NHS LONG TERM PLAN REPORT:

Healthwatch Birmingham & Healthwatch Solihull

healthwatch
Birmingham

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Introduction

The NHS in England has published a ten-year plan setting its priorities for the future, with a focus on prevention and early detection. Local NHS organisations will be working with their local councils to develop and implement their own plans for the next five years. These strategies will set out how they intend to take the ambitions from the NHS Long Term Plan and turn them into actions to improve services and the health and wellbeing of their local communities, with a specific requirement to reduce health inequalities.

NHS England asked Healthwatch England (via local Healthwatch) to engage with the public on the content of the NHS Long Term Plan (LTP). This engagement will help the local Sustainability & Transformation Partnership (STP) in developing strategic plans based on patients, the public and local stakeholders' needs, and as a result, the level of care provision will improve for people and their families, through every stage of life. This report gives the findings from Healthwatch Birmingham and Healthwatch Solihull.

How did we hear people's views?

The research included two surveys and a series of focus groups.

Survey methods:

Both Healthwatch Birmingham and Healthwatch Solihull used a range of communication channels to advertise the survey and obtain responses.

Two questionnaires were designed by Healthwatch England (one general, one condition specific). These were available as online, paper and in easy read formats.

The general questionnaire asked four key questions: What is most important to you to help you live a healthy life? What's most important to you to be able to manage and choose the support you need? What is most important to you to help you keep your independence and stay healthy as you get older? What is most important to you when interacting with the NHS?

The specific questionnaire was based on questions about what local NHS could do to give people with long-term conditions better support. Long-term conditions included cancer, mental health conditions, heart and lung diseases, diabetes and arthritis, learning disabilities, autism and dementia.

Focus Group Methods:

The focus groups enabled us to hear the views of people who are seldom-heard. These groups helped us to develop a deeper understanding of what these people would like the NHS and Social Care to do to help support them to look after their own wellbeing.

This report includes the themes raised in seven focus groups. We heard the views of the LGBT community, people with sight loss, people with a learning disability, people who have experienced mental health problems, young people, carers and people with hearing loss. The topic guide covered four key questions: What does 'being well' mean to you? What do you do to stay well? What are the barriers to 'you helping yourself to stay well' and How would you prefer to access help, support or information?

What did people tell us?

This report draws on the views of 503 people who took part in the general survey (B=270; S=233): 123 in the conditions survey (B=76; S=47) and 68 in the focus groups (B= 54; S=14).

What works well

Many people valued the support, information and signposting they get from health and social care professionals, and want more access to these in order to support them to self-care. People also valued help from professionals for signposting to services. For example, people with sight loss told us about the invaluable help provided by the Eye Clinic Liaison Officer (ECLO). They also hugely valued the work of the third sector and community organisations.

In the conditions survey people told us that what went well when people accessed care and support included: getting support at home, having a statement of needs or care plan, training, financial support, support managing condition, guidance on health and well-being, regular checks/reviews, access to specialist care and quality staff, follow-on support, access to appointments and quick referrals, access to information and advice, and access to support services especially local community resources.

What could be better?

People told us that their ability to self-care would be improved by more control and choice over decisions, more health education, support to maintain mental health, more easily accessible information, timely access to information and services, more community groups, reduced societal stigma, and more support from the NHS and Social Care.

Control and choice over decisions

In the conditions survey, a majority of people said they wanted 'some support' from the NHS to help them stay healthy, with a smaller number stating they needed a lot of support. The level of shared decision-making varied between people. In the general survey, some people wanted self-care to be the joint responsibility of the patient and the health professional. Others told us that they would like professionals (who have more knowledge than the patient may have) to make decisions.

Control and choice over the services people in Birmingham access was also a key topic in Healthwatch Birmingham's recent report: Direct Payment in Birmingham: Choice, Control and Flexibility[1]. A hindrance to choice and flexibility for direct payment users was low awareness of direct payments, a lack of clear, consistent information and guidance about entitlement, delays in receiving assessments from social care, and difficulties in accessing a service of choice. The report found a need amongst the respondents for greater support and guidance in the process of accessing social care support. Birmingham City Council will be using the report to shape the future customer journey, and are developing plans for raising awareness and knowledge of Direct Payments among both Council staff and service users and carers.

More widely, people would like to be more involved in the design of the services they are using. This may be partly why our focus groups were well-attended and included lively discussions about how the LTP could help support people to self-care.

Mental and physical health education

Even if people want to self-care, they may not have the knowledge to do so. For example, they may need the training to use the internet, to appraise the trustworthiness of the health information they find, and resources to act on this information (both their own and public resources in Birmingham and Solihull).

Mental health

The NHS also needs to support people to maintain their mental health. We heard in the focus groups that good mental health is central to people's wellbeing. This understanding and interest in the importance of emotional health ran throughout all the focus groups, from young people to those in their 70s, including people with a wide range of conditions. Services and activities to self-care should be wider than those that explicitly target mental health. They need to bring people together; sharing knowledge, skills and support. The outcome, rather than the explicit purpose of this type of support, should be good mental and physical health. Such examples include knitting groups, physical activities and cooking classes.

These groups and services should also be accessible to all people who wish to access them. People want and need to be able to get out of their houses, to be able to afford to use public transport and to have a sense that they are part of a community. It is particularly important that people who would otherwise suffer isolation are able to access these resources. The importance of the NHS and social care providing appropriate support to people who want to self-care by improving their emotional wellbeing cannot be overstated.

A recent Healthwatch Birmingham report described the experiences of people with a mental health problem, autism, dementia or brain injury when they visited their General Practice[2]. Because of that report, Birmingham & Solihull CCG, together with Sandwell & West Birmingham CCG, are to co-produce Patient Rights Leaflets with patients. These leaflets will help patients to overcome some of the issues they face when getting the support they need.

More easily accessible patient information

People need trustworthy sources of health information that they can understand. This topic ran throughout the focus groups and surveys.

Many people told us that they felt the internet is vast and the information often not accessible for them to understand and act on. They also provided us with examples of inaccessible information from the NHS, e.g. blind people being given written material, and people with learning disabilities sent letters with clinical 'jargon' they do not understand. It was clear that the NHS needs to improve the accessibility of much of its information, and to consistently meet the Accessibility Information Standard.

Healthwatch Solihull has previously recommended that GPs should use communication methods appropriate to the individual patient e.g. use of visual aids and Makaton when speaking to patients with learning disabilities[3]. The report states that is a need for patients to be able to express their feelings to their doctor and equally for them to receive information back regarding their health. It is not clear how effectively this happens. There is the need to examine what further aids can be used to help the individual communicate with their GP e.g. anatomical diagrams and pictures to identify how the patient is feeling.

Timely access to information and services.

Access to information and services is raised throughout this report. Just under half (44%) ranked "access to help

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[1] https://healthwatchbirmingham.co.uk/wp-content/uploads/2019/05/HWB-DP-Report-F-Online-Version-F.pdf

[2] https://healthwatchbirmingham.co.uk/wp-content/uploads/2019/05/Healthwatch-Birmingham-GP-FINAL-REPORT-F-Online.pdf

[3] https://healthwatchsolihull.org.uk/download/access-to-screening-for-people-with-learning-disabilities/

and treatment I need when I want it" as "most important" in the general survey. This was a key topic highlighted by Healthwatch Birmingham's recent report: "What matters most: support people want from general practices in Birmingham"[4]. Delays in access to information and services affect people's ability to self-care and their health and wellbeing. In one group it was suggested that delays were often due to funding cuts for activities, which resulted in them happening less often and reduced the number of people who could attend.

Access to initial appointments

In the general survey, people said they wanted easier access to appointments through improved booking systems. In the conditions survey, people told us that their overall experience of getting help and support was mostly 'negative' or 'average'. They added that if they had more than one condition, it was even harder for them to access services the services they need. In the conditions survey, appointments and waiting times were one of the main issues raised by people with a mental health condition. They expressed concern with the time taken to get an appointment, especially for treatment such as therapy.

They also told us in the conditions survey that they had experienced long waiting times. The majority of people found their experience of waiting for an initial assessment to be 'slow' or 'very slow'. These issues might mean that those with the financial means are able to have private assessment and are able to progress their cases quicker than those not able.

Timeliness of diagnosis

A source of frustration for people participating in the conditions survey was the long wait between appointments in the process of getting a diagnosis. For example, waiting times for test results are still unreasonably lengthy. In the general survey, we heard that the NHS could speed these up through better use of technology.

Timeliness of and access to follow up and ongoing support or treatment

In the conditions survey, only 16% of people found the wait between the initial assessment and receiving treatment to be 'fast' or 'very fast'. Also, accessing ongoing support was often 'difficult' or 'very difficult', with only a little over half of the people indicating that they had been offered access to further health and care support. People told us that it is important that patients are able to access treatment before they reach a crisis point.

It seemed to some Birmingham people that therapeutic services are run in affluent areas (e.g. Moseley), and crisis services are delivered in more deprived areas. People told us there needs to be fairness and distribution of services across the city rather than just prevention for the "posh areas".

People also told us they also experienced a lack of contact with services. It was worrying for people when they had to wait for long, especially between appointments, without contact or information.

We also heard about the difficulty of travelling to appointments and activities, and parking when they got there. Parking was highlighted as one of the stressful areas for people who are chronically ill. The NHS needs to address the shortages of parking spaces and the cost of parking. These concerns with parking are an issue that has been highlighted by patients in Healthwatch Birmingham's recent report on people's experiences of hospital waiting rooms[5]. That report also highlighted the issues that people with hearing and/or sight impairment have when in hospital waiting rooms. The report made individual recommendations for each trust to improve their waiting rooms. In autumn 2019, Healthwatch Birmingham will track the progress of these improvements, requesting an update from the Trust, which evaluates the specific changes made to improve patient's experiences of waiting rooms.

More community groups

Community groups could be more utilised to provide self-care support, through peer support where appropriate. This would also help to reduce isolation. Participant's felt that there were insufficient numbers of community centres to help people to self-care. It was suggested that the STP should use some of the LTP funding to support community groups. This could be by funding community centres to reopen, helping community organisation staff to upskill, or simply providing rooms for peers to meet and support each other. They suggested that City Councillors, as central figures in the community, could be more involved with making sure that their area has community centres. Another suggestion was that the Councils should tell property owners that their empty business premises need to be given over to community organisations, or they would have to pay full business rates.

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4. https://healthwatchbirmingham.co.uk/wp-content/uploads/2019/05/Healthwatch-Birmingham-GP-FINAL-REPORT-F-Online.pdf
5. https://healthwatchbirmingham.co.uk/wp-content/uploads/2019/05/HW-Birmingham-Hospital-Waiting-Room-Summary-Report-2019-F1.pdf

It is important that the STP values the role of peer support to help people to self-care. People told us it enables them to socialise with people that have the same problems; and, as mentioned above, socialising with others is important for people's wellbeing. Peer support also provides them with the information they need to self-care from trusted sources that they can relate to.

More public understanding of disabilities and conditions

Stigma affects people's ability to self-care because it reduces mental health, leading to a downhill spiral. Therefore, it is important that Health and Social Care try to break down barriers between people with disabilities and those currently living without a disability. This would necessitate the NHS educating the wider public about disabilities and encouraging more understanding.

More support from the NHS and Social Care

People told us that the NHS and Social Care system needs to be set up to fully support people to self-care. System change is needed, with an underlying change in the culture about the NHS's role in supporting people to self-care. People felt that professionals need to see it as the NHS's role to ensure that patients self-care, to check up on them and provide them with support. This support might be direct practical support or through coaching.

To support patients, professionals need to properly listen to the concerns that patients voice, and have the time and the training to see the whole person not just the condition. This need for improved patient-centred care was recently reported by Healthwatch Birmingham[6]. The forthcoming patient rights leaflet, being jointly developed together by Birmingham and Solihull CCG and Sandwell and West Birmingham CCG, as a result of that report may help patients to ask for the support they need to maintain their health.

The development of more joined-up services was thought important in both the general survey and in the focus groups. Carers felt that the lack of joined-up services acted as a barrier to them self-caring, and wanted consistency across services with similar types of services offering the same care and support. This would enable Health and Social Care to be more effective, and for patients and carers to better maintain and improve their wellbeing.

Better use of technology by the NHS could help people to self-care, but only where appropriate. Some people, for example, older people and those with learning disabilities, may find it difficult to use technology to access this information. Others prefer face to face contact and were worried that technology will decrease this. Unsurprisingly, given the older population of Solihull, they were keener than Birmingham residents to be able to access services using their phone, whereas the younger Birmingham residents thought it more important than the Solihull residents to be able to make appointments online. The STP may need further feedback to understand how different communities and demographics might be helped or hindered through the use of healthcare technology.

Executive Summary Conclusion

Healthwatch Birmingham and Healthwatch Solihull are grateful to all the people that took part in the surveys and focus groups. Their feedback has made it clear that, in order for the LTP and STP's ambitions to be met for patients to self-care more, there needs to be a culture change.

Although many professionals do encourage self-care and try to empower their patients, it seems from people's feedback that many professions do not. These professionals need to learn to listen to patient's issues, empower them, and provide them with the information, treatment and equipment they feel they need to self-care.

To be able to do this, all professionals need up-to-date knowledge and training. Focus group participants told us that most patients now have access to the internet, and therefore to information about the most recent developments in healthcare. If health professionals are to be able to answer patients' questions so they can self-care, the NHS needs to find a way of ensuring that their knowledge is as up-to-date as their patients'.

Throughout the surveys and focus groups, people also told us they wanted better signposting to other services.

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[6] https://healthwatchbirmingham.co.uk/wp-content/uploads/2019/05/Healthwatch-Birmingham-GP-FINAL-REPORT-F-Online.pdf

Where services are available often people do not know about them. If they do know about them, they often cannot access them (e.g. due to waiting lists, bureaucracy, and/or lack of money).

It is also important that the STP does not see self-care as a way of cutting back on services. People in the focus groups and surveys clearly indicated that they need these services to work well in order for them to self-care. People want a service that effectively and quickly diagnoses their conditions, offers the appropriate treatment in time so that their condition does not worsen, responsive, knowledgeable and empathetic healthcare staff, better reviews and follow-up.

Next Steps

The findings of this report outline what is valued most by Birmingham and Solihull citizens to support them to self-care and live healthier, happier lives. In response to the NHS long-term plan, the development of the local Birmingham and Solihull STP plan should consider the findings of this report. The needs of local residents should be at the heart of future health and social care services. Based on the findings of this report, the local plan should:

- **Clearly lay out how the health and social care system will improve communication pathways with patients.** This will result in patients feeling listened to, equipped with the information they need to understand their condition and provided with the resources they need for their wellbeing. Methods used to do this need to ensure patients feel involved in decisions about their care and the design of services available to them.
- **Address individual and community skill gaps for self-care.** Empowering individuals to have the skills to use the available interventions and appraise the trustworthiness of what is available. In the development of new initiatives to self-care, careful consideration needs to be given to the skills and resources patients need. Also, how individuals can be supported to reduce inequitable access, and how community assets can be developed to address individual and community challenges.
- **Eliminate the gaps in meeting the Accessible Information Standard that exist locally.** Services should demonstrate how information is accessible to all. It should also address the constraints of the current systems. Initiatives developed as part of the local plan need to be flexible and appropriate to individual needs to reduce the current inequalities identified.
- **Reflect on the availability of services to support individuals,** with improvements made to referral pathways, waiting lists/times and the distribution of services. This will enable individuals to access support in a timely manner, and avoid worsening health or crisis.
- **Implement actions, where waiting times are unavoidable, to support individuals to self-care.** This will prevent their condition from getting worse and prevent individuals from entering into crisis.
- **Detail how assets within communities will be supported and developed, identifying and addressing any gaps across Birmingham and Solihull.** The plan needs to identify how communities and peers can be upskilled and resourced to provide support for local communities to build self-care initiatives.
- **Address how the local STP will work across all partners to reduce the stigma** of mental health, disability and other conditions, support individuals and build self-efficacy for self-care.

By addressing these in the development of the plan, the STP will go some way to shift the culture of health and social care, and the public. This will increase the self-efficacy and control of communities to look after their own health and wellbeing, and in doing so empower individuals to self-care.

Birmingham and Solihull Sustainability and Transformation Partnership (STP) response

The Birmingham and Solihull Sustainability and Transformation Partnership (STP) would like to acknowledge this report, and thank Healthwatch Birmingham and Healthwatch Solihull for a very insightful piece of research. We would also like to thank the participants who contributed to the research, sharing their valuable views and experiences regarding the NHS Long Term Plan (NHS LTP).

The STP's ambition to help people to help themselves to live long, happy and independent lives, requires us to understand and act on what really matters to them. This report will help us to do just that; as we develop our local NHS LTP implementation plans, to reduce health inequalities, improve local services and ultimately improve the health and wellbeing of local people, throughout every stage of their lives.

We will now take time to have a very detailed look at the findings in the report, taking them into careful consideration, to ensure that local people's needs are at the heart of any future services. We will then look forward to sharing our plans more widely at the end of this year, in line with national timelines.

Rachel O'Connor, Assistant Chief Executive for Birmingham and Solihull STP.

Introduction

The NHS in England has published a ten-year plan setting its priorities for the future. It is forecasted by NHS that the Long Term Plan could save up to 500,000 lives over the next ten years. It plans to do this by focusing on prevention and early detection.

The plan comes after the Government announced the NHS budget would be increased by £20bn a year by 2023. Local NHS organisations will be working with their local councils to develop and implement their own plans for the next five years. These strategies will set out how they intend to take the ambitions from the NHS Long Term Plan and turn them into action to improve services and the health and wellbeing of their local communities, with a specific requirement to reduce health inequalities.

With growing pressure on the NHS - an ageing population, more people living with long-term conditions and lifestyle choices affecting people's health - it needs to make sure everybody gets the support they need. NHS England asked Healthwatch England (via local Healthwatch) to engage with the public on the content of the NHS Long Term Plan. As a result, Healthwatch Birmingham interacted with the local community by conducting focus groups and holding engagement events across the city.

- Survey: the aim of the survey was to know people's experiences of their local NHS and social care services. We particularly targeted seldom-heard groups and helped them to complete the LTP survey forms.
- Focus groups: these explored what people told us they would like the NHS and Social Care do to help support them to look after their own wellbeing. We ran these with seldom-heard groups.

Broadly the LTP survey findings will help NHS to improve and do better, including making it easier for people to access support closer to home and via technology, doing more to help people stay well, and providing better support for people with long term health conditions. At the local level, survey findings will help in more collective and informed decision making at Birmingham and Solihull level. This engagement will help the local Sustainability & Transformation Partnership (STP) in developing strategic plans based on patients, the public and local stakeholders' needs, and as a result, level of care provision will improve for people and their families, through every stage of life.

Background information: Birmingham and Solihull

The map shows the geography of our local health and care system[7]. It includes all of the Solihull Metropolitan Borough Council and much of Birmingham City Council. West Birmingham is included in the neighbouring Black Country and West Birmingham STP, with the two STP areas working closely together.

In addition to the two local authorities, the Birmingham and Solihull STP partnership includes:

- Birmingham Community Healthcare NHS Foundation Trust
- Birmingham and Solihull Mental Health NHS Foundation Trust
- NHS Birmingham and Solihull Clinical Commissioning Group (GP Practices)
- Birmingham Women's and Children's NHS Foundation Trust
- University Hospitals Birmingham NHS Foundation Trust
- The Royal Orthopaedic Hospital NHS Foundation Trust

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[7] This section is adapted from the Birmingham & Solihull STP Strategy 2018 https://www.livehealthylivehappy.org.uk/wp-content/uploads/2018/10/Draft_v6_BSol_STP_Strategy_Autumn2018.pdf

Roughly 20% of the Birmingham population resides in 'West Birmingham' which is part of the Black Country and West Birmingham STP. Within this STP, the Birmingham Partners include:

- Sandwell and West Birmingham CCG (GP Membership)
- Sandwell and West Birmingham Hospital Trust
- Birmingham Community Healthcare NHS Foundation Trust
- Birmingham and Solihull Mental Health NHS Foundation Trust
- Birmingham City Council.

The West Midlands Ambulance NHS Foundation Trust is an associate member. Both STPs have close relationships with neighbouring areas, such as Staffordshire, and Coventry & Warwickshire, in some cases providing services for each other's citizens.

Birmingham and Solihull have a large and diverse population. The Birmingham area has a population of c.1 million, making it the largest local council in the country, and Solihull has c.210,000 residents. Over a hundred different languages are spoken in Birmingham and in some wards of the city up to 80% or residents are from Black, Asian and Minority Ethnic groups.

Birmingham is a growing city that has the youngest average age of the core cities of Europe, with almost half of the population under 30 years of age. Some 90% of the adult population owns a smartphone, which is the highest coverage in Europe. Solihull has an older population, on average, with 21% aged over 65.

In common with other developed countries, the overall structure of society is changing as people live longer lives. Ageing societies are one of the great challenges for health and care systems across the developed world, and Birmingham and Solihull are no exception. In three decades, the number of people over 65 years of age is expected to increase by a third. The number over 85 years of age will double, as will the number living with cancer and dementia, diseases that are often associated with ageing. This will increase costs significantly because, on average, the healthcare costs for someone over 65 are four times higher than for a working-age adult, and they are eight times higher for a person over 85.

Both Birmingham and Solihull have stark inequalities in terms of the health and wealth of their citizens. In Birmingham, 440,000 people, or 46% of the population, live in the 10% of most deprived areas in England, which accounts for some very poor health outcomes. The city has a level of homelessness that is more than three times the national average, long-term unemployment two and a half times higher, and one in three children live in poverty. One in four people live with a mental health condition that started in childhood.

Solihull has sharp contrasts in wealth and deprivation across different areas, although on average is more affluent than England as a whole. In the most northerly part of the borough, around one in three children live in a household without work or reliant on benefits. Whilst improving, there is a relatively high rate of homelessness.

People born in the most affluent parts of Birmingham and Solihull will live, on average, 9 - 11 years longer than those born in the most deprived wards.

What is Healthwatch?

Local Healthwatch were established in every local authority area across England following the Health and Social Care Act 2012. Our key role is to ensure those who commission, design and deliver health and social care services hear, and take into account, the public voice. Healthwatch listens to and gathers public and patient experiences of using local health and social care services. Examples of such services are general practices, pharmacists, hospitals, dentists, opticians, care homes and community based care. We hear these experiences via our Information and Signposting Line, our online Feedback Centre, and through our community engagement activity, led by staff and volunteers. You can read more about the work of Healthwatch Birmingham here: https://healthwatchbirmingham.co.uk/ and the work of Healthwatch Solihull here: https://healthwatchsolihull.org.uk/

General and Condition Surveys

How did we contact people?

Both Healthwatch Birmingham and Healthwatch Solihull used a range of communication channels to advertise the survey and obtain responses. These included online, direct contact with organisations and community events with patients and service users.

Online: website, volunteer and stakeholder bulletin and extensive use of social media.

Direct contact with organisations: email, phone and letters.

Engagement events: visiting third sector organisations for people to complete the survey.

> **Birmingham:** Bethel Health & Healing Network, Castle Vale Community Housing, Forward Thinking Birmingham, Birmingham Mind, Birmingham City University, St Barnabas Carers Group and Zinnia Centre. We engaged people all over the city, representing different segments of society and facilitated them in completing the LTP survey forms.
>
> **Solihull:** GP surgeries, Solihull College, The Core, Carers Forum and Older Peoples Knowledge Exchange. We engaged people from both the North and South of the Borough, representing different segments of society and facilitated them in completing the LTP questionnaires.

Questionnaires

Healthwatch England developed two questionnaires (general/condition specific) to gather people's views. These questionnaires were available online, paper and in easy read formats.

The general questionnaire asked four key questions:

- What is most important to you to help you live a healthy life?
- What's most important to you to be able to manage and choose the support you need?
- What is most important to you to help you keep your independence and stay healthy as you get older?
- What is most important to you when interacting with the NHS?

The specific questionnaire was based on questions about what could local NHS do to give people with long-term conditions better support. Long-term conditions included cancer, mental health conditions, heart and lung diseases, diabetes and arthritis, learning disabilities, autism and dementia.

General Survey

Who completed the General Survey Questionnaire?

The majority of the 503 people who responded were aged between 25 and 64 years, female, heterosexual and White British[8]. The appendix includes the full demographic data and compares Solihull (N=233) and Birmingham (N=270) based citizens. Our samples reflect the younger more ethnically and religiously diverse population of Birmingham residents compared to those of Solihull.

