healthwatch

# NHS Long Term Plan

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

Bristol, North Somerset and South Gloucestershire

# Contents

# Executive summary

## Background

This report contains the findings of an engagement project carried out by Local Healthwatch in Bristol, North Somerset and South Gloucestershire (BNSSG) during April and May 2019.

This engagement was part of a national project commissioned by NHS England and Healthwatch England. It focused on the NHS Long Term Plan and asked local people **'What would you do?'** with the additional money that has been committed by central government to improve and enhance the provision of NHS services over the next 10 years.

This project was delivered through the use of **two surveys** created by Healthwatch England. One survey focused on people's general experiences of using health and care services, the other was targeted at people with long-term conditions and their experiences of receiving treatment and support.

Across the country Local Healthwatch gathered survey responses from over 18,000 people. Locally we gathered:

- **433** general surveys
- **183** condition-specific surveys.

Through discussion with colleagues at Healthier Together, the name for the BNSSG sustainability and transformation partnership, it was agreed that the local priority topics for this project should be **learning disabilities and autism**, and **cancer services**.

Local Healthwatch carried out **five focus group discussions** with local people on these specific topics, the results of which are captured in this report.

## An overview of BNSSG

Almost one million people live in Bristol, North Somerset and South Gloucestershire (BNSSG), and similar to other areas of the UK, the local population is expected to grow significantly in the next few years (around 35,000 by 2020).

The area is relatively affluent and people's health is good, but there are significant pockets of deprivation – with around one in ten people living in a deprived location.

Some people within the area experience high levels of illness linked to low income, poor housing or disability. Average life expectancy varies between those living in the most and least deprived areas by around six years, with some places seeing a startling 15 years difference.

The annual BNSSG health budget is around £1.5bn. Funding for the NHS is growing year on year but it is not able to keep pace with current demand for services. Continuing as we are is not an option so local health and social care services are working together to try to build an improved health and care system that meets the needs of everyone that lives in BNSSG.

## General survey responses by region

The response rate for South Gloucestershire was lower than the other two regions (20% vs 32% and 42% for Bristol and North Somerset respectively). Hence, any conclusions drawn in relation to responses from South Gloucestershire should be treated accordingly.

| Please tell us where you live | No. of respondents | % of respondents |
|---|---|---|
| Bristol | 141 | 33% |
| South Gloucestershire | 88 | 20% |
| North Somerset | 183 | 42% |
| (Blanks) | 21 | 5% |
| **TOTAL** | **433** | **100%** |

| Who are you responding on behalf of? | No. of respondents | % of respondents |
|---|---|---|
| Yourself | 398 | 91% |
| Someone else | 18 | 4% |
| (Blanks) | 21 | 5% |
| **TOTAL** | **433** | **100%** |

## Key findings – General survey (433 respondents)

*(full analysis can be viewed pages 7 – 19)*

- **Easier, more timely access to help, treatment and information when they need it**. This was particularly pertinent to GP services, which consistently received negative reports of long waiting times, inconsistent/ unhelpful booking systems, and inadequate appointment length to enable full discussion of patients' concerns.

- Respondents recognised the need for individual responsibility when looking after their health and preventing illness, however there was a clear request for help to do this through **increased investment in and availability of public health interventions and information**.

- **Respondents told us that they want to be listened to**. They don't want to have to repeat their story multiple times with multiple providers. They would like services to be more joined up, and are open to the increased use of technology in order to support this.

- **Respondents expressed a strong desire to be involved in making decisions about their care and treatment**. They want to be informed about the options that are available to them - including details such as waiting times, risks, benefits etc. - and supported through adequate and timely discussion with clinicians/ health professionals in order to do this.

- Respondents **want to live in their own homes for as long as possible**, and hope that there will be community-based medical, social, emotional and spiritual support available to them to facilitate this.

- Respondents were **open to the potential of technology in the health and care system** – particularly where it meant faster and more convenient access to services, such as GPs, and better communication between health providers, e.g. GPs and hospitals. However there were **consistent concerns about data sharing, security and privacy of information**, particularly if they were to manage/ access their own patient records via smart phones, tablets and PCs.

## Condition-specific survey responses by region

The response rates for Bristol and South Gloucestershire were significantly lower that North Somerset (23% vs 17% and 52% respectively). Hence, any conclusions drawn in relation to responses from these areas should be treated accordingly.

| Please tell us where you live | No. of respondents | % of respondents |
|---|---|---|
| Bristol | 43 | 23% |
| South Gloucestershire | 31 | 17% |
| North Somerset | 95 | 52% |
| (Blanks) | 14 | 8% |
| **TOTAL** | **183** | **100%** |

## Key findings – condition-specific survey and focus groups (183 respondents)

The greatest number of comments from the condition-specific surveys related to learning disabilities and autism (54 comments, 30%), and cancer services (36 comments, 20%).

We received 58 comments about long-term conditions, however once this was broken down into the myriad of conditions that people had, it made drawing any statistically significant results about experiences through the different care pathways very difficult.

A summary of the feedback received from respondents and the key themes that emerged can be viewed on pages 29 – 39.

- **Waiting times to access services and support were highlighted as an issue,** with respondents reporting waiting times varying from two weeks to two years plus. This was deemed particularly problematic where it was felt that a quicker assessment or diagnosis may have prevented circumstances from deteriorating. This was frequently raised in relation to mental health services.

- **Support works best when it is joined up and person-centred.** Again respondents told us that they don't want to have to repeat their stories and they wished services spoke to one another. Some respondents said that they feel they "are their condition" and have to continually champion their cause in order to prompt assessment, monitoring and diagnosis.

- **Respondents expressed a desire to receive more information about local support options,** particularly those that are located in or near to their community

Based on response rates, we took the decision to focus our detailed analysis of the condition-specific surveys on learning disabilities and autism, and cancer services. This approach meant that the quantitative data gathered through the surveys could be cross-referenced with the rich qualitative feedback that was received through the focus group discussions. This has enabled us to pull out more themes from the focus groups and provide a clearer view of what people are experiencing.

## Cancer services *(full analysis can be viewed pages 24 – 29)*

- Overall feedback was positive. Focus group attendees reported positive experiences of assessment, diagnosis and treatment.
- From the survey results, 64% answered yes to having received support that met their needs when they first tried to access help with 79% describing their overall experience of getting help as 'very positive' or 'positive'.
- The positive trend continued with 66% describing the time they waited to get an initial assessment or diagnosis as 'fast' or 'very fast'.
- When asked about ongoing support, 59% said they found it 'very easy' or 'easy' to access ongoing support post-diagnosis or assessment.

## Learning disabilities and autism *(full analysis can be viewed pages 30 - 50)*

Unfortunately the findings from the surveys and focus groups presented a less positive picture to that reported of cancer services. Some of the themes emerging were as follows:

- Diagnosis is not always followed by support and support for carers needs to be improved.
- The length of time taken to get a diagnosis impacts on both the individual and those caring for them.
- There is a lack of joined-up services for people with multiple conditions. Having more than one condition was considered to make things harder and could mean people missed out on care.
- Changes to benefits are impacting on individuals and carers abilities to access services. Increased stress and difficulties accessing the system is exacerbated by the increase in one-off and cyclical assessments, and the short periods support is available for.
- Workforce issues including lack of available staff, poor information sharing, handover and silo working by services make accessing and using care services

difficult and at times led to failures in care provision. Appropriately trained staff were not always available.

- Difficulties in getting adequate support were common with a lack of support highlighted in mainstream education. Two people mentioned children being unlawfully excluded due to their autism. Positive experiences were reported of specialist providers.

## Key findings - Engaging people in health service delivery *(full analysis can be viewed page 51)*

This short section collates feedback received through focus group discussions regarding how people would like to be involved and engaged in the delivery of health services in the future.

### What people expect during their treatment journey

- Feedback should be asked for on a regular basis and as a minimum at the end of a piece of support/ discharge from a service. Respondents highlighted that this didn't happen regularly.

### What people expect during service change and transformation

- Service users and carers need to be involved from the beginning – before the *"first draft"* so that their involvement can be meaningful.
- Co-design was seen as the gold standard with change starting from what users need rather than what the service thinks they need.
- Reasonable adjustments shouldn't come after – they shouldn't be needed as they should have been built in from the start through co-design.
- Services need to use the feedback, reports and insight already provided. Checking back on what has come before. It was felt that the same questions and ideas are put forward in cycles with many of the solutions already having been identified by previous engagement and consultation.

## What will happen next?

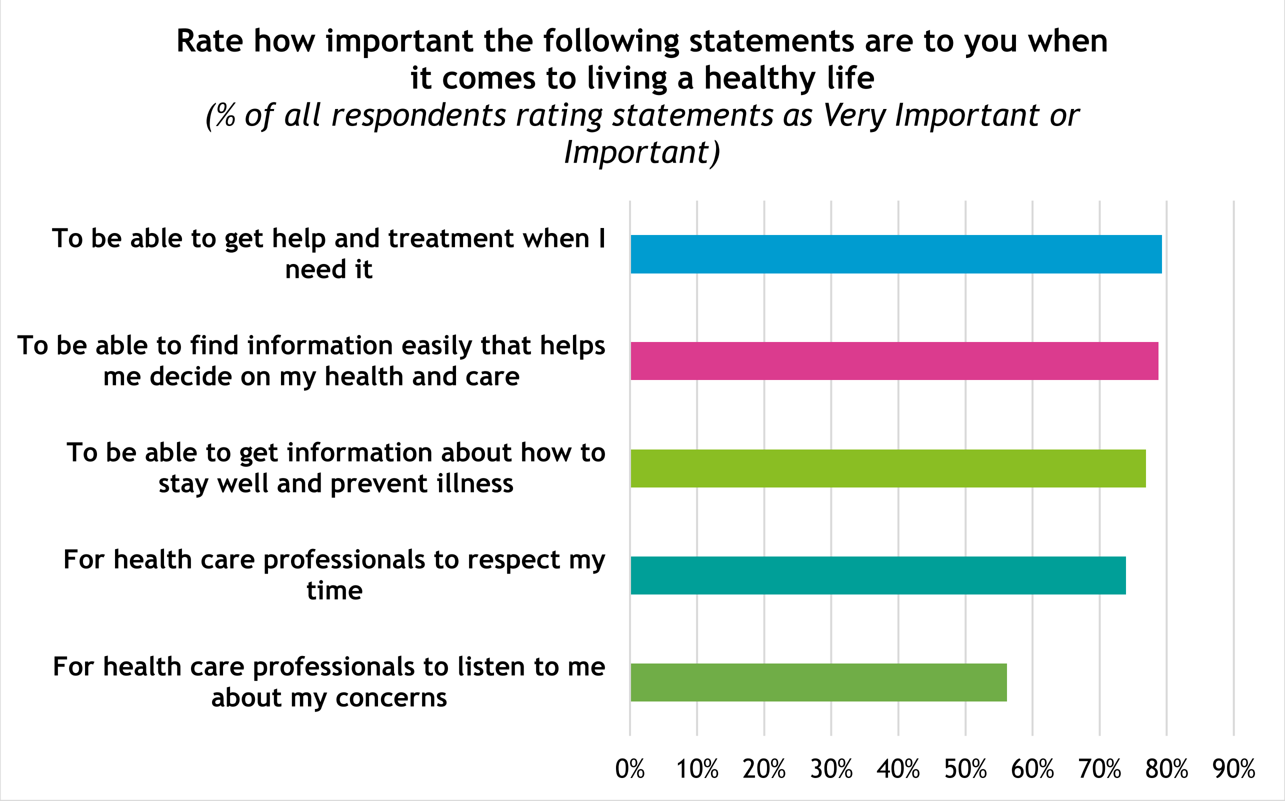
Feedback from this project has been shared with Healthier Together, the local sustainability and transformation partnership in order to help them to develop a Five Year System Plan. This will be coupled with feedback from insights from the Healthier Together Panel – a representative sample of 1,000 people from across the BNSSG area who are invited to take part in surveys, and feedback from staff who work across the 13 health and care organisations that make up the Healthier Together partnership.

Healthier Together will carry out a second phase of more detailed public engagement, including a public survey, further conversations with staff and in-depth conversations with the public and key stakeholder groups on particular topics. For further information, please read the full statement from Healthier Together on page 68.

# General survey responses

## What matters most to people in Bristol, North Somerset and South Gloucestershire (BNSSG)?

### Q1 Tell us what you think local services could do to help you stay well by rating how important the following things are to you when it comes to living a healthy life.



'To be able to get help and treatment when I need it' was rated as the most important statement, with 327 respondents (75%) rating this as 'Very Important'. Adding in those respondents who felt this was 'Important' as well bring the total to 343 respondents (79%).

Combined rating of 'Very Important' or 'Important'. Being able to access information easily to help decide on health and care (341 respondents, 79%), and stay well and prevent illness (333 respondents, 77%); and for health professionals to respect your time (320 respondents, 74%).

These ratings were consistent from respondents across all three local authority areas.

**IN FOCUS:** 67 survey respondents reported that they have a disability. Of these, 63 respondents (94%) rated 'For health care professionals to listen to me about my concerns' as 'Very Important' or 'Important'. This differs greatly from how the overall cohort rated this question, with only 56% of people rating this statement as 'Very Important' or 'Important'.

A similar strength of feedback was received from the 153 survey respondents who reported having one or more long-term conditions. 138 of whom (90%) rated 'For health care professionals to listen to me about my concerns', and 146 (95%) rated 'To be able to get help and treatment when I need it' as 'Very Important'.

35 respondents identified themselves as carers. Of these, 32 (91%) rated 'To be able to get help and treatment when I need it' and 'For health care professionals to listen to me about my concerns' as 'Very Important'. These results are considerably higher than the overall cohorts' responses of 75% and 56% respectively.

In North Somerset, 22 carers (100%) reported that being able to get information about how to stay well and prevent illness was 'Very Important' or 'Important'. A small cohort, but still significantly higher than the overall cohorts' response rate of 77%, potentially reflecting the importance of staying healthy and well in order to fulfil the role of being a carer.

*"To see the same GP who knows me each time, would be quicker for both parties and have better continuity. I know in an emergency I have to see someone else but at all other times"* (Bristol resident)

**As a follow up question, respondents were asked 'if there was one more thing that would help you live a healthy life, what would it be?'**

**120 comments were received from respondents. The key themes of which were as follows:**

**1)** 32 comments (27%) were regarding GP services, and appear to support the high response rate for the statement about being able to get help and treatment when needed.

The vast majority of these comments focused on **the challenges people face in accessing GP appointments**, including long waiting times, different booking systems and the difficulties faced in trying to see a named GP, or having continuity in the GP/ health professional that they see to discuss ongoing health concerns/ conditions.

*"Being able to get to see the same GP, when I need to, about anything related to my impairments. I don't care who I see for short-term illness related to common viral/bacterial infections but, when it relates to my impairments it is very important I see the same person. Being able to do this quickly is very important in my being able to stay healthy/live a healthy life."* (Bristol resident)

On the whole respondents felt that GP surgeries could play a vital part in helping to support the prevention and self-care agenda. Better information and access to signposting, and greater links with other professionals and groups were all quoted as being useful.

Respondents also highlighted **the value of regular wellness checks**, e.g. the 'Wellman' assessment, to enable people to address concerns such as weight issues and high blood pressure before they become problematic. Respondents' comments suggested some inconsistency in how these checks are currently offered across BNSSG, with some respondents reporting that they attend regularly, e.g. annually, whilst others had either never had one, or had but not for some years.

*"Annual check-up, partly as reassurance that all is ok, but also to enable it to act as a preventative and catch things at an early stage - i.e. If simple things such as high blood pressure is detected, it may encourage more of a life style change to manage this rather than detect it when medication is needed." (Bristol resident)*

*"Periodic examinations to ensure good health – I am (just) over 70 and have heard mention of tests being offered by GP surgeries, but have never had anything from mine." (North Somerset resident)*

A small number of comments (five) highlighted concerns about staff attitudes within GP services. Comments about GP receptionists are not a new phenomenon, but several respondents felt there needs to be more respect between GPs/ support staff and patients, particularly where people have long-term conditions (and are often experts in their condition) or require reasonable adjustments.

**2)** 45 comments (37% of those received) related to public health information and interventions, appearing to support the second and third highest rated statements about easy access to information.

Respondents wished for **public health information and interventions to be more abundant, more accessible and better funded**. Examples of the kinds of activities respondents would like to access include: walking groups, smoking cessation services, guidance on weight loss, consistent and easy to understand messages on healthy eating, information and practical advice on how to buy, cook and eat healthy food.

*"Learning how to cook and thus avoid 'ready meals' and fast food takeaways" (South Gloucestershire resident)*

*"Having better information about local support groups / events tailored towards a heathier lifestyle easily accessible with information up to date" (South Gloucestershire resident)*

*"Encourage/prescribe exercise, mindfulness and diet related life style changes as standard rather than medication…" (Bristol resident)*

*"Training in schools to promote healthy foods, eating, more funding for sports to keep people active to prevent obesity" (Bristol resident)*

Many respondents highlighted the need **for fruit and vegetables to be more affordably priced**. In many cases respondents considered the price of fresh produce to be far less cost effective than 'unhealthy' foods such as takeaways and ready meals. Respondents also highlighted the cost of gym membership, swimming and exercise classes, which for many was perceived as a barrier.

*"Cheaper fruit and vegetables or incentives to eat more" (North Somerset resident)*

Respondents also requested **greater infrastructure and adaptation to the physical environment to support/ facilitate healthy living**, for example more trim trails in local parks, extended walking and cycling trails/ lanes, improved public transport network (particularly in Bristol) and more incentives to encourage active travel.

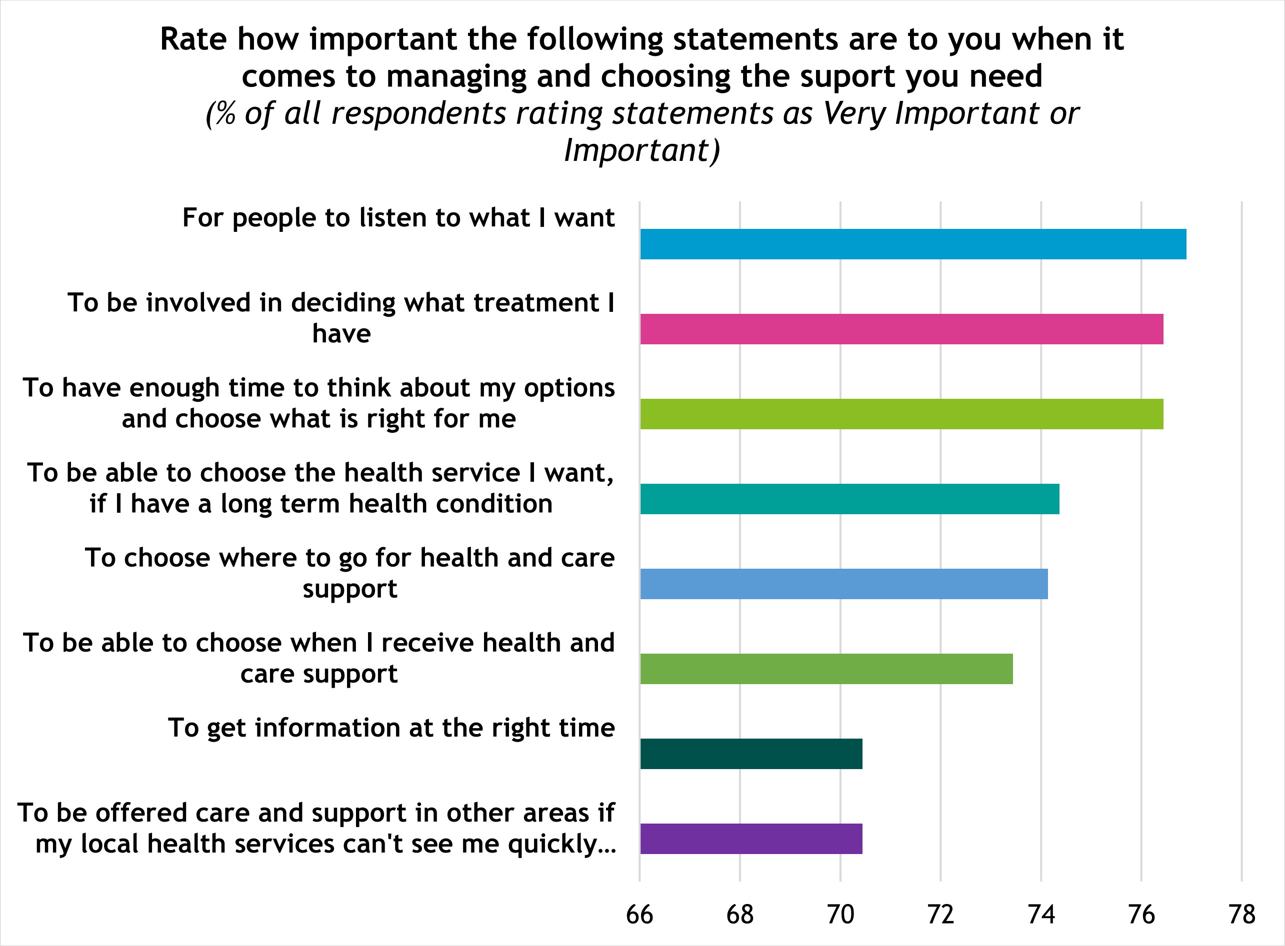
*"Improved public transport in and around Bristol to reduce private car use and effects of road traffic congestion/ pollution" (Bristol resident)*

*"Better access to physical activity through cheaper (free?) classes/ memberships for people on low incomes, more cycle lanes and better parks/green spaces. (Bristol resident)*

**3)** A small number of comments (seven in total, six of which were from Bristol residents) related to mental health services and waiting times. Access to Bristol Wellbeing Therapies was specifically mentioned, for example:

*"At the moment when a patient visits their doctor to discuss depression or mental health issues they are referred to Bristol Wellbeing Therapies. Once they have contacted them, patients must then wait up to 8 weeks for a telephone consultation and then potentially have no option to speak to a counsellor 1-1 or wait up to 6 months. I genuinely worry that people will die due to these waiting times and the severe lack of resources." (Bristol resident)*

## Q2 When you are unwell and need support or treatment for your condition you need to be properly informed to make choices about what works best for you. Rate how important the following things are to you when it comes to managing and choosing the support you need.



All eight statements received ratings of 70% or more from respondents making it difficult to draw conclusions on respondents' priorities.

Marginally taking the top spot, with 261 respondents (60%) rating it as 'Very Important' was the statement 'To be involved in deciding what treatment I have'. Closely behind this, with 255 respondents (59%) rating it as 'Very Important' was the statement 'To get information at the right time'.

However combined ratings of 'Very Important' and 'Important' outline that the majority of respondents want to be listened to (340 respondents, 77%); involved in decisions about treatment (333 respondents, 76%); and want to have enough time to consider their options and choose what is right for them (331 respondents, 76%).

These ratings were consistent from respondents across all three local authority areas.

**IN FOCUS:** 67 respondents reported that they have a disability, 64 of whom (97%) rated 'For people to listen to what I want' and 'To have enough time to think about my options and choose what is right for me' as 'Very Important' or 'Important'. This is significantly higher than the overall cohorts' rating of these statements (77% and 76% respectively) and supports the need for services to be more person-centred.

*"I want professionals to engage with me as an expert in my impairments" (Bristol resident)*

Of the 153 respondents who reported having one long-term condition or more, 150 (98%) rated 'To get information at the right time' as 'Very Important' or 'Important'. This clearly contrasts to the overall cohorts' rating of 70.5% and supports the themes that emerged from the qualitative feedback regarding a desire for shorter waiting times between referral and receipt of ongoing support, and greater awareness of local support options.

*"It feels like the healthcare professionals aren't as clued up about treatment options as service users. A local service user online forum perhaps that professionals were also linked in to would allow us all to keep abreast of new developments, training opportunities, etc." (North Somerset resident)*

35 respondents identified themselves as being carers, of these 28 (80%) rated 'To be involved in deciding what treatment I have' as 'Very Important'. Including those who rated this as 'Important' this figure increases to 34 respondents (97%) which is notably higher than the overall cohorts' response of 76%.

*"To always work with me and listen to what has and hasn't worked in past and if necessary not have to follow protocols that never work" (Bristol resident)*

*"Recognise that empathy and understanding are not just a question of saying "there, there, there" or "I understand it's difficult". Empathy/ understanding are about recognising that your patients do not spend every day within the NHS. When you start talking about "pathways" or "processes" respect that we don't know the context you are working in, don't understand what these things mean and it's scary!" (North Somerset resident)*

**As a follow up question, respondents were asked 'what else the NHS could do to support this?'**

**104 comments were received from respondents. The key themes of which were as follows:**

1) 24 comments (23%) were received regarding being listened to, having **the opportunity to be actively engaged in decisions about treatment and care, and having adequate time with a professional** to be informed and supported to do this. Some of these comments related specifically to GPs and how the amount of time scheduled for GP appointments prevents/ limits the use of this approach. However most comments were general in nature with respondents referring broadly to 'clinicians, doctors or health professionals'.

