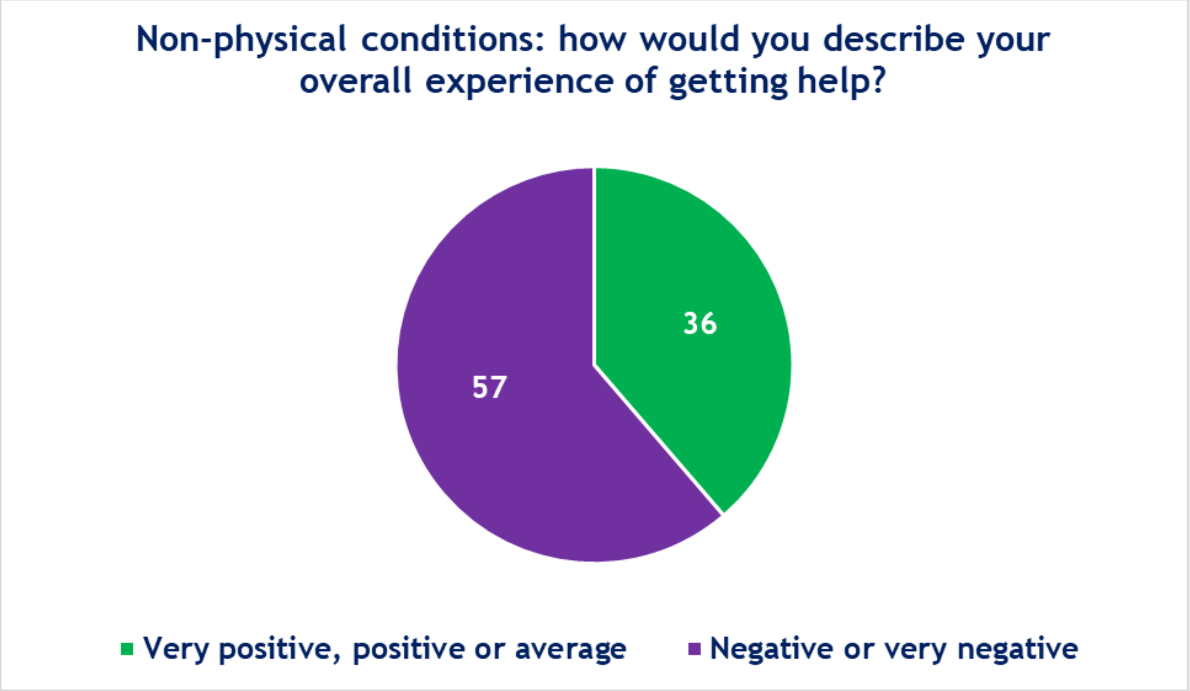
“Went to the GP and just felt they were fobbing us off” (dementia)

Q6: How would you describe your overall experience of getting initial help?

Again, there is a divergence between the experiences of people with physical and non-physical conditions.

People with non-physical conditions were more than twice as likely to have a negative experience of seeking help than people with physical conditions.

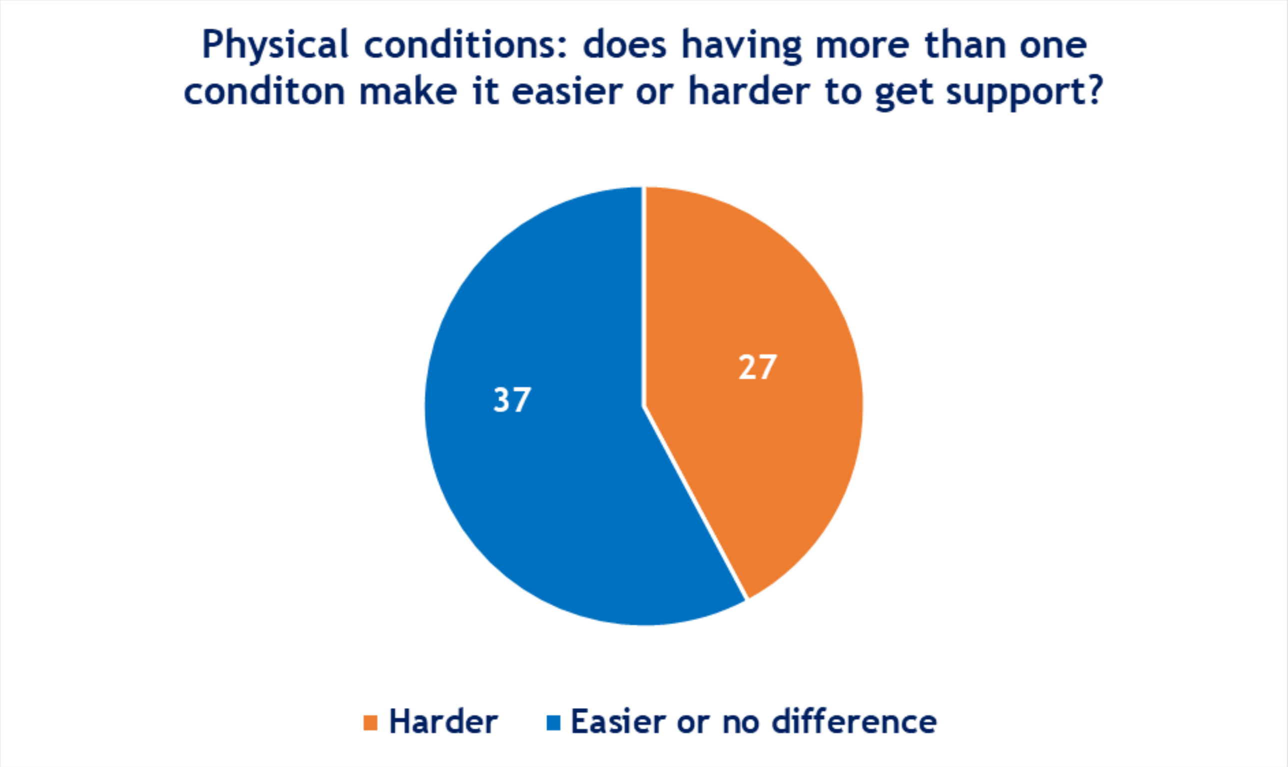


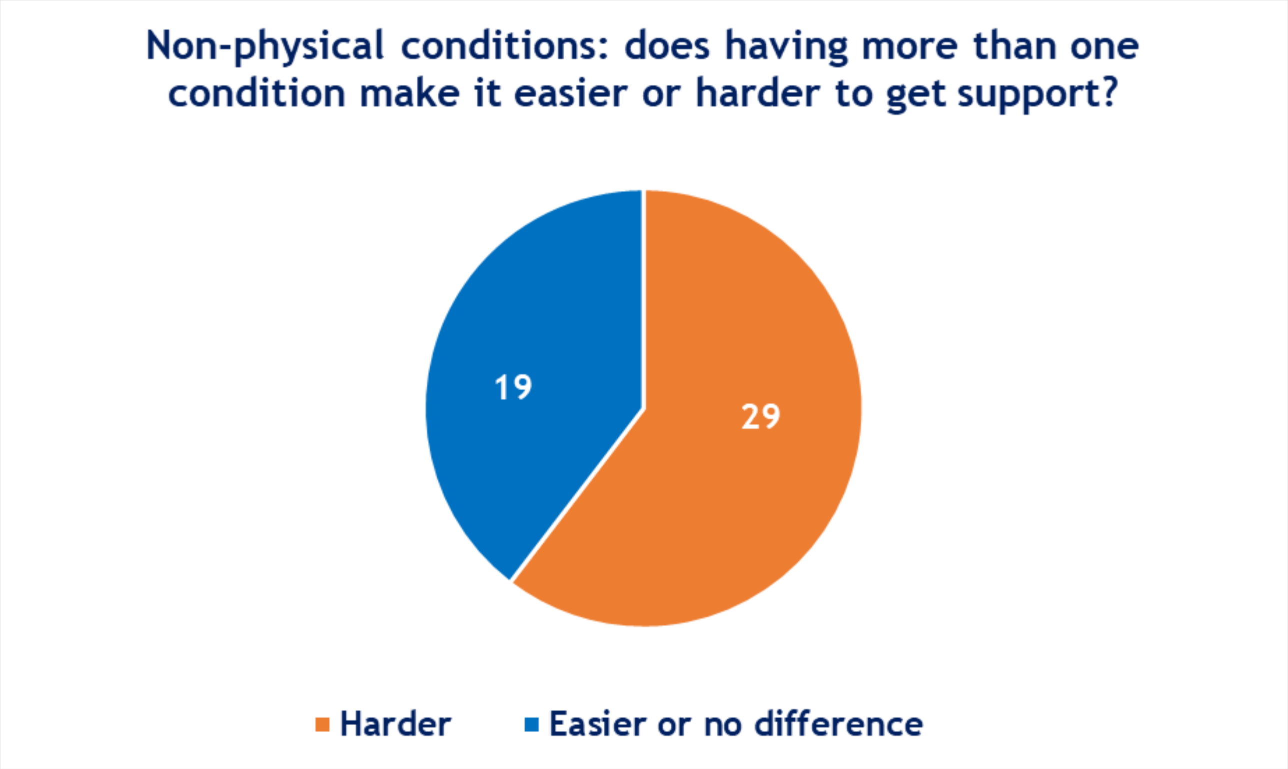


Q7: Do you have any other conditions? If you do, did that make it easier or harder to get initial support for your main condition?

People with physical conditions were as likely as people with non-physical conditions to have another health concern. 53% of people in both groups have another condition.

A significant number of people with conditions of all kinds said that having more than one condition made it harder to get support. However, people with a non-physical condition are more likely to give this response.





Section 3: Waiting times

As we saw in Section 2, long waiting times to get initial support were a particularly significant issue for people living with non-physical conditions. This trend largely appears to persist as they move further through the care journey.

As a general rule, people with physical conditions reported quicker access to support than people with non-physical conditions, whether they were waiting for an initial assessment, treatment or an appointment with a specialist. However, the picture was subtly different across each condition group.

Q8: How long did you have to wait for your assessment, treatment or appointment with a specialist?

Cancer: very fast

People with cancer have the most consistently positive experience with waiting times at every stage in the care process, with "very fast" being the most commonly chosen option to describe diagnosis, treatment and specialist care.

- 69% (18 out of 26) said waiting for a diagnosis was fast or very fast;
- 74% (20 out of 27) said waiting for treatment was fast or very fast;
- 70% (16 out of 23) said seeing the specialist was fast or very fast.

Heart or lung conditions: mainly fast

While most people reported a fast service at every stage in the care process for heart or lung conditions, the trend was notably less marked than for cancer patients.

- 54% (7 out of 13) found waiting for a diagnosis fast or very fast;
- 50% (6 out of 12) found the process fast or very fast at the treatment stage;
- 55% (6 out of 11) found waiting to see a specialist fast or very fast.

Other long-term conditions: mixed

The care process was slow overall for people with other long-term conditions, but appeared to speed up a little post-diagnosis.

- 52% (50 out of 96) found getting an initial assessment slow or very slow;
- 43% (40 out of 94) of patients found waiting for treatment slow or very slow. 36% (35 out of 94) of people found this stage of the process fast or very fast;
- 38% (27 out of 72) found seeing a specialist slow or very slow, compared with 32% (23 out of 72) who found it fast or very fast.

Autism and learning disabilities: mainly slow

64% (14 out of 22) of people with autism and learning disabilities find getting an initial assessment a slow or very slow process. The picture improves slightly once they have got their diagnosis:

- 53% (10 out of 19) say the wait to get treatment was slow or very slow (7 out of 19 or 37% said it was OK);
- 11 people with autism or learning disabilities we spoke to were able to tell us about waiting to see a specialist, of whom 4 (36%) said it was OK and 4 (36%) very slow.

Dementia: mainly slow

55% (6 out of 11) of the people we spoke to found the wait for an initial assessment slow or very slow. Again, the picture improved slightly post-diagnosis, with fractionally fewer people having a slow or very slow wait for treatment (45%, or 5 out of 11). However, of the 8 with experience of waiting to see a specialist, half thought the waiting period was OK, with the remaining half saying it was slow or very slow.

Mental health: very slow

People with mental health conditions appear to have experienced the longest waiting times.

- 43% (23 out of 54) of the people who were able to tell us about waiting for an initial assessment said the process was very slow; a further 19% (10 out of 54) said it was slow;
- The picture does not improve post-diagnosis, as 43% (21 out of 49) again found the wait for treatment very slow and 24% (12 out of 49) slow;
- This trend continues but becomes less marked when people are waiting to see a specialist. 43% (13 out of 30) said the wait was slow or very slow, and 27% (8 out of 30) said it was OK.

Q9: Tell us more about the length of time you waited

Some of the people who answered this question told us how their wait affected them. The comments below provide an idea of the impact of waiting times at every stage in the care process:

“It took three months to diagnose which seemed a long time for me because of the pain and discomfort I was in” (cancer)

“My son was diagnosed with dyspraxia at 5, dyslexia at 7, but although autism was suspected, that diagnosis didn't come until he was 13. By that time the impact on his mental health was irreversible” (autism)

"From the time he noticed signs of dementia to diagnosis was approximately three years. I had to write to our MP on two occasions in order to get the diagnosis" (dementia)

"6 weeks which was then another 2 weeks for a referral and another 2 weeks or more for another referral which may or may not happen. Each time I have to talk about multiple traumas without any follow-up support other than crisis numbers." (mental health)

"If I tried to take my life and got sectioned it would be shorter but I shouldn't have to take that step to get help faster" (mental health)

Around 8 respondents told us that waiting times had influenced their decision to seek private care:

"I saw doctor privately and they then placed me on their NHS list for follow-up treatment and tests. It was much faster" (other long-term)

"When seeking an assessment for my daughter the waiting time was around 4 years. We had to pay for a private assessment which cost £3k" (autism)

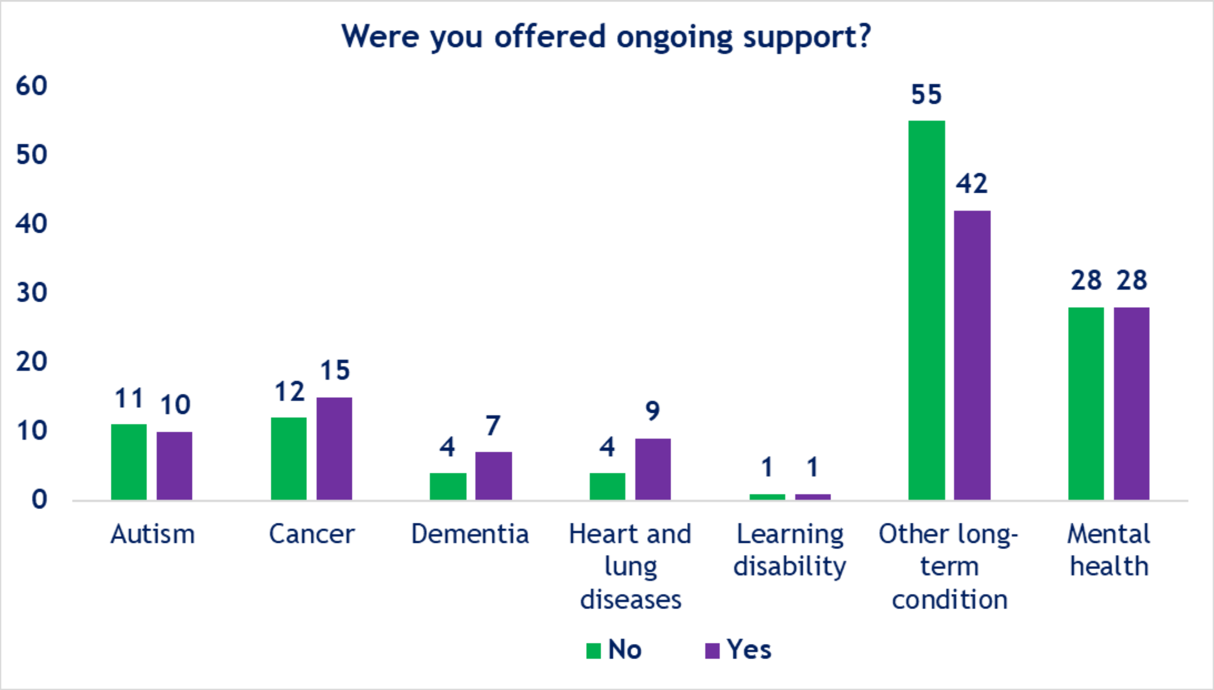
"Less than 6 months but still that's far too long, so I ended up going private, which has left me with significant financial problems" (mental health)

Section 4: Ongoing care and support

Q10: After being diagnosed or assessed, were you offered access to ongoing support?

Overall, there were only small distinctions between physical and non-physical conditions when it comes to being offered ongoing care. 48% (66 out of 137) of people with physical conditions report being offered support; the figure for non-physical conditions is 51% (46 out of 90).

