healthwatch Northamptonshire

Northamptonshire Health and Care Partnership

Public views and experiences to inform the NHS Long Term Plan in Northamptonshire

Healthwatch Northamptonshire

what would you do?

It's your NHS. Have your say.

Contents

What does choose well, stay well and live well mean to us right now?
PROUD OF NORTHAMPTONSHIRE
my family
TOGETHER WE CAN!
1 2 3 4 5 MAKE YOURSELF COUNT
LET'S JOIN IT UP!
MY FAMILY MATTERS!
Help us to shape a positive lifetime of health, wellbeing and care in our community by writing or drawing your ideas above.

Summary

Purpose of this report

The Government is investing an extra £20bn a year in the NHS. The NHS has produced a Long Term Plan, setting out all the things it wants health services to do better for people across the country. For these plans to work, the NHS needs to shape local plans based on local needs.

The purpose of this report is to inform local health and care organisations about what people in Northamptonshire think and feel about local NHS services and what improvements could be made to how these services are delivered in the future. It draws on comments and feedback gathered at local events, including a public engagement event held jointly with Northamptonshire Health and Care Partnership[1] (NHCP), and through responses to a survey that asked ‘What would you do?’ to improve services and inform the local plans. We heard from 300 people about what they wanted from local services in Northamptonshire.

The key issues people identified across all themes were information/communication, access to services, community services, support and personalised or person-centred care.

What matters most to people in Northamptonshire?

Information and communication

Both the need for **better communication between services and better communication with patients/the public** was highlighted across all areas and conditions. Specifically, people felt there was a need for a directory of services, that the public and professionals could access, and better centres for information and advice (virtual and physical). There was also a desire for better patient records and particularly for these to be shared across services so care could be more coordinated.

Access to services

Faster access to services, particularly GP appointments, was the most important issue for survey respondents. Those who spoke to us about **mental health and autism** also highlighted difficulties they had, including delays in getting assessments and a lack of follow-up support.

Community

Across all themes, the **value of communities, local initiatives** and having **care and support close to home** was highlighted, particularly to help people stay well and age well. People also wanted to be able to **stay in their own home** for as long as it is safe to do so, and felt that it was important that there should be **more care at home or close to home.** It was felt that this would especially help those in rural areas where access to public transport can be an issue and would help tackle isolation.

Support

Some people with a specific condition felt they **lacked support** and told us about having to **actively seek** advice and support. Again, those talking about **mental health and autism** did not feel the support they received when they first tried to get help met their needs. It was also suggested that more experts (such as dementia specialists), non-medical support and technological innovations could help support people to live well and stay well.

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[1] www.northamptonshirehcp.co.uk

Personalised and person-centred care

All themes mentioned the importance of **caring for the whole person**, treating them as **individuals** and having people's **wellbeing** at the centre. People said that they valued having **choice** and a say about their care.

What changes do people want to see? – The 'big ideas'

The following suggestions for improvement were identified through our engagement activities, and as a consensus across all four conditions/workstream priorities of the Northamptonshire Health and Care Partnership ('My Community', 'Mental Health', 'Ageing Well' and 'Breathing'):

Information

- Improve the flow of personal health and care information by introducing a 'health and care passport' to make it easier for people to access the right care in the right place at the right time.
- Provide a single directory of local services, groups and activities that can support people's health and care needs, to be accessible to all (not just online).
- Coordinate care to enable patients to move seamlessly through and between services and make pathways easier to understand.

Community support

- Provide advice and support to guide individuals through their health and care journey and to help them access a range of services, according to individual need and choice. The role could be based on the wellbeing navigator or community connector roles that already exist locally.
- Build 'buddying' networks linking older people in good health with those in need, providing friendship as well as support.
- Develop community hubs that provided information and signposting to local services, both face-to-face and on the telephone.

Carers

- Improve support for carers, who often have health needs of their own, to relieve pressure on the health and care system. Commission a county-wide carer support service based in local community hubs.
- Ensure the voice of carers is heard and included in decisions about people's health and care.

Personalised care

- Focus on the needs of the whole person to support people to stay well and live well, including physical and mental wellbeing and nutritional support.
- Develop personalised mental health care plans to empower individuals and prevent crisis situations.
- Provide mental health advocacy to aid people's access to health and non-health services.

Engagement

- Continue to engage with service users and the public to ensure they are involved with shaping improvements to local services.

Next steps

Northamptonshire Health and Care Partnership

'Healthwatch Northamptonshire and Northamptonshire Health and Care Partnership (NHCP) have worked collaboratively to engage on the national NHS Long Term Plan requirements. This included the public engagement event held in May 2019. This listening event was highly successful and provided much insight into people's experiences of and priorities for local NHS and social care services.

The findings of this report have been presented to NHCP and below is its response and next steps.

Here in Northamptonshire, we're responding to what our local people and stakeholders are telling us about the way in which they want to receive their health and care. We welcome the thorough feedback that this report provides and are working with it as we continue our listening journey.

The public views and experiences expressed in this report will, as part of a wider programme of engagement, inform the development of Northamptonshire's response to the NHS Long Term Plan requirements. They give us further valuable insight to make sure that we are all working to address the feedback of our community. This will support us in developing co-ordinated, responsive strategic priorities and objectives across our Partnership.

The "Big Ideas" generated and agreed at the Choose Well, Stay Well, Live Well community engagement event have been shared with colleagues across all NHCP workstreams. NHCP's Collaborative Stakeholder Forum[2] has taken on the responsibility to ensure that the "Big Ideas" are interwoven with the shaping and delivery of local health and care transformation through the work of NHCP.

Conversations and engagement with our community will continue as, together with our stakeholders across the county, we develop our local response to the NHS Long Term Plan, called the Northamptonshire Health, Care and Wellbeing Plan. This will serve as a single strategic plan for the future of health and social care in our county, incorporating a refreshed strategy for Northamptonshire's Health and Wellbeing Board.

During the autumn of 2019 we will provide further opportunities for our community and stakeholders to share their views on health and care in the county and be guided by national, mandated timelines in order to produce and publish the plan.'

Healthwatch Northamptonshire

Following this successful joint engagement, Healthwatch Northamptonshire will continue to work with NHCP and others so that people in Northamptonshire can share their views to inform the development of health and care services in the county.

We will share this report with the providers of health and care in Northamptonshire and, as members of the Collaborative Stakeholder Forum and Health and Wellbeing Board, we will encourage all organisations involved in the planning and delivery of health and care to use the priorities of the public highlighted in this report to ensure services meet people's needs.

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[2] The Collaborative Stakeholder Forum is made up of representative of staff, public and voluntary organisations. Its responsibility is to ensure that the views of the people – which includes the public, patients, service users, the voluntary/community sector and local government – are being properly considered with the work of the NHCP.

Background

In January 2019, the NHS in England published a ten-year Long Term Plan[3], setting out its priorities for the future to make sure everyone gets the support they need. With growing pressures on health and care services, as people live longer and with long-term conditions, and as lifestyle choices affect people's health, the plan outlines the things it wants health services to do better for people, including more focus on prevention and early detection.

Local health and care organisations are working in partnership to develop and implement their own local plans for the next five years. These plans 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.

Northamptonshire services and the need for change

The local partnership, Northamptonshire Health and Care Partnership (NHCP), consists of key health and care organisations in the county who are committed to working together to improve the quality of care and the health and wellbeing of our community (read more about NHCP on page 75).

Northamptonshire's growing population (741,000 in 2018 and expected to increase by more than 8% in the next 10 years[4]) is served by two clinical commissioning groups (CCGs) who work closely together (NHS Nene CCG and NHS Corby CCG), two general hospitals (Kettering General Hospital NHS Foundation Trust and Northampton General Hospital NHS Trust), one integrated mental health and community care trust with three community hospitals (Northamptonshire Healthcare NHS Foundation Trust), two mental health in-patient units, 104 GP practice premises (70 practices in four federations)[5], and social care is provided by Northamptonshire County Council[6].

Whilst there are eight main towns in the county, approximately 31% of the population live in rural or fringe areas[7] and getting to health services, particularly the hospitals, by public transport can be an issue for people living outside of the towns. Northamptonshire borders seven other counties and people living near these borders sometimes report communication and coordination issues, e.g. having their GP practice in one county and their nearest hospital or social care provision in another.

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[3] www.longtermplan.nhs.uk

[4] www.northamptonshirehcp.co.uk/reasons-to-change

[5] Northamptonshire Health and Care Partnership – overview booklet - www.northamptonshirehcp.co.uk

[6] Northamptonshire County Council and the seven district and borough councils will transition into two unitary authorities in 2021.

[7] Approximately 31% of the county's population lives in the densely populated town of Northampton. In total, 69% of the county's population live in 'urban city and town' areas, 20% in areas classified as 'rural town and fringe' and 11% in 'rural villages and dispersed', Northamptonshire's Joint Strategic Needs Assessment, Demography 2017. www3.northamptonshire.gov.uk/councilservices/health/health-and-wellbeing-board/northamptonshire-jsna/Pages/default.aspx - Source: ONS, Census 2011 and mid-2015 population

Many of Northamptonshire's health and care organisations are delivering good or outstanding care, but it is clear more needs to be done to make sure the health and care provided in our county has a positive future. A mid-2018 review[8] of how organisations work together to support older adults aged over 65 by the Care Quality Commission (CQC), the independent regulator of health and social care in England, identified that improvements are needed, particularly to the care for older people.

NHCP has identified the following local reasons for change[9]:

- **Growing population** - The number of people living in Northamptonshire is expected to grow from 741,000 in 2018 to 803,000 by 2028 – that's an increase of more than 8% in 10 years.
- **People are living longer** - It's estimated there will be a significant increase in the number of people aged over 65 in our county, rising around 65% from 122,000 in 2014 to 201,000 by 2034.
- **Deprivation** - Around 40% of our population (300,000 people) live in areas where levels of deprivation are above the England average.
- **Inequalities** - Children born in our most deprived areas can expect to live 7.8 years less than those born in the most affluent parts of the county. People in our most deprived areas are likely to spend 13 fewer years in good health than those living in the least deprived areas.
- **Mental health** - In 2018/19 more than 21,000 adults entered mental health services in Northamptonshire – that's around 4% of the total adult population. Our intention is to support service users and carers to live as independently as possible.
- **Finance** - By 2020/21, the cost of providing health services in Northamptonshire could be £200 million higher than the amount of funding available unless something is done to change how we work. This is also in the face of our additional local authority financial pressures.
- **Unhealthy lifestyles** - Around one in six people in Northamptonshire smoke. Two out of three people in our county are overweight or obese, while nearly one in four do not do enough physical activity.
- **Children** - Nearly 70% of children in Northamptonshire are reaching a good level of development by Reception class (age 4-5 years). This falls to just over half reaching good level of development if they are receiving free school meals.

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[8] www.cqc.org.uk/news/releases/northamptonshire-cqc-publishes-its-review-how-local-health-social-care-systems-work

[9] www.northamptonshirehcp.co.uk/reasons-to-change

Purpose

To support the development of a local plan to implement the ambitions set out in the NHS Long Term Plan, NHS England asked Healthwatch England, through its network of local Healthwatch, to find out what local people felt about their health and care services and how they think these could be delivered in the future. Healthwatch England created two surveys – a general survey, and one for individuals living with specific conditions (such as cancer, dementia and autism).

Locally, Healthwatch Northamptonshire and NHCP worked together to run a public engagement event to give people the opportunity to share their views on health and care services and what can be done to ensure quality, integrated services that meet local needs and are fit for the future. The event was attended by around 90 Northamptonshire residents and health and care professionals.

In addition, Healthwatch Northamptonshire spoke to a group of 20 carers supported by the organisation Northamptonshire Carers, and collected 189 survey responses from Northamptonshire residents.

Both engagement events involved listening to people's experiences of local NHS and social care services and discussing ways they could be improved.

Objectives

With the Northamptonshire Health and Care Partnership we agreed to gather the views of people living in Northamptonshire around the key Partnership themes of 'Choose well, Stay well, Live well':

- **Choose well** - Taking action before things happen: Making sure the right services and the right choices are available to help us look after our own health and prevent illness.
- **Stay well** - Understanding the causes of ill health and getting the right treatment: Putting the right health and care services in place locally to detect, diagnose and treat illness as early as possible.
- **Live well** - Keeping you well supported and cared for: Providing the right care and support in the right place to help us to manage our health as we get older or live with long-term illness.

We asked people about:

- What would you do to create a positive lifetime of health, wellbeing and care in Northamptonshire?
- How can services make it easier for people to take control of their own health and wellbeing?
- What is important to you for your care and for the care in your local community?

We did this by:

- Holding a joint community and stakeholder engagement event for the public and professionals to kick start ongoing engagement around 'Choose well, Stay well, Live well: Creating a positive future for health and care in Northamptonshire'. This event focused on the Health and Care Partnership Primary, Community and Social Care workstream priorities and certain conditions highlighted in the NHS Long Term Plan, particularly:
    - Older age/ageing well
    - Care in my area
    - Mental health
    - Breathing (respiratory problems)

  The event discussions were led to develop headline 'big ideas' on how people can be supported to 'choose well, stay well and live well' in Northamptonshire.
- Carrying out a focus group on the same priorities with a group of carers.
- Sharing the national Healthwatch general and condition-specific surveys with as many people as possible.

Who we heard from

In total we heard from nearly 300 people[10]:

- 189 survey responses (143 general surveys, 46 condition specific surveys). 10% (14) general survey responses and 37% (17) condition specific survey responses were completed on behalf of someone else.
- 88 engagement event attendees (including members of the public, health and care professionals, Healthwatch Northamptonshire and NHCP staff).
- 20 carers at a group supported by Northamptonshire Carers.

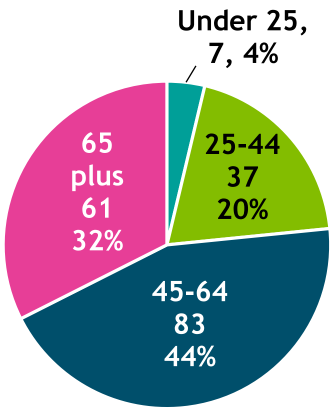
We assume those who completed a survey live across the county[11] but as the national survey only asked which county they live in, we are unable to tell. Some of the attendees at the engagement event in Northampton had travelled from across the county, including Corby, Daventry, Wellingborough and East Northamptonshire.

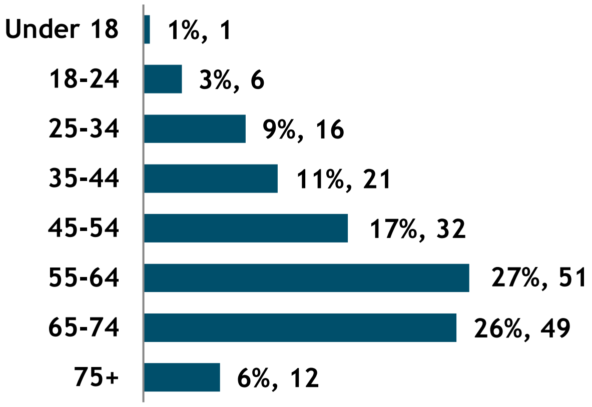
We collected further demographic information from those who completed the surveys (breakdown by survey shown in appendix).

Age

Compared to the overall population of Northamptonshire[12], older adults were over-represented in our surveys.

Three-quarters (77%) of the people who completed a survey were age 45 or above, with 45% being 45-64 years old (compared to 35% of the general population of Northamptonshire over the age of 19) and 32% being 65 years old or more (compared to 23% of the population over the age of 19). One person under 18 and six aged 18-24 took part.





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[10] The number of unique individuals will be less as some may have completed both surveys and/or completed a survey as well as attending an event.

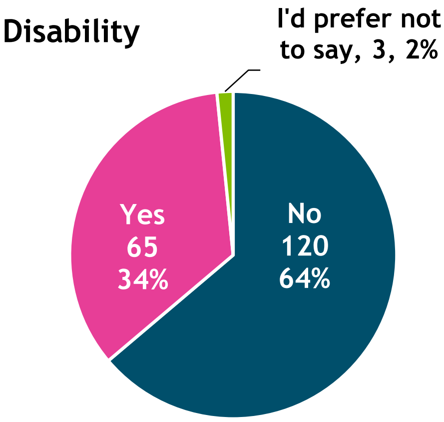
[11] Based on the five people who completed a paper survey and told us which town or district they lived in (two in Northampton, two in East Northamptonshire and one in South Northamptonshire).

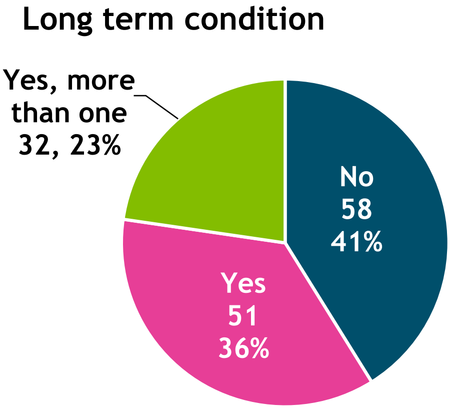
[12] Mid-2016 estimates - Source: Population Estimates Analysis Tool, Office for National Statistics www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesanalysistool.

Disability and long-term conditions

One-third (34%) of survey responses came from someone who considered themselves to have a disability, which is higher than the 21% of the county estimated to have a disability[13]. This is not surprising because the surveys asked for people to share their experience of using health and care services. Half (50%, 23) of the 46 people who answered the specific conditions survey said they had a disability, compared to 29% (42) of the 143 general survey respondents.

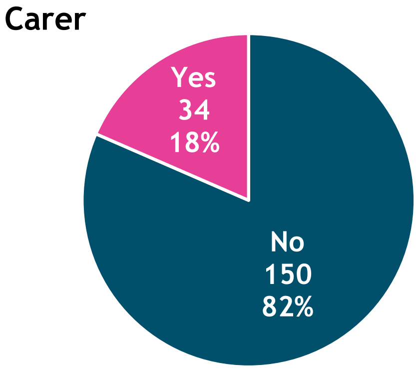
We assume that all the 46 people who answered the survey about their specific condition consider themselves to have a long-term condition. 59% (83) of those who completed the general survey also considered themselves to have one or more long-term condition(s).





Carers

Nearly one-fifth (18%) of survey respondents said they were a carer, higher than the national estimate of one in ten people being unpaid carers[14].



Gender

Almost three-quarter (73%) of the survey responses were from women, who are significantly over-represented (compared to the mid-2016 county population of women being 50.6%)

Ethnicity

90% or survey respondents were White British, similar to the 88% of Northamptonshire residents who identified as White British in the 2011 Census[15].

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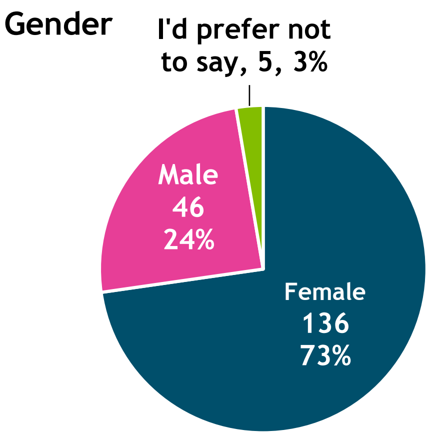
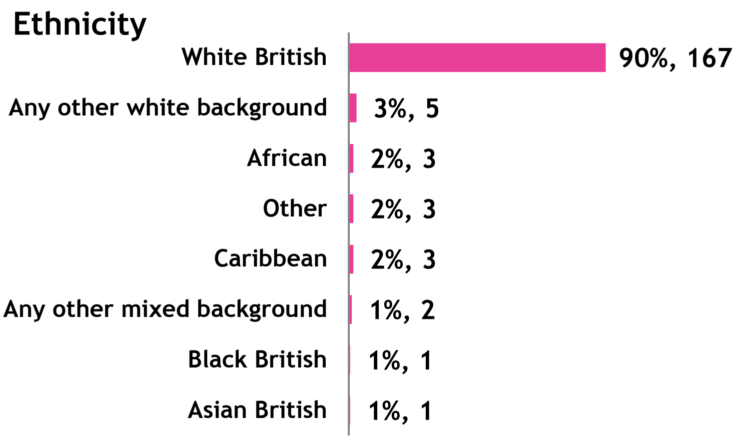
[13] Northamptonshire's Joint Strategic Needs Assessment, Adults with disabilities JSNA 2017. www3.northamptonshire.gov.uk/councilservices/health/health-and-wellbeing-board/northamptonshire-jsna/Pages/default.aspx

[14] 10% of the Northamptonshire population identified as carers in the 2011 census.

[15] Northamptonshire's Joint Strategic Needs Assessment, Demography 2017. www3.northamptonshire.gov.uk/councilservices/health/health-and-wellbeing-board/northamptonshire-jsna/Pages/default.aspx



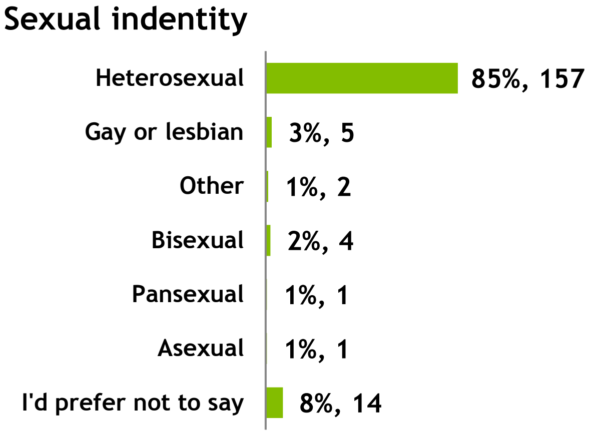


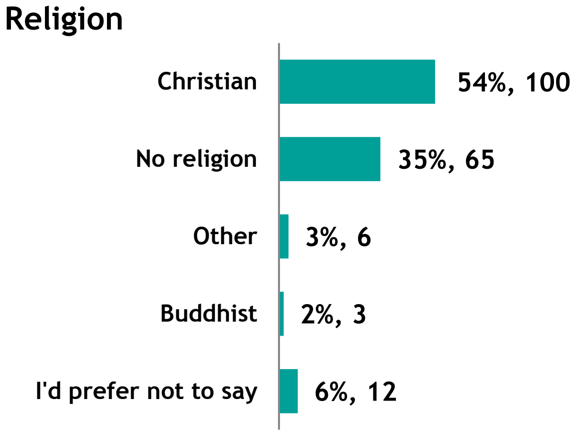
Sexual identity

92% (157) of those who gave an answer to this question (excluding those who did not want to say) said they were heterosexual. In 2015, 1.7% of the UK population identified themselves as lesbian, gay or bisexual[16], implying that these groups were appropriately represented in our survey.