*"There is no one-size fits all and yet with less time for talking at individual appointments, and only able to discuss one issue with a GP/ nurse when actually there are often several things going it, it feels like things can so easily be missed that can be really important and have a big impact on my health (e.g. bullying at work). Healthcare workers should always strive to offer individualised and holistic care, but time constraints can make this really difficult." (Bristol resident)*

*"They could support decision making processes at the clinician/ patient interactions. I would like a proper and accurate evaluation of the risks and benefits of treatment in words that make sense to me. No jargon. I want clinicians to value what matters most to me" (North Somerset resident)*

*"…although personal choice is important, often there is not time within consultations to fully explain the consequences of choices. People can be afraid to ask or not know who to ask so if the emphasis on them making these decisions without the appropriate support we are more likely to get poor outcomes." (Bristol resident)*

*"Clearer guidance about how various referral systems work. What can I access only by referral from my GP? What can I refer myself to? Contact details for departments I have been referred to so I can chase up referrals that get lost. Be informed about the alternatives available and their waiting list times" (Bristol resident)*

Also important to respondents was the need for services to be more joined up in order to prevent people having to tell their story repeatedly, and to ensure seamless transition of care between services, e.g. GP and hospital.

*"Better communication between health professionals, particularly between primary and secondary health care providers. Often primary care practitioners do not know or hold information gathered by secondary care and vice-a-versa. This can lead to confusion, misunderstandings and even misinformation." (South Gloucestershire resident)*

*"Better joined up care e.g. Attendance at A&E for example should be able to generate referrals to other specialist and not be slowed down by having to go back to GP (or at least better information sharing so having a letter to provide to GP). This will also reducing need for patients to tell their story many times" (South Gloucestershire resident)*

**2)** Again, **access to GP services** came through as being important to people, with 29 comments (28%) received. As with question three previously, the vast majority of these comments focused on long waiting times for GP appointments. Comments received covered other elements of GP service provision, including:

- GP surgery opening times and the challenge in accessing your surgery if you work full-time or have caring commitments
- the length of GP appointments (as outlined above)
- appointment booking systems and the perceived complexities of navigating 'urgent' and 'non-urgent' appointments

*"Not have to wait weeks for an appointment or queue at 8am in a morning to get an appointment that day. Could mean going to the health centre twice that day. OK if you have a car but difficult on public transport."* (North Somerset resident)

*"Need more flexibility in times of day and available at the weekend"* (South Gloucestershire resident)

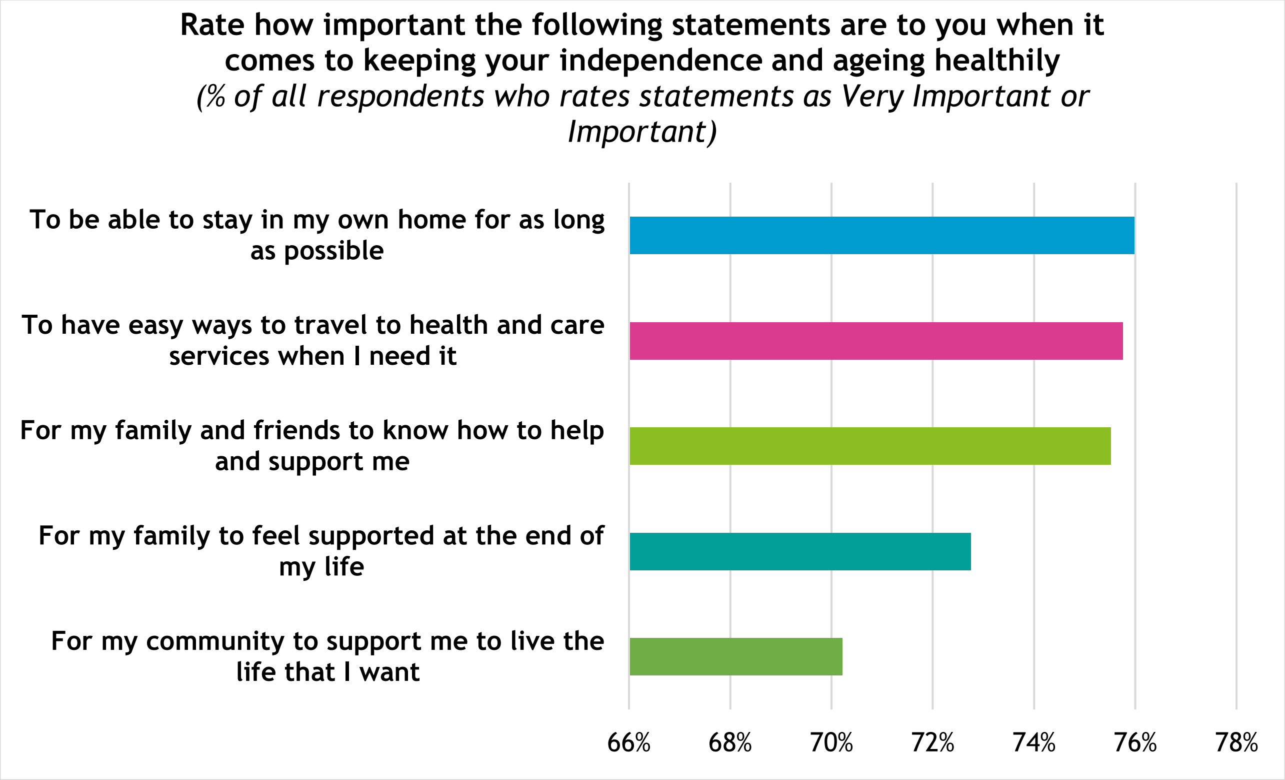
**3) National NHS strategy**

10 comments (9.6%) were received regarding **how NHS services are planned, funded and implemented at a national level**. These included pleas to *"tackle waste in the NHS"* and *"stop privatising and preparing for private profit"*, alongside specific concerns such as:

*"minimize penalty charges for breaches of RTTs and allow Trusts to reallocate funding in to improving patient care"* (South Gloucestershire resident)

*"To better prioritise what are, and are not, key treatments and services, so patients do not have to wait a disproportionately long time for access. A national discussion is long overdue as to what the NHS should/should not be providing free at the point of use as part of a plan to trim wait times and boost capacity for essential services and treatments."* (Bristol resident)

## Q3 Our ageing population is placing greater demands on the NHS. We know that people want to be able to look after themselves for longer, and the NHS wants to help you to do that. Rate how important the following things are to you when it comes to keeping your independence and ageing healthily.



266 respondents (61%) ‘to be able to stay in my own home for as long as possible’ as ‘Very Important’. In close second, with 259 respondents (60%) rating it ‘Very Important’ came ‘for my family to feel supported at the end of my life’.

However combined ratings of ‘Very Important’ and ‘Important’ highlight that the majority of respondents want to ‘be able to stay in my own home for as long as possible’ (329 respondents, 76%); ‘to have easy ways travel to health and care services when I need it’ (328 respondents, 75%); and ‘for my family and friends to know how to help and support me’ (327 respondents, 75%).

These ratings were consistent from respondents across all three local authority areas.

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**IN FOCUS:** 67 respondents reported that they have a disability, 65 of whom (97%) rated ‘to be able to stay in my own home for as long as possible’ and ‘to have easy ways to travel to health and care services when I need it’ as ‘Very Important’ or ‘Important’. This is significantly higher than the overall cohorts’ rating of these statements (76% and 75% respectively).

153 respondents (35%) reported having one or more long-term conditions. In line with responses from the overall cohort, 124 respondents (81%) rated ‘to be able to stay in my own home for as long as possible’ as ‘Very Important’. 146 respondents (95%) rated ‘for my family and friends to know how to help and support me’ and ‘to have easy ways to travel to health and care services when I need it as ‘Very Important’ or ‘Important’. These results suggest a real strength of feeling about remaining independent for as long as possible, and being able to access support within the community to be able to do that.

*“Ease of access to support - good communication between services, community hubs for mutual support and continued self care education”* *(Bristol resident)*

*“I also want control over my own life, not to be dependent on neighbours etc. Neither do I want to turn my friends into carers - it compromises both roles. It is also important that you think more seriously about - the safeguarding risks; and - the lack of autonomy (because you need to fit in with them rather than them with you); involved in expecting people to rely on neighbours/community members for support”* *(Bristol resident)*

*“Provision of a range of services that provide a 'menu' for me to make choices about personal care. eg on-line support/ provision; links to local specialists or general groups as required”* *(North Somerset resident)*

Of the 35 respondents who identified themselves as carers, 100% rated ‘for my family to feel supported at the end of my life’ as ‘Very Important’ or ‘Important’, notably higher than the overall cohorts’ response of 73%.

*“For the people who have the decision making powers to understand that the cost is not just about the money, it is also about the emotional and physical costs. It is important to into account both when deciding”* *(Bristol resident)*

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**As a follow up question, respondents were asked ‘What else would help you to stay independent and healthy for as long as possible?’**

**128 comments were received from respondents. The key themes of which were as follows:**

1) 34 comments (27%) were related to **access to services either in or close to people’s home.** This included access to health and social care services, in addition to groups, activities and support provided by the voluntary, community and social enterprise sector, alongside places of worship and other community settings.
   Cost and ease of parking, convenience (time) and public transport provision – particularly in North Somerset – were highlighted as some of the current barriers people face when accessing health and social care services, such as hospitals.

Respondents shared concerns about isolation and loneliness (particularly where they don't have family nearby) and the aim to remain active within their community in later life in order to retain independence and wellbeing.

*"Having support within the community and knowing where to access support so that people are not left vulnerable and alone. Support should be proactive and not wait for individuals to be in crisis." (South Gloucestershire resident)*

*"Travel to all areas - supermarkets, shops, social clubs and activities, places of worship. More links between young community and older ones- befriending and community engagement projects, house share opportunities so young people can live on reduced rent if they provide companionship to older people by living in their home. Support for LGBT older people - as I age I want to feel I am equally able to access services and be connected to the community. It can be lonely for older LGBT people as we are less likely to have children to support us, so I know people like me will need extra sources of support as I age. Also social groups and loneliness services for older LGBT people, and LGBT training and resources for care homes." (Bristol resident)*

*"A single bus route that runs from Clevedon/ Portishead to Southmead, and from Clevedon to Weston (WAHT)" (North Somerset resident)*

2) 21 comments (16.5%) discussed the need for **people to have responsibility for their own health, and how making healthier choices earlier in life can help with this.** Again, access to public health information and interventions were considered important, alongside the personal motivation and willingness to make changes now in order to help in later life.

*"Being more aware of things I can do now to keep me healthy (e.g. reducing risk of falls, developing diabetes, having a heart attack, etc.) and getting support to make changes to my home, if required, before it's too late." (Bristol resident)*

*"Support with eating properly. Community input to help stay mentally and physically active and engaged with society" (Bristol resident)*

*"Keep up the promotional advice messages…..And provide examples/ reference of what the NHS is already doing and achieving positively." (North Somerset resident)*

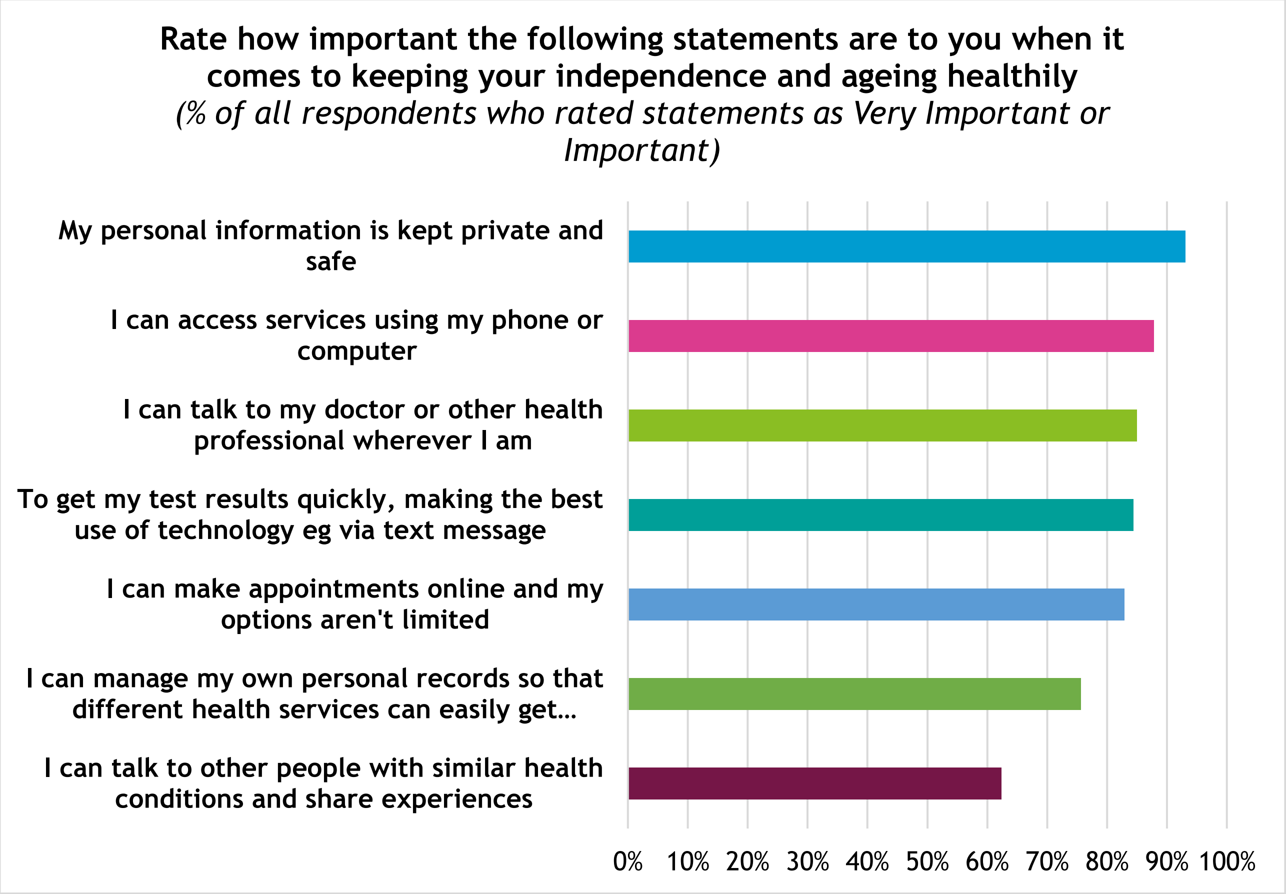
3) 16 comments (12.5%) were related to social care services, including care/ nursing homes, domiciliary care and social workers. **Access to care services within the home** was frequently cited by respondents as being important, with concerns expressed about supply/ demand, cost, staff availability, length of visits and the level of support that could potentially be provided.

From the comments received it appeared that very few respondents were currently in receipt of any social care services, so the comments were based on perceptions, experiences of friends and family, and/ or their own hopes for how they could/ would be supported in the future if required.

*"Better home care services...staff given the time to really care without the patient feeling rushed & end up confused & upset." (South Gloucestershire resident)*

*"Not yet needed but looking forward speedy access to home based care and support is vital. From observation of others this provision is often fragmented and delayed making life and hospital discharge difficult"* *(North Somerset resident)*

## Q4 The NHS wants to adapt to make it easier for people to access support they need, when they need it. Rate how important the following things are to you when it comes to keeping your independence and ageing healthily.



239 respondents (55%) rated the statement ‘my personal information is kept private and safe’ as ‘Very Important’. A further 82 respondents (19%) rated this statement as ‘Important’ bringing the total of those respondents who rated it ‘Very Important’ or ‘Important’ to 321 (93%).

Following this, four statements received similar ‘Very Important’ and ‘Important’ ratings as follows: ‘I can access service using my phone or computer (303 respondents, 88%); ‘I can talk to my doctor or other health professional wherever I am’ (293 respondents, 85%); ‘To get test results quickly, making the best use of technology eg via text message’ (291 respondents, 84%); and ‘I can make appointments online and my options aren’t limited’ (286 respondents, 83%).

These ratings were consistent from respondents across all three local authority areas.

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**IN FOCUS:** Comparing responses from different cohorts, including people who reported that they have a disability and people with one or more long-term condition, it was evident that 'my personal information is kept private and safe' was by far the highest rated statement (94% and 95% respectively), echoing the strength of feeling from the overall cohort (93%).

*"Ensure that health data remains confidential and that there is a clear covenant between the NHS and patients not to disclose information without consent to third parties or private enterprise"* (Bristol resident)

Other statements also received similar responses, as follows:
'To get test results quickly, making the best use of technology eg via text message' - 128 respondents (84%) who reported having one long-term condition or more rated this as 'Very Important' or 'Important', in line with the overall cohort (84%).

Similarly, 'I can access service using my phone or computer (126 respondents, 82%) and 'I can talk to my doctor or other health professional wherever I am' (126 respondents, 82%). These results suggest no significant differences in priorities for respondents regarding how they stay independent and age healthily, irrelevant of health status or disability.

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**As a follow up question, respondents were asked 'What would make it easier for you to manage and choose how the NHS supports you?'**
**100 comments were received from respondents. The key themes of which were as follows:**

1) 24 comments (24%) received were in relation to technology and **the use of technology to help improve access to NHS services**.

   19 of these comments were positive in sentiment, with respondents highlighting potential scope for Skype and FaceTime consultations, easier arrangement of appointments through online booking systems, easier management of prescription information and receipt of test results. It is important to note that even where respondents replied positively to the increased use of technology they often accompanied their comments with a caveat around security, privacy and data sharing.

*"Make it easier to get information and advice from GP's via electronic sources. GP's in my experience miss opportunities to use email. In my professional role I often find email information missing from health centre contact information. An advice line via email might not be suitable for all, but could well be suitable for many, especially important to get people to get used to using electronic sources so they become a routine way to get information. This might free up time for phone lines. I recognise there may be GDPR concerns with the safety of information over the internet, but this is something that would significantly improve services for me."* (Bristol resident)

*"Video calls to replace costly (time and money) yet routine personal hospital consultation visits would be a start. Half a day spent travelling and waiting for a 10 minute consultation is not an efficient use of a patient's time. Ditto for GP consultations for basic health reviews etc. Frees up parking and reduces miles travelled. Being assured that my records will not be given to Google/Deep Mind or any other tech biz without my explicit consent - sharing/monetising records like this is unethical." (Bristol resident)*

*"To look at other ways in which patients can contact their health provider (e.g. there are already phone appointments with GPs, but video-links like FaceTime might provide a more personal service)." (North Somerset resident)*

The additional six comments were either neutral or negative in nature. The general theme amongst this handful of comments was a concern that online methods would gradually become the only way that people can access NHS or social care services. The specific groups of people that respondents felt could be particularly disadvantaged by this approach included people with sensory loss or impairment, the elderly, people with mental health problems and rural residents who may have limited network/ broadband coverage.

*"There is too much reliance on service users/patients having to access services/information on line. This is a huge disadvantage to people unable to use technology including mobile phones eg text messages from service providers" (Bristol resident)*

*"To be able to speak to staff is important, the current reliance on technology is making things difficult - text messages, online communication etc is not something all of us have ready access to or ability to use." (Bristol resident)*

*"I cant use text or internet – any results must be phoned through to me because of my condition, or through to my son" (North Somerset resident)*

*"NOT text thanks, no mobile reception where I live – don't forget rural areas!" (North Somerset resident)*

**2)** 15 comments (15%) were related to **the use of technology to help overcome challenges in accessing GP services**. These were all positive in sentiment. GP access is a cross-cutting theme throughout this report, with respondents from across BNSSG highlighting the challenges that they face with waiting times.

Feedback received through this question suggests inconsistency across the three local authority areas with implementation and use of online booking systems. One respondent praised their GP surgery (Backwell, North Somerset) for their use of technology to manage visits, however most respondents shared less enthusiastic views:

*"Being able to book / cancel appointments online. Being able to have over the phone consultations with GP for matters which do not need to be present. Being able to have consultations with other professionals if they are better suited e.g. physio / nurse (rather than having to waste GP appointment first). Being given information about treatment options / ways of accessing support readily before appointments. Being told*

*at appointments the expectations e.g. if a referral onward is to be made, will that service make contact / will there be any confirmation once referral is made. Enabling service users to be able to query when certain action has not been taken and have clear protocols in place for raising concerns, where concerns are raised there should be feedback on action taken."* (South Gloucestershire resident)

*"I get frustrated that I can't make online doctors appointments. I can only access information about my prescriptions online but not my complete records. I have to call in for test results to be told they are all fine. I would like to see my results. To make routine online appointments for the nurses to take bloods would be helpful. There is great disparity in these things some areas give access to all of the above."* (North Somerset resident)

**3)** Nine comments (9%) were regarding integrated records and an appetite to see **greater use of technology to share patient information between health and care providers**. The vast majority of these comments were positive in sentiment and focused primarily on reducing the need to repeat your story.

*"Integrated seamless record systems between health of social care professionals and teams. I often find test results received in hospital have not been passed to my GP, or community health notes cannot be seem by hospital clinicians, or social care services are unable to see interventions being undertaken by community health staff. People involved in my care often need to make decisions based upon a partial picture or being unaware they don't hold all the information. I find I regularly have to repeat my story to new people. Whilst I agree with the person centred approach of the patient being the* ***expert*** *in the health & care needs I do not believe this should include being the clinical expert! I should not have to repeat details of my own care and treatment keeping track of my medications, treatments and interventions so that I can update the professionals involved in my care!!"* (South Gloucestershire resident)

*"In North Somerset we sit within 3 different hospital trust catchments which aren't able to share information such as X-ray requests - this is frustrating and it would be great if the NHS became universal rather than trust specific"* (North Somerset resident)

## North Somerset specific questions

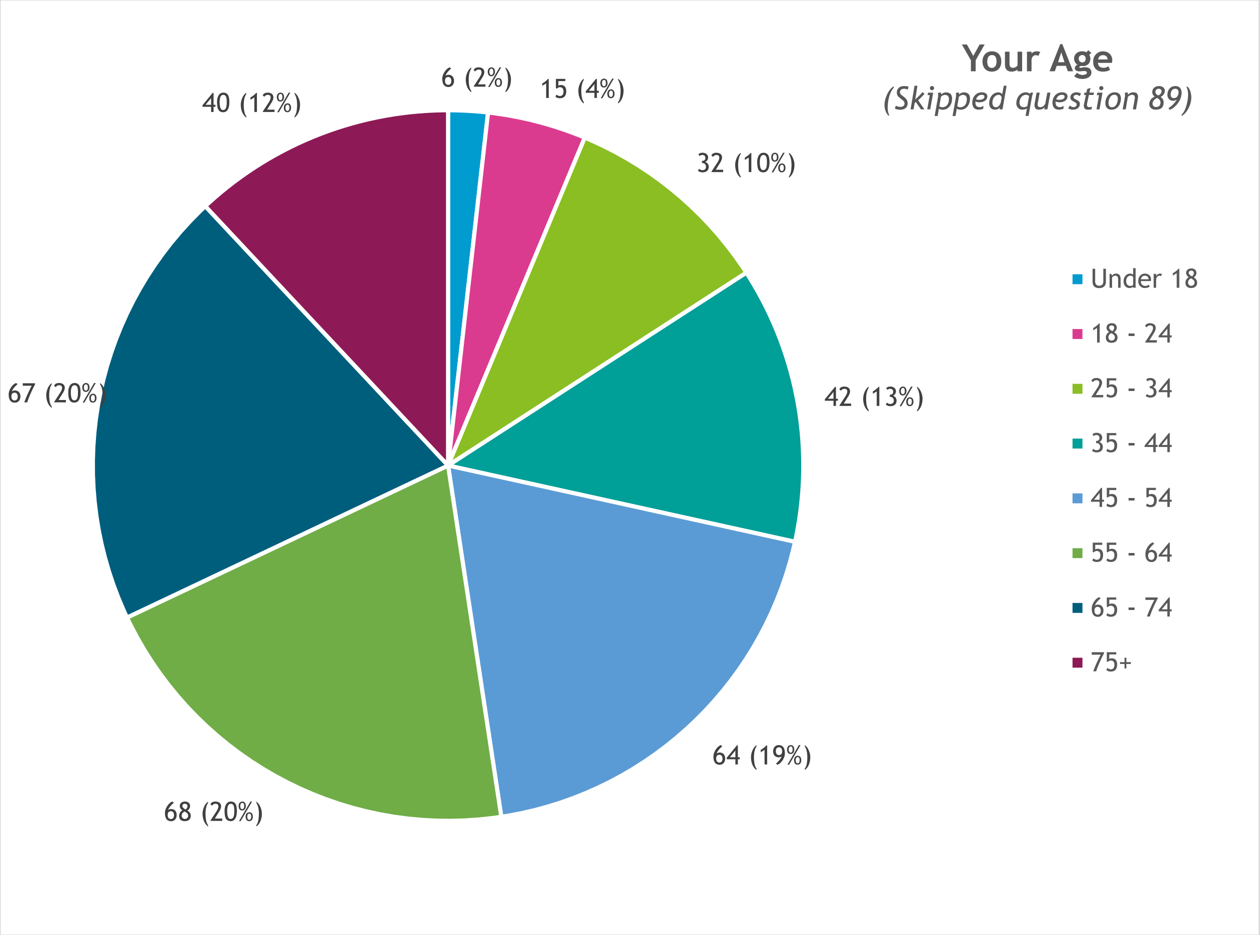
Healthwatch North Somerset added four further questions to the general survey, offering local residents an opportunity to share their experiences and views on urgent, emergency and critical care services provided locally and across BNSSG as part of the ongoing 'Healthy Weston' programme. To find out more **W:** https://bit.ly/2LOboiQ