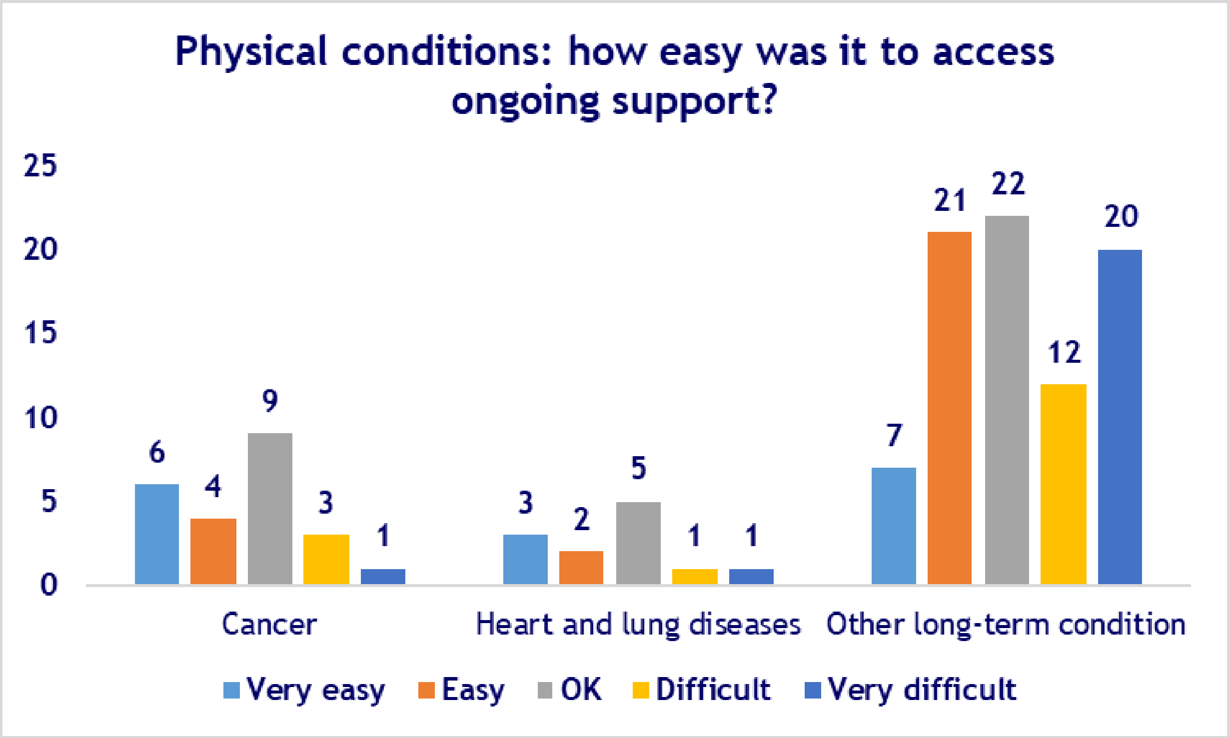
Of all the conditions, people with an "other" long-term condition were least likely to report being offered support.



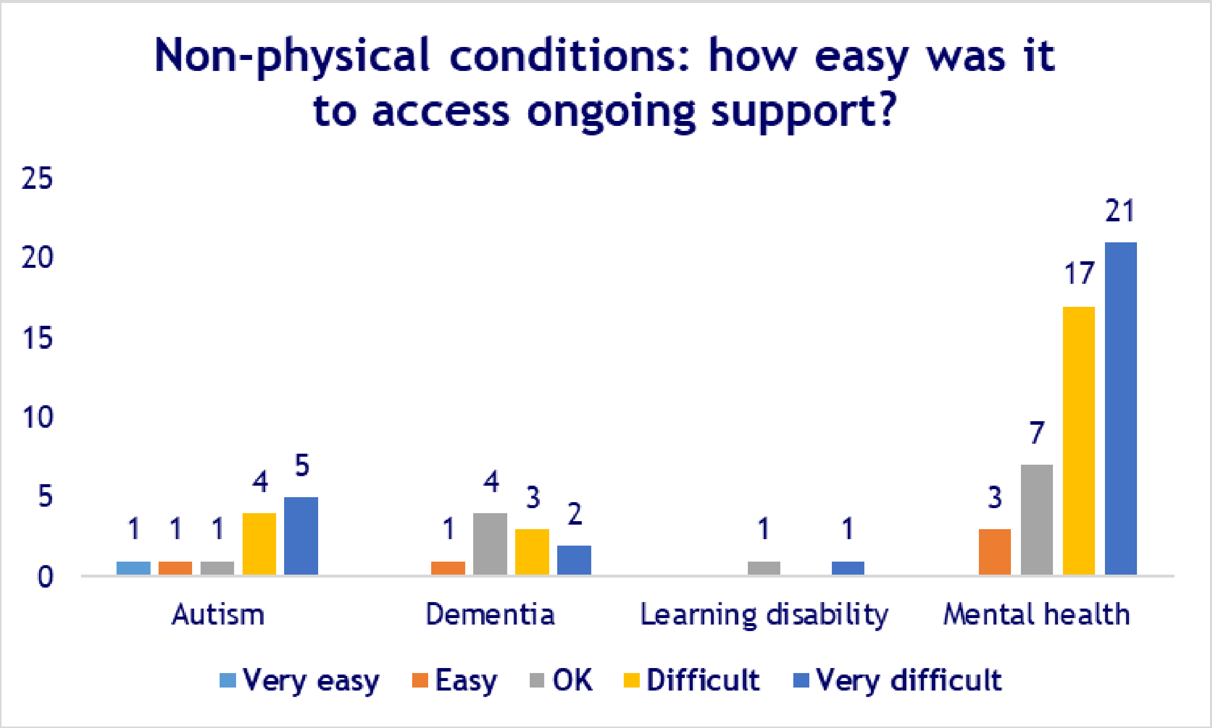
Q11: How easy did you find it to access ongoing support after you were diagnosed?

We have seen that people with non-physical conditions were slightly more likely on the whole to be offered ongoing help than people with physical conditions. However, people with physical conditions generally found it easier than people with non-physical conditions to access that support.

This said, it should be noted that while people with cancer, heart and lung disorders and so on find it easier on the whole to get support than people with, for example, mental health conditions, that is not to say they always find it “easy”. A significant number (31% or 36 out of 117) describe their access to ongoing support as merely “OK”. Furthermore, people with long-term conditions other than cancer or heart and lung disorders are comparatively likely to report difficulties.



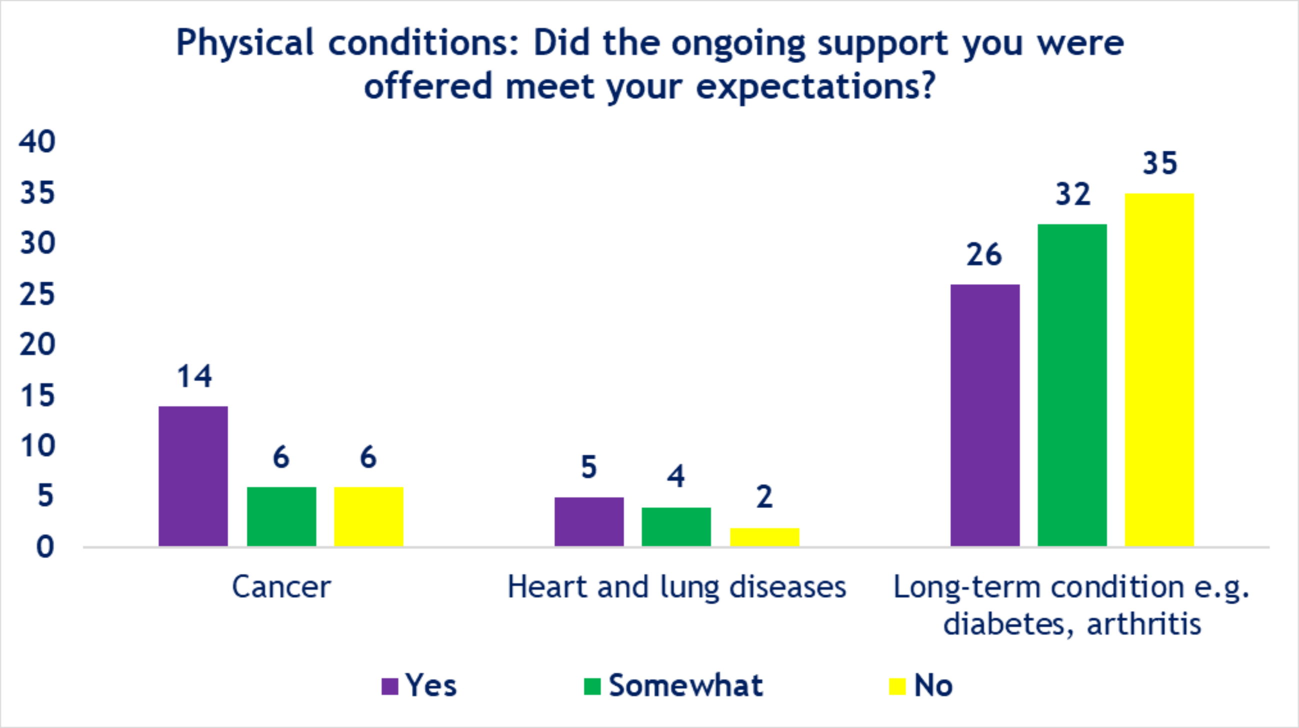
Whilst a person with a non-physical condition is likely to find accessing support difficult or very difficult, this is even more the case if he or she has a mental health condition or autism. 79% (38 out of 48) of people in the former group reported difficulties, as did 75% (9 out of 12) of people with autism.



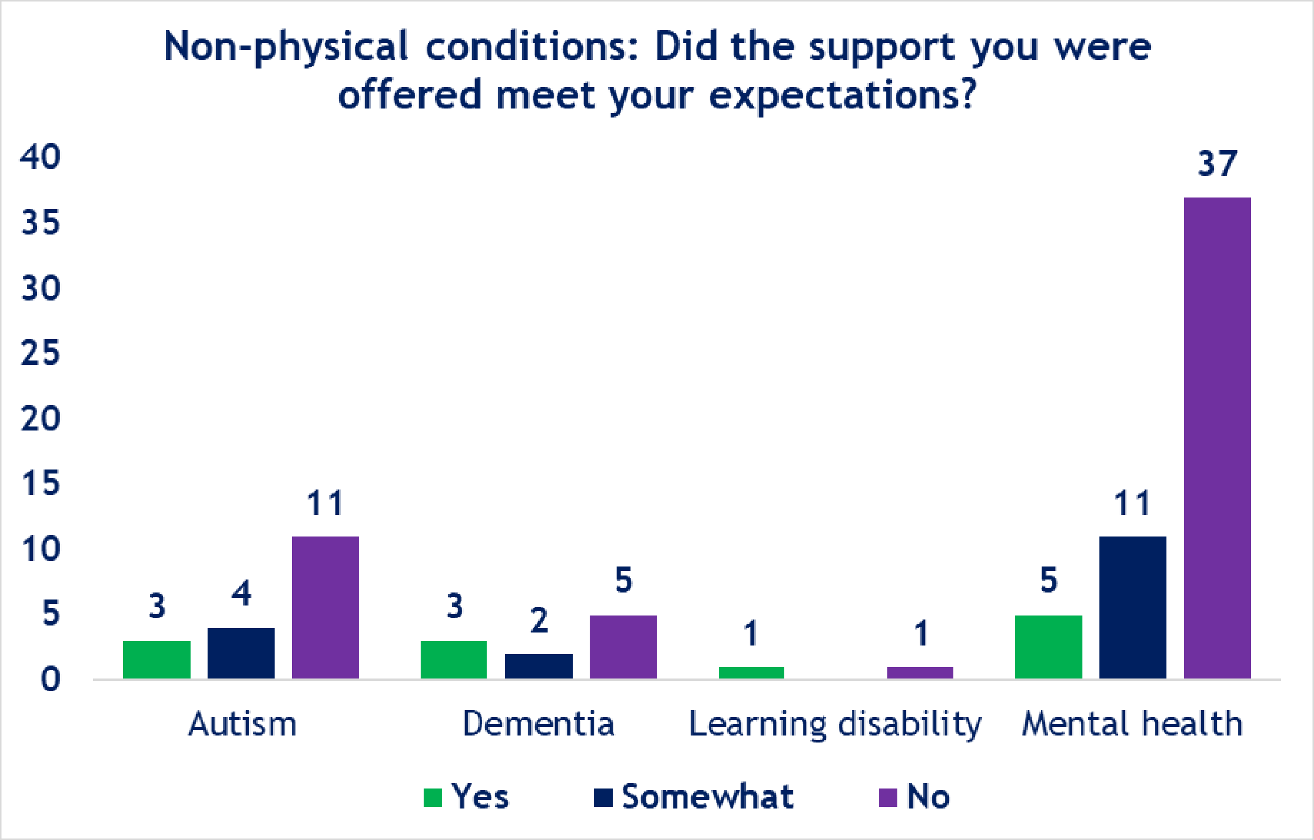
Q12: Did ongoing support meet your expectations?

When they did get support, people with physical conditions were also more likely than those with non-physical conditions to find it met their expectations.

People with cancer or heart and lung disease are likely to be at least partially satisfied with their post-diagnosis support. This is less often the case for people with other long-term conditions, 38% (35 out of 93) of whom reported that ongoing support did not meet expectations.



At least 50% of people with any non-physical condition felt the ongoing support offered was inadequate; that figure rises to 61% (11 out of 18) in the case of autism and 70% (37 out of 53) in the case of mental ill health.



Q13: What aspects of ongoing support worked well?

People's responses to this question showed that having regular and reliable contact was the main positive, irrelevant of condition.

While different professionals were mentioned as providing ongoing support (for example physiotherapists or Macmillan nurses), what worked well for people was having ongoing access to some kind of person-to-person support.

Condition	Support cited	What people said…
Cancer	NHS/Macmillan nurses (including palliative care nurse)	*"I established contact with MacMillan through whom I received much support at a time when I was somewhat bemused by the diagnosis and the rapidity with which things were moving. Their calm, no nonsense attitude to the problems perceived by me helped me to face the situation. I still have regular contact with them"*
	Age UK	
	Support groups	
	Cancer mental health service	
	Occupational therapist	
Heart and	Cardiac rehab	
	Lung function nurse	

lung	Nurse practitioner	
	Support groups	
	Heart specialist	
	Respiratory physio	
Other long-term	Physiotherapist	*"Being seen regularly at outpatients appointment"* *"Having a named person who was there to help and with whom a rapport could be built"* *"I now go to a regular clinic once a month and feel very knowledgeable of what I can and can't do"*
	ABA Leeds (support organisation)	
	Regular clinic	
	GP, specialist doctor, nurse	
	Dietician	
	Occupational therapist	
	Desmond group	
	Health groups	
	Low vision clinic	
Autism/LD	SCIP school	*"Quality of preschool support good, but only for 1 hr per week. NHS support for school age autistic children is non-existent."* *"Signposted to Leeds Autism Hub which was very helpful"*
	Portage visits	
	Speech & language	
	Pre-school support	
	Autism Hub	
Dementia	Social worker	*"We had a support person come to the house with a wealth of recommendations, most of which we accessed and found useful"*
	Mental health clinics	
	District nurse	
Mental health	Touchstone	*"I was offered regular appointments"* *"Counselling was hugely helpful, and I only wish I could have got more of it, more regularly."*
	Respite service	
	Support groups	
	LADS	
	Counsellor	
	Community psychiatric nurse	

Q14: What aspects of ongoing support could be improved?

People across all conditions reported the following gaps and problems in their ongoing care.

Problem	What people said…
I feel that I have been left to cope on my own	*"After my initial referral to mental health support worker I have just been cut loose"* (mental health) *"I think you should be given a dedicated supporter to contact with concerns during and after treatment (with contact times of course and not forever)"* (cancer) *"Absolutely no holistic, wrap around care and support with living with a progressive condition […] This meant that my husband and I were left totally behind and constantly scrabbling to keep up with everything"* (other long-term) *"All the support is means tested and we do not qualify. I therefore have no support in looking after G's needs and I care for him on my own"* (dementia) *"Waited months for a social worker. Then didn't have one for long. [My relative is] mainly left to struggle on her own"* (dementia) *"Initially, I had a mental health support worker - I was making real progress. After 6 sessions this came to an end and I am now struggling"* (mental health)
The support wasn't tailored to my circumstances	*"We don't understand what support is out there. We live in a household where both parents work full-time and we have a child under the age of 10 - so we're busy. We need to know what's available […] outside of working hours."* (long-term other) *"I was referred to a stroke club for old people but I was only in my 40's, it was not suitable for a younger person"* (long-term other) *"There only seems to be services which cater for people with higher dementia needs. There should be some support for people who have dementia but can still function in society"* (dementia)

I have to constantly chase services up	*"If you're willing to work hard to pursue the care you need, you can access it"* (mental health) *"Felt as a parent I needed to be well educated about my son's condition and proactive in asking for help in some areas."* (autism)
The mental health or emotional support I needed wasn't there	*"Better emotional support. Annual diabetic reviews do not provide the right platform for meaningful discussion unless you are extremely comfortable in your ability to articulate your needs"* (long term other) *"One aspect that may have been missing is the support regarding the impact the cancer had on my day to day life in terms of mental impact. I obviously had a lot of issues to deal with and whist there is offers of support it is often somewhat lacking"* (cancer)

We also noted a significant trend in responses from people living with mental health conditions. It was particularly common for people in this group to say support was inadequate because they felt that their diagnosis was incorrect or therapy did not meet their needs:

"I'm still waiting to see a real person. Am using an online supporter but it's not really what I need."