Religion

Most survey respondents told us they were either Christian (54%) or had no religion (35%).





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[16] Sexual identity, UK: 2015, Office for National Statistics, www.ons.gov.uk/peoplepopulationandcommunity/culturalidentity/sexuality/bulletins/sexualidentityuk/2015

Support for specific conditions

Forty-six people completed the survey asking about how the NHS supports people with a specific condition. Over half (59%) of answers were from 45-64 year olds (the full demographic breakdown is shown in appendix). The most commonly experienced conditions were other long-term conditions (such as diabetes and arthritis) (16) and mental health (14). The remaining 16 responses were from people with experience of four other conditions:

Condition	Started within last three years	Started longer than three years ago	Total
Long-term condition e.g. diabetes, arthritis	4	12	16
Mental health	6	8	14
Cancer	4	2	6
Heart and lung diseases	2	3	5
Autism	1	3	4
Dementia	0	1	1
Learning disability	0	0	0
Total	*17*	*29*	*46*

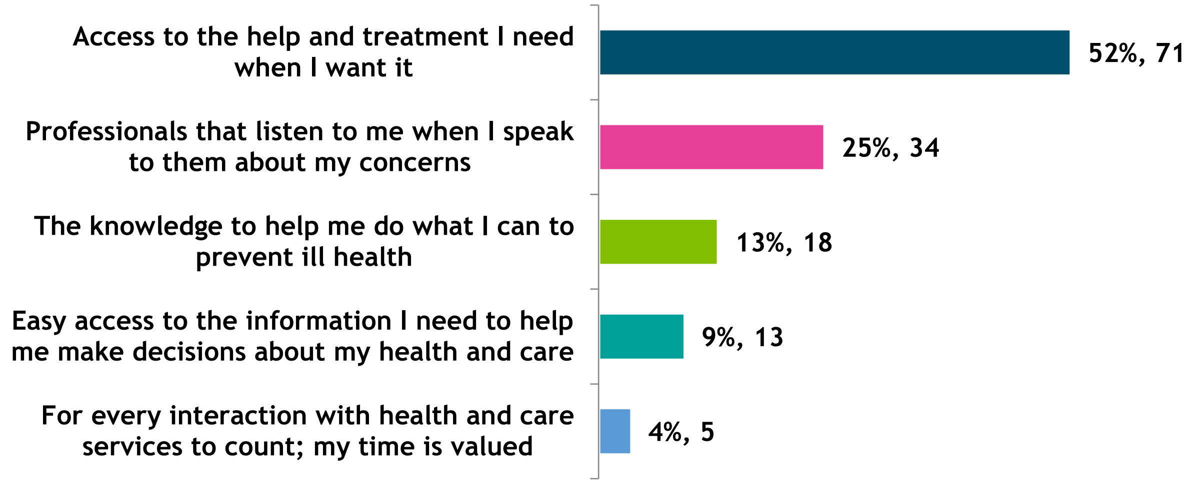
Choose well - prevention and/or early intervention

Living a healthy life

In the general survey we asked people to tell us what was most important to them to help them live a healthy life by selecting from a range of topics.

Over half (52%) thought that access to the help and treatment they need when they want it was the most important things to help them live a healthy life.

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' was the most important answer for all demographic groups looked at except for the ten people who had a sexual identity other than heterosexual, where more thought that having 'professionals that listen to me when I speak to them about my concerns' was most important (five people). People aged 65 and over also valued having 'professionals that listen to me when I speak to them about my concerns', with the difference between the answers for this group and the other age groups being statistically significant[17].

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[17] Age 65 plus compared to other ages, Chi-square 18.87, P<0.001.

	Access to the help and treatment I need when I want it	Professionals that listen to me when I speak to them about my concerns	The knowledge to help me do what I can to prevent ill health	Easy access to the information I need to help me make decisions about my health and care	For every interaction with health and care services to count; my time is valued	*Total number who answered*
Carers	59%	27%	5%	14%	5%	*22*
Disability	50%	26%	8%	13%	3%	*38*
Long-term condition	51%	28%	9%	8%	5%	*79*
Non-White British	43%	21%	14%	21%	0%	*14*
Non-Heterosexual	20%	50%	10%	20%	0%	*10*
Female	56%	25%	10%	7%	4%	*97*
Male	38%	24%	22%	14%	3%	*37*
Under 25s	50%	0%	33%	17%	0%	*6*
24-44 years old	38%	31%	14%	17%	0%	*29*
45-64 years old	69%	11%	15%	9%	0%	*54*
65 plus[17]	40%	38%	9%	2%	11%	*47*

People were also asked to rate how important each statement was to them. Whilst most people felt all the statements were either very important or important, having ‘professionals that listen to me when I speak to them about my concerns’ was rated as very important by slightly more people than ‘access to the help and treatment I need when I want it’. Both these statements were rated as very important by more people than the other statements[18]. None were rated as ‘not at all important’.

The order of importance for these statements was the same for carers, people with a disability, people with a long-term condition, and those aged 45 and over. The order was different for other groups, as below (but these differences were not statistically significant).

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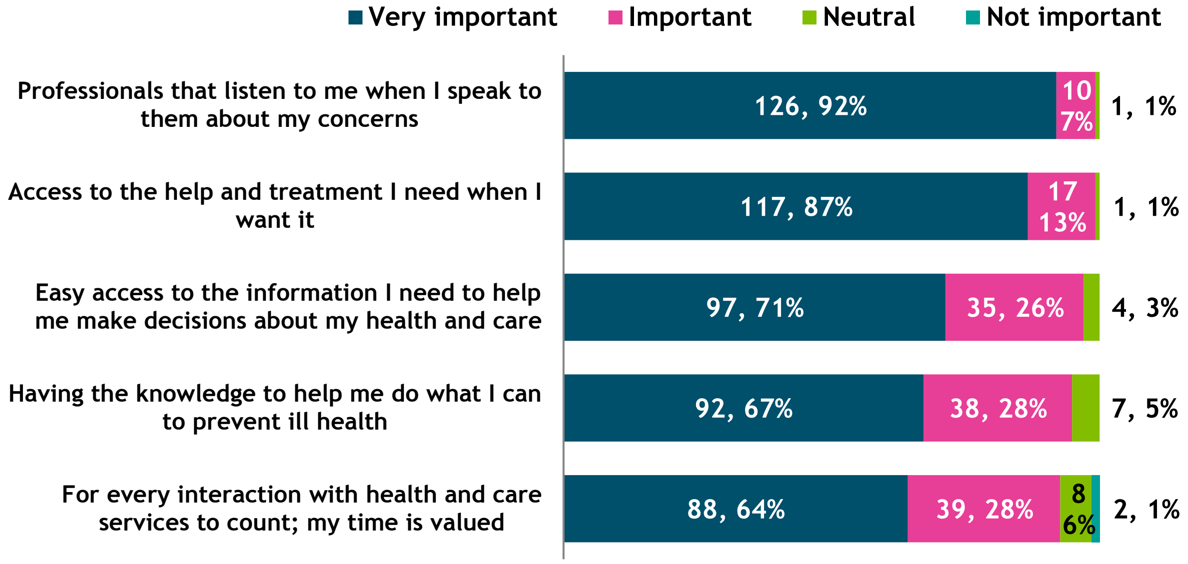
[18] Statistically significant differences between the top two statements and bottom three, Chi-square $P<0.05$

Rate how important the following statements are to you when it comes to living a healthy life



Statement	Order of importance (based on percentage ‘very important’)					
	Under 25	25-44	Non-white British	Non-Heterosexual	Female	Male
Professionals that listen to me when I speak to them about my concerns	1	1	2	1	1	1
Access to the help and treatment I need when I want it	2	2	3	=2	2	2
Easy access to the information I need to help me make decisions about my health and care	=4	5	1	5	3	4
The knowledge to help me do what I can to prevent ill health	3	4	4	4	5	3
For every interaction with health and care services to count; my time is valued	=4	3	5	=2	4	5
Number of people	*6*	*29*	*14*	*10*	*97*	*36*

What else is important to help people live a healthy life and 'choose well'?

The engagement event asked people to reflect on their good and less good experiences of services relating to the 'choose well' prevention theme and then to come up with three ideas or priorities as a table group to help people 'choose well' (i.e. what matters most).

The general survey also asked people if there was anything else that would help them to live a healthy life. Eighty-eight people commented, and these comments were grouped into nine overarching themes[19]. The most commonly mentioned things related to **accessing services**, **communication** and **having knowledge or information**.

Access

Some people at the event said they struggled to access health services, such as **getting a GP appointment** or **getting a visit from a district nurse**. **Delays in accessing the right support** can lead to health problems worsening and becoming more urgent. This was also an issue when there are **long waiting times** to see a specialist following a referral.

Thirty-five survey respondents also mentioned aspects of **appointments or referrals**: wanting easier access, particularly **GP appointments** or services (14 people), and two mentioned **wanting to see their own GP** for continuity. Most of the more informative comments were given by people aged 55-64 with a disability and long-term condition, for example:

> "Access to a GP. Getting a doctor's appointment is very difficult it puts you off investigating concerns." *(Age 55-64 with a disability and long-term health condition)*
>
> "Being able to access GP appointment within an acceptable timeframe. Having to deal with the 'care navigation system' for appointments is stressful and deflects me from seeing who I need for my complex medical issues. I manage routine coughs and colds, etc. myself but when I do need my GP, it's a series of hoops and barrels to get through. And often not successful, which results in seeing a GP who is unfamiliar with my history. Previous system was fine." *(Age 55-64 with a disability and more than one long-term health condition)*
>
> "Being able to quickly and easily access appointments. It has become increasingly difficult to make an appointment. Also, I feel that I should be able to develop a relationship with my GP rather than having to speak to someone I have never met before each time I attend." *(Age 55-64 with a disability and more than one long-term health condition)*

Other survey comments relating to access included wanting better **access to physiotherapy or hydrotherapy** (five people), **health checks** (four people), a **minor ailment clinic** (two) and access to **complementary therapies** (two). The following were all suggested by individuals: being able to self-refer to specialist; more social care; better healthcare for the homeless; and shorter waiting times. For example:

> "As I have osteoarthritis, I have found hydrotherapy twice a week invaluable. I have paid additionally for a physiotherapist, as has my husband prior to having a hip replacement recently. This has been hugely beneficial to us both and has certainly helped me and my mobility. Paying a fee has been reasonable, and I would feel very upset if this resource was withdrawn." *(Age 65-74 with a disability and a long-term health condition)*
>
> "Hydrotherapy pool is an excellent resource to be able to support my son with best start in life, by being able to be active from an early age." *(Age 35-44)*

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[19] Four people gave comments which were classed as more than one theme.

“An annual MOT, because some people try never to go to doctors, but they need to be checked, especially as they get older.” *(Age 65-74)*

“To have more proactive health tests available, e.g. aortic aneurysm at earlier ages. Several people I know have died before the 65 years test threshold.” *(Age 55-64)*

“A drop-in clinic where I could go to discuss minor ailments I sometimes suffer from. I do not feel some issues are worth bothering my GP with but equally they could develop into something more serious because I keep putting it off.” *(Age 55-64 with a long-term health condition)*

“Healthcare team designated to go out to homeless in each town, to include dentistry, which appears to be unavailable to those with no fixed abode. Support agencies to be able to access, e.g. street pastors, homeless drop-in service volunteers.” *(Age 45-54 with a disability and more than one long-term health condition)*

Information

People at the engagement event reported difficulties in **finding the right information** about services available and where to seek support for a positive lifetime of health. It was felt that some areas of the county are better than others in gathering and sharing information about local services, groups and activities, and that **a single place for storing and transmitting information for health and care** was needed.

Twelve survey respondents suggested better or more information, particularly about **diet and/or exercise** (nine), two mentioned wanting **consistent information** and one suggested information about **support groups**. For example:

“More information around healthy eating and regular exercise that is free or cheap. Information that is easy to access without having to download an app all the time. Information on services that are still running and that are funded correctly so that the voluntary sector does not always have to fight for funding.” *(Age 25-34)*

“Support to lose weight.” (Age 55-64 with a disability and more than one long-term health condition)

“Joined up thinking between GP receptionists and GPs in the same surgery - too often they contradict each other about what the options are. It's a waste of time and stressful.” *(Age 45-54 with a disability and a long-term health condition)*

Person-centred

Nine survey respondents mentioned the importance of **being listened to** and **valued as individuals**, including wanting their health and care professionals to be caring and communicate well (three), have a better understanding that patients are experts in their own conditions (two), listening to carers, feeling respected, having things explained well, and being community and person-orientated (one each). For example:

“People who genuinely care and understand my concerns and can communicate with me, so I understand everything thoroughly.” *(Age 18-24 with a long-term health condition)*

“Doctors that listen and offer help instead of saying that they can't help and don't offer anything else.” *(Age 25-34 with a disability and more than one long-term health condition)*

“Taking more account of information a family or a carer has about a patient.” *(Age 75+ carer with a long-term health condition)*

> "To not be pigeon-holed or treated like a jigsaw piece. For them to see how my illness affects mine and my family's life every day so they get a bigger picture." *(Age 35-44 with more than one long-term health condition)*
>
> "GPs and other medical professionals understanding more about long-term chronic pain conditions - we are the experts in our own conditions, we ask for the help we know we need, we are used to dealing with it. They need to listen and signpost us correctly. It can't be 'fixed' quickly." *(Age 35-44 with a long-term health condition)*

Support

Eight survey respondents suggested **more or better support**, mostly for social wellbeing (five people). One person wanted more **help to live independently**, one better support for disabled people and one better **support for carers** and people with learning disabilities. For example:

> "The ability to maintain links with the community in which I live and so remain a member of society." *(Age 75+ with a disability and a long-term health condition)*
>
> "More interaction with other people. I live alone but am not necessarily "lonely"." *(Age 65-74)*
>
> "More choice and rights and social life and Easy Read information and a lot more hours to help and support me … to be a lot more happy and safe out in the community and at home with a lot more personal assistants with a lot more hours for us in Northamptonshire." *(Age 45-54 with a disability)*

Transport

Transport difficulties, particularly in rural areas and where bus services are limited or have been cut, have an adverse impact on people accessing health and support services. At the engagement event, concern was expressed that many people experience **social isolation**, having no family or friends living nearby, and this can affect both physical and mental health.

Four survey respondents also suggested improvements to transport, for example:

> "Easy public transport access to my local health centre." *(Age 65-74 with a long-term health condition)*
>
> "Recognition that access to transport is an essential element of maintaining health." *(Age 75+ with a disability and more than one long-term health condition)*

Environment

Five survey respondents suggested a **cleaner or safer environment** would help them and promote better health, for example:

> "Better air quality." *(Age 55-64)*
>
> "Cycle lane infrastructure that encourages people of all ages and abilities to use cycling as a means of getting around town. There are very few cycle lanes in the county and the ones that are provided are not maintained and vehicles park in them, which is dangerous for cyclists." *(Age 45-54)*
>
> "Reduce speeding in my village." *(Age 55-64)*

Better services

Five survey respondents mentioned needing **improved services** (better scans to detect tumours, care for veterans, and mental health care and prevention) or **continuity between services** (two), for example:

> "Continuity of care. I'm always having to repeat myself at every appointment." *(Age 65-74 with a long-term health condition)*
>
> "Full, timely, proper care for former service personnel." (Age 65-74 with a disability and more than one long-term health condition)

Prevention and education

At the event, the reduction in **support at community level**, particularly children's centres, was raised as a concern, and people felt that **more preventative work on healthy living**, including nutritional advice, should be given in schools.

Four survey respondents suggested there should be more focus on prevention and education, for example:

> "Better mental health care. Stronger emphasis on mental health problem PREVENTION rather than putting out fires." *(Age 18-24 with a long-term health condition)*
>
> "I have M.E. (CFS) and I swear most doctors I talk to have no idea what that is or how it affects sufferers. I have never been offered any ongoing investigations or treatment, just a diagnosis of the condition and told there are no treatments." *(Age 55-64 carer with a disability and more than one long-term health condition)*
>
> "Preventative collaborative work between health, social care and the voluntary sector are all important. The NHS seems just to be there for when people need crisis support." *(Age 55-64 carer with a disability and more than one long-term health condition)*

Communication

Three survey respondents highlighted the importance of **good communication** between professionals, as well as with the patient, for example:

> "That communication between professionals and me are timely, correct and available." *(Age 65-74 carer with a disability and a long-term health condition)*
>
> "Have a communication system that encourages consultants to talk with each other effectively." *(Age 65-74 with a long-term health condition)*

Other

Three survey respondents mentioned **better funded services** or the **impact of personal finances** and one 'better working conditions'.

In focus – Carers' viewpoint and an example of needing to support people with congenital conditions

Carers gave similar answers to the survey questions about living a healthy life as the other groups of people. Two carers highlighted in the comments above the importance of both health and care professionals listening to carers as they have valuable information about the people they care for and looking after carers' own health and wellbeing.

One person highlighted various ways people with a long-term condition/congenital syndrome or learning disability, and their carers, could be better supported:

"Training for those who care for young people with a syndrome which is not going to be undone (from birth) and a recognition of the limitations of living with the syndrome i.e. learning disabilities (LD) which will have a life time affect with possible early onset dementia, for example. When young people with LD and health-associated conditions turn 18 they are no longer under a paediatrician which has huge ramifications. This young person would still have been under an ophthalmologist, for example, and not almost lost the sight in an eye with the other one badly affected as this person was steered towards a general optician who did not know about this common complaint (why would they after all!!) in those with this syndrome and was not 'looking' for it!

It is a bit like falling off a cliff for these young people turning 18. I would recommend they stay under the one consultant paediatrician until they are 25, just as there is a remit for those receiving social care and EHCP's [Education, Health and Care Plans] to be in young people services up to 25 then, in this case, this young person would have avoided surgery and three A&E visits!

Also, there was evidence that older consultants need to change their thinking...some are still hesitant to offer some kinds of surgery on the basis of no evidence in the 'syndrome'. This should be investigated generally to ensure this is not used as an excuse to deny surgery (which in this case was successful after all).

The once a year check with the GP is good but fairly basic, perhaps needs a review to ensure it covers what is needed in light of new research.

Keeping family carers in good health is essential and information; signposting and free training on health conditions should be accessible, along with respite and general support. If you really want to help family carers stay well then they must be treated with utmost dignity and respect as they save the NHS thousands of pounds annually and therefore why are they always having to 'fight' for services, especially with social care?

I am concerned that many who have a well-known common syndrome causing LD from birth do not seem to get a 'health' budget from the 'get go' and not until much later on will need to apply usually at crisis point...could health do an audit of the EHC Plans (health side) to see just how many people are needing physio, occupational therapy and speech and language within them? … This audit would enable better planning for those coming through the system transitioning through school to adult services and enable carers to have some hope their young person would still receive the health interventions necessary i.e. physio, speech and language therapy."

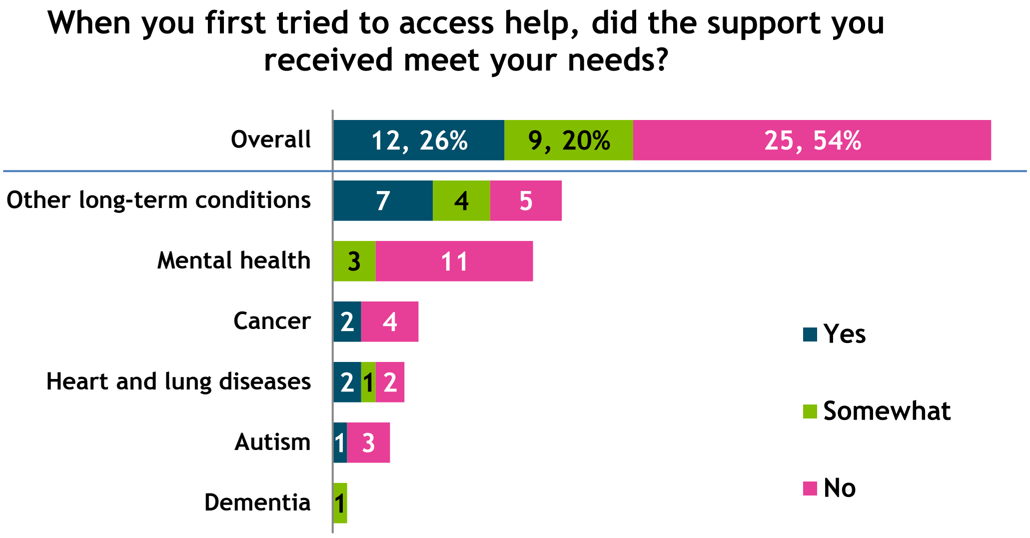
(Age 18-24 with a disability and more than one long-term health condition)

Experience of getting help and support for specific conditions

Due to the small sample sizes, all the differences reported in this section are not statistically significant.

Support

Over half (54%) the people with a specific condition told us that the support they received when they first tried to get help did not meet their needs. This was particularly the case for people with a mental health condition, none of who felt the support met their needs entirely.



Experiences may have been more negative for people whose condition started longer than last three years ago, carers and under 45 year olds.

Group	Yes	Somewhat	No	Total
Started within last three years	35%	24%	41%	17
Started longer ago	21%	17%	62%	29
Carer	8%	8%	83%	12
Disability	39%	22%	39%	23
Under 45[20]	13%	25%	63%	8
45-64	22%	22%	56%	27
65+	50%	10%	40%	10
Male	43%	0%	57%	7
Female	22%	22%	56%	36

People's overall experiences of getting help for a specific condition were mixed. Overall, 44% reported a negative or very negative experience, compared to 30% having a positive or very positive experience. Only one person with a mental health condition had a positive experience and three of the four people talking about autism had a negative or very negative experience.

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[20] Only one person was under 25 so the youngest two groups were combined.