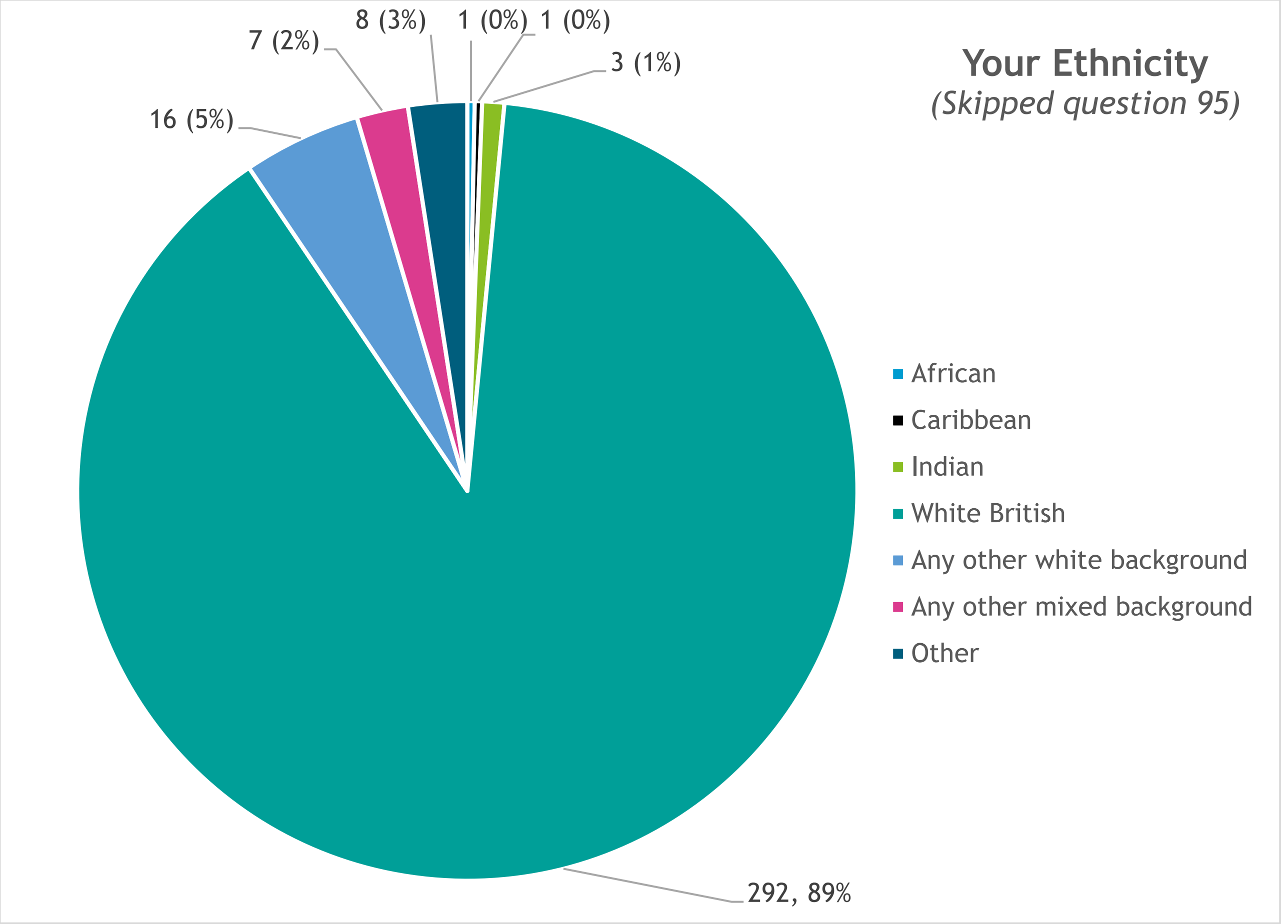
159 responses were received to these questions along with masses of additional commentary. In order to ensure that this information is used effectively, Healthwatch North Somerset are going to produce a separate report capturing the feedback received from local residents. This will be released in September 2019 and will be published online at **W:** www.healthwatchnorthsomerset.co.uk

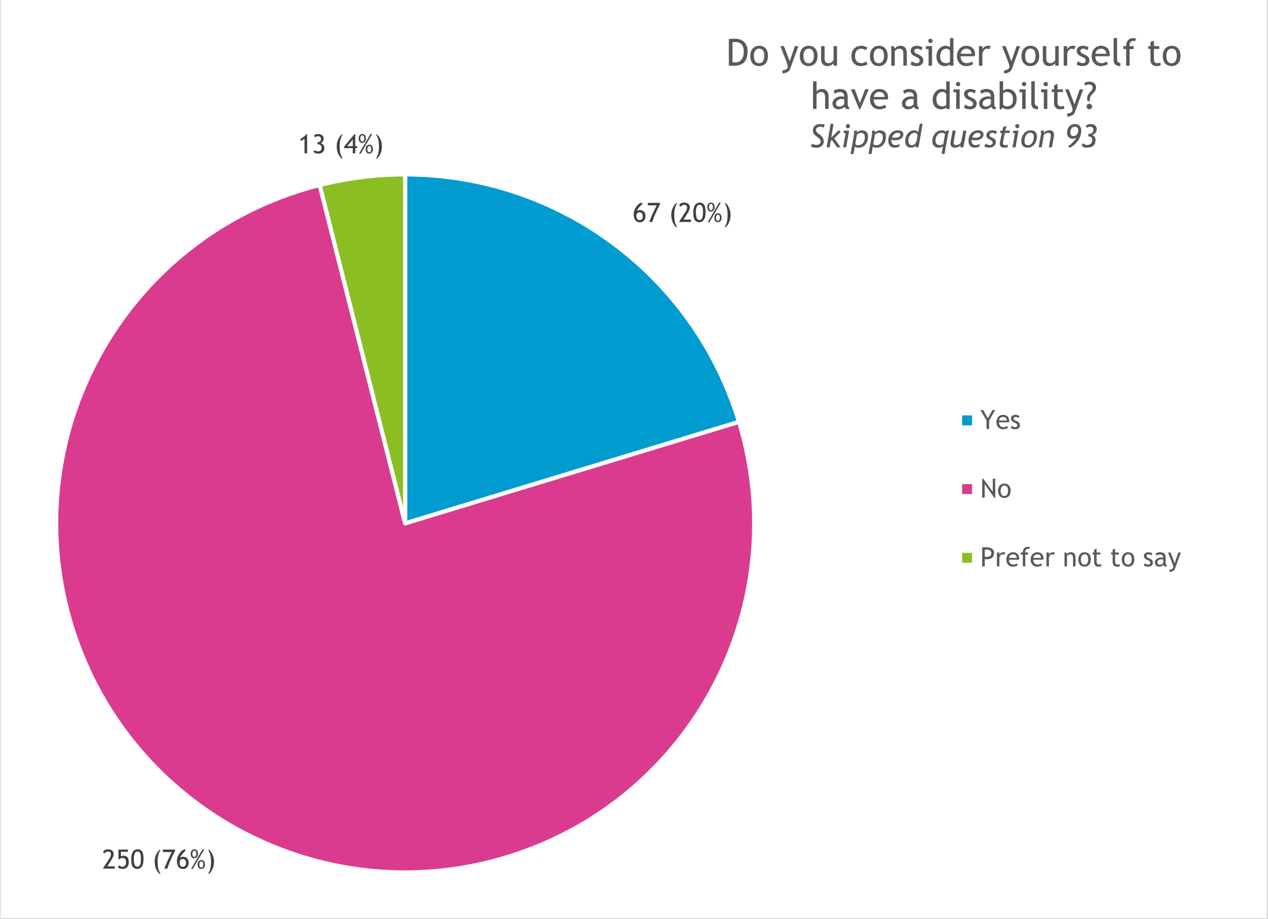
# Who replied to this survey?

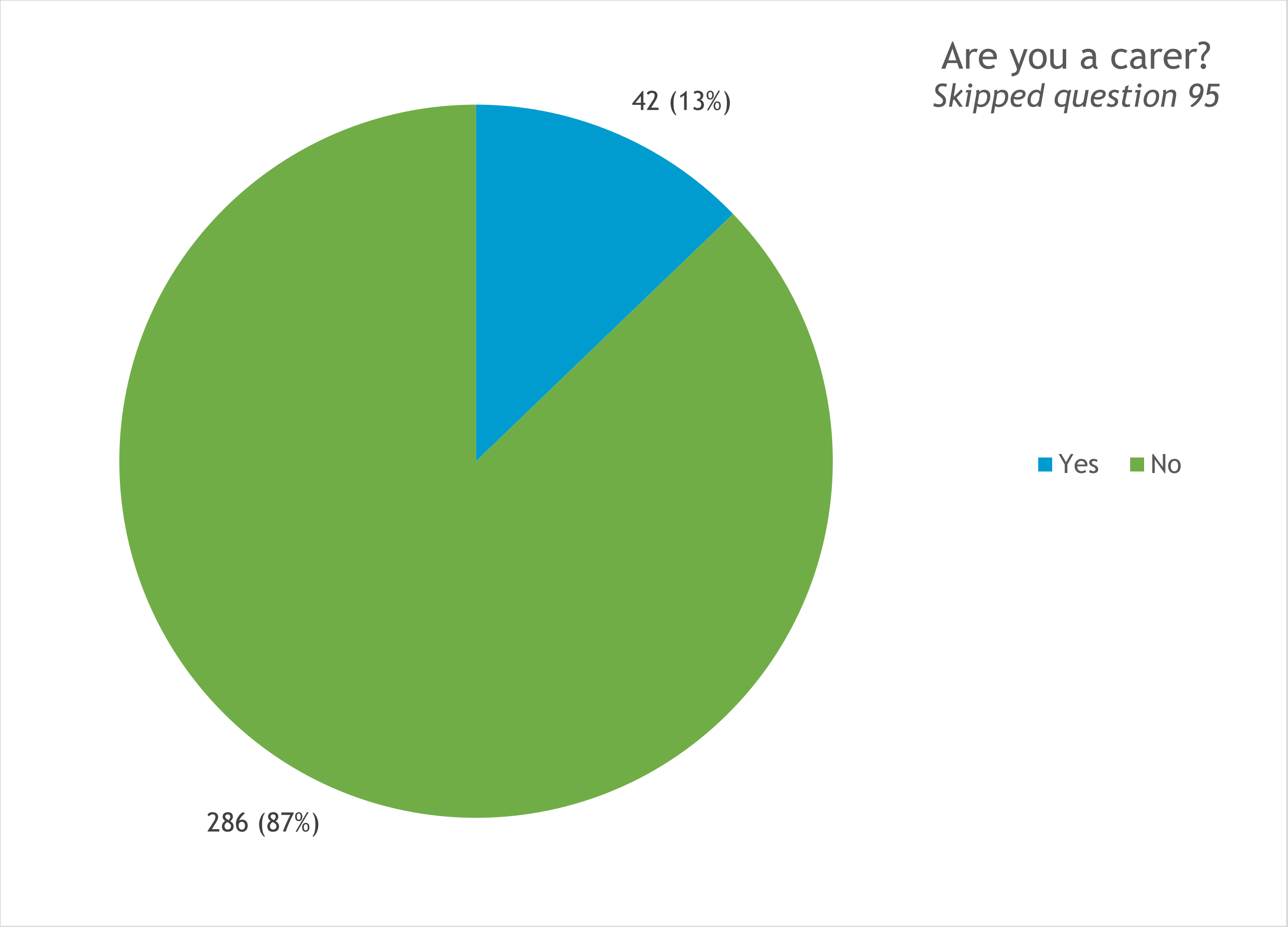
Using information collated from all three local authority areas we have been able to provide a demographic breakdown of survey respondents which is set out over the following pages.

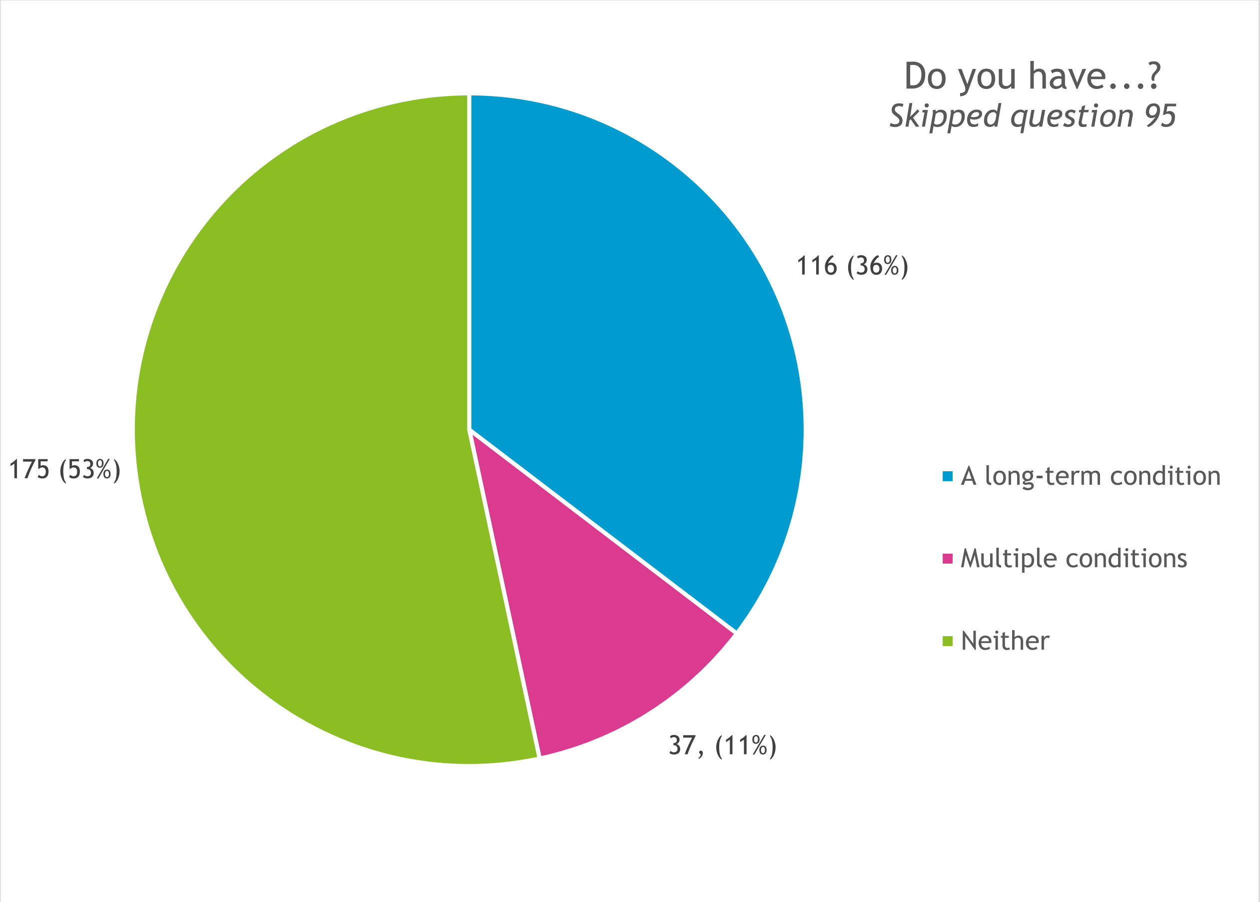
The small cohorts of demographic data received through this survey means that drawing any statistically significant conclusions about the experiences of different demographic groups has been limited. This would need to be explored in greater detail through further survey work or public engagement.

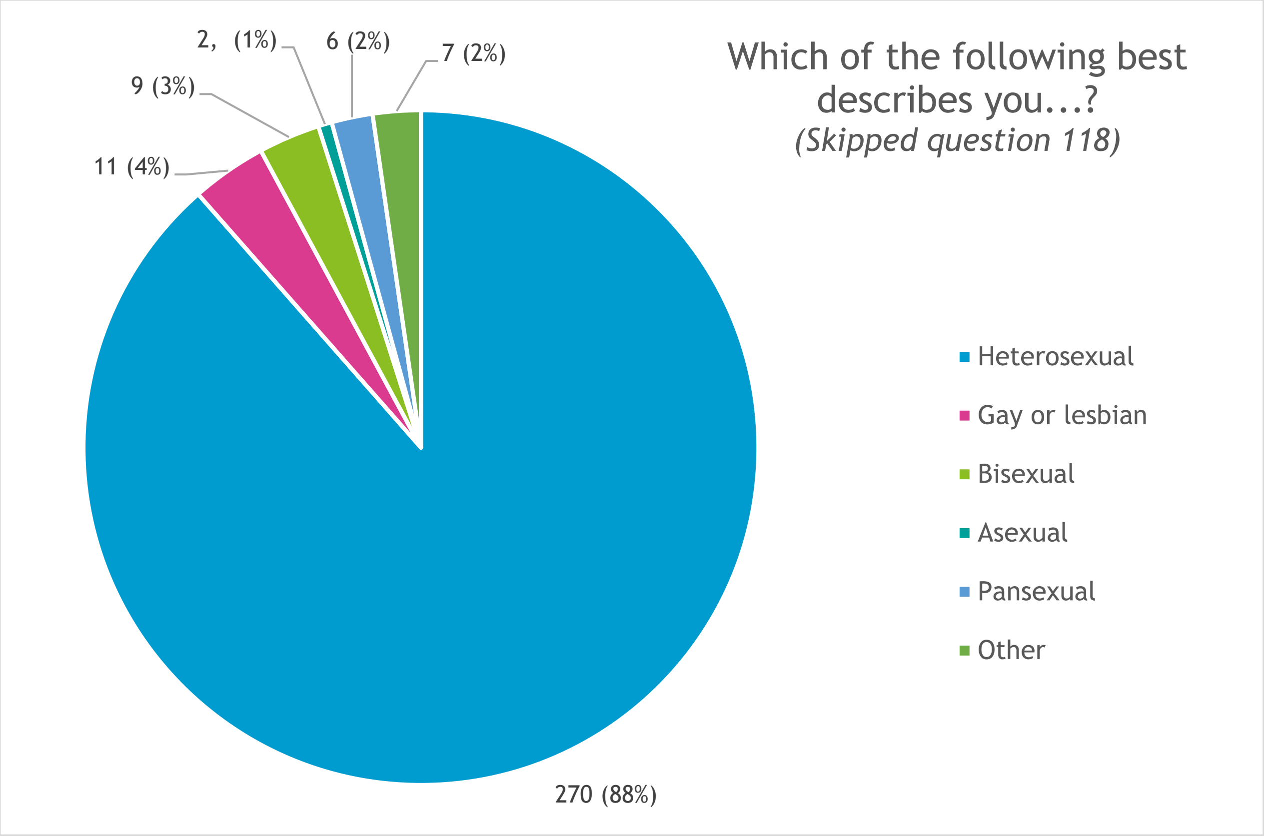


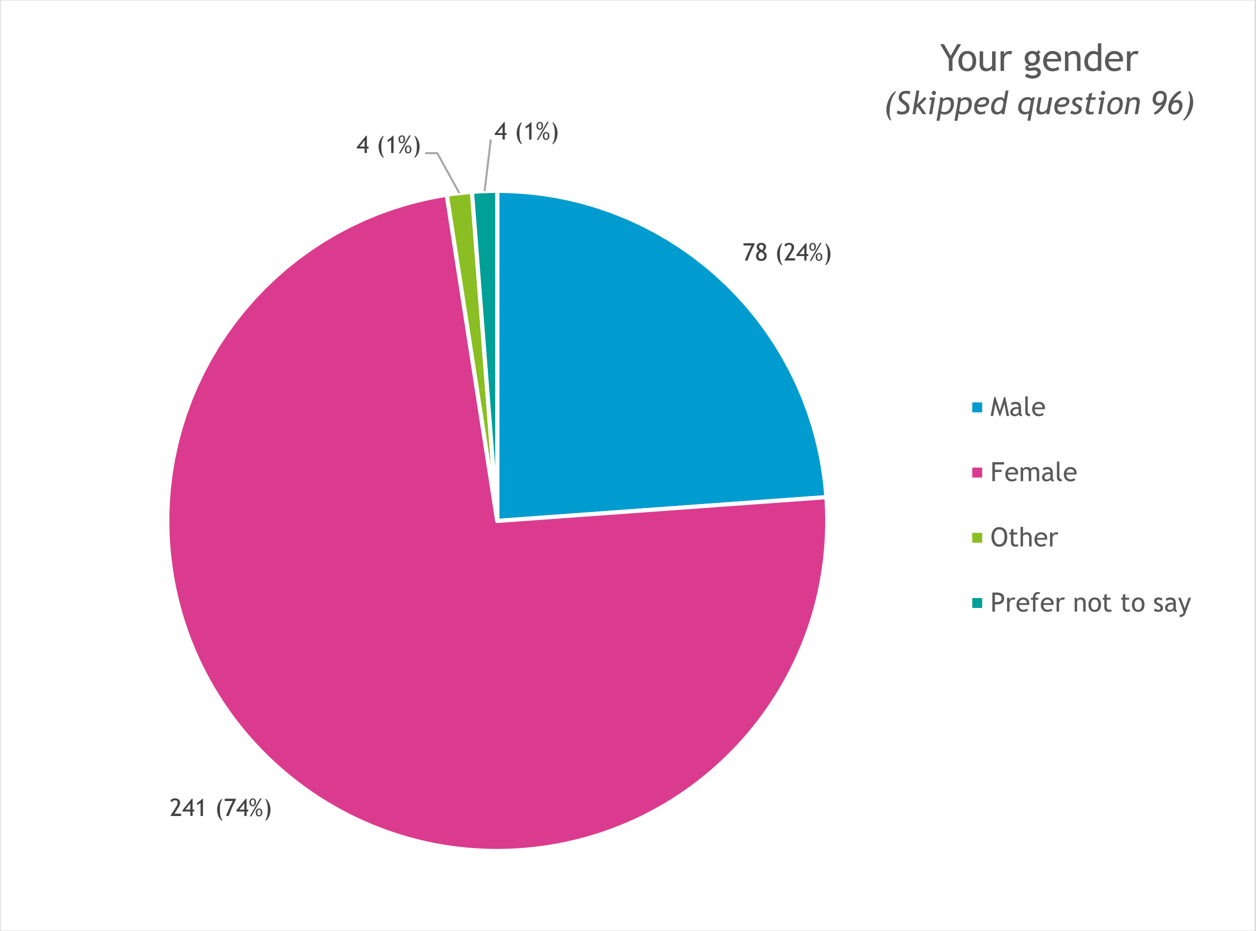

Your Ethnicity
(Skipped question 95)
8 (3%)
1 (0%)
1 (0%)
7 (2%)
3 (1%)
16 (5%)
292, 89%
African
Caribbean
Indian
White British
Any other white background
Any other mixed background
Other

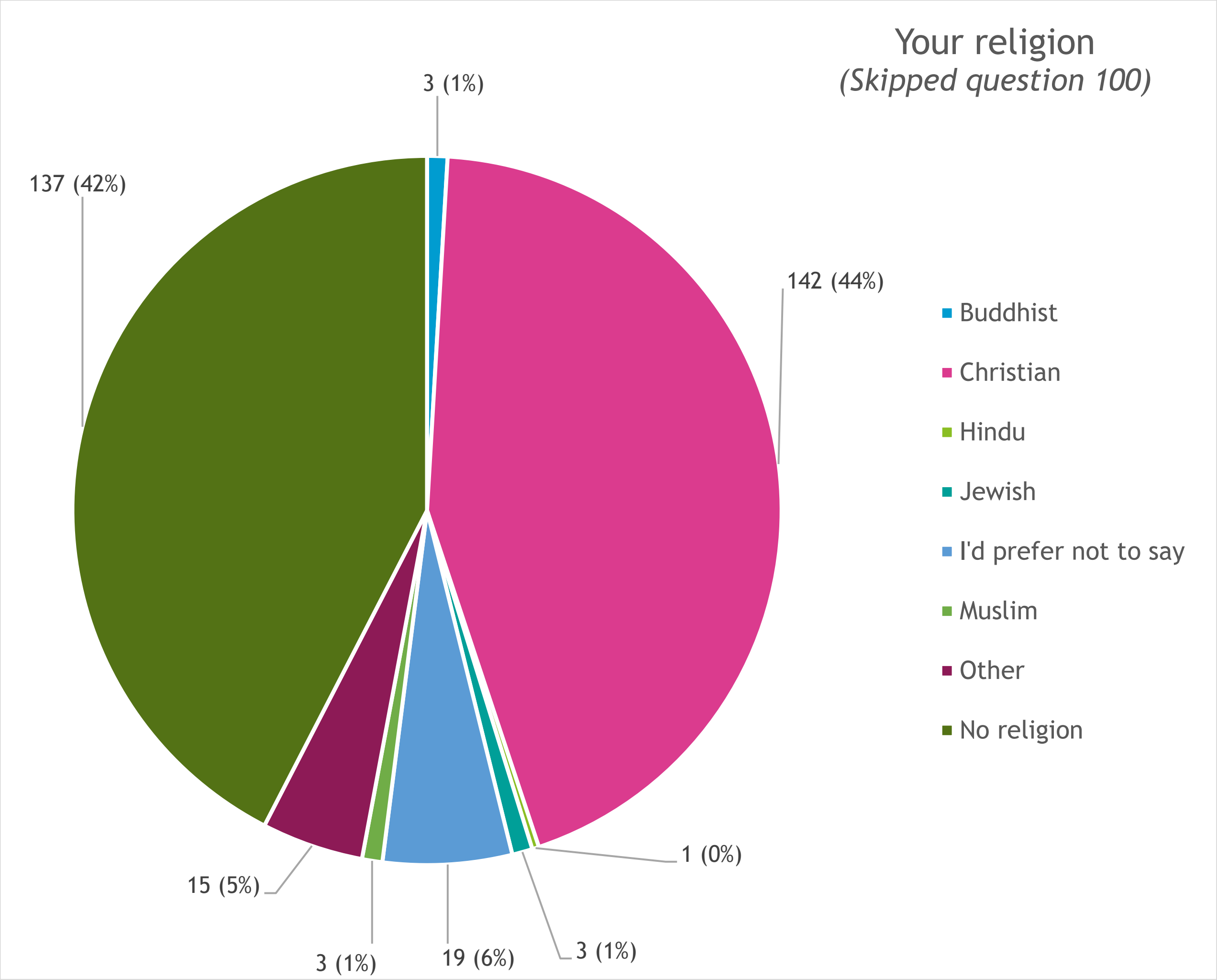

Do you consider yourself to have a disability?
Skipped question 93
13 (4%)
67 (20%)
250 (76%)
Yes
No
Prefer not to say