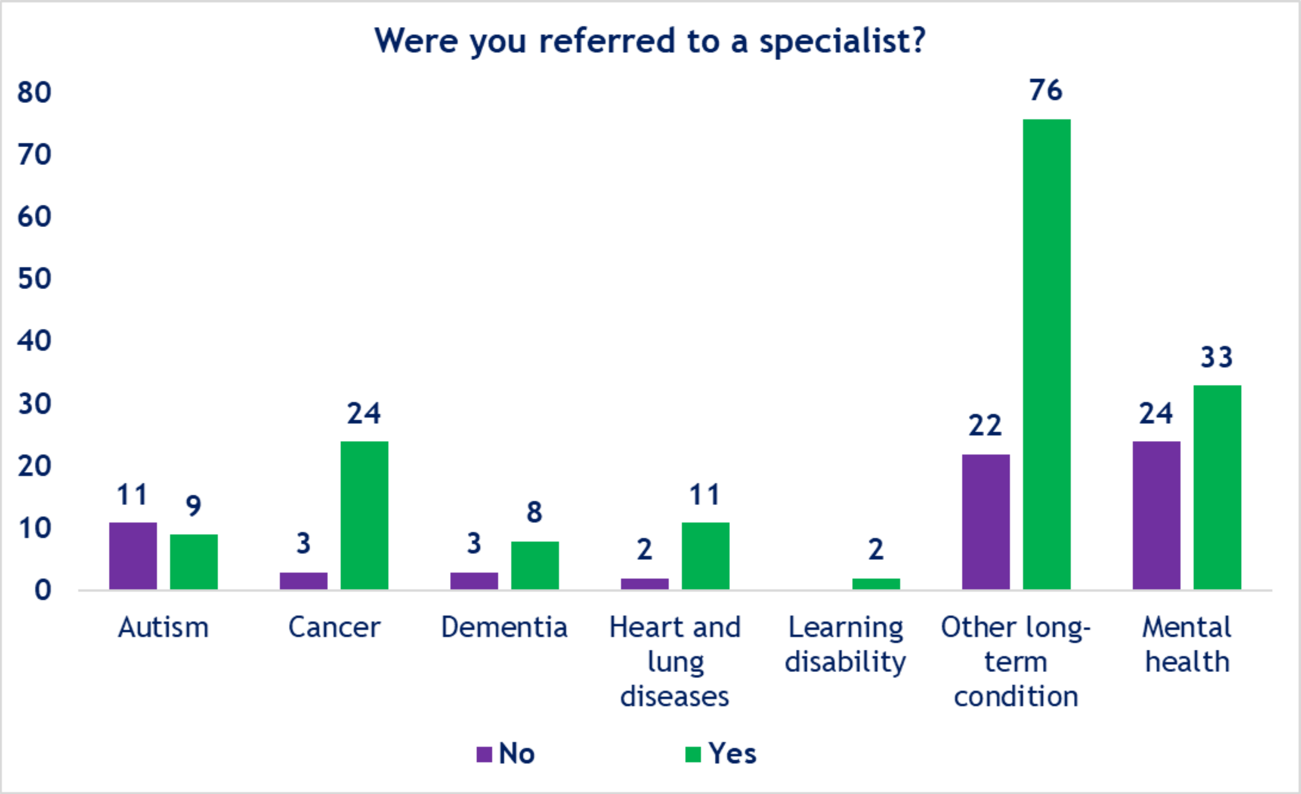
"GP didn't recognise I had bipolar for years, just giving me antidepressants, which were actually making me worse even though I said I was hallucinating"

"I accessed IAPT talking therapies/CBT but did not find this to be very helpful. A more supportive coaching type of approach could have been better."

"It would have been better to have a full assessment. I found out recently that I have autism which causes my depression. This was missed and I had years of unsuccessful treatment in the form of medications which caused lots of side effects."

Q15: Were you referred to a specialist?

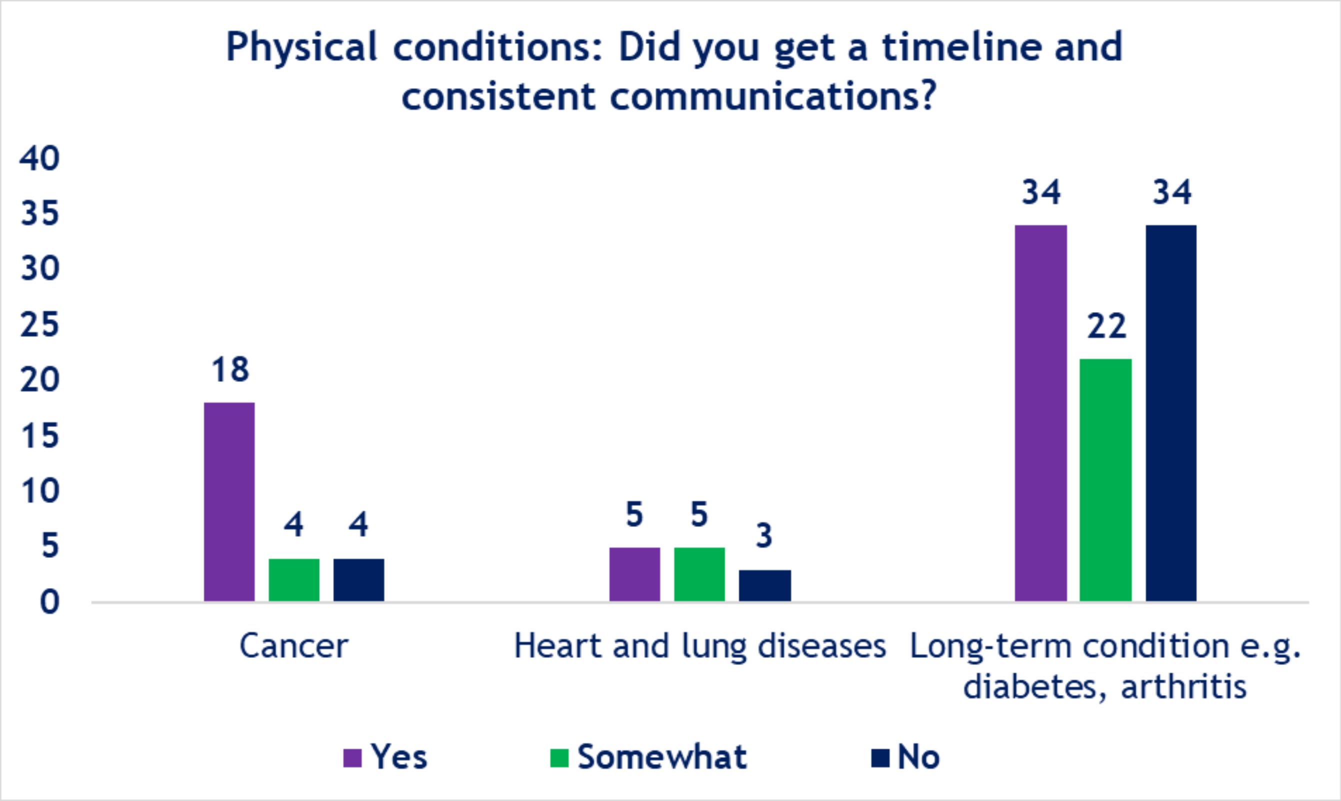
More people than not were referred for specialist care – except in cases of autism. More research is needed to determine why this might be, but it is worth bearing in mind that a number of respondents with autism note elsewhere in the survey that they have been waiting many months or years to get the care they need.

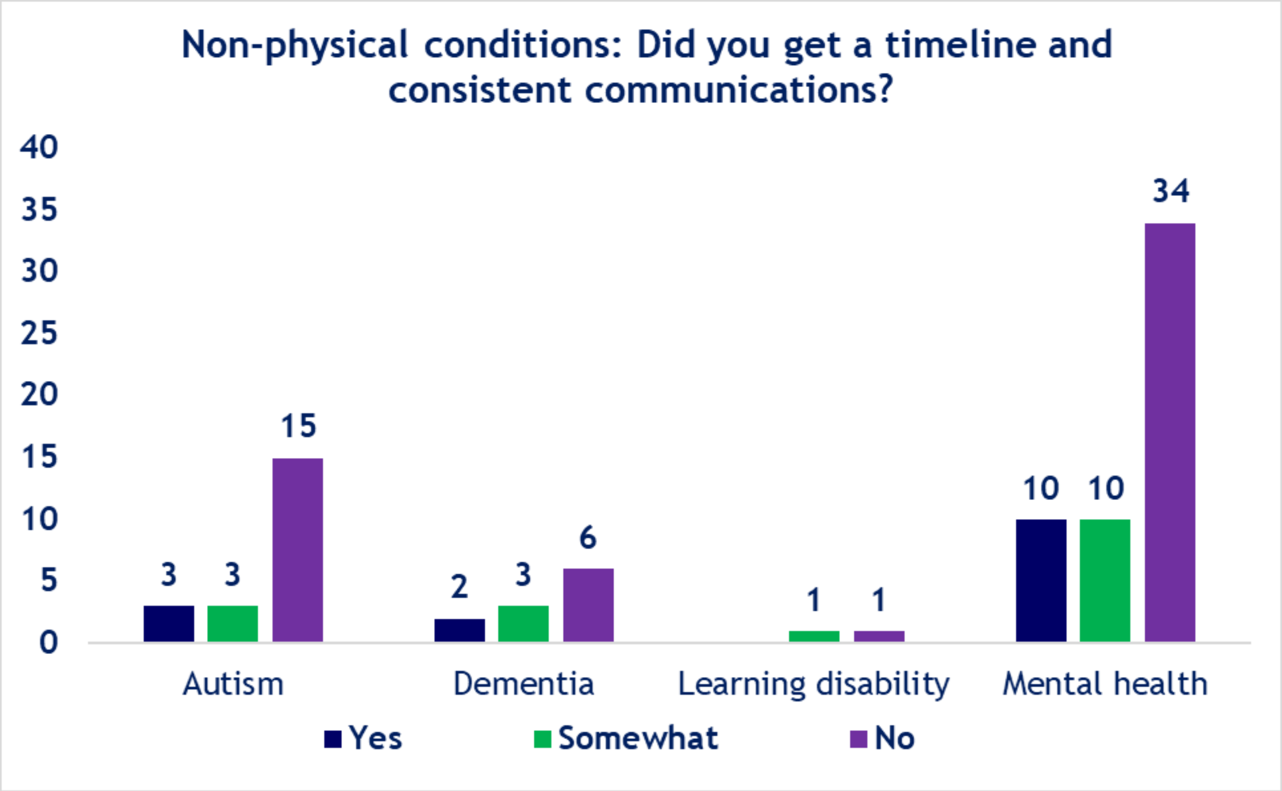


Section 5: Communications

Q19a: During your whole experience of getting support, did you receive a timeline and consistent communication from all the services you came into contact with?

Cancer services appear to be particularly good at communicating consistently, whilst people using mental health and autism services reported significant difficulties in this area. 71% (15 out of 21) of people with autism and 63% (34 out of 54) of people with a mental health condition say they did not get consistent communications, as opposed to 69% (18 out of 26) of cancer patients who say that they did.





Q16: Did the communications you got meet your expectations?

Answers to this question largely mirrored responses seen elsewhere in the questionnaire, touching on, for example, a feeling of being left to cope alone and having to chase up professionals.

We received a small amount of evidence around the following issues:

Problem	What people said…
Inconsistent messages	*“Local nurse says grapes are "sugar bombs", expert says they're ok to have a few as part of healthy diet - how can they be polar opposites?”* (other long-term) *“Some clinicians will say you should qualify for foot care and then others tell you that this isn't the case”* (other long-term)
A lack of clarity when managing multiple conditions or referrals	*“Calls aren't returned, you speak to someone different each time, no joint working between mental health and learning difficulties, their databases don't even match up”* (mental health) *“Constantly being told we need new referrals here there and everywhere makes you it feel like no-one can be bothered unless they have the correct piece of paper”* (other long-term)
A lack of communication	*“It should be easier to ask queries. It's difficult to think straight during and after treatment and any minor concerns seem huge. Do you ring your GP or the specialist? How do you contact a specialist direct? I ended up not getting help at all and gave myself avoidable anxiety.”* (cancer) *“Mental health team discharged me claiming I'd not responded to the letter but I never received letters”* (mental health) *“Not getting the check-in phone calls they told me would happen while I waited. Limited communication through letters and sometimes not telling me who I was seeing for what reason. Not good for anxiety!”* (mental health)
Communications weren't tailored to my needs	*“Everything was given in easy read, not appropriate for my ability level. Felt like a child. Need diversity for all adults”* (autism) *“I have serious sight loss but they still send letters, appointment cards, emails with inaccessible attachments”* (other long-term)

	“Whilst there is a place for written information, the amount of leaflets that are used to convey information rather than it be explained means that you often can't ask questions when appropriate” (cancer) *“Letters sent straight to my father who has dementia. […] I think people who have dementia should be asked if they want a "nominated person" to send information to”* (dementia)
Communications didn’t include the whole family	*“More collaborative working with the family”* (dementia) *“My daughter was discharged from CAMHS without our knowledge. Although an adult, she is like a child and nobody will speak to me because she's over 18, even though I care for her.”* (autism)

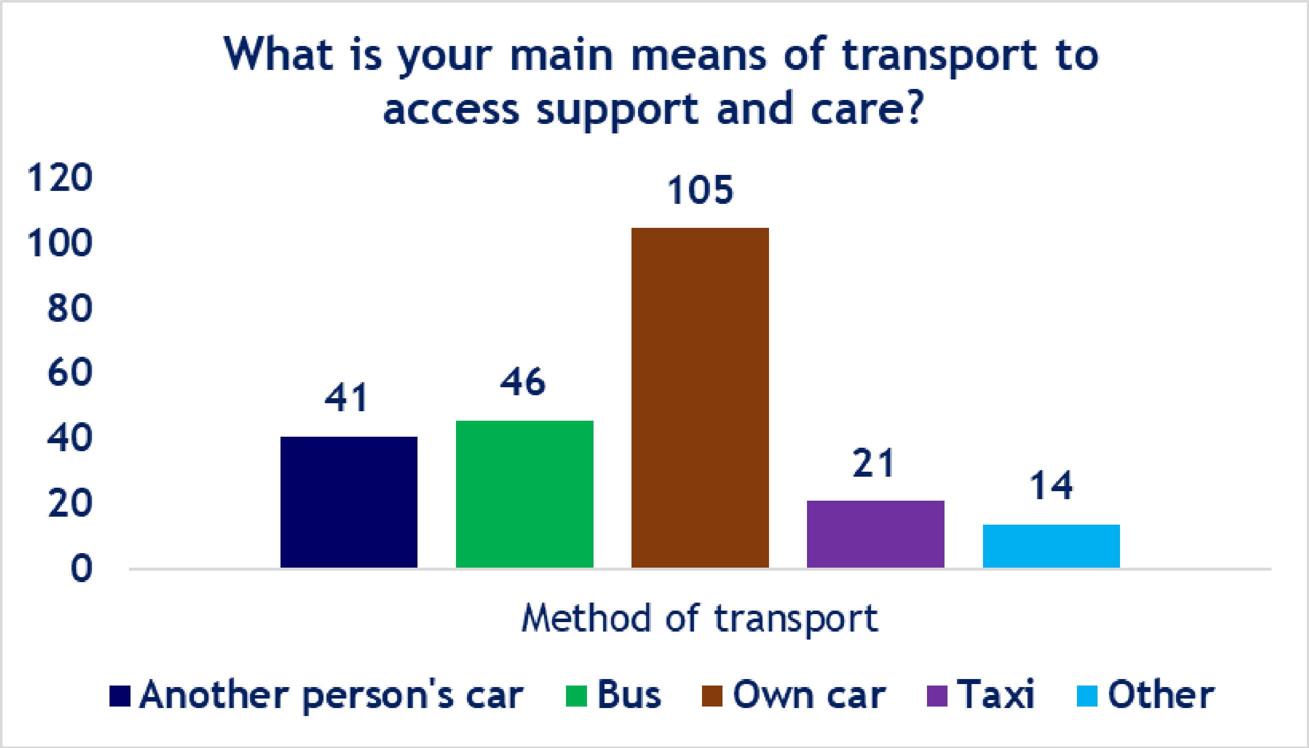
Section 6: Travelling to access support and care