	Overall experience of getting help					
Group/Condition	Very positive	Positive	Average	Negative	Very negative	Total
Long-term condition	25%	31%	19%	13%	13%	16
Mental health	0%	7%	36%	14%	43%	14
Cancer	17%	17%	33%	0%	33%	6
Heart and lung	0%	40%	20%	40%	0%	5
Autism	0%	0%	25%	50%	25%	4
Dementia	0%	0%	0%	100%	0%	1
Started within last three years	18%	24%	29%	18%	12%	17
Started longer ago	7%	17%	24%	21%	31%	29
Carer	0%	8%	17%	25%	50%	12
Disability	13%	26%	22%	13%	26%	23
Under 45	0%	11%	33%	22%	33%	9
45-64	11%	19%	30%	19%	22%	27
65+	20%	30%	20%	10%	20%	10
Male	29%	14%	0%	29%	29%	7
Female	8%	22%	33%	11%	25%	36
Overall	*11% (5)*	*20% (9)*	*26% (12)*	*20% (9)*	*24% (11)*	*46*

Twenty-seven of the 46 people (59%) said they had additional conditions or disabilities to the one they were answering about in the survey. Half of these (52%, 14) said having to seek support for more than one condition at a time made it harder to get support, compared to four (15%) who said it made it easier (seven, 26%, said it made no difference). Six of the 14 who said it was harder had a mental health condition, three autism, three heart or lung disease and two a long-term condition. The four who said it was easier all had a long-term condition and a disability and were not carers, although nine of the 19 with a disability said it made it harder.

There was little difference between demographic groups. Over 65 year olds possibly found it easier and seven of the nine carers found it harder.

How support did not meet needs or could be improved

When asked to tell us more about whether the support they received when they tried to first access help met their needs and how it could have been improved, 36 people commented[21] and these comments were grouped into four overall themes.

1. Lack of support, information, follow-up or access

Fourteen people commented on how they felt they lacked support, including **having to actively seek support** (four), lacking **information/signposting** (four), a lack of **follow-up** (one), **treatment for autism** (one), **support for their condition** (one), **having to source their own hydrotherapy** (one) and being concerned about a **'postcode lottery'** (one).

2. Workforce

Eight people commented on aspects of workforce, including three **positive comments** about professionals who **listened**, were **supportive** or were **knowledgeable**. Two people **did not feel listened** to or **involved** in decision-making, one mentioned **having good support but an indirect referral**, one a **lack of knowledge about their condition** and one **having to travel far to see experts.**

3. Diagnosis

Seven people commented on diagnosis, including having a **delayed diagnosis** (four) or **having to fight for one** (one). One person said the **telephone assessment was unhelpful/intimidating**.

4. Appointments, referrals and waiting times

Two people mentioned **not having to wait long**, two that they **had to wait a long time** to be seen urgently (in A&E), one **could not get a referral** and one said there were **infrequent appointments** and **poor transition to adult services.**

Long-term conditions

The most commonly mentioned theme for six people with a long-term condition, such as diabetes or arthritis, was a **lack of support and information, having to source their own hydrotherapy** (one) and being concerned about a **'postcode lottery'** (one). For example:

> "I was given a diet that did not help my diabetes and I had to find out through books and the internet how to help myself." *(Age 55-64)*
>
> "A lot of information has to be sourced yourself so you can arm yourself with that information and ask for things that you should be being signposted to as a matter of course." *(Age 45-54 with a disability)*
>
> "There is very little osteoporosis support in the county. There needs to be a fracture liaison service at the hospitals, so that anyone with a fragility fracture is referred on to osteoporosis diagnosis and support services. My own diagnosis came after a DEXA scan … There was no further follow up, no referral to, for example, physiotherapy, no information about support services such as the National Osteoporosis Society. … Access to the rheumatology department is now more difficult. I have been able to access other facilities through the GP surgery when in need, but it has taken many weeks/months to receive an appointment, although worthwhile once there." *(Age 75+ with a disability)*

Three people gave **positive comments** about professionals who **listened**, were **supportive** or were **knowledgeable,** and one person said they **received care quickly**.

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[21] One comment gave three themes.

Mental health

Three people with a mental health condition mentioned a **lack of support** (having to seek it out), **treatment** or **follow-up**. For example:

> "Had no follow- up from GP unless made an appointment or mental health team at all. Until now when crisis point was reached." *(Age 45-54 carer)*
>
> "I have learned a lot about my own disability and it is manageable with the right support in place. The problem is that so many people are pigeon-holed and treated by the book, or not at all. I've been mistreated for so many years which has actually made my condition worse, giving me post-traumatic stress. I have struggled to get the right support which helps me to help myself. I now am afraid to ask for help of mental health or crisis services because I see how poor they are with others, particularly some of my homeless friends who need the crisis services." *(Age 65-74 carer with a disability)*

Two people mentioned issues with **not being listened to** or **decisions being made without them**:

> "Transferred from a different area and a decision on my care was made without meeting me so did not receive the right care." *(Age 55-64 carer with a disability)*
>
> "I have PTSD and depression and needed counselling sessions and talking therapies, but felt that they did not listen and were trying to sell me what they thought I needed, instead of listening to me …" *(Age 45-54)*

Two mentioned issues to do with waiting times, including **infrequent appointments and poor transition** to adult services, for example:

> "Appointments were scarce and often left unaware if I was even being treated still because at least a month would go by without any contact from the psychologist and their team. Then later had an amazing psychologist in CAMHS but now it's been three-quarters of a year with no psychological treatment as I transition between child to adult services." *(Age 18-24)*

One person mentioned a negative aspect of their **diagnosis**:

> "Having a telephone assessment to ascertain how ill you are is inhuman and immoral and likely to exacerbate depression and anxiety - horrendous. Having to be open with someone you do not know, have never met and are then threatened with serious consequences if you do not reply is inhuman!" *(Age 55-64 with a disability)*

One person made a suggestion for **appointments**:

> "More time to help those through counselling, assessments and aftercare. For those that have been admitted better follow up after care. Make sure assessments are done. Make sure they receive at least counselling. Make sure you give them more than just a room to do art in to help adjust to life outside of a ward/hospital." *(Age 25-34 with a disability)*

Cancer

Two people mentioned **having to seek support** themselves, for example:

> "More support from Macmillan services. My father had to contact them and not the other way around." *(Age 25-34 carer)*

Two people suggested more appropriate or earlier scanning, so cancer is **diagnosed sooner**, for example:

> "Eleven months before GP surgery decided an ultrasound might discover something. It did: ovarian cancer. By then incurable." *(Age 65-74)*

One person told us how their oncologist **did not understand their rare form of cancer**:

> "I had a rare form of breast cancer (only 1%). My oncologist didn't understand it and was going to discharge me after surgery, but I sought a second opinion from a professor at the Royal Marsden who offered advice to my oncologist and then she arranged chemotherapy. I had to chase up everything … I am still fighting now to have follow-up scans." *(Age 55-64)*

Autism

Two people told us how people with autism **struggle to get a diagnosis**:

> "Long wait for ASD diagnosis assessment" *(Age 45-54 carer)*
>
> "We had to fight to get any help and eventually got a diagnosis. Not much more help." *(Age 35-44 carer)*

Two highlighted **issues with support**, for example:

> "People actually being knowledgeable about the condition would've been helpful but also people knowing who to signpost you to instead of doing seven years of ever-decreasing circles achieving nothing." *(Age 35-44 carer with a disability)*

Heart and lung diseases

One person told us about a **delayed diagnosis**, one about a **delay being seen** in A&E, despite their condition being urgent, and one **struggled to get a referral**. One person highlighted how they **have to travel a long way** to see experts. For example:

> "Couldn't get a referral to a cardiologist initially - had to go privately. When heart failure nurses were involved, support and information greatly improved." *(Age 45-54 carer)*

Dementia

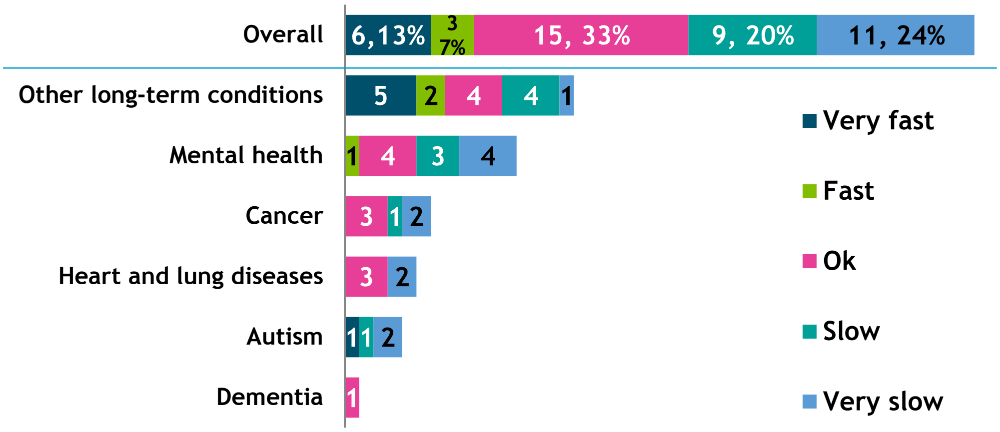
One person mentioned a **lack of information and support**:

> "My mum received a diagnosis of mixed dementia but no information about what might happen or the support available." *(Age 55-64)*

Waiting times

Just under half of people with a specific condition (44%, 20 of 45 responses) described the amount of time they had to wait to receive their initial assessment or diagnosis as ‘slow’ or ‘very slow’, compared to 20% (nine) who said it was ‘fast’ or ‘very fast’. Most of the people who answered ‘fast’ or ‘very fast’ had a long-term condition and three of the four people talking about autism answered ‘slow’ or ‘very slow’.

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



There was no noticeable difference between the speed of initial assessment/diagnosis for those with a condition that started within the last three years or longer ago. More people with a disability (22%, five of 23), over 65 years old (30%, three of ten) and males (43%, three of seven) reported ‘very fast’. Half of carers (50%, six of 12) reported a ‘very slow’ experience.

When asked to tell us more about the length of time they waited, eight people told us ‘years’, seven said ‘months’, five said ‘weeks’, three said ‘hours’, three said ‘quick’ and three said ‘too long’.

Long-term conditions

Three people with a long-term condition said they waited ‘years’, and one person said they “went private in the end”. For example:

> “I had several conditions that were very debilitating and this seemed to spur the medical team on to help me resolve the problems, but it has taken a few years to get to where I am now. Not cured but living much easier than previously.” *(Age 65-74 with a disability)*

Four people told us about being seen quickly, for example:

> “When I noticed pain in one of my limbs and saw a doctor, I was sent to the hospital and treated urgently.” *(Age 75+ with a disability)*

Mental health

Three people told us about having to wait a long time, including one person implying that it took longer to diagnose other conditions due to their neurological condition or mental health. For example:

"Autism diagnosis was quick when he was young but the mental health seems to be harder for services to diagnose. Been waiting years for someone to tell us what is causing the psychosis, I believe it's stress from a lack of support over a few years." *(Age 45-54 carer)*

"I have been diagnosed with ME but this took five years. It took three years to get a referral for a hysterectomy that I needed because of symptoms being put down to my neurological condition." *(Age 55-64 carer with a disability)*

Four people told us about long waits that lasted 'months', for example:

"I waited at least six weeks from self-referral to receiving a call back. Another wait then for assessment over phone, and again a wait of around eight weeks for any support." *(Age 45-54)*

"Have just had to wait approximately eight to ten weeks to see the crisis/short term mental health team." *(Age 45-54 carer)*

One person told us more about a short wait:

"Due to the physical complications of my illness, I was offered an initial appointment after roughly two to three weeks." *(Age 18-24)*

Cancer
Two people told us they waited one to three years, one person felt they had no support and one person told us about a two week waits at each stage:

"We never received any support and no pain management plan." *(Age 25-34 carer)*

"At least three years, in real terms longer because tumour didn't show on mammograms." *(Age 55-64 with a disability)*

"Initial diagnosis from GP, two week wait for first hospital appointment. Each extra appointment (scans, CT, MRI, PET) meant another wait (sometimes of two weeks)" *(Age 55-64)*

Autism
Three people told us about a slow experience, for example:

"Still waiting for my daughter and three years and counting for my son." *(Age 35-44 carer)*

"Eight month wait for assessment." *(Age 45-54 carer)*

One person (age 25-34 with a disability) had a fast diagnosis but felt unsupported afterwards.

Heart and lung diseases
One person had a six month wait, one told us they only had to wait a few weeks for an appointment and one told us about waits at different stages, which they felt were reasonable. For example:

"Was called quickly and offered an appointment for a few weeks' time. When I explained the circumstances to the nurse she brought the appointment forward." *(Age 45-54 carer)*

"Immediate A&E admission on presenting to 'out of hours'…. Three months for COPD tests. One month for throat cancer test. All in all I don't think this was at all bad timing." *(Age 55-64)*

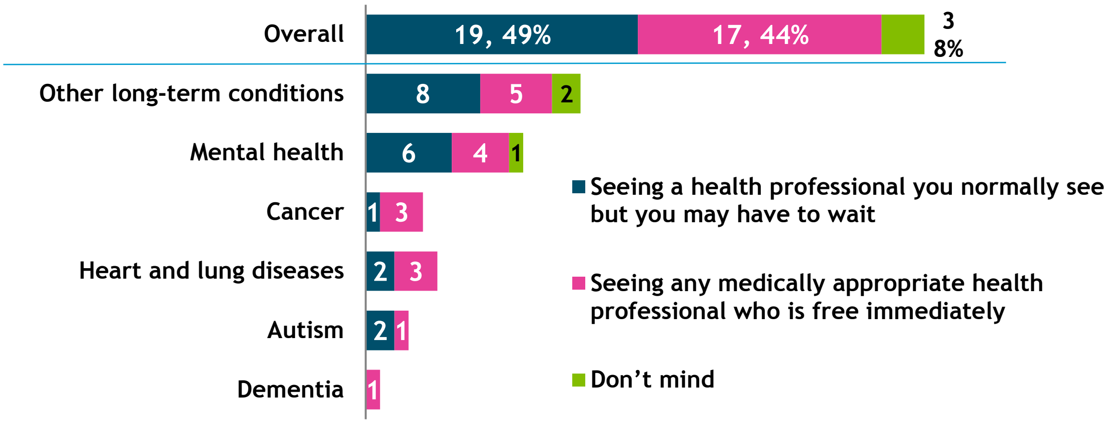
Dementia

The experience with a dementia diagnosis was several years ago and the person could not remember the amount of time they waited.

Willingness to wait to see their usual health professional

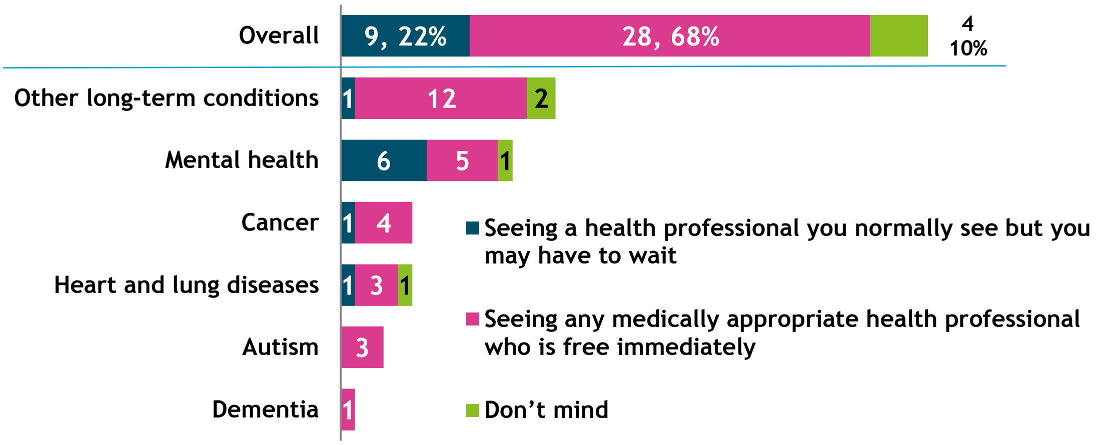
When first seeking help, most people with a specific condition thought that 'seeing any medically appropriate health professional who is free immediately' was more important to them that 'seeing a health professional you normally see but you may have to wait'. This was the case for all conditions except mental health, where half (50%, six of 12) would like to see someone they normally see even if they may have to wait. None of the eight under 45 year olds preferred to see someone they normally see. Slightly more carers (30%, three of ten) prefered to see someone they normally see.

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



When first receiving a diagnosis and explanation of treatment or support options, almost half (49%, 19 or 39) would prefer to wait to see someone they normally see, particularly those with a long-term (53%, eight of 15) or mental health (55%, six of 11) condition, those with a disability (60%, 12 of 20), carers (60%, six of ten) and women (52%, 16 of 31).

What is most important to you when first seeking help?

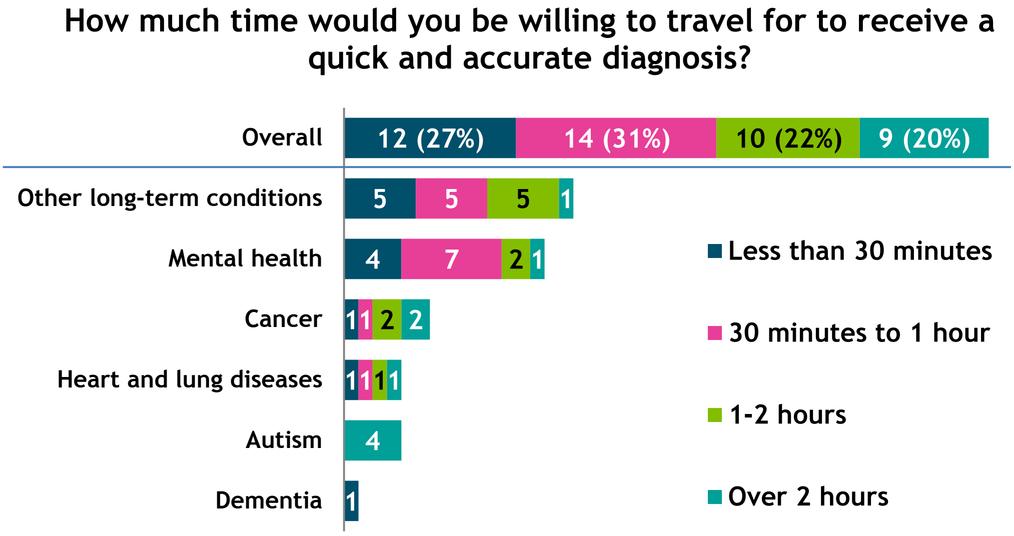


Willingness to travel for a diagnosis

The willingness of people to travel to receive a quick and accurate diagnosis seems to vary by condition. Overall, 42% were prepared to travel over an hour, although all four people talking about autism were prepared to travel over two hours, probably reflecting the difficulties they reported in getting a diagnosis. People with a mental health condition were less willing to travel more than an hour, only three of 14.

Only those with their own car or access to another person's car as their main means of transport were willing to travel over two hours.

Over 65 year olds preferred travelling less than 30 minutes (four out of nine), as did disabled people (eight out of 22).



Conclusion – what helps people to 'choose well' - prevention and/or early intervention

What works well?

People at the engagement event told us that the care they receive through the NHS is 'generally good'. They highlighted **technological developments** that make it easier for people to book appointments online and to support people to live independently in their own homes (e.g. personal alarm services).

People talked very positively about **supportive networks in some communities**, such as Rushden and Moulton, where the **voluntary sector organisations signpost people** effectively to the services and support they need.

What could be better?

A **directory of services** and centralised **information system**, which patients, professionals and the voluntary sector had access to was thought to be important to help people know what help and support is available and to make an informed choice. The directory should include county-wide and local services, and support should be available to help people use a directory.

Community connectors could play an important role in linking people to services and reducing social isolation.

Access to services, particularly **GP appointments and referrals to specialists**, was the biggest issue faced by survey respondents. Some people with a specific condition felt they **lacked support** or were not followed up on and had to **actively seek it.**

Maintaining and caring for the **whole person** to ensure continuity within their long-term care and ensuring all have access to patient records through a **'patient passport'** were also felt to be important.

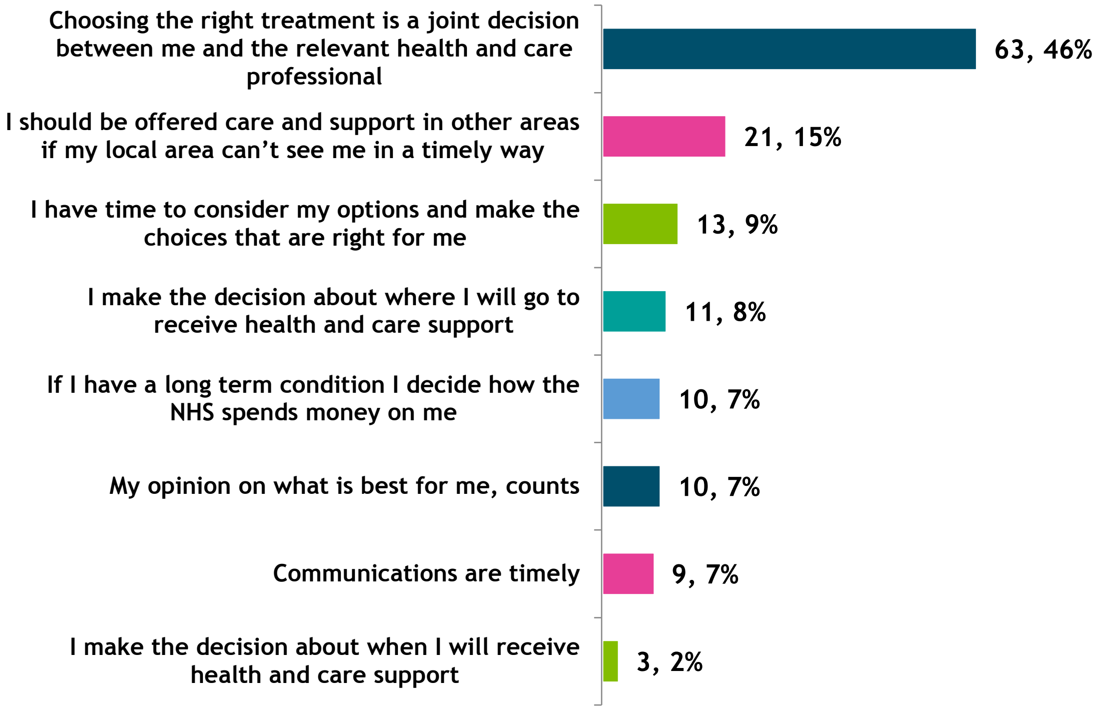
Stay well - assessment, diagnosis and treatment

Managing and choosing the support people need

In the general survey we asked people to tell us what was most important to them to be able to manage and choose the support they need from a range of topics.