Of those people that provided their age, 20% were below 25 years of age, 58% were between 25-64 years, and 19% were 65 years or over. Sixty-five percent were female and 27% male. Fifty-nine percent were White British; the remaining people were Pakistani, Asian British, Black British, African Caribbean, 'any other mixed background', 'any other white background', or Indian. Only two percent were Arab or Bangladeshi. The majority of people were heterosexual (82%), with 6% stating they were gay, lesbian or bisexual. One-fifth stated they have a disability, and 14% were carers. Just under a quarter had long term health conditions, with an additional 7% stating that they had more than one long term health conditions.

What did Birmingham and Solihull citizens tell us?

This section individually answers each of the four key questions included in the general questionnaire. Due to the demographic differences between Solihull and Birmingham, for each question, we provide separate and total results[9] [10].

We asked: 'What is most important to you to help you live a healthy life?'

Forty-four percent of people ranked 'Access to the help and treatment I need when I want it' as being the most important factor to help them to live a healthy life (see Table 1).

Table 1: What is most important to you to help you live a healthy life?

	Number	%
Access to the help and treatment I need when I want it	211	44%
The knowledge to help me do what I can to prevent ill health	89	18%
Easy access to the information I need to help me make decisions about my health and care	81	17%
Professionals that listen to me when I speak to them about my concerns	84	17%
For every interaction with health and care services to count; my time is valued	18	4%
Total	483	100%

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[8] In addition, we heard from the LGBT community, people with sight loss, people with a learning disability, people with mental health problems, and young people through our focus groups (see focus group section).

[9] For all charts, percentages were calculated after 'blanks' had been filtered out.

[10] For each of the factors, people also scored their answer on a five-point scale from 'Very important' to 'Not at all important'. For all of the above factors, most people gave a score of either 'Important' or 'Very Important'. Due to this lack of spread in the data, subgroup analysis using demographic variables did not result in any differences between age groups etc.

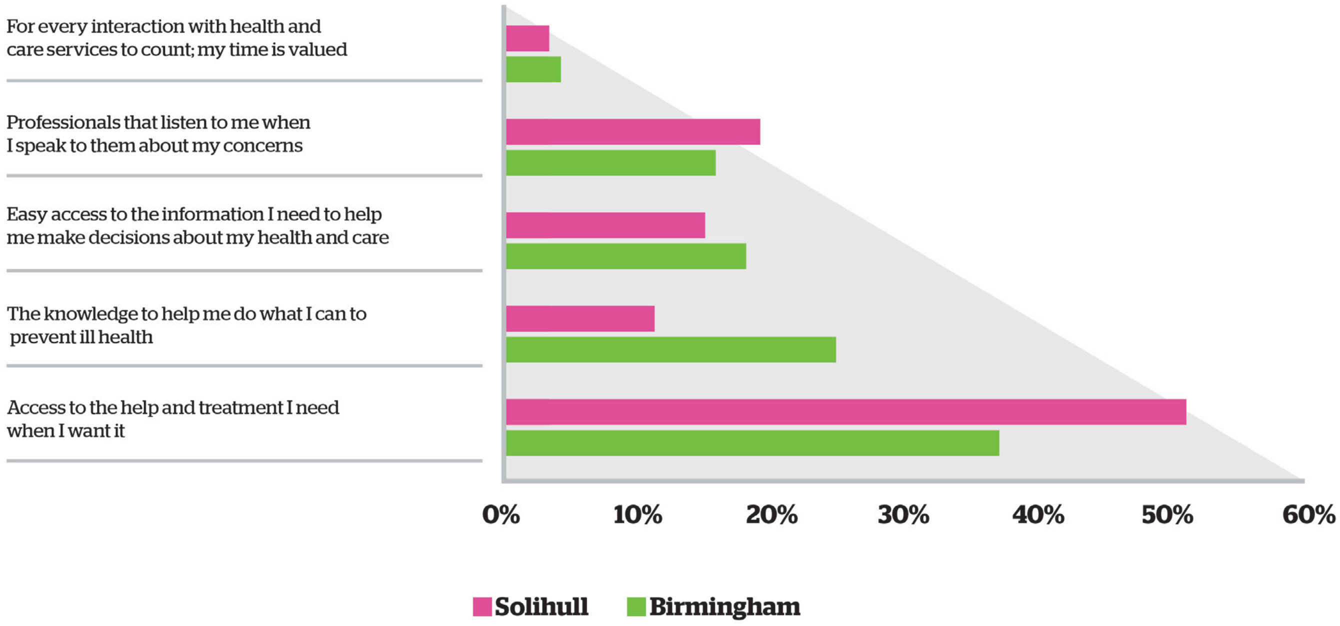

Fig 1: What is most important to you to help you live a healthy life?

For each option, the questionnaire gave people the opportunity to write free text comments. We discuss the themes that emerged from these comments below.

In addition to the combined total findings above, the difference between Solihull and Birmingham citizens for this question are provided in Figure 1 above. This indicates that people in both localities selected the same option, 'Access to the help and treatment I need when I want it', as being the most important.

Further comments on multiple choice options

People made additional comments relating to each of the multiple-choice answers to the question 'What is most important to you to help you live a healthy life?'

Access to the help and treatment I need when I want it

People described some of the frustrations and concerns they have when they cannot access the help and treatment they need when they want it. We grouped these additional comments into four categories: access to appointments and referrals, better services, joined-up services, and check-ups. Some people also highlighted the importance of individual responsibility.

Appointments and referrals

> *Being able to get the right people and treatment at the time you need it. (S, 64-74).*
>
> *More flexible access to where and when I can get the regular blood test monitoring that I need. (B, 55-64).*
>
> *I think in primary care, in particular, what the larger partnerships and at scale providers aren't doing actively is telling their patients that they can go to other sites to access appointments and additional services ... It's like the receptionists don't know that they can or should be doing this. (B, 25-34).*

My GP referred me to a general gynaecologist who again had to refer to a specialised gynae (still waiting to get an appointment with this specialised gynae...) It's been 8 months, 4 times cancelled. And the first general gynae appointment was a waste of time and energy for me, and a waste of money for the NHS. (B, 25-34).

> *I'm not asking to be spoon-fed with convenience. Health care is a valuable privilege and I don't mind making a bit of effort to gain access to it. But getting a GP appointment in good time is a proper ordeal when you're ill. Please find more streamlined ways to do that! (B, 25-34).*

Better services

> *Better mental health services with full support around the city! (B, 18-24).*
>
> *More investment is required in the Specialist services such as neurology and long term this reduces the impact on Mental Health e.g. learning disabilities. (B, 35-44).*
>
> *More help in mental healthcare for children with learning disabilities. (B, 55-64).*
>
> *Need for improvements to aftercare services following surgery. (S, 55-64).*

Joined-up services

> *Better access to GP and hospital services as and when required. More confidence in the cohesion and collaborative working between the NHS and social care and partner agencies. (B, 55-64).*
>
> *Better communication and smoother pathways between health care organisations. Here's a specific example to support my point. This year it was only through taking the time out to read an old letter from a (private/paid for) consultant I saw years ago (with regards to gynaecology) that I found I had an abnormality in this area, this wasn't a life-threatening or even a poor health issue but it could have meant that it affected my fertility and it highlighted the need for further investigation because of this. Had I not raised this for investigation with my GP and then went back to the consultant myself, years down the line, I doubt my GP would have ever suggested getting this looked at. It's far too easy for things like this to slip the net - it's like the GPs don't have enough time to read everything through - I actually feel for them. In this instance I can see where the failings occurred - the consultant didn't actually highlight on the letter than further investigation was needed (even though it was) and the GP didn't pick this up either. It was only through me reading up on fertility information that I realised I needed this abnormality looking at to determine the scale of the issue (now at a stage where I'm thinking about starting a family). (B, 25-34).*
>
> *Improved communication between different services – don't want to repeat and share my story over and over. (S, 45-54).*
>
> *Centralised computer systems. If you go to the hospital, they should be able to access medication records. (S, 45-54).*
>
> *Better communication needed between professionals if you are suffering from more than one problem, e.g. if you have a heart problem and need back surgery. (S, 65-74).*
>
> *Please do not repeat questions more than once. (S, 75+).*
>
> *No one knows when we may need health services but confidence in the joint working of partner agencies is of utmost importance. (B, 55-64).*
>
> *Ongoing measures to ensure that joined up working is a continual endeavour. (B, 55-64).*

Check-ups

> *Perhaps a yearly health check could be introduced for teenage boys to get us used to access healthcare as we grow up. (S, Age not submitted).*
>
> *Health and wellbeing assessment by GP as a standard offer every 5 years. Done properly will save money. (B, 55-64.)*
>
> *Regular 'MOT' health checks. Especially after 60. At the moment, it seems ad-hoc. (S, 65-74).*
>
> *Adopting a preventive approach and more health screening. (B, 18-24).*
>
> *I have recently been diagnosed with incurable stage 4 bowel cancer, so lowering the screening age to 50 which I understand is the practice in the US would have made a huge difference to me. (S, 45-54).*

Individual responsibility

Some people pointed out that in addition to access to healthcare, people need to take responsibility for their health:

> *But I also believe that I should not expect unconditional support and care from NHS in the face of a reckless and abusive lifestyle. (S, 65-74).*

> *People helping themselves to stay well (not drinking too much) - then burdening services to detriment of others who may need help. (B, 45-54).*
>
> *More generally, I believe that each individual in the society is responsible to live a healthy lifestyle. In the presence of abundance (if not totally coherent) information and advice, individual responsibility should be paramount, with NHS as the last resource and at arm's length. (S, 65-74).*

The knowledge to help me do what I can to prevent ill health

People mentioned a range of different types of knowledge they need, provided through technology, individual sessions with a professional, or group programmes. They also said they need information not only to prevent ill health but also to self-care once they have an illness.

Diet

Several people said that they would like support to improve their diet and exercise:

> *Promotion of healthy and balanced lives, care for our city - especially more deprived and run down areas. (B, 45-54).*
>
> *Easier access to weight management services and when referred to them more regular appointments than what is currently offered. (B, 35-44).*

Although the questionnaire did not ask about whether finances were a barrier to self-care, many people mentioned the prohibitive cost of eating well and exercising:

> *Having affordable leisure facilities with more exercise classes available. (B, 55-64).*
>
> *Affordable healthy food that doesn't cost an arm and a leg and breaks the bank when buying food. (B, 35-44).*

Access to physical activities

People made the following suggestions to increase access to physical activities:

> *More easy access for free clubs to do exercise in a group setting. No matter what physical ability you have or whatever age you are and whatever your illness. (B, 45-54).*
>
> *Legislation which makes employers provide opportunities at work - such as longer lunch breaks - to enable activity and exercise. (B, 55-64).*
>
> *An increase in cycle routes. (S, 55-64).*
>
> *Gym passes for those with a physical disability, professional personal trainer sessions. Vouchers or money off to continue. Making sure there is some follow up - you do it yourself and they check progress. (B, 45-54).*
>
> *I go to a ladies only gym, there is nothing in my area, I go to one in Boldmere Sutton Coldfield, although it takes 15/20 mins to get there, I wouldn't go to any other gym, but something similar in my area would be good for ladies who feel uncomfortable working out with men. (B, 65-74).*

They also saw the role of the NHS and Social Care to provide programmes that support people to self-care, preferably with other people coping with similar challenges to their own:

> *Healthy living programmes - e.g. gym. (B, 25-34).*
>
> *Better prevention scheme. Weight loss supports, life-style supports and education. (B, 45-54).*
>
> *Free community courses on health issues. (B, 25-34).*

Help to keeping on track

They saw the role of the NHS to monitor self-care, ensuring that they were keeping on track. This could be in consultations with humans or with technology.

> *General check-ins that the NHS could hold you to account for. (B, 25-34).*
>
> *The use of technology (Alexa) to prompt me with appointments, medication and general monitoring of my health. (S, 65-74).*
>
> *Knowledge on how to keep fit and healthy through in-depth consultation with a qualified health professional on the condition treated. (S, 25-34).*

> *Someone keeping me on track. (B, Under 18).*
>
> *Someone I can talk to when needed, so I don't fall off the program. (B, 65-74).*

Easy access to the information I need to help me make decisions about my health and care

Some people wanted more general information on physical and mental health

> *Think Health and Education could do more to offer health awareness sessions in schools and colleges. (S, 18-24).*
>
> *More education on mental health. How to deal with it? Who to talk to? (B, 18-24).*

The types of information people wanted easy access to included, alternatives to biomedical treatment, information about side effects, and up to date information given in an accessible format. One person said that the public need to be informed about the side-effects of medication, and the NHS should consider introducing more holistic healthcare. Others said:

> *That the professionals that are giving me advice are giving me up to date advice, as in medicine it changes all the time. (S, 55-64).*
>
> *Clarity and clear communication of information given - different formats. (S, 65-74).*
>
> *Care navigation is an important component is the health and care system. (S, 55-64).*

Professionals that listen to me when I speak to them about my concerns

Unsurprisingly, people want to be listened to by professionals. This may result in the prevention or timely treatment of illness, and improved quality of life.

> *Not to be made to feel my concerns and thoughts count for little or nothing to the medical profession. (B, 65-74).*
>
> *My health is very important for me and I want to be listened to regarding my health and involved in care management. (B, 55-64).*
>
> *Listen to what you are saying because you (the patient) might know yourself better. (B, 55-64).*
>
> *Believe me when I report things, don't just ignore or downplay symptoms. (B, 25-34).*
>
> *It took me 15 years to get a diagnosis for a condition severely affecting my quality of life because I wasn't believed or taken seriously. (B, 25-34).*

A related issue is that some people were concerned that greater use of technology, such as phone appointments, might result in feeling less listened to by a health professional:

> *Professional expertise is important so do not let technology take over / replace people contact. There is no replacement for expert face to face contact. (S, Age not submitted).*
>
> *I don't want technology to be the answer to everything. Human contact is important. Just like it is important to meet up with a professional rather than dealing with the problem over the internet or the phone. This seems impersonal and uncaring. An individual always has access to 'Dr Google', but another opinion with a caring explanation is far more important. (S, 55-64).*

For every interaction with health and care services to count; my time is valued

The main issue was that making a GP appointment can take excessive amounts of time – there were many comments about the difficulties of booking a GP appointment – also that hospital consultations can be lengthy.

> *Better access to doctors' appointments time wise - having to ring at 8 am in competition with others for an appointment. (S, 65-74).*
>
> *A general practice premises or drop-in centre that is truly local, within the nominal practice boundary, and easily accessible on foot by older patients whose roaming range is age restricted. Having to take two (or more) buses is unacceptable for elderly patients, particularly those living alone and suffering from conditions involving a tendency to suffer confusion, as is having to traverse an elevated footbridge over a very busy road. Taxis are unacceptable when the patient has a hearing deficiency necessitating being on the constant lookout and waiting time delays, not to mention the cost. The time duration of visits to the practice or not necessarily local hospital in such conditions appear to have been given little or no consideration. It is completely unacceptable*

> *in an urban first world society that a specialist consultation should involve five hours or more of a patient's time, as has proved to be the case in my experience. (B, 75+).*

We asked, 'What's most important to you to be able to manage and choose the support you need?'

Thirty-eight percent of people ranked 'Choosing the right treatment is a joint decision between me and the relevant health and care professional' as being the most important factor to help them to live a healthy life (see Table 2).

Table 2: What's most important to you to be able to manage and choose the support you need?

	Number	%
Choosing the right treatment is a joint decision between me and the relevant health and care professional	184	38%
I should be offered care and support in other areas if my local area can't see me in a timely way	77	16%
Communications are timely	52	11%
I make the decision about where I will go to receive health and care support	53	11%
I make the decision about when I will receive health and care support	36	7%
If I have a long term condition, I decide how the NHS spends money on me	29	6%
My opinion on what is best for me, counts	27	6%
I have time to consider my options and make the choices that are right for me	24	5%
Total	482	100%

In addition to the combined total findings above, the difference between Solihull and Birmingham citizens for this question are provided in Figure 2.

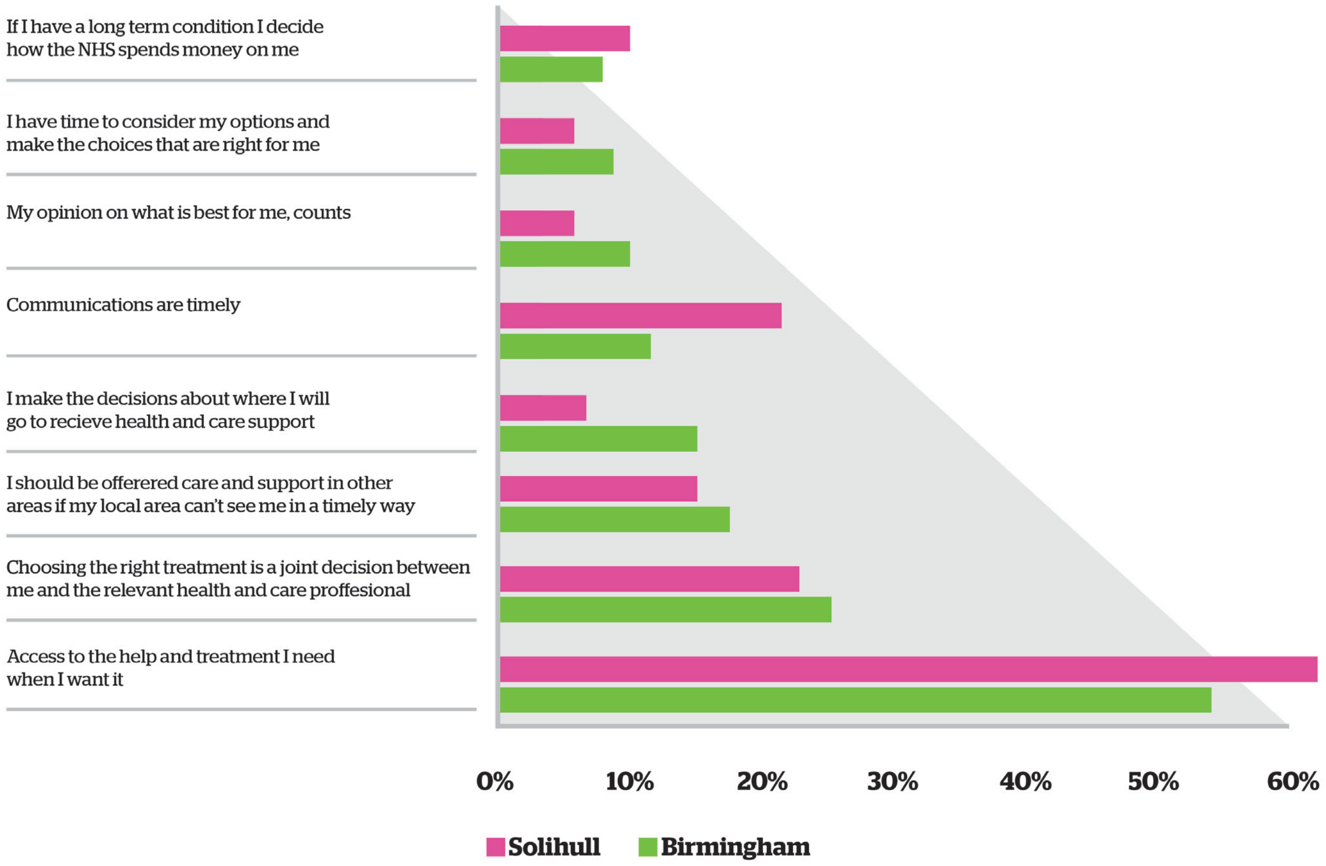

Fig 2: What's most important to you to be able to manage and choose the support you need?

Further comments on multiple choice options

People also made additional comments relating to each of the multiple-choice answers to the question What's most important to you to be able to manage and choose the support you need?

Choosing the right treatment is a joint decision between me and the relevant health and care professional

For professionals to support patients to make decisions, they need to have a high level of wellbeing themselves:

> *Professional staff who are not over-worked and tired, to help me make the right choice for my treatment. Also taking into account the professional staff's own wellbeing to be able to help me and understand me and my condition - lupus. (B, 45-54).*

Although over a third of people thought this was important, not all people want to be included in the decision-making:

> *Let doctors do their job without letting my uninformed whimsies reduce the quality of my care. (B, 35-44).*
>
> *I'm not a medical professional, so I've had no medical training and no medical expertise. I don't want to have to try to figure out what's best for me. I want a say, but ultimately a well-trained professional knows better than me. Let them do their job without forcing me to interfere in ignorance. Then I can concentrate on getting better, instead of worrying about choices when I don't even understand what issues are involved. I was offered a choice between two hospitals for an operation. I knew nothing about the quality of their work and their care philosophy. I just went for the one that was easiest to get to. That's no basis for deciding where to get surgery! My GP knows a load more than me, and I'd have preferred to leave it to his professional opinion to get me the best care. (B, 35-44).*
>
> *In the end, what I think I need is not always realistic. The health professionals have an expertise that I don't have and although I can express an opinion I have also to accept their knowledge - the result of training and practice. (B, 75+).*

> *I would rather leave those important, medical decisions to the Doctors to decide what's best for me. (B, 55-64).*

I should be offered care and support in other areas if my local area can't see me in a timely way

Sixteen percent of people thought this was the most important factor. One person told us:

> *I should be able to access professionals outside of the local area, who are specialists in my particular health issues if there is no-one with those skills within our area. There are no specialists within our area at all for the conditions my son and I have, yet we cannot get referrals out of the area for specialist assessment and care because 'it's against policy'. So, others with the same condition get better/appropriate treatment purely because they happen to live near the relevant specialists. (S, 45-54).*

Communications are timely

Some people mentioned that they wanted better use of technology to ensure that communications are timely and easily conducted. Others simply wanted more communication so that they know about their condition, and associated appointments.

> *Better NHS IT systems, e.g. making online appointments is still relatively challenging, as is ordering repeat prescriptions, communications from the hospital or GP are still by letter. (B, 55-64).*
>
> *Better communication needed between professionals if you are suffering from more than one problem, e.g. if you have a heart problem and need back surgery. (S, 65-74).*
>
> *To ensure that communications are carried out properly. I have had instances when I have found out by accident that I have an appointment but have received no communication. If I had not learnt of it by another means, I would have missed my appointment and that would have been seen as a 'no show'. (B, 75+).*

I make the decision about where I will go to receive health and care support

People want to have access to the services that are most local to them:

> *Not having services moved from Solihull Hospital e.g. an ambulance takes you to Heartlands when Solihull is less than a quarter the distance. (S, 45-54).*
>
> *To have local advisory services without having to travel to unfamiliar venues. (S, 65-74).*
>
> *Appointments should be available at my GP Surgery when needed, rather than being re-directed to a walk-in centre due to lack of availability of appointments. (S,45-54).*

We asked, 'If there was one more thing that would help you manage and choose how the NHS supports you, what would it be?'

When asked what else would help them manage and choose how the NHS support them, people commented on the running of the NHS, patient centred care and having clear listings of required payments.

Improved NHS

> *Better communication internally within the NHS such that mistakes are ironed out. (S, 75+).*
>
> *Trust in you know what you are doing. (S, 55-64).*
>
> *I believe the workload of staff should be so balanced as to provide adequate and focused care and attention where needed. (S,65-74).*
>
> *Good administration at all levels. (B,45-54).*
>
> *Give nurses and doctors a pay rise. (S, 55-64).*
>
> *Digitalisation - how can this improve NHS service delivery. (S,65-74).*

One person commented on this current survey, saying:

> *The questions are very heavily reliant upon there being adequate resources for everyone to have what they need when they need it ...this is unrealistic. (S, 55-64).*

Patient centred care

> *Think about people who need a different setting and environment to make appointments. Don't exclude me because I am difficult to understand or need special considerations because of my mental health or LD. (B, 55-64)*
>
> *Living well - right to die. (B, 65-74).*

Clear pricing

> *Price of objects clearly listed. (B, 18-24).*

We asked, 'What is most important to you to help you keep your independence and stay healthy as you get older?'

Forty-six percent of people ranked 'I want to be able to stay in my own home for as long as it is safe to do so' as being the most important factor to help them to live a healthy life (see Table 3).

Table 3: What is most important to you to help you keep your independence and stay healthy as you get older?