Our data suggests there are no significant differences between conditions in terms of:

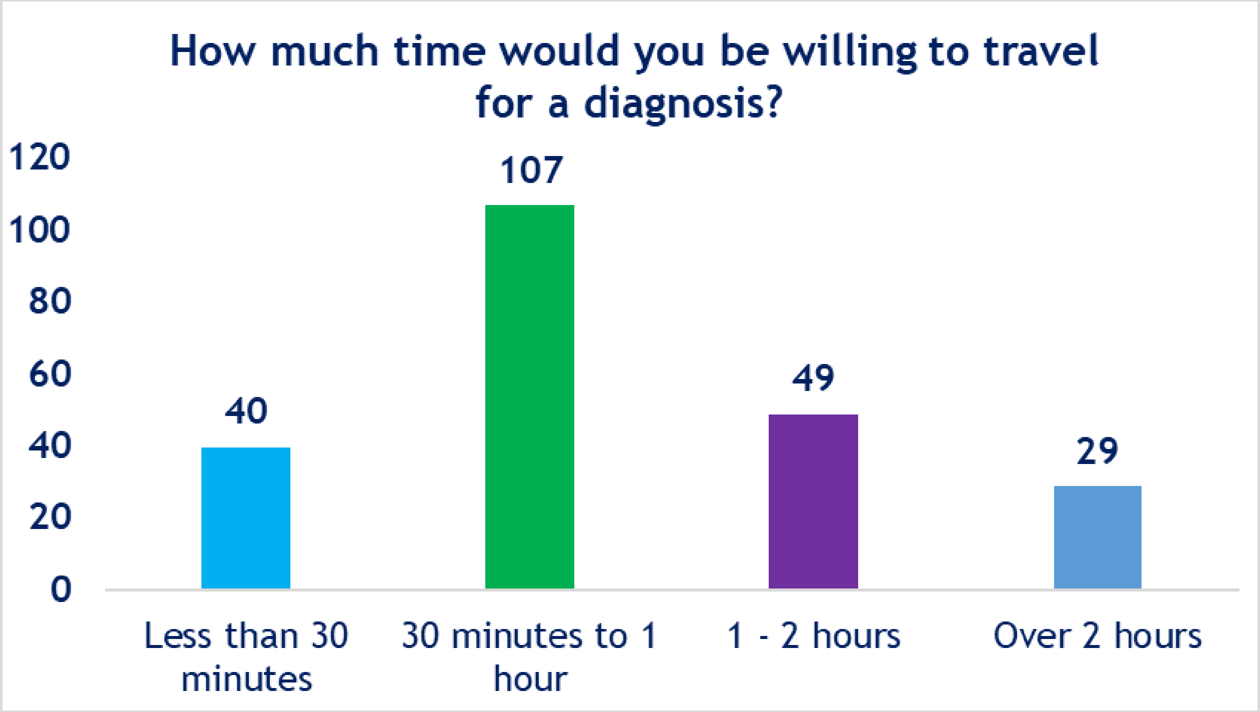
- How people travel to appointments
- How far they would be willing to travel to get a diagnosis
- How far they would be willing to travel to get specialist treatment

People are generally slightly more willing to travel further to see a specialist than to get a diagnosis.

Most respondents drive. People are more likely to rely on public transport (bus) than private transport (taxi).



Most people felt it was reasonable to travel up to an hour to get a diagnosis.

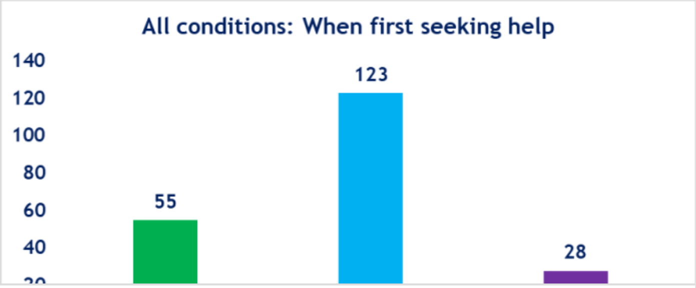


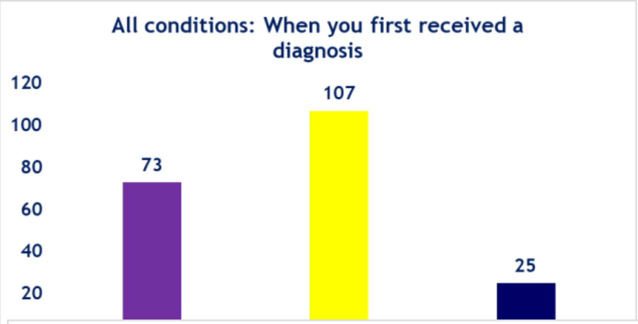
People are slightly more willing to travel longer distances to see a specialist: 22% (49 out of 225) of people would be willing to travel up to 2 hours for a diagnosis, but that figure rises to 33% (75 out of 226) for consultations with a specialist.

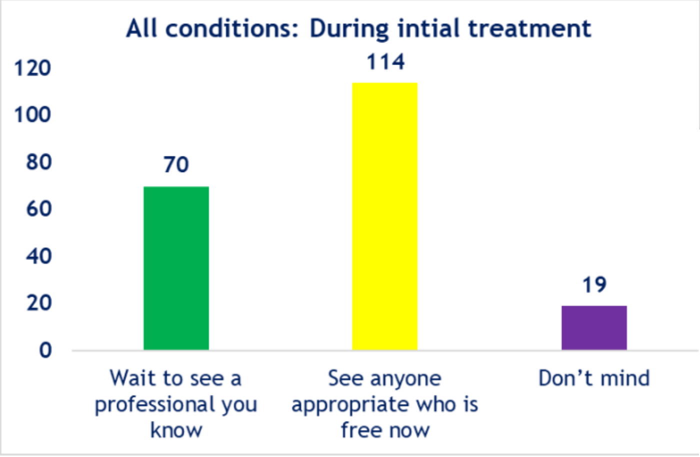
Section 7: Do you prefer to see someone quickly or to see someone you know?

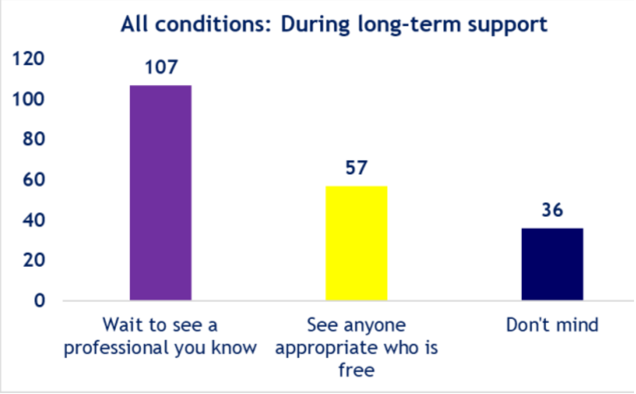
As a general rule, during the initial stages of the care process, people prized speed over familiarity with individual health care professionals.

However, once they have had received their initial diagnosis and treatment, they would then generally prefer to wait longer to see a professional they knew.





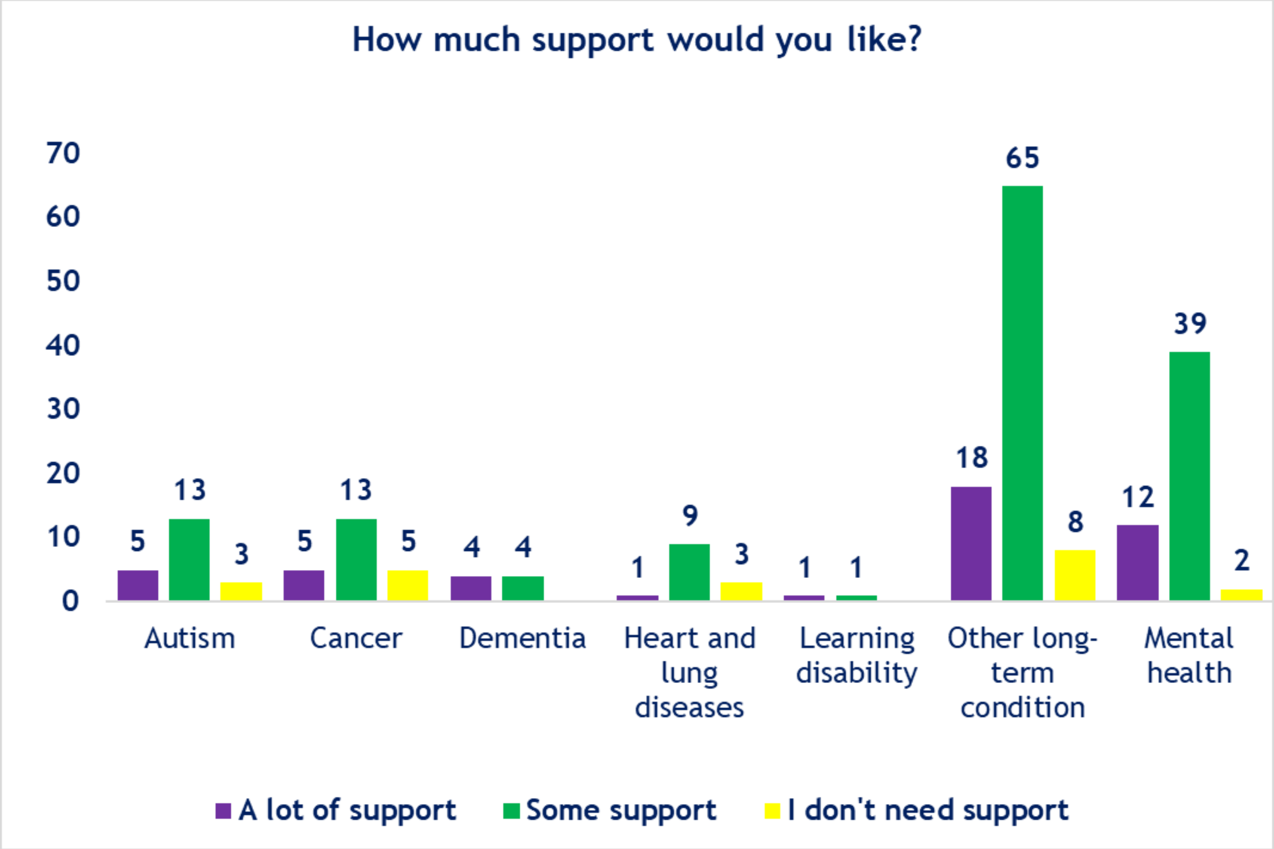




Section 8: Supporting you to have more control over your care

Q17: What level of support do you want the NHS to provide to help you stay healthy?

Most people across every condition said they would like “some support” to stay healthy.



Q18: What could the NHS do to help you stay healthy or manage any condition you have?

Across all conditions

Individuals expressed a wide range of suggestions in response to this question. As reflected by the word cloud below, the most common responses across all conditions were around getting relevant information and advice and access to help and support from health professionals when needed.

Often, and particularly amongst those with "other" long-term conditions, people wanted to have a contact person who was available if they had any questions about their condition.

"It would be nice to have someone to talk to if you have any questions that would eventually get back to you when you phone them. Not have to wait until you see your specialist." (other long-term)

"Have a regular drop-in clinic to see a health professional who knows you and understands the complexity of long term conditions that have multiple symptoms. Not necessarily a doctor. Provide a place to go to talk to

someone and other patients with long term conditions and get information. Even once a month would help." (other long-term)

"Open a telephone line to an expert advisor. It might save some newer patients having to call an ambulance. We need more active help to learn to self-manage our condition." (heart and lung)

Some people expressed how they were happy with the care and support they receive from the NHS and expressed their gratitude with how it had helped them. Some were happy to self-manage their condition, whilst others said they needed support to do this.

"I manage it myself. If there was a problem I would like there to be someone out there to help" (other long-term)

The NHS providing more continuity and co-ordination of care were important for a significant number of people with long term conditions, particularly those with more than one condition.

"I like to see someone who knows me and can see the whole picture - fragmented care where I see different doctors all the time is no good" (heart and lung)

"Don't look at conditions separately - one person should have a team of professionals" (dementia)

"There should be more input from the community nursing team… If someone is classed as housebound, would it not be better to have a housebound co-ordinator, for example a community matron, who can take ownership of the person and co-ordinate all that is required, including all these referrals? Just having one person to contact would make life so much easier for us." (other long-term)

Other people said they wanted:

- Emotional support for long-term conditions
- Support groups and courses to educate about specific conditions
- More access to physiotherapy, occupational therapy and neurology
- More info and advice around diet and nutrition and opportunities to exercise that were local, affordable and tailored to people with long-term conditions

"Giving dedicated swimming facility to disabled persons at a free or reduced rate. Having access to a dedicated swimming place all day would encourage more disabled persons to maintain as much good health as they

could in a place where others aren’t judging or we feel we’re in their way” (other long-term)

“Get more neurologists so waiting times are reduced. Neurology is abysmal now compared to what it used to be” (other long-term)

- To be treated as a person and not just seen as a condition
- Medical professionals to have more knowledge of rare conditions
- Better care for vulnerable people in A&E

“I have accompanied my mum [to A&E] and time spent there is definitely an eye opener as there were a number of elderly people there who were too ill to do anything but mainly left to their own devices due to the shortage of staff. The 89-year-old man in the next cubicle had both his buzzer and his calls ignored for some 20 minutes until my nephew collected and furnished him with a urinal to enable the poor desperate patient to relieve himself. Similarly, we were providing basic care for my mum as the staff were just not there to do this for her” (heart and lung)

Mental health

For those with mental health conditions, there was a focus on having more access to appropriate professionals, not just support for those people in crisis, and also people said they wanted to be listened to. Some people suggested that more mental health support available from GP surgeries, and less reliance on their GP.

“I think there should be more focus on prevention rather than the cure. Making people understand the cause of things could help. Need to educate people, especially in my community (Muslim) where people don't know so much about healthy eating and especially about mental health” (mental health)

Autism

What also comes across for people with autism is the need to be listened to and understood.

Dementia

Some people commented on the good support they’d received from their GP and that this was something that the NHS was doing well to help them manage their condition. The main thing that stood out for dementia was that there needed to be more help and support for carers to cope and know what to expect.

Next Steps

Each local Healthwatch involved in this piece of work will be looking at the data for their local area to pull out any local variations and themes.

This report will be shared with West Yorkshire and Harrogate Health and Care Partnership. They have said that they will use what is said in this report to develop their plan setting out their ambitions for the next five years and identifying any work needed to align with the NHS Long Term Plan. It will build on their work to date and will be a refresh of their 'Next Steps to Better Health and Care for Everyone'.

We will work with West Yorkshire and Harrogate Health and Care Partnership to ensure that this is done throughout their five year strategy and that people's views are taken into account.

We will also share the content of this report with as many other strategic partners as possible in health and care and wider.

We will thank participants and share findings with them via direct email where they have requested it and also more generally by sharing through all local areas' communications networks. The report will also be published on all of the West Yorkshire and Harrogate and Craven local Healthwatch websites, as well as the West Yorkshire and Harrogate Health and Care partnership website.