Almost half (46%) thought that the most important thing was that choosing the right treatment was a joint decision between them and the relevant health and care professional.

What is most important to you 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' was the most important answer for all demographic groups looked at.

'If I have a long-term condition I decide how the NHS spends money on me' was more important for carers, people with a disability, those who are not White British and those who are not heterosexual. Interestingly, it was not rated as most important by many people with a long-term condition.

	Choosing the right treatment is a joint decision between me and the relevant health and care professional	I should be offered care and support in other areas if my local area can't see me in a timely way	I have time to consider my options and make the choices that are right for me	I make the decision about *where* I will go to receive health and care support	If I have a long-term condition I decide how the NHS spends money on me	My opinion on what is best for me, counts	Communications are timely	I make the decision about *when* I will receive health and care support	*Total number who answered*
Carers[22]	36%	14%	0%	9%	23%	5%	9%	5%	*22*
Disability	50%	16%	5%	5%	16%	5%	0%	3%	*38*
Long-term condition	47%	18%	8%	9%	9%	5%	3%	3%	*79*
Non-White British[23]	14%	7%	14%	14%	21%	0%	14%	14%	*14*
Non-Heterosexual	40%	10%	0%	10%	30%	0%	10%	0%	*10*
Female	41%	15%	9%	8%	7%	9%	7%	2%	*97*
Male	59%	14%	11%	5%	5%	0%	3%	3%	*37*
Under 25s	50%	17%	17%	0%	0%	0%	17%	0%	*6*
24-44 years old	38%	24%	14%	0%	10%	7%	7%	0%	*29*
45-64 years old	43%	11%	7%	9%	9%	9%	6%	6%	*54*
65 plus	55%	13%	9%	13%	2%	4%	4%	0%	*47*

People were also asked to rate how important each statement was to them. Again, most people felt all the statements were either very important or important, and 'communications are timely' was rated as very important by more people, with all rating it as very important or important. Only 38% felt that 'if I have a long-term condition I decide how the NHS spends money on me' was very important, and eight people (6%) felt it was not, or not at all important.

The order of importance of these answers may imply that people want to be involved in the decisions made about their treatment but do not think that their opinion is more important than that of a health or care professional.

The order of importance for these statements varied slightly for different demographic groups, except those with a long-term condition and women (but these differences were not statistically significant).

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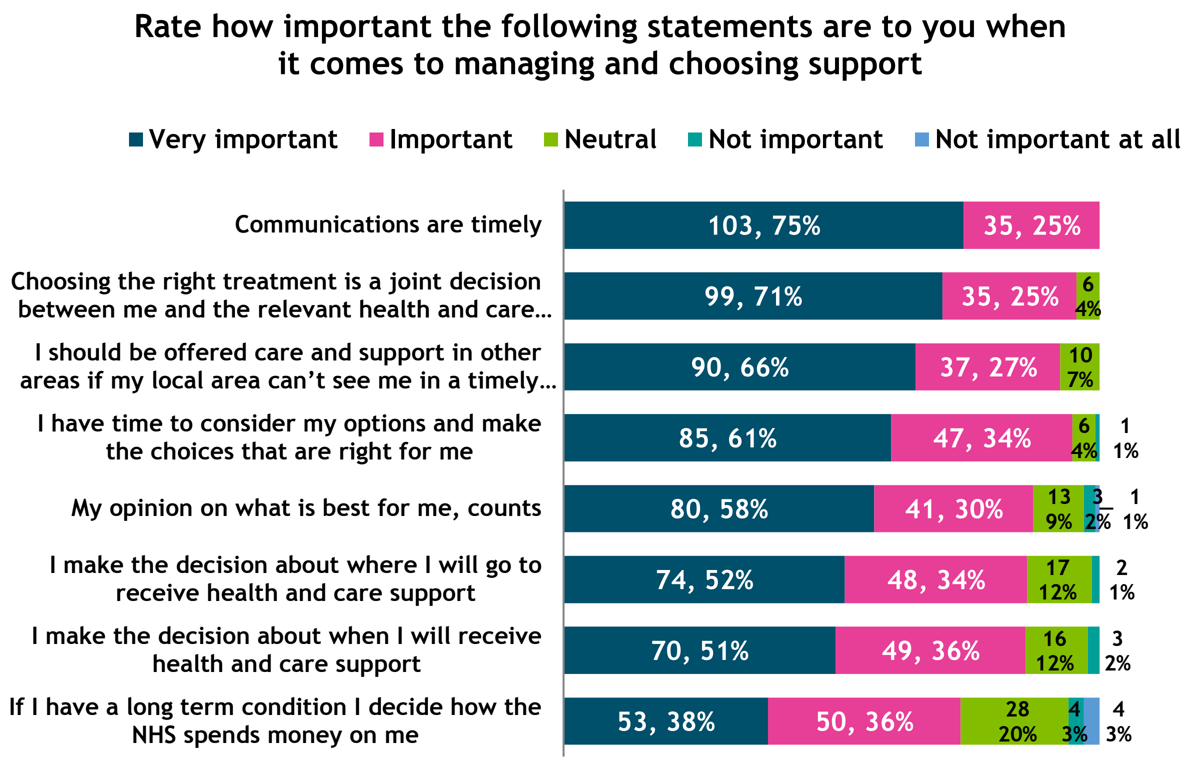
[22] Top five categories for carers compared to not carers, Chi-square 11.52, P<0.05.

[23] Top five categories for White British compared to not White British, Chi-square 11.66, P<0.05.


Rate how important the following statements are to you when it comes to managing and choosing support

Statement	Order of importance (based on percentage 'very important')								
	Carers	Disability	Under 25	25-44	45-64	65 plus	Non-white British	Non-Heterosexual	Male
Communications are timely	1	1	1	=1	1	2	1	1	1
Choosing the right treatment is a joint decision between me and the relevant health and care professional	2	2	=3	=1	3	1	=4	=2	2
I should be offered care and support in other areas if my local area can't see me in a timely way	4	3	2	4	2	=3	=6	=2	3
I have time to consider my options and make the choices that are right for me	3	4	=3	5	5	=3	3	8	4
My opinion on what is best for me, counts	5	5	=3	3	4	6	=1	4	=5

I make the decision about *where* I will go to receive health and care support	=6	7	=7	=6	7	5	8	=5	7
I make the decision about *when* I will receive health and care support	8	6	=3	=6	6	7	=4	=5	=5
If I have a long-term condition I decide how the NHS spends money on me	=6	8	=7	8	8	8	=6	=5	8
Number of people	*21*	*41*	*6*	*29*	*54*	*47*	*14*	*10*	*36*

What else is important to help people manage and choose how health and care supports them and to 'stay well'?

The engagement event asked people to reflect on their good and less good experiences of services relating to the 'stay well' treatment theme and then to come up with three ideas or priorities as a table group to help people 'stay well' (i.e. what matters most).

The general survey also asked people if there was anything else that would help them manage and choose how the NHS supports them. Sixty-six people commented, and these comments were grouped into six overarching themes[24]. The most commonly mentioned things again related to **accessing services, communication** and **having knowledge or information**.

Access

At the event, **problems of capacity** and **long waiting times** were mentioned as issues when seeking assessment, diagnosis and treatment, particularly through their GP. Having **GPs as the first point of contact** was not seen as sustainable by some people and as one person told us, 'delays in diagnosis can cause critical situations'.

Twenty survey respondents also mentioned aspects of **appointments or referrals**, including wanting easier or quicker access, again referring to **GP appointments** or services (five people), **waiting times** (five people) and six mentioned wanting **longer appointments** where they could be listened to. Two people valued being able to **see the same or right person** and one person wanted to access their GP via an app. For example:

> "Easier access to GP appointments, i.e. not having to wait three weeks." *(Age 55-64 with a disability and more than one long-term health condition)*
>
> "Being referred to the right place in a timely manner, not waiting until you get worse and then sending you somewhere." *(Age 25-34 with a disability and more than one long-term health condition)*

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[24] Four people gave comments which were classed as more than one theme.

> “Quicker referrals, less waiting time especially for mental health and talking therapies.” *(Age 45-54 with more than one long-term health condition)*
>
> “More time to talk to healthcare professionals – they never seem to have enough time and it always feels as though you are being rushed out of the door.” *(Age 75+ with more than one long-term health condition)*
>
> “Stop this nonsense of one appointment, one problem at GP's. Often patients put off seeing a doctor, they go when something is very serious but then they are told not to talk about any other symptoms they have because they only made one appointment. Those other issues could actually be the early signs of something significantly more serious that the doctor may pick up on before the patient is really aware.” *(Age 55-64 carer with a disability and more than one long-term health condition)*

Communication

Seventeen survey respondents mentioned aspects of communication by professionals.

People at the event reported difficulties with **understanding clinical language** and the **process of diagnosis, treatment and care** (not everyone understands the term ‘pathway’), including **what choices are available** and routes for seeking help other than from their GP.

Two survey respondents also mentioned this:

> “Better communication, given in layman terms.” *(Age 45-54 with a long-term health condition)*
>
> “To articulate and explain things/health conditions in more user-friendly terms.” *(Age 25-34)*

Event participants also told us about a **lack of communication and coordination between services**. Information about a person and their needs is not always transferred in a timely and accurate manner, particularly when treatment involves admission to hospital. Problems with the flow of information had contributed to delays in treatment, an inability to deal with people’s multiple conditions and **prescribing difficulties** (including incorrect medication being prescribed and instructions being incorrect or misunderstood). Such problems can lead to a person’s condition deteriorating and considerable distress for patients and their carers.

Seven survey respondents also mentioned this, including the need for **good admin and IT systems**, for example:

> “Communications between services and departments needs to be better. Too often the patient is reliant on themselves knowing specific information to aid their healthcare professional, and this information should have already been shared between services. It is unfair as a patient cannot always fully understand all the information and specifics of what needs to be shared so they can receive the correct care, so the service they receive is subpar.” *(Age 18-24 with a long-term health condition)*
>
> “Admin mess ups are so common. Can’t get notes sent from one hospital/consultant to another because of different computer systems - in this day and age, really? Leads to delays, lost paperwork and patients begging secretaries who can't help for progress. It's a disgrace. I know the NHS is struggling but this lack of patient info sharing is antiquated.” *(Age 35-44 with a long-term health condition)*
>
> “Ensure that health records are available online so that if you need to see a doctor out of your area he can access your records.” *(Age 65-74 carer with a long-term health condition)*

People also told us that they don't want to be seen as a condition or a diagnosis; they want to be treated in a **holistic way**, with a focus on their **overall wellbeing** and with respect for **individual choice**.

Five survey respondents felt that professionals should have **more understanding or knowledge or conditions such as autism and learning disabilities**, for example people told us they wanted to see the following:

"If they had the capacity to actually understand my needs." *(Age 45-54 with a long-term health condition)*

"I would like services to be autism-aware." (Age 45-54 with a disability and long-term health condition)

"People in health are trained in my condition (designated nurse/person). Communication key using augmented communication available, i.e. BSL, Makaton, signs/symbols. Fast track system at A&E as many with a learning disability can become anxious and disruptive whilst waiting (not their fault, just they may feel vulnerable, tired and disorientated)." *(Age 18-24 with a disability and more than one long-term health condition)*

Information
Twelve survey respondents suggested better or more information, particularly about **their conditions and treatment options** (seven) and about **services** (two). For example:

"Access to information that will assist me in making the best decision on my health." *(Age 25-34)*

"Full information about options. I would also want my choice to be informed by my health professionals' advice and guidance." *(Age 45-54)*

"Someone who has the time to translate and clarify some of the choices - how would I know what area of specialist is needed for my condition? Triage points would help GP's and patients." *(Age 55-64)*

"More information on local NHS websites, and for these to be user-friendly." *(Age 25-34 with a disability and more than one long-term health condition)*

Other individuals suggested better **information about waiting times**, more **information in Easy Read** and **lifestyle advice** and support (one mention each).

Choice/location
Ten survey respondents wanted **more local services** or a **choice of location** (seven) or a **choice of time** or treatment option (three). For example:

"A closer to home hospital or support system in my locality." *(Age 35-44 carer)*

"More choice locally – I had to travel from Corby to Northampton for radiotherapy." *(Age 65-74)*

"More options when referred on a 'choose and book' system, i.e. the ability to request out of area if a quicker response. To have more community options." *(Age 55-64 with a long-term health condition)*

"More options for attending appointments around my working hours." *(Age 45-54 with a disability and more than one long-term health condition)*

Person-centred

Five survey respondents felt care and treatment should be more person-centred, including **making decisions jointly with doctors** (two) and people with **multiple or complex conditions** having easier access to appointments (two). For example:

> "People who are health professionals should be able to make decisions if that is what is best, but the person experiencing the care should be able to agree the important decisions." *(Age under 18)*
>
> "Any NHS professionals responding to my needs must take note and account for all my multiple conditions, not just the one condition/issue they see or observe at the one time. Too many times other conditions are ignored/overlooked/not considered when as a whole they greatly impact on every aspect of my daily life 24/7, even at rest." *(Age 65-74 carer with a disability and more than one long-term health condition)*
>
> "The computer-scripted 'care navigation system' for appointments that's detrimental to those with complex health conditions, the elderly who 'don't like to make a fuss' and those suffering with their mental health. This system sets patients and clinicians apart. Nothing is better than a human and compassionate person on the end of the phone." *(Age 55-64 with a disability and more than one long-term health condition)*

Better services

Three people mentioned wanting better services, care in the county for Lymphoedema patients and more efficient GP practices (one mention of each).

Other

Two survey respondents mentioned **funding** (improving funding and informing the public of the need to balance how money is spent), one person felt there should be fewer cancelled appointments, and one suggested research:

> "Collect information from following patients with the same health problems on their experiences with treatments and their decision-making process." *(Age 18-24)*

In focus – Carers' experiences with discharge from hospital

At the carers' group in particular, we heard multiple stories of **difficulties around discharge from hospital**, where carers felt they were not fully involved in decisions and where family members were discharged from hospital without proper assessment of their needs or adequate notice to carers of the arrangements: "Professionals need to understand the family dynamics when the patient is considered vulnerable", one carer told us.

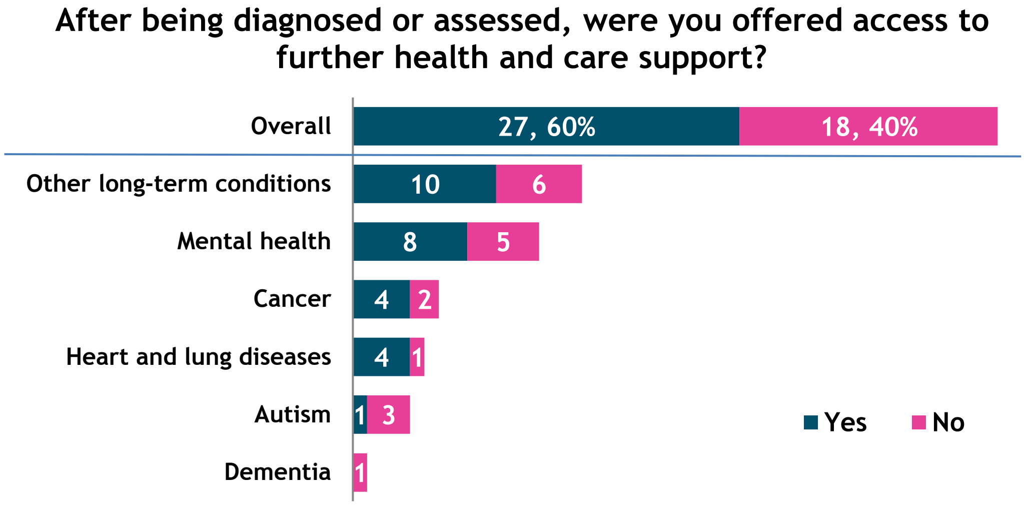
One survey respondent told us, *"Carers and family carers need to understand and have training in what is considered a 'best interest decision' and what is the paperwork surrounding this if their loved one has a hospital admission."* (Age 18-24 with a disability and more than one long-term health condition)

Experience of receiving help and support for specific conditions

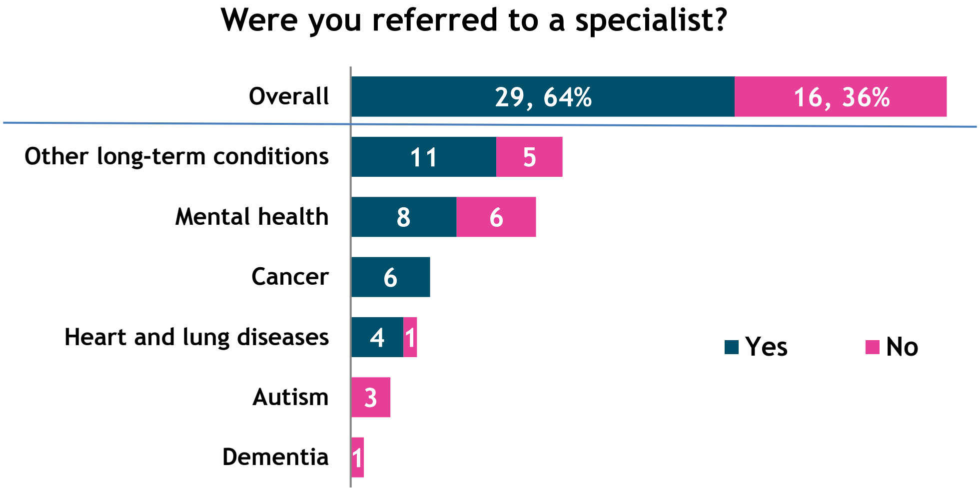
Due to the small sample sizes, all the differences reported in this section are not statistically significant.

Support after being diagnosed or assessed

Twenty-seven of the 45 people with a specific condition (60%) were offered access to further health and care support after being diagnosed or assessed. Three of the four people talking about autism were not.



Almost two-thirds (64%) of people were referred to a specialist. The three people talking about autism and one about dementia said they were not referred to a specialist.

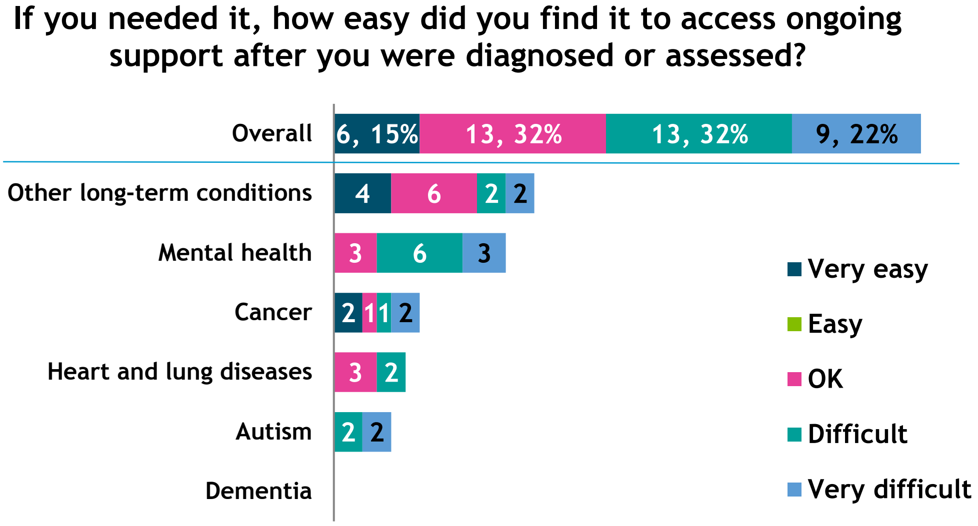


What about support worked well or could be improved

Those with a specific condition who accessed support were asked what worked well and what could be improved. Most of the comments about things that worked well (ten of 13) were about aspects of **treatment**. Two mentioned **information or explanations** and one mentioned **prevention**. Improvement suggestions again related to **access or treatment** (eight), **support from individuals/professionals** (three), and **information, signposting or communication** (three).

Ongoing support

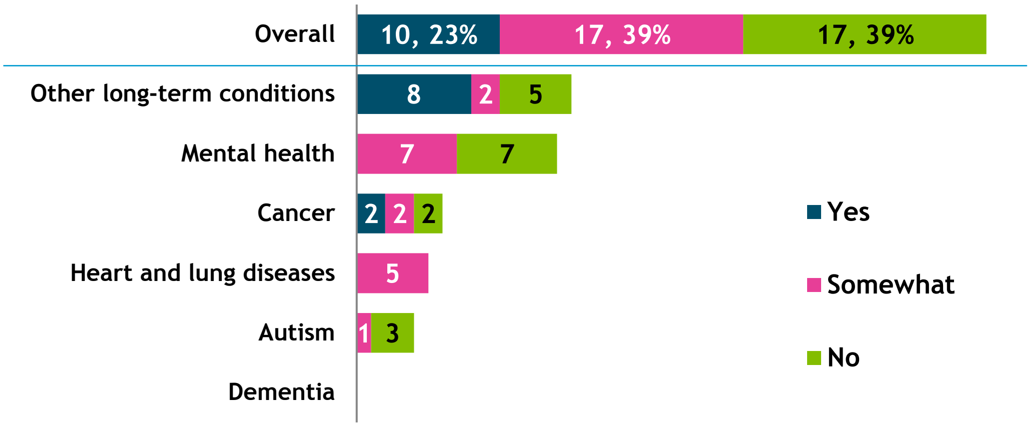
How easy people with a specific condition found it to access ongoing support after they were diagnosed or assessed varied. Six people (13%) found it ‘very easy’, four of whom had a long-term condition, and two had cancer. All four people talking about autism found it ‘difficult’ or ‘very difficult’, as did nine of the 12 with a mental health condition. No carers or people under 45 years old reported an ‘easy’ experience.



	Overall experience of getting help					
Group	Very easy	Easy	OK	Difficult	Very difficult	Total
Started within last three years	2	0	7	4	2	15
Started longer ago	4	0	6	9	7	26
Carer	0	0	2	5	5	12
Disability	3	0	7	5	5	20
Under 45	0	0	1	3	4	8
45-64	3	0	11	7	4	25
65+	3	0	1	3	1	8
Male	2	0	0	2	2	6
Female	4	0	12	10	6	32

Whether the support option people were offered for their specific condition met their expectations also varied, with more people answering ‘no’ (39%) than ‘yes’ (23%). Only people with a long-term condition or cancer answered ‘yes’.

