

The NHS Long

Term Plan:

Views from

Hertfordshire

July 2019

whot
would you do?

It's your NHS. Have your say.

Executive summary

Background

In response to growing pressure, the NHS in England announced an ambitious 10-year plan showing how services will be improved, with the key priorities being: improving how the NHS works, helping more people to stay well, more money invested into technology and making care better. NHS organisations must plan how these priorities will be delivered in their area. As a part of this, Healthwatch Hertfordshire (HwH) worked with Herts and West Essex Sustainable Transformation Partnership (STP) and the residents of Hertfordshire to give people the opportunity to have their views and experiences shape how the national plan is delivered locally.

Aims and Objectives

- To understand from local residents how they would like local NHS and Social Care services to work and interact with them
- To actively seek views and experiences from local people with conditions such as cancer, mental health, dementia, lung and heart diseases and learning disabilities, long term conditions and autism, to understand if these services currently meet their needs
- To identify how NHS and Social Care services can be improved from the public's perspective
- To share the findings and recommendations of this report with decision makers and providers who can make a difference

Methodology

HwH conducted two surveys designed by Healthwatch England. One of which was a general survey, gathering the public's views on ways the NHS can give people more control over their health. The second, more specific survey, was regarding how care could be improved for those with conditions that the NHS has made a national priority (cancer, heart and lung diseases, stroke, diabetes, mental health conditions, learning disability and autism).

To support these surveys, a workshop/focus group was carried out focusing on personalised care (a key priority of the long term plan), which looked at how personalised care works currently and how participants would like it to work in the future.

Summary of Findings

As seen in this summary and in the findings section later, most of the conclusions align with the aims of the local STP, for example the need to help people make the right choices about their health, and to have integrated services built around the needs of patients and the public.

The main findings of the general survey were that participants would like to see timely access to help and treatment, professionals that listen to them and involve them in decisions, and technology that would give them easier access to professionals and their records - with an emphasis on keeping data secure. When considering aging well, being able to stay in their own homes as long as possible was of the highest importance. Of less importance to this group were access to information and community support networks.

The survey directed at those with specific conditions showed that those with heart and lung diseases and long term conditions generally had a more positive experiences regarding the help and support they received, whereas those with mental health conditions disclosed negative experiences, and emphasised a need for local services linked to ability and willingness to travel. Echoing the general survey, respondents across all conditions noted the delay both in getting initial assessment and treatment, and ongoing support after initial assessment.

Supporting this, the participants of the focus group also highlighted the possibility for disparity in experiences, dependent on the condition. The focus group respondents reflected the responses to the general survey, stating that future service provision should give real and transparent choice, flexibility of care and enable independence with adequate support from professionals to help people stay well. The group stressed the need for integrated NHS and Social Care services to ensure continuity in care.

Background & Aims

Background

The NHS is changing:

With growing pressure on the NHS - people living longer, more people living with long-term conditions, and lifestyle choices affecting people's health - changes are needed to make sure everybody gets the support they need.

The Government has announced that the NHS budget will be increased by £20bn a year. In January 2019, the NHS in England published an ambitious ten-year plan showing how this extra money will be spent and how the NHS wants to do better, including:

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

Locally, NHS organisations have been asked to come up with a local plan¹ explaining how these priorities will be delivered within their area. Our aim as part of this work was to work with Herts and West Essex Sustainable Transformation Partnership (a group of local organisations that have developed the plan) and the residents of Hertfordshire, to give people the opportunity to have their views and experiences shape how the national plan is delivered locally.

The priorities for the Herts & West Sustainable Transformation Plan (STP) are outlined below:

- Helping people to make the right choices about their health, living as independently as possible and accessing support at the right time and place.
- Improving support to people through partnerships with district councils, third sector, employers and community organisations.
- Integrating primary, community, mental health and social care teams around defined communities and their needs.
- Introducing consistent best practice pathways, supported by integrated models of delivery.
- Ensuring people are admitted to hospital at the right time for the right reason, and only when hospital is the right place for them.
- Putting in place support to enable people to be quickly discharged from hospital when they are ready.
- Making effective and efficient use of available resources across the STP area.

¹ <https://www.healthierfuture.org.uk/sites/default/files/publications/2019/April/nm-summary-version-draft-hwe-integrated-strategy-executive-slide-deck-v71.pdf>

Aims & Objectives

- To understand from local residents how they would like local NHS and Social Care services to work and interact with them
- To actively seek views and experiences from local people with conditions such as cancer, mental health, dementia, lung and heart diseases and learning disabilities, and autism to understand if these services currently meet their needs
- To identify how NHS and Social Care services can be improved from the public's perspective
- To share the findings and recommendations of this report with decision makers and providers who can make a difference

The results of this research will be shared with all the organisations that comprise the Herts & West Essex Sustainable Transformation Plan (STP), partners within the Community and voluntary sector, Local Authorities and the CQC to help inform commissioning organisations and health regulators of the views and experiences of local patients in accessing and shaping NHS & Social Care services.