	Number	%
I want to be able to stay in my own home for as long as it is safe to do so	230	48%
I want my family and friends to have the knowledge to help and support me when needed	84	18%
I want my community to be able to support me to live my life the way I want	67	14%
I want my family and me to feel supported at the end of life	64	13%
I want there to be convenient ways for me to travel to health and care services when I need to	35	7%
Total	480	100%

In addition to the combined total findings above, the difference between Solihull and Birmingham citizens for this question are provided in Figure 3 below.

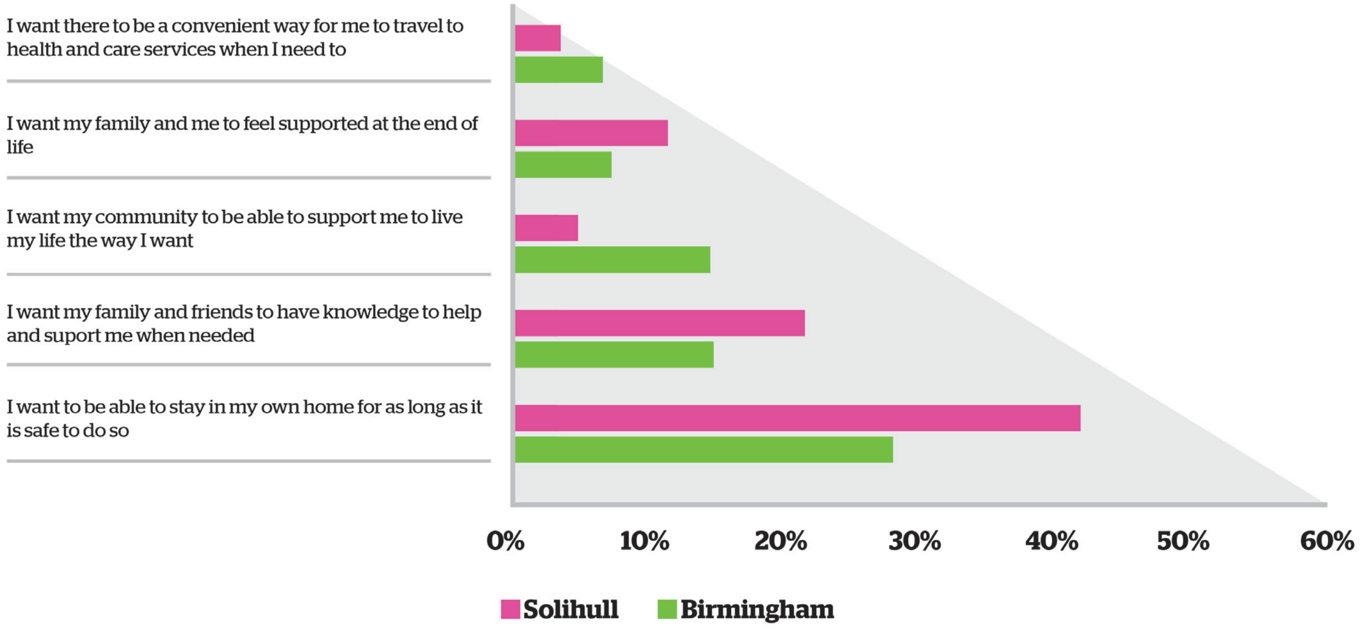

Fig 3: What's most important to you to help you keep your independence and stay healthy as you get older?

Further comments on multiple choice options

People made additional comments relating to each of the multiple-choice answers to the question, What is most important to you to help you keep your independence and stay healthy as you get older?

I want to be able to stay in my own home for as long as it is safe to do so

To be able to stay in their own home people said they need the correct support:

> *Community and NHS/GP/Health agencies support in house. Avoiding being interned in a care home. (B, 55-64).*
>
> *Better funding for patients who want to remain in their own home and maintain independence. (B, 55-64).*

More access to day centres and help at home. It is difficult to access help and find the right people to contact when you need help. Social Services are difficult to navigate to get help. (B, Age not submitted).

> *Access to health provision at home, that is timely, responsive and supportive at key times in people's lives to prevent them needing to attend hospital. Accessible OT, in a timely and responsive manner, that supports to provide people to have equipment or adaptation to help them retain Independence and manage within their homes. (B, 45-54).*
>
> *Adaptions within my home when I become in need of it. Also for this process to be more efficient as some people have died by the time the adaptions have been done and not lived to make use of them. Make the application process simple and not always online. (B, 45-54).*

I want my family and friends to have the knowledge to help and support me when needed

In order for family and friends to have the knowledge to support patients, they need professionals to communicate with them, but Health and Social Care should not expect friends and neighbours to support people:

> *More communication between patient's doctors and families. (B, 55-64).*
>
> *Home care support if needed by well trained, skilled, qualified people - who care and who are given*

> *the time necessary to complete the task. This for most ordinary people is severely lacking currently. (B, 45-54).*
>
> *To have my nursing and social care needs to be met by the NHS equally with all UK citizens without the worry of having to pay a huge sum of money at the end of my life. (S, 65-74).*

I want there to be convenient ways for me to travel to health and care services when I need to

Some people said that it would be good to have support traveling to health and care services. Others mentioned that support is also needed to travel to activities to self-care, perhaps by improving public transport generally across the city:

> *To provide health professionals within the home and not rely solely on family and friends, to give care and support. If travelling to see a professional is unavoidable, this should be provided close by and transport provided. (S, 55-64).*
>
> *Better public transport. Easier access to a local swimming pool/gym. (B, 55-64).*
>
> *Excellent public transport so car use becomes less. Clearer air, better public transport, fewer cars. (S, 65-74).*
>
> *Clearer air, better public transport, fewer cars. (B, 75+).*

We asked, 'If there was one more thing that would help you retain your independence and live healthily for as long as possible, what would it be?'

People also told us of a range of other ways that would help them retain their independence and live healthily for as long as possible. In addition to access to physical activities and healthy eating (themes that emerged throughout the answers to the questions), people also mentioned:

Less isolation

> *Wouldn't want to feel isolated. (B, 45-54).*
>
> *Interdependence - an end to this crushing isolation. (B, 35-44).*
>
> *More activities for the elderly - to keep them as mobile as possible - too many sit alone at home deteriorating. (S, 45-54).*

Support within the community

> *Good community care. (S, 65-74).*
>
> *Activities in the local area to bring the community together e.g. classes. (S, 25-34).*
>
> *Sharing and interaction with the younger generation. (B,55-64).*
>
> *I think community-based activities and support with a strong social aspect have a really important role to play - there are a number of groups run out of our local library - walking, craft, IT, and others that I think are really positive. I think care a nursing homes can have a bigger role as a base for activities that bring a wider range of people together and make better use of facilities and expertise for the community, not just residents and users, and can help provide a route to link people to the whole range of support that can help - somebody to odd jobs, gardening etc - which doesn't always need to be specialist health and care staff and can help stimulate new community business . I think the Community Catalysts model is a really interesting one. (S, 45-54).*

Cost of treatment and social care

> *Money to pay for care, treatment and aids. (S, 65-74).*
>
> *NHS being cheaper. (B, 18-24).*
>
> *Not to worry about the huge cost of social care. I would rather everybody contribute in the same way as we contribute to the NHS. As a pensioner, I would even give a monthly contribution to a social care fund rather than leave my children with a huge bill to pay at the end of my life. (S, 65-74).*
> *The cost I have to pay in future care worries me greatly. (S, 65-74).*

Accessibility of the location of services

> *Accessible services that have been approved by somebody with a physical disability - very useful. (B, 45-54).*
>
> *Organisation of services must be close to a train station. (B, 45-54).*
>
> *With the new trend for centres of excellence and some treatments only being carried out at certain locations, it is important that there are means for patients who may have physical problems to be able to get to their appointments. (B, 75+).*

Individual support and guidance to self-manage

> *Patient advocates - to help me manage the various clinical and non-clinical services I'm likely to be involved with. (S, 55-64).*
>
> *The use of technology (Alexa) to prompt me with appointments, medication and general monitoring of my health. (S,65-74).*
>
> *Someone to help me and be there for me. (B,18-24).*

End of life support

> *That we all start to talk about death much more and plan for what we want to happen. (S, 55-64).*
>
> *More smaller homes or bungalows, in all areas so that people can downsize from a big house when it gets too much for them to maintain, but be able to stay in the same area, keep in touch with neighbours/friends and be able to use the same doctor/dentist etc. (B, 65-74).*
>
> *Choice on end of life care. (S, 45-54).*

We asked, 'What is most important to you when interacting with the NHS?'

Forty-four percent of people ranked 'I can talk to my doctor or other health care professional wherever I am' as being the most important factor to help them to live a healthy life (see Table 4).

Table 4: What is most important to you when interacting with the NHS?

	Number	%
I can talk to my doctor or other health care professional wherever I am	143	32%
Any results are communicated to me quickly making best use of technology	80	17%
I have absolute confidence that my personal data is managed well and kept secure	70	15%
I can make appointments online and my options are not limited	63	14%
I can access services using my phone or computer	48	10%
I manage my own personal records so that I can receive continuity in care	38	8%
I am able to talk to other people who are experiencing similar challenges to me to help me feel better	18	4%
Total	460	100%

In addition to the combined total findings above, the difference between Solihull and Birmingham citizens for this question are provided in Figure 4 below.

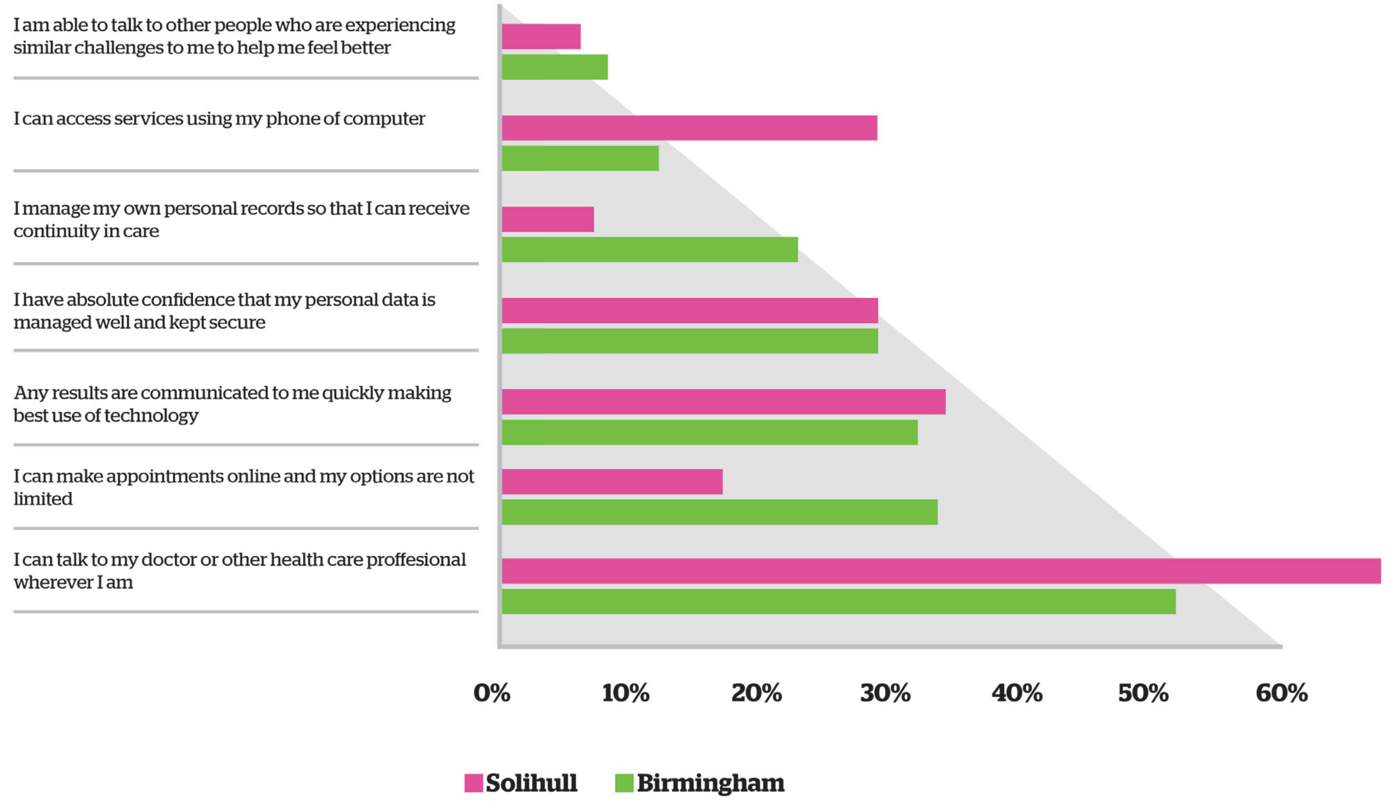

Fig 4: What is most important to you when interacting with the NHS?

Further comments on multiple choice options

People made additional comments relating to each of the multiple-choice answers to the question, What is most important to you when interacting with the NHS? Although I can talk to my doctor or other health care professional wherever I am was the highest-ranking option, no comments were made on this. People did comment though on the remaining options, and these are discussed below.

Any results are communicated to me quickly making best use of technology

People told us that waiting for test results was anxiety-inducing, and sometimes resulted in the GP receptionist trying to interpret the results for the patient. Not having to endure agonising waits for test results

> *Improved waiting times for diagnostic test results. (S, 65-74).*
>
> *Access to blood results without having to call GP Surgery and get the reception staff interpretation which I do not value. (B, 65-74).*
>
> *Test result to be return in a timely manner. (B, 25-34).*
>
> *Reduce anxiety suffered and delayed treatment waiting for test results. (S, 55-64)*

Some people felt that although technology is available to improve this situation, it is not adequately used by the NHS.

> *The promised benefits of technology too often in practice prove to be pie in the sky. (B, 75+).*
>
> *Waiting times for diagnostics / test results are unacceptably long and are often followed by another wait of 1-2 weeks for a clinic appointment to learn the results. The benefits of electronic reporting have not been passed on to patients. It's the operational systems that have not been changed to ensure patients benefit. Patients continue to be told 'results will be available in 2 weeks' - not true - most results are available within a few days. It's the operational Systems and processes that need to be changed to ensure results are communicated to patients more quickly and patients can benefit from this multi million pound investment. (S, 55-64).*

I have absolute confidence that my personal data is managed well and kept secure

Fifteen percent thought that this was the most important thing to them when interacting with the NHS. However, improvements are needed:

> *The first statement 'I have absolute confidence that my personal data etc.', I do consider it very important, but I don't have absolute confidence that it is well managed, from personal experience that is not the case. (S, 55-64).*

I can make appointments online and my options are not limited

Online booking of appointments was favoured by many of the people who responded. They requested:

> *More ways to contact. (B, Under 18).*
>
> *Be able to book appointments online. (S, Under 18).*
>
> *Making appointment making easier and more accessible for people with anxiety e.g. through a text message. (B, Under 18).*

However, one size does not fit all:

> *The thought that all elderly persons have an access to a computer, can read, can understand all the changes that have occurred and occurring i.e. as an elder I have personally been brought up to expect that the NHS is in a certain way however the involving changes are not cascaded down into the wider community thus causing distresses when the NHS needs to be accessed for care. (B, 55-64).*

I can access services using my phone or computer

Similarly, accessing services by phone or computer was thought by some people to be important. It can be better than attending the GP surgery for a second appointment, and simpler:

> *Sometimes GP calls us back to discuss our health problem, but I don't like this method. A patient can be checked on the phone. (B, Age not submitted).*
>
> *Simpler access to doctor or healthcare professional, e.g. online / face-time. There is often no need for physical appointments. (S, 45-54).*
>
> *Maybe online check-ups from GP surgeries to see how patient Is doing instead of waiting to be contacted; Some patients might not feel comfortable contacted doctor about same ongoing problem. (B, 45-54).*
>
> *Easy access to GP appts, online etc. to suit a working lifestyle, evening appts etc. (S, 25-34).*

There are difficulties with this though. It is unpleasant to be waiting for the phone to be answered, and the phone systems need to be fit for purpose:

> *Always to be informed what number I am in the telephone queue. (S, 65-74).*
>
> *Make sure there are regular checks that doctors answer their phones. (B, 18-24).*
>
> *Everything is important, but technology is not the way forward for everyone, people who want to ring their GP need better upgraded systems, online systems do not alleviate the volume, we need to be able to pick up the phone and call. (S, 55-64).*

I manage my own personal records so that I can receive continuity in care

Although some patients want to manage their own records, the comments indicated that many wanted to at least be able to access them:

> *My medical record being owned by me, not the NHS. (S, 55-64).*
>
> *Better access to GP appointments when needed. Being able to access my own blood results etc. (B, 45-54).*
>
> *Integrated records ... so the appropriate people (including myself) can see all relevant information to support my care. (S, 55-64).*
>
> *Full access online to my health records. (B, 65-74).*
>
> *Better access to personal records at GP. NHS results more timely. Better quicker access to GPs (more GPs?). (B, 55-64).*

I am able to talk to other people who are experiencing similar challenges to me to help me feel better

Some people wanted access to peers who are facing similar challenges to themselves:

> *Group meetings where people can share information or what works/best treatments. (B, 65-74).*
>
> *Communicating with other with a similar problem is of great importance because this helps people to understand more and become more aware. (S, 55-64).*

We asked, 'If there was one more thing that you think needs to change to help you to successfully manage your health and care, what would it be?'

When asked what else would help them to successfully manage their health and care when interacting with the NHS, people commented on finances and joined up services:

Finances

> *Money to live on. (S, 55-64).*
>
> *Free prescriptions. (B, 25-34).*
>
> *A truly national health service not one that depends on ability to pay. (B, 75+).*

Joined up services

> *Centralised computer systems: If you go to hospital, they should be able to access medication records. (S, 45-54).*
>
> *Integrated records that are accessed by the right people at the right time. (S, 45-54).*
>
> *All professionals Police, Housing, Fire service having access to my health information. (S, 45-54).*
>
> *Properly aligned with better funding for social care so that they're [the NHS] not effectively forced to compete between who had to make the savings and with better resourcing for public health to focus on prevention. (S, 45-54).*
>
> *Please do not repeat questions more than once. (S, 75+).*
>
> *No one knows when we may need health services but confidence in the joint working of partner agencies is of utmost importance. (B, 55-64).*

General Survey Conclusion

Patients want better access to healthcare – when and where they want it – and the opportunity to make decisions with health professionals. There were some differences between the Solihull and Birmingham residents. For example, Solihull residents placed more importance on health professionals listening to them, whereas in Birmingham residents placed more importance on the knowledge needed to self-care. This difference would need further exploration to understand but may be due to a higher proportion of White British and older citizens in the Solihull subgroup. Such differences have implications for how the STP supports such varied demography within and between the boroughs.

Patients want health professionals to listen to them, even when the health professional believe they already understand. If health professionals presume to know what the issue is, they may miss diagnoses and not provide much-needed treatment. It is also difficult for patients to self-care if they do not have the treatments they need.

By listening and sharing decisions with patients, self-care becomes the joint responsibility of the patient and health professional. GPs may not need to provide this support; a health coach who checks the patient's progress and helps them towards their goals may be more appropriate. It is important to patients though that health professionals, whether GPs, nurses or health coaches, possess up-to-date knowledge. Most patients now have access to the internet, and can, therefore, find health information. They may not know if this information is trustworthy though. They need health professionals to be knowledgeable and guide them to make the right decision.

Some patients were worried about the impact of technology on patient-centred care. They were concerned that more communication via telephone calls, and more use of 'apps' would result in decreased communication between themselves and health professionals. These patients wanted face-to-face support from a caring and informed professional. Others were happy with the introduction of technology but felt that its benefits have not been utilised enough by the NHS. For example, waiting times for test results are still unreasonably lengthy. The NHS could speed these up through better use of technology. Similarly, the NHS could consider sharing patient records with other agencies such as the police. Further use of technology, therefore, does have a role, but the NHS needs to use it appropriately. Some people, such as those who are older, will need face-to-face support in order to self-care and access healthcare.

Patients particularly wanted better access to information and advice about diet and exercise. This should be accessible, i.e. in formats that people with disabilities can access. There are further barriers though to exercising and eating healthily: it is of concern that many patients who responded to our survey wanted to exercise and eat healthily but could not afford to do so. Patients also wanted information about integrative healthcare (e.g. about complementary therapies such as yoga). This fits well with the move towards social prescriptions.

Patients also wanted to be able to choose whether to travel to a service of their choice, or whether to access a service closer to home. Again, lack of money is a barrier for some people to travel to the services. People told us that better local transport would help with this, making it easier to travel to appointments, and to activities that they need to do in order to self-care.

Lastly, almost half of all people want to be able to stay in their own home for as long as possible. The percentage in Solihull was almost 60%, possibly reflecting the older sample. In order to stay in their own home, people need to have health and social care in their own home, as well as access to day centres.

Condition Survey

Who completed the Condition Survey Questionnaire?

A total of 123[11] (Birmingham = 76; and Solihull = 47) people responded to the NHS Long Term Plan survey (conditions). The majority (63%) were between the age of 25 and 64 years of age, 21% were 65+ whilst 16% were below 25 years of age. Sixty-eight percent were female, 29% were male, and 2% preferred not to state their gender and 1% stated "other gender". Although the majority were white British (73%), there was representation from other ethnic groups including Pakistani, Asian British, Caribbean, Indian, Bangladeshi, Arab, 'any other mixed background', and 'any other white background'. The majority indicated that they were heterosexual (79%), with 5% stating they were bisexual, gay or lesbian and 1% asexual or pansexual. Forty-eight percent were Christian, 26% had no religion, 12% were Muslim and others were Buddhist, Sikh or Hindu. Twenty-three percent were carers.

Overall, 52% of people had a mental health condition; 27% a long-term condition (e.g. diabetes, arthritis), 12% had a heart and lung condition, 10% had autism, 4% cancer, 3% dementia and 2% a learning disability. Seventy-eight percent responded to the questionnaire on their own behalf whilst 22% responded on behalf of someone else. Overall, for 46%, their condition had started within the last three years. Excluding those people with a mental health condition, at least 50% and above, indicated that they had other/additional conditions. Overall, 47% stated that they had a disability.

The conditions questionnaire included five key questions. This section answers each question in turn. For each question, we also present data based on the seven conditions (autism, cancer, dementia, heart and lung, learning disability, long-term condition, and mental health).

What did people tell us?

Experience of getting help and support

Thirty-five percent of people indicated that when they first tried to access help, the support they received did not meet their needs. This view was more common amongst those with autism, dementia, learning disability and mental health conditions. At least 50% of people with these four conditions respectively, said the support did not meet their needs. However, 28% of people said the support met their needs, whilst 34% indicated that in some ways it did and in other ways, the support did not meet their needs.

When people were asked about their overall experience of getting help, 35% reported positive/very positive experiences, 34% reported a negative/very negative experience, whilst 31% reported an 'average' overall experience of getting help. For the conditions under discussion in this report, people with mental health and an autism condition indicated more negative than positive/very positive overall experience of getting help. On the other hand, more people with 'heart and lung diseases' and 'long-term conditions' reported positive/very positive experiences of getting help. Those with cancer indicated mostly average or positive/very positive overall experience (see Table 5).

Table 5: How would you describe your overall experience of getting help?

	Very negative	Negative	Average	Positive	Very positive
Autism	3 (25%)	3 (25%)	4 (33%)	1 (8%)	1 (8%)
Cancer			3 (60%)	1 (20%)	1 (20%)
Dementia	2 (67%)		1 (33%)		
Heart and lung diseases	2 (13%)	1 (7%)	4 (27%)	3 (20%)	5 (33%)
Learning disability		1 (50%)	1 (50%)		
Long-term condition e.g. diabetes, arthritis	2 (6%)	6 (18%)	8 (24%)	11 (33%)	6 (18%)
Mental health	7 (13%)	14 (27%)	17 (33%)	11 (21%)	3 (6%)
Total	16 (13%)	25 (20%)	38 (31%)	27 (22%)	16 (13%)

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[11] For all numerical data including percentages, these were calculated after 'blanks' were filtered out.

Table 6 indicates that more people who had other or additional conditions (to those listed) indicated that it was harder when they sought support for more than one condition at a time. At least 50% and above of people who had autism, a long term condition, cancer, and mental health found it harder than those with dementia, heart and lung condition, and a learning disability. Overall, twenty-seven percent of people said their additional conditions made no difference when getting help whilst 7% said it made it easier.

Table 6: How would you describe the experience of seeking support for more than one condition at a time?