Did the support options you were offered meet your expectations?



More over 65 year olds (five out of ten) said the support offered met their expectations. No carers said ‘yes’.

When asked to explain how the care did or did not meet people’s expectations and how it could be improved, people gave 26 negative comments and seven positive comments. Negative themes were a **lack of follow up or support** (nine), aspects of **poor treatment** (nine), **not being listened to** (three), **poor communication** (two), **delays** (two) and a **lack of continuity** (one). The positive themes were **treatment or care** (three), **communication** (three), a general positive comment saying they couldn’t fault anything.

Long-term conditions

The negative comments from people with other long-term conditions were around appointment cancellations, a **lack of follow-up support**, **poor or confusing communication**, **care not being in line with guidance** and the **whole person not being considered** (one each). For example:

> “I had no follow-up care. The only time I've discussed my osteoporosis with a doctor since diagnosis has been when I’ve asked for an appointment to do so. It wasn't even noticed when I stopped taking the prescribed medication, which didn’t suit me at all. Ideally there needs to be an osteoporosis clinic at the GP practice. Failing that, there could be one shared between GP practices that a patient could be referred to. As a bare minimum, the practice should give patients printed information about the condition, about the importance of exercise and healthy diet, and where to find support (for example, the Royal Osteoporosis Society).” *(Age 55-64)*
>
> “I’ve had routine annual appointments cancelled and rearranged for months later, which means annual appointments become more like 18 months.” *(Age 25-34)*
>
> “I have been referred to specialists for different reasons which may be related to my long-term conditions. However the specialists appear to only consider the immediate concern, rather than the person and conditions as a whole - this is a very limited way to deal with things. For example, a simplistic way of looking at it, but you wouldn't take a vehicle in for a full service and the garage say they could only change the tyres but not the oil!” *(Age 35-44 with a disability)*

Positive themes were seeing a consultant in **hospital**, **appropriate treatment and signposting**, being **seen quickly by a kind and helpful physiotherapist**, and everything (one each). For example:

"I had an emergency operation because of a blockage in my bowel - as a result I have a stoma. This was very distressing and life changing and I cannot praise highly enough the care I received from all the staff at NGH." *(Age 55-64 with a disability)*

"I was prescribed appropriate medication and pointed in the direction of further assistance … It was very easy to access advice and to adjust the medication if necessary." *(Age 75+ with a disability)*

"I was referred to physio and was seen within a month, and they were very kind and helpful." *(Age 45-54)*

Mental health

All 11 comments about ongoing support were negative. Three people mentioned a **lack of follow-up or support** and two said their **treatment did not help**. Other themes were a **lack of choice**, **not being listened to**, a **lack of therapists**, **waiting times**, **lack of GP continuity** and **issues with transition to adult services** (one each). For example:

"There is little support for dual autism and mental health." *(Age 45-54 carer)*

"In terms of mental health, I was given medication by my doctor, told it was a low dosage which turned out to be false and was not made aware of the common name of the drug I was prescribed, which made me feel very uncomfortable." *(Age 25-34 with a disability)*

"I was hoping for something other than medication. I had to go seeking alternatives myself, one of which involved a telephone assessment, which if you have anxiety like me, can take years to get the courage to try again. The first time I couldn't phone them, so they wrote back saying they assume services no longer required." *(Age 25-34 with a disability)*

"Child services were good but confidentiality was an issue as the ability to be completely honest is taken away due to fears of my parents being informed. Adult services/transition is awful. The long waits and constant referrals to different services puts distress on the patient after they are asked repeatedly, similar questions and repeatedly being turned away. Eventually I have found a service, but it has taken three months to be allocated a psychologist and I still haven't been given an appointment, which they said would only take five weeks." *(Age 18-24)*

Cancer

People talking about cancer gave four negative themes – two mentioned a **lack of follow up or support**, one **having to wait for results**, and one a **poor transition between services**. For example:

"Had to wait for biopsy results then full results from surgery. More accurate scanning would have picked up tumour when significantly smaller and contained, i.e. not spread to lymph glands." *(Age 55-64 with a disability)*

"Only option was a hospice. After receiving excellent care in Leicester coming back to NGH they asked him why he was here and no consultant would take him on their case load because he was terminally ill and originally based in Leicester. No transfer/crossover between services. Left in a bed for two days before a consultant would take him on. No care received in this time." *(Age 25-34 carer)*

Two positive comments were received about **Macmillan nurses**.

Heart and lung diseases

All three comments were negative and included: having to **chase for support**, **not feeling listened to** and **staff attitude**:

> "I had to call constantly to get support." *(Age 45-54 carer)*
>
> "I was discharged with two heavy weight inhalers that once I was tested for COPD they decided that this was not needed. I felt I was getting side effects from taking too much - this was hard to get over to anyone. I did not know what to expect as this was my first experience with hospital or GP post illness." *(Age 55-64)*

Autism

All three comments were negative: a **lack of support**, feeling **no-one was willing to help** and **still waiting** for help. For example:

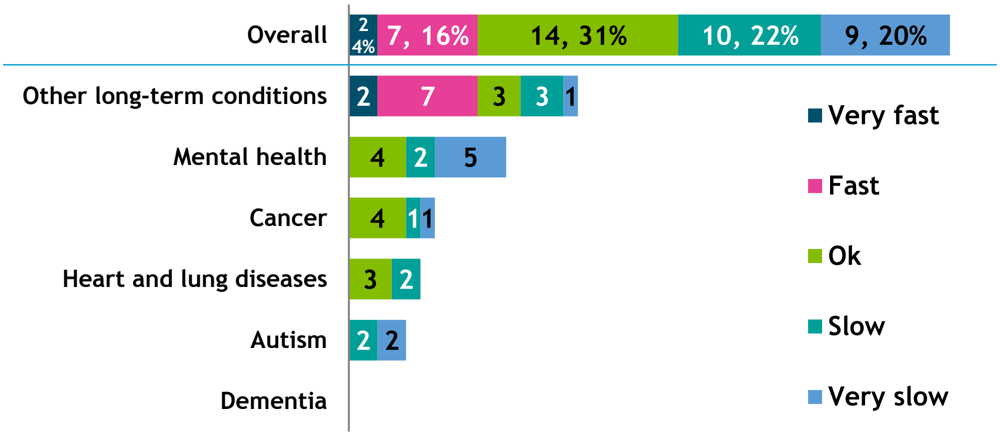
> "I have been passed from one team to another and no one seems to be able to help." *(Age 25-34 with a disability)*

Waiting times

As with receiving initial help, just under half of people with a specific condition (42%, 19 of 45) described the amount of time they had to wait between their initial assessment or diagnosis and receiving treatment as 'slow' or 'very slow', compared to 20% (nine) who said it was 'fast' or 'very fast'. All of the people who answered 'fast' or 'very fast' had a long-term condition and all four people talking about autism answered 'slow' or 'very slow'.

There was no noticeable difference between the perceived speed of receiving treatment for those with a condition that started within the last three years or longer ago. More people with a disability (32%, seven of 22) and over 65 years old (44%, four of nine) reported 'very fast' or 'fast'. Two-thirds of carers (67%, eight of 12) reported a 'very slow' or 'slow' experience.

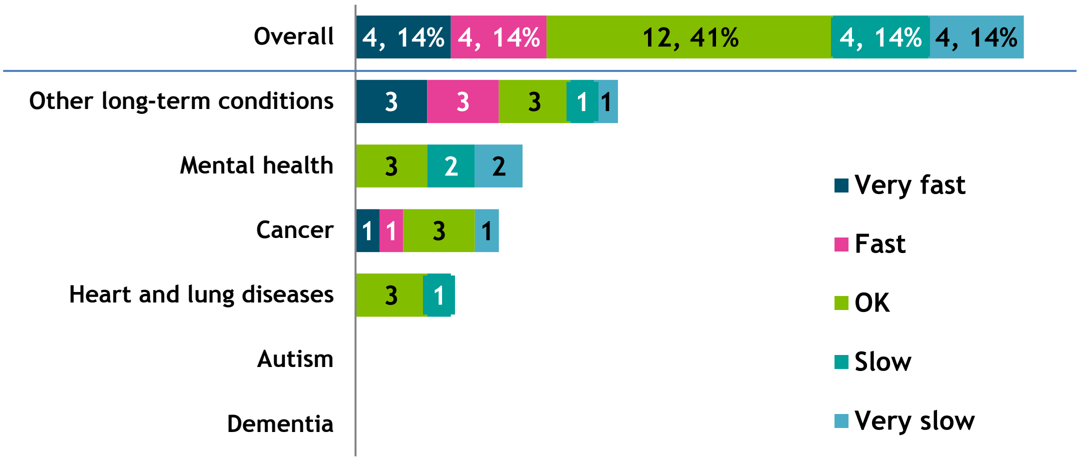
How would you describe the time you had to wait between your initial assessment /diagnosis and receiving treatement?



The amount of time people had to wait between their initial appointment and seeing a specialist varied. Most (41%, 12 of 29) felt it was 'ok'.

There was no noticeable difference between the speed of seeing a specialist for those with a condition that started within the last three years or longer ago. More people with a disability (38%, six of 16), over 65 years old (60%, three of five) and men (50%, two of four) reported 'very fast' or 'fast'. Half of carers (50%, three of six) reported a 'very slow' or 'slow' experience.

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



When asked to tell us more about the length of time they waited, six people told us 'months', seven said 'weeks', two said 'hours', two said 'quick' and one said 'too long'.

Long-term conditions
Five people told us about 'fast' experiences, including being seen within a month (one) or two week (one). Two of the 'fast' experiences were when people were already in hospital. For example:

> "I was fast-tracked to see a cancer specialist. I had a lot of tests and scans at this time but not sure if the cancer scare expedited some of the other unrelated scans and tests, but it made me happier." *(Age 65-74 with a disability)*
>
> "I saw the consultant on the assessment ward the following day and every day following until my discharge three weeks later." *(Age 55-64 with a disability)*

One person told us about a 'slow' experience and one person sought private treatment:

Mental health
Two people told us they waited six to eight months and two people two to three weeks. For example:

> "Six months and that's just for a half hour appointment. Then you get one half hour appointment every three months." *(Age 45-54 carer)*

One person told us "once they were referred it wasn't too bad" *(Age 55-64 carer with a disability)*.

Cancer
Three people told us they waited a week or two. One person had a six month wait:

> "Six month wait for a suspected gallstone, sent to specialist, eventually diagnosed with pancreatic cancer." *(Age 25-34 carer)*

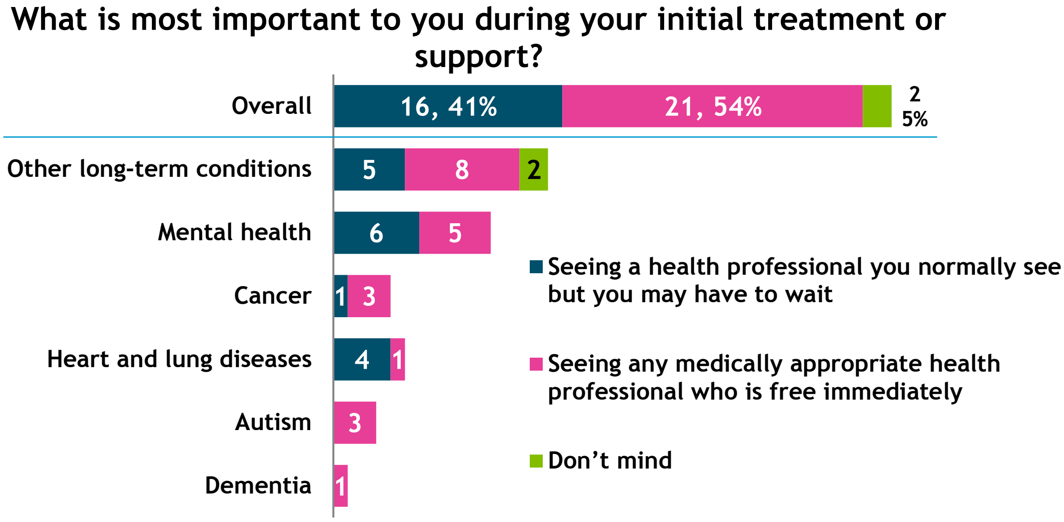
Heart and lung

Three people told us about mixed experiences:

> "The person on whose behalf I am responding usually received appointment within appropriate timescale but waited almost 12 months for news [about] rehab." *(Age 75+ with a disability)*
>
> "Throat issue was quicker - as it was ignored during stay in hospital - they were annoyed with me for being a smoker and not concerned that I felt my throat was an issue … COPD tests were good, but I was told I was to go on some course, but nothing more was said about it or arranged." *(Age 55-64)*
>
> "Saw heart failure nurses quickly, but waited months to see a specialist." *(Age 45-54 carer)*

Willingness to wait to see their usual health professional

During their initial treatment or support, the opinion of people with a specific condition was split between 'seeing any medically appropriate health professional who is free immediately' and 'seeing a health professional you normally see but you may have to wait'. This was the case for all conditions except autism and dementia, where all four would rather see someone immediately and not wait.



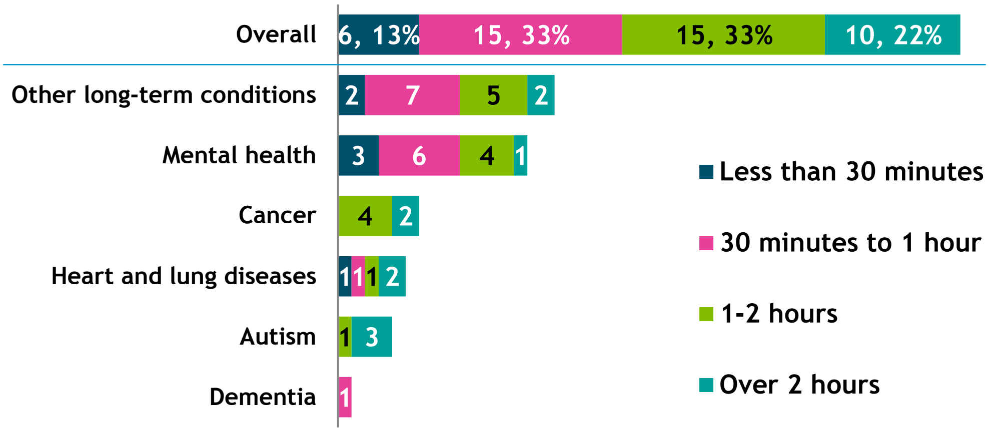
Willingness to travel to receive specialist treatment or support

The willingness of people to travel to receive specialist treatment or support varies. Overall, 55% were prepared to travel over an hour. All six people talking about cancer and all four people talking about autism were prepared to travel over one hour.

Only those with their own car or access to another person's car as their main means of transport were willing to travel over two hours.

Under 45 year olds were more willing to travel further (seven out of nine would travel over one hour).

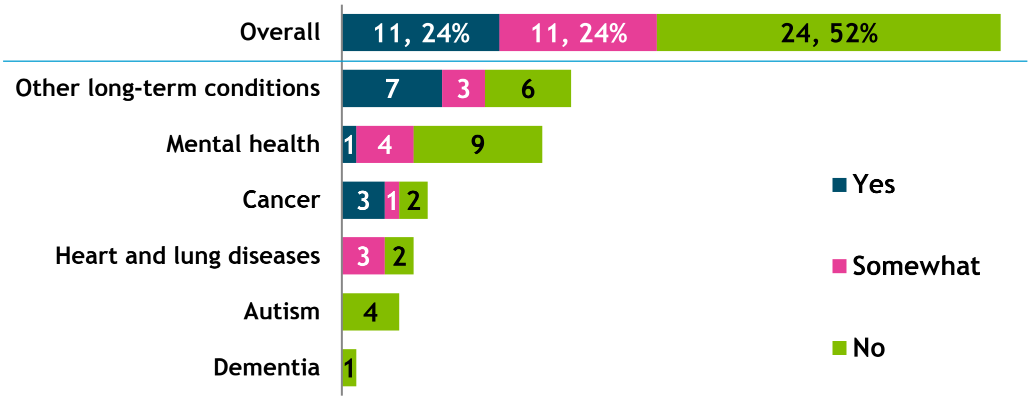
How much time would you be willing to travel to receive specialist treatment or support?



Communications

Half of survey respondents with a specific condition (52%) felt that they did not receive timely and consistent communication from all the service they came into contact with. This was particularly the case for people with autism and dementia. Half or more of those with cancer or a long-term condition did have good communications. The findings were similar for all groups, with nine of the eleven carers saying communications were not good.

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



When asked to explain how the communication did or did not meet people's expectations and how it could be improved, people gave 18 negative comments, five positive comments, two mixed comments and two suggestions for improvement. Negative themes included **not being kept informed or no follow up** (11), **condition or medication not explained** (two) and **poor communication** (two). The positive themes were **good explanations or support line** (two), **communication** (two) and **good care** (one).

Long-term conditions
The four negative comments were about **things not being explained**, for example:

> "When I was first diagnosed, my GP should have asked me to make an appointment to discuss my results. … It needs careful and sensitive handling by GPs, not a report and prescription in the post. … I had no support, no care, nothing, just a prescription and left to my own devices." *(Age 55-64)*

> "Sometimes I haven't been copied in to letters between different consultants so when I see one they think I know what they've been told." *(Age 25-34)*
>
> "I have been referred to specialists by my GP without even being told why, I just get a call from reception to collect an e-referral form and that's it." *(Age 35-44 with a disability)*

Three of the four positive comments also about **good communication** or **explanations** and one about good **care**. For example:

> "I was given the number for rheumatology nurses to ring if I had any questions or problems. I would leave a message, and someone would get back to me that day." *(Age 45-54 with a disability)*
>
> "Everything thing was explained to me every step of the way." *(Age 55-64 with a disability)*

Mental health
All seven comments were negative, three were about **not being informed**, two about **staffing** or **funding**, one about a **lack of explanation**, and one about having to **wait**. For example:

> "I felt as if I was just another patient and they forget this is the first time I am being told these things." *(Age 55-64 carer with a disability)*
>
> "Basically given medication and sent away no real follow up after first 12 months on the medication, not told would end up like a Zombie and forgetting what happened during the 10 years that I was taking the medication, had to wean self off the medication to start feeling human again." *(Age 45-54 carer)*
>
> "Long wait between self-referral and then being given access to support. Thought I had been forgotten." *(Age 45-54)*

Cancer
All three negative comments were about lack of contact or follow-up, for example:

> "I had to request letters and had to arrange my own appointments." *(Age 55-64)*
>
> "Generally a sense of being left to get on with it." *(Age 55-64)*

One person was positive about their partner being able to attend appointments with them:

> "I was very fortunate in that my partner has, and still is attending every appointment, chemo therapy, check-up, ultrasound, GP appointment with me." *(Age 65-74)*

Heart and lung diseases
Respondents told us about mixed experiences:

> "Heart failure nurses were very good at giving advice, but [it was] difficult to get advice from cardiologist or to access hospital admission when required." *(Age 45-54 carer)*

Autism
The three negative comments about autism were to do with a **lack of support** or **communication**:

> "Case closed with no communication." *(Age 25-34 with a disability)*

"We've had to push all the way and still are." *(Age 35-44 carer)*

"Nobody communicated and everybody was lacklustre and blamed everybody else instead of taking responsibility." *(Age 35-44 carer with a disability)*

Conclusion – what helps people to 'stay well' - assessment, diagnosis and treatment

What works well?

At our engagement events, we heard about improvements to **diagnostics** and **patient self-care**. **Technological advancements** were welcomed, although it was pointed out that some developments are **not accessible to all** ('those who have difficulties with technology fall under the radar').

Being able to **access support from other healthcare professionals at the local GP surgery** was another positive development that people valued and were keen to see more of – for example, seeing a counsellor or physiotherapist. Having provision at a local level addresses some of the travel difficulties identified earlier in this report.

People with specific conditions gave some examples of having received prompt and positive **treatment**.

What could be better?

Again, people at the event suggested **better information about services**, such as a county-wide facility which can signpost to services and social support, including **face-to-face advice** and a manned **telephone system** as well as a **website** ('like 111 but just for information').

A **shared care record** or 'health and care passport' that an individual can hold and can be accessed and understood by all relevant parties was again thought to be important to improve communication and the flow of information. Survey respondents in particular felt that there was a **need for better communication and coordination between services**.

The needs of patients should be fully understood, and they should have a **choice** and be allowed to **move with ease through systems and services**. **Individual care plans** could be used to avoid crisis situations, and people should be treated holistically with a focus on their strengths rather than weaknesses. People's **wellbeing** should be at the core of health and care.

One suggestion made was for **community hubs** that could serve as a central point where people can go to meet other and understand all services available to them would help. People should be able to **provide feedback** through the introduction of more forums.

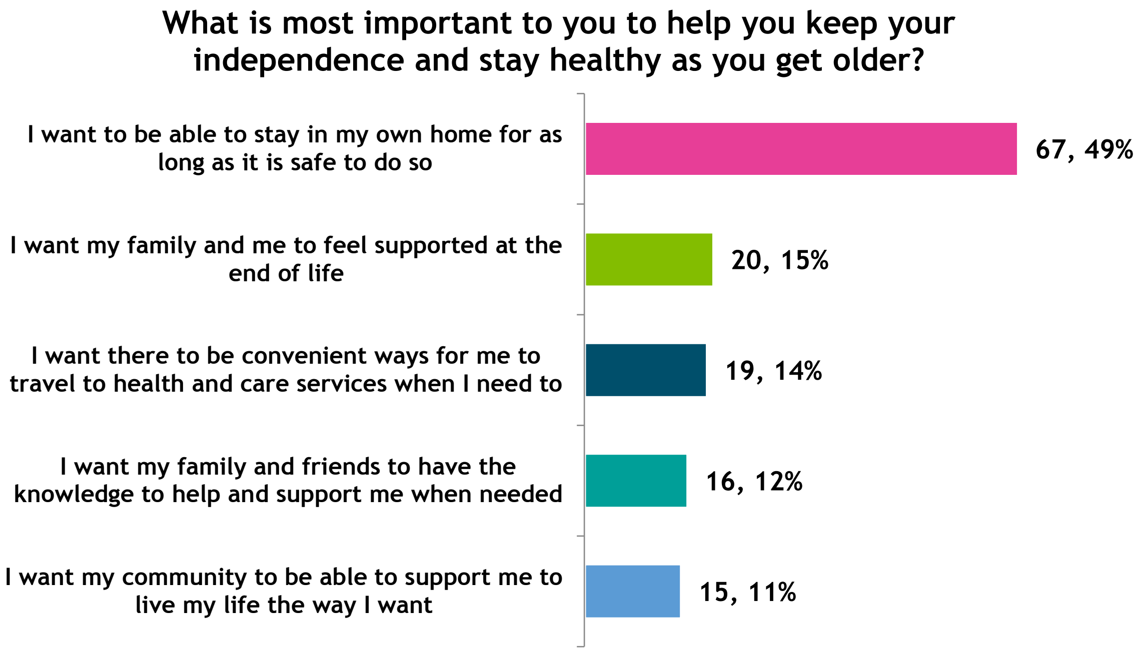
Survey respondents said they want to be **involved in decisions** about their treatment, receive **timely communications** and have **easier and quicker access** to services. Some people suggested having **longer appointments** so they could be listened to. There were some suggestions for **more follow-up** when it came to ongoing support.