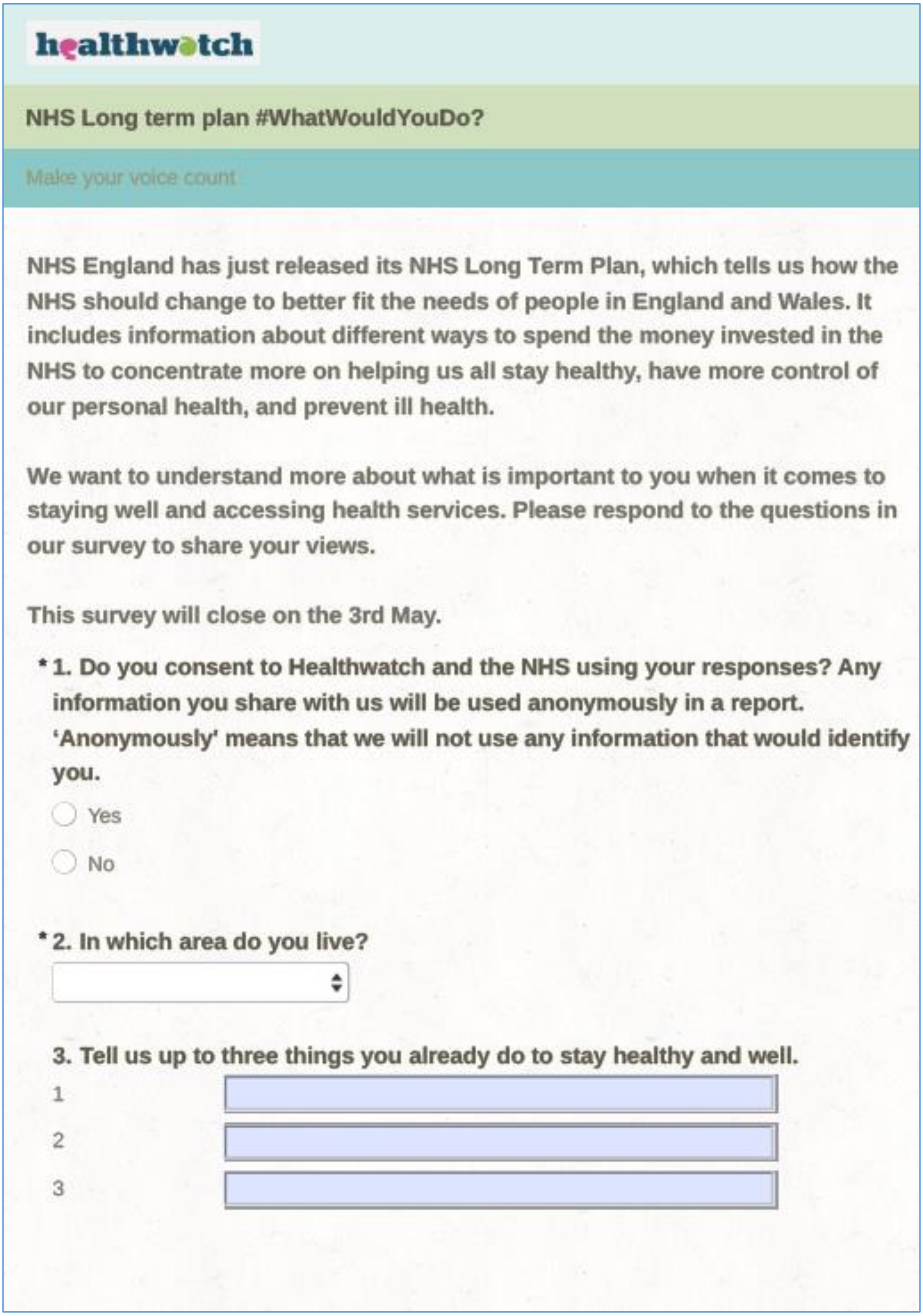
Thank you

This report has been written by Harriet Wright and Anna Chippindale, project workers at Healthwatch Leeds, in collaboration with Parveen Ayub, Tatum Yip, Stuart Morrison and Craig McKenna.

Thank you to Healthwatch Bradford, Calderdale, North Yorkshire and , Kirklees, and Wakefield for being key partners in making this work happen and to Parveen Ayub who co-ordinated most of the focus groups and pulled the project together. Thank you also to Mark Gerdes, volunteer from Healthwatch Bradford who helped us with some of the data analysis, report writing and the word cloud.

Finally, a big thank you to everyone who took the time to share their views and to all the community groups who kindly hosted us to do a focus group: a full list can be found in Appendices 3 and 4.

Appendix 1: General survey questions



healthwatch

NHS Long term plan #WhatWouldYouDo?

Make your voice count

NHS England has just released its NHS Long Term Plan, which tells us how the NHS should change to better fit the needs of people in England and Wales. It includes information about different ways to spend the money invested in the NHS to concentrate more on helping us all stay healthy, have more control of our personal health, and prevent ill health.

We want to understand more about what is important to you when it comes to staying well and accessing health services. Please respond to the questions in our survey to share your views.

This survey will close on the 3rd May.

*** 1. Do you consent to Healthwatch and the NHS using your responses? Any information you share with us will be used anonymously in a report. 'Anonymously' means that we will not use any information that would identify you.**

○ Yes

○ No

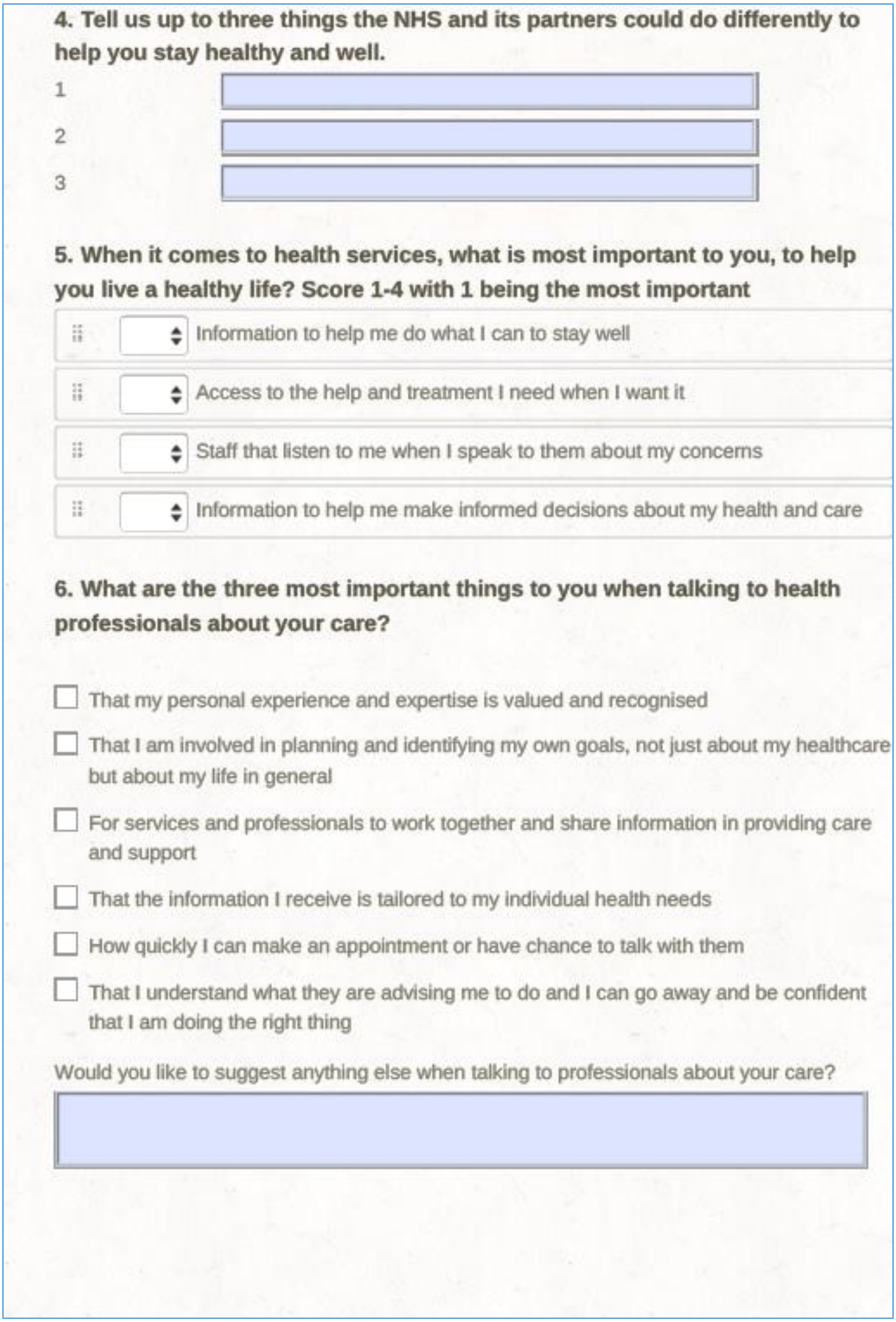
*** 2. In which area do you live?**

3. Tell us up to three things you already do to stay healthy and well.

1

2

3



4. Tell us up to three things the NHS and its partners could do differently to help you stay healthy and well.

1

2

3

5. When it comes to health services, what is most important to you, to help you live a healthy life? Score 1-4 with 1 being the most important

- Information to help me do what I can to stay well
- Access to the help and treatment I need when I want it
- Staff that listen to me when I speak to them about my concerns
- Information to help me make informed decisions about my health and care

6. What are the three most important things to you when talking to health professionals about your care?

☐ That my personal experience and expertise is valued and recognised

☐ That I am involved in planning and identifying my own goals, not just about my healthcare but about my life in general

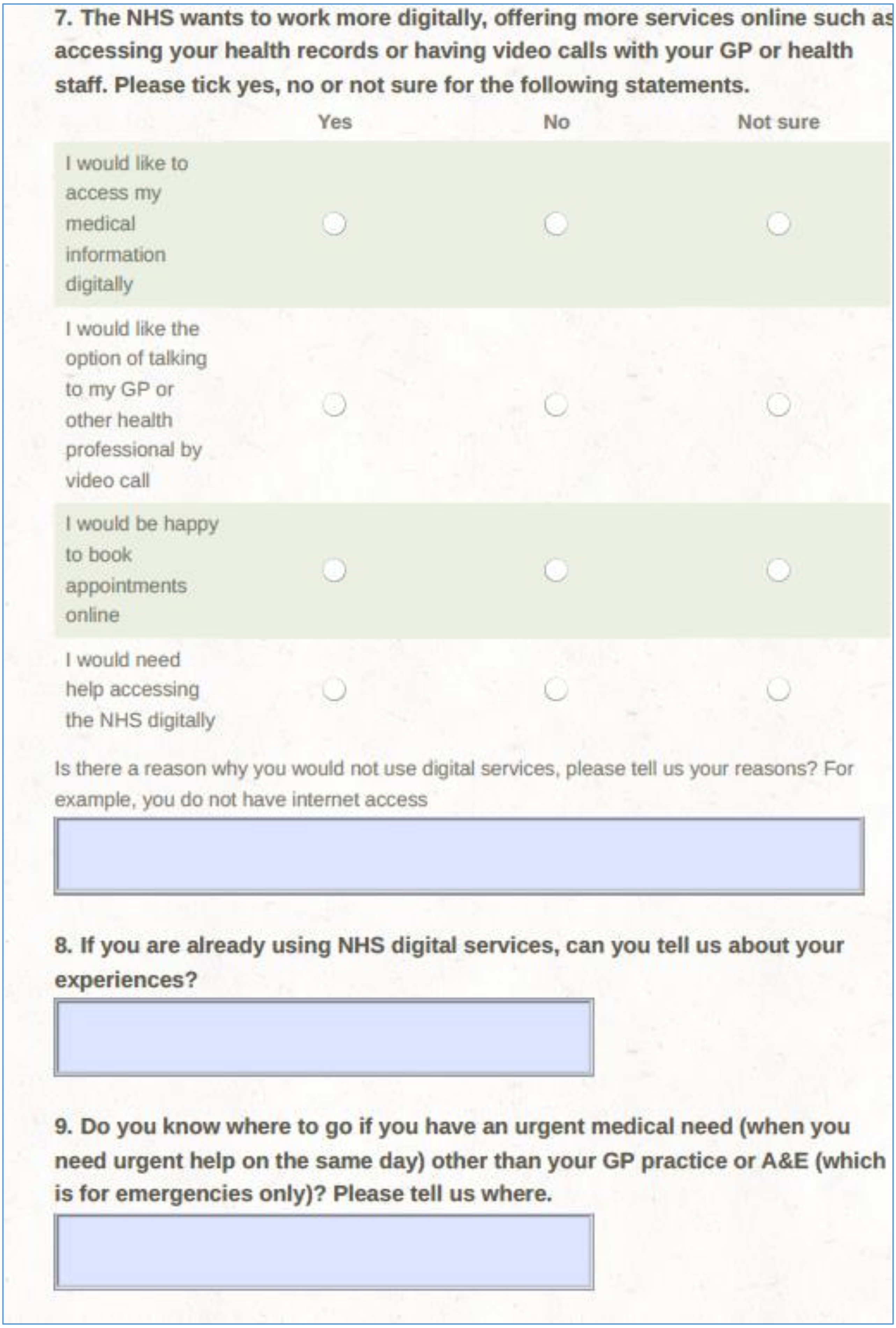
☐ For services and professionals to work together and share information in providing care and support

☐ That the information I receive is tailored to my individual health needs

☐ How quickly I can make an appointment or have chance to talk with them

☐ That I understand what they are advising me to do and I can go away and be confident that I am doing the right thing

Would you like to suggest anything else when talking to professionals about your care?



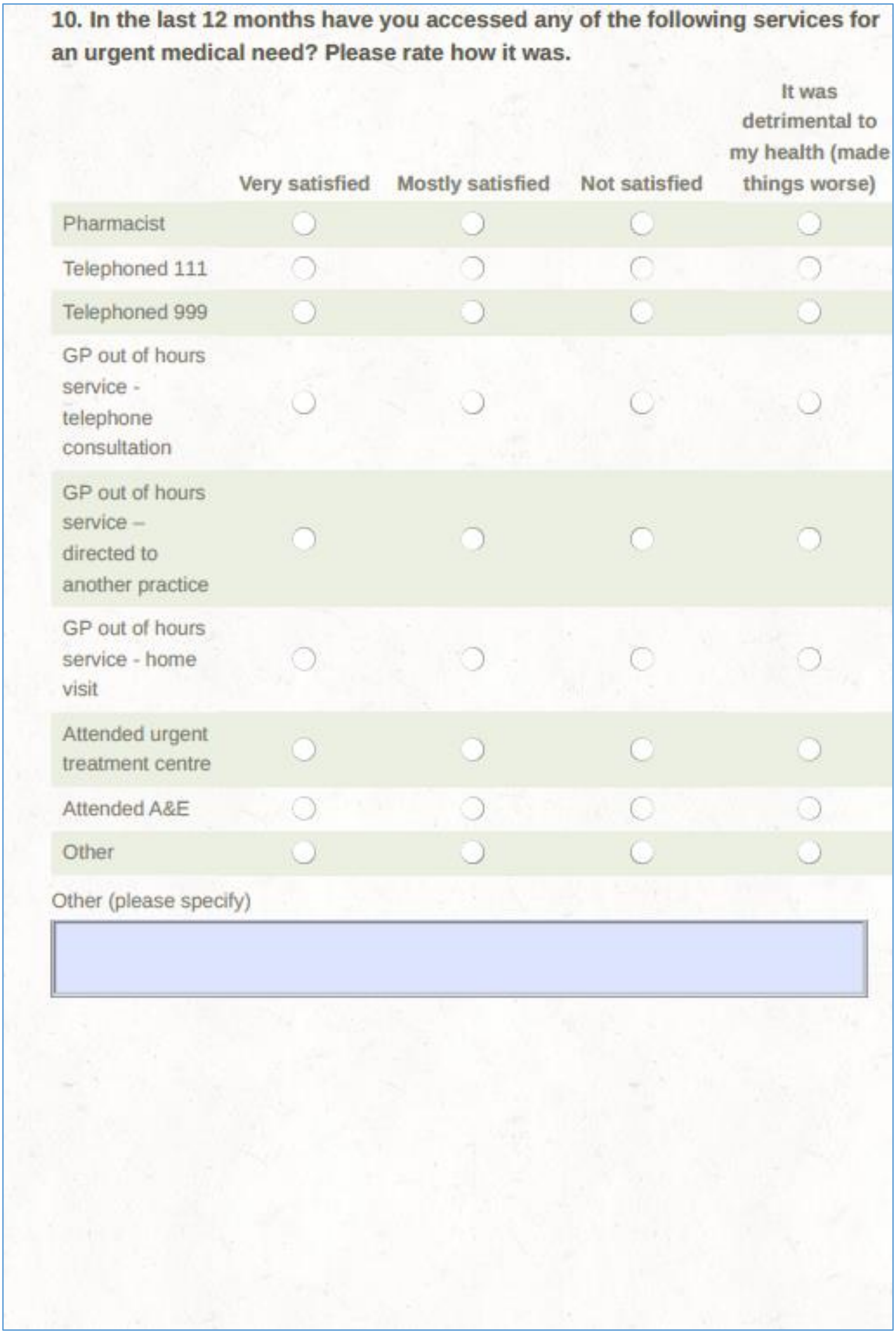
7. The NHS wants to work more digitally, offering more services online such as accessing your health records or having video calls with your GP or health staff. Please tick yes, no or not sure for the following statements.