Are you a carer?
Skipped question 95
42 (13%)
286 (87%)
Yes
No


Do you have...?
Skipped question 95
116 (36%)
37, (11%)
175 (53%)
A long-term condition
Multiple conditions
Neither

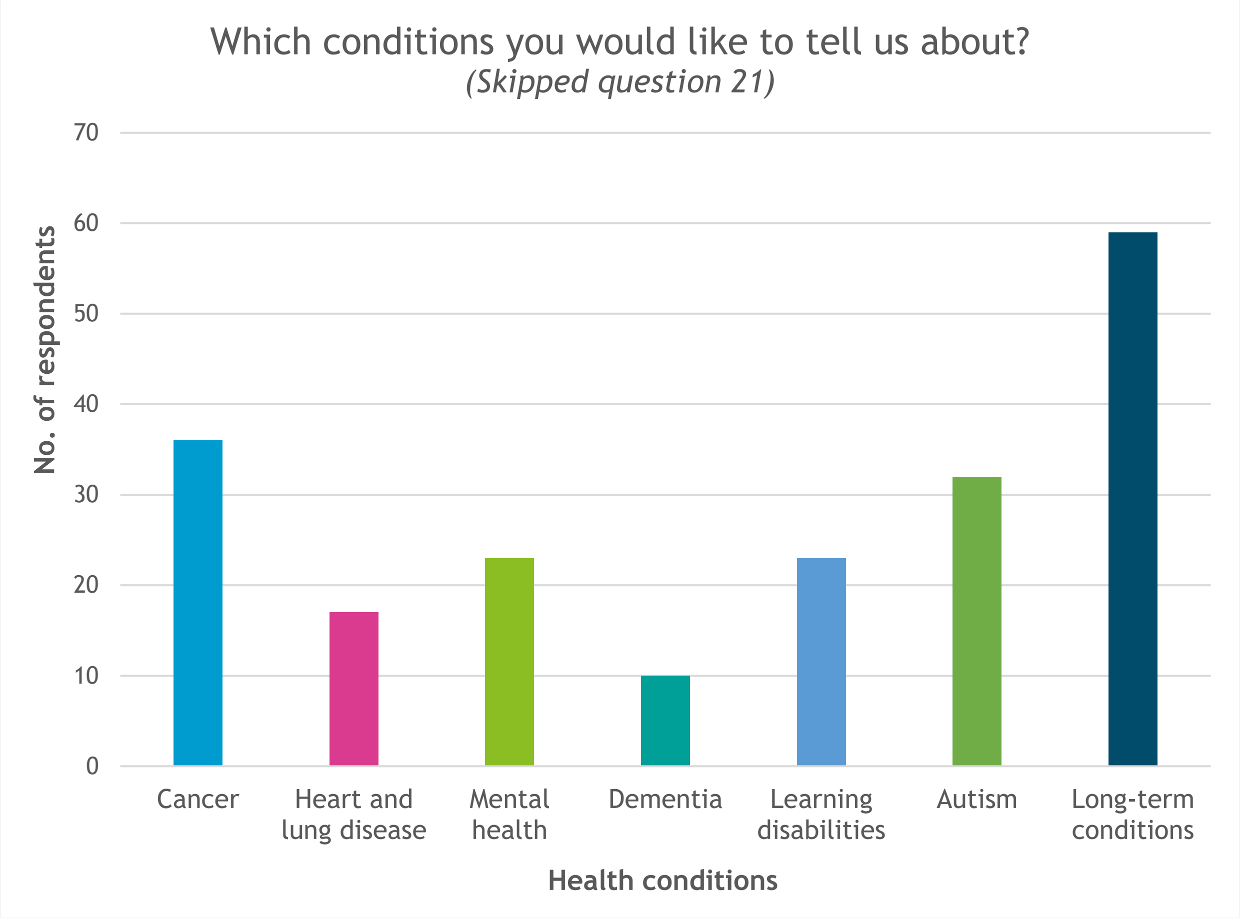

Which of the following best describes you...?
(Skipped question 118)
270 (88%)
11 (4%)
9 (3%)
2, (1%)
6 (2%)
7 (2%)
Heterosexual
Gay or lesbian
Bisexual
Asexual
Pansexual
Other


Your gender
(Skipped question 96)
78 (24%)
241 (74%)
4 (1%)
4 (1%)
Male
Female
Other
Prefer not to say


Your religion
(Skipped question 100)
3 (1%)
137 (42%)
142 (44%)
1 (0%)
3 (1%)
19 (6%)
3 (1%)
15 (5%)
Buddhist
Christian
Hindu
Jewish
I'd prefer not to say
Muslim
Other
No religion

# Condition-specific survey responses

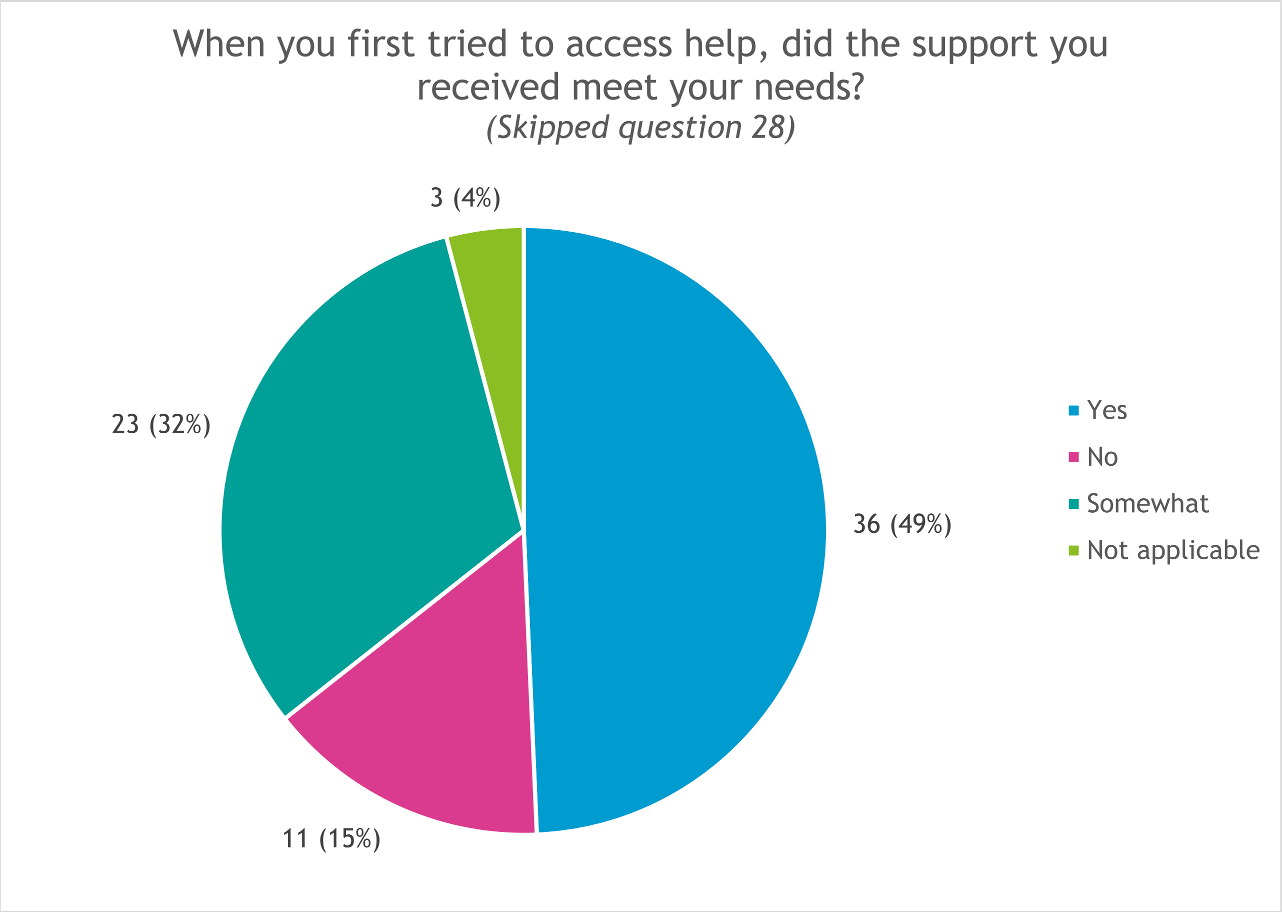
183 people completed the condition-specific survey. This survey, developed by Healthwatch England, listed seven of the most frequently discussed health conditions that people could share their experiences about. Respondents were able to highlight the conditions that were applicable to them and choose the one that they wanted to share their experiences of. Responses for the seven health conditions/ areas were as follows (***please note:*** *respondents were able to choose more than one condition)*



The greatest number of comments from the condition-specific surveys related to learning disabilities and autism (54 comments, 30%), and cancer services (36 comments, 20%).

We received 58 comments about long-term conditions, however once this was broken down into the wide range of conditions that people had, it made drawing any statistically significant results about experiences through the different care pathways very difficult. The conditions respondents shared experiences of included:

- Auto immune conditions, e.g. Coeliac disease
- Diabetes
- Arthritis/ Rheumatoid Arthritis
- Chronic pain
- Musculoskeletal conditions
- Infectious disease, e.g. Lyme disease
- Chronic fatigue syndrome/ ME
- Inflammatory bowel disease, e.g. Crohn’s disease



73 respondents (40%) answered this question as outlined above.  Of those, 70 provided commentary on their experiences of receiving help.  Three main themes emerged - which were consistent across the three local authority areas - as follows:

**1)** 14 respondents (20%) highlighted long waiting times to access services
**2)** 12 respondents (17%) stated that they had not received as much support as they would have liked following their diagnosis

*"It was hard to be taken seriously, access any kind of reliable or medium- to long-term support, waiting lists were very long, and staff kept leaving the service which meant I was passed from person to person" (Bristol resident)*

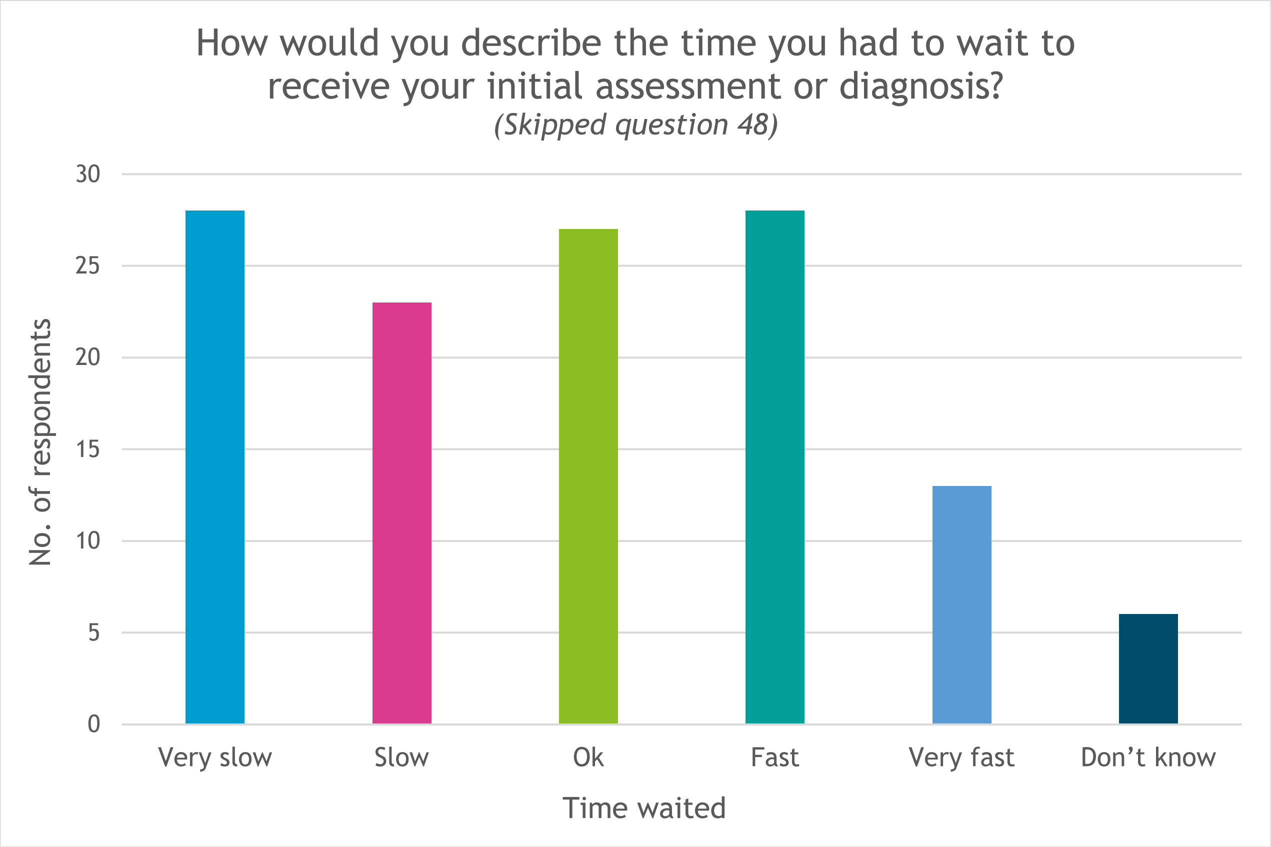
*"No, I was told to go away and look on the internet about the condition and not given any information about treatments available - I was told to take paracetamol!" (South Gloucestershire resident)*

*"Treated by GP with no advice on diet as I'm diabetic. Had conflicting advice over the years, now referred to Diabetic Clinic at Hospital. There is still help required and I have regular checks" (North Somerset resident)*

**3)** 16 (23%) respondents reported experiencing a lack of understanding and/or awareness of their conditions among health care professionals which they believe resulted in delayed diagnoses.

*"I had crohn's disease for over 5 years before it was finally diagnosed. Finally an MRI scan discovered the disease. An earlier scan would have saved a lot of suffering and cost less for the NHS" (South Gloucestershire resident)*

*"I have coeliac condition. This was not diagnosed for 20 years - during which time, I was told I was "not eating properly" (because malnourished) and "This kind of thing is common in women of your age" - i.e. my digestive pains"* (Bristol resident)

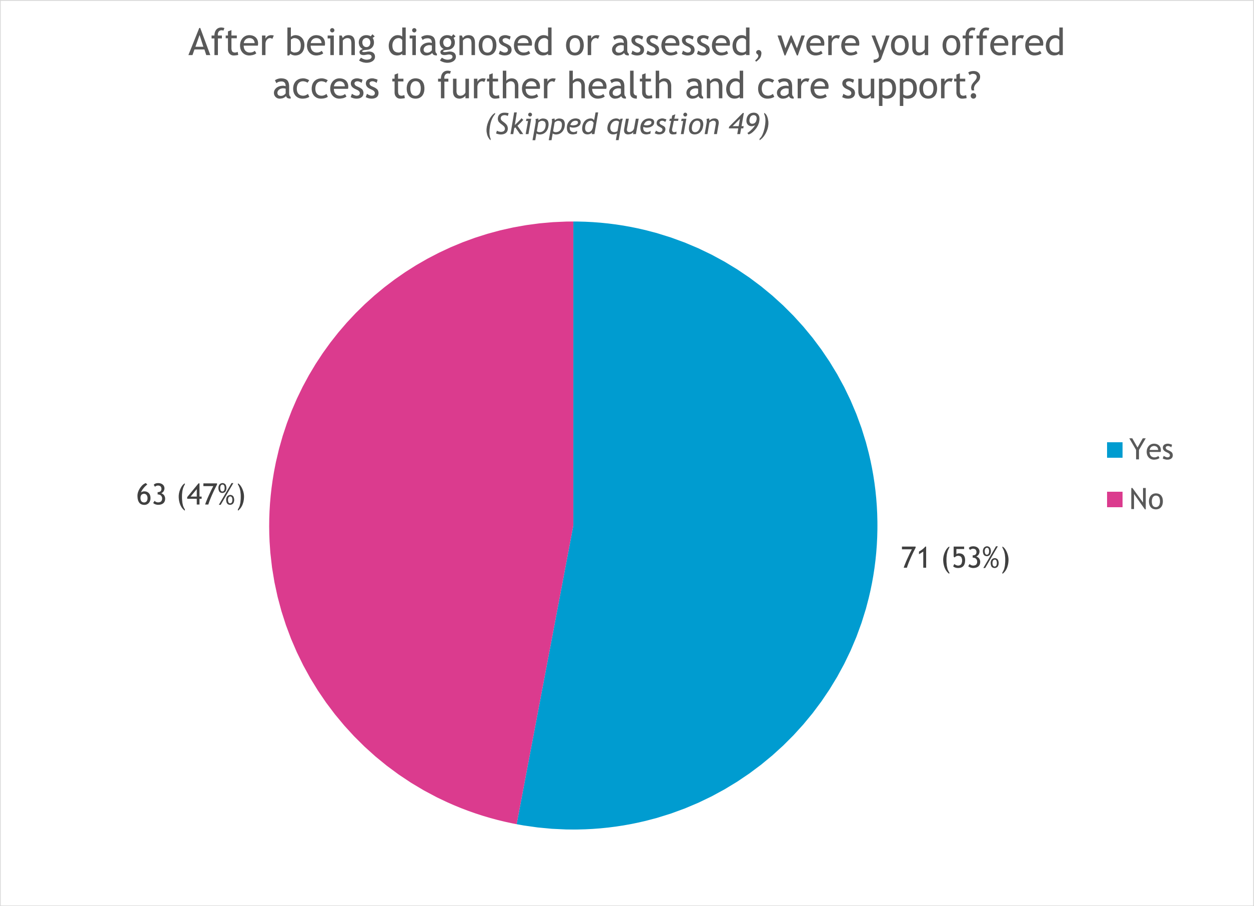


135 respondents (74%) answered this question, 87 of whom shared comments about their experiences. The commentary received highlighted real diversity in the length of time that people reported having to wait for diagnoses. This was consistent across all three local authority areas. 51 respondents provided details of the time they had had to wait as follows:

| Length of wait for diagnosis | No. of respondents | % of respondents |
|---|---|---|
| Up to 2 weeks | 4 | 5% |
| 2 - 4 weeks | 3 | 3 |
| 1 - 3 months | 11 | 13 |
| 3 - 6 months | 4 | 5 |
| 6 - 9 months | 5 | 6 |
| 12 months | 7 | 8 |
| 18 months | 2 | 2 |
| 2 years or more | 15 | 17 |
| (Blanks) | 36 | 41 |
| **TOTAL** | **87** | **100%** |

*"I was told last year there were no rheumatologist appointments in the area. I waited 10 months for the appointment in the end, in severe pain with daily dislocations"* *(South Gloucestershire resident)*

*"About nine months. The difficulty of getting an early diagnosis for an otherwise healthy person needs to be addressed"* *(North Somerset resident)*



134 respondents (73%) answered this question. Respondents were encouraged to explain which aspects of the support they had accessed worked well and what needed to be improved.

## What worked well?

Responses received were very varied but there were several key themes - consistent across the three local authority areas - as follows:

1) Support with wider concerns, such as finances, housing, and provision of lifestyle advice, e.g. support to stop smoking
2) Treatment combined with support from a specialist nurse/ practitioner, e.g. renal diabetic nurse, mental health nurses, breast care nurse etc.
3) Clear, consistent information, e.g. via leaflets, resources and websites.
4) Regular monitoring and checks

## What could be improved?

Responses received were very varied but there were several key themes - consistent across the three local authority areas - as follows:

- Waiting times to access services and support, particularly where it was felt that a quicker assessment or diagnosis may have prevented circumstances from deteriorating. This was frequently raised in relation to mental health services.

*"Quicker initial assessment so not waiting until crisis to be seen. Physical illnesses would not be allowed to wait like this" (North Somerset resident)*

- Joined-up, person-centred care with information shared between organisations

*"The renal diabetic nurse post at Southmead hospital was abolished. I now have to see the renal consultant for my kidneys and go to my GP for diabetic checks etc. This does not work. The GP, apart from being almost impossible to get an appointment, does not make any connections with my CKD and does not have the specialist knowledge of the two conditions combined that the renal diabetic nurse had, I feel the treatment I receive has deteriorated significantly over the last 18 months" (Bristol resident)*

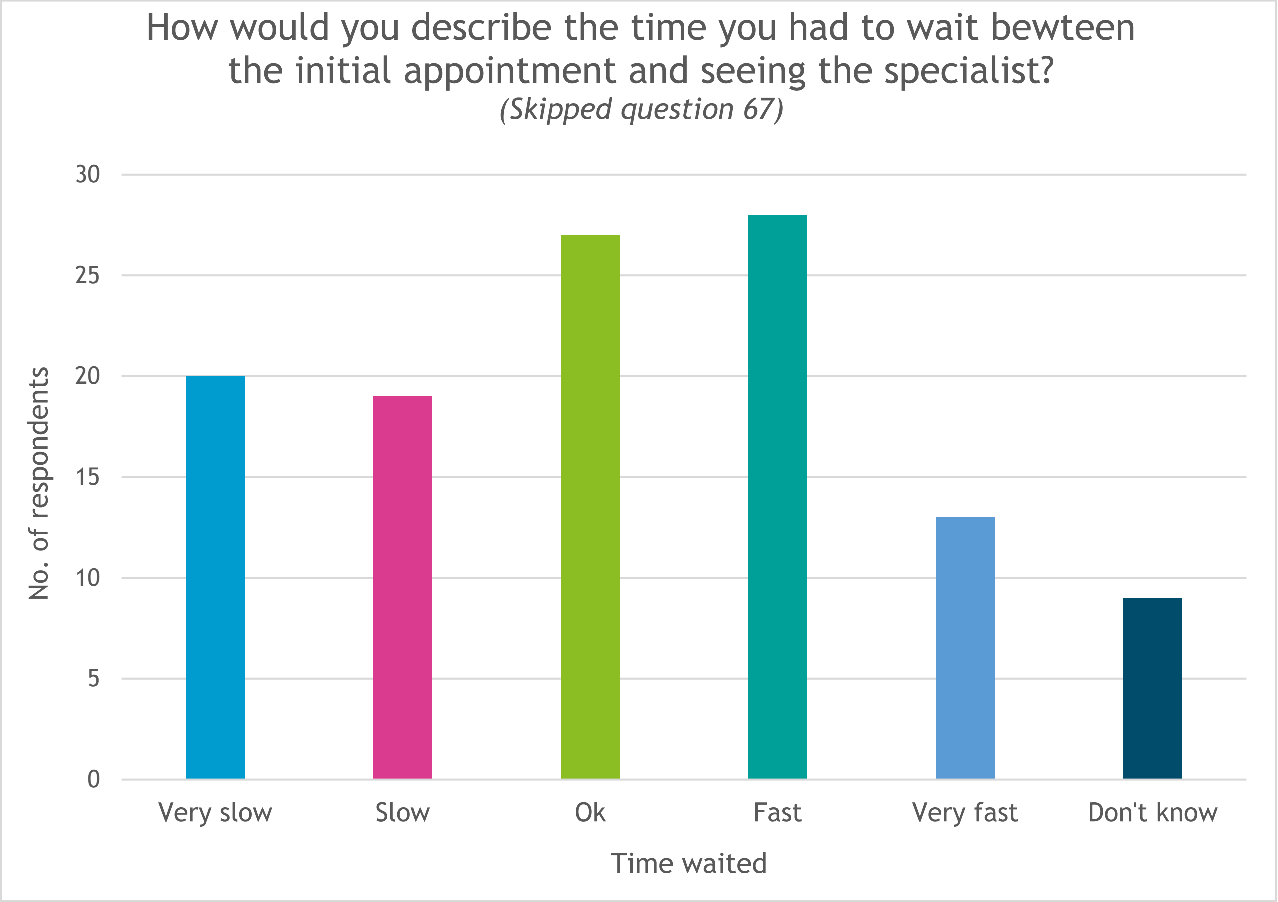
*".. My long term condition is a syndrome that affects various systems in my body and subsequently has had psychological/emotional issues as well as many surgical interventions. Physical surgical care has been outstanding, but in between I have relied heavily on family and friends for physical and emotional support. Going from appointment to appointment, in various hospitals, to see various (always fantastic) specialists, about different problems associated with my syndrome, usually needing to explain the other problems so needing to hold important information regarding the syndrome, can be exhausting and I often feel like I am my illness, when I very much want to get on with my life. A more comprehensive picture of how my whole body is affected would help individual professionals to understand how the aspect they are treating may be affected, or may affect, another complication of the disease. Treatment/medication that's right for one problem can have a negative impact on another. A more holistic view would also help to include my head! - my psychological/emotional self, sometimes just as affected as my body, and just as important a consideration for treatment/therapy" (Bristol resident)*

*"I could have done with some multi-agency support in the same place at one time rather than all the different appointments across the region" (North Somerset resident)*

- More information and signposting to support and help within the local community, both before and after diagnosis

*"Support should be offered before it is needed not as a reaction to circumstances. Early intervention would reduce the impact of adverse events and aid recovery" (location not specified)*

*"Information should be given by local clinics about local support groups" (South Gloucestershire resident)*



116 respondents (63%) reported that they were referred to a specialist as part of their support, for example a hospital consultant, psychiatrist or physiotherapist. 64 people shared comments about their experiences. The commentary received highlighted real diversity in the length of time that people reported having to wait to access specialist staff or services. This was consistent across all three local authority areas. 23 respondents provided details of the time they had had to wait as follows:

| Length of wait to access specialist staff or services | No. of respondents | % of respondents |
|---|---|---|
| Up to 2 weeks | 5 | 8% |
| 2 - 4 weeks | 2 | 3% |
| 1 - 3 months | 8 | 13% |
| 3 - 6 months | 5 | 8% |
| 6 - 9 months | 1 | 1.5% |
| 12 months | 1 | 1.5% |
| 18 months | 6 | 9% |
| 2 years or more | 0 | 0% |
| (Blanks) | 36 | 56% |
| **TOTAL** | **64** | **100%** |

*"Very dependent on urgency of need with surgeons. With other specialist there have been wide variations, some appointments coming through within a couple of weeks and others being months away" (Bristol resident)*

*"6 months to see a consultant, 6 months to get tests, 6 months to see someone to discuss the results of the tests" (North Somerset resident)*

## North Somerset specific questions

As with the general survey, Healthwatch North Somerset added some additional questions to the condition-specific survey in order to understand local residents' experiences of the services that were being discussed. The additional questions covered three main topics:

- people's experiences of services and support received during cancer treatment (including those of carers and relatives)
- experiences of digital technology to make appointments, seek referrals and support
- a short series of questions for people with learning disabilities and/or autism regarding personal budgets, transition between children's and adult services and support received for carers and relatives.