Live well - the provision of ongoing care and support

Keeping independent and staying healthy as we get older

In the general survey we asked people to choose from a range of topics to tell us what was most important to help them keep their independence and stay healthy as they get older.

Almost half (49%) thought that the most important thing was being able to stay in their own home for as long as it is safe to do so.



‘I want to be able to stay in my own home for as long as it is safe to do so’ was the most important answer for all demographic groups looked at, except for the nine people who had a sexual identity other than heterosexual, where more thought that ‘I want there to be convenient ways for me to travel to health and care services when I need to’ and ‘I want my community to be able to support me to live my life the way I want’ were most important (three people each), and the six under 25 year olds, who thought ‘I want my community to be able to support me to live my life the way I want’ was the most important (three people).

People aged 65 and over also valued ‘I want there to be convenient ways for me to travel to health and care services when I need to’ (eight people), and the 29 answers from 22-44 year olds were more spread over the five options, with the difference between the answers for this group and the other age groups being statistically significant[25].

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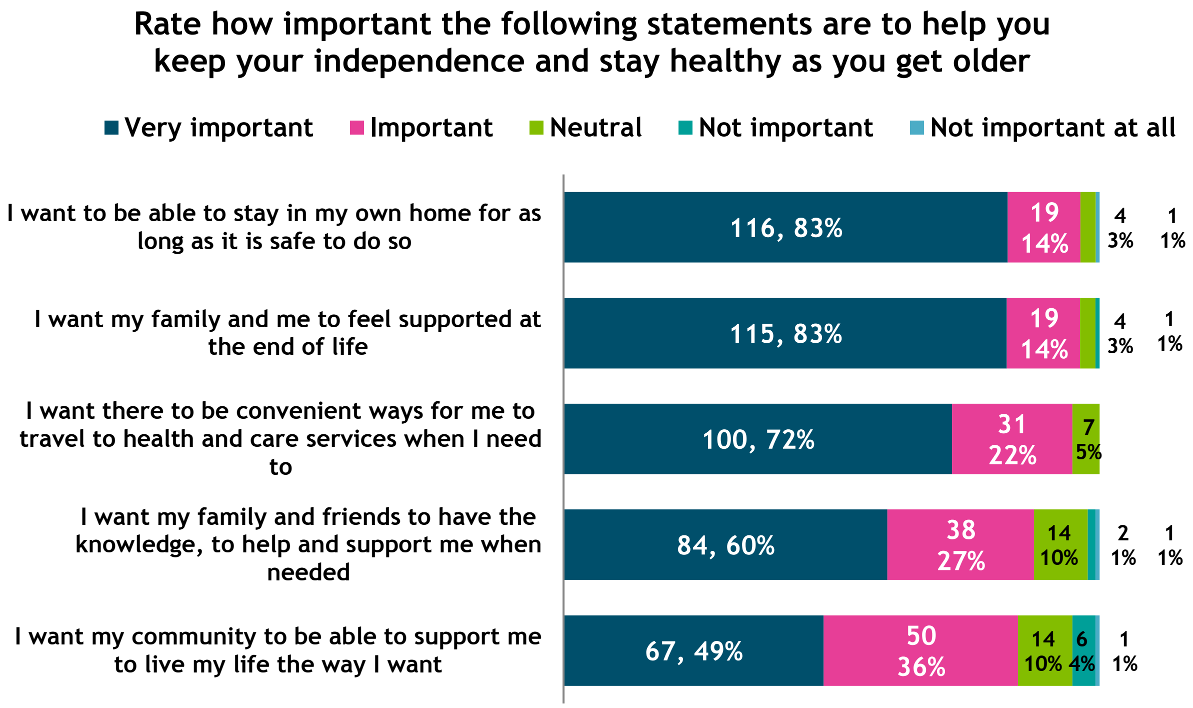
[25] Age 22-44 compared to other ages, Chi-square 18.54, P<0.001.

	I want to be able to stay in my own home for as long as it is safe to do so	I want my family and me to feel supported at the end of life	I want there to be convenient ways for me to travel to health and care services when I need to	I want my family and friends to have the knowledge to help and support me when needed	I want my community to be able to support me to live my life the way I want	*Total number who answered*
Carers	77%	5%	5%	9%	9%	*22*
Disability	43%	11%	22%	11%	14%	*37*
Long-term condition	49%	10%	17%	12%	13%	*78*
Non-White British	43%	7%	14%	21%	14%	*14*
Non-Heterosexual	11%	22%	33%	0%	33%	*9*
Female	45%	15%	14%	14%	11%	*97*
Male	58%	14%	14%	6%	8%	*36*
Under 25s	0%	33%	0%	17%	50%	*6*
24-44 years old[25]	21%	31%	17%	24%	7%	*29*
45-64 years old	59%	13%	11%	7%	11%	*54*
65 plus	61%	4%	17%	9%	9%	*46*

People were also asked to rate how important each statement was to them:



Again, most people felt all the statements were either very important or important, and ‘I want to be able to stay in my own home for as long as it is safe to do so’ was rated as very important by more people, as was ‘I want my family and me to feel supported at the end of life’. Only 49% felt that ‘I want my community to be able to support me to live my life the way I want’ was very important, and seven people (5%) felt it was not at all important.

The order of importance for these statements varied slightly for those aged 25-44, over 65, not White British and not heterosexual but these differences were not statistically significant.

Statement	Order of importance (based on percentage ‘very important’)									
	Carers	Disability	LTC	Under 25	25-44	45-64	65 plus	Non-white British	Non-Heterosexual	Male
I want to be able to stay in my own home for as long as it is safe to do so	1	1	1		3	1	1	1	4	1
I want my family and me to feel supported at the end of life	=4	=4	5	2	1	2	5	5	3	=2
I want there to be convenient ways for me to travel to health and care services when I need to	=4	2	2		4	=3	2	=3	=1	=2
I want my family and friends to have the knowledge to help and support me when needed	=2	=4	4	3	2	5	=3	2		5
I want my community to be able to support me to live my life the way I want	=2	3	3	1	5	=3	=3	=3	=1	4
Number of people	*22*	*37*	*78*	*6*	*29*	*54*	*46*	*14*	*9*	*36*

What else is important to help people keep independent and stay healthy as they get old, i.e. ‘live well’?

The engagement event asked people to reflect on their good and less good experiences of services relating to the ‘live well’ theme of ongoing care and support and then to come up with three ideas or priorities as a table group to help people ‘live well’ (i.e. what matters most).

The general survey also asked people if there was anything else that would help them manage and choose how the NHS supports them. Sixty-five people commented, and these comments were grouped into seven overarching themes[26]. The most commonly mentioned things related to **support (including care at home), community services and information**.

Support, including support at home

Nineteen survey respondents suggested ways of supporting people more, including more **health and care services at home** (nine people) and **support for people with dementia** (two), **learning disabilities** (one), the **homeless** (one), better **access to a GP** (one), **more specialised care for the elderly** (one), **better housing for the elderly** (one) and **access to appropriate medication** (one). For example:

> "Home care and health professionals are allowed to spend more time with their clients. Not the 30 mins allotted to them these days." *(Age 65-74 with a long-term health condition)*
>
> "Free care in your own home if you need it." *(Age 45-54)*
>
> "I want services to be dementia-aware … and learn about the various ways they can make small changes to make big impacts for people affected by dementia (and possibly other people who will benefit from changes too)." *(Age 45-54 with disability and a long-term health condition)*
>
> "Reach out to homeless [people], provide more supported living." *(Age 45-54 with disability and more than one long-term health condition)*

Community services

Ten survey respondents thought there should be more **community-based services, health, care and initiatives**, with two mentioning this would **tackle isolation** and two highlighting **transport** issues. For example:

> "Access to local services such as libraries." *(Age 45-54 with disability and more than one long-term health condition)*
>
> "To have more people working in the community so as to reduce admission to hospital." *(Age 55-64 with a long-term health condition)*
>
> "Local access to general facilities without having to travel to hospital and wait for hours to be seen." *(Age 65-74)*
>
> "Older people need contact with the outside world especially as many are women living on their own and may have family abroad. Cutting services to rural communities for transport, for example, due to money saving is a mistake if you want our older people to be connected… Loneliness caused by isolation is one of the biggest problems for older people who live in rural, cut-off communities." *(Age 18-24 with disability and more than one long-term health condition)*

At the engagement event people reported **transport difficulties** as a barrier to living well in the community and they reported problems with ambulance services. Many people are unable to access the support groups and activities available without the provision of transport, particularly in rural areas. Community transport is a valued but scarce resource. For **people on low incomes**, particularly those living on benefits with long-term health conditions, the cost of transport and the charges to attend groups can be prohibitive.

One survey respondent also mentioned wanting easier access to efficient public transport.

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[26] Four people gave comments which were classed as more than one theme.

Information

Eight survey respondents suggested more or better information, particularly advice about **social care** (three), **community support** (two), **mobility and home adaptations** (two) and **wellbeing** (one). For example:

"Access to local information and knowing where to go. More community-led initiatives to link all services together." *(Age 35-44 with a long-term health condition)*

"To have modifications to my own home and to be fully informed of all the help and support that is available for me to be able to retain independence." *(Age 45-54)*

"Everyone should be provided with information on how to live life healthily and happily." *(Age under 18)*

Systems/Integration

At the focus group with carers we heard about problems with **readmission to hospital for recurring health issues**. In one case an older person with renal problems required **repeated attendance at accident and emergency**, even though the problem was recurring and discharge had been recent – the person was told they could not be readmitted directly to the relevant ward. Another older person told us that they were required to attend accident and emergency for recurring catheter problems as they were unable to get medical support in the community in the timeframe needed to address the problem. Such examples illustrate how additional pressure is being placed on accident and emergency provision and can cause distress through potentially long waiting times in accident and emergency areas.

Five survey respondents told us they thought **community, health and wellbeing services should be more joined up** (four) or **person-centred** (one). For example:

"A more integrative approach, linking to all medical and complementary and wellbeing healthcare portals." *(Age 45-54 with a long-term health condition)*

"Linked up support for long-term terminal conditions and end of life care in the community to avoid hospital admission." *(Age 25-34)*

"A good care system that can adapt to my needs." *(Age 55-64 carer with disability and more than one long-term health condition)*

Workforce

Five survey respondents mentioned needing **sufficient care staff** who are **properly trained and funded** (three) and the need for **continuity of healthcare professionals** (two). For example:

"I'm concerned about the training and expertise of carers when interacting with people with complex needs (including mental health)." *(Age 55-64 with a long-term health condition)*

"Enough carers available who are capable, willing, and paid properly to do an important job." *(Age 65-74)*

"Same nurse and doctor to treat me... not a mix of unknowns who do not know my health issues." *(Age 65-74 carer with a long-term health condition)*

Prevention

Five survey respondents mentioned aspects of prevention, including **healthy lifestyles** (two), **better or earlier diagnosis** (two) and **health checks** (one). For example:

"Local drop-in centres to promote healthier living." *(Age 25-34)*

"Having a healthy life as a young and middle-aged person to give you the best chance at a healthy future." *(Age 35-44 with a long-term health condition)*

"Better preventative care! Speeding up critical diagnosis and treatment so the time spent suffering is very short." *(Age 45-54 with disability and more than one long-term health condition)*

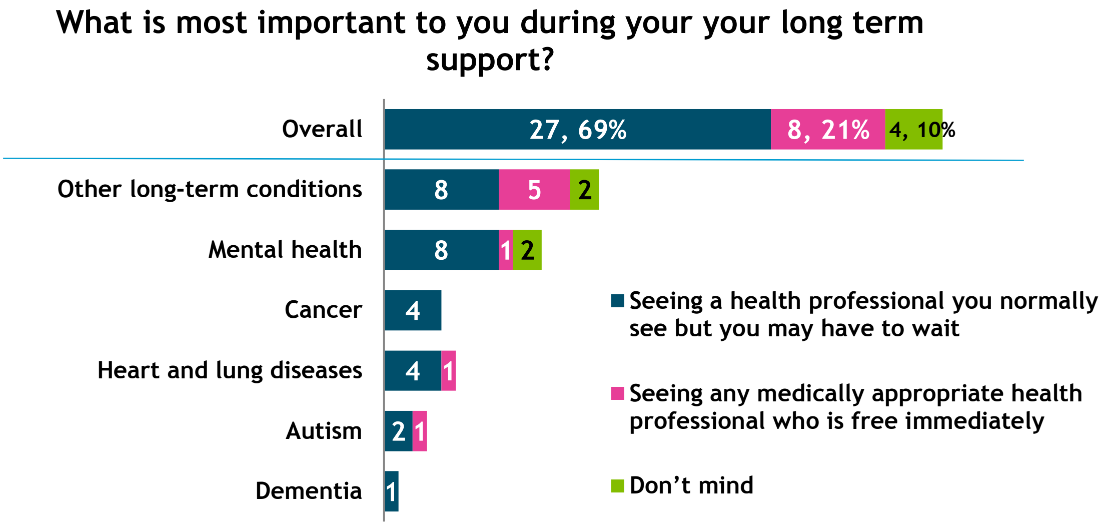
Other
Four survey respondents mentioned **funding for services,** two the need for **correct treatment** without errors, two suggested **more or better care homes instead of community care.**

Views of people with specific conditions

Due to the small sample sizes, all the differences reported in this section are not statistically significant.

Willingness to wait to see their usual health professional

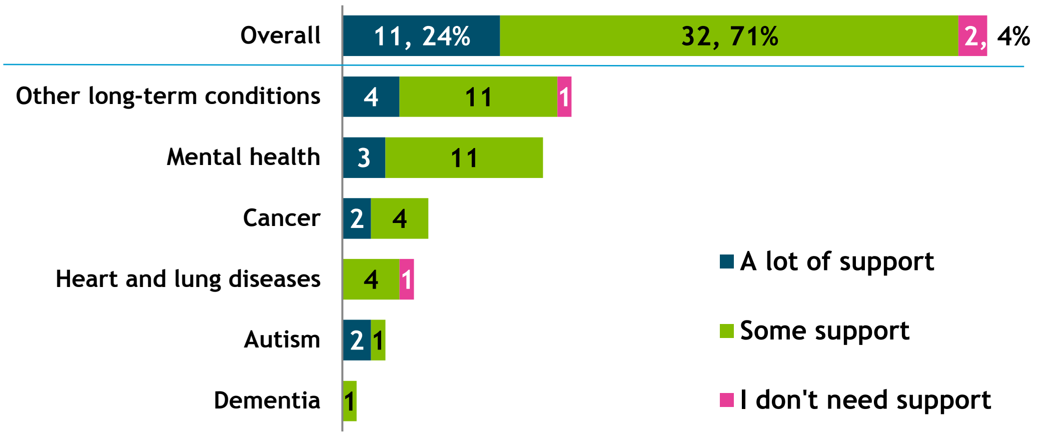
To receive long-term support, most people (69%) said they would rather see a health professional they normally see (even if they have to wait), rather than 'seeing any medically appropriate health professional who is free immediately'. This was the case for all conditions and demographic groups, except over 65 year olds, four of whom would rather see any medically appropriate health professional who is free immediately.



Supporting people to have more control over their own care

Almost all (96%) respondents with a specific condition would like the NHS to provide them with at least some support to help them stay healthy. The findings were similar for each demographic group.

What is most important to you when first seeking help?



Twenty-nine people gave suggestions for what the NHS could do to help them stay healthy or manage any condition they have, and these suggestions were grouped into eight themes: **better or quicker access to services** (six people), **person-centred** approaches that **value people** (six), **check-ups and ongoing support** (five), more access to **specialist** (five), better **joined up working or information sharing** (four), being **able to talk to someone** (two), better **understanding of conditions** (two) and **wellbeing help** (two).

Long-term conditions

Two people suggested more **support or advice from specialists** and one person wanted to see the **right person**, two mentioned **ongoing check-ups or support**, one wanted **sensitive communication**, one for **information to be shared**, one suggested **lifestyle help**, one thought **professionals should be educated** about their condition, one wanted **quicker access to referrals**, one access to **occupational therapy** and one wanted **pain relief**. For example:

"Be sensitive to patients' needs, provide ongoing support, either at the GP surgery or at the local hospital, have a specialism within the surgery in the same way that is provided for diabetes, heart health, smoking cessation etc." *(Age 55-64)*

"Ensure I see the right professionals who work as a team and communicate effectively, as well as organising scans when they feel necessary, i.e. annually/quarterly, etc." *(Age 25-34)*

"Provide timely appointments and referrals to other agencies. Undertake further diagnostic action as condition changes, rather than saying you can't be fully screened and can only have one area of body screened due to cost - it's either necessary and helpful or not." *(Age 45-54 with a disability)*

Mental health

Three people suggested **valuing people** more or having a more **personalised/person-centred** approach, two people valued **seeing the same person** and two suggested **access to specialists**. One person suggested more **proactive and community mental health support**, one **ongoing check-ups** and support and one **wellbeing help**. For example:

"Be more aware that face-to-face communication and feeling you actually matter is an essential aspect of a mental health journey." *(Age 55-64 with a disability)*

"A known, trusted person to be there for occasional psychological letting off steam and to reassure. This saves my condition getting worse. Access to further investigation if deemed necessary. My GP surgery is very good and could care for my needs if they had more resources." *(Age 65-74 carer with a disability)*

"Not always offer medication as a first step. Sometimes all that's needed is some short term help with sleeping and the right people to talk to." *(Age 25-34 carer)*

Cancer

Two suggestions were to do with **information** (share information and publish symptoms, one was for **equality of care**; one was for more **practical support** and **follow-up** and one for more **care at home**. For example:

"Provide equality of care/provision - I moved hospital to one 50 miles from home to enable me to see specialists in my cancer and have access to clinical trials." *(Age 55-64)*

"More practical support, pain management, physio, counselling. None provided. I have had to chase for everything I have got." *(Age 55-64 with a disability)*

Heart and lung diseases

Two suggestions were made about **communication and information**:

"Be available if and when I should need reassurance." *(Age 55-64)*

"Communicate better with different teams." *(Age 45-54 carer)*

Autism

The three comments suggested **access to mental health** and **better working with social care**, **faster diagnosis**, and **being seen quicker** and **valuing the person**. For example:

"Give me access to quality mental health services and work in partnership with social care." *(Age 25-34 with a disability)*

"See me in a timely manner when I asked to be seen. Have an understanding of my conditions. Have a proper understanding of autism not their perception of what autism means. Talk to me as an equal, not someone who lacks intelligence." *(Age 35-44 carer with a disability)*

Dementia

One comment was made about more **prevention/early intervention**:

"Put money into prevention and early intervention such as helping people with dementia stay at home safely for longer and keeping them out of hospital (where they almost universally deteriorate)." *(Age 55-64)*

Conclusion – what helps people to 'live well' - the provision of ongoing care and support

What works well?

People at the engagement event were able to cite examples of good ongoing care and support, particularly **peer support** for people with mental health and breathing conditions that can inspire and encourage recovery. The best examples of good practice were where **communities and professionals are working together, with voluntary sector organisations** playing an important role, for example in making contact with older patients following their discharge from hospital.

What could be better?

Again, **centres** that could give **information and advice**, including the ability to **triage** people, using the right people at the right time, would help people, as would a **single directory of services**. **Care coordinators** and **health and care passports** would also help people to live well.

Building **befriending and 'buddying' networks** within communities would help people support each other and connect with local services. Having **advocates** speak on behalf of individuals across the entire 'system', including health, social care, Department of Work and Pensions, police, etc. could help support many people who are struggling with mental health and help them gain control of their lives, ultimately lowering the risk of crisis.

It was also felt important to ensure that people have **choices and a say** in their health and care services.

Survey respondents thought that being able to **stay in their own home** for as long as it is safe to do so was important and that there should be **more care at home, community support initiatives** and **information**.

Further comments

What else needs to change to help people successfully manage their health and care?

The general survey asked people if there was anything else they thought needed to change to help them to successfully manage their health and care. Fifty-one people commented, and these comments were grouped into seven overarching themes[27]. The most commonly mentioned things related to communication, technology and access to services.

At the end of the general survey people were given the opportunity to give us any further comments. Twenty people told us more and these comments reflected the themes previously identified.

Communication

Between the two questions, aspects of communication were mentioned 23 times, including **better communication between services and health and care professionals**, particularly regarding **medical records and letters** (15), and better communication with patients and the public (seven). For example:

> "There's a lack of communication between services. I couldn't get hospital results from my GP and it was all so confusing. These services need to be in contact." *(Age 18-24 with a long-term health condition)*
>
> "Each hospital in Northants appears to communicate with a different GP surgery in a different way, there needs to be consistency in methods and speed." *(Age 55-64)*
>
> "I have received conflicting advice on several occasions. This is counterproductive and confusing. I've personally experienced incidences where my GP has told me one thing, a referral to a specialist has told me another, and both of these were contradicted by the NHS website, causing me confusion as to who to trust." *(Age 35-44)*
>
> "When test results are produced by the hospital or elsewhere they should be communicated in full to me so that I know the actual results rather than just 'good or bad'." *(Age 65-74 with a disability and more than one long-term health condition)*
>
> "All patients, regardless of healthcare trust, should have access to all test results online. I need to be aware and responsible of my results." *(Age 45-54 with a disability and more than one long-term health condition)*
>
> "Having different options of contact, not just phone or online but several options that fit my lifestyle." *(Age 25-34)*

Technology

Between the two questions, aspects of communication were mentioned 14 times, including better **systems/online access to records** (five), using **email and newer technologies** (four), needing **to educate people about the benefits** of technology (two). On the other side, four people highlighted that **other methods of communication are needed too**, particularly so **older people aren't left out with use of technology**.