	Yes	No	Not sure
I would like to access my medical information digitally	○	○	○
I would like the option of talking to my GP or other health professional by video call	○	○	○
I would be happy to book appointments online	○	○	○
I would need help accessing the NHS digitally	○	○	○

Is there a reason why you would not use digital services, please tell us your reasons? For example, you do not have internet access

8. If you are already using NHS digital services, can you tell us about your experiences?

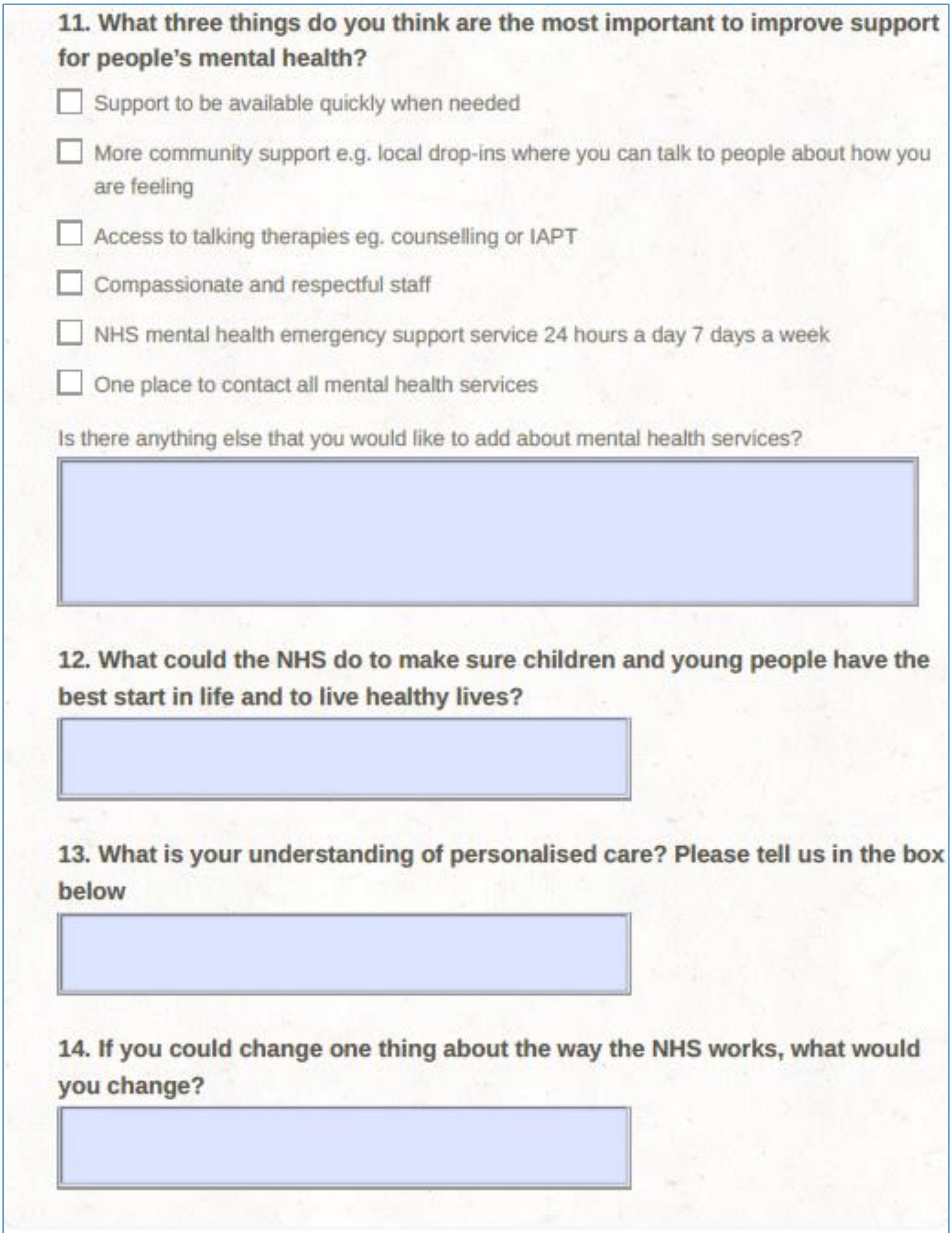
9. Do you know where to go if you have an urgent medical need (when you need urgent help on the same day) other than your GP practice or A&E (which is for emergencies only)? Please tell us where.



10. In the last 12 months have you accessed any of the following services for an urgent medical need? Please rate how it was.

	Very satisfied	Mostly satisfied	Not satisfied	It was detrimental to my health (made things worse)
Pharmacist	○	○	○	○
Telephoned 111	○	○	○	○
Telephoned 999	○	○	○	○
GP out of hours service - telephone consultation	○	○	○	○
GP out of hours service – directed to another practice	○	○	○	○
GP out of hours service - home visit	○	○	○	○
Attended urgent treatment centre	○	○	○	○
Attended A&E	○	○	○	○
Other	○	○	○	○

Other (please specify)



11. What three things do you think are the most important to improve support for people's mental health?

☐ Support to be available quickly when needed

☐ More community support e.g. local drop-ins where you can talk to people about how you are feeling

☐ Access to talking therapies eg. counselling or IAPT

☐ Compassionate and respectful staff

☐ NHS mental health emergency support service 24 hours a day 7 days a week

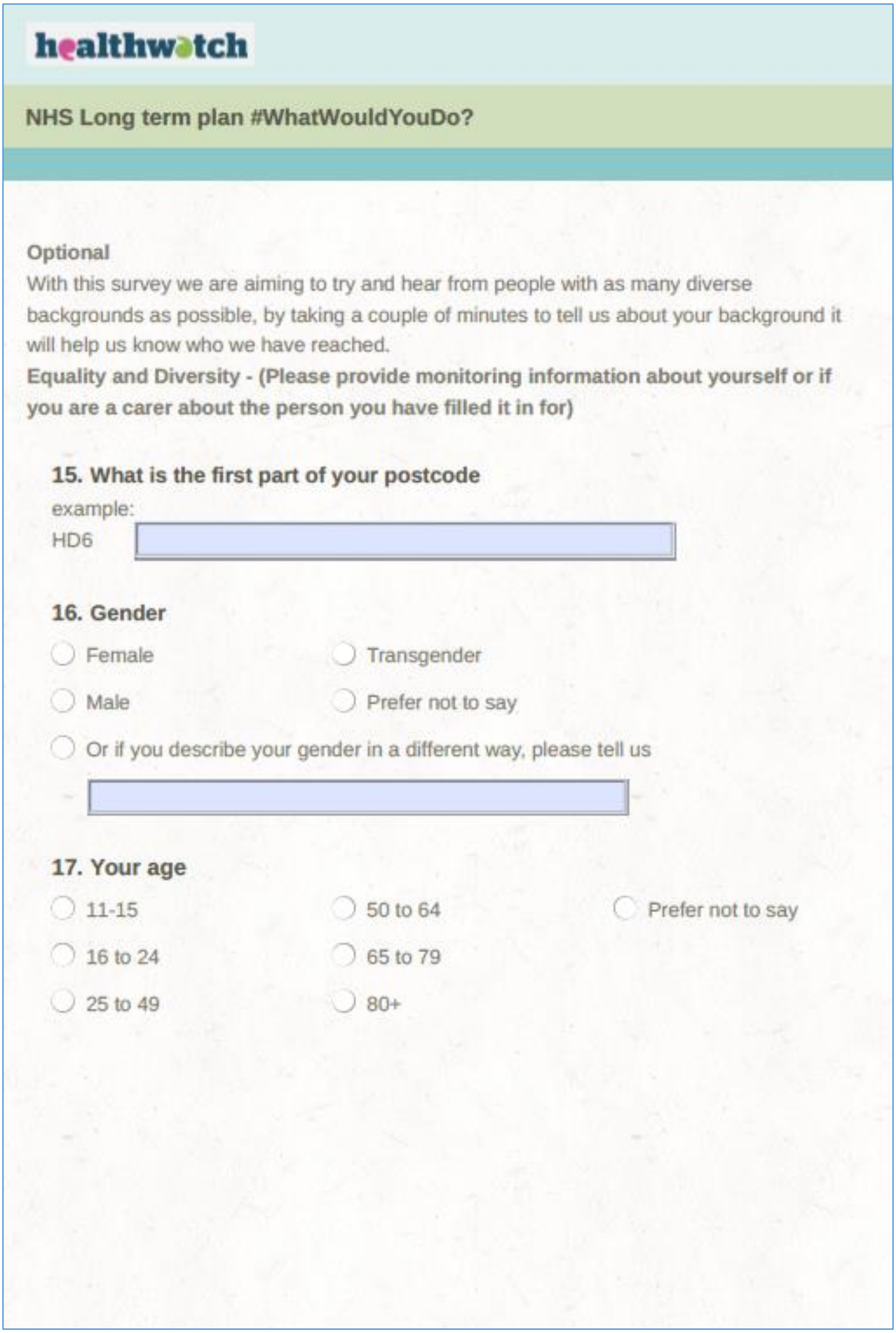
☐ One place to contact all mental health services

Is there anything else that you would like to add about mental health services?

12. What could the NHS do to make sure children and young people have the best start in life and to live healthy lives?

13. What is your understanding of personalised care? Please tell us in the box below

14. If you could change one thing about the way the NHS works, what would you change?



healthwatch

NHS Long term plan #WhatWouldYouDo?

Optional

With this survey we are aiming to try and hear from people with as many diverse backgrounds as possible, by taking a couple of minutes to tell us about your background it will help us know who we have reached.

Equality and Diversity - (Please provide monitoring information about yourself or if you are a carer about the person you have filled it in for)

15. What is the first part of your postcode

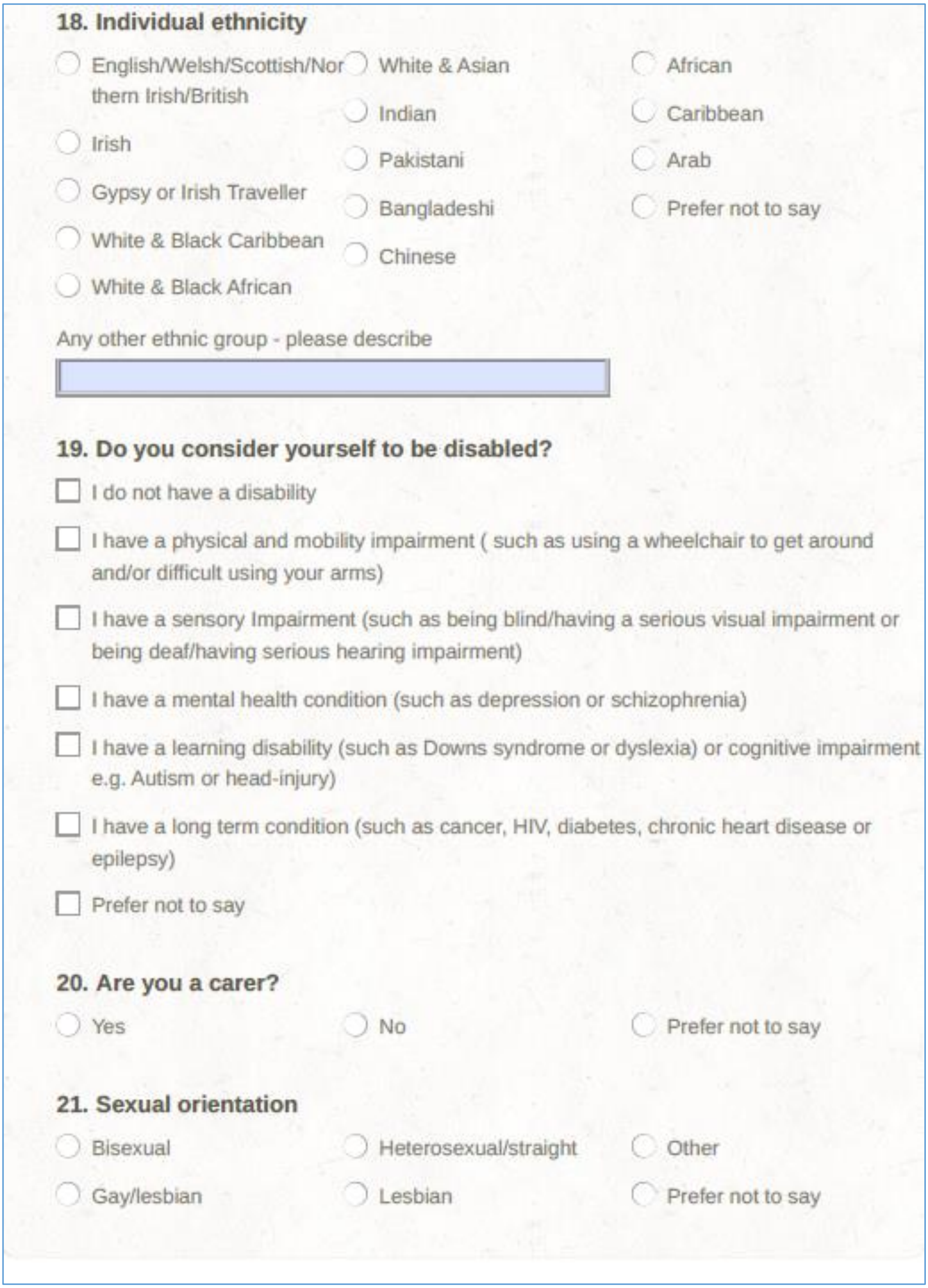
example:
HD6

16. Gender

○ Female
○ Male
○ Transgender
○ Prefer not to say
○ Or if you describe your gender in a different way, please tell us

17. Your age

○ 11-15
○ 16 to 24
○ 25 to 49
○ 50 to 64
○ 65 to 79
○ 80+
○ Prefer not to say



18. Individual ethnicity

○ English/Welsh/Scottish/Northern Irish/British
○ Irish
○ Gypsy or Irish Traveller
○ White & Black Caribbean
○ White & Black African
○ White & Asian
○ Indian
○ Pakistani
○ Bangladeshi
○ Chinese
○ African
○ Caribbean
○ Arab
○ Prefer not to say

Any other ethnic group - please describe

19. Do you consider yourself to be disabled?

☐ I do not have a disability
☐ I have a physical and mobility impairment (such as using a wheelchair to get around and/or difficult using your arms)
☐ I have a sensory Impairment (such as being blind/having a serious visual impairment or being deaf/having serious hearing impairment)
☐ I have a mental health condition (such as depression or schizophrenia)
☐ I have a learning disability (such as Downs syndrome or dyslexia) or cognitive impairment e.g. Autism or head-injury)
☐ I have a long term condition (such as cancer, HIV, diabetes, chronic heart disease or epilepsy)
☐ Prefer not to say

20. Are you a carer?

○ Yes
○ No
○ Prefer not to say

21. Sexual orientation

○ Bisexual
○ Gay/lesbian
○ Heterosexual/straight
○ Lesbian
○ Other
○ Prefer not to say

Appendix 2: Specific Conditions survey questions

1.Do you consent to Healthwatch using your responses?

☐ *Yes (If yes, go to Q2)*
No (If no, go to Q27)

2. Where do you live? E.g. Bradford, Wakefield, Calderdale, Leeds

3. Please select the condition you would like to tell us about

☐ Cancer
☐ Heart and lung diseases
☐ Mental Health
☐ Dementia
☐ Learning disability
☐ Autism
☐ Long-term condition e.g. diabetes, arthritis

4. Who are you responding on behalf of?

☐ Myself
☐ Someone else

5. Has the condition you are telling us about started within the last three years?

☐ Yes
☐ No

Your experience of getting help and support

6a. When you first tried to access help, did the support you received meet your needs?

☐ Yes
☐ No
☐ Somewhat
☐ Not applicable

6b Tell us whether the support met your needs and how it could have been improved

7. How would you describe your overall experience of getting help?

☐ Very positive
☐ Positive
☐ Average
☐ Negative
☐ Very negative
☐ Don’t know

8. Do you have any other/additional conditions including long term conditions or disabilities?

☐ Yes
☐ No

9. If so, how would you describe the experience of seeking support for more than one condition at a time?

☐ It made getting support easier
☐ No difference
☐ It made getting support harder
☐ I don’t know
☐ Not applicable

The health and care support you received after initially seeking help

10a. How would you describe the time you had to wait to receive your initial assessment or diagnosis?

☐ Very slow
☐ Slow
☐ Ok
☐ Fast
☐ Very fast
☐ Don’t know

10b. Please tell us more about the length of time you waited

11a. How would you describe the time you had to wait between your initial assessment/diagnosis and receiving treatment?

☐ Very slow
☐ Slow
☐ Ok
☐ Fast
☐ Very fast
☐ Don’t know

12 After being diagnosed or assessed, were you offered access to further health and care support?

☐ Yes *(Go to Q13)*
☐ No *(Go to Q15*

13.If you accessed support, what aspects worked well?

14. If you accessed support, what aspect could be improved?

15. Were you referred to a specialist? For example, a hospital consultant, psychiatrist or physiotherapist

☐ Yes *(If yes, go to Q16)*
☐ No (If no, go to Q17)

16a. How would you describe the time you had to wait between the initial appointment and seeing the specialist?

☐ Very slow
☐ Slow
☐ Ok
☐ Fast
☐ Very fast
☐ Don't know

16b. Please tell us more about the length of time you waited

17. If you needed it, how easy did you find it to access ongoing support after you were diagnosed or assessed?

☐ Very easy
☐ Easy
☐ OK
☐ Difficult
☐ Very difficult
☐ Don't know
☐ Not applicable

18a. Did the support option you were offered meet your expectations?