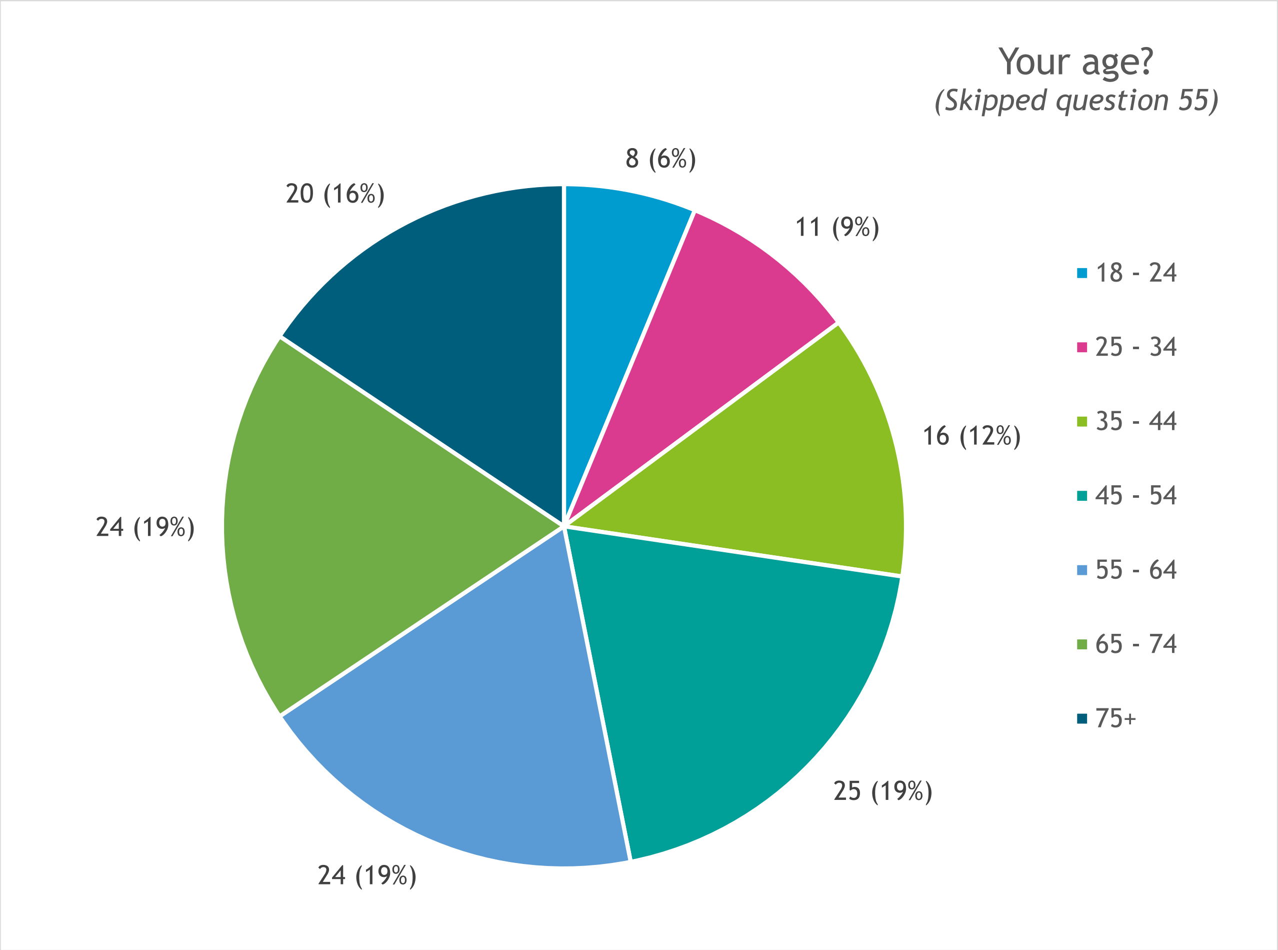
Some of this feedback – specifically that related to cancer services and learning disabilities and autism - has been captured in this report through the 'Services in focus' section (see page 40 onwards).

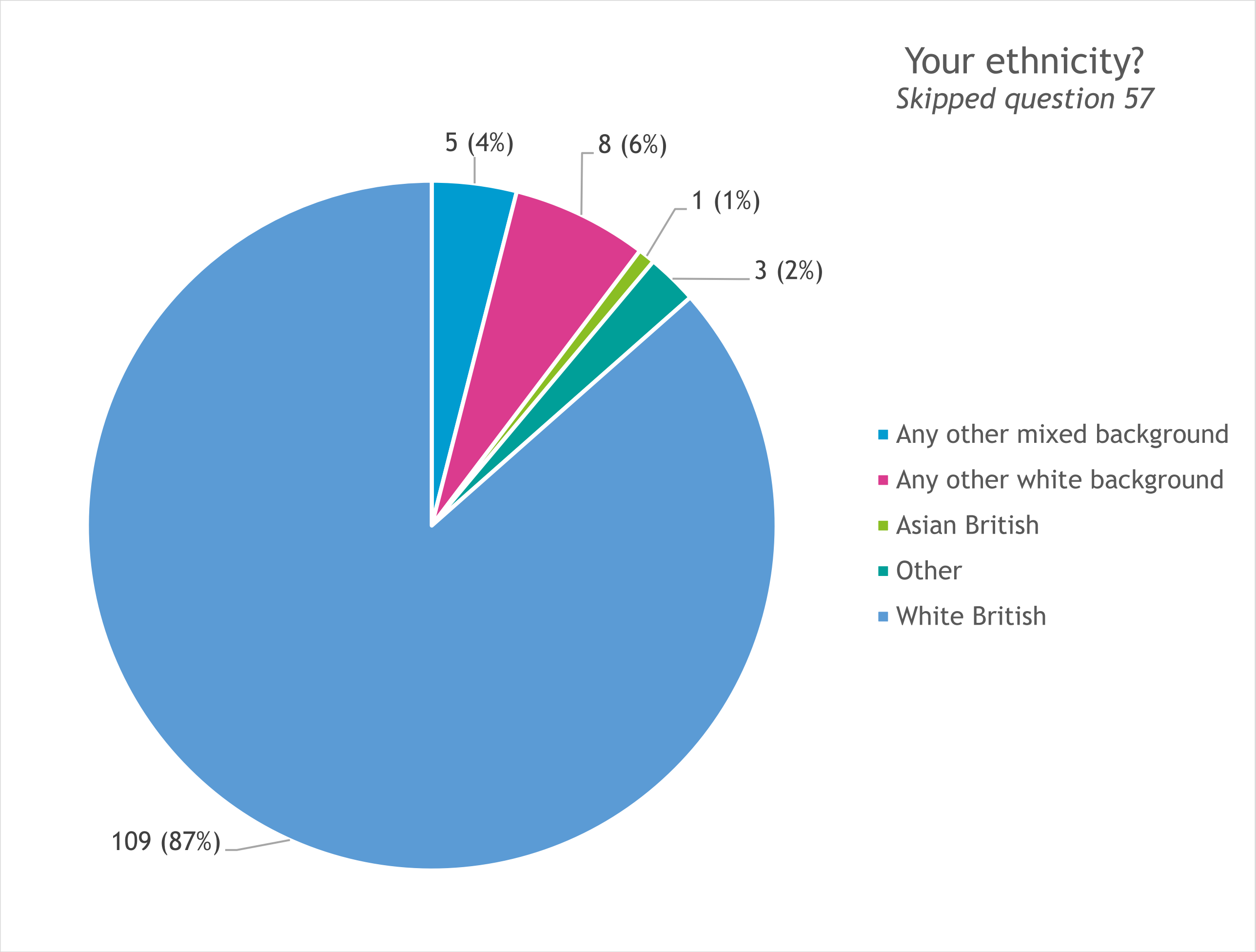
In order to ensure that all of the information that North Somerset residents shared is used effectively, Healthwatch North Somerset will produce a separate report capturing people's responses to the additional questions. This will be released in September 2019 and will be published online at **W:** www.healthwatchnorthsomerset.co.uk

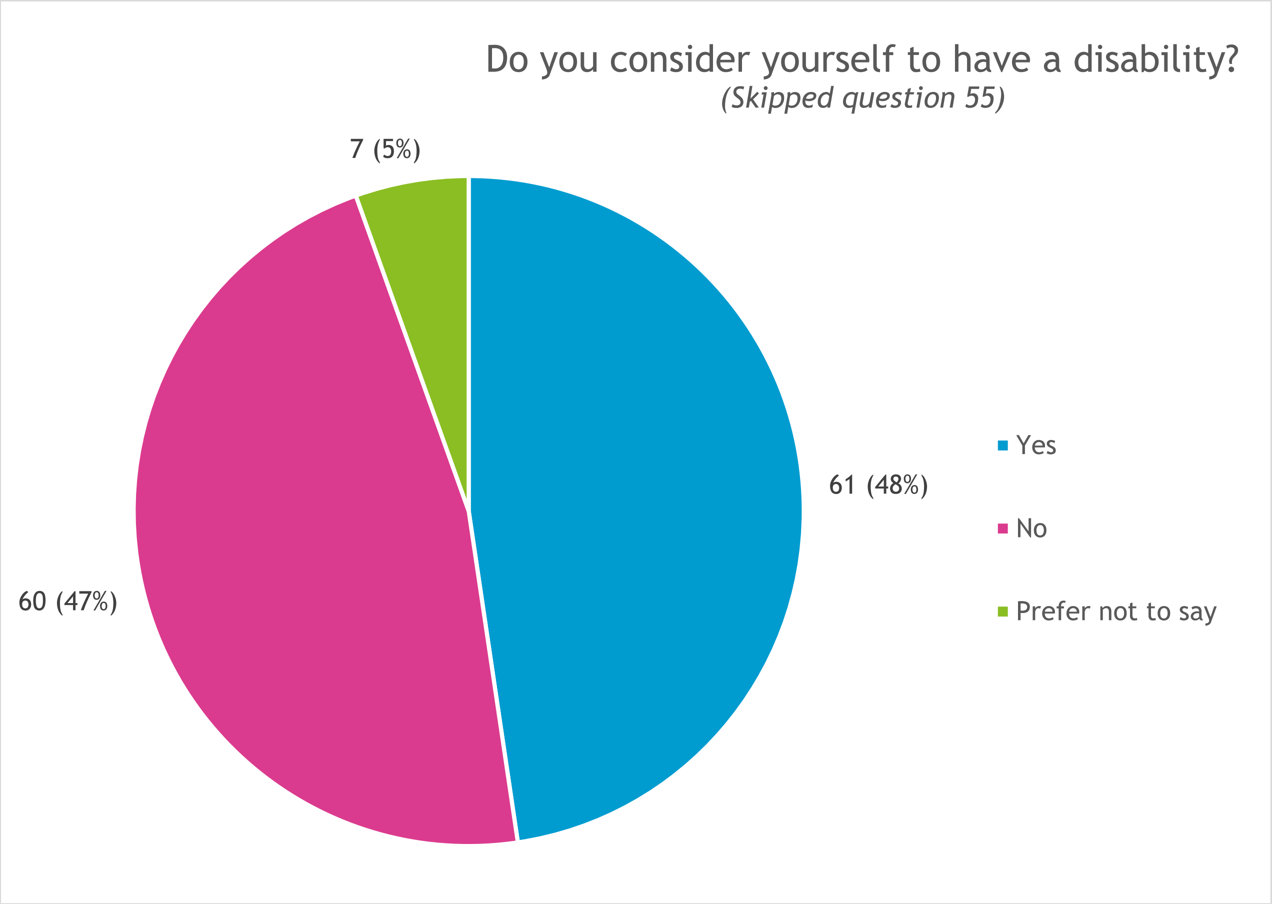
# Who replied to this survey?

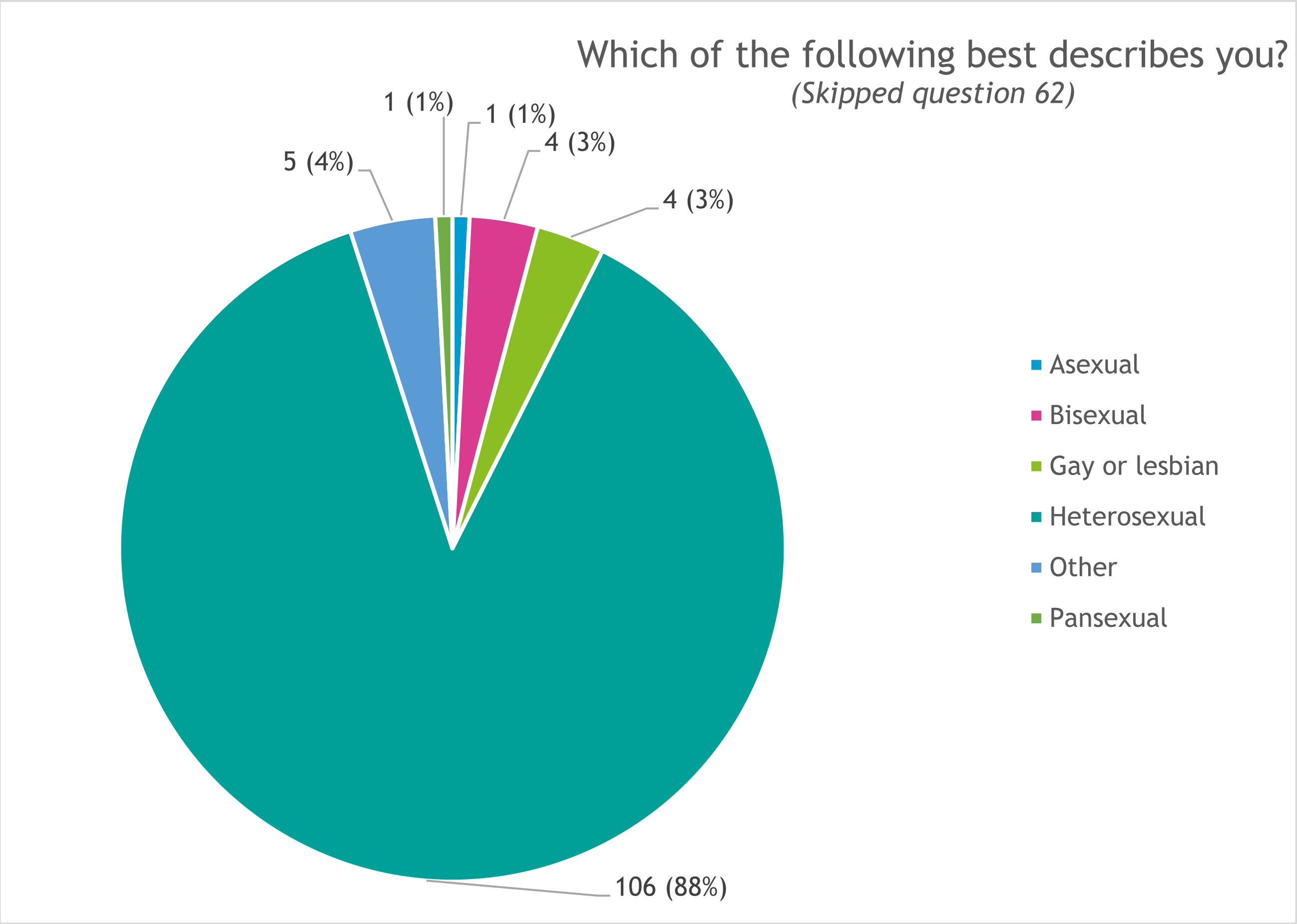
Using information collated from all three local authority areas we have been able to provide a demographic breakdown of survey respondents which is set out over the following pages.

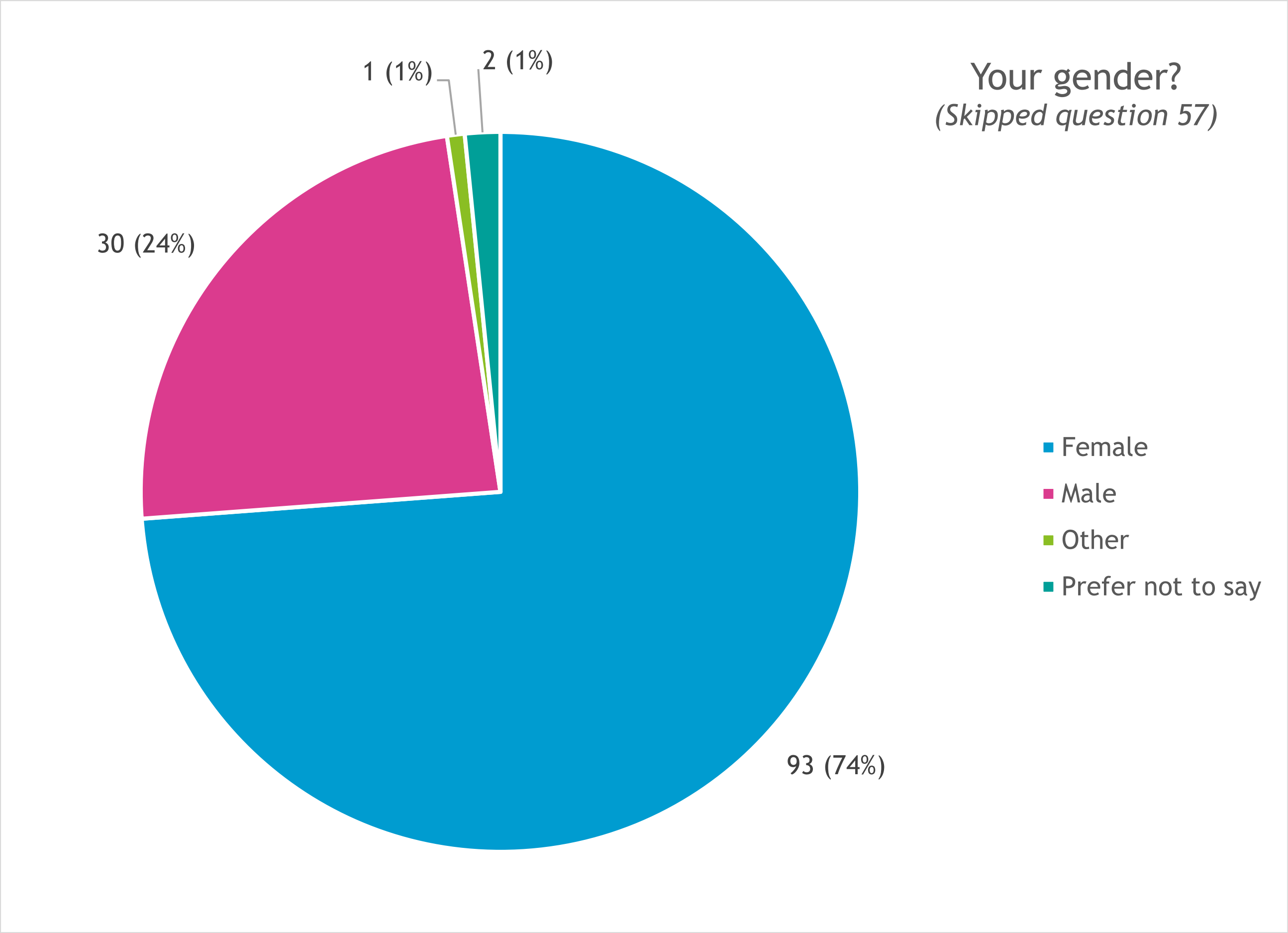
The small cohorts of demographic data received through this survey means that it is not possible to draw any statistically significant conclusions about the experiences of different demographic groups.  This would need to be explored in greater detail through further survey work or public engagement.

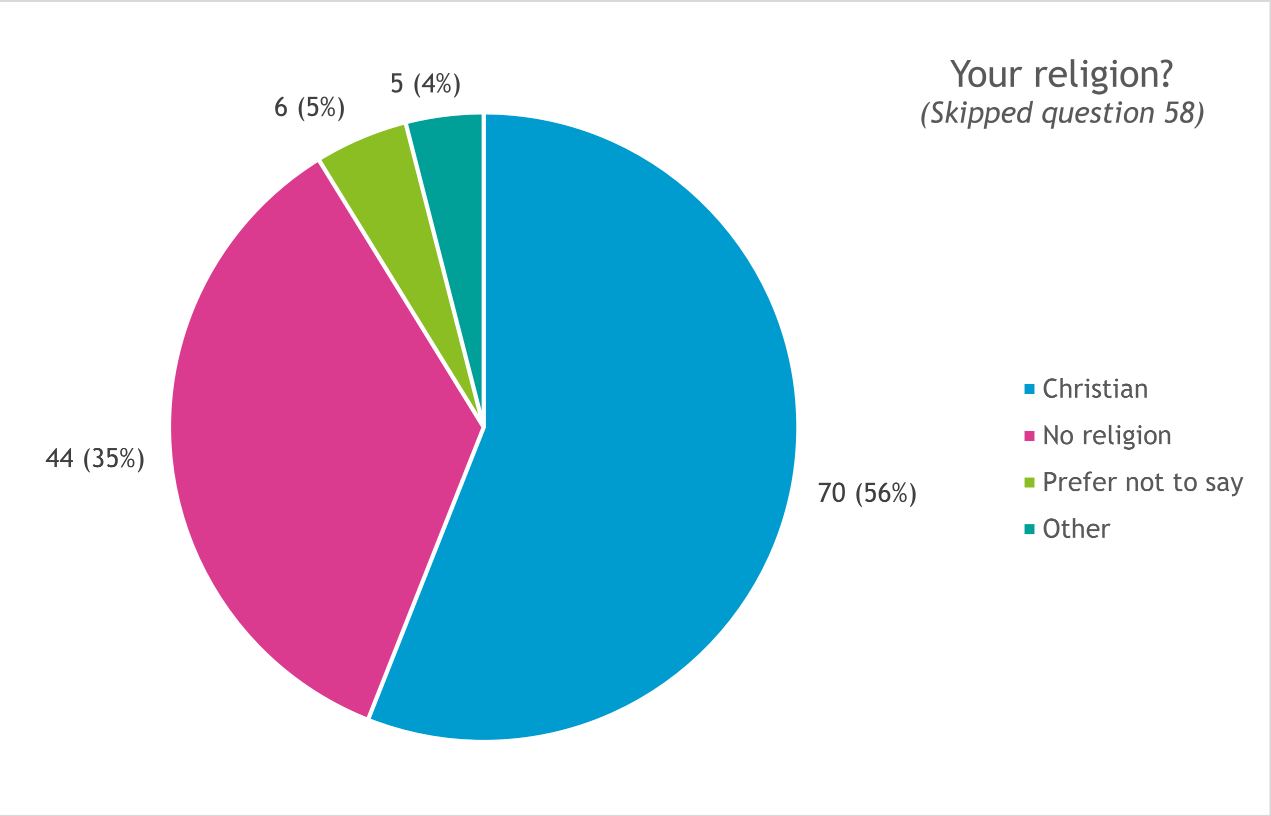



Your ethnicity?
Skipped question 57
5 (4%)
8 (6%)
1 (1%)
3 (2%)
109 (87%)
Any other mixed background
Any other white background
Asian British
Other
White British


Do you consider yourself to have a disability?
(Skipped question 55)
7 (5%)
61 (48%)
60 (47%)
Yes
No
Prefer not to say


Which of the following best describes you?
(Skipped question 62)
1 (1%)
1 (1%)
4 (3%)
5 (4%)
4 (3%)
106 (88%)
Asexual
Bisexual
Gay or lesbian
Heterosexual
Other
Pansexual


Your gender?
(Skipped question 57)
1 (1%)
2 (1%)
30 (24%)
93 (74%)
Female
Male
Other
Prefer not to say


Your religion?
(Skipped question 58)
70 (56%)
44 (35%)
6 (5%)
5 (4%)
Christian
No religion
Prefer not to say
Other

# Services in focus…

Through discussion with partners at Healthier Together, the sustainability and transformation partnership for Bristol, North Somerset and South Gloucestershire, it was decided that the two local priority topics for this work should be learning disabilities and autism, and cancer services.