	It made it harder	No difference	It made it easier	Don't know	Not applicable
Autism	5 (71%)	1 (14%)		1 (14%)	
Cancer	2 (67%)	1 (33%)			
Dementia	1 (33%)	2 (67%)			
Heart and lung diseases	2 (29%)	2 (29%)	2 (29%)		1 (14%)
Learning disability		1 (100%)			
Long-term condition e.g. diabetes, arthritis	8 (50%)	5 (31%)	2 (13%)	1 (6%)	
Mental health	13 (59%)	4 (18%)		2 (9%)	3 (14%)
Total	31 (53%)	16(27%)	4 (7%)	4 (7%)	4 (7%)

People were given an opportunity to write free text comments. The data presented here has been split according to each condition. These in some cases are presented as themes if enough data is given.

When asked whether the support they received when they first sought help met their needs and how it could have been improved, people told us the following.

Autism

Waiting times

Concerns about waiting times included time taken to see a GP, waiting times in A & E, time taken to have an assessment and get a diagnosis, and time taken to access support services. Below is a selection of the comments:

> *I was only diagnosed at 39 so have spent all my life wondering what was wrong with me and asking for help or assessments. Eventually, I saved the money and had a private assessment. (S, 35-44).*
>
> *I needed support with communication/speech therapy. It was not offered for a very long time until it became pronounced. I think support of this nature should be offered when initial problem is identified. (B, Under 18).*

Impact of long waiting times

> *Was refused an assessment as [did not have] enough supporting evidence at the initial request stage. Then once I had a diagnosis of ADD and under CAMHS crisis team he was accepted, but had to wait almost 8 months to be diagnosed which is too long for a child in crisis and resulted in him being signed off medically unfit from school for almost 2 years. (S, 35-44).*
>
> *There are considerable barriers to a diagnosis for autism. Some are natural - it is a complex condition that requires a multi-agency approach and does not always present obviously in young children - but many are caused by funding issues. We waited nine months to see a consultant, for example, and each delay exacerbates the developmental delay experienced and makes the work of the services who are eventually engaged more challenging and damages the prospects and experience of the service user. (B, 35-44).*

Difficulties with getting support

> *No service wants to know unless you are 100% impaired. (B, 35-44).*
>
> *Trying to get any professional to listen to concern regarding my son's behaviour and autistic traits was very difficult. (S, 18-24).*
>
> *No support at all in Solihull area, I now pay to travel out of borough go to support group to receive correct support. (S, 18-24).*

> *Lack of support for both my autism and ADHD. Received completely nothing other than medication for ADHD without regular check-ups from GP. (S, 18-24).*

One person highlighted concerns with the lack of support for those who are in post-16 education.

> *There is no support of any kind for anyone out of a school setting for over the age of 16 but then in school. [It] is dependent on whether your school buys in or not so it is potluck. The waiting list is ridiculous for assessment and then it's just a report. There is no social and emotional support of any kind, there is no referral on process for other needs that are often associated with ASD (such as SALT as it was closed, physiotherapy needs as it's a GP referral only or any type of actual focused learning needs support) because there is a social judgment that it is down to the schools and that is that when there is no direct route for schools to access this either. (S, 18-24).*

Cancer

The overall experiences of accessing the help that met the needs of people with cancer were either average or positive/very positive. None reported having negative or very negative experiences. They indicated that they often had a quick referral and diagnosis and organisations like Macmillan had been of help in understanding their condition and getting support. However, people were concerned by the lack of specialist nurses, with one person saying there are not enough specialist colorectal nurses and there is no support if you have a mental health issue alongside having cancer and a colostomy. Another indicated a concern with poor information and advice, especially when moving between services:

> *GP referred me to a hospital who then referred me to another hospital, all a bit confusing about who I was going to be seen by and when. (B, 55-64).*

Dementia

For those with dementia, whilst one person indicated that they had had a positive experience when they were first diagnosed and felt well informed about the diagnoses, another felt that there is a lack of advice. Three of the four people with dementia described their overall experience as very negative or average.

> *[You are] always given web sites to 'sort out what you think will help'. Would appreciate someone who would listen to the problems and give some advice. Maybe check on a regular basis to see how things are getting along or not as the case may be. (B, 75+).*

Heart and lung diseases

Overall, there were slightly more people with heart and lung diseases that indicated positive/very positive overall experience of getting help that met their needs. In comparison, seven of the fifteen people indicated average or negative/very negative overall experience of getting help. Concerns they raised were on waiting times for the first appointment, for others it was the time taken to see a consultant, have tests and get results. Another person indicated that they felt there *"seemed to be a reluctance to operate a regular review of my condition".* At least two people indicated that the long waiting times had an impact on their mental health as it increased their anxiety.

Waiting times

> *Dr referred my husband to hospital for [test redacted] due to diagnosis of Atrial Fibrillation in mid-December with results coming through to us [date redacted]. The results show Severe Mitral Regurgitation and necessary to see Cardiologist. However, we are still waiting to see him and have today been told the first appointment will be [date redacted]! This is having a bad effect on my husband's mental health and we are worried about the effect the delay is having on his physical health. We were never offered a choice of hospitals and haven't been offered an alternative due to the long delay. I realise this is our right but when the doctor was asked about this it was dismissed with the wait would be the same elsewhere and tests would have to start all over again. We are now going to go back and discuss our right to be referred to another, private hospital, for a quicker waiting time. We believe this is our right and the NHS would have to cover the cost. I constantly say 'we believe' because no one has actually told us this, this is from us searching on the internet. (B, 65-74).*

> *Response time to seeing a consultant, having tests and further delay in receiving results is too long. (S, 65-74).*

> *We were able to contact our GP but waiting time was too long. (B, 18-24).*

People noted that the following issues should be improved by the NHS in order to improve their overall experience of getting help.

> *I believe that more needs to be done to speed up waiting times, to give emotional support to those having to wait a long time to see consultants for serious health problems as the wait takes its toll in more ways than just possible physical ones. (B, 65-74).*
>
> *Patients need to be kept informed throughout the process. Also more contact with doctors. Lack of contact leads to increased anxiety for the patient. (S, 65-74).*

Learning disability

The main issue for those with a learning disability was around information and advice, and quality of care for those with multiple needs.

> *Not enough information is provided by the services for patients or being diverted properly to get help. (B, 35-44).*
>
> *Some support did meet the needs but there has been a lack of dealing with someone who has multiple needs. Myotonic Dystrophy, it seems, is not understood by some medical staff. (B, 35-44).*

Long-term condition

People with a long-term condition other than those listed expressed more positive views on how well the support received met the needs. Fifty-one percent of people indicated that they had positive/very positive experiences. Forty-eight percent said they had negative/very negative and average experiences. People noted the impact of changes to thresholds and terminology in their ability to self-manage, concerns with or lack of diagnosis, staff attitudes and waiting times.

Diagnosis, waiting times and treatment

> *After 4 years my health condition is still undiagnosed, and I am no longer under any consultants. I feel they looked for the most obvious answer and when that wasn't right didn't bother looking again and just discharged me. (S, 35-44).*
>
> *I have had to buy my own blood tests in order to diagnose my conditions because rude GPs asserted there was 'nothing wrong with me' even though I was sleeping 16 hours a day. I was told 'some people just need more sleep than others.' Then after diagnosis, I was sent to rude specialists who implied the reason my condition wasn't well controlled was that I wasn't compliant with my medication, so I have had to pay out of pocket for private specialists who felt like doing their jobs today. My experience of 'support' for these life-altering symptoms has made me rather resentful of GPs. (S, 25-34).*

> *It was a very long process with the arthritis and was on and off crutches for 3 years. (S, 35-44)*
>
> *Only through accident did I get seen to. But now waiting 3 years to see a pain clinic. (B, 55-64).*
>
> *Goitre treated by removing thyroid. But there was the assumption that one pill a day would keep you in good health. Which in my case is not the truth. (B, 65-74).*

Guidance and thresholds

These people noted that changes to guidance and thresholds have not improved their lives:

> *The NICE guidelines on liothyronine have made recent life even worse. (B, 65-74).*
>
> *Practical steps to self-manage [following diagnosis and GP follow-up] affected by inconsistency of terminology and change of threshold which undermined my confidence that this was not a media and targets driven agenda. (S, 65-74).*

Staff attitudes

> *When I was first diagnosed 30+ years ago with chronic Crohn's Disease the support I received met my needs, but I could have done with a registrar who showed more compassion and understanding for my problem. He really could have done with some training of how to approach people who are being told they have an illness for which there is no cure. (B, 55-64).*

People who responded suggested that there should be more time given during consultation in order to diagnose and treat the condition effectively; more advice given, especially around healthy eating; and shorter waiting times for appointments, especially appointments for treatment.

Mental Health

Forty percent of people with a mental condition indicated that the support they received met their needs. For 33% the support they received and the extent to which it met their needs was average whilst 27% reported positive/very positive experiences. The two cases presented below encapsulates what people with a mental health condition go through when trying to get help at different points in their lives (e.g. as an adult or a child/young person). It highlights issues around diagnosis, problems with treatment or not getting the right treatment, difficulties with getting treatment evaluated, signposting to services, long waiting times for treatment and at times treatment not being given until there is a crisis, and poor support from healthcare professionals.

> *I struggled with depression after bereavement. Went to GP as I had a lot of physical symptoms and pain everywhere. I was tested in hospitals for all kinds of things, but they found nothing wrong with me. In the end I was diagnosed with depression. I think they should have immediately asked me at GP how I was emotionally as it would have saved the NHS a lot of money. I was then referred to counselling but the waiting time was insane and they didn't help me at all. It was just about eating well, doing exercise etc. I already knew all that and was making healthy choices to improve my emotional wellbeing. I needed some real talking therapy but didn't get any. In the end I had to pay private counselling but it shouldn't be like that! They need to have a more holistic approach to diagnosing and treating people. Body and mind can't be separated so I don't understand why medicine separates them so clearly. GP's need to do social prescribing as a standard and use some of the money to prescribe acupuncture, massage, therapy, gardening, exercise groups etc. This is what works. (B, 35-44)*
>
> *Mental health issues as a child/young person were not picked up on even when teachers tried to raise concerns, help never offered. When I tried to access counselling to discuss the traumatic childhood events that possibly led to my mental health issues, no counselling available through NHS, had to pay although was lucky the counsellor gave me a discount due to being young (19ish). Without help from my parents I would still not have been able to afford this. When I was at my lowest (around 24) and struggling with suicidal thoughts I paid to see a psychiatrist as I was told I would never be able to see one on the NHS - or at least not for months. Was diagnosed with a personality disorder which I had already surmised I was living with. Was told my need was not great enough to receive acute NHS care (since I had suicidal thoughts but had not attempted) but that they didn't think I would benefit from Cognitive Behavioural Therapy (CBT)/counselling. Did not pay for any further mental health support and never received follow up from the doctors I had been in touch with. I am now on anti-depressants, which do help. However I find it hard to get my concern about*

> *serious side effects I have taken seriously and feel there isn’t a very in depth understanding. Ideally would like to see a specialist but my needs aren’t acute enough. Ideally there would be mental health nurses working with GPs to deliver universal mental health care to stop problems escalating to the point where “”acute services”” are necessary. Generic wellbeing advice isn’t enough and most people (especially young people) cannot afford to pay for counselling, let alone therapy. The way the system is currently means desperate people may feel their only avenue to get help is to attempt suicide and even then that doesn’t guarantee adequate support afterwards. (S, 25-34).*

Health professionals lack of knowledge about mental health and poor attitudes

> *Expertise in Mental Health very limited. (B, Under 18).*

> *GP did not know enough about mental health to diagnose my condition. (B, 45-54).*

> *It didn’t meet my needs as the people I spoke to didn’t understand enough about mental health to help. (B, 18-24).*

> *GP was a waste of time and was not aware of interventions available for first time support. Later on was counterproductive in not listening to problems and arranging a heavy handed bungled mental health assessment. (S, 65-74).*

> *I had CBT and my therapist made me feel criticised for having anxiety. (B, 25-34).*

Appointments and waiting times

Appointments and waiting times were one of the main issues raised by people with a mental health condition. They expressed concern with the time taken to get an appointment, especially for treatment such as therapy.

> *I received no support for at least nine months because of waiting lists and referrals needing to be processed. Then when I eventually got an initial assessment they were already wanting to discharge me because the ‘demand for services is too high. (B, 25-34).*

> *I was able to see my GP on a regular basis however I am awaiting for CBT therapy as I am on a waiting list and it seems to be taking some time. (S, 35-44).*

> *Went to GP first - helpful straight away, getting an appointment at CMHT took a long time when referred here. (B, 18-24).*

> *I have been put on a waiting list for CBT that have no available spots until June. (B, 18-24).*

> *I sought help from doctors who said they’d refer me to a support group and never did. (B, 18-24).*

Some people argued that appointments seem to be given when people reach crisis:

> *It is almost impossible to get any 1-1 for mental health issues until a full collapse or break down. (B, 45-54).*

> *It took a year to get the support I needed. Was way too long and made the situation worse. Had to borrow money to go private. Could have been improved by seeing me sooner and giving me therapy not drugs. (B, 25-34).*

> *To access any support takes so long that the situation deteriorates and can cause other health issues in my case I developed Fibromyalgia. I was on a waiting list for 12 months just to get told I do need trauma based counselling and put on another 9 month waiting list. (B, 35-44).*

One person noted that waiting could be made easier by better communication from services:

> *I’ve now been on a waiting list for 3 months to receive counselling. So basically I’m still having to try and deal with it all by myself. I understand a lot of people need the services but having an update even an email to say your still on the list or here’s helpful numbers if there’s an issue in between might help. (B, 35-44)*

Treatment and follow-on support

Some people pointed out that there was a poor evaluation of treatment and therefore poor adjustments to treatment. In addition, some people felt that they were given medication to keep them quiet.

> *At first I was told I was suffering depression and anxiety given tablets and sent away, I wasn’t doing well on medication and tried on several occasions to explain this to my GP who just said I hadn’t given them time to work, but after several weeks of daily bad headaches I took myself off tablets*

> *which didn't go down well, In this time I'd had a couple of appointment with mental health service and was told if I don't need medication I don't need support?! They found me a coffee morning to go to and that was it. (B, 45-54)*
>
> *Went to GP, just given medication for anxiety and depression. Just given medication which doesn't work. (B, 35-44).*
>
> *My experience, especially when in hospital, that they just drug you up to your eyeballs to keep you quiet. (S, 45-54).*
>
> *Autism is often medicated without Cognitive Behavioural Therapy (CBT). (S, Age not provided)*

Several suggestions were made by people to improve their experience of accessing support that met their needs. This included:

> *Providing [patients] with knowledge about medication side effects and self-help groups. (B, 35-44).*
>
> *It could be improved by having individuals at services who have been through it themselves. Less of a corporate manner - treat patients as a human being. Teach staff people skills so they build a true connection, human to human, who want to be there to help, rather than turning up for the paycheck. Better support workers in social care. If you miss a call the support workers just drop you. You have to go back through GP. When I had one, only saw them twice. Don't see one now - majority I can't speak to because of their English skills. (B, 25-34).*
>
> *More Competent doctors and nurses. (B, 18-24).*
>
> *Adequate signposting or referrals to specialists. (B, 18-24).*
>
> *Shorter waiting times for therapy. (S, 18-24)*
>
> *More support groups available. (B, 18-24).*

Conclusion: Experience of getting help and support

Views about experiences of getting help and support were varied across the different conditions and between people. Some people indicated that the support they received when they first tried to access help did not meet their needs. In addition, their overall experience of getting help was mostly negative or average. Their experiences of getting help were further affected if they had more than one condition, which made it harder for people to access services that provided effective care and support. People argued that in some cases healthcare professionals failed to provide care that addressed the different conditions they had.

People indicated the following as some of the reasons why the care they accessed did not meet their needs:

- Long waiting times, not only for GP appointments and A&E, but also diagnosis and access to treatment that potentially worsened their condition. For instance, a child in crisis waited over 8 months for a diagnosis. This resulted in them being signed off as medically unfit from school for two years.
- The lack of staff with the expertise to understand and manage their condition.
- The lack of contact with services, as one person indicated - they would like someone to listen to them rather than being referred to websites. Another person added that the lack of contact leads to increased anxiety.

People want:

- Healthcare professionals to review their condition on a regular basis, including post-treatment.
- Improvements in waiting times throughout the process, not just for diagnosis but also treatments.
- Better integration of services.
- Better information and advice. This was important across the different conditions, especially when people are waiting to access services. As one person indicated, waiting could be made easier by better communication and better support.
- Better signposting to other services.
- More time given during consultation in order to diagnose and treat the condition effectively.

Overall, a service that effectively and quickly diagnoses their conditions, offers the appropriate treatment in time so that their condition does not worsen, responsive, knowledgeable and empathetic healthcare staff, better reviews and follow-up.

Health and care support received after initially seeking help

When asked how they would describe their experience of waiting to receive an initial assessment, 53% of people found the wait 'slow or very slow'. Twenty-five percent said the wait was 'ok', whilst 17% said the wait to receive an initial assessment was 'fast or very fast'. Overall, the majority of people with autism, dementia, and mental health found the wait to receive an initial assessment 'slow or very slow'. For those with a long-term condition, more people found the wait 'slow/very slow' than those that found it 'fast/very fast' and those that found the wait 'ok'. Forty percent of people with cancer found the wait to be 'slow/very slow' and 'fast/very fast' respectively, with 20% finding the wait 'ok' (see Table 7).

Table 7: How would you describe the time you had to wait to receive your initial assessment or diagnosis?

	Don't know	Very slow	Slow	Ok	Fast	Very fast
Autism	1 (8%)	7 (58%)	2 (17%)	1 (8%)	1 (8%)	
Cancer			2 (40%)	1 (20%)	1 (20%)	1 (20%)
Dementia			3 (100%)			
Heart and lung diseases	1 (7%)		4 (29%)	6 (43%)	1 (7%)	2 (4%)
Learning disability	1 (50%)					1 (50%)
Long-term condition e.g. diabetes, arthritis	1 (3%)	9 (27%)	6 (18%)	11 (33%)	5 (15%)	1 (3%)
Mental health	2 (4%)	19 (40%)	10 (21%)	10 (21%)	5 (10%)	2 (4%)
Total	6 (5%)	35 (30%)	27 (23%)	29 (25%)	13 (11%)	7 (6%)

Autism

The length of time that people had to wait to receive an initial assessment ranged from two months to ten years.

> *I have waited months to see someone, now have to wait 2 months for them to see my parents and then probably another wait after that to see the doctor. (B, 35-44).*
>
> *Took years of asking for support from school GP for support and referral then the waiting list for assessment was 9 months. (S, 18-24).*
>
> *12 months from initial GP referral. (S, 35-44).*
>
> *[It took] 10 years plus. (B, 35-44).*
>
> *We took over two years to move from initial appointment to diagnosis and this included three substantial spells of waiting for appointments (nine months, six months, and five months). (B, 35-44).*

For some people the long waiting times have led them to pay for a private assessment:

> *I gave up waiting for an NHS assessment and went private as the wait was so long. (S, 35-44)*
>
> *I am still waiting and have had to go private for a lot of it as there is either no department as they were closed or classed as "purely a learning need" or no one knows how to refer to help needs. This means that I can have 3 different health professionals that I have researched and tracked down (I have actually had to do this) tell me that I need a specific department for help but no one knows exactly how to access it. (S, 18-24).*

People who responded noted that long waiting times are caused by *"a lack of due process"* or by the GP failing to identify autism faster: *"if GP were able to identify quicker, the time would been quicker as it took 2 psychiatrists at different times to identify autism".*

Cancer

The length of time people had to wait for an initial assessment and surgery, ranged from two weeks to two months.

> *Within 15 mins of seeing doctor, I was referred to the hospital. Within one month, I had a biopsy. Within 2 months I had surgery. (S, 45-54).*

> *Anything out of the ordinary like extra training for my stoma took 4 weeks because of lack of nurses. (S, 45-54).*

Dementia

People with a dementia condition told us that they waited between twelve months and four years to get a diagnosis. Then they also had a significant wait for social services support.

> *Because the diagnosis was at first mild cognitive impairment over 12 months before the diagnosis was dementia. Then getting social services involved was another 10months. (B, 65-74).*
>
> *Waited 4 years for Alzheimer's diagnosis for my husband. (B, 75+)*

Heart and lung diseases

For most people with a heart and lung condition, the wait was between two weeks and three months including significant waits for results. One person had to wait ten weeks for results of an MRI scan whilst another had to wait four months for an appointment with a cardiologist to discuss test results. They found waiting without any contact or information unsettling and upsetting. One person noted that *"more urgent referrals are required"* for people with this condition.

> *For me the huge length of time you are left without any information is unsettling and adversely affects your daily life. For example, after MRI scan was told results would be available after two weeks; I had to wait ten weeks. (S, 65-74).*
>
> *From the diagnosis of Atrial Fibrillation to Echocardiogram was only about 3 weeks and then another 4 weeks for the results. That was acceptable. What isn't acceptable is being told you have a serious heart condition then having to wait a further 4 months for an appointment with a cardiologist to discuss the findings and what that will mean moving forward. Our doctor believes it will mean a heart operation but the uncertainty of not knowing exactly if that is the case and when that may be has put our lives on hold. My husband is 68 and it feels like he has been written off already. (B, 65-74).*

Long-term condition

The waiting time for initial assessment/diagnosis for people with a long-term condition was between two weeks and 15 years with some people having to pay privately for a diagnosis.

> *15 years for a diagnosis of autoimmune disease. And I paid for the test. (S, 25-34).*
>
> *3 years from initial diagnosis. (S, 35-44).*
>
> *6 months for an MRI scan of head and spine but about 1-2 months for a neurology consultant appointment. (S, 35-44).*
>
> *A month or so and it was diagnosed as pre diabetic. I never got to the bottom of what that meant but was told I was diabetic, and then I wasn't. (S, 65-74).*
>
> *Did not get diagnosis from doctor. Went private for another condition and got diagnosis which gave clearer picture. (B, 45-54).*

An issue of concern for people was what happens in between appointments as this person said: *"it is more the time between appointments which is the problem".*

> *Very slow as I still haven't received a diagnosis. I waited months for each appointment and generally received no follow up. (S, 35-44).*
>
> *The time factor isn't relevant in my case it's the effect disability & painful joints has on oneself. (B, 55-64).*
>
> *Recently endocrinologist halved my thyroid medication for a "three month trial", there was no three month appointment, just six month. The hospital is supposed to be prescribing as GP refused because of NICE guidelines. It takes me at least three weeks of ringing to get any response. (B, 65-74)*

Mental Health

It was common amongst those with a mental health condition to be waiting two weeks up to a year for an initial diagnosis. In some cases, people waited for over a year and in one case for eight years.

> *Referral took 2-3 weeks, [assessment] appointment was a couple of months. (B, 18-24).*
>
> *From 8-16 years old for a diagnosis. (S, Age not provided)*
>
> *Nine months. Then another six months because I needed a new referral after inappropriately being discharged. (B, 25-34).*

Some people had to pay privately for diagnosis or treatment:

> *It took months to get help and in the end I had to pay for private counselling, which was expensive and also with really long waiting times. There has to be more money invested in therapy. (B, 35-44).*
>
> *I wouldn't have been able to get my diagnosis on the NHS without proving I was 'ill enough' and waiting many months, so had no other option but to pay. (S, 25-34).*

Similar to concerns raised by those with a long-term condition, people indicated that problems were with the time taken to receive treatment following diagnosis or assessment.

> *I had a diagnosis years ago it's the waiting when u need extra support that's not as quick to gain. In a previous area I had to wait 8 months for counselling. (B, 35-44).*
>
> *I waited for two months for initial assessment for therapy, then never got any help with that. (B, 35-44).*
>
> *[The diagnosis] took a few weeks which was understandable and fine, but a five month waiting list for therapy is ridiculous. (S, 18-24).*
>
> *My waiting for a group session was over 20 weeks. (B, 45-54).*
>
> *Still waiting on Cognitive Behavioural Therapy after 2 months. (S, 35-44).*

The impact of this for some people is that they are put on medication that they would prefer not to take as they wait.