☐ Yes
☐ No
☐ Somewhat

18b. Please explain how the care did or did not meet your expectations and how it could have been improved.

19a. During your whole experience of getting support did you receive timeline and consistent communication from all of the services that you came into contact with?

☐ Yes
☐ No
☐ Somewhat

19b Please explain how the care did or did not meet your expectations and how it could have been improved.

Time spent travelling to access support and care

20.What is your main means of transport?

☐ Own car
☐ Another person's car (getting a lift)
☐ Bus
☐ Train
☐ Bicycle
☐ Taxi
☐ Other

21.How much time would you be willing to travel for to receive a quick and accurate diagnosis?

☐ Less than 30 minutes
☐ 30 minutes to 1 hour
☐ 1-2 hours
☐ Over 2 hours

22. How much time would you be willing to travel for to receive specialist treatment or support?

☐ Under 30 minutes
☐ From 20 minutes to one hour
☐ From one to two hours
☐ More than two hours

Your expectations at each stage of your care

23. What is most important to you?

	Seeing a health professional you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately	Don't mind
When first seeking help			
When you first received a diagnosis and explanation of treatment or support options			
During your initial treatment or support			
During your long term support			

Supporting you to have more control over your own care

24. What level of support do you want the NHS to provide to help you stay healthy?

☐ A lot of support
☐ Some support
☐ I don't need support
☐ Don't know

25. What could the NHS do to help you stay healthy or manage any condition you have?

26. If you have any further comments please write them below

Tell us a bit about you – Optional

By telling us more information about yourself, you will help us better understand how people's experiences may differ depending on their personal characteristics. However, if you do not wish to answer these questions you do not have to.

Your age

☐ Under 18
☐ 18-24
☐ 25-34
☐ 35-44
☐ 45-54
☐ 55-64
☐ 65-74
☐ 75+

Your ethnicity

☐ African
☐ Arab
☐ Asian British
☐ Bangladeshi
☐ Black British
☐ Caribbean
☐ Gypsy or Irish Traveller
☐ Indian
☐ White British
☐ Pakistani
☐ Any other white background
☐ Any other mixed background
☐ Other

Do you consider yourself to have a disability?

☐ Yes
☐ No
☐ I'd prefer not to say

Are you a carer?

☐ Yes
☐ No

Do you have:

☐ a long term condition
☐ multiple conditions

☐ Neither

Which of the following best describes you?

☐ Heterosexual
☐ Gay or lesbian
☐ Bisexual
☐ Asexual
☐ Pansexual
☐ Other

Your gender

☐ Male
☐ Female
☐ Other
☐ Prefer not to say

20. Your religion

☐ Buddhist
☐ Christian
☐ Hindu
☐ Jewish
☐ Muslim
☐ Sikh
☐ Other
☐ No religion
☐ I'd prefer not to say

Appendix 3: Focus group and survey numbers

Healthwatch	General survey	Specific condition survey	Number in focus group	Total engagement
Bradford District and Craven	361	29	24	417
Kirklees	146	10	8	164
Calderdale	216	39	28	284
Leeds	369	111	34	506
Wakefield District	230	52	29	307
North Yorkshire	115	47*	13	128*
Total	1437	233*	136	1806*

* Although 47 people from North Yorkshire completed the specific condition survey, due to significant delay in receiving the data from Healthwatch England, we were unable to include the quantitative data from this area in the analysis. We have however used some quotes from the data in this report. The total figures represent do not include the 47 North Yorkshire responses.

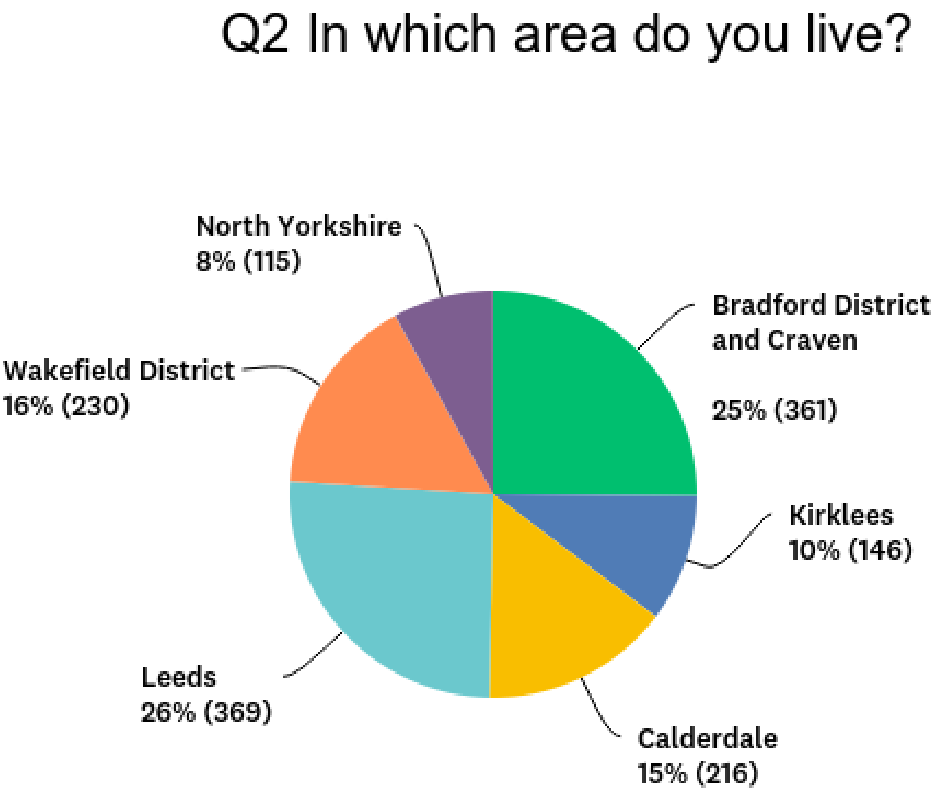
Healthwatch Area	Special Characteristics	Number of participants
Bradford District and Craven	South Asian Men's Group	11
	Black Caribbean Elderly	13
Calderdale	People with Dementia and Carers	15
	Young Volunteers	7
	Residents Group	3
	Parents of children with disabilities	3
Kirklees	People with a Mental Health Condition and Carers	8
Leeds	Hindu Faith Group	15
	YouthWatch	8
	Lesbian, Gay, Bisexual, Transgender, Queer/Questioning (LGBTQ)	5
	People with Sight Loss	6
Wakefield District	Working Age Population	14
	People with Hearing Loss	7
	Cancer Alliance	8
North Yorkshire	People with a Mental Health Condition	13

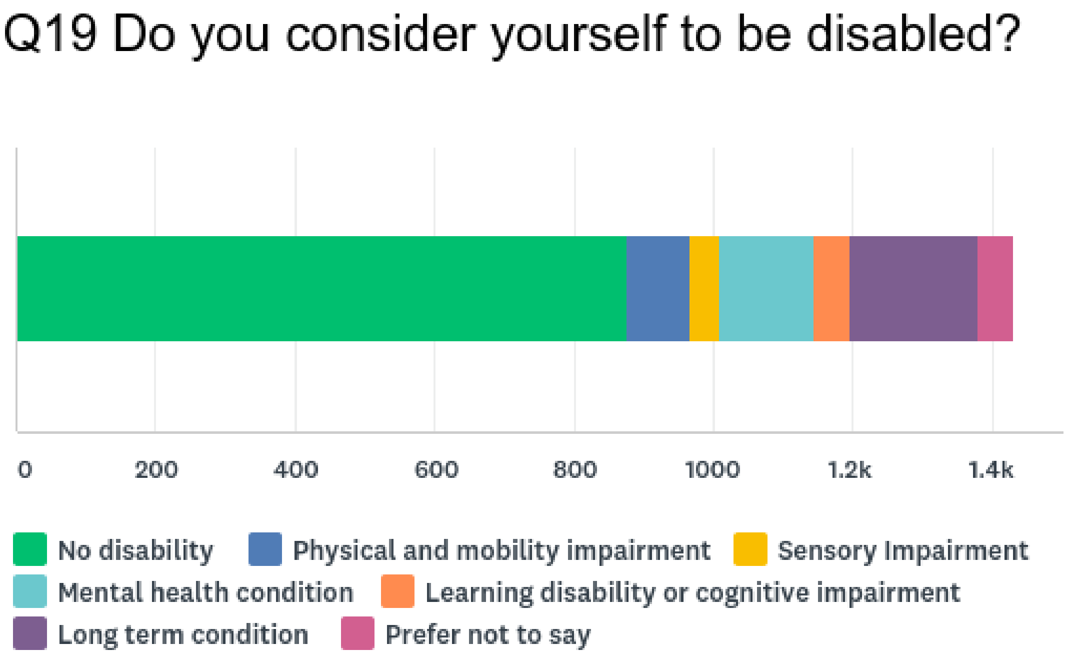
Appendix 4: Outreach data by area

Healthwatch Area	Where surveys were completed
Bradford District and Craven	Have been to many other places but would like to especially mention these groups: South Asian Men group @ Sangat Centre, Bradford Keighley College Learning Disability group @ Keighley People First, Keighley BME Elders @ Dominican Association, Bradford
Calderdale	Life changes women's support group Illingworth Moor Methodist Church
Kirklees	Mirfield over 50's group Calderdale Huddersfield Foundation Trust (CHFT)
Leeds	Roscoe Methodist Church, Hindu Temple Sanskar group – cardigan centre Leeds Teaching Hospital Trust A&E and Outpatients Café Slate BAME Centre Touchstone BME Dementia café Autism Hub YouthWatch Angels of freedom - LGBT
Wakefield District	South Elmsall Library St George's Community Centre Tieve Tara Medical Centre Wakefield District Sight Aid (multiple groups) Ryhill Councillors surgery Hemsworth Library Breastfeeding Group Cedars Children's Centre Havercroft and Ryhill Learning Centre Eastmoor community centre Pontefract Library Kinlsey and Fitzwilliam Community Centre Families and Babies (FAB) Yorkshire MESMAC Carers Wakefield St James Church Ryhill City of Sanctuary Health Common Gypsy and Traveller Site

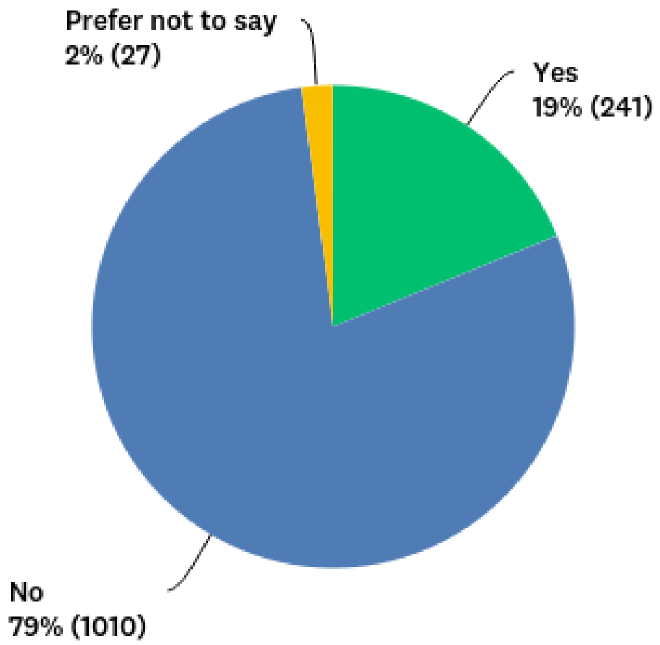
North Yorkshire	North Yorkshire Disability Forum Youth Voice Conference North Yorkshire Learning Disability Partnership Board Harrogate Service User and Carer Involvement Tesco in Skipton Skipton Library Harrogate Library Ripon Library Boroughbridge Library Craven Communities Together

Appendix 5: General survey monitoring data

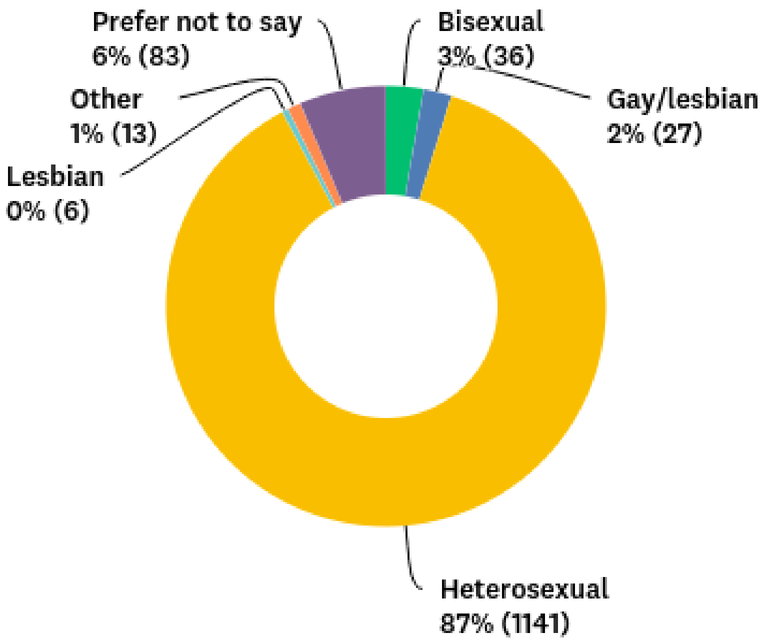


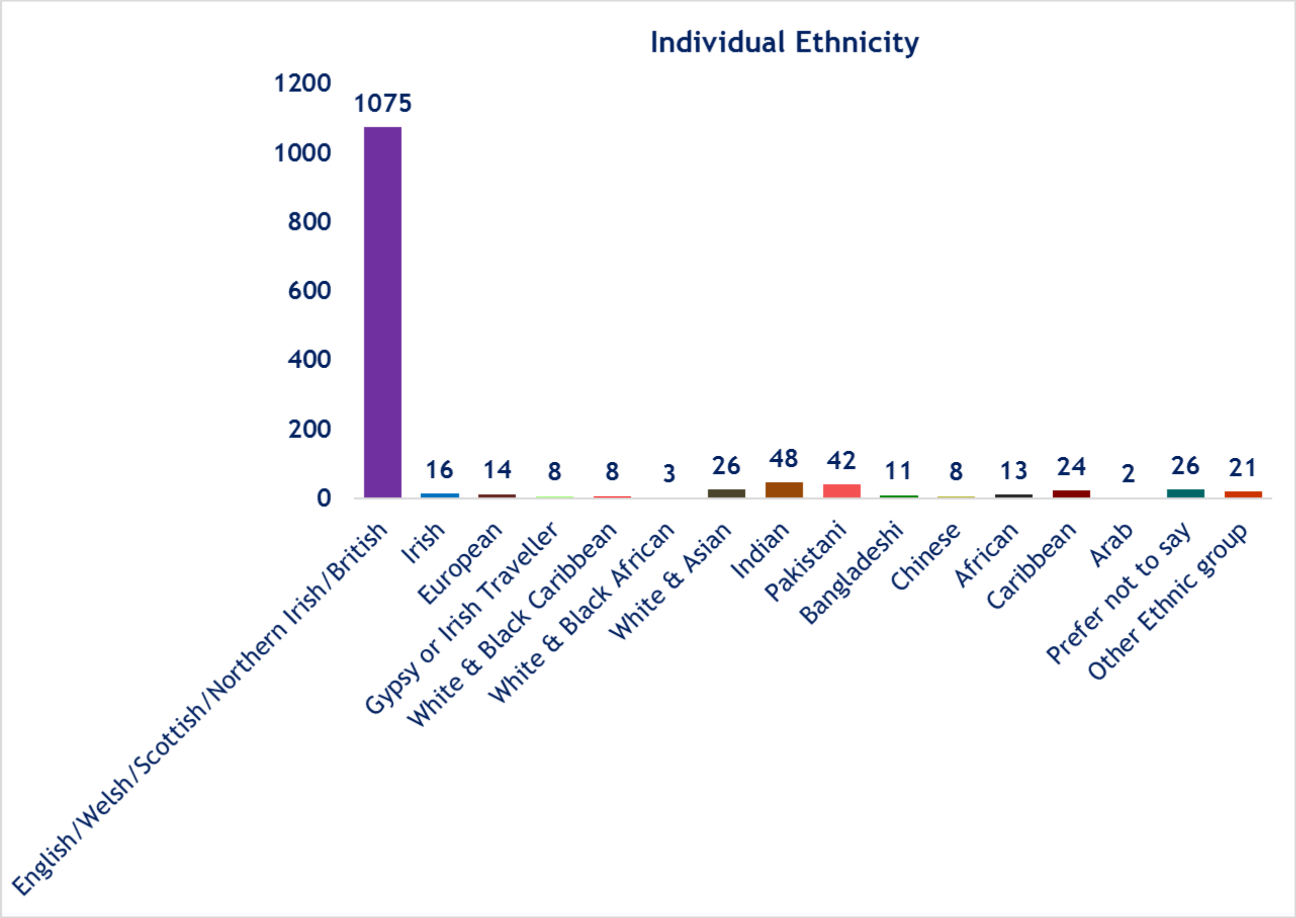


Q20 Are you a carer?