These are two service areas that have had a lower amount of public engagement through the work of Healthier Together to date, therefore it was felt that Local Healthwatch could add real value in carrying out targeted engagement with people around these services in order to understand local experiences.

Local Healthwatch across BNSSG proceeded to carry out focus group conversations with people who have experience of these services, and also promoted the condition-specific survey that had been developed by Healthwatch England with relevant community and patient groups in order to gather a wider response.

These three subject areas received 90 condition-specific survey responses. These have been cross-referenced with the rich qualitative feedback that was received through the five focus group discussions that Local Healthwatch carried out. This has enabled us to pull out more themes from the focus groups and provide a clearer view of what people are experiencing.

The findings from this work are set out over the following pages.

# Cancer health and care services

The main themes identified under each part of the treatment journey are drawn from the combined qualitative responses of the Bristol and South Gloucestershire (BSG) focus group and the free text response sections of the BSG and North Somerset (NS) long term condition-specific surveys. The themes are presented in alphabetical order and do not denote a hierarchy of importance.

Quantitative results are drawn from the surveys and have been combined for Bristol, North Somerset and South Gloucestershire due to the low number of respondents for Bristol and South Gloucestershire – a combined total of seven respondents. North Somerset had 29. Both surveys were filtered to only include respondents with Cancer as the condition they were answering the survey about.

## Summary of findings

Overall the feedback was positive. The focus group attendees reported positive experiences of assessment, diagnosis and treatment. Areas of concern or in need of improvement are highlighted in the focus group, and free text response sections of the survey are presented below under each stage of the treatment journey.

From the survey results, 64% answered yes to having received support that met their needs when they first tried to access help with 79% describing their overall experience of getting help as very positive or positive.

The positive trend continued with 66% describing the time they waited to get an initial assessment or diagnosis as fast or very fast. With 70% describing the time between initial assessment/diagnosis and treatment as fast or very fast. 76% answered yes to having been offered access to further health and care support after diagnosis or assessment.

When asked about ongoing support, 59% said they found it very easy or easy to access ongoing support post-diagnosis or assessment, with 62% answering yes to the support option offered meeting their expectations.

When asked about seeing the health professional they would normally see or any medically appropriate health professional who was free immediately, respondents had a preference to see someone who was free immediately when first seeking help (65%), when first receiving their diagnosis (53%) and during initial treatment and support (47%). As they moved through their treatment journey, this changed moving to wanting to see the same health professional (with implied longer waiting times), for long term support (53%). There was also an option of 'don't mind' which received a low score for all questions.

## Assessment, diagnosis and treatment

**Getting the information you need:**
Overall people felt that they were provided with the information they need, and communication from services was good.

- **Where to find or access information about the individual's specific condition (type of cancer) and what support is available was not always obvious.** This could lead to people unable to make informed choices or to miss out on support and services that could benefit them.
- **Signposting and information on where to find further information and support services needs to be provided as standard.** Where communication was poor, the main concern was different services not having passed on or shared information and individuals having to chase up appointments or results.

| **Bristol and South Gloucestershire** | |
|---|---|
| "As a former nurse, I feel I would have known where to look for information. For people who have no knowledge, it must be a terrible shock to them." | Focus Group |
| "A little bit of knowledge can really help you know where to look or ask. But if you don't have that you may not even know what to ask or that you can ask for help." | Focus Group |
| "Information wise, they [BRI] have an open evening and show you around and all the machines in radiology. I went, and it was very reassuring." | Focus Group |

| North Somerset | |
|---|---|
| "Lots of appointments were changed - a total of 26 times during my treatment. Communication was very poor, and I had no treatment plan." | Survey |
| "Each nurse/carer knew exactly what was going on/was needed. Good comms between teams (day and night)." | Survey |

**Healthcare professionals:**

- **Being able to see your GP is important at all stages of the treatment journey.** As is your GP having an understanding of your local cancer health and care services.
- **Specialist nurses are highly valued** and considered central to a positive experience of cancer health and care services.
- **Who you see post-treatment/in recovery.** It was felt it would be beneficial to still be able to see your specialist nurse alongside those doing your tests or check-up.

| Bristol and South Gloucestershire | |
|---|---|
| "When I saw my nurse for the last time she was very good, she was terribly clear if you have any issues, you can come to us directly." | Focus Group |
| "I would want to see my GP initially and just hope it is a really good GP." | Focus Group |
| "My experience of breast cancer treatment recently at Southmead Hospital, I can't praise it enough. From the original diagnosis to the consultants to having the opp. I can't actually fault anything." | Focus Group |
| "Fantastic Specialist Nurse support from the gynae-oncology team at St Michaels Hospital." | Survey |
| "My named breast care nurse was very good and responded to me very quickly." | Survey |
| "Would be much better to have local [not ones from other areas travelling in] health visitors attached to the surgery and the same nurse each time, so you could get to know them." | Survey |
| "Unfortunately, particularly when receiving my diagnosis and immediate care at Southmead Hospital, my care was not compassionate. I felt very let down and disappointed, to say the least." | Survey |

| **North Somerset** | |
|---|---|
| "I am on a friendly basis with my GP, and they are a great help, and I feel I get the best advice." | Survey |
| "One thing I do know is that the Macmillan worker helped me to survive the dreadful first impact of the diagnosis and by treating me as a human being, and allowing herself to be human with me she gave me hope in those early dark days." | Survey |

## The provision of ongoing care and support

**Transport:**

- Access to affordable transport is essential to ensure people are able to get to treatment and complete their treatment and recovery.
- Lack of affordable parking or adequate public transport alternatives can lead to people missing out on care and support.
- Treatment needs to be geographically accessible. Multiple visits requiring travel over significant distances while suffering from side effects impact on people's ability to manage and complete treatment.

| **Bristol and South Gloucestershire** | |
|---|---|
| "No one ever checked in to see about transport and if you could get easily to appointments that I remember." | Focus Group |
| "I knew I would find a way to get there, but sometimes I can't walk as far as the bus stop so I understand how it could be a real problem for other people." | Focus Group |
| "If you live somewhere like Weston Super Mare, you are requiring people to come daily for five weeks to the oncology centre from there to Bristol and with the side effects and the costs. [Imagine] something like chronic diarrhoea as a side effect and then trying to get a bus." | Focus Group |
| **North Somerset** | |
| "Even though I can drive, the thought of having to get on the motorway and travel to get the help I need is daunting. I am on my own, and I need to go where I am familiar. Please don't move services out of Weston Hospital." | Survey |

## Treating the whole person - not just the cancer

- **Psychological support and whole person care are as important as treating the cancer.** It was felt that this was not always as available or joined up as it could be.
- **Complimentary therapies that support physical and psychological wellbeing are important** and aid recovery and improve quality of life for individuals at all stages of the care journey.

| **Bristol and South Gloucestershire** | |
|---|---|
| “NHS interventions are very good and treat the cancer, but the [non-medical] effects of the treatment they don’t deal with… You revisit your identity, it has been sullied by the pathological identity you have been given of cancer, rather than the whole person. So you need to do both.” | Focus Group |
| “One of my daughters has had to have both breasts removed, and the care she got (not in this area, up in Ascot) has been absolutely appalling. They don’t seem to have taken into account that at just 40 the impact it has had…[Here] she would have had the sort of care [I had] and the proper support for the impact psychologically that it has on a youngster.” | Focus Group |
| “What often seems to be missing is that psychological support that brings you back into the real world in a sense after the medical and science part. All the things you can have to help you live with the cancer or in recovery.” | Focus Group |
| “Patients with mental health problems are particularly vulnerable. How do you [make] sure they don’t get lost in the system. There are real issues where people with learning disabilities have developed symptoms and they have been ignored or the individual not supported to have them investigated and diagnosed.” | Focus Group |
| “[Support] works well when coordinated by one person and the person is seen as a whole for all conditions.” | Survey |
| “I am a complex patient with many long term conditions when I then got cancer no one really wanted me, my care was split between three hospitals and I had no cancer support.” | Survey |
| **North Somerset** | |
| “It is difficult to describe the impact of the cancer diagnosis, and I am not sure that anyone service could have met all of my needs at that time.” | Survey |
| “I accessed the support of Macmillan and the We Hear You Counselling service. This worked well although it seemed a bit ad hoc at times, and to be driven by funding decisions beyond my control.” | Survey |

| | |
|---|---|
| "Overall [the ongoing support offered was] very good, much was charity not NHS." | Survey |
| "I had no support from any agencies. I was given a support nurse who I saw once. I relied on friends and family." | Survey |

## Prevention and/or early intervention

**Testing and screening:**

- **Time taken to receive test results.** One area people felt could be improved was the speed with which test results came back and in some cases, people chose to have them done privately to speed up the process. Waiting for test results, particularly at the diagnosis stage was highlighted as something that caused anxiety and distress.
- **Screening should continue past the current cut off age (if there is one)**. The importance of screening and getting people to attend appointments were felt to be central to prevention and early intervention. It was felt it should be offered on a 'lifelong basis' and not have a cut off age.
- **Genetic testing - availability and how prepared services are for its increased use.** It was felt genetic testing should be more easily available. Concerns were also raised about how well prepared services were for an increase in its use, particularly around supporting patients and those genetically related to them psychologically, where there are indications or implications from the results of the test.

| **Bristol and South Gloucestershire** | |
|---|---|
| "If I hadn't been for my regular mammogram it would never have been found. The tumour was so small at that time that I would never have detected it. And that was the very last time I was going to have one as I was 69 then." | Focus Group |
| "I've been back every year for my check up and I never see anyone else apart from the radiologist. I do feel it would be nice if the clinical nurse met you when you went in for your scan to check how you were. Some person to person contact." | Focus Group |
| "Mine was also [diagnosed] due to mammograms, it wouldn't have been picked up physically." | Focus Group |
| "My husband died of breast cancer and because of that we got genetic testing, and [are a] family who have inherited the gene." | Focus Group |
| "Doing [genetic] tests is great but what is the impact of those test results, what support is needed? We need to make sure we are putting the right support services in place. You talk to a medic and it is all about the medical side of it, and that is fine but the psychological impact hasn't been taken into account in the same way." | Focus Group |

| | |
|---|---|
| “Due to how long test results were going to take for what turned out to be a minor case of leukaemia, we went private. That was great but very expensive, but meant we could get the answer faster.” | Focus Group |
| “It was the prospect of waiting in limbo for long periods of time for diagnosis that motivated the use of private, not wanting that ‘not knowing’ having to wait for a result. [We were] lucky that we could afford to.” | Focus Group |
| **North Somerset** | |
| “I do not agree [with] my annual mammogram being removed now I am over 70.” | Survey |

# Learning disabilities and autism

The main themes are drawn from the combined qualitative responses of the Bristol and South Gloucestershire, and North Somerset focus groups and the free text response sections of each areas long term condition specific survey. Themes are presented in alphabetical order and do not denote a hierarchy of importance.

Key quantitative results from the long term condition surveys are presented for each stage of the treatment journey. Bristol and South Gloucestershire are shown as a combined figure due to the low number of respondents - Bristol 8, South Gloucestershire 6. North Somerset had 30 respondents. Both surveys were filtered to only include respondents with learning disability or autism as the condition they were answering the survey about.

Abbreviations used throughout

- BSG – Bristol and South Gloucestershire
- NS – North Somerset
- CAMHS (North Somerset) – Children and Adolescent Mental Health Services

## Assessment, diagnosis and treatment

### Diagnosis is not always followed by support

**Key messages:**

- **Support is not always provided for the individual despite a diagnosis.** This causes isolation and impacts on mental health and individuals and carers financially.
- **Support for carers needs to be improved.** There is only limited carer specific support available and it can be hard to access or find out about. Being able to find out more easily what support is available, and the facilitation of peer support for carers were key improvements suggested. Support also varied by geographic area as much of it was provided by local charities and groups.

| **Bristol and South Gloucestershire** | |
|---|---|
| "Very little communication when I was on the waiting list for assessment, no signposting to any services afterwards." | Survey |
| "[We] need joined up thinking, need to facilitate peer networking for both patients and for parent/carers. To let people network and connect with each other." | Focus Group |
| **North Somerset** | |
| "Misconception - People believe once CAMHS have given a diagnosis to the parents, the help will come next, but it does not." | Focus Group |
| "Many people are not told that there is a carers card in Bristol and other places, that gives discounts…there is no such thing in North Somerset." | Focus Group |

| | |
|---|---|
| "[As parents] we feel like we are on our own." | Focus Group |
| "My son was given a diagnosis at 4. He is now 10. We have had no parenting courses or support." | Survey |
| "After being diagnosed with autism, there is no support. I was later diagnosed also with ADHD, and there is no support. I have lots of questions and need advice, but there's no one to ask." | Survey |

## Flexibility and suitability of where assessment, consultations and service provision takes place

The needs of individuals with learning disabilities or autism mean that a single option for how a service can be accessed does not work. If the location or environment isn't right, then people can't or won't access those services.

**Key messages:**

- **At home provision**. Services coming to people in the environment that is most appropriate and suitable for them. This was particularly important for first or early visits. Seeing someone in a place that works for them will help ensure the best outcomes for that consultation or provision of service.
- **Location of service provision to take into account sensory needs.** Rooms or specialist departments may be inaccessible due to being located in buildings or environments (such as large hospitals) that mean people cannot get to them due to sensory sensitivity issues.
- **Flexibility and openness of staff to adapt non-specialist service environments.** Examples were given of GPs coming out to someone's car in the surgery carpark as that was a space the individual could manage. Lighting and other room layout factors being adjusted pre-consultation. Patients not having to wait in main waiting rooms. Quiet, low sensory waiting or rest spaces provided.

| **Bristol and South Gloucestershire** | |
|---|---|
| "[At Southmead Hospital] the building design makes navigating it to even get to the specialist services too much. The levels of noise from the high ceiling reverberations mean it isn't usable" (Adult with high functioning autism) | Focus Group |
| "[At the dentist for] my son…there is too much stimulus in the room. His challenging behaviour means he also may trash rooms…and people could get hurt when he is frightened and panicked...it means that people [the patient] in that situation never get proper care or access to services." | Focus Group |
| "I used to be able to come in to see the nurse - now I can't walk in I have to call to book." [which the individual finds difficult so doesn't always do] (Service user at The HIVE South Gloucestershire) | Focus Group |

## Impact of delays and not being able to get a diagnosis

The length of time taken to get a diagnosis impacts on both the individual and those caring for them. Not being able to get a diagnosis due to differences in assessment criteria being used, local policy or an adult individual refusing assessment were all highlighted.

**Key messages:**

- **Long of waits for assessment and diagnosis**. Reports of this impacting on mental health and worsening of an individual's specific condition. The significant variation in waiting times in different areas was highlighted. In North Somerset focus groups attendees cited an average 18-month waiting time for a referral from a GP to paediatric SCAMP assessment vs a 20-week wait in Somerset. Some respondents said they had to wait years for a diagnosis.
- **Waiting times mean people feel they have to use private healthcare services**. This had cost implications for individuals and some also commented on the difference in service, with private being seen as providing a higher level service with more knowledgeable specialists.
- **Differences in assessment criteria being used lead to inequalities in care provision**. It was felt it was harder to gain a diagnosis dependent on where you live. North Somerset does not recognise private diagnosis of autism or learning disabilities, this was highlighted as a barrier to care.
- **Not having a diagnosis means no support was available, leading to isolation for individuals and carers.** Individuals who felt they should have an autism diagnosis and carers looking after adults who refused assessment spoke of the impact not having a diagnosis has. Key issues were lack of access to support and services, isolation, impact on mental health and the financial burden of providing care.

| **Bristol and South Gloucestershire** | |
|---|---|
| "NICE guidelines are not being met [for time taken for initial assessment or diagnosis]." | Survey |
| "I was denied autism diagnosis due to use of ADOS test and criteria which have been proven to be biased towards male presentation of autism… I am unable to access help, as I was not given an NHS diagnosis." (Female respondent) | Survey |
| **North Somerset** | |
| "Diagnosis [a few years ago] took a long time and involved a significant fight which at times felt very combative, especially with education…most recent experiences have been better." | Survey |
| "The private consultant was much more knowledgeable in [the condition]…than the [NHS] person who eventually saw us." | Survey |
| "Despite the GP referring us to the priory who did [our private] assessments, NS would not recognise it, and I had to go back into the system to have the diagnosis again." | Focus Group |

| | |
|---|---|
| "I have been told my child does not meet [the] criteria, but they are assessed by people who do not even meet the child. A consultant from CAMHS did a report without meeting my child." | Focus Group |

## Lack of joined-up services for people with multiple conditions

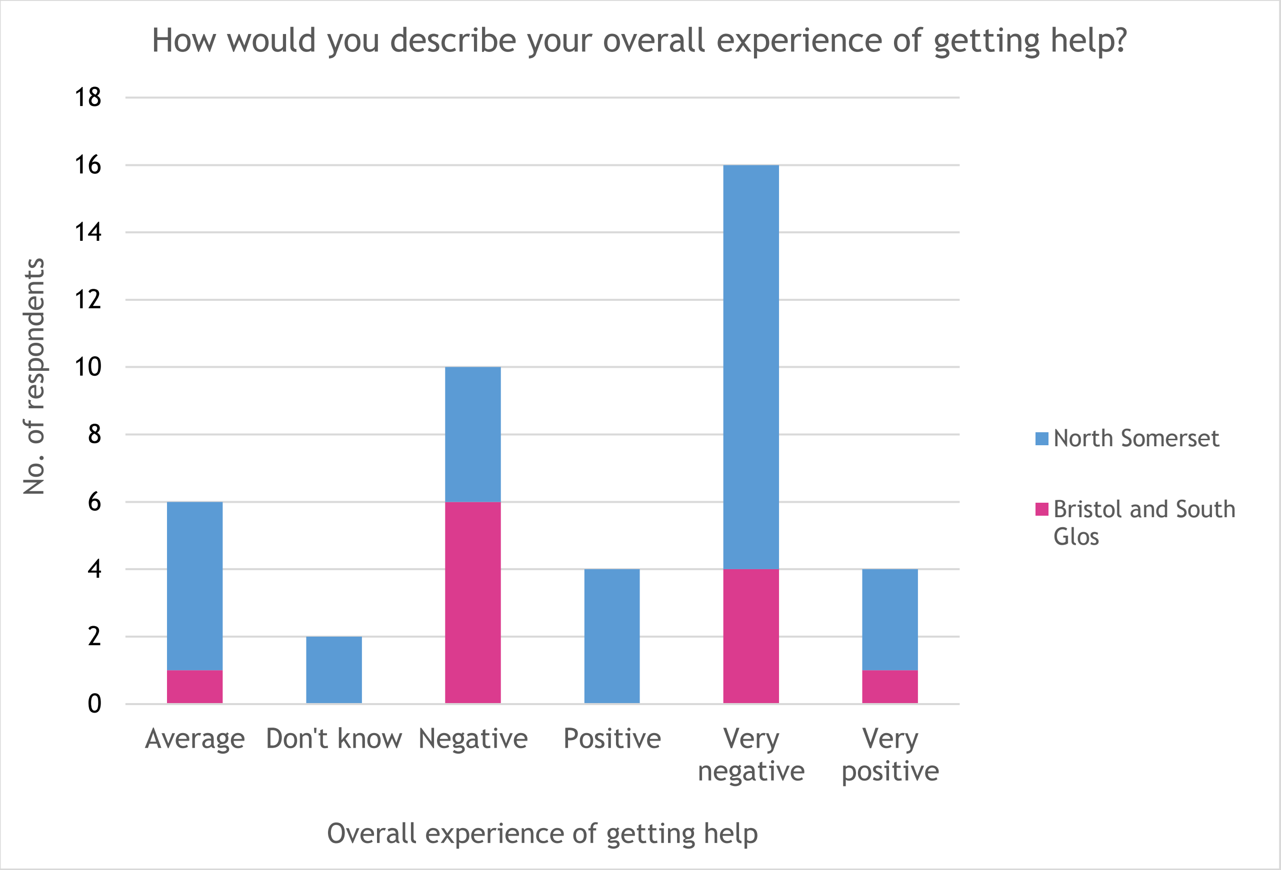
Having more than one condition was considered to make things harder and could mean people missed out on care.

**Key messages:**

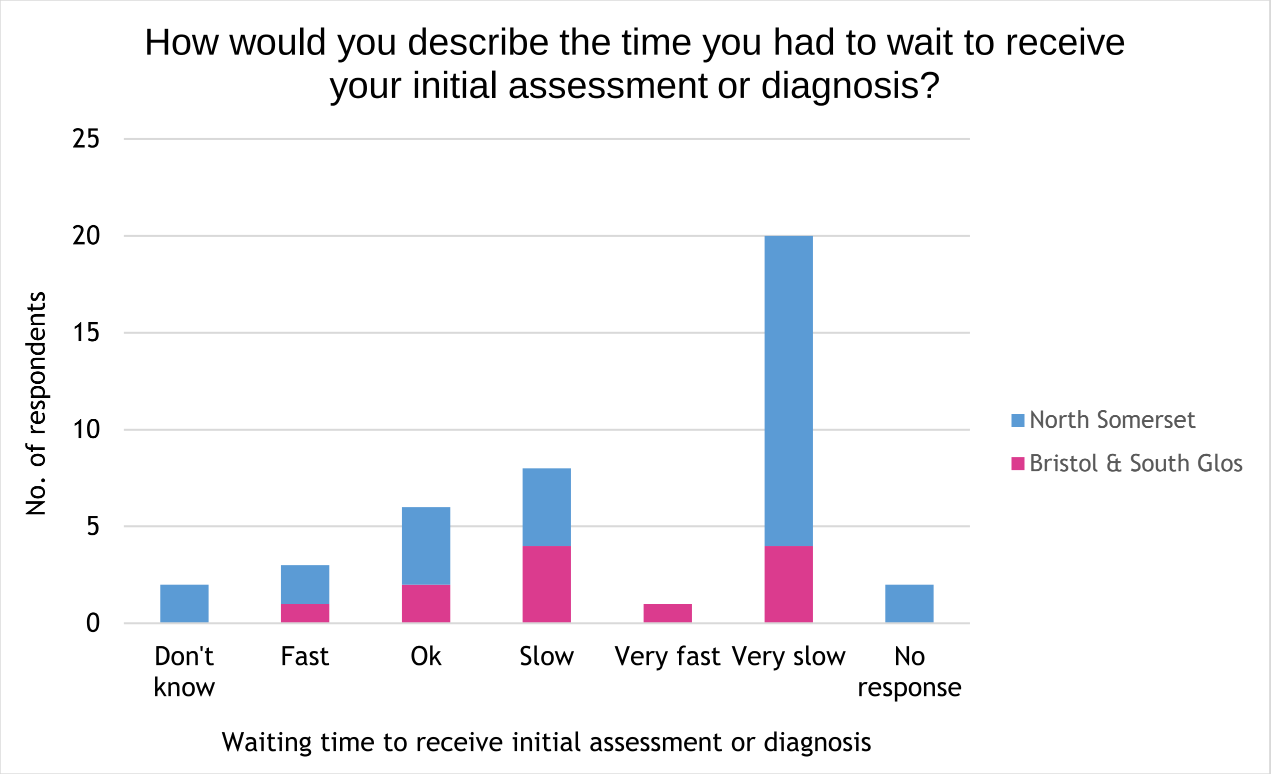
- **Services for different conditions and are not able to work in a joined-up way to provide whole person care.** Mental health services were highlighted as a service that should be more integrated with the specialist services for people with learning disabilities and autism.
- **Non-specialist services are not adaptable or simply not accessible for people with learning disabilities or autism.** Sensory sensitivity needs, language and information not being appropriate to enable understanding, general lack of knowledge or understanding of learning disabilities and autism by staff at all levels were all issues that made accessing services for other conditions difficult, and in some cases people said had led to individuals not being able to access them at all.

| **Bristol and South Gloucestershire** | |
|---|---|
| "[given] condition specific only advice, not taking into consideration the whole problems." | Survey |
| "Learning Disabled since birth 35 years ago, [she has] never had the information or support to meet very complex health needs, no one now, as an adult, wants to look at her as a whole and deal with all the problems together. We are often given conflicting advice. It needs to be much more coordinated." | Survey |
| "There should be a helpline for people dealing with long term health conditions and chronic conditions to get advice out of hours; most service just do not know what to do when you turn up in A&E or ring 111." | Survey |
| **North Somerset** | |
| "Problems come down to a lack of training in [the] health sector." | Focus Group |
| "I have a learning disability as well as mental health problems – no team can seem to meet these needs together, and that would help." | Survey |