> *Took five months from diagnosis to getting to see a psychiatrist, then eight months to actually get therapy. In the meantime I got put on five different psychiatric drugs I didn't want. (B, 25-34)*

> *After being under mental health services for a couple of years seeing a couple of community psychiatrist nurse (cpn's) and doctors who really wasn't interested how my life was affecting me because all they talk about is medication, and if you don't want to take it … they don't want to know, I was told I'm weak, oh for god's sake just get on a bus (which I was really struggling with) I should on line date, I'm a massive animal and nature lover and was told by one doctor shouldn't be hard to socialise then there's loads of people who are animal lovers . After more distress in my life I was given yet another cpn who I'm still seeing. (B, 45-54).*

Overall, more people (47%) found the wait between initial assessment/diagnosis and receiving treatment to be 'slow/very slow', whilst 16% found the wait 'fast or very fast'. Thirty percent of people found the wait 'ok' (see Table 8).

Table 8: How would you describe the time you had to wait between your initial assessment/diagnosis and receiving treatment?

	Don't know	Very fast	Fast	Ok	Slow	Very slow
Autism	2 (17%)		1 (8%)	4(33%)	1 (8%)	4 (33%)
Cancer			3 (60%)	1 (20%)	1 (20%)	
Dementia						3 (100%)
Heart and lung diseases		2 (14%)	1 (7%)	6 (43%)	2 (14%)	3 (21%)
Learning disability	1 (50%)					1 (50%)
Long-term condition e.g. diabetes, arthritis	1 (3%)	1 (3%)	4 (13%)	14 (44%)	6 (19%)	6 (19%)
Mental health	5 (10%)	2 (4%)	4 (8%)	10 (20%)	16 (33%)	12 (24%)
Total	9 (8%)	5(5%)	13(11%)	35 (30%)	26(22%)	29 (25%)

Overall, whilst 53% of people were offered access to further health and social care support, this was only 6% more than those that were not offered further support. Slightly more people with autism, dementia and mental health condition, did not get offered access to further support than those that were offered support. Considerably more people with a long-term condition were offered further health and care support than the other conditions (see Table 9).

Table 9: After being diagnosed or assessed, were you offered access to further health and care support?

	No	Yes	Total
Autism	7 (58%)	5 (42%)	12
Cancer	2 (40%)	3 (60%)	5
Dementia	2 (67%)	1 (33%)	3
Heart and lung diseases	6 (46%)	7 (54%)	13
Learning disability	1 (50%)	1 (50%)	2
Long-term condition e.g. diabetes, arthritis	11 (34%)	21 (66%)	32
Mental health	25 (25%)	23 (48%)	48
Total	54 (47%)	61 (53%)	115

What worked well when you accessed support and what can be improved?'

When asked what went well when they accessed support, people mentioned the following: getting support at home, statement of needs, training, financial support, support managing condition, regular checks/reviews, access to specialist care and quality staff, follow-on support, access to appointments and quick referrals, access to information and advice, and access to support services especially local community resources. Below are some of the comments from people.

> *Our son is pre-school and autistic. We receive one hour fortnightly in-home support. This is excellent. (B, 35-44).*
>
> *Special educational needs Statement at secondary school really helped me. For example, support to help recognise different result. (B, 18-24).*
>
> *We get disability support and I also get carer support. (B, 35-44)*
>
> *The sensory processing course was very informative ... Healthy lifestyle course ... Went on a pain management course which has done more for me than all the pills ... Mindfulness training. (S, 55-64).*
>
> *Blood pressure checks and regular blood tests ... Gastroenterologist follow up appointment and necessary blood tests. (S, 45-54).*
>
> *Access to specialist teams, e.g. MS nurses, physios ... Knowledge of Consultant but it took a long time to find a knowledgeable person. (S, 45-54).*
>
> *Help to get back to college and help to get back to work. Help to meet others who had the same experiences / illness. (B, 45-54).*
>
> *[Access to services like] Mind, SOLAR, Mental Health Team. (S, 35-44).*
>
> *Recovery/Rehab service linked to local community resources. (B, 45-54).*

Regarding what could be improved, people outlined the following issues:

Autism

> *As my son was a late diagnosis at 13 he needed more input from Occupational therapy like sensory diets as his biggest difficulty is his sensory processing. He only received his diagnosis report and was refused any further assessment or help. (S, 35-44).*
>
> *Mental health support should be started much sooner, special educational needs statement done as soon as possible, as early as year 5 to help with transition to secondary school for people who struggle with change. (B, 18-24).*
>
> *The follow-up support and guidance from the Child Development Centre at Allen's Croft is very good, but clearly inhibited by funding challenges (e.g. a two hour workshop which had so much different information packed in that most of the message was lost - this needed to be held over several sessions). (B, 35-44).*

Cancer

> *Self-catheterisation was not offered until after 3 urethrectomies - some of these might have been unnecessary if offered quickly. (S, 55-64).*

Heart and lung diseases

> *[Make it] easier to get GP and nurse appointments. (B, 75+).*

Learning disability

> *Better understanding of [condition] especially, Myotonic Dystrophy. It is one of the most complicated diseases with many different aspects. (B, 35-44).*

Long-term condition

> *Better access to physio. (S, 65-74)*
>
> *Consistency of diagnosis with which I can be confident. (S, 65-74).*
>
> *More access, advice as required when symptoms fluctuate. (B, 45-54).*
>
> *Not all support was quick, e.g. specialist groups within physios due to demand on the service and funding for that service e.g. FES clinics. (S, 45-54).*
>
> *Feel GP awareness of Coeliac Disease could be heightened. (S, 45-54).*
>
> *Better information. You have to threaten action or nothing gets done. (B, 55-64).*
>
> *Safeguarding issues never taken forward seriously. (B, 45-54).*
>
> *Just easier access to appointments. (B, 45-54).*

Mental Health

> *Getting the appropriate Consultant at the right time. (S, Under 18).*
>
> *GP's should come to home instead of Nurse. (B, 45-54).*
>
> *To try and speed up the waiting time and to have more sessions. (S, 45-54).*
>
> *Improve choice and reduce distance one has to travel for treatment – Lack of choice at some services. Distance was too long to travel and work pattern didn't fit even going every other week. Progression at some services wasn't quick. (B, 18-24).*

Were you referred to a specialist?

At least 70% of people reported that they had been referred to a specialist with 30% stating they had not. Autism was the one condition which had more people who were not referred to a specialist. For cancer, 100% of people had been referred to a specialist, with over 60% of those with dementia, heart and lung, mental health and a long-term condition also being referred to a specialist (see Table 10).

Table 10: Were you referred to a specialist? For example, a hospital consultant, psychiatrist or physiotherapist

	No	Yes	Total
Autism	7 (58%)	5 (42%)	12
Cancer		5 (100%)	5
Dementia	1 (33%)	2 (67%)	3
Heart and lung diseases	1 (7%)	13 (93%)	14
Learning disability	1 (50%)	1 (50%)	2
Long-term condition e.g. diabetes, arthritis	7 (23%)	24 (77%)	31
Mental health	18 (37%)	31 (63%)	49
Total	35 (30%)	81 (70%)	116

Despite the high numbers of referrals to specialist services, overall, more people indicated that the wait to see a specialist was 'slow/very slow' with very few stating it was 'fast'. Forty-two percent said the wait to see a specialist was 'ok'. People with cancer had a more positive experience with 80% stating that seeing a specialist was 'fast' and 20% stating it was 'ok'. People with a mental health condition had a more negative experience than other conditions with 57% stating that the time taken to see a specialist was 'slow/very slow' (see Table 11).

Table 11: How would you describe the time you had to wait between the initial appointment and seeing a specialist?

	Don't know	Fast	Very fast	OK	Slow	Very slow
Autism				4 (80%)		1 (20%)
Cancer		4 (80%)		1 (20%)		
Dementia					1 (50%)	1 (50%)
Heart and lung diseases	1 (8%)	1 (8%)	2 (17)	5 (42%)		3 (25%)
Learning disability	1 (100%)					
Long-term condition e.g. diabetes, arthritis		3 (13%)		14 (61%)	3 (13%)	3 (13%)
Mental health	1 (3%)		3 (10%)	9 (30%)	6 (20%)	11 (37%)
Total	3 (4%)	8 (10%)	5 (6%)	33 (42%)	10 (13%)	19 (24%)

The time taken for people to see a specialist ranged from the same day to one year. The length of wait seemed to be dependent on the severity of condition or services one wants to access.

> *I had a scan which showed stage 4 bowel cancer and I was seen the same day. (S, 45-54).*

> *GP identified asthma not stable and quickly refereed to special service. (B, 35-44).*
>
> *A day. I contacted the therapist myself. (B, 18-24).*

Some people indicated that the main problem was not the initial appointment with a specialist, but the follow-up.

> *Follow up tests, results and consultations took longer. (S, 65-74).*
>
> *Initial appointments always reasonable time it is the ongoing lack of interest in follow up which is annoying. (B, 65-74).*

Other people expressed concern with the quality of appointment with a specialist:

> *Also any consultation is very cursory, one describes how ill one feels but only hand tremors looked for, nothing else. The only time I have had any examination was from a private consultation. (B, 65-74).*
>
> *They don't want you there if you have other illnesses. (B, 55-64).*

Accessing on-going support

All people with a dementia condition found it 'difficult' to access ongoing support after they were assessed or diagnosed. None of people with autism said they found it 'easy' to access ongoing support. Indeed 59% said they found it 'difficult or very difficult' and 25% found it 'ok'. None of people with cancer found it 'difficult' to access ongoing support, although only 20% said it was 'easy' and 60% said it was 'ok'. Forty-five percent of people with mental health indicated that they found accessing ongoing support 'difficult/very difficult' with only 16% finding it 'easy'. There were more people with a heart and lung disease and a long-term condition, who found it 'ok' to access ongoing support than those who found it 'difficult' (see Table 12).

Table 12: If you needed it, how easy did you find it to access ongoing support after you were diagnosed or assessed?

	Don't know	Very easy	Easy	OK	Difficult	Very difficult	Not applicable
Autism				3 (25%)	2 (17%)	5 (42%)	2 (17%)
Cancer		1(20%)	1 (20%)	3 (60%)			
Dementia					2 (67%)	1 (33%)	
Heart and lung diseases		3 (21%)	2 (14%)	3 (21%)	3 (21%)		3 (21%)
Learning disability		1 (50%)			1 (50%)		
Long-term condition e.g. diabetes, arthritis	1 (3%)		3 (10%)	17 (55%)	4 (13%)	6 (19%)	
Mental health	2 (2%)	2 (4%)	6 (12%)	14 (29%)	14 (29%)	8 (16%)	3 (6%)
Total	3 (3%)	7 (6%)	12 (10%)	40 (34%)	26 (22%)	20 (17%)	8 (7%)

Did the support option offered to you meet your expectations?

Overall, 39% of people indicated that the support options offered did not meet their expectations. This was more so for those with autism, dementia, learning disability, and a mental health condition. More people with a heart and lung disease and a long-term condition said the support met their expectations. Although none of the people with a cancer condition indicated that the support did not meet their expectations, 60% said the support 'somewhat' met their expectations (see Table 13).

Table 13: Did the support option you were offered meet your expectations?

	No	Somewhat	Yes	Total
Autism	7 (64%)	3 (27%)	1 (7%)	11
Cancer		3 (60%)	2 (40%)	5
Dementia	3 (100%)			3
Heart and lung diseases	1 (9%)	3 (27%)	7 (64%)	11
Learning disability	1 (50%)	1 (50%)		2
Long-term condition e.g. diabetes, arthritis	10 (32%)	8 (26%)	13 (42%)	31
Mental health	21 (45%)	19 (40%)	7 (15%)	47
Total	43 (39%)	37 (34%)	30 (27%)	110

People who responded made the following comments concerning how the care did or did not meet their expectations. In some cases, they made suggestions as to how things could be improved by the NHS.

Autism

Regarding care that did not meet expectations, people with autism mentioned lack of support to improve their ability to do everyday tasks if they have difficulties; poor support systems for adults with autism and another condition such as mental health; lack of continuity of care; lack of support post-diagnosis; lack of options; inconsistencies in assessments between different health professionals; and concerns with multiple systems that those with autism have to go through. As one person suggested, "have one system instead of multiple".

A child with sensory difficulties particularly should have access to an occupational therapist to help them establish a programme of support to help them function better. As it is we have had to pay for it privately which we should not have to. (B, 55-64).

For an adult diagnosed with autism there is very little support available you don't qualify for mental health services to help with anxiety due to autism but there are no support systems in place. (S, 35-44)

I was offered nothing. (S, 18-24).

Most of the professionals that we have seen have since been made redundant and their work has not been adequately processed or followed up on. (B, 35-44).

No support was offered post diagnosis. (S, 18-24).

There were no options, my son was just dropped. It was the beginning of the fight for help not the end of my battle to try and do the best for my son and his ASD along with his additional needs to the point where I have had some health professionals tell me he needs X, Y and Z and others telling me I am wasting time. It is not my child's fault there is a cut to services but he is the one that is suffering because of it. (S, 18-24).

Cancer

A majority of people with cancer found the care they received to be generally good. They were happy that their support *"team supplied contact details for continued support."* However, people mentioned that there is not enough staff which impacts on the time they spend with specialists.

Dementia

People with a dementia condition expressed concern with the lack of ongoing support following diagnosis. Carers indicated a concern with the lack of support or someone to call when their relative with dementia is in crisis. They indicated that if this support were available then they wouldn't have to call 999 for help in times of crisis.

Heart and lung disease

A key concern for some people with a heart and lung condition was the lack of support received. One person indicated that *"regular reviews of ongoing conditions are not offered, [it's like they are saying] if you drop dead give us a ring"*. Another person said that *"I felt that I was just left on my own. Talking to a professional would have helped"*.

Learning Disability

Comments from one person highlighted issues concerning the lack of understanding of the various aspects of an individual's condition. As a result, some aspects of an individual's condition are addressed whilst others remain unresolved. It is one of the requirements under the Equality Act 2010 that healthcare staff understand the needs of people with a learning disability in order to make reasonable adjustments. The person suggested that one way to improve care and the understanding of people's conditions is to ensure that healthcare professionals are aware of the various support groups or organisations with information on different conditions.

> *Because of the many aspects of Myotonic Dystrophy, i.e. cataracts, those aspects which were well known were dealt with expertly, but we had difficulty in finding consultants who understood all aspects of the condition. More information was available from the Myotonic Dystrophy Support Group. If possible, could these groups be learnt about by the NHS? (B, 35-44).*

Long term condition

Some people indicated that the care met their expectations. For example, one person told us that their regular six-monthly reviews were excellent, and the specialist podiatry service is outstanding. They also said they received good information and the staff were friendly; they had regular reviews; guidance on health and well-being; ease of making an appointment for support and treatment.

> *[I was] given guidance on eating tips. (B, 55-64).*
>
> *If I needed support or treatment all I had to do was contact medical/surgical teams secretary's and would be out on the consultants next clinic, obviously the wait time depended on what day I phoned. Could have been between 1-7 days as there was only one clinic per week. (B, 55-64).*
>
> *Good information and friendly people. (B, 18-24).*

People who indicated that the care received did not meet their expectations stated concerns with long waits for appointments, including delays between appointments; poor understanding and misconceptions about illnesses; poor health outcome following surgery; slowness in issuing prescription; lack of personalised care; inadequate number of sessions; inadequate information given when first diagnosed; difficulties in getting results; and poor follow-up of issues and lack of further investigations when treatment is not working. This person's comments captured the issues faced by people with a long term condition:

> *Long delays between appointments at hospital, slowness in issuing prescriptions. No interest in seeking possible issues, such as conflicting medication. One of my blood pressure tablets was identified by a private consultant as interfering with my thyroid medication, no comment from NHS consultant. GP only sees "depression". Endocrinology seems to have a total lack of interest in thyroid patients and has an over reliance on the thyroid stimulating hormone test and a naive faith in normal ranges. Research papers are also pretty poor (often really bad statistics) where the researched are often seen as homogenous rather than different by virtue of the many reasons one has an under active or non-existent thyroid. (B, 65-74).*

Other people made the following comments about their expectations not being met:

> *I feel Coeliac Disease is a hidden illness which is sadly confused with lifestyle choices or fads. Increased awareness is needed (although the health professionals I have seen have been very good). (S, 45-54).*
>
> *I still experience pain following a complete knee replacement over a year ago. I was told I need to exercise more. I exercise 3/4 times a week. (S, 35-44).*
>
> *Not enough sessions. (S, 65-74).*
>
> *Physio was too short and no follow up was offered. (S, Age not provided).*
>
> *The specialist I saw mixed up my patient records with someone else and just told me to come back in three months. (S, 25-34).*
>
> *I wanted some more information as I suffered from bad asthma when I was first diagnosed and didn't understand the condition. (B, 25-34).*
>
> *Swift service - but some wait (1-2 month). A long wait for MRI scan and for FES Physio appointment. (S, 45-54).*

One person mentioned that better access to support when you are in an emergency, especially when support breaks down would have made the experience better.

Mental Health

The attitudes of staff, their expertise and knowledge were cited as an example of why care was judged to have met their expectations. They also highlighted the frequency at which they met staff and the level of support as important.

> *Every 6 months I see the nurse, they talk to you about general health and medication review, and they are not intrusive. (B, 55-64).*
>
> *I got the right expert at the right time. (B, 55-64).*
>
> *Care received was very good. Staff supported myself and child through difficult time. (S, 35-44).*

Other people indicated that the care they received did not meet their expectations because of long waiting times, lack of support whilst waiting; ineffective treatment, treatment not tailored to individual needs or concerns; lack of continuity of care; limited help offered and very slow in providing support; lack of choice when to take up treatment; regular cancellation or rearrangement of appointments, poor follow-up and signposting; being discharged before the patient is well enough; and lack of diversity in the gender of doctors.

> *Far too long waiting times and no help whilst waiting. (S, 35-44).*
>
> *It took me 6 months to see a consultant, after diagnoses of brain tumour. (B, 45-54).*
>
> *Long waiting time with limited help. (B, 18-24).*
>
> *I have been suicidal due to separation anxiety disorder & have been told I need psychotherapy but it's a year's wait till initial assessment not even a year to get treatment. (S, 45-54).*
>
> *Group sessions are by nature, more specific a quite unstructured. Not everyone has the same needs. Group settings are so hard. (B, 45-54).*
>
> *The counselling sessions were weekly but didn't offer any practical ways to improve the condition therefore CBT would have been better. (B, 35-44).*
>
> *I did not like the talking therapy. (B, 18-24).*
>
> *It just didn't help me, I felt like I needed to sit down and talk to someone. (B, 18-24).*
>
> *There should have been a follow up, check if I was better. I could have also been signposted to bereavement groups and support. (B, 35-44).*
>
> *I'm just managing at this moment it's about self-managing. (B, 25-34).*
>
> *Too slow when I had urgent need. (B, 25-34).*
>
> *I was offered initial 6 week counselling but was not ready for this at the time. Would have preferred to access when ready. More effective. (B, 45-54).*

This person's comments summarised the above views. The person stated that the problems were around:

> *Discharge. Lack of contact. No monitoring. No care of physical problems. Virtual excommunication. No carers identified nor offered assistance even though that would have been really easy at the start. (S, 65-74).*

People who responded suggested the following things that they noted could be improved: personalised care, a better understanding of mental health issues by healthcare professionals and more information on extra methods that can help manage the condition. A person indicated one issue that needs addressing is continuity of care stating *"I feel you need to see the same person, it's not easy to keep explaining what's wrong constantly. They do keep rearranging and cancelling appointments and I've found lots of them leave the job".* Another indicated that *"care needs to be more tailored to the person being cared for". (B, 45-54).*

Communication from services

Overall, more people indicated that they had not received 'timeline and consistent communication' from all the services they came into contact with than those that did. Twenty-nine percent of people said, to a limited extent ('somewhat'), they received 'timeline and consistent communication'. People with autism, dementia, and mental health condition were more likely to not receive 'timeline and consistent communication' when accessing services. On the other hand, people with cancer, heart and lung, and a long-term condition had more positive than a negative experience. However, more people with a long-term condition, and learning disability (100%) to a limited extent received 'timeline and consistent communication' when they accessed services (see

Table 14).

Table 14: During your whole experience of getting support, did you receive timeline and consistent communication from all of the services that you came into contact with?

	No	Somewhat	Yes
Autism	7 (64%)	1 (9%)	3 (27%)
Cancer	1 (20%)	1 (20%)	3 (60%)
Dementia	2 (67%)	1 (33%)	
Heart and lung diseases	2 (18%)	3 (27%)	6 (55%)
Learning disability		2 (100%)	
Long-term condition e.g. diabetes, arthritis	7 (24%)	12 (41%)	10 (34%)
Mental health	23 (51%)	11 (24%)	11 (24%)
Total	42 (40%)	31 (29%)	33 (31%)

When people were asked to explain how the care did or did not meet their expectations and how it could have been improved, they made the following comments:

Autism

Two key issues were stated by people with an autism condition, to have led to the care they received not meeting their expectations. This was around the lack of support including in between appointments and poor understanding of autism by hospital staff.

> *During waiting for assessment there was no support offered. (B, 18-24).*
>
> *Hospital is far the worst [they have] no understanding of autism at all especially in accident and emergencies. (B, 35-44).*

Cancer

For some people with cancer, the care they received met their expectations mainly because *"All of the staff I have met in NHS have been really good in the main".* Another person indicated that, although initially confusing, the service was excellent. However, other people said the care did not meet their expectations because they had to *"call to chase for appointments"*, and that there is a *"lack of communication between doctors [and] different advice is given".*

Dementia

One person indicated that the care did not meet their expectation because of a lack of communication from services with them as a carer of someone with a dementia condition. People who responded said: *"I had to do all the phone calls and so on. No one ever just contacted me as my husband's carer".* One person said that their expectations could have been met if they had access to opportunities for socialising: *"would appreciate the occasional contact with the outside world as life can be very lonely".*

Heart and lung diseases

Poor communication between services and lack of continuity of care were some of the issues mentioned by people with a heart and lung disease. This comment captures some of these views:

> *Better communications between hospital and GP. Being able to access the same GP who would be responsible for your case would be a big step forward. You can usually get an appointment with 'a doctor', but then they're scrabbling through your notes and letters from the consultant to try and find out what's going on with you. Another appointment would be with a different doctor; process repeats itself. (S, 65-74).*

One person indicated that having information about managing their condition could have improved their expectations:

> *It is sometimes difficult to accurately assess what attention needs to be given to the condition in*

> *everyday life. For instance, what is the best regime to follow? (B, 75+).*

Learning disability

Not being able to have a carer in the hospital is the one key concern that people indicated. They said this impacted them as they were unable to do things for themselves.

> *Once when in hospital, the ward sister would not allow my carer to be with me. This was essential for me as I was unable to do some things for myself. (B, 35-44).*

Long term condition

Key concerns for people with a long term condition were around on-going support including waiting times, lack of inclusion in care and decisions around care, poor information sharing and poor follow-up of safeguarding concerns. Regarding waiting times, people indicated concerns with waiting times for appointments *"sometime appointment are months late"*, time taken to receive results *"I'm still waiting for the results of a scan I had last yearand issue prescriptions, and time taken to receive a report following clinic visits "waited quite some time before endoscopy report received, about 6/8 weeks"*. One person commented on the impact long waiting times have on the care received:

> *I find written communications are very long winded, i.e. Can take up to 4/6 weeks to receive letter after clinic visits. I also feel that ALL scan results take too much time in getting the reports to consultants this then had a knock on effect and leaves the patient visiting a clinic where there is no results, wasting patients and more importantly consultant's time. It also does little to help with stress factors for the patient.*

People also pointed out that poor ongoing support and lack of involvement in the decision-making around care being received was a key factor in their expectations not being met.

> *Most of the time I wasn't copied in to letters sent to my GP. I was told I would have follow up appointments but the consultant just wrote to my GP and discharged me with no diagnosis and no further investigation. (S, 35-44).*
>
> *No ongoing support other than when I eventually got a doctor's appointment. (S, 55-64).*

In terms of how care could have met their expectations, people indicated the following:

> *Some leaflets about diabetes. (B, 55-64).*
>
> *They all need to chill out a bit. (S, 65-74).*
>
> *Quicker communication between services. (B, 18-24)*
>
> *Safeguarding should have been followed up.*
>
> *Interest in your condition would help. (B, 65-74).*

Mental Health

There were varied reasons given by those with a mental health condition as to why the care they received did not meet their expectations. This included cancellation of appointments, lack of continuity of care, lack of support, long waiting times, lack of transparency, lack of follow-up, poor communication and information advice, needs not considered, lack of mental health staff at different level in NHS services, failure to involve carers effectively, and failure to address complaints. Long waiting times included times waiting for appointments, and for urgent help, and long waiting lists for treatment.