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[27] Five people gave comments which were classed as more than one theme.

"It can currently take weeks to receive letters or referrals. That's insane in the 21st century. Should be using email where possible to save time and paper. Why does it take even longer for hospital to update GP? Why isn't anything any medical professional adds to my record immediately available for any other medical professional to see? I had the unpleasant experience of having to break the news of a cancer diagnosis to my GP who still hadn't been told after a month." *(Age 45-54 with a long-term health condition)*

"There needs to be a consistent use of technology. I want to be able to make appointments and see my records and results online, not just one or the other." *(Age 55-64 with a long-term health condition)*

"The aim to use technology may be appropriate in 30 years' time but there's many elderly people who do not have access to the internet or are afraid of it. The result of this is that they feel isolated and forgotten and as a result their health deteriorates unseen until it's too late for effective intervention." *(Age 65-74 carer)*

"Being able to talk to a real person about my concerns. Technology is not enough when you're older and/or feeling unwell." *(Age 65-74)*

Access to services

Between the two questions, aspects of access to services were mentioned 12 times, including **easier access to GPs** (seven) or the **right health and care professional** (two), **more walk-in access** (one), **shorter waiting times** (one) and the **ability for carers, etc. to manage appointments** for people lacking capacity (one). For example:

"The lack of ability to make appointments with a GP unless one feels it is an urgent condition is detrimental to managing a condition that is not extremely urgent. The lack of continuity in appointments with GPs is not conducive to establishing communication and confidence. The service is poor and not because of the people on the front line." *(Age 65-74 with more than one long-term health condition)*

"The big issue is being able to see a doctor. Please introduce video conferencing." *(Age 55-64)*

"Increase access to walk-in surgeries, recruit more GPs to reduce the ridiculous waiting times and enable you to see your own GP face to face at each appointment without a protracted wait." *(Age 65-74 carer)*

"I know that good communication is key in all areas of treatment. This is about keeping myself healthy, access to professionals and appropriate care; being able to make good choices in discussion with the appropriate professional." *(Age 75+ carer with a long-term health condition)*

One person who completed the specific condition survey commented on the need to have the **same standard of care everywhere** to avoid having to travel for specialist care.

Workforce

Six people mentioned issues to do with staffing, mostly wanting **continuity of the GP or other healthcare professional** they see (four), as well as a need for **more GPs** generally (one) and education of healthcare professionals about the **Armed Forces Covenant**[28] (one). For example:

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[28] www.afcnorthamptonshire.co.uk

"Developing a relationship with main health care professional so they understand my needs and know me. It's about developing trust, this has gone." *(Age 65-74 with a disability and more than one long-term health condition)*

"Ensure that all the support services, GPs, hospitals, consultants, doctors, and medical administrative staff are educated, informed and checked that they are aware of the Forces Covenant and how to properly implement it and push veterans through the waiting list as appropriate and permitted." *(Age 65-74 carer with a disability and more than one long-term health condition)*

One person who completed the specific condition survey suggested there was a **need for dementia training** for hospital staff **and better communication with relatives**:

"Dementia training for hospital staff seems almost non-existent. Relatives of people with dementia, especially those in the mid to later stages, should be treated like parents of sick children. My mother has been discharged twice without my knowledge, the second time without the knowledge of the social worker … in a dressing gown and slippers, in December." *(Age 55-64 on behalf of someone with dementia)*

Integration/systems

Five people again mentioned needing **integration between health and social care services** and **treating people as a whole** (two), having **more consistent services across the county and borders** (two) and **increasing capacity of services** (one). For example:

"Managing the whole NHS system better will save so much money and this can be achieved by utilising a more integrative approach to health and wellbeing. I am glad to see the start of this happening with social prescribing and hope this will be continued in the future, bringing in more and more natural non-invasive therapies and tools to use by qualified professionals to provide a full package of care." *(Age 45-54 with a long-term health condition)*

"There continues to be national issue needing resolution in terms of health and care support to overcome the issues arising from the current structure of separate heath and care services and geographical differences." *(Age 65-74 with a long-term health condition)*

"The challenges within Northampton are that there is not enough availability for GP appointments and A&E is always so busy. The town itself has vastly increased in population with new houses being constantly built. Unfortunately, the hospital has not increased in size and has difficulty coping with the amount of patients that require treatment. In addition, there is not enough care places for the elderly, if they cannot return to their own home on discharge from hospital, meaning they have to stay in hospital, which is not always beneficial to their mental as well as physical health." *(Age 45-54)*

One person who completed the specific condition survey also commented on the need for **joined up support and care**, particularly to **consider mental and physical health together**:

"There really needs to be some joined up thinking in the approach to long-term conditions, I think self-management is key and this takes considerable input from services initially and a commitment from all those involved. The link between physical and mental health has not been addressed. For example when in pain, I can become mentally distressed and/or depressed yet still, physical and mental health are two very separate issues to services - but not to the patient!" *(Age 55-64 carer with a disability and a long-term condition)*

Support and advice

Three people mentioned wanting more support (a lack of support groups, support for people with a learning disability and outreach to the homeless). Two people wanted advice about medication or about whether they needed to see a GP. For example:

> "Lack of support groups, especially for long-term chronic pain. There used to be a great NHS expert patients' course, very helpful. It's disappeared, and it ran on volunteer time." *(Age 35-44 with a long-term health condition)*

Two people who completed the specific condition survey also commented on the need for **more and continuous support** and **early assessments for adults with complex needs**, for example:

> "Adults should have early support assessments (like children do) so a lead person can assess and ensure services and actions are supporting someone with complex needs." *(Age 45-54 carer on behalf of someone with a mental health condition)*

Person-centred

Three people said they wanted to see more person-centred approaches, involvement in treatment or choice, for example:

> "Doctors and professionals who specialise in the area of illness who can also give the time to look deeper into the cause of issues - more time, linking and listening to patients using video conference meetings like Zoom or secure Skype." *(Age 45-54 with a long-term health condition)*

One person who completed the specific condition survey also commented how they would like to be **treated with dignity** at appointments and one commented on how the **removal of free treatment** was **not person-centred or holistic.**

> "Some treatments have been removed from NHS, such as treatment of verrucas. I think this is too simplistic for people with long-term health conditions, especially if there is a likelihood of immune related conditions." *(Age 35-44 with disability and a long-term health condition)*

Autism

Two people who completed the specific condition survey also commented on the need for **better autism support**:

> "There needs to be autism adult services that are multiagency to support [people] holistically." *(Age 25-34 with a disability and autism)*
>
> "Autism and ADHD are not mental health issues so why are they put under this heading? They are neurological, not able to be cured." *(Age 35-44 carer on behalf of someone with autism)*

Other

Other comments mentioned better funding and staffing (two), prevention through health checks (one), better social services (one), standardised care and treatment (one), use of more volunteers (one), to hold engagement event outside of work hours and to use the feedback (one), to deliver on promises (one), to know more about health and care professionals' qualifications, and to ensure patients have dignity (one). One person who completed the specific condition survey praised the staff at Northampton General Hospital.

In focus – Support for people with learning disabilities and people who are homeless

Two people gave further comments about supporting people with learning disabilities and homeless people:

"Care in the community was an idea in the 80's and 90's and many hospitals, institutions closed as a result. Great. However, how you keep people with learning disabilities (LD) and mental health 'safe' in the community and online is another matter. In my experience it is one of the hardest ideas to actually fulfil but we do not want re-institutionalisation ever again and it appears this is what is happening because it is such a hard task to fulfil, to allow people freedom in our communities and yet safeguarding too! The local authority want to enable people with LD to live more independently in community including how they choose to live (supported living) but recognise how expensive this is going to be and seem to be looking again at 'residential' with everything under one roof (day provision and residential like the good old days) or remaining at home long term. This would lead to depression and loneliness and possible hospital admissions. The bottom line is that real community access for those with these conditions is going to be more costly and is difficult and we need to get on with this and embrace it and prepare for it and not close down access. Look at good models elsewhere. Look at what works well and let the rock face users shape their own services and not the other way around. This will help both the wellbeing of carer and cared for person with the LD and also with mental health. Get the community integration and experience right and you will have happier, healthier people (such as good facilitation into work - which there is none in this county!!!!!). Get respite and care packages right and carers will feel supported and healthier."

(Age 18-24 with a disability and more than one long-term health condition)

"I am doing this from perspective of homeless people who I volunteer with. There is little access to health care, including dental care. There is little opportunity to shower or wash clothes which means they pick up illness more easily. Outreach for preventative care and crisis care would be helpful."

(Age 45-54 with a disability and more than one long-term health condition)

Conclusions on priority areas

Mental health

What works well?

Crisis cafes and contact telephone numbers were highlighted at the engagement event as something that helped support people with a range of problems, as did a **listening service** that is available for people who are anxious when visiting a GP practice. It was thought that **social prescribing** would help reduce social isolation and **voluntary groups** frequently helped people into work or to feel they had a purpose, such as the Northamptonshire ACRE Good Neighbours scheme. The county **suicide review and prevention group** was also mentioned as a positive thing.

What could be better?

At the engagement events people told us that it was **difficult when seeking help** for mental health issues, often resulting in 'numerous calls to a succession of professionals in order to obtain the right type of care', and this could be **particularly difficult for people on benefits** (and being in receipt of benefits itself has a link with poor mental health). **Carers reported difficulties in accessing appropriate support** at a time of mental health crisis, and feeling unable to keep family members safe in accident and emergency departments. None of the people with a mental health condition who completed the specific condition survey felt the **support** they received **when they first tried to get help** met their needs. They also **found access to ongoing support** difficult, particularly mentioning a **lack of follow-up** or support.

At both the events and via the survey, we heard about **problems with transitions from child to adult** mental health services, and problems with some **healthcare professionals not having sufficient awareness and understanding** of mental health issues. It was also felt that access to mental health services should be easier for people using illegal drugs and **waiting times** could be improved.

Better communication and promotion of what help is available, including support in **schools**, would help patients choose and receive the right services first time and know how to access them, and it was felt there was value to **using social media more**, and to find ways to **engage men** in particular. Information should have a **clear and simple message**, avoid jargon and identify what is important for each community. It was also felt important to make all people aware of how to **recognise points of crisis** and understanding triggers of suicide in all ages.

Personalised care was felt to be important, where professionals **treat individuals rather than conditions**, and not make assumptions about the problems. **Patient passports** would help. They should also recognise that **there may be a social solution rather than medication**. Once people find what works for them there needs to be more **support** in helping them to achieve this. Understanding and support around budgeting food, money and benefits would help some people, as would understanding the impact of social isolation and other anxiety and stresses.

People thought that **support should be available locally**, and services that work well should be made available across the county. Services should cater for **different cultural backgrounds**. Permanent **advocates** to speak on behalf of people would help many.

Breathing

What works well?

The engagement event highlighted the benefits of people being able to **self-refer** to services and the positive developments in the county where **professionals, groups and other**

stakeholders are coming together to look for improvements and **alternative ways** to help people manage breathing issues, some of which are already available.

What could be better?

At the event it was felt that **non-medical support for people would be beneficial**, including intervention services that are led by experienced patients and peers offering support and plans of action. Maintaining good **relationships** between patients, carers and professionals will ensure consistency and continuity of care.

Joined up communication between services and systems and **information about pathways** and services that steers clear of confusing jargon would help people know what is available. Identifying who is not already connected in communities would help.

Focusing on every part of people's wellbeing, ensuring flexible services, offering alternative care and support and delivering clear messages to maintain choice and exploring how incentives could help people stay well.

Ageing well

What works well?

At the engagement event the **voluntary sector** was valued for being able to identify the most vulnerable people in communities and help them to stay well. The 'community connector' role in Moulton and partnerships with Age UK, such as the Age Well project in Wellingborough, were given as examples of schemes that work well to support and connect people to services. It was felt there were good **befriending** schemes, particularly in some rural areas. It was also felt that **acute care** itself was excellent and that **care navigation** at GP practices was valuable (although more was needed). Telecare/personal alarm buttons were given as an example of **technology** that helps older people live independently.

The (dementia) **memory assessment service** was also highlighted as something that works well, particularly as patients are assessed at home, as were the new rooms designed for people with dementia in A&E. Phone calls to older people recently discharged from A&E to offer support was another example given of a recent positive initiative.

What could be better?

A **directory of services** and **online and physical places to access information** (from one source, including social and wellbeing services) were again things suggested at the event that would help people age well, as would **social prescribing** and health and care professionals **knowing what services are within the community**, including people who could provide **advice**, perhaps through a telephone line. A healthy **'age well' information pack** was suggested at the event, which could include information about opportunities to integrate and maintain social wellbeing, as prevention and early intervention are vital to maintain good health and wellbeing later in life.

It was recognised that the **community** plays an important role in supporting people to age well and itself **needs support** to meet this responsibility, including **funding** for services that work well and ensuring that can be access across the county and locally to people. Wider **wellbeing support** from the county, such as access to parks and recreation was also suggested, and facilities (physical buildings) where people could go for support to directly address social isolation and social prescribing.

Public transport schemes and services within the community and improved access to technology in towns and rural areas were suggested to help people access services, as would social support within GP practices for those who require it or do not have close family or friends to help them attend appointments.

Regarding workforce issues, it was felt that **more dementia specialists** were required in hospitals and that dedicated commissioning of **paid carers** could increase the number of carers to look after people in their own homes. Investing in **technology** could also help elderly people live well at home are reduce dependence on carers as well, as could providing more support and access to nutritional meals.

Care in my area/primary care

What works well?

At the engagement event it was felt that **GP support** was generally good, people cited were examples of GP practices offering same day appointments, and there had been recent improvements locally in the services available to people as well as the access through technology, such as online booking.

There were also examples of **active and caring communities** (Rushden was given as an example), where there were opportunities to bring together groups and agencies to jointly support people, and examples of **charities and voluntary sector organisations** having good links and the ability to signpost.

At the event **school immunisations** was given as an example of a service with a good structure that was well managed and had good communication. It was also felt that people are taking more responsibility for **self-care**.

What could be better?

People answering the surveys particularly felt that **access to GP appointments** needed to be improved. At the engagement event, it was felt that **waiting times** could be improved and that more services, such as **podiatry and alternative services, should be run from GP practices**, and that access to service should be **consistent** across the county. The importance of looking after the **whole person** and considering all their symptoms was flagged at both the engagement event and in the surveys.

At the engagement event it was felt that people sometimes **struggled to understand the care choices available to them and how to access them**. They also felt that **information** that GPs had was often out of date and that clinical jargon was used sometimes, which confuses patients. An **information 'hub' and liaison person** were suggested to explain what services are available and different care pathways, as well as information about patient experience/engagement and events. A need for advice and community projects about **healthier lifestyles** was also highlighted, including education for schools and families.

The survey and event raised the need for **better communication between services** and departments/teams and **better access to and sharing of patient records** to assist the flow of information. An **integrated care system** and better **partnerships with Third Sector** organisations was also suggested, which could be achieved through social prescribing to help ease the pressure on health services and give people a choice in what works best for their health and wellbeing. **Funding** for the voluntary sector was felt to vital to support this.

Concern about the **isolation of people** without families and those living in rural areas was voiced, particularly regarding them accessing services with a **reduction in public transport** in some areas. A greater amount of **care in the community and care at home** was suggested by people at the event and survey respondents, including support for carers. Generally building a bigger and better **sense of community** by maintaining and developing social connectedness was also suggested.

Carers

Carers can play a key role in supporting people to stay well, access services, and participate in activities and community life. To do this they need to be valued and communicated with. At the carers' focus group, people spoke to us mostly about their experiences or the person they care for receiving healthcare in community settings and acute hospitals.

What works well?

People told us about positive experiences of a prompt response to a mental health crisis by the GP and arrangement of therapeutic input at the patient's own GP surgery. This meant that the person did not need to travel to unfamiliar places, thus reducing the likelihood of further complications. Some carers reported hospitals and social services working well together to ensure there is support for both carer and patient upon discharge.

What could be better?

We heard multiple stories of **difficulties around discharge from hospital**, where carers were not fully involved in decisions and where family members were discharged from hospital without proper assessment of their needs or adequate notice to carers of the arrangements. People also told us of problems around medication upon discharge, and how difficult it was to resolve prescription queries or errors made by hospital pharmaceutical services once home from hospital. Among some people there was a lack of awareness of other services available, such as the NHS 111 telephone service for urgent medical problems.

In focus - Autism

Only four people completed the specific conditions survey about autism, but their experiences highlighted common difficulties with getting an assessment and diagnosis and ongoing care and support. People felt passed from service to services and it was suggested that service needed to work together better, and recognise the difference between autism and mental ill health.

These experiences mirror the more detailed findings from our 2018 report[29] that found the process of seeking a diagnosis of, and help for, Autism Spectrum Disorders and Attention Deficit Hyperactivity Disorder often takes so long and is so fragmented that children and their families are left struggling.

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[29] www.healthwatchnorthamptonshire.co.uk/asdandadhdreport

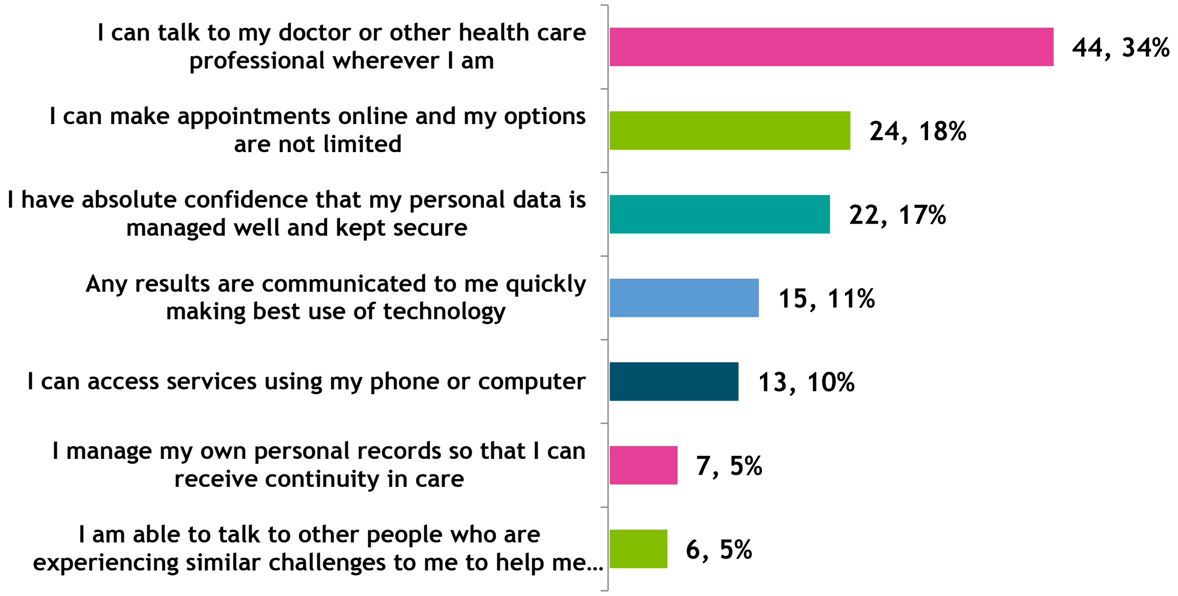
Engaging people in health service delivery

What people expect during their treatment journey - interacting with the NHS

In the general survey we asked people to tell us what was most important when interacting with the NHS from a range of topics.

One-third (34%) thought that the most important thing was being able to talk to their doctor or other health and care professionals wherever they were. Being able to have a choice of appointments online and being sure that personal data was well manged and secure were also important.

What is most important to you when interacting with the NHS



The order of importance for these statements was slightly different for most demographic groups (except females, males and those age 45 or over) (but most of these differences were not statistically significant). People with a disability[30] or a long-term condition[31] had a stronger preference for 'I can talk to my doctor or other health care professionals wherever I am'.

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[30] Top five categories for disabled compared to not disabled, Chi-square 14.19, P<0.01.

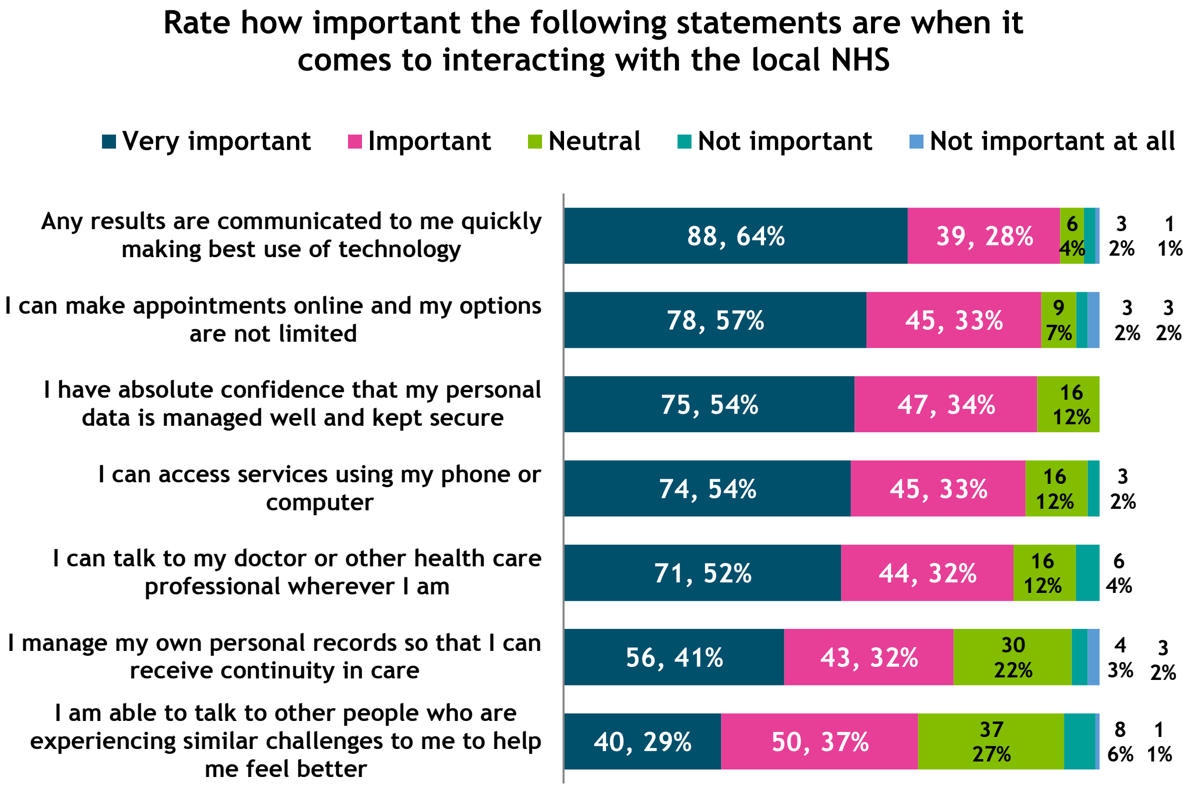
[31] Top five categories for LTC compared to not LTC, Chi-square 9.73, P<0.05.