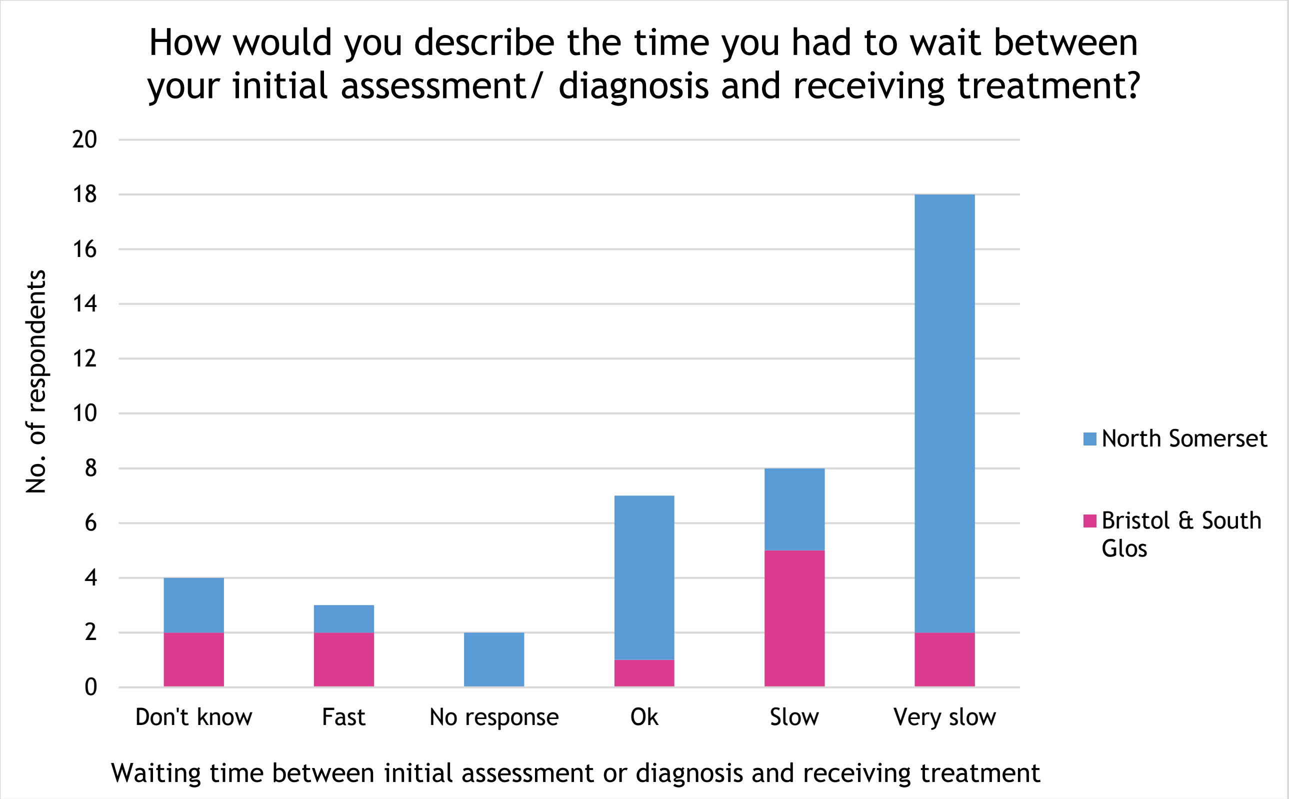
## Condition specific survey results relating to this stage of the care journey



| Response | North Somerset | Bristol and South Glos | TOTAL |
|---|---|---|---|
| Average | 5 | 1 | 6 |
| Don't know | 2 | | 2 |
| Negative | 4 | 6 | 10 |
| Positive | 4 | | 4 |
| Very negative | 12 | 4 | 16 |
| Very positive | 3 | 1 | 4 |
| **TOTAL** | **30** | **12** | **42** |



| Response | Bristol & South Glos | North Somerset | TOTAL |
|---|---|---|---|
| Don't know | | 2 | 2 |
| Fast | 1 | 2 | 3 |
| Ok | 2 | 4 | 6 |
| Slow | 4 | 4 | 8 |
| Very fast | 1 | 0 | 1 |
| Very slow | 4 | 16 | 20 |
| No response | 0 | 2 | 2 |
| **TOTAL** | **12** | **30** | **42** |



| Response | Bristol & South Glos | North Somerset | TOTAL |
|---|---|---|---|
| Don't know | 2 | 2 | 4 |
| Fast | 2 | 1 | 3 |
| No response | 0 | 2 | 2 |
| Ok | 1 | 6 | 7 |
| Slow | 5 | 3 | 8 |
| Very slow | 2 | 16 | 18 |
| TOTAL | 12 | 30 | 42 |

# The provision of ongoing care and support

## Availability of information and good communication

Poor or non-existent communication causes misunderstandings, stress and meant individuals missed out on the care they are entitled to.

**Key messages:**

- **Effective signposting - knowing what support is available**. Respondents felt they had no easy way to find out what support was available for them in their area and for their specific needs. This meant people were left in a 'pot luck' situation often only hearing about services or support by chance. It was felt that signposting was poor, with too much reliance that people could 'look on the web'.
- **Being kept informed during processes and being able to understand the information provided or imparted.** There was a strong feeling that individuals, patients and carers were often 'left to hang' with no regular updates or contact while waiting for assessments or results. Information was not always provided in a format or using language that people with learning disabilities or autism could understand, this was both for verbal and written communication.

| Bristol and South Gloucestershire | |
|---|---|
| "One of the things that doesn't work - one of the only reasons I come to meetings like this is to find out about things I don't know [about]." | Focus Group |
| "Very little communication when I was on the waiting list for assessment, no signposting to any services afterwards." | Survey |
| **North Somerset** | |
| "[in North Somerset] when it comes to signposting doctors are asking parents for advice. They don't know where to send people." | Focus Group |
| "Many people are not told that there is a Carers card in Bristol and other places, that gives discount…there is no such thing in NS." | Survey |
| "[I was] told to look on the internet for support groups by GP, not helpful for finding Mental health services." | Survey |
| "Being signposted would improve things. I was given an ADHD survey to fill in but not told why it helped." | Survey |

## Benefits and assessment cycles and access to services

Changes to benefits are impacting on individuals and carers abilities to access services. Increased stress and difficulties accessing the system is exacerbated by the increase in one-off and cyclical assessments, and the short periods support is available for.

**Key messages:**

- **The introduction of the Personal Independence Payment (PIP) has had a significant impact on individuals and carers.** This has been both through the loss of income and the pressures of the assessment.
- **Personal Budgets are a good development.** They are successful for those who had them but not the solution for everyone. It was felt more support should be available to help people access and manage them successfully.
- **Constant re-assessment and provision of support for short periods are detrimental.** People felt much of the re-assessment cycle was irrelevant as lifelong chronic conditions related to learning disabilities and autism were unlikely to change. Support and therapy services were only provided for a short period and then had to be reapplied for. There was a strong feeling this was not an appropriate care model for people with long term conditions and that the burden on individuals and carers meant people were not continuing to access the care they needed.
- **Length of waiting lists and time to get assessed is too long.** Individuals in crisis or urgent need can't get the appropriate support in a timely way. Long waiting times and repeated short intervention cycling back to waiting on a list again means people are dropping out of the system and not receiving the care they need.

| Bristol and South Gloucestershire | |
|---|---|
| "For someone who has continuing needs and you've been through that, and those have been identified, you have to prove all of those needs again. You get six weeks of physiotherapy then you are back on the waiting list again. You get six weeks of anything and your back on the waiting list." | Focus Group |
| "Things that are lifelong disabilities should be looked at differently – they should be given a lifelong award." | Focus Group |
| "One of the biggest changes are direct payments. They have meant I have been able to take control and provide the services, and it has literally saved my sons life and means he is getting a better life. Although it is a big thing to take on." | Focus Group |
| "Many services are short term and stop after six to eight weeks, but if you have a chronic need for services ongoing it is extremely difficult to get without fighting all the time." | Survey |

| North Somerset | |
|---|---|
| "We need support as and when we need it' rather than not at all or all the time." | Focus Group |
| "If you are let go by a professional and signed off and there is no way back into the service without being on a waiting list again, this is frightening. There should be somewhere to go back to, at times when you need extra support, without putting your name on a waiting list again." | Focus Group |
| "The assessment that came was just an inaccurate letter, which says he can walk to shops, go to the toilet and eat on his own – all untrue. No one came to see him." | Focus Group |
| "[Personal budgets are] working quite well because we have more control of the carers for my son, and offer him more consistency." | Survey |
| "CAMHS provided my child with six sessions for thirty minutes over six weeks - that's it." | Survey |
| "I get a personal budget which pays for support from North Somerset People First. I can ring them and have support, learn life skills and coping mechanisms." | Survey |

## Continuity of care and level of staff training

Workforce issues including lack of available staff, poor information sharing, handover and silo working by services make accessing and using care services difficult and at times led to failures in care provision. Appropriately trained staff were not always available.

**Key messages:**

- **Lack of availability of staff and consistency in who an individual is seen or treated by.** This leads to inconsistent or poor care outcomes and individuals and carers having to repeat information. For some individuals with learning disabilities or autism, constant changes in staff affected their ability to cope with consultations or assessments, meaning care could not be delivered successfully. The use of LOCUMS was a strong theme in the North Somerset group.
- **Services are not joined up. Handover and succession process between staff and services do not work.** Feedback highlighted that most people with learning disabilities or autism need to see a range of services. The services lack of joint working meant that individuals or carers had to take on coordinating care, and it was felt there was an increased risk of people 'falling through the gaps'.
- **Staff need to be appropriately trained.** Particularly if undertaking a role in a specialist service. Levels of awareness and understanding of learning difficulties and autism need to be raised across the care services workforce as a whole.

| Bristol and South Gloucestershire | |
|---|---|
| “Autism [is] not included in medical training as standard. The only professionals who get any decent time training are Learning Disability nurses, and they are very thin on the ground.” | Focus Group |
| “Doctors and nurses need to lead the push for them to be trained in it…Not just a ‘lecture’ but by and through meeting people with lived experience.” | Focus Group |
| “Before I moved areas, I arranged a meeting for the lead commissioner for mental health and the lead for social work for my town and they had never met before! And I think that is appalling.” (Adult with high functioning autism) | Focus Group |
| **North Somerset** | |
| “In North Somerset…there are frequently Locum psychiatrist.' / ‘We never see the same consultant.’ / ‘We have dealt with so many LOCUM’s, and sometimes we must explain what autism is.” | Survey |
| “Teaching Assistants are used at CAMHS as if they are therapeutic workers, but they have had no appropriate training.” | Survey |
| “There are so few NHS people to help that many parents must use private OT and speech and language therapists.” | Survey |
| “[The support] was very basic, and I felt I knew more than the person who was supposed to be informing me.” | Survey |

## Education services

Difficulties in getting adequate support were common with a lack of support highlighted in mainstream education. Two people mentioned children being unlawfully excluded due to their autism. Positive experiences were reported of specialist providers.

**Key messages:**

- Adequate support is not available for children with learning disabilities and autism in mainstream education.
- There is a lack of staff training and specialists which compounds the difficulties faced by individuals and parents.
- Parents feel that schools don’t support or back them and even victimise them.

| Bristol and South Gloucestershire | |
|---|---|
| “Support from [the] school system was appalling.” | Focus Group |

| North Somerset | |
|---|---|
| "Vulnerable Learners Service is no longer there in North Somerset - all the staff have left." | Focus Group |
| "We have been told 'if you don't send your child to school (who has autism and anxiety) we will report you to the council social services, and they will be taken away'. But the help at school is very poor quality for our child and she doesn't like her 1 to 1 as she was told to 'shut your mouth'." | Focus Group |
| "Problem with training at Academies – no training and no consistency and the Local Authority has no power to intervene. Academy teachers don't have to be autism trained." | Focus Group |
| "Schools use safeguarding to disapply people from some events. Legally the school can say due to safeguarding they cannot take them on trips and allow them to see events at schools – sometimes these are the very things that these types of children love to do and should do as it is getting them outside." | Focus Group |
| "Fortunately three years ago we contacted Weston Bay [part of Weston College], and our child has accessed the Aspirations Course there which has been excellent. They are now travelling independently, undertaking a voluntary role and working on employability strategies." | Survey |

## Impact of funding cuts and funding silos

Feedback gathered highlighted the impact funding cuts had on both the capability of services to deliver and on the services available. The issue of funding silos was also highlighted, most often presenting in 'not our area [of work]' or 'were not funded to do that' responses to individuals from services.

- A compelling personal story evidencing the impact of funding cuts was shared at the BSG focus group:

  *"When my (adult) daughter was living in South Gloucestershire, and the government cut funding to services, she was then left on her own most of the day. She was sexually assaulted by multiple men, she was so vulnerable. Over two months she had men picking her up off the street and lost £15,000 out of her bank account. Care providers weren't on top of that even though they were meant to be looking after her money. It is probably the worst thing that has ever happened to her and to me. When they took that funding away, it meant [the services] didn't work. It has taken a lot for me to let her go again [to live independently], even just down the road, and she is getting a lot more support than she did, but it didn't work when they took that money away and left her vulnerable and alone. She just wanted people to like her and men took advantage."*

## Importance of person-centred/whole person care and partnership working

**Key messages:**

- **The range of conditions considered as learning disabilities and the breadth of the autism spectrum.** This means only a person centre/whole person care approaches can work.
- **Partnership working is essential.** The individual, carer/parent and professionals need to work as equal partners in the development and delivery of care.

| **Bristol and South Gloucestershire** | |
|---|---|
| "I have a very good relationship with my sons, GP. We work in partnership alongside the people who care for him on a day to day basis. But to get that working I did some preparation, going to the practice manager and GP and saying 'this is what will work' 'will be the best way' to get something good out of an interaction or consultation." | Focus Group |
| "I moved into South Gloucestershire from Gloucestershire. Hugely different in terms of what they offer. A year before I moved, I engaged with the BASS service and they helped me through finding the perfect GP. So we looked at all the options around me. Those who were willing to accept patients and we wrote to each of the practice managers and found the right one for me. In that regard that has worked incredibly well for me and I've got a GP who is fantastic now." (Adult with high functioning autism) | Focus Group |
| "The one size fits all model doesn't work. You can't fit people into boxes, you need to work with people to create a package of care that suits them. In a way that is beyond reasonable adjustment." (Adult with high functioning autism) | Focus Group |
| "There is an assumption learning difficulties means the 'mild' end but isn't the case. The spectrum is so massive. Almost unhelpful to have that catch-all term. The answer is person centre planning and approaches and thinking." | Focus Group |
| **North Somerset** | |
| "It is not person-centred. I have to fit in with other people, my needs don't get covered." | Survey |
| "The type of support depends on the person, and you can't pigeonhole people" | Survey |

## Involvement of individuals, parents and carers in decision making

### Balancing the rights of parents/carers with those of the individual

**Key messages:**

- **Individuals, parents and carers are the people with the specific and the historical knowledge and information needed to make care decisions.** It is vital they are included and listened to as part of any decision making process.
- **There needs to be a balance between the rights of an individual and those caring for them.** Individual (adult patient) rights needed to be respected but the complexity and needs of people with learning difficulties and autism mean an inflexible approach leads to parents and careers not being consulted or included in decision making and in some cases the care needs of the individual are compromised.
- **The needs and individuals capacity to make decisions varies and fluctuates.** The ability of an individual to engage, understand and make decisions about some aspects of their care while not being capable in others was not being taken into account. This was leaving some individuals vulnerable or with compromised care.

| Bristol and South Gloucestershire | |
|---|---|
| "Carers aren't listened to… I've got 35 years of experience with my daughter, and I know when things are wrong, and they are telling me they are not." | Focus Group |
| "Whenever I go through the exploratory [process with my social worker] of a service who might be able to help the impression I get, is that me as the patient or as careers we know ourselves better than any professional would, and that really isn't focused on enough." (Adult with high functioning autism) | Focus Group |
| "Your GP may have something, hospitals all around the country may have bits, but they don't have everything. Were the only ones who hold everything and they don't listen." | Focus Group |
| "There are times when even high functioning people need support. The system doesn't always have enough play in it so that a career can be kept in the loop." (Adult with high functioning autism) | Focus Group |
| "My son decided he didn't want to go for or needed PIP, and so now we can't access any money but are still caring for him fully." | Focus Group |

## The transition from child to adult services

There is a significant drop in the availability of services and support when moving from child to adult services. The impact of the change in the legal status and rights of an individual from child to adult was also highlighted.

**Key messages:**

- **Services provided for children are not available to adults.** Comparable services were either non-existent or greatly reduced. Where services were available, there wasn't always comparable specialist staff to be transferred to.
- **Loss of continuity of care – having to start again**. Poor transition processes mean information and records are not being passed over where they could be. Individuals with learning disabilities and autism struggle when having to engage with new people or services – minimising this should be a priority.
- **Change in legal status and rights**. Once 18, the change to an individual's legal right to manage their care can cause difficulties. This was particularly around services no longer being able to automatically speak directly to parent carers or consult them.
- **Flexibility to transition services when most appropriate**. A high functioning autistic adult attending the BSG focus group highlighted the benefits of a flexible transition point.

*"My transition took place in Gloucestershire. I turned 18 in January and was due to go to University in September, and the child services did there kept me on their books until I went to University. Having that flexibility to stay with the child services to complete what is actually the transition – you transit with the school cycle, or when you start a job - worked incredibly well and the University was then able to pick up the majority of my care needs. It meant I had a smooth transition into adult services."*

| Bristol and South Gloucestershire | |
|---|---|
| "It's like they think you're cured at 18." | Focus Group |
| "[Transition from] Bristol's children's hospital often there is no one comparable in adult, so you don't have anyone to be transferred on to. There is no continuity. You literally get transferred to an adult with a [single] piece of paper [to hand over] if you even get that." | Focus Group |
| "At 18, my son was dropped from any paediatrician [services]… he wasn't transitioned into adult services, and he was basically sent back to his GP — the GPs not known him as he has always been under consultants. I now have the problem where the GP will not talk to me, because he is an adult…you don't have any say in their care. As an autistic youngster, they don't know what they want or what they need - it is down to the career or whoever is with that person and you're not given that [input]. You don't get adult mental health services… a doctor… physiotherapists, it just goes." | Focus Group |
| **North Somerset** | |
| "We have been given very little help for Autism. Mental Health has been disastrous. [Our son] was under CAMHS…in fact, until they wanted to discharge him due to his age [he] hadn't seen someone for over a year! He was then moved to adult services, but due to delay couldn't be transferred, he needed to be a new patient!" | Survey |

## Travel and geographic location of services

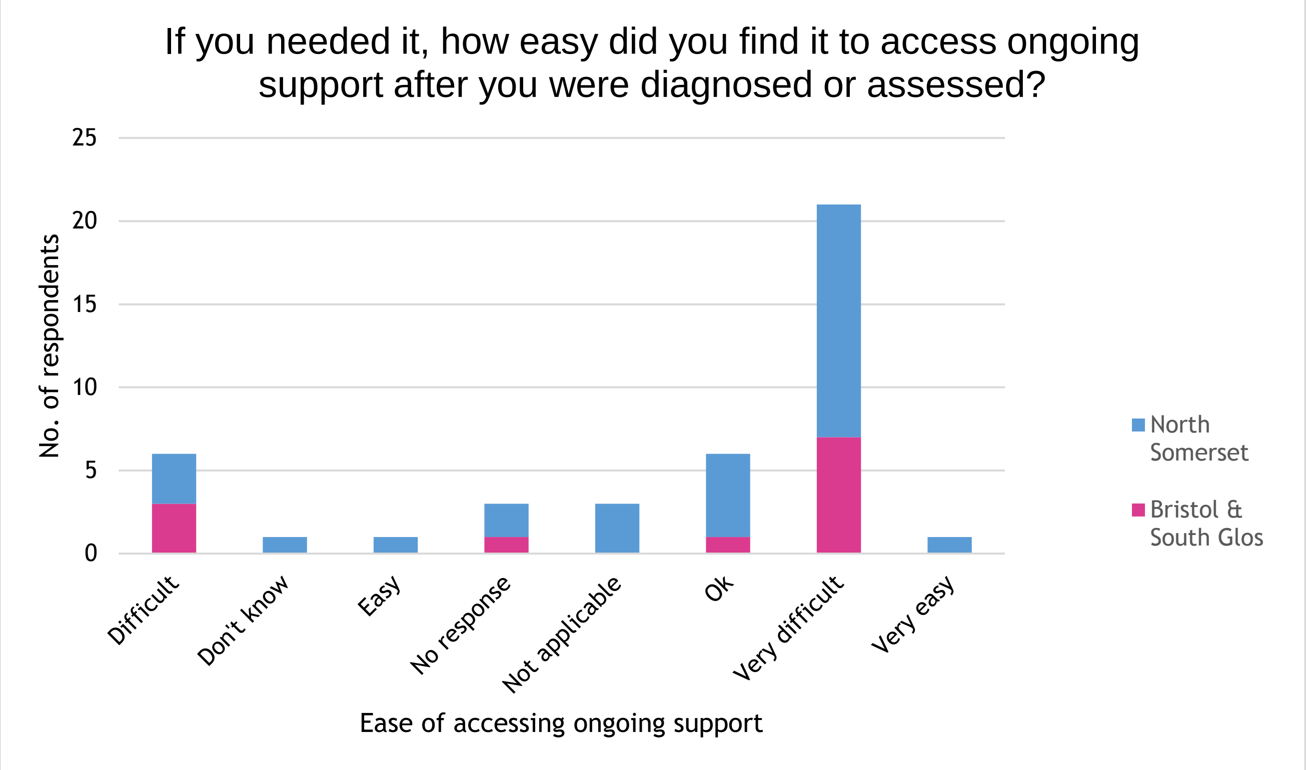
Both of these are significant issues and barriers to individuals accessing care and support.

**Key messages:**

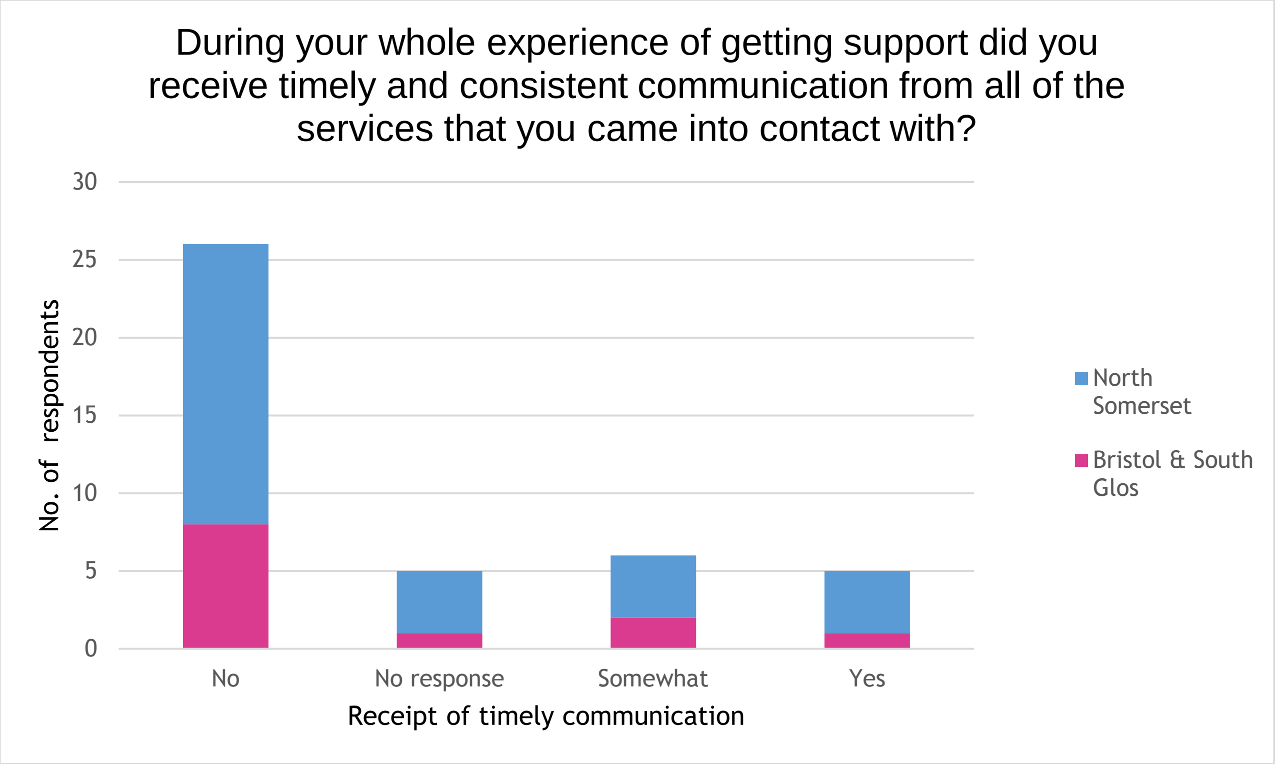
- **Cost of travel, including parking and specialist transport**. Financial support and availability had reduced, and individuals and carers were having to pick up the cost. The alternative was not being able to access that service.
- **The distance you have to travel to a service should be reasonable and as short as possible.** The lack of specialised services meant peoples care is often spread over a large geographical area if they are to gain access to the best or the most appropriate services for their needs.