> *I needed urgent help. It took months to get, letting me get worse. (B, 25-34).*
>
> *Psychology was offered too late, due to waiting list of up to one year. (B, 45-54).*
>
> *The waiting times were too long. In the end by the time appointments came through I was already feeling better, but it could have been the opposite and for many people it is. (B, 35-44)*
>
> *Usually I have to ring to get an appointment to see a psychiatrist - as opposed to them writing a letter. Therefore, appointments vary as it takes me to phone them. (B, 55-64).*
>
> *The waiting times are ridiculous. Services are struggling to provide adequate care under the current demand. (B, 25-34).*

Other people expressed some concerns with staff, in relation to expertise on mental health, staff shortages and staff attitudes. This, they argued, affected the quality of care, continuity of care and in some cases led to the cancellation of check-ups and lack of follow-up of patients' post-treatment.

> *Check-ups with the mental health teams are often cancelled due to staff shortages and rearranged months later than they were supposed to be. Most appointments are with locus so they have no understanding of history and are unable to help. (S, 35-44).*
>
> *GP is fine and I do think they do what they can, I understand they are not specialists. Other low or mid-level mental health services through the NHS seem to be non-existent. (S, 25-34).*
>
> *The doctors referred me to a support group, but never contracted them or me after my meeting. (B, 18-24).*
>
> *With the female psychologist the communication was good, yes. I had two others before that - I was criticised, no - couldn't wait to get out of the system. It knocked my confidence. I don't know what could have been better, perhaps empathetic. (B, 65-74).*

Some people pointed out that poor communication and information led to care not meeting their expectations. This included communication between services and communication with patients which in one case led to their needs not being listened to.

> *[There was a] lack of transparency and information. (B, 18-24)*
>
> *Lack of communication between NHS services. (S, 45-54).*

Lack of general support, lack of support for carers including failure to involve them, and failure to address complaints were some of the issues mentioned by some people.

> *The next questions are irrelevant as none [support] was offered. I contacted Rethink but this did not help. I contacted independent advisers. I contacted private individuals in and outside family. All said they were surprised at zero support and I must go back to NHS, but this was too hard with no contacts offered. So nil response to next questions. (S, 65-74).*

Other people stated a number of things that resulted in the care they received meeting their expectations. This included regular meetings, reviews and communication.

> *I had a weekly online review with the specialist who was looking after me. (B, 18-24)*
>
> *I was given letters explaining my meetings and communicated with via text. (B, 18-24).*
>
> *They arranged regular meetings. (B, 35-44).*

Some people stated that the following issues would have improved the care they received:

> *Consistent report and recognition. (B, 18-24).*
>
> *Improve by [making] more groups available and shorter waiting time. (B, 18-24).*
>
> *Shorter wait times. (S, 45-54).*
>
> *They should have listened to my needs more. (B, 35-44).*

Conclusion: Communication from services

The majority of people found their experience of waiting for an initial assessment to be slow or very slow. Indeed, across the seven conditions, only 17% of people found their wait for an initial assessment to be fast or very fast. For some conditions like autism, the wait for an initial assessment was as long as ten years. A source of frustration for people was the long wait between appointments in the process of getting a diagnosis. As one person said, it took two years from initial diagnosis which included three spells of waiting for appointments (nine months, six months, and five months). Long waiting times led some patients to pay for private assessments. This might mean that only those with the financial means or someone who can financially support the private assessment and are able to progress their cases quicker than those not able.

The time taken to receive results was of concern for some people. One person reporting waiting ten weeks for the results of an MRI scan and another four months to discuss test results with a cardiologist. Equally, the time taken to receive treatment was also of concern for people, leaving some without support for long periods of time. Only 16% of people found the wait between initial assessment and receiving treatment to be fast or very fast. This in some cases made their conditions worse. For example a person reported waiting 8 months to get counselling.

Some people were concerned about the lack of consistent communication when they accessed services. It was worrying for people when they had to wait for long, especially between appointments, without contact or information. They reported an ongoing lack of interest in following up patients by NHS services that in some cases they had to chase to NHS for appointments and information. Lack of communication appeared to also affect carers. One carer said no healthcare professional ever contacted them as a carer of a spouse and they always had to chase for information.

Accessing ongoing support was often difficult or very difficult with only a little over half of people indicating that they had been offered access to further health and care support. People's views were varied concerning how well the support offered met their needs, with more people indicating that it did not.

Things that went well when people accessed care and support included: getting support at home, having a statement of needs or care plan, training, financial support, support managing condition, guidance on health and well-being, regular checks/reviews, access to specialist care and quality staff, follow-on support, access to appointments and quick referrals, access to information and advice, and access to support services especially local community resources.

To improve the care and support they receive, people want quicker diagnoses, quicker support, better follow-up support, reviews and guidance, better understanding of condition by healthcare professionals, easier access to GP appointments, better information and advice, improved access to services and increased choice, shorter waiting times in-between appointments, improved quality of appointments with specialists, consistent diagnoses, continuity of care, clear systems and processes, personalised care, better access to support when in crisis or in an emergency, transparency, and lack of inclusion of patients in their care and decision-making.

Time Spent travelling to access support and care

Overall, 47% of people used their own car to access support and care. More people with a dementia, heart and lung, a long term condition, Autism and mental health used their own car. Most people with cancer and a learning disability condition used a taxi whilst 40% (cancer) used their own car and 50% (learning disability) used another person's car. Overall,

Twenty-three percent of people indicated that they travelled by bus. This was the second most popular means of transport for people with autism, dementia, heart and lung, and mental health. Overall, 11% used another person's car, 10% a taxi, 3% a bicycle, and 1% used the train (see Table 15).

Table 15: What is your main means of transport?

	Another person's car	Bicycle	Bus	Other	Own car	Taxi	Train
Autism	1 (8%)		4 (33%)	1 (8%)	5 (42%)	1 (8%)	
Cancer					2 (40%)	3 (60%)	
Dementia			1 (33%)		2 (67%)		
Heart and lung diseases			2 (15%)		11 (85%)		
Learning disability	1 (50%)					1 (50%)	
Long-term condition e.g. diabetes, arthritis	6 (21%)		4 (14%)		16 (55%)	3 (10%)	
Mental health	4 (8%)	3 (6%)	15 (31%)	6 (12%)	17 (35%)	3 (6%)	1 (2%)
Total	12 (11%)	3 (3%)	26 (23%)	7 (6%)	53 (47%)	11 (10%)	1 (1%)

When asked how much time they would be willing to travel to access quick and accurate diagnosis, a majority (52%) said 30 minutes to an hour. This was the topmost choice across the different conditions. Twenty-four percent indicated they are only willing to travel less than 30 minutes. This was a first and second choice for people with dementia, heart and lung, learning disability, long-term condition and a mental health condition. Twelve percent said they could travel one to two hours, and another 12% over two hours. Only two conditions (autism and cancer) indicated that they could travel over two hours as their second choice. However, this was a third or fourth choice for most people (see Table 16).

Table 16: How much time would you be willing to travel to receive a quick and accurate diagnosis?

	Less than 30 minutes	30 minutes to 1 hour	1 - 2 hours	Over 2 hours
Autism		9 (75%)	1 (8%)	2 (17%)
Cancer		2 (40%)	2 (40%)	1 (20%)
Dementia	1 (33%)	2 (67%)		
Heart and lung diseases	3 (20%)	9 (60%)	2 (13%)	1 (7%)
Learning disability	1 (50%)	1 (50%)		
Long-term condition e.g. diabetes, arthritis	6 (21%)	14 (50%)	5 (18%)	3 (11%)
Mental health	16 (33%)	22 (46%)	4 (8%)	6 (13%)
Total	27 (24%)	59 (52%)	14 (12%)	13 (12%)

Equally, when asked how much time they would be willing to travel to receive specialist treatment, 49% of people indicated that they would only be willing to travel 30 minutes to an hour. Twenty-one percent said they could travel 1-2 hours for specialist treatment, followed by 19 % who said less than 30 minutes and 11 % who indicated more than 2 hours.

- For people with an autism condition, the majority (66%) said they were willing to travel 30 minutes or less and up to an hour and 34% said 1-2 hours or more.
- Eighty percent of people with cancer were willing to travel only 30 minutes to an hour with 20% willing to travel more than 2 hours.
- None of the people with dementia were willing to travel more than 2 hours with 33% willing to travel between 30 minutes and two hours.
- Sixty percent of people with a heart and lung condition indicated that they were willing to travel less than 30 minutes, 20% between 1 – 2 hours, 13 % less than 30 minutes and only 7% more than 2 hours.
- All people with a learning disability were willing to travel between 30 minutes or less up to an hour.
- More people with a long term condition (38%) and mental health (54%) were willing to travel 30 minutes up to an hour.
- Thirty-one percent of people with a long term condition were willing to travel between 1 -2 hours, 17% less than 30 minutes and only 14% more than 2 hours.
- Eighteen percent of people with mental health said they were only willing to travel 1-2 hours or under 30 minutes respectively with only 5% willing to travel more than 2 hours (see Table 17).

Table 17: How much time would you be willing to travel to receive specialist treatment or support?

	Less than 30 minutes	30 minutes to 1 hour	1-2 hours	More than 2 hours
Autism	4 (33%)	4 (33%)	2 (17%)	2 (17%)
Cancer		4 (80%)		1 (20%)
Dementia	1 (33%)	1 (33%)	1 (33%)	
Heart and lung diseases	2 (13%)	9 (60%)	3 (20%)	1 (7%)
Learning disability	1 (50%)	1 (50%)		
Long-term condition e.g. diabetes, arthritis	5 (17%)	11 (38%)	9 (31%)	4 (14%)
Mental health	9 (18%)	27 (54%)	9 (18%)	5 (10%)
Total	22 (19%)	57 (49%)	24 (21%)	13 (11%)

Conclusion: Time spent travelling to access support and care

A majority of people used their own car to access support and care with a smaller percentage travelling by bus or using another person's car. Parking was highlighted as one of the stressful areas for people who are chronically ill. One person indicated that the NHS needs to address the shortages of parking spaces and the cost of parking. These concerns with parking are an issue that has been highlighted by patients in Healthwatch Birmingham's recent report on people's experiences of hospital waiting rooms[12].

There appears to be a preference for shorter travelling time to access care and support amongst people we spoke to. More people across the seven conditions said they are willing to travel 30 minutes to an hour to access a quick and accurate diagnosis with fewer indicating they could travel more than two hours. Equally, a higher percentage of people said they were only willing to travel between 30 minutes to an hour for specialist treatment with fewer saying they would travel more than two hours.

Your expectations at each stage of care

People were asked what is most important to them when first seeking help. Overall, 48% said 'seeing any medically appropriate health professional who is free immediately'. This was more important for people with autism, cancer, dementia, learning disability, long term condition and a mental health condition. It was equally important for people with autism, learning disability, and a long term condition to 'see a health professional

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[12] https://healthwatchbirmingham.co.uk/wp-content/uploads/2019/05/HW-Birmingham-Hospital-Waiting-Room-Summary-Report-2019-F1.pdf

they normally see even if they have to wait'. People with a heart and lung condition listed this (i.e. seeing a familiar healthcare professional) as the most important thing. Overall, 37% of people indicated that 'seeing a health professional you normally see but you have to wait' is most important (see Table 18).

Table 18: What is important to you when first seeking help?

	Autism	Cancer	Dementia	Heart and lung	Learning disability	Long term condition	Mental Health
Don't mind (n =14,14%)	1 (9%)		1 (50%)	2 (15%)		5 (19%)	5 (13%)
Seeing a health professional you normally see but you may have to wait (n=36,37%)	5 (45%)			6 (46%)	1 (50%)	11 (41%)	13 (34%)
Seeing any medically appropriate health professional who is free immediately (n=47,48%)	5 (45%)	4 (100%)	1 (50%)	5 (38%)	1 (50%)	11 (41%)	20 (53%)

People were asked what is important to them when they first received a diagnosis and explanation of treatment or support options. Forty-nine percent of people said it was important that they saw any 'medically appropriate health professional who is free immediately'. This was the topmost choice for six of the conditions (autism, cancer, dementia, heart and lung, learning disability, and long term condition) with the exception of mental health. More people with a mental health condition indicated that seeing a familiar professional, even if they had to wait, was more important than seeing one who was free. Overall, 38% of people said 'seeing a health professional they normally see but they may have to wait is important whilst only 13% said it did not matter whether they were seen by someone familiar or someone who is free (see Table 19).

Table 19: What is important to you when you received a diagnosis and explanation of treatment or support options?

	Autism	Cancer	Dementia	Heart and lung	Learning disability	Long term condition	Mental Health
Don't mind (n=12,13%)			1 (50%)	1 (8%)		6 (23%)	4 (11%)
Seeing a health professional you normally see but you may have to wait (n=36,38%)	3 (27%)			4 (31%)	1 (50%)	10 (38%)	18 (49%)
Seeing any medically appropriate health professional who is free immediately (n=47,49%)	3 (73%)	4 (100%)	1 (50%)	8 (62%)	1 (50%)	10 (38%)	15 (41%)

People were asked what is important to them during the first initial treatment or support. Overall, 50% indicated that 'seeing a health professional they normally see but may have to wait' was important. This was more important for people with autism, a learning disability, long term and a mental health condition. Thirty-five percent said 'seeing any medically appropriate health professional who is free immediately' was important.

This was more so for people with cancer, dementia, heart and lung disease and a learning disability. Fifteen percent of people said it did not matter whether they saw a familiar health professional or someone who was free (see Table 20).

Table 20: What is important to you during your initial treatment or support?

	Autism	Cancer	Dementia	Heart and lung	Learning disability	Long term condition	Mental Health
Don't mind (n=14,15%)			1(50%)	1 (8%)		6 (23%)	6 (16%)
Seeing a health professional you normally see but you may have to wait (n=48,50%)	7 (64%)			5 (38%)	1(50%)	14 (54%)	21 (55%)
Seeing any medically appropriate health professional who is free immediately (n=34,35%)	4 (36%)	4 (100%)	1(50%)	7 (54%)	1(50%)	6 (23%)	11 (29%)

People were asked what is important during their long-term support. Overall, the majority (68%) of people indicated that seeing a professional they normally see even if they have to wait was important. Seeing someone familiar was more important for people with autism, heart and lung disease, long-term condition and a mental health condition. Views were split between people with cancer, dementia and a learning disability, with 50% indicating it was important to see a familiar health professional or someone who was free immediately (respectively). Nineteen percent of people said 'seeing a medically appropriate health professional who is free immediately' was important. Thirteen percent indicated that it did not matter whether they saw someone familiar or someone who is free immediately (Table 21).

Table 21: What is important to you during your long term support?

	Autism	Cancer	Dementia	Heart and lung	Learning disability	Long term condition	Mental Health
Don't mind (n=13,13%)	1 (9%)			2 (15%)		4 (15%)	6 (15%)
Seeing a health professional you normally see but you may have to wait (n=67,68%)	6 (55%)	2(50%)	1(50%)	9 (69%)	1(50%)	19 (73%)	29 (71%)
Seeing any medically appropriate health professional who is free immediately (n=19,19%)	4 (36%)	2(50%)	1(50%)	2 (15%)	1(50%)	3 (12%)	6 (15%)

Supporting you to have more control over your own care

When asked the level of support people needed from the NHS to help them stay healthy, the majority (68%) said they needed some support. This was the topmost choice for the seven conditions, with the exception of cancer where an equal percentage said they would like some support and a lot of support (40% respectively). Overall, 25% of people said they needed a lot of help. This was the second choice for all the seven conditions. Overall, only 3% said they did not need any support (see Table 22).

Table 22: What level of support do you want the NHS to provide to help you stay healthy?

	Don’t know	I don’t need support	Some support	A lot of support
Autism	1 (8%)		6 (50%)	5 (42%)
Cancer	1 (20%)		2 (40%)	2 (40%)
Dementia			2 (67%)	1 (33%)
Heart and lung diseases		1 (8%)	9 (69%)	3 (23%)
Learning disability			2 (100%)	
Long-term condition e.g. diabetes, arthritis	1 (3%)		21 (72%)	7 (24%)
Mental health	2 (4%)	2 (4%)	36 (72%)	10 (20%)
Total	5 (4%)	3 (3%)	78 (68%)	28 (25%)

People were asked what the NHS could do to help them stay healthy or manage their conditions. People told us the following:

Autism

People with an autism condition told us several things that would help them stay healthy or manage their condition: support for carers and patients, socialisation opportunities, skills training, better support for those with multiple conditions, more access to face to face support, continuity in care, better referral routes and free prescriptions. Below are some of the comments:

> *As a parent of a child with additional needs the NHS needs to more readily monitor the parents for signs of exhaustion, depression and stress. At no point have I been offered support and even when I asked for it I was just offered antidepressants. (S, 35-44)*
>
> *Cooking skills, social groups, managing money, and trips out. (S, 18-24)*
>
> *I have autism and I have other health conditions that after 4 years still have not been diagnosed so I get no help. I am in constant pain suffer falls frequently and have to use crutches or a wheelchair. I get absolutely no help. (S, 35-44).*
>
> *Seeing a familiar professional every time. (B, 18-24).*
>
> *Not have to pay for medication. (B, 35-44).*
>
> *Provide a service with proper referral routs and proper community support. (S, 18-24)*
>
> *The lack of support for autistic people is really poor this often leads to alienation of the autistic person and further mental health problems. (S, 18-24).*

Cancer

Information and advice, regular reviews, access to GPs, continuity of care, and training and support with staying healthy, were some of the issues that were important to people with a cancer condition. They said:

> *More information and training for young people about staying healthy for life. (S, 45-54).*
>
> *More regular appointments and check-ups. (B, 65-74).*
>
> *Provide better access to GP services including consistency of seeing one doctor. (S, 55-64).*
>
> *Access to advice and information when needed. (B, 55-64).*
>
> *[Support] with managing condition and guidance to stay healthy. (S, 45-54).*
>
> *[Support] linking with other health groups. (S, 45-54).*

Dementia

For people with a dementia condition, support for carers was important, better access to safe respite care, reduction in the cost of looking after patients at home, and ensure that care homes have the responsibility and skills to manage varied conditions that a patient might have. As indicated by the comments below:

[I need] a place of safety for the sufferer whilst the carer has an hour or so to relax and recharge the spirits. (B, 75+).

Provide more help at home not at such a great cost and help to provide the care needed for the patient myself. (B, 65-74).

Regulate care homes so they are responsible for looking after not just the dementia but other illnesses as well if it is just monitoring them. Doctors made to help with this and keep carers in the loop. (B, 65-74).

Heart and lung diseases

A majority of people with a heart and lung condition indicated these key concerns: access to quick appointments, regular reviews, and access to information and advice.

Provide regular reviews of illness management. (B, 25-34).

Arrange regular reviews of specific conditions that are serious. (B, 75+).

Be able to book appointments at GP quick and easy. (B, 18-24).

Easy access to a doctor. (S, 65-74).

Make quicker my cardiologist appointment. (B, 65-74).

[I want to be] fully informed on my condition and be given the information I need to manage it as best as I can whilst I await any treatment I may need. (B, 65-74).

Dietary support and encouragement to stick with it. (B, 75+).

Learning disability

People with a learning disability condition indicated that quick appointments, access to support groups, guidance on healthy living, and access to equipment would help them to stay healthy and manage their condition.

Long term condition

There were varied views on how the NHS can help support people with a long term condition stay healthy or manage their conditions. However, comments were mainly around issues of diagnosis (i.e. ensuring that their condition has been diagnosed appropriately), information and advice, appointments and continuity of care, regular checks and reviews, communication, staff, better access to ongoing support, prescriptions, parking concerns and improvements in listening to patients by health professionals.

Access to appointment and continuity of care

Always seeing the same GP who knows my condition very well. (B, 35-44).

Not reduce current access. (S, 65-74).

Physio services could be more accessible. (S, 55-64).

When problems occur, to have quick access and support to health professionals who can give advice and equipment if needed. (S, 45-54).

Regular checks and reviews

Have regular check-ups. (B, 75+).

More appointments for checks or advice when needed or guidance. Not just medicines. (B, 45-54).

Regular arthritis assessments in line with asthma checks. (S, 35-44).

Regular wellness and diabetes clinics. (S, 65-74).

Keep in touch with me not all the time but maybe every six months just to ensure I have not deteriorated. (B, 55-64).

Listening to patients

Recognise when a person of a certain age says they are in pain, not to be dismissive but to explore other reasons that may be the primary factor. (S, 65-74).

Take patients seriously. (S, 25-34).

Communication, Information and Advice

> *Am currently waiting on ophthalmologist report - letter says within 18 weeks. (S, 55-64).*
>
> *Communication levels need to be increased. (B, 18-24).*
>
> *Tell me all the options I have and could have to prevent asthma attacks in future. (B, 25-34).*

Staff

> *Inform the GPs to be better. (B, 55-64).*
>
> *Emergency care of qualified vetted people especially if someone can't live without care. (B, 45-54).*
>
> *Greater awareness and promotion of what Coeliac Disease is and its lifelong and long term implications. (S, 45-54).*

Access to parking

> *One thing I think that should be addressed is certainly, parking facilities, this is one of the most stressful areas for people who are chronically ill. First and foremost there are invariably insufficient spaces in the car parks for the amount of outpatients and visitors on a daily basis, I am fortunate enough to have a blue badge but even that doesn't always help, in fact we (my husband and I, who has cancer) went to the hospital and had to ride around 2 multi story car parks and 2 outside car parks and couldn't find a space, eventually we found what we thought was an ok place to park only to come back an hour later to find a parking ticket which cost us £25 (this on hospital grounds is unacceptable !!! £25 constitutes a large part of our spare income for food. So not only do you have illness stress you also end up with financial stress. Particularly when that week we had to go to hospital appointments between both of us Sun, Tues, Thurs and Sat. (B, 55-64).*

One person pointed out that there needs to be an improvement to medication regimes, including the involvement of patients in research so that they can access other treatments as well as challenging overpricing of medication.

> *Improve the poor medication regimes. Research into the use of T3 amongst existing patents, do not dismiss their evidence as anecdotal, it is evidence, Research/license Natural Dessicated Thyroid. Challenge the overpricing of medications by big Pharma. If necessary, import from other counties where the price is lower, i.e. be more flexible with licensing. Set up a manufacturing facility for generic medicines to help patients rather than lining the pockets of plutocrats. (B, 65-74).*

Another person stated that the NHS should:

> *Get rid of CCGs [as] they are obstructive and cost too much money. [Further stating] just consider the battles some thyroid patients are having. (B, 65-74).*

Mental Health

Access to services and support

People's views concerning access and support were around choice in the services they access, getting the support that actually addresses their condition, support to stay healthy, and more healthcare roles that can help people with a mental health condition.

> *Actual support and therapy for conditions. (B, 18-24).*
>
> *Give me more choice. (B, 35-44).*
>
> *Make more services available for mental health. (B, 25-34).*
>
> *Have more access to mental health walk-ins or provide more referral. (B, 18-24).*
>
> *Help to stay healthy in general - I look after myself, it would be general help needed. (B, 55-64).*
>
> *Mentors for severe cases of patients. (B, 18-24).*
>
> *More public health role. (B, 25-34).*
>
> *Offer access to counselling, CBT/DBT, support groups. Access to a mental health nurse based at the GP surgery who could offer mental health advice/support to people who are struggling but still able to manage themselves before symptoms get worse. Ideally the NHS would have adequate funding to offer people diagnosis and treatment before they reach crisis point. (S, 25-34).*

A person pointed out that support (e.g. treatment) should be holistic (including prescriptions for social groups and exercise) and not just reliant on drugs:

> *[The NHS should] have a more holistic approach to health. People should be prescribed massage therapy and talking therapy instead of just drugs. Social groups, exercise etc. Things people can't afford but that really help! For example now my back is really sore because of stress and I know massage would help (I already do regular exercise) but I can't afford it. It makes my overall health so much worse. I would only need a few times massage and the problem would be gone. Now it may just get worse and worse. (B, 35-44).*

Another person also stated that support should take into account regular changes that people with a mental health condition go through.

> *My fibromyalgia is inconsistent- some days I can't walk or dress. Other days I am fine. I don't get any help because I am not impaired every day. What happens when I am though? (B, 45-54).*

Better prescription management support for those receiving prescriptions from multiple sources was of concern to one person:

> *I get prescriptions from five different sources and it's not linked up. I need help with it, and managing my symptoms. (B, 25-34).*

Referral

Whilst one person said more *"counselling sessions would provide them with someone to speak to" (B, 18-24),* another said they prefer a referral to a psychiatrist. They argued:

> *Refer us to a psychiatrist because I had to go to a private one. They refer me to counsellors every time and I want a more direct approach. (B, 18-24).*

Reduce waiting times and reviews

People suggested that waiting times should be shorter, care more consistent and better follow-up following consultations.