	I can talk to my doctor or other health care professional wherever I am	I can make appointments online and my options are not limited	I have absolute confidence that my personal data is managed well and kept secure	Any results are communicated to me quickly making best use of technology	I can access services using my phone or computer	I manage my own personal records so that I can receive continuity in care	I am able to talk to other people who are experiencing similar challenges to me to help me feel better	*Total number who answered*
Carers	36%	14%	23%	9%	9%	5%	5%	*22*
Disability[30]	54%	5%	11%	5%	11%	5%	8%	*37*
Long-term condition[31]	40%	15%	10%	10%	13%	8%	4%	*78*
Non-White British	15%	0%	38%	0%	15%	23%	8%	*14*
Non-Hetero-sexual	11%	22%	11%	22%	22%	0%	11%	*9*
Female	31%	18%	18%	14%	9%	7%	3%	*96*
Male	39%	21%	15%	6%	9%	0%	9%	*33*
Under 25s	17%	33%	33%	17%	0%	0%	0%	*6*
24-44 years old	30%	7%	11%	19%	15%	11%	7%	*27*
45-64 years old	25%	26%	19%	8%	9%	8%	6%	*53*
65 plus	49%	13%	16%	11%	9%	0%	2%	*45*

People were also asked to rate how important each statement was to them. Most people thought most statements were either very important or important, although more people rated the importance as ‘neutral’ than in previous questions. When asked this way, being able to talk to their doctor or other health care professionals wherever they are was less important than receiving results quickly (although the difference was not statistically significant).

The two least important statements again were ‘I am able to talk to other people who are experiencing similar challenges to me to help me feel better’ and ‘I manage my own personal records so that I can receive continuity in care’.

The order of importance for these statements varied slightly for different demographic groups (but these differences were not statistically significant). The six under 25 year olds felt that being able to make appointments online and having access to their records was more important but were less concerned about data security. ‘I manage my own personal records so that I can receive continuity in care’ was more important for carers and ‘I can talk to my doctor or other health care professional wherever I am’ was more important for people with a disability.


Rate how important the following statements are when it comes to interacting with the local NHS

Statement	Order of importance (based on percentage 'very important')										
	Carers	Disability	LTC	Under 25	25-44	45-64	65 plus	Non-white British	Non-Heterosexual	Male	Female
Any results are communicated to me quickly making best use of technology	2	=1	1	=4	1	1	1	=1	=1	2	1
I can make appointments online and my options are not limited	1	3	=2	=1	3	2	4	=1	=1	1	=2
I have absolute confidence that my personal data is managed well and kept secure	5	5	5	7	=4	3	3	=1	=5	3	4
I can access services using my phone or computer	7	4	4	=1	2	4	5	=1	3	5	=2
I can talk to my doctor or other health care professional wherever I am	4	=1	=2	=4	=4	5	2	=1	4	4	5

I manage my own personal records so that I can receive continuity in care	=2	6	6	=1	6	6	6	7	=5	6	6
I am able to talk to other people who are experiencing similar challenges to me to help me feel better	6	7	7	=4	7	7	7	6	7	7	7
Number of people	*21*	*40*	*81*	*6*	*29*	*55*	*49*	*14*	*10*	*38*	*97*

What people expect during service change and transformation

At our engagement events people told us they **want to be involved in conversations about improving health and social care** services, and that we needed to maintain the momentum for participation and involvement.

We heard that **innovations need to be tried and tested** fully before being rolled out across the county.

One person commented on the importance of **following through with improvements** if promised:

"I want an end to initiatives which promise all these things yet only do so on paper. Don't put them in place unless they are meaningful. Don't tell me I can see a healthcare professional when I need to, then not allow me to do so because of underfunding. Don't tell me I will get the treatment I need, then deny it me because you won't fund it. Don't keep passing all my problems back to me, my friends and family." *(Age 55-64 carer with a disability and more than one long-term health condition)*

Another comment from the general survey gave some thoughts about engagement:

"Leadership is about leading and motivating others in a given task or goal, love the NHS help to make a difference, I'd rather be invited to a fundraising event, or be asked to plan one in my area to help me feel I'm making a difference rather than be invited to an event during work hours which means my voice would not be represented and I would already hit a barrier to attending and to talk about what? What is the agenda, what are the goals from the event, what good would I have attained from taking a day from work, what difference would I have made? Apologies for the tone, but realistic honest feedback and having someone act upon and learn from and promote positive real change is important for me." *(Age 35-44 with a disability and more than one long-term health condition)*

Methodology

Surveys

Healthwatch England designed two surveys, one about experiences and views in general and one for people with specific conditions. These were made available online, as paper copies and in ‘easy read’ format.

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

The survey was advertised on our website, newsletter and social media channels and shared by local health and care partners and voluntary and community sector organisations. The national survey link was also promoted by Healthwatch England. The survey was taken to an African community health and wellbeing event.

Survey analysis was undertaken and Chi-square testing for statistically significant differences between groups was used where the sample size was big enough. Charts and tables were calculated once blank/missing answers had been removed.

Engagement event

The engagement event was jointly designed, planned, run and funded by Healthwatch Northamptonshire and NHCP and advertised by both alongside the survey. The event was designed to be a stakeholder and community engagement and activation event for the general public and professionals to kick start ongoing engagement around ‘Choose well, stay well, live well: Creating a positive future for health and care in Northamptonshire’.

This event focused on the NHCP Primary, Community and Social Care workstream priorities and certain conditions in the LTP, particularly: breathing, ageing well, mental health and ‘care in my area’.

The event began with presentations about the priorities and work currently taking place to give context and then took the form of deliberative table discussions on the different priorities. The groups were led through three activities by briefed table facilitators to identify what works well, what could be better and priorities for improvement for each of the ‘choose well’, ‘stay well’ and ‘live well’ themes, coming up with consensus ‘Big Ideas’ to be taken forward at the end of the event.

Focus group

A focus group was undertaken by attending an existing Northamptonshire Carers meeting. Due to only having one and a half hours at this meeting, the feedback was gathered using a semi-structured approach, following the main themes of ‘what are your experiences of local NHS services?’ and ‘what would you like to see improved?’

Limitations

Survey results are reported for different demographic groups, but due to the small number of responses, particularly for the specific conditions survey, statistically significant differences were not often found between groups.

The national survey did not ask where in the county people lived so results cannot be broken down further by locality.

It was not possible to carry out a more structured carers' focus group as we were attending an existing meeting rather than have a dedicated event.

Acknowledgements

We are very grateful to all those who took the time to share their views and experiences with us.

A special thanks to NHCP communications and engagement colleagues for working so well with us to deliver the joint engagement event.

Thank you to all the health and care colleagues and Healthwatch Northamptonshire volunteers who facilitated table discussions at the engagement event.

Thank you to Northamptonshire Carers for allowing us to attend one of their carer's groups.

Thank you to all local organisations who shared and promoted the event and surveys.

Thank you to Healthwatch England for the resources and support that enabled this project to happen.

About Healthwatch Northamptonshire

Healthwatch Northamptonshire is the local independent consumer champion for health and social care. We are part of a national network of local Healthwatch organisations. Our central role is to be a voice for local people to influence better health and wellbeing and improve the quality of services to meet people’s needs. This involves us visiting local services and talking to people about their views and experiences. We share our reports with the NHS and social care, and the Care Quality Commission (CQC) (the inspector and regulator for health and social care), with recommendations for improvement, where required.

Our rights and responsibilities include:

- We have the power to monitor (known as “Enter and View”) health and social care services (with one or two exceptions). Our primary purpose is to find out what patients, service users, carers and the wider public think of health and social care.
- We report our findings of local views and experiences to health and social care decision makers and make the case for improved services where we find there is a need for improvement
- We strive to be a strong and powerful voice for local people, to influence how services are planned, organised and delivered.
- We aim to be an effective voice rooted in the community. To be that voice, we find out what local people think about health and social care. We research patient, user and carer opinions using lots of different ways of finding out views and experiences. We do this to give local people a voice. We provide information and advice about health and social care services.
- Where we do not feel the views and voices of Healthwatch Northamptonshire and the people who we strive to speak on behalf of, are being heard, we have the option to escalate our concerns and report our evidence to national organisations including Healthwatch England, NHS England and the Care Quality Commission.

healthwatch
Northamptonshire

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About Northamptonshire Health and Care Partnership

Northamptonshire Health and Care Partnership (NHCP) consists of key health and care providers in the county.

While we all remain as separate organisations with our own local responsibilities for the services we provide, we are committed to working together towards a positive future for our community services.

By working more closely in partnership we are being ambitious about doing things differently and clear on our local priorities; so together we can improve the quality of care and the health and wellbeing of our community.

Members of our Partnership include:

- Our general hospitals
- Community health services
- GP practices
- Social care
- Local government
- Voluntary and community services
- Ambulance service
- Health and care commissioners

Our vision and mission

Our **vision** for the future of Northamptonshire's health and care services is for a **positive lifetime of health, wellbeing and care in our community.**

Our **mission** in working together, the reason we do what we do, is to **empower positive futures**. Wherever we work and whatever our role we all want people in Northamptonshire to be able to **choose well, stay well, live well**.

About Connected Together

Connected Together Community Interest Company (CIC) is the legal entity and governing body for Healthwatch Northamptonshire.

The remit of the Connected Together CIC includes:

- Contract compliance
- Legal requirements
- Financial and risk management
- Sustainability and growth
- Agreeing strategy and operations
- Agreeing policies and procedures

Connected Together CIC is a social enterprise and a partnership between the University of Northampton and Voluntary Impact Northamptonshire. It aims to be first for community engagement across the county of Northamptonshire and beyond.

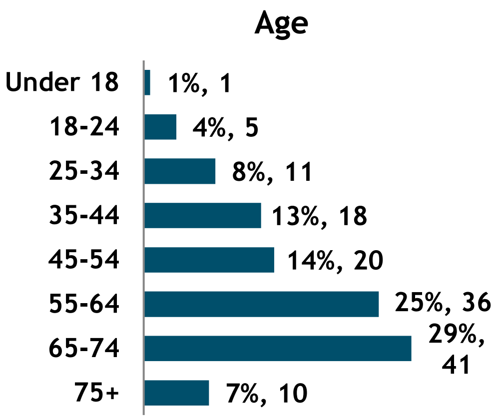
Connected Together
First for Community Engagement

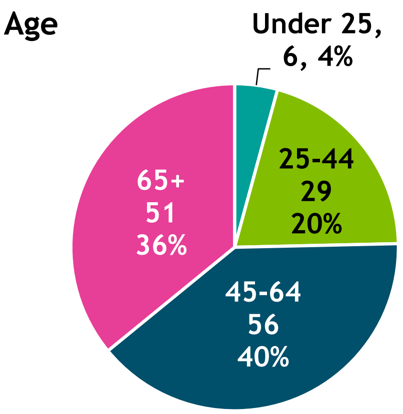
VOLUNTARY IMPACT NORTHAMPTONSHIRE

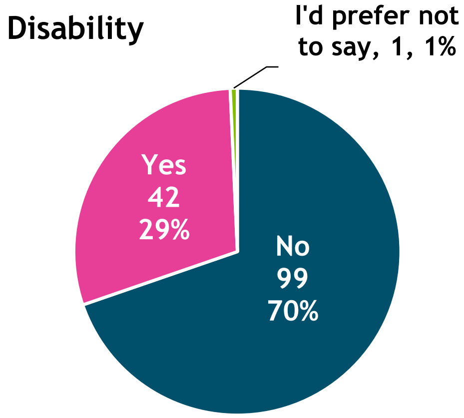
UON University of Northampton

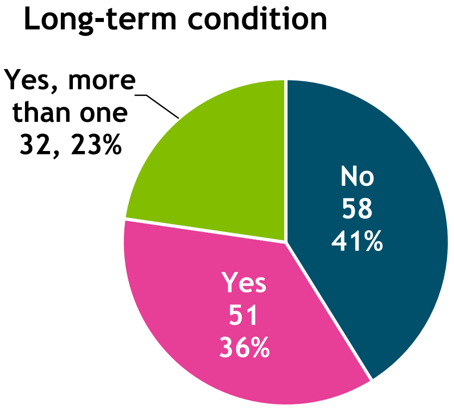
Appendix - demographic breakdown of each survey

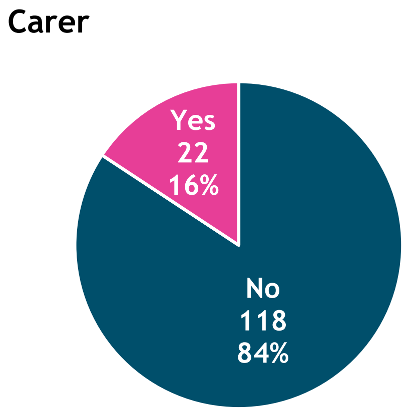
General survey

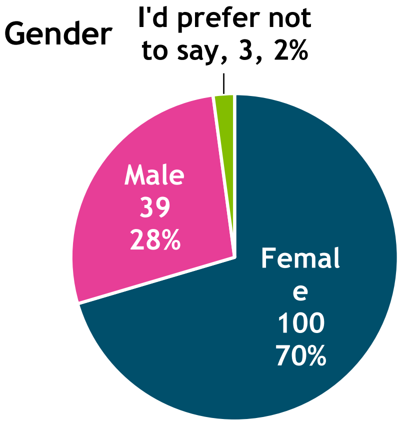


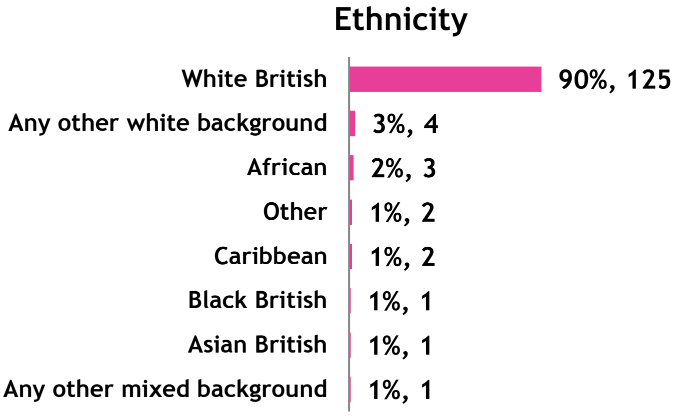


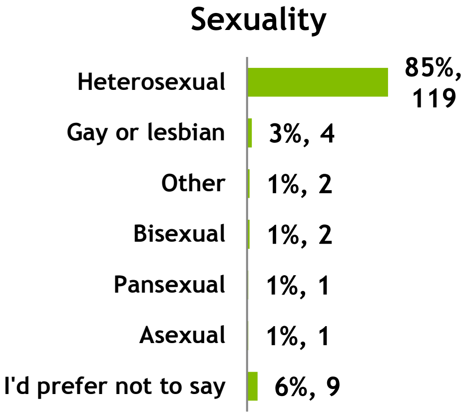


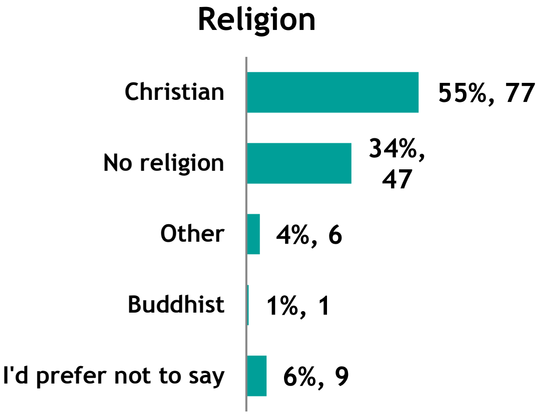




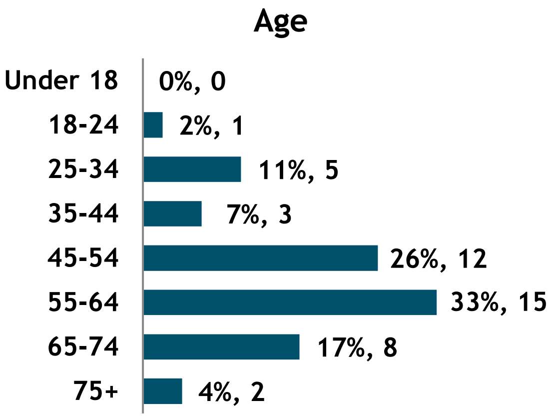


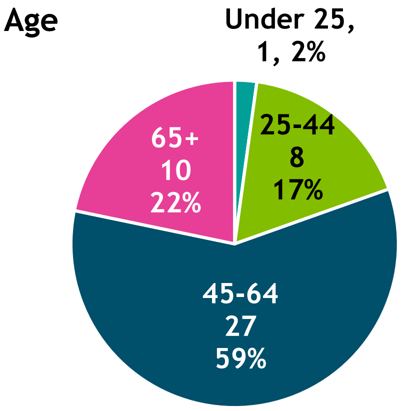


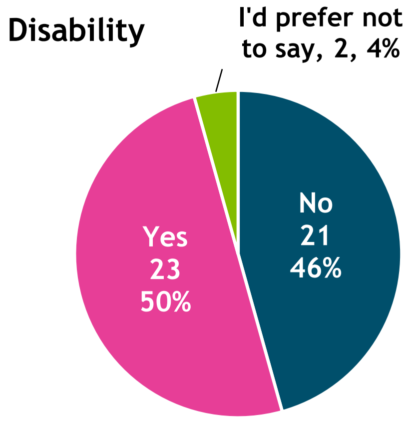


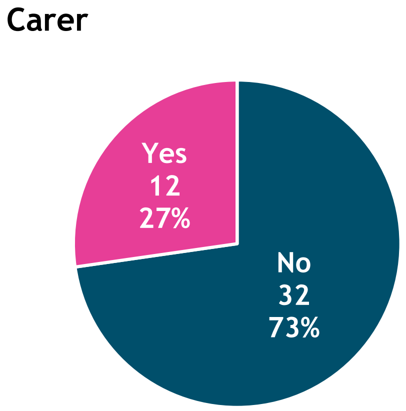


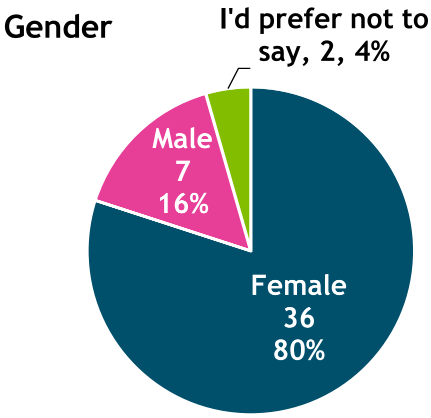
Specific condition survey

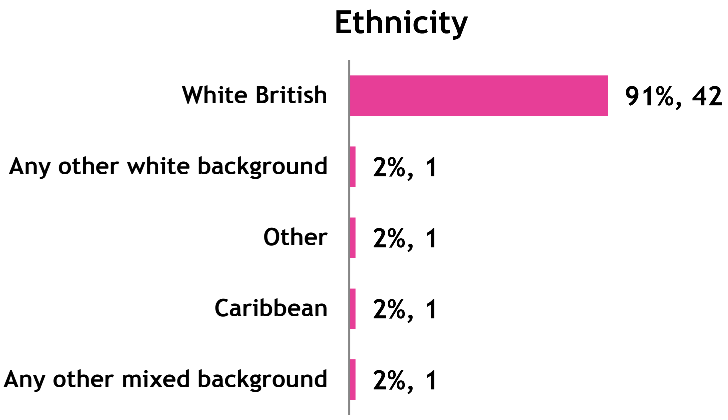


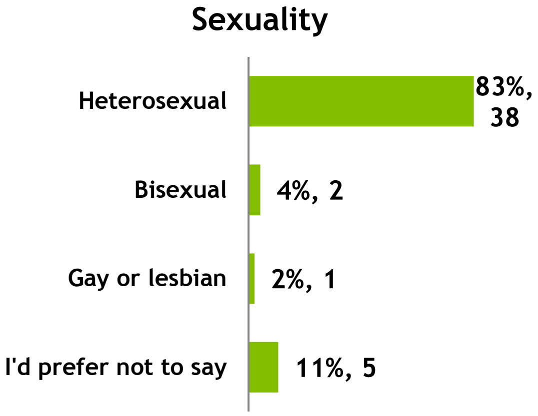


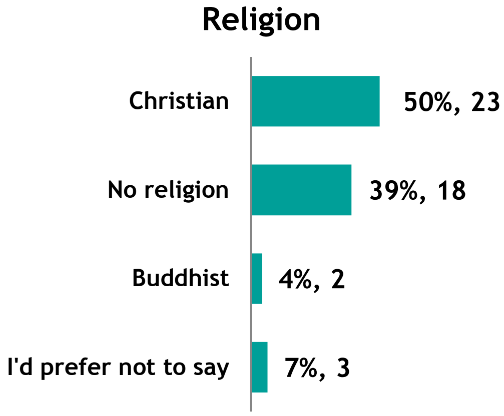

Disability
I'd prefer not to say, 2, 4%
No
21
46%
Yes
23
50%


Carer
Yes
12
27%
No
32
73%


Gender
I'd prefer not to say, 2, 4%
Male
7
16%
Female
36
80%


Ethnicity
White British
91%, 42
Any other white background
2%, 1
Other
2%, 1
Caribbean
2%, 1
Any other mixed background
2%, 1


Sexuality
Heterosexual
83%, 38
Bisexual
4%, 2
Gay or lesbian
2%, 1
I'd prefer not to say
11%, 5


Religion
Christian
50%, 23
No religion
39%, 18
Buddhist
4%, 2
I'd prefer not to say
7%, 3