| **Bristol and South Gloucestershire** | |
|---|---|
| "The only thing that made it feasible for me to access certain services was that I was already aware of the help with travel costs scheme that is run by the NHS. It is a scheme that is really not advertised and is available to anyone claiming means-tested benefits." (Adult with high functioning autism) | Focus Group |
| "In some instances, you have no choice. My daughter has profound epilepsy, she is currently living in Torbay as it is the only place that can meet her needs, but she has to come back to Southmead for certain things." | Focus Group |
| **North Somerset** | |
| "Ravenswood School fully prepared my child to go to college, but two days before he started the local authority said they could not provide transport to Weston College. [He] ended up not continuing his education." | Focus Group |
| "Difficult to get hold of specialists as there isn't enough staff. I live in Weston-Super-Mare and services are in Bristol. GPs aren't specialists so can't help." | Survey |
| "I have ADHD, and there are no services in Weston super Mare. Every six months I have a 30min appointment in Clevedon, which isn't enough." | Survey |

## Condition-specific survey results relating to this stage of the care journey

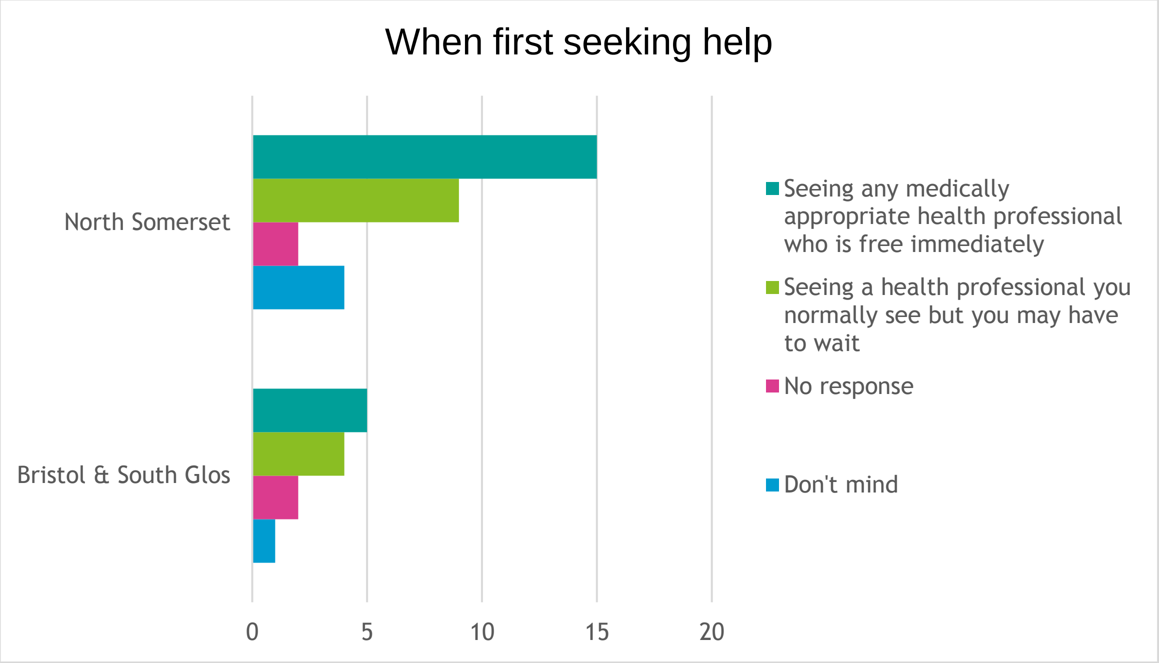


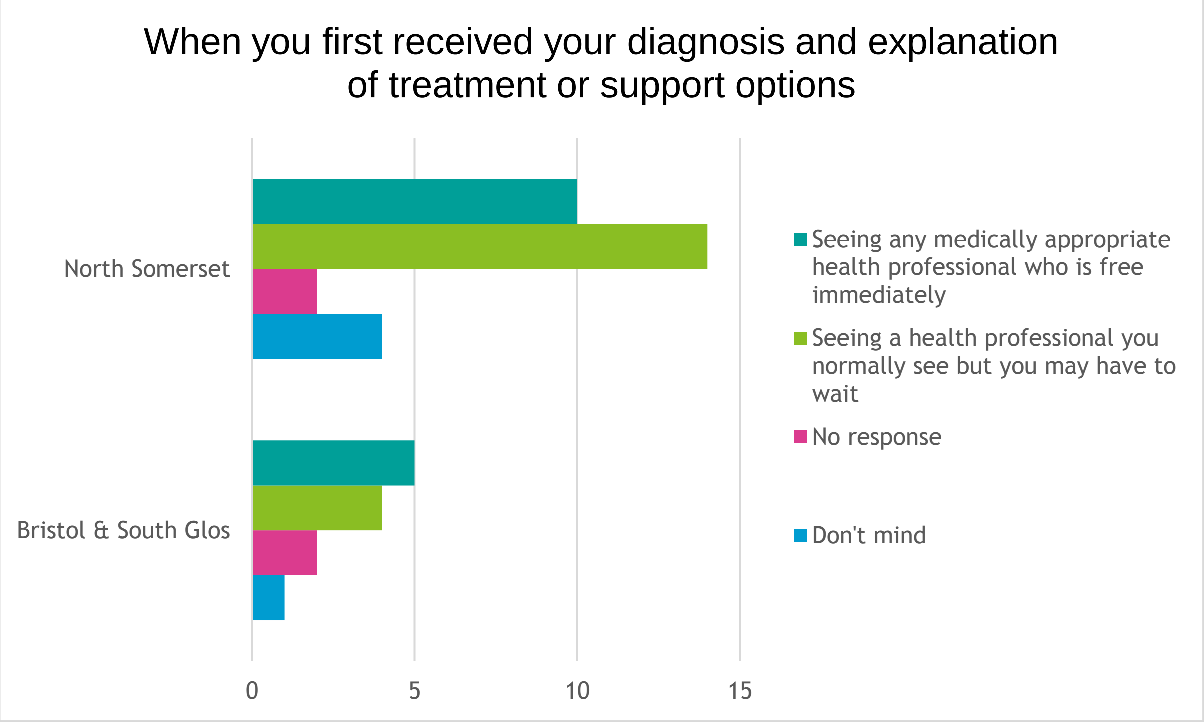
| Response | Bristol & South Glos | North Somerset | TOTAL |
|---|---|---|---|
| Difficult | 3 | 3 | 6 |
| Don't know | 0 | 1 | 1 |
| Easy | 0 | 1 | 1 |
| No response | 1 | 2 | 3 |
| Not applicable | 0 | 3 | 3 |
| Ok | 1 | 5 | 6 |
| Very difficult | 7 | 14 | 21 |
| Very easy | 0 | 1 | 1 |
| TOTAL | 12 | 30 | 42 |

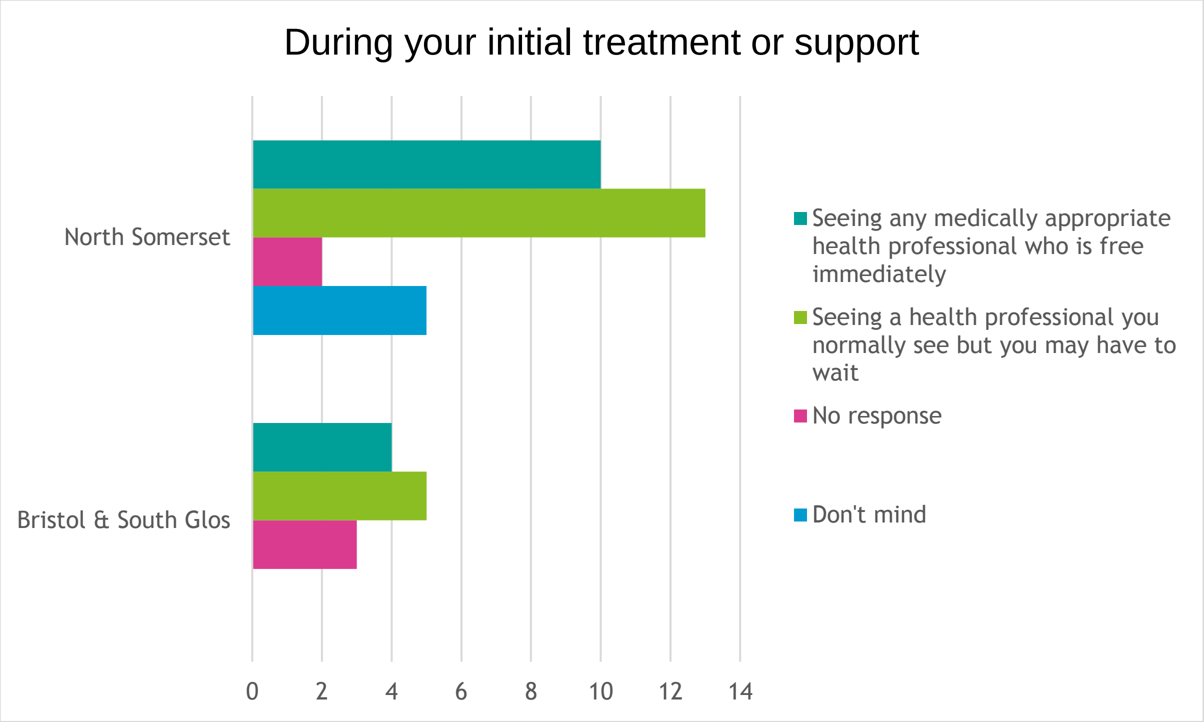


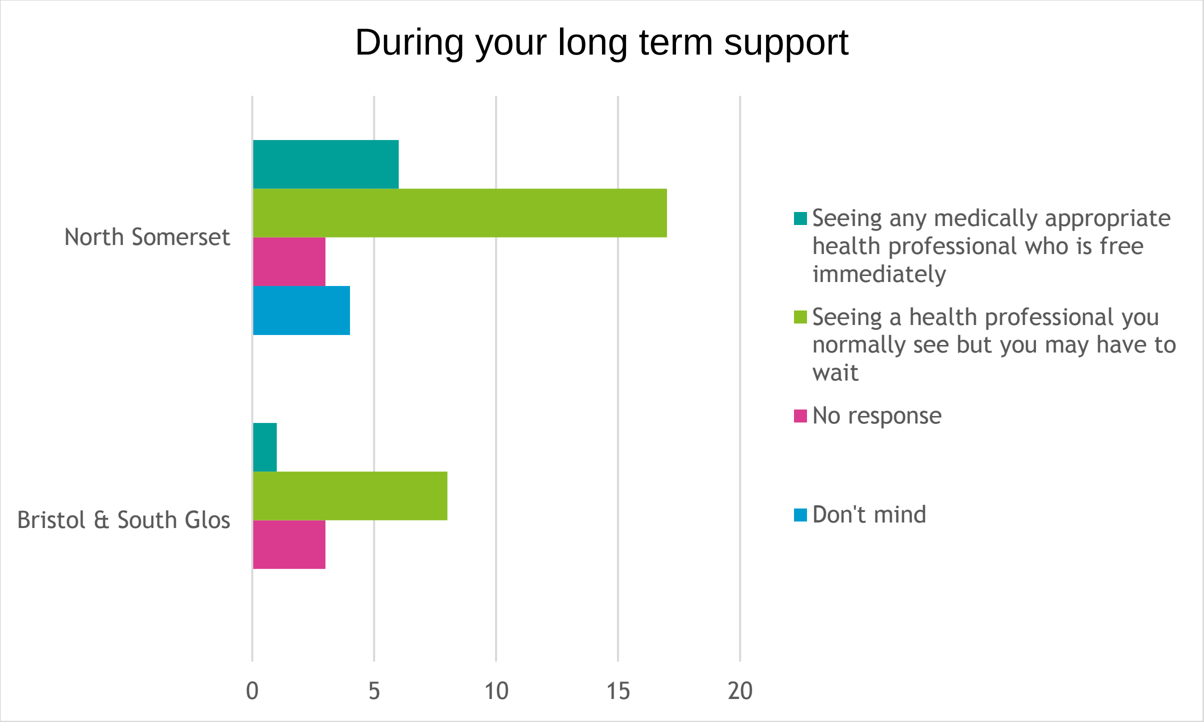
| Response | Bristol & South Glos | North Somerset | TOTAL |
|---|---|---|---|
| No | 8 | 18 | 26 |
| No response | 1 | 4 | 5 |
| Somewhat | 2 | 4 | 6 |
| Yes | 1 | 4 | 5 |
| TOTAL | 12 | 30 | 42 |

## What is most important to you?






During your initial treatment or support
North Somerset
Bristol & South Glos
0
2
4
6
8
10
12
14
Seeing any medically appropriate health professional who is free immediately
Seeing a health professional you normally see but you may have to wait
No response
Don't mind


During your long term support
North Somerset
Bristol & South Glos
0
5
10
15
20
Seeing any medically appropriate health professional who is free immediately
Seeing a health professional you normally see but you may have to wait
No response
Don't mind

## Prevention and/or early intervention

For learning disabilities and autism prevention and/or early intervention was not an area focus group participants or the long term condition survey chose to focus on.

**Key messages:**

- **Agreed policy and guidelines need to be adhered to**. Feedback was that if existing policies, guidelines and best practice were implemented and adhered to many of the issues would be addressed and problems prevented.
- **Knowing where to go and who to speak to.** People don't know who to ask or where to go for support so early signs, or intervention opportunities are missed or not acted upon.
- **Listening to parent carers and take action.** If services and staff don't listen to the people most likely to notice early signs or changes in behaviour, then there is no chance for early intervention or prevention.

| **Bristol and South Gloucestershire** | |
|---|---|
| "We shouldn't have to keep reinventing the wheel. There is a policy sitting somewhere on a shelf that is not being implemented. So we've got safeguarding that is not being implemented, actually listening to careers, partnership working - that's not working. Why do we have to keep saying this when actually we've done all the leg work, the policies are there so what can we do to make sure people are following their own policies." | |
| "Everything around autism is law, for learning difficulties is just guidance so we can't force the issue in the way we can with autism." | |

No questions in the condition specific surveys related to this part of the care journey.

# Engaging people in health service delivery

## What people expect during their treatment journey

- Feedback should be asked for on a regular basis and as a minimum at the end of a piece of support / discharge from a service. Respondents highlighted that this didn't happen regularly.
- It should be easier to feedback and let services know when something hasn't worked without having to go via a complaints process.

*"Perfect opportunity for feedback is when I am discharged from a service, for example a cycle of IAPT, there is always some learning that could be taken from it. There is no proper opportunity. You just go back to your GP."* BSG focus group attendee.

## What people expect during service change and transformation

- Service users and carers need to be involved from the beginning - before the "first draft" so that their involvement can be meaningful.
- Asking for retrospective feedback when key decision have already been made is "a waste of time".
- Co-design was seen as the gold standard with change starting from what users need rather than what the service thinks they need.
- Any change or transformation of a service needs to be seen in the wider context of who and how it will be accessed and used - "you can create a great service and then put it in the wrong location and people won't use it".
- Engagement should happen at all levels, nationally, regionally right down to services within services. It should involve, and go back to "people right at the top".
- Reasonable adjustments shouldn't come after - they shouldn't be needed as they should have been built in from the start through co-design.
- Getting the right people involved is key to successful change and transformation and then retaining them.
- Services need to use the feedback, reports and insight already provided. Checking back on what has come before. It was felt that the same questions and ideas are put forward in cycles with many of the solutions already having been identified by previous engagement and consultation.

*"They should look in their filing cabinet - so much information and feedback seems to have disappeared."* BSG focus group attendee.

*"We* [the service users feed into] *report upon report and they just sit there and no one acts on them. Or there is so much change that you do a report then that person goes to do something different. So that report doesn't get acted on. Then a new person comes in and doesn't know the report was done before so does another report and we get asked the same things again... We say it is like we are on a bicycle wheel - we go round and round with people constantly asking us the same questions."* BSG focus group attendee.

# Next steps

Healthier Together
Improving health and care in Bristol, North Somerset and South Gloucestershire

The Healthier Together partnership welcomes the feedback collated by Healthwatch, which is both thorough and timely. The work of Healthwatch will complement our public engagement around the Five Year System Plan and will be carefully considered to help inform priorities.

Our partnership wants to work with the public and staff to develop a Five Year System Plan. This plan will build on all the existing good work already underway and will help us to make sure we are creating an ambitious but realistic local plan that takes account of national priorities (as set out in the NHS Long Term Plan), but more importantly, our local communities.

Healthier Together has been engaging with the public, those with lived experience and other key stakeholder groups on a number of topics, in particular mental health and providing more care closer to home (integrated community localities) in recent months. These are ongoing conversations that will continue through from design to implementation and beyond.

Feedback from these conversations is all relevant to our work to develop a Five Year System Plan. In addition, we are taking insights from our Healthier Together Panel – a representative sample of 1,000 people from across the BNSSG area who are invited to take part in surveys. We are also seeking feedback from staff who work across the 13 health and care organisations that make up the Healthier Together partnership.

We will take stock of all this initial feedback to help inform a second phase of more detailed engagement. This will include a public survey, further conversations with staff and in-depth conversations with the public and key stakeholder groups on particular topics.

The development of our Five Year System Plan is an opportunity for everyone to focus on the health and care needs and outcomes in a way we haven’t done so before. We want our plan to be truly transformational and ambitious and we can only achieve this if we work as a whole system, including our citizens.

Many of the general findings such as; easier access, need for more joined up services, being involved in decisions, independence, and making greater use of technology – are recurring themes that we recognise from our ongoing conversations with patient groups and the public. These areas identified are things that we hope to build on and improve through our work to become a more integrated health and care system. In particular we are looking to seek further insights regarding shared decision making and use of technology through our Healthier Together Panel.

We are pleased to see the generally positive feedback in relation to Bristol, North Somerset and South Gloucestershire (BNSSG) cancer services regarding assessment, diagnosis and treatment. However, we recognise that there is always more that can be done to improve people’s experience of cancer services and support.

In BNSSG we are part of the Somerset, Wiltshire, Avon and Gloucestershire (SWAG) Cancer Alliance. The Alliance is responsible for working with providers, commissioners and other partners to help deliver patient focused improvements in outcomes of experiences. We also work closely with Public Health England (PHE) in relation to preventative measures.

We were disappointed to hear that some respondents experienced a poor experience of signposting to support services. This is something that BNSSG is trying to improve through national funding and the establishment of a 'Living Well With and Beyond Cancer' programme which is now in place as of 2018/19.

The programme has been developed in collaboration with a wide range of stakeholders and aims to provide a holistic approach to supporting patients and their families who are impacted by cancer. A SWAG Cancer Alliance evaluation of this new programme is planned to help us understand if it is providing improved support to people with cancer and their families.

In addition, feedback regarding 'treating the whole person – not just the cancer' is also something that we hope will improve through the Living Well With and Beyond Cancer programme.

We understand that diagnosis and awaiting test results is a particularly anxious and distressing time for people. In line with feedback received, we recognise that improvements could be made to the speed in which test results are received. This is also a national issue and as such from April 2020 there will be a new national standard focused on being seen and receiving diagnosis within 28 days. This is something that we will be striving to achieve across BNSSG.

Feedback regarding the need for genetic testing to be more readily available is useful. Early meetings and discussion regarding this are underway and it is likely that we will want more detailed conversations with stakeholder groups as this work develops.

We will ensure the findings from this report are shared and discussed with the SWAG Cancer Alliance and relevant PHE colleagues. It will also be carefully considered through working groups supporting the development of the five year system plan.

The insights in relation to learning difficulties and autism reflect much of the anecdotal feedback we are aware of and historic issues that have surrounded these services for a number of years. There are some particularly upsetting experiences contained within the report which help to reinforce the importance that must be placed on ensuring health and care services work even more closely together to support those with learning difficulties/ autism and their carers.

Waiting times are an issue of concern but recent developments in the Bristol Adult Autism Spectrum Services (BASS) have seen a reduction in adult waiting times from 11 months to four months – but we recognise there is still more to do. The Clinical Commissioning Group has also secured funding from NHS England to commission delivery of online assessments for children and young people. For example, Skype could be used for appointments in some circumstances. We envisage this will in part help drive a reduction in waiting times, particularly within North Somerset and South Gloucestershire.

Working with NHS England we are also looking into a funding proposal to evaluate the BASS post-diagnostic service to understand the impact of different interventions on unmet need post diagnosis. This will give further insight on care and support needs across the range of commissioned services by both the CCG and the respective local authorities. This will help to inform a range of service development/ improvement options that optimises the use of stretched resources in order to deliver improved outcomes for people with autism.

We are also committed to putting detail to many of the ambitions in the NHS Long Term Plan around learning disabilities and autism and will be working with our partners across the broader health and social care environment to apply 'reasonable adjustments' within mainstream services; increase the uptake of Annual Health Checks; ensure staff have the necessary skills and competencies to work alongside people with a learning disability and/or autism and their carers; and deliver improvements across both mainstream and specialist services that promotes wellbeing, integrates care and support and reduces the many inequalities experienced by people with a learning disability and/or autism.

In addition to the priorities noted in the NHS Long Term Plan there are other priorities defined by local requirements and we are committed to working with our partners in the wider system to deliver improved outcomes for people with a learning disability and/or autism. Some of the priorities will be CCG led but in other areas we will support initiatives across the commissioning environment and our local authority partners to ensure services are able to meet the needs of individuals, their families and their carers.

We recognise frustrations around the importance of joined up services, particularly to ensure there is continuity of care for people with learning difficulties/ autism and their carers. Through the Healthier Together partnership we are strengthening our relationships with the three local councils to bridge the gap that is sometimes apparent between health and social care services to try and make sure we are much more closely aligned.

We will ensure the findings that particularly relate to learning difficulties and autism are shared and discussed with our social care colleagues from the local authorities. It will also be carefully considered through working groups supporting the development of the Five Year System Plan.

Our broad timeline for developing our Five Year System Plan is as follows:

- Phase one – initial engagement: March – June 2019
- Phase two – topic specific engagement: July – September 2019
- Development of plan (in parallel and taking account of engagement activities): June – September 2019
- Sign off of plan: September – October 2019
- Publication of plan: November 2019

We would like to thank everyone that has taken the time to feedback on local health and care services, and to Healthwatch teams for seeking the views from local people and collating this into a report. The feedback received provides some rich insight, but we appreciate that this is a snapshot and that further work will be required on our part to bring together other necessary strands of intelligence.

Work to develop our BNSSG Five Year System Plan is ongoing and we welcome further feedback and insights from local citizens and organisations to help inform our plans. Feedback can be provided by emailing bnssg.ltp.feedback@nhs.net or calling 0117 900 2583.

We greatly value public contributions to shaping the future of our health and care services and want to involve citizens as our Healthier Together programmes of work develop. This includes ensuring consistent methodologies for co-production are embedded across our transformation work.

The Healthier Together partnership is committed to ensuring successful delivery of our Five Year System Plan. However, this is something we can't do on our own – we will need individuals and families to take a more proactive role in their health and care as we know that this can result in an improved experience of services, provide more focus on what matters most to individuals and better outcomes.

We intend to publish the Five Year System Plan and an easy read summary to ensure that our local communities are able to clearly hold us to account on the plans that we commit to over the next five years.

# Methodology

***Engagement Method:*** Core activities (promotion of the surveys and delivery of the focus groups) was undertaken by each Local Healthwatch to gather relevant evidence to answer research questions and meet objectives.

- A test survey was carried out with Healthwatch volunteers.
- Survey responses were not be analysed at the same time as the demographic data. Findings/ conclusions have been reviewed by a third party (Healthwatch England research lead) to control for confirmation bias during analysis.
- Varied methods were used to collect feedback, including paper surveys and online sampling in order to attempt to reach a representative sample of the population. Gaps were pre-empted and addressed where possible (e.g. through working with specialist equalities providers and groups to reach those who are less likely to engage). We used translation/ interpretation services where required.

***Data Management:*** How evidence was collected, collated and kept secure.

- Most feedback was collected directly through a Survey Monkey link that was set up and hosted by The Care Forum (provider of Healthwatch Bristol and Healthwatch South Gloucestershire).
- Data was cleaned before use in order to remove blank survey forms, surveys that were clearly submitted multiple times in error etc.
- We introduced awareness of statistical significance when drawing conclusions (i.e. not making claims based on statistically insignificant data).
- We have not applied findings across geographical boundaries where there was no strong rationale for doing so, particularly through qualitative feedback.
- We have demonstrated an understanding of the differences between how we can use quantitative and qualitative feedback.

***Research participants:*** *ethical considerations*

- We gathered verbal consent at the beginning of each focus group. All surveys had a tick box to gain consent on the use of the information provided. Where respondents said no this data has been cleaned from the results.
- No one was forced to give feedback.
- Confidentiality and anonymity will be honoured.
- Participants were encouraged to complete the relevant survey.
- We did not interview anyone who was not able to give informed consent to share their views.
- We did not pay people to share their views, other than the payment of expenses.
- Any safeguarding or similar issues flagged will be promptly dealt with under out safeguarding policy.

***Consent:*** The purpose of the survey or focus group was explained to all participants before they took part and they had the option to opt out at this point. They were also informed that any responses that they gave would be used in a report that may be shared with Healthwatch England, NHS England, local decision makers and stakeholders.

***Who was engaged:*** Our engagement plan was to reach a broad range of people via face to face interviews, social media and via the Healthwatch website.

We carried out targeted engagement via focus groups aimed to reach people living with the locally agreed specific conditions of Cancer and Learning disabilities/ autism.

## Acknowledgements

*We would like to thank colleagues within local health and social care organisations across BNSSG for their help in promoting the project to local residents.*

*We would like to thank the voluntary, community and social enterprise sector across BNSSG for helping to share and promote this project to their clients and service users.*

*We would like to thank the residents who took the time to complete the surveys and attend focus groups for sharing their views, experiences and being so willing to talk to us.*