> *Waiting time of 4 weeks at the max. (B, 18-24).*
>
> *Less waiting time more consistent care. (S, 35-44).*
>
> *Follow-ups on all consultations. This never happens or is rare. (S, 65-74).*

Information and advice

People said they would benefit from having access to information and advice that helps them manage their condition and access alternative services, and advice offered through varied communication means (such as phone call chats, emails). They also noted that health services would benefit from information on different conditions.

> *Awareness and information for myself to understand what I have. (B, 18-24).*
>
> *Practical ways to implement into daily life so don't have to use NHS resources each time have a crisis. (B, 35-44).*
>
> *Education programmes. Short guides from Pharmacy. (B, 45-54).*

Healthcare Staff

Generally, people felt that staff should:

> *Be consistent. (B, 45-54).*
>
> *Be more sympathetic to hidden illnesses affecting work ethics/daily activities. (B, 18-24).*
>
> *Help me, talk to me and understand me. (B, 45-54).*
>
> *Be more caring and sincere and not talk about patients that have just been discharged in front of you, as it is unprofessional. (S, 45-54).*
>
> *Make sure they are addressing the right condition by reading information thoroughly. (S, 45-54).*
>
> *Help me gain access to the appropriate treatment rather than making it more difficult. (B, 25-34).*

Other people pointed out that GPs should enable patients to talk about mental health problems they are facing, and a good understanding of mental health. They also noted that there needs to be more investment in primary care services.

> *Make it easier to talk about mental health problems, I function fairly well on a daily basis but when I go downhill, I find it hard to talk my GP as he will just say its stress. (B, 35-44).*
>
> *The service that I want to see invested in is front line services - GP services. GPs are having breakdowns, seeing so many patients. If you have good GPs who have good psychological understanding. (B, 65-74).*

Another person indicated that there should be better involvement of carers in mental health as it is for dementia to ensure that the patients are involved in their care:

> *Don't write-off the patients without intelligent input where patient is unable to i.e. through carers. It works for dementia without asking. Should be ditto for mental health ups and downs. Doctors don't appear to understand using patient confidentiality in a positive effort for patient outcome, rather than a Tool for dismissing valuable input. (S, 65-74).*

General Comments

People were asked to provide any further comments on what the NHS can do to make care better. Generally, most people expressed appreciation for the NHS, recognised that staff work really hard and indicated that the NHS had supported them through some of their most difficult moment. However, they noted that improvements were needed for ongoing support, increased investment in the NHS, better involvement of carers, better access to appointments and changes to the appointment system, more staff, research that looks beyond the numbers, better support for patients, improvement to the whole process, quicker waiting times for treatment, and improvement to services.

Investment in the NHS

> *The 'internal marketplace' created within the NHS is a disgrace and prioritises the wealth of a few over the health of the country. The professionals we have experienced have been EXCELLENT and their hard work/dedication is undermined by the underfunding and conscious degradation of services. (Autism /B, 35-44).*
>
> *Thought the NHS were promised billions, not £20 million. (Cancer / S, 45-54).*
>
> *More doctors and nurses needed. (Learning disability / B, 35-44).*

Ongoing Support

> *The lack of support pre and post diagnosis is very poor this leads to further problems for the autistic person and their families who have to battle constantly for help and support which often leads to mental health issues for the person and their carers further putting strain on the NHS. (Autism / S, 18-24).*
>
> *No ongoing support for Fibronyalgics - no benefits available but struggling to work. (Long term condition / S, 55-64).*
>
> *NHS is awful. They couldn't even refer me to a nutritionist/dietician. I found one myself and I pay a lot. NHS has been useless. (Mental Health / B, 18-24).*
>
> *Please give help when it's needed, not a year later. Don't make people loose years of their lives. (Mental health / B, 25-34).*

Appointments

> *Doctors' appointments are very difficult to obtain when needed, little wonder that A&E Departments are bursting at the seams. (Dementia / B, 75+).*
>
> *Access to clinician appointments are restricted by triage and there is no system for dealing with matters of real urgency. Example person who was seeking urgent support for a husband who was taken ill at work was not given an immediate appointment or told to take him to A&E but advised to telephone the next day for an appointment! (Heart and Lung condition / B, 75+).*
>
> *Typically telephoning for an appointment can take between 20 and 30 calls (Heart and Lung condition / B, 75+).*
>
> *Revising appointment system. Some input into making a suitable appointment. It's frustrating when*

> *you are waiting for an appointment and the letter comes giving a date when you are on holiday! You then go back into the process and have to wait another six weeks! Too cumbersome. (Heart and Lung condition / S, 65-74).*

Conclusion: Supporting you to have more control over your own care

Although views varied across the seven conditions, most people indicated they would be happy to see any medically appropriate healthcare professional who is free immediately when first seeking help or when receiving a diagnosis and explanation of treatment or support options. However, many people said they would prefer to see a healthcare professional they normally see even if they have to wait, during their long-term support.

A majority of people said they wanted 'some support' from the NHS to help them stay healthy with a smaller number stating they needed a lot of support. This was the second topmost choice across the seven conditions.

People want the NHS to provide sufficient support for carers and patients, support them with socialisation opportunities, skills training, better support for those with multiple conditions, better referral routes, free prescriptions, regular checks and reviews, better access to GPs, continuity of care, support with staying healthy, skills training, access to safe respite care, better information and advice, better access to equipment, access to support groups, involvement of patients in decisions about their care including better involvement of carers across the different conditions, continuity of care, improvement in diagnosing conditions, better access to ongoing support (especially when conditions change), and an increase in healthcare roles to support people (e.g. mental health staff at A & E).

Some people also indicated that more major changes are needed to the appointment system, improvement to the whole process of accessing care and support, general improvement to services and there needs to be better financial investment in the NHS. Other people said research carried out within the NHS should look beyond the numbers and understand the needs of patients better.

Focus Groups

Who did we include in the focus groups?

We conducted focus groups to enable us to hear the views of people who are seldom-heard. These groups helped us to develop a deeper understanding of what these people would like the NHS and Social Care to do to help support them to look after their own wellbeing.

Healthwatch Birmingham ran five focus groups, which heard the views of the LGBT community, people with sight loss, people with a learning disability, people who have experienced mental health problems, young people. Healthwatch Solihull ran two focus groups, which heard the views of people with hearing impairment, and parents and carers.

Sixty-eight people took part in the focus groups. All focus groups were mixed-sex, with ages ranging from 18 to 74 years.

- the LGBT community (Ageing Better, 10 people: (9 male)
- people with sight loss (Thomas Pocklington Trust, 7 people, (5 male)
- people with a learning disability (Casba, 20 people, (3 male)
- people who have experienced mental health problems (Changing Futures, 7 people, (5 male)
- young people (Lighthouse, 10 people, (8 male))
- parent carers (Parents/Carers Forum, 7 people, (0 male))
- people with hearing loss (East Birmingham and Solihull Hard of Hearing Club, 7 people, (0 male).

The topic guide covered four key questions:

- What does 'being well' mean to you?
- What do you do to stay well?
- What are the barriers to help yourself stay well?
- How would you prefer to access help, support or information?

What did people tell us in the focus groups?

What was 'wellbeing' for our participants?

All of the focus groups started by asking people what they wellbeing meant to them. This is important as it provides a clear sense of the goal of self-care. People mainly talked about a combination of physical and/or mental health, optimal functioning, and general quality of life.

Physical and mental health

For many of the people who participated in our focus groups, wellbeing meant being both physically and mentally well, as these are interrelated. A young person told us that when their mental health is bad it affects their physical health. It is then a downward spiral. This understanding ran across the focus groups. One woman with a learning disability told us that when she feels physically energised her mental health improves. We found that young people were particularly vocal about this relationship:

> *Your mental health and physical health go hand in hand ... when you're low your physical health is affected, which then makes your mental health worse. (Young person's Focus Group)*

However, some people found it difficult to maintain both their mental and physical health. A carer told us that they felt they had to ignore their physical needs in order to stay physically well. They said,

> *I do not have time to worry about myself when I am trying to deal with my kids; we lose our own identity.*

Other people, such as some people with disabilities, can find it challenging to exercise:

> *There is an issue for people with disabilities ... there are lots of people that just don't want to go out-and-about, but they may not be happy with that. (Sight-loss Focus Group)*

Other people thought of wellbeing in terms of being physically well. For example, one person with learning disabilities wanted to not be out of breath and use an inhaler, another in the same focus group wanted to be physically well so that physical activities would be easier.

However, across all groups, people gave more emphasis to mental health rather than physical health. This was because they felt that mental health affects every aspect of their lives.

> *If I'm not mentally well, then I feel negative about everything, and then it dominoes throughout the day. So, for me, it's less worrying about finances, job, the way the world is going. (Mental Health Experts by Experience Focus Group)*

A person with a learning disability summed this up well by saying that if they feel happy they can do a lot more. People can often cope with, e.g. sight loss, if they are emotionally well. One person said that because he has normalised sight loss is not part of his thinking about wellbeing; rather what is important is not feeling stressed and able to sleep.

The ability to function optimally, regardless of the disability or condition, was also raised in the LGBT focus group. Mental health enables them to feel in control of their life and knowing when to go and see a GP:

> *Being in control of my life other than being the effect of the conditions. (LGBT Focus Group).*
>
> *How is ten minutes in front of a doctor any help? They aren't going to be able to tell [if you are having mental health problems] I think you've got to be able to know when to go and ask for help ... however, you should have some sort of check-in while you are doing that. (Mental Health Experts by Experience Focus Group)*

They thought it was important that the NHS helped them to do this.

> *Optimal functioning. What that means is that we are functioning to our best potential. Regardless of what conditions you've got .., you are striving to do your optimal functioning ... [how can the NHS] work with patients to look at how can we keep our optimal functioning going? (LGBT Focus Group)*

Lastly, it is noteworthy that the young person's focus group showed a high level of knowledge of, and interest in, emotional intelligence. One person said that mental wellbeing is about having control of your emotions:

> *Being well is about having control of your emotions. Having an understanding of your own*

> *emotions and those of others. If you feel you want your own space, it's about having time for that and understanding that others might feel the same and giving them space. (Young person's Focus Group)*

Quality of life

People who participated also defined wellbeing as having the freedom to 'get out and about' independently and cheaply. A Mind Expert by Experience told us that this is particularly difficult for people with limited mobility, for example, some elderly people. They said it was important to have access to shops locally and to a good public transport system so that they could visit places. This emphasis on cheap public transport to be able to attend activities was also raised by people with learning disabilities, who said that this was important as it was too expensive to pay for a taxi. Carers said that being able to go out is important to their wellbeing.

> *Being able to get out-and-about, to be honest with you. I used to love hiking and going for long walks. Now I can't because of the restrictions in being to visualise everything properly... If it wasn't for my cane, I'd be tripping up all over the place - which I do regularly! ... For me, getting out and about, and not having to rely on someone else, I don't want that! (Sight-loss Focus Group)*

These definitions of wellbeing may provide the goal to be achieved as a result of self-care. Participants want to feel happy, to get out of their house, attend activities and feel independent.

We asked, 'What do you do to self-care?'

Focus groups participants said they do a huge range of activities to stay well. These included hobbies, such as art, music, gardening and knitting, listening and writing music, meditation and prayer, as well as simply enjoying nature.

> *I'm a registered carer for my mother who lives with me. I have done at mindfulness course and wellbeing good. They are very good...They make you feel better physically and emotionally (LGBT Focus Group)*

People get out of the house to improve their wellbeing, but as mentioned above, this is also a sign of well-being; producing a 'virtuous circle' of wellbeing.

> *Those little things can go a long way to making someone feel okay. Without needing more expensive interventions. Going to the pub once a week, and knowing your route to the pub, is getting you out-and-about. It makes sure you are not isolated and stuck at home in a rut. (Sight-loss Focus Group)*

People also told us about the importance of exercise in order to self-care, and about the importance of support to exercise:

> *I go rowing. To be on a river, first thing in the morning, with the glistening light on the water, on my own. That is the most calming, collected peace for me. (Sight-loss Focus Group)*

> *There needs to be support for young people to reach their goals. It needs to be flexible for the individual... I had a 1-2-1 at the Lighthouse and I now have a goal to go to one boxing class before my next 1-2-1. This is manageable for me. (Young person's Focus Group)*

Others self-care by stopping 'bad habits' such as giving up smoking and eating fast food.

> *My diet is pretty poor, to be honest, it makes you feel a bit crap really. If you are not eating well, you go to the Doctors more; you're stressed, not sleeping very well. (Sight-loss Focus Group)*

People also highlighted the importance of rest and relaxation, as was keeping busy. One carer told us that they self-care by going to work as it gives them a break from being a carer. Some people cared for themselves by volunteering to care for others. An LGBT focus group participant explained this by saying that by shifting his focus away from himself to helping others gave him a raison d'etre for living. A person in the sight-impaired group shared a similar experience with us:

> *I started to lose my vision in 2012 ... I found it very tough mentally. And I isolated myself. I wouldn't go out, I wouldn't talk to anyone, and that led to a decline in me physically... I started to want to do more, so I volunteered with RNIB. Then this guy came, he had lost his sight and was in a poorer mental state that I was. And I realised that if I kept on doing what I was doing I would end up like that, so I started to feel better about myself, became more physically active and got better mentally. (Sight-loss Focus Group)*

People also told us that prevention is key, for example preventing a crisis in a child's health keeps families who are carers well. In addition, MIND Experts by Experience suggested that the government need to invest in services for people earlier on before people actually get into crisis - this would be more cost-effective.

Other ways that carers self-cared was by switching off emails one day a week, and by not dealing with professionals during rest periods:

> *In school holidays and weekends, I won't deal with professionals; they cause more stress. That keeps me sane. (Parents/Carers Forum Focus Group)*

Why do some people not self-care?

This question was not a focus of this project, but some people offered answers to this question, therefore this section is brief but important. Services can be offered, but if people do not use them, then their well-being will not improve. As with the general survey findings, people in the focus groups said it was important for patients to take responsibility for self-care, and this requires building independence and patient choice. One person expressed the view that a culture change is needed away from expecting the NHS to 'fix' people. This person explained that in countries where people pay for their healthcare there is more of an incentive to stay well.

However, there was an acknowledgement that motivating people to self-care is complicated and that they need help to self-care.

> *I am a bit cynical about self-help. There are so many people who will not self-help. And I'm sure there is a lot of illnesses and problems because people don't self-help... There are a lot of barriers. There is nothing like this wonderful exercise of Brexit to show how different people are. We are so individually different. (LGBT Focus Group)*

> *Self-care is always going to depend on the individual. Some motivated to maintain well, others are not. I needed help to get to a place of being motivated. (Mental Health Experts by Experience Focus Group)*

We asked, 'What do you need to self-care?'

Control and choice over decisions

Mind Experts by Experience told us they needed to have the independence to make choices and decisions, for example, to have the autonomy and freedom of choice to access the services they choose to access. For some carers, this meant better access to GP appointments, and others said they would be willing to travel further for better care.

In the young person's focus group, they suggested that the NHS needs to provide more counselling, however, another member of this group said that counselling does not always work for people. There need to be more options for people so if one thing does not work there is something else to try.

Mental and physical health education

We were told that sometimes the support for people with disabilities is too basic, and therefore does not provide the support needed to self-care. For example, personal resilience is important in order for the person themselves to develop coping strategies:

> *Lots of this is about personal resilience - how you cope and how you come up with strategies to cope... talk to a rehab officer, they can teach you the route to the bus stop, but when you ask about coping strategies they can't help. (Sight-loss Focus Group)*

In order to self-care, patients need to be provided with health education. People with sight loss told us that they need to be taught how to be aware of indicators of poor health that they then need to seek help about.

After the diagnosis of a condition such as sight-impairment, it is important that health and social care professions provide an appropriate level of training and equipment for the person to remain independent. We were told that this is often too basic:

> *Given no help from H&SC to stay independent. Teach you how to cut food, but if my cane broke, I couldn't afford to buy a new one. I'd be stuck in the house. (Sight-loss Focus Group)*

People with sight loss also told us that many newly diagnosed people do not receive any referrals to services when they are diagnosed. This means that they are often not supported to self-care, to retain the remaining sight they have, or to manage with the disability. The effect of this on people is increased isolation and deterioration.

More easily accessible information for Patients/Service users/families

Participants wanted the NHS and Social Care to help people access the knowledge they need in order to self-care. This included trustworthy information, providing understandable and accessible information in relation to their appointments and tests and signposting to other services,

Trustworthy, understandable information

Participants told us that in order to self-care they need trustworthy information on which to base their decisions, but this was very difficult to find. There are several barriers:

Technological barriers

Many of the people we spoke to with LD do not know how to use smart phones and apps, and they cannot access the internet easily. This barrier also exists for older people:

> *There are a lot of elderly people that are frightened of using the internet and don't know how to use apps. If they don't have people to help them with the use of these, and the information is provided via these formats, then they will be left out of a hell of a lot of information. (LGBT Focus Group)*

Information overload

Even if a person can access the internet, a common point of view was that there is so much information on it; it is difficult to find the correct information:

> *There so much information, you just don't know where to start, you don't know how to sieve. You need to be helped out, rather than being bombarded by so much information. It's Google everything! It's so vast. You need to be shown how to find what you need. (Sight-loss Focus Group)*

Knowing if the information is trustworthy

Even if the technological barriers are overcome, and the person finds relevant information, how do they then know that it is trustworthy? People in Solihull with hearing impairment told us that they just did not know if the health information they found on the internet was correct. A member of the LGBT focus group described his frustration with knowing if the information was trustworthy by saying:

> *There is evidence online that [herb name redacted] will make you lose all your weight ... but if you read Google, there is all the evidence that there is no evidence! ... It is like actually a huge factor that makes this that tells you how good it is. (LGBT Focus Group)*

This same group explained that even if they find trustworthy information it is often hard to know how to act on that information. For example, current food labelling providing grams of salt and fat etc. is difficult to relate to their own food choices. This group felt that notice boards and leaflets providing trustworthy information would be helpful. Participants in East Birmingham and Solihull Hard of Hearing Club felt that NHS 111 was a good source of information, others in this group suggested talking with a pharmacist, if you feel they are qualified to answer the question. Members of the learning disability focus group supported both of these recommendations. However, they felt that they need easy-read information with pictures to know when it was appropriate to call NHS 111.

Accessibility Information Standard

Participants generally felt there is a lack of the delivery of the Accessibility Information Standard (AIS), and this is a barrier to self-care. People said they need to understand the information given to them by health professionals, including leaflets, appointment letters and test results. Because of this third sector organisation such as CASBA need to help their members understand these communications.

Leaflets and labels

Leaflets need to give sufficient information, but not too much. One person told us that patient information about diabetes care is usually too vague or too clinical. It is above their head. LGBT. A person with sight-loss told us that some GPS are still providing blind people with paper leaflets, that they cannot see. This not only impacts self-care because the person cannot read the information but also reduces the independence of the patient.

Similarly, medication labels can use words that some people with a learning disability do not understand, possibly leading to the person not being able to self-care as well as they would like to. Also, people with a learning disability may need to have information provided in large print, to make it easier to understand.

Letters

The NHS is also still sending blind people paper letters. One person described the impact on his self-care:

> *My dad was asking me all sorts of questions because I had to get him to read the letter [from the GP]. (Sight-loss Focus Group)*

When patients do not understand appointment letters, this may result in them not attending appointments. One woman with a learning disability told us:

> *When you have a smear, when they send the information out in the normal version to explain what the appoint is for - they don't have the easy read version. Difficult for people with LD to understand. So people don't go as they don't understand what they are being invited to. (Learning disabilities Focus Group).*

Test results

Test results also need to be understandable, using appropriate language for the patient. In consultations, health professionals need to use language that the public can understand, so that they can then act on the information to self-care. People in the learning disability focus group suggested that GPs can easily see that a person has a learning disability in their file, and knows how to use the appropriate level language.

In the Learning Disability focus group, people told us that words such as 'suspect' in a test result letter are very frightening. An LGBT focus group participant told us that in order to self-care, it would be good to have the actual results, and not just being told that you are okay or not. It is also important not to just give the results but to explain their meaning and implications in a way that the patient can understand.

> *Professionals talk in a clinical way, in jargon. They need to make sure that the average 'man on the street' can understand what you are writing. They are talking in jargon. (Sight-loss Focus Group)*

A woman with learning disabilities told us it would be good if her disability was marked on file, and then the general practice could give her more time, explain things better and provide accessible information.

Services for people with language barriers

A person in the LGBT group told us about an Asian lady he knows who wants to improve her mental health by learning cake-making. However, she speaks very little English and can therefore not take part in any of the groups. She feels like she is being told 'you've got to fit with us or we can't offer you anything'.

Signposting

A lack of signposting to services and groups is a barrier to self-care. A person with sight impairment told us they had taken part in a focus group to discuss what the 'front door' for services in Birmingham should look like. His point was that it is hard even to find that 'front door'.

> *We did some work with the Birmingham City Council Citizen Engagement team; they asked, 'what would you like the front door to look like when you contact services?' And we said, 'It's not what the front door looks like, it's how do you find it!' That's the first question they need to be asking, and they had never considered that" (Sight-loss Focus Group)*

People valued the help of a professional that provides signposting to services. People with sight impairment described the high value they place on the help of the Eye Clinic Liaison Officer (ECLO). One man had been stuck at home, feeling isolated, and the ECLO (funded by Birmingham Vision) had provided him with a lifeline by telling him of all the groups and services that are available for people with sight loss. The ECLO signposted him to Birmingham Vision, and Birmingham Sight Loss Council.

> *Nobody apart from the ECLO officer told me anything, I would have been isolated with him. (Sight-loss Focus Group)*

The person explained to us that although he may have eventually come across those organisations online, for someone to have contacted him and told him about them made a huge difference and gave him encouragement to contact the organisations.

The group added that confidence is probably the biggest thing that people with such disabilities lack, for professionals to make direct contact with them makes a big difference. They also added the social media had made people more isolated.

Participants also told us that after they had been diagnosed with a condition, they found it difficult to self-care as the professional providing the diagnosis did not signpost them to support or information.

> *For instance, I fought for ten years to get diagnosed with autism, I got diagnosed, brilliant, fantastic, lovely, there was then nothing like "now you can have support from this group". "You're 66, why do you need any help?" (LGBT Focus Group)*

In the LGBT focus group, it was suggested that the role of the neighbourhood networks is to share knowledge, to find the gaps in services, put services in a place where there aren't any, and to signposted people to these. They added that everything should be kept in one place so that people can find information and services to help them to self-care.

Timely access to information and services

People told us that delays in access to information and services affected their ability to self-care. For example, people can get motivated to do an activity as part of their own self-care, but then they find out that there is a long waiting list.

> *Sometimes you get really excited - I'm going to do this! And then you're told 'Well, you're going to have to wait three months for this" You get frustrated and then go back into your shell. (Mental Health Experts by Experience Focus Group)*

The MIND Experts by Experience focus group suggested that this was due to funding cuts for activities, which resulted in them happening less often and reduced the number of people who could attend.

They also said that sometimes they ask professionals for information in order to self-care, but the professional does not know the answer and says they will provide it at the next appointment in a few months' time, and then they do not. Sometimes they do not provide the information at all to self-care. A man with sight loss developed neck pain from his position trying to see his computer screen. He asked for help with the pain but the health professional did not give it:

> *So what I did is watch about 10 videos on YouTube, started doing the exercises, and the pain was gone within a few months. (Sight-loss Focus Group)*

More community groups

In all focus groups, people agreed that there are insufficient numbers of community centres to help people self-care.

> *If we didn't come here [to CASBA] we wouldn't know where to go. (Learning disabilities Focus Group).*
>
> *We get so much from the Lighthouse, and Street League, but there is nothing else there need to be more options for when you are not working or in education. (Young Person's Focus Group)*

Participants felt that the STP should use some of the LTP funding to reopen local community centres.

> *There are community centres that no longer open because they aren't funded. Maybe some of the funding can be used to reopen these local community centres? (LGBT Focus Group)*

Participants felt that City Councils should improve this situation. One person suggested that City Councillors, as central figures in the community, could be more involved with making sure that their area has community centres. Another suggested that the Council should tell property owners that their empty business premises need to be given over to community organisations, or they have to pay full business rates.