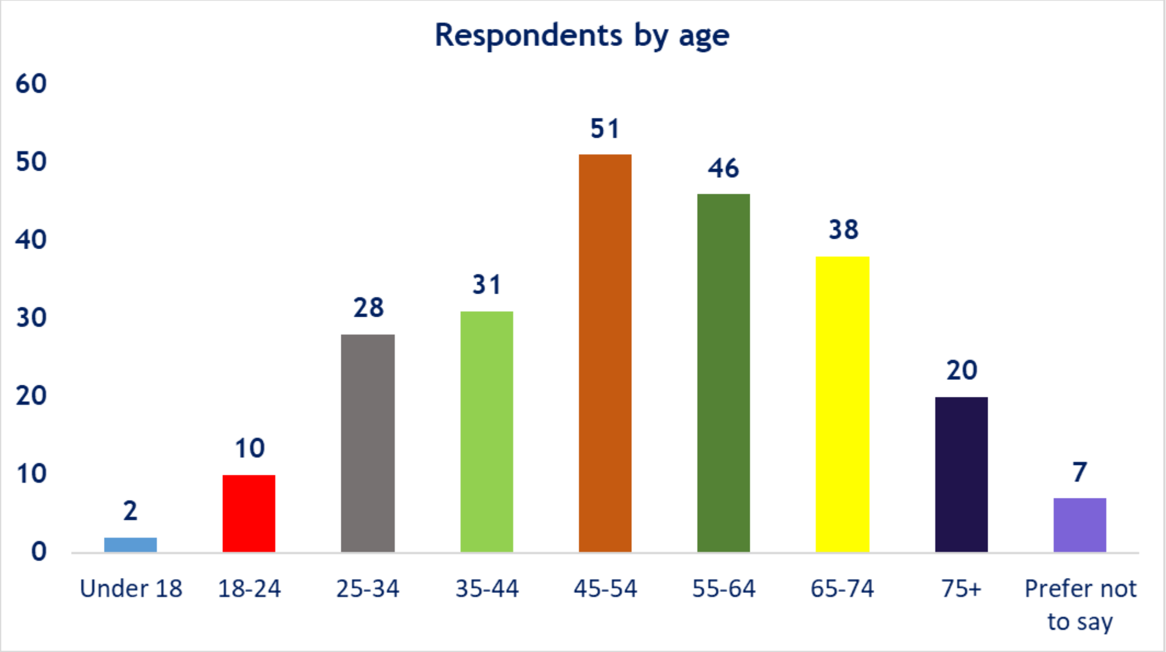


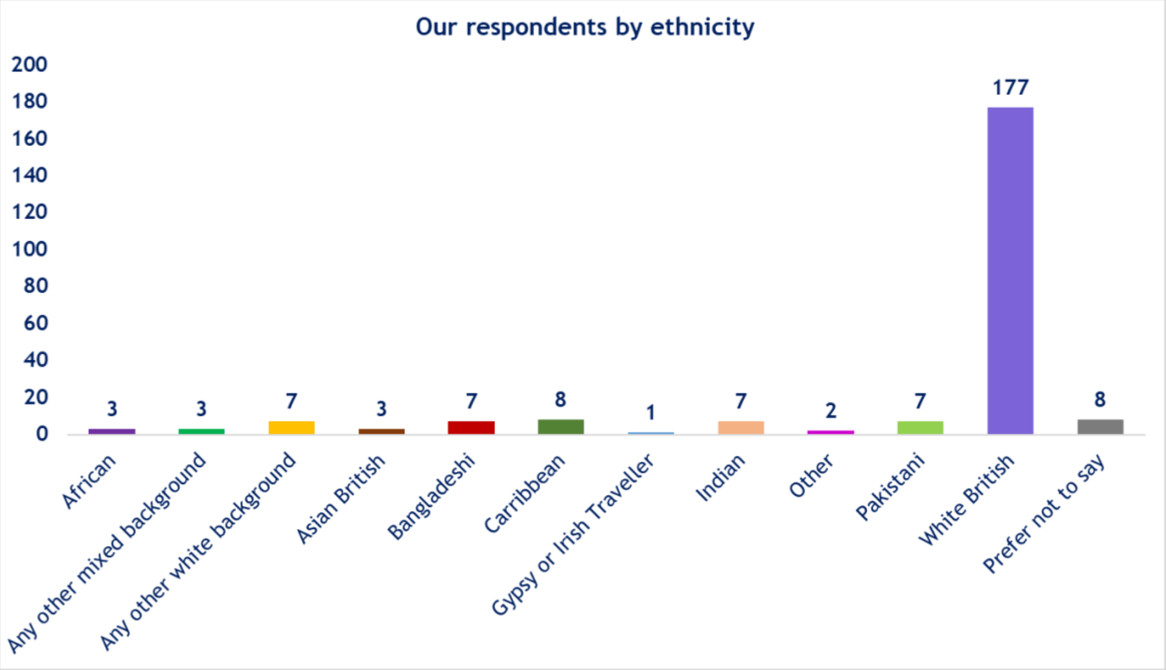
Q21 Sexual orientation

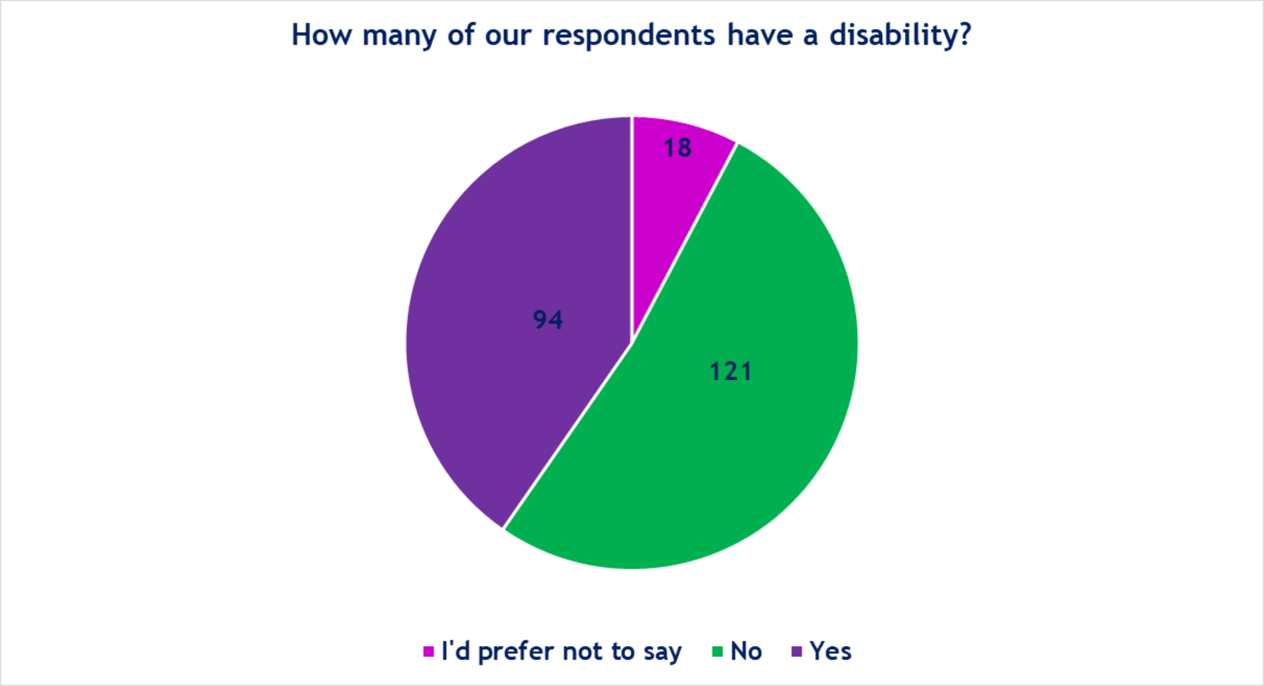


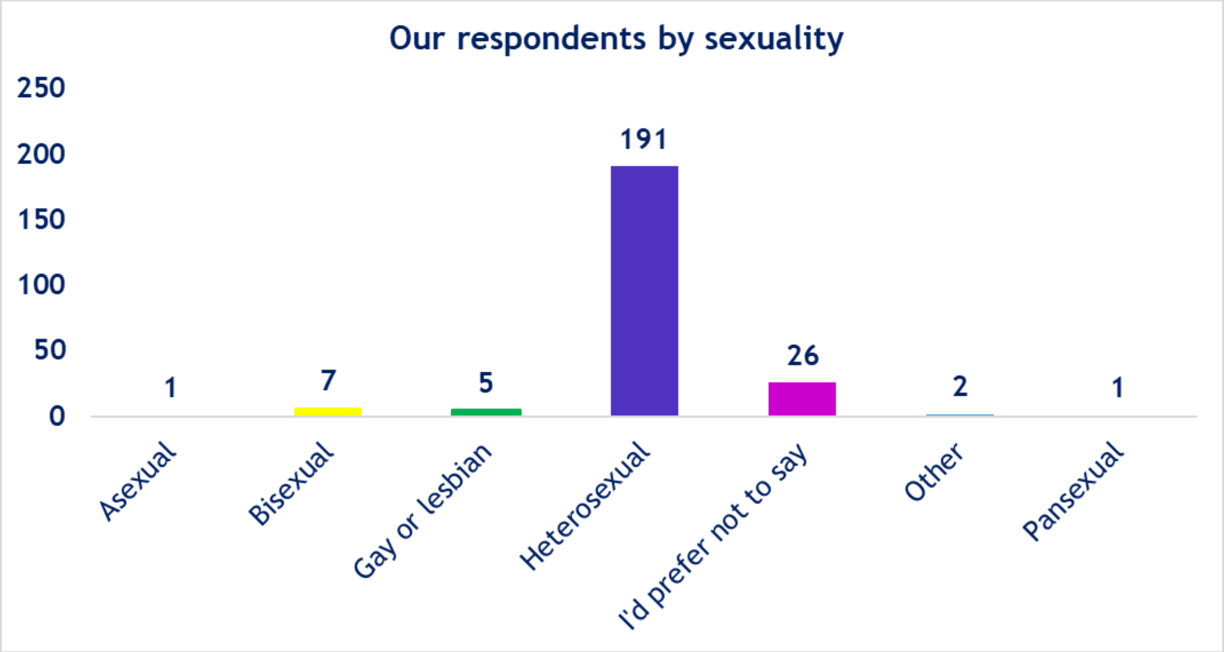

Individual Ethnicity
1200
1000
800
600
400
200
0
1075
16
14
8
8
3
26
48
42
11
8
13
24
2
26
21
English/Welsh/Scottish/Northern Irish/British
Irish
European
Gypsy or Irish Traveller
White & Black Caribbean
White & Black African
White & Asian
Indian
Pakistani
Bangladeshi
Chinese
African
Caribbean
Arab
Prefer not to say
Other Ethnic group

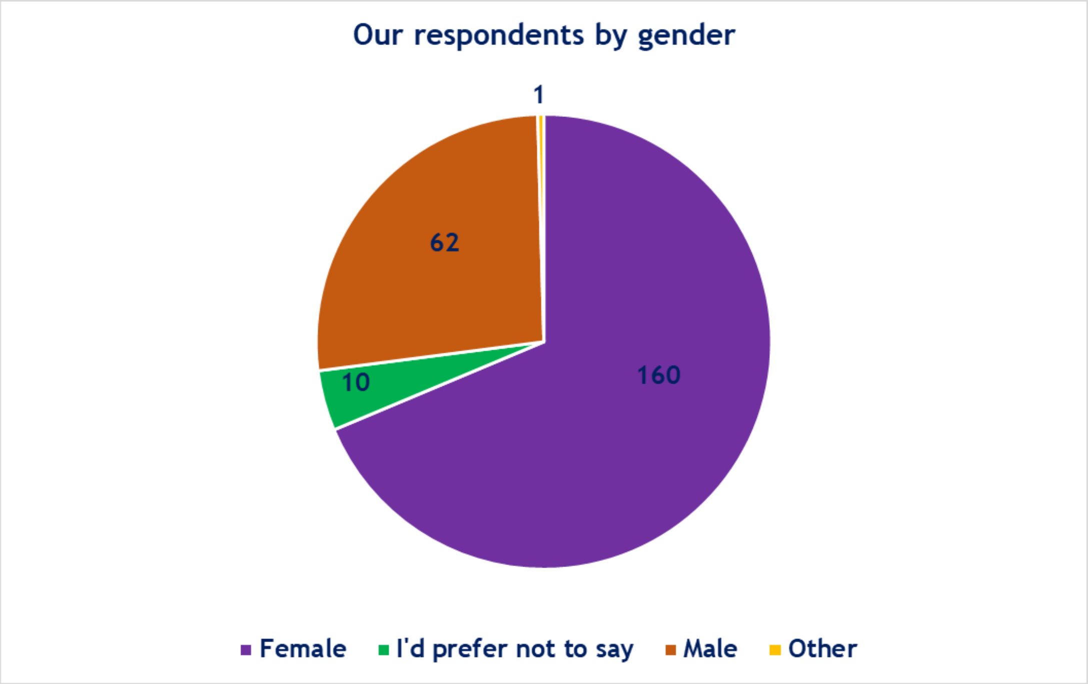
Appendix 6: Specific conditions monitoring data

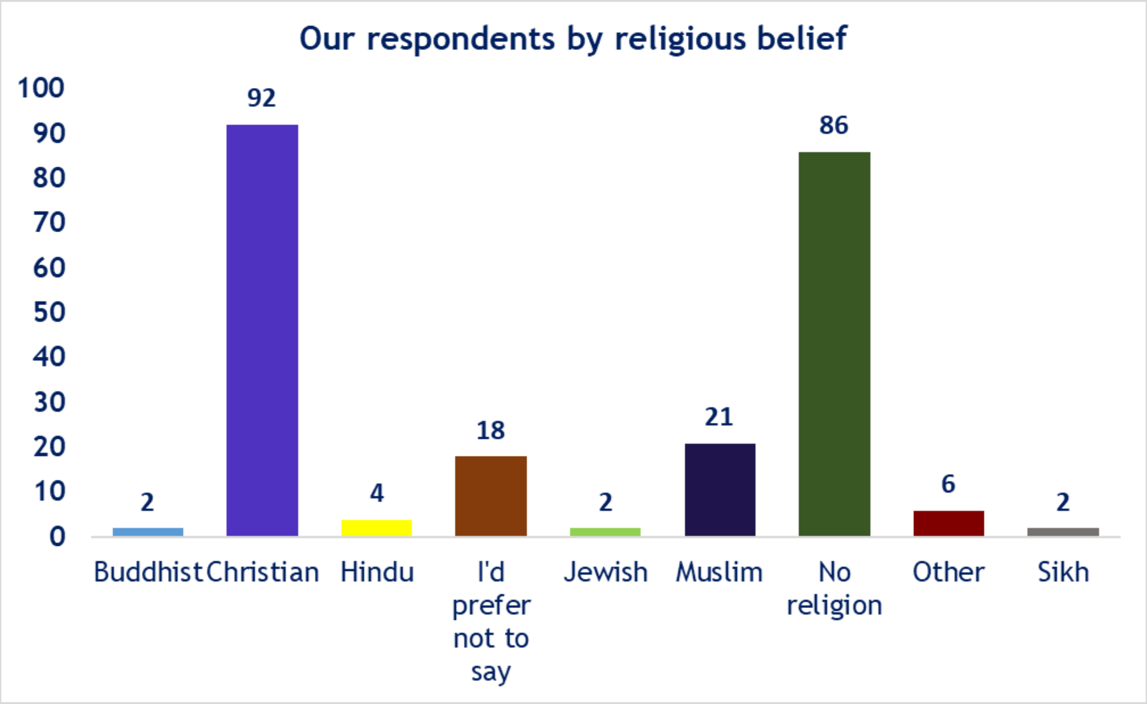





How many of our respondents have a disability?
18
94
121
I'd prefer not to say
No
Yes


Our respondents by sexuality
250
200
150
100
50
0
1
7
5
191
26
2
1
Asexual
Bisexual
Gay or lesbian
Heterosexual
I'd prefer not to say
Other
Pansexual


Our respondents by gender
1
62
10
160
Female
I'd prefer not to say
Male
Other


Our respondents by religious belief
100
90
80
70
60
50
40
30
20
10
0
2
92
4
18
2
21
86
6
2
Buddhist
Christian
Hindu
I'd prefer not to say
Jewish
Muslim
No religion
Other
Sikh