> *The problem is, there isn't a community, there is no hub, there is no centre. There are lots of different ones. There are the mosques, there are maybe churches ... There used to be pubs, there really aren't community local pubs. We haven't really got community centres anymore. That is the problem. (LGBT Focus Group)*

Mind Experts by Experience specifically thought that there should be more support groups for mental health and for obesity as there seems to be a big gap with lots of alcohol support, but not much for some other disorders. The role of the NHS in setting up these were debated in the focus group, with some members believing that the NHS should take a lead (e.g. providing resources such as a room, and perhaps some type of structure); others thought that the groups should be led by community organisations, for example in the same way that Alcoholics Anonymous is.

The LGBT group also discussed this issue, with one member saying that the NHS has too much legislation and policies for them to be involved in 'grass roots' work. The group agreed that they wanted to see more joined up working:

> *The message I would like to see in the report is that health is everybody's business, not just the NHS. And, what I mean by that is that we can't heavily rely on the NHS only, and the NHS can't assume that we will suddenly wake up tomorrow, all self-care activists. We want to see the NHS and local council coming together investing more in grass root organisations and community groups around preventative work. I don't think the NHS can do this preventative work because there is a lot of legislation, and policies that they would have to go around to get there. (LGBT Focus Group).*

This person added though that voluntary sector would need to skill up if they were to run such groups:

> *... the voluntary sector could do a lot of things based on the goodwill of volunteers. [They need] Staff that have the skills that are required to that level. So if it was just about raising awareness about how to look after yourself if you have diabetes, you don't need to be a qualified diabetic nurse, you could just to a four-day training course with Diabetes UK, all the basic knowledge and go out and roll it out. So I want to see more investment from the NHS going out to the grass root organisations, and grass root organisations scaling up and sustaining themselves for prevention and self-care work. (LGBT Focus Group)*

Would reduce isolation

Community and third sector organisations play an important role in reducing the isolation that, as reported above, is an important aspect of people's self-care and wellbeing.

People with sight loss told us that the most fundamental thing they face is loneliness.

> *The most fundamental thing we are facing is loneliness, not having the support. Normally, people are lonely but for people with disability, it is even worse... I was stuck in my cubbyhole at home. If it wasn't for you guys, for Birmingham Vision, and the Sight Loss Council, I would never have come out. I would have been stuck at home. (Sight-loss Focus Group)*

The Mind Experts by Experience agreed, saying that loneliness is a killer, and it is important to bring the community together. Our young people agreed, saying that the stigma around mental health issues meant that they felt unable to talk about their mental health and seek support. This can increase their isolation.

> *For instance, when you break something and have a cast everyone groups around you, signing your cast and you feel supported. This isn't the case with mental health and people feel alone. (Young Person's Focus Group)*

Would provide more peer support

Peer support is important for self-care. Participants told us it enables them to socialise with people that have the same problems, and as mentioned above socialising with others is important for people's wellbeing.

> *Support from parent carer groups are what keep me going, without the groups of people who are like minded and understand I'd be lost. (Parents/Carers Forum Focus Group)*

Peer support also provides them with the information they need to self-care from trusted sources that they can relate to. These could be either via groups or individually via the telephone.

> *It would be great to have somewhere, where you can go and be safe, talk to someone, like a peer group ... and maybe you could also find out about services. (Mental Health Experts by Experience Focus Group)*

A Mind Expert by Experience told us that he needs support from someone that he can relate to, with the same type of background and life experiences. Speaking about doctors, he said:

> *If someone turns up in a £15K car and writes a prescription, I can't relate to someone like that. Privileged middle-class people often can't understand people's experiences from a different background (Mental Health Experts by Experience Focus Group)*

Would support training to self-care

People may have a range of training that they need to increase their ability to self-care, such as being able to use the internet to find information:

> *Having a buddy – at Ageing Better we trained some people in computers and they were pretty good*

> *at it. But you wouldn't do it on your own at home, you wouldn't have the confidence (LGBT Focus Group)*

They may also benefit from learning how to cook cheap and healthy meals. Casba, for example, has been running cooking courses for people with learning disabilities. Their focus groups members felt that it is important that the NHS funds groups like this, for people experiencing the same challenges, as people feel less embarrassed to attend such groups, and are therefore more likely to attend.

Information about local groups

As mentioned above, it is often difficult for people to know what is happening in their area, and to access information in order to self-care.

> *There are loads of things out there, but we haven't got the communication in the disability community generally to know what's available. (Sight-loss Focus Group)*

Young people suggested doing this via social media, although they also felt that too much time on social media was detrimental to their wellbeing. Similarly, a member of the MIND Experts by Experience group suggested that there was somewhere online where people can share information with each other. A group discussion then took place about whether someone from the NHS would need to moderate that information. There were also concerns about whether this type of service could be kept up-to-date, and not just turn into a chat room. It was also suggested in this focus group that it also might be possible to adapt the existing databases so that patient feedback about the services could be submitted. One problem highlighted is that there are many such databases covering this locality, many of which are out of date. The group agreed it would be better to have just one directory.

Often people find out about activities through 'word of mouth', with the person being in the right place at the right time, and knowing the right people:

> *A lot of it is standing about having a fag somewhere, and saying 'I'm thinking about this, what can I do?' And them saying what they know. (Mental Health Experts by Experience Focus Group)*

> *And this social prescribing that they do these days, well I do Tai Chi, but I didn't find out about it through a doctor... I discovered a had a Tai Chi class around the corner from me, free of charge, which I didn't know was there... I found out from someone else in the area who just told me. I didn't see a sign anywhere, nowhere medical... I live a mile away! I don't know how you find out (LGBT Focus Group)*

People often rely on the recommendations of their peers when making a decision about attending groups. As one MIND Expert by Experience explained:

> *You just have to have a fellowship of people that are of the same thing. You can't promote something like that, it's got to be an attraction. Other people have got to see that you are coming out of those groups better than you went in. (Mental Health Experts by Experience Focus Group)*

Support of faith organisations

Faith organisations have an important role in helping people to self-care, as they do not just have a spiritual duty to people, they also have a duty to help people with their wellbeing.

For example, mosques can provide support for older people, particularly if they have a separate community centre where there is preaching.

> *My Dad always says "Thank God there are mosques around. They can sustain us older people, because where would we go?" If you are a Muslim man and you are old ... you could almost therapeutically be active going and coming five times a day, spending time in the mosque with your friends having tea and biscuits, then doing some meditation ... so there is a lot of things to keep them occupied. But my heart goes out to communities where they don't have that, e.g. the Church is open for the Sunday service but then is often closed, unless you are part of very organised activity. ... I would like to see how to get into this self-care by bringing other religious organisations on board with us, so they are 'part and parcel' with working with the health and wellbeing agenda. (LGBT Focus Group)*

Members of the LGBT focus group suggested that the NHS works more closely with Birmingham and Solihull mosques. One model of this type of working is already happening in Manchester with men who could not originally be bothered to get a diabetes check;

> *In Manchester … nurses started coming (to the mosque) on a Friday and started getting them when they were leaving. And the service was so good! Some of them didn't realise that they were borderline diabetic… suddenly they started to see the importance of being screened … (LGBT Focus Group)*

Reduced societal stigma

The public poorly understands some conditions, and this detrimentally affects people's wellbeing and ability to self-care.

Public/employers more aware/understanding of disabilities/conditions

Mind Experts by Experience suggested that schools provide mental health awareness. This would help change the negative language sometimes used by people to describe people with mental health problems and to remove the stigma.

In addition, employers need to work to reduce the stigma of mental health issues and support people to self-care. One man told us:

> *What would have helped me for years, I struggled for years, and a lot of it was from hiding mental health problems. I was in a high powered job, in an environment (the University) where they were trying to get rid of people was not on. There was no help for anyone, not even the students. In my 30 years working for the University, I was only given one hours training to help spot students with mental health problems. (Mental Health Experts by Experience Focus Group)*

One focus group member felt that, even within BSMHFT, employees rarely admit that they have a mental health problem. They asked:

> *'How are NHS organisations going to get rid of stigma in public if they don't get rid of it in their own organisation? (Mental Health Experts by Experience Focus Group)*

Stigma also affects the wellbeing of people with physical disabilities. One man with sight loss told us that:

> *It's the way you are treated in society, that really impacts your mental health more [than the disability]. (Sight-loss Focus Group)*

Another member of this group said that he needed people to understand that having no sight does not make people stupid. He said:

> *[In order to maintain independence …] people need to understand. I have never had any sight. People need to understand that that doesn't make us stupid. (Sight-loss Focus Group)*

More support from the NHS and Social Care

The NHS and Social Care system needs to be set up to fully support people to self-care. People who participated said that these organisations could support them to self-care by providing better access to services (e.g. support workers), patient centred GP consultations, well-trained professionals, continuity of care, better patient and public involvement (PPI) in the design and delivery of services, and joined-up NHS/Social Care with good online systems.

Better access to services

Support workers

People with learning disabilities told us that their time with support workers was very time-limited, and they would like more time with them. This report has described above the difficulties for some patients of understanding verbal or written information communicated by health professionals. In addition to providing information that meets the AIS, another way of overcoming this barrier might be for support workers to attend appointments with people with learning disabilities.

In addition, an acknowledgement that disabilities and conditions sometimes mean that however motivated the person is to self-care, they still need to support the NHS and/or Social Care.

Location and timing of service provision

We were told, in the LGBT focus group, that it seems that in Birmingham that therapeutic services run in affluent areas (e.g. Moseley), and crisis services are delivered in poor deprived areas. Therefore, if a person in mental health crisis lives in an affluent area they then have to go to an area of Birmingham or Solihull that they do not know or feel com comfortable in. Similarly, people who live in deprived areas should not have to travel to affluent areas to receive therapeutic help. Participants told us there needs to be fairness and distribution of services across the city, not just, 'prevention is for the posh areas'.

Participants in the MIND focus group suggested that information is taken out to communities, for example by having a parked truck.

People with sight loss also find it difficult to travel to unfamiliar locations and suggested that more services should be available via telephone, particularly those where it is unnecessary to see the person face to face.

Often self-help training provided by the NHS is during working hours, and therefore many people with jobs cannot attend:

> *I was recently diagnosed as pre-diabetic, so they want me to go on this eight-week course, but I work Monday to Friday, and I could only get these courses during working hours... That's not practical... it would be helpful if it were on an evening or weekend. (Mental Health Experts by Experience Focus Group)*

Patient Centred consultations

People value the support and information that they get from General Practice, and generally wanted more support from their general practice to self-care. They would like health professionals to focus not just on the long-term emotional health issue or physical disability, but to provide help and self-care advice for other health concerns that the patient is presenting. We describe above in this report how important mental health is important to many people's sense of wellbeing. People who participated want health and social care professionals to take a more holistic approach to patient care, that is, to see the person as an emotional and physical whole, rather than focusing on discrete problems. People who participated also felt that health professionals need to see it as their role to ensure that patients to self-care and provide them with the support the patient needs to do this, whether direct practical support or by coaching them.

Support from General Practice to self-care

People see GPs as a valuable source of information to self-care. For example, people who were have hearing impairments said that they would go to the GP if they wanted information about their health. Similarly, young people and people with learning disabilities told us that they would seek information from their general practice to self-care. They valued not just the support of GPs, and felt that more patients should be encouraged to speak with their practice nurse:

> *Practice nurses might the best people to explain minor conditions (LGBT Focus Group)*

It was also suggested that there are mental health nurses based in GP practices, so care devolved out of the GPs hands.

Some people said that they valued personal face-to-face conversations with people:

> *... you want the personal contact as well, particularly if you are 84 and living alone, you need someone to say, "How are you?" (LGBT Focus Group)*

Holistic assessments to help self-care

People with sight-loss told us that health and social health professionals tend to focus on their disability, rather than the health and social issue that the patient wants to talk with the professional about:

> *Health professionals really focus on that aspect [sight loss]. You can go in about anything, you need a new hip, anything, but as soon as you say 'I can't see very much' they say 'Oh, how do you cope with that'. And I think, I'm not here to talk about my eyesight, but it completely changes the focus of the appointment. (Sight-loss Focus Group)*

They also felt professionals often had a lack of understanding about how meaningfully to support patients and carers to self-care. For example, they give magnifiers out in low vision clinics; as if it solves all problems. Similarly, a professional simply telling a patient how to make a hot drink has limited benefit. Participants would like the professionals to see them as a whole person, to ask about their needs, and what they need to know to self-care, for example how to take the dog for a walk now they are blind. In addition, they would like professionals to ask them about their wellbeing, including their mental health, and to be signposted to other organisations if needed.

Healthcare professionals include in their role supporting people to self-care.

The Experts by Experience want health professionals to be more proactive and check in with patients to make sure that they are engaged in their self-care.

> *[about mental health] I hadn't been to the doctor for years, because I thought everything was okay. But it patently wasn't. Sometimes you need somebody external to tell you hard facts, and how your behaviour is damaging yourself. You need someone to give you a kick up the backside. (Mental Health Experts by Experience Focus Group)*

People with sight loss were keen that, even if they self-cared, health professionals were still available to help them with small but important checks. For example, one man told us:

> *I had to go to the Drs last week about a mole that someone had seen on my back. Just to check out it wasn't skin cancer... I can't see this. I would have no idea if I had blood in my urine. (Sight-loss Focus Group)*

Well-trained, knowledgeable professions

H&SC professionals more aware/understanding of disabilities

People with sight loss told us they would like health professionals to be more aware of disabilities; to go that little bit extra. They want health and social care professionals to be more aware of what people with sight loss can do, and what they can't do. One man told us that he once approached his general practice reception, guided by his dog. Then the receptionist asked him to go to the screen and sign in.

> *It all comes back to the awareness of health and social care professionals about sight loss are so poor. For example, I will walk in my GP surgery with a guide dog and stand there, the glass will go back, and I'll get told to go and sign in on the screen. When that's the start of your day, when you're already low, it's tough... Nobody is bothered. (Sight-loss Focus Group)*

Small waiting rooms make some people with LD very anxious; they may think other people are looking at them. One woman with learning disabilities said that her general practice was very understanding:

> *When I don't want to come [to a GP appointment] I phone the GP. The receptionists then say "Okay, we understand the situation, we'll put you in a quieter part [of the waiting room]. And they will do that for me, they are pretty good with that. They've done it twice. (Learning Disability Focus Group)*

Another member of this group felt that hospital staff should be trained to support people with dementia, saying that at the moment it seems that they are not trained at all.

We were told that, for health professionals to help people to self-care, they need to be completely up-to-date.

> *My daughter is a size 20, and she has been on a very strict diet with low carbs. She was pre-diabetic; she is not now. She has lost so much weight. She's now happy ... but my GP may have not heard of such a thing, because this is a new thing, and he may have done his training 30 years ago (LGBT Focus Group)*

Continuity of care

In order to self-care, people felt that they needed ongoing support. A young person told us that they often got help for a short period and then they were left – they felt they need ongoing support. Similarly, a woman with learning disabilities told us that when she was discharged from BSMHFT she did not even get a referral, and had to ask her church to support her to get support.

One of the carers we spoke with felt that the continuity of care was inconsistent across general practices:

> *My friends GP knows her and her kids inside out, he knows to leave the door open and his triggers so visits are easier, my GP if I get to see him never remembers me, and most of the time I can't see my own GP anyway. (Parents/Carers Forum)*

Patient Public Involvement (PPI)

In order to have the services they need to self-care, many people said that they felt patients and carers should be more involved in the design of those services. This is particularly important with a change in culture, such as persuading health professionals that a big part of their role is to support people to self-care, providing accessible information etc.

> *They [the NHS] are now taking the point now that they have to get users involved in the delivery*

> *and design of services ... It's like anything in the NHS. It's like turning around a cruise liner. A lot of commissioners are still in the 1970s way of thinking, and there is a lot of resistance, usually at the clinician level. (Mental Health Experts by Experience Focus Group)*

Young people agreed. They felt they should have input into how services to support self-care are designed, and this seems to be one of the reasons they attended the focus group. They didn't want decisions just to be made by the NHS without their input. Similarly, people in the LGBT focus group wanted to help plan services with the NHS:

> *We want the best out of the NHS. The NHS does not work with you – They need a vision. (LGBT Focus Group).*

A member of the Mind Experts by Experience focus group felt that the lack of involvement by patients in the actual running of services may be because the NHS is risk-averse:

> *One of the problems with the NHS is that they are so worried about adverse effects. They are actually getting experts by experience to deliver some services in Birmingham, but they won't talk about it until they have got the evidence. They are really worried that something will go wrong. (Mental Health Experts by Experience Focus Group)*

Joined up services

We were told that, with regard to the extra funding provided as part of the LTP, it should not be thought that throwing money at the situation would necessarily result in people being provided with the support to self-care.

> *I think it is very easy to throw more money at things and think that that solves, and it doesn't always. I think more conversations need to be had about joining up services and more signposting. (Sight-loss Focus Group)*

Carers felt that the lack of joined-up services acted as a barrier to them self-caring, and wanted consistency across services, all offering the same care and support:

> *I feel like I'm doing the professionals jobs, contacting them all on behalf of each other, telling services what they need to be doing for my kids. (Parents/Carers Forum)*
>
> *Services make our job harder because as well as struggling to access, when we do, we have to pass messages between services. (Parents/Carers Forum)*

Like the parent carers, people with sight loss felt there needs better integration between health and social care and the voluntary sector (all 3). They did not want to have to sit down with lots of different professionals to tell the same story. They want to tell their history once,

> *You need to just tell your story once. The social worker refers you to the GP who then just gives you the number of somewhere to self-refer. Why can't the social worker just do it instead of having to tell your story to everyone else? (Sight-loss Focus Group)*

Carers also want to tell their story once, and suggested that the NHS could do this by different services all using the same systems:

> *All NHS services should be using the same IT system with the same capabilities; same records so we don't have to tell stories again and again. (Parents/Carers Forum)*

Parent carers also told us that they would like online systems that provide the ability to order medications:

> *Ordering meds online, instead of needing an appointment which is a waste of time, some surgeries take requests on the phone ... Why are they all different? (Parents/Carers Forum)*

Online systems could also improve preventative care. For example, a patient's general practice record could flag that they are a carer when they call, and this would enable the general practice to check quickly the caller's wellbeing.

Conclusion: Focus Groups

Seven main themes emerged from the focus group data. People told us that their ability to self-care would be improved by control and choice over decisions, mental and physical health education, more easily accessible information, and timely access to information and services, more community groups, reduced societal stigma about their condition, more support from the NHS and Social Care.

Although many professionals do encourage self-care and try to empower their patients, it seems from people's feedback that many professions do not. These professionals need to learn to listen to patient's issues, empower them, and provide them with the knowledge, treatment and equipment they feel they need to self-care. To be able to do this, all professionals need up-to-date knowledge and training. Most patients now have access to the internet, and therefore to information about the most recent developments in healthcare. If health professionals are to be able to answer patients' questions, the NHS needs to find a way of ensuring that their knowledge is as up-to-date as their patients'.

The NHS also needs to support Birmingham and Solihull residents to maintain their mental health. We heard in the focus groups that mental health is central to people's wellbeing. This understanding and interest in the importance of emotional health ran throughout all the focus groups, from young people to those in their 70s, and covered people with a wide range of conditions.

Services and activities to self-care should be wider than those that explicitly target mental health. They need to bring people together, sharing knowledge, skills and support. The outcome rather than the explicit purpose of this type of support should be good mental and physical health. Such examples include knitting groups, physical activities and cooking classes. These groups should also be accessible to all people who wish to access them. People want and need to be able to get out of their houses, to be able to afford to use public transport and to have a sense that they are part of a community. It is particularly important that people who would otherwise become isolated are able to access these resources. The importance of the NHS and social care providing appropriate support to people who want to self-care by improving their emotional wellbeing cannot be overstated.

Next Steps

The findings of this report outline what is valued most by Birmingham and Solihull citizens to support them to self-care and live healthier, happier lives. In response to the NHS long-term plan, the development of the local Birmingham and Solihull STP plan should consider the findings of this report. The needs of local residents should be at the heart of future health and social care services. Based on the findings of this report, the local plan should:

- **Clearly lay out how the health and social care system will improve communication pathways with patients.** This will result in patients feeling listened to, equipped with the information they need to understand their condition and provided with the resources they need for their wellbeing. Methods used to do this need to ensure patients feel involved in decisions about their care and the design of services available to them.
- **Address individual and community skill gaps for self-care.** Empowering individuals to have the skills to use the available interventions and appraise the trustworthiness of what is available. In the development of new initiatives to self-care, careful consideration needs to be given to the skills and resources patients need. Also, how individuals can be supported to reduce inequitable access, and how community assets can be developed to address individual and community challenges.
- **Eliminate the gaps in meeting the Accessible Information Standard that exist locally.** Services should demonstrate how information is accessible to all. It should also address the constraints of the current systems. Initiatives developed as part of the local plan need to be flexible and appropriate to individual needs to reduce the current inequalities identified.
- **Reflect on the availability of services to support individuals,** with improvements made to referral pathways, waiting lists/times and the distribution of services. This will enable individuals to access support in a timely manner, and avoid worsening health or crisis.
- **Implement actions, where waiting times are unavoidable, to support individuals to self-care.** This will prevent their condition from getting worse and prevent individuals from entering into crisis.
- **Detail how assets within communities will be supported and developed, identifying and addressing any gaps across Birmingham and Solihull.** The plan needs to identify how communities and peers can be upskilled and resourced to provide support for local communities to build self-care initiatives.
- **Address how the local STP will work across all partners to reduce the stigma** of mental health, disability and other conditions, support individuals and build self-efficacy for self-care.

By addressing these in the development of the plan, the STP will go some way to shift the culture of health and social care, and the public. This will increase the self-efficacy and control of communities to look after their own health and wellbeing, and in doing so empower individuals to self-care.

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Solihull: GP surgeries that participated, Solihull College, The Core, Carers Forum, Older Peoples Knowledge Exchange and East Birmingham and Solihull Hard of Hearing Club

Appendix

Demographic data for general questionnaire survey[13].

Age	Birmingham	Solihull	Total
Under 18	12%	0%	7%
18-24	21%	5%	14%
25-34	11%	8%	10%
35-44	12%	12%	12%
45-54	19%	20%	19%
55-64	12%	27%	19%
65-74	7%	21%	13%
75+	6%	6%	6%
Total	100%	100%	100%

Ethnicity	Birmingham	Solihull	Total
White British	48%	79%	62%
Pakistani	7%	3%	5%
Black British	7%	3%	5%
Asian British	5%	5%	5%
African	7%	1%	4%
Any other mixed background	6%	2%	4%
Caribbean	6%	0%	3%
Any other white background	3%	3%	3%
Other	3%	2%	3%
Indian	4%	1%	3%
Arab	2%	0%	1%
Bangladeshi	2%	0%	1%
Total	100%	100%	100%

Disability	Birmingham	Solihull	Total
No	78%	79%	79%
Yes	21%	17%	19%
I'd prefer not to say	1%	4%	3%
Total	100%	100%	100%

Carer	Birmingham	Solihull	Total
No	82%	88%	85%
Yes	18%	12%	15%
Total	100%	100%	100%

Long term condition	Birmingham	Solihull	Total
No	70%	67%	69%
Yes I have a long term health condition	23%	24%	23%
Yes I have more than one long term health condition	7%	9%	8%
Total	100%	100%	100%

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[13] For all charts, percentages were calculated after 'blanks' had been filtered out.

Sexuality	Birmingham	Solihull	Total
Asexual	0%	0%	0%
Bisexual	3%	0%	2%
Gay or lesbian	8%	0%	5%
Heterosexual	84%	97%	90%
I'd prefer not to say	2%	1%	2%
Other	3%	1%	2%
Total	100%	100%	100%

Gender	Birmingham	Solihull	Total
Female	69%	69%	69%
I'd prefer not to say	0%	1%	0%
Male	30%	30%	30%
Other	1%	0%	1%
Total	100%	100%	100%

Religion	Birmingham	Solihull	Total
Christian	39%	54%	45%
No religion	34%	30%	32%
Muslim	14%	5%	10%
Other	3%	4%	3%
Hindu	3%	3%	3%
I'd prefer not to say	3%	3%	3%
Buddhist	2%	0%	1%
Jewish	2%	0%	1%
Sikh	1%	1%	1%
Total	100%	100%	100%

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