Methodology

Over the period of March - May 2019 HwH conducted two surveys, one focused on gathering the public's views on ways in which the NHS can give people more control over their health, and the second focused on understanding how care could be improved for people with conditions that the NHS made a national priority (cancer, heart and lung diseases, stroke, diabetes, mental health conditions, learning disabilities and autism). The survey was designed by Healthwatch England in order to standardise data collection across all local Healthwatch areas, so that comparisons to be made nationally.

Both surveys were distributed electronically through our partners within the NHS, Social Care, community and voluntary sector, as well as through our membership, website and social media channels. Through our newsletter and partner forums, we sent hard copy versions of the questionnaire and reached people who were less likely to complete surveys online (we received 106 completed surveys through this channel). We also created and shared easy read versions of the surveys and received 2 in this format. Lastly, we held four events (community and hospital stalls) across the county (Watford, Stevenage, Broxbourne and St Albans) to promote and conduct face to face surveys. These towns were targeted as they are in areas where the population tend not to contact HwH through the usual communication channels.

Additionally, a workshop/focus group towards the end of April concentrated on the plans around personalised care listed within the Long Term Plan. This session focused on hearing people's experiences of how this is working currently, and what participants would want this to look in the future. Participants were recruited through the same channels used for distributing the surveys. We reached the maximum number of participants we could facilitate in one session (14).

Summary of Findings

What did they tell Healthwatch?

General Survey: Gathering the public views on the ways in which the NHS can give people more control over their health

The aim of this survey was to understand what Hertfordshire residents felt local NHS and Social Care services should look like and do. The focus was not on how things work currently, but how these services would work if they had control in shaping them. The questions were split into the following themes:

1. Supporting people to stay well and live healthier lives
2. Making it easier for people to take control of their own health and wellbeing

Demographics

There were 299 respondents to this questionnaire of which 35% (105) were male and 61% (183) were female; 39% (117) respondents were between 18-64 years and 173 (58%) respondents were 65 years and older; 63% (189) respondents considered themselves to have a disability and 54% (160) respondents have one or more long term conditions.

Supporting People to Stay Well: Access, Involvement and Independence

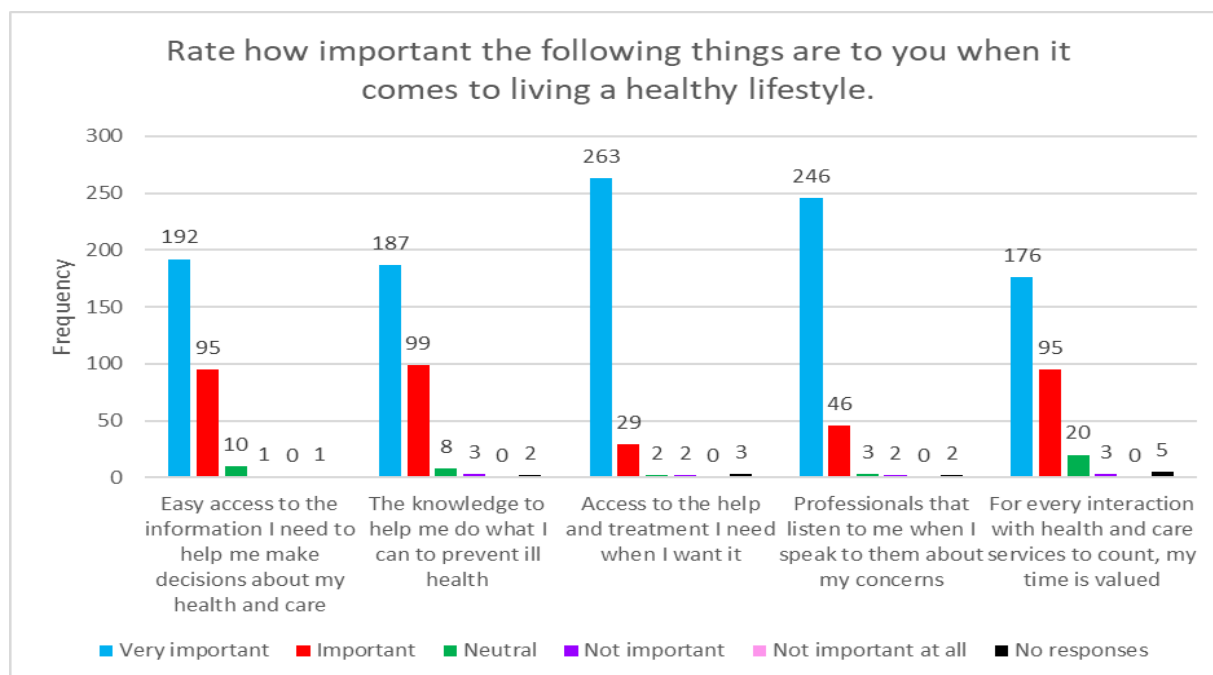


Figure 1: Frequency of Category Selection for Q.3a.

In Figure 1 all the categories were considered “Very Important” by the participants when trying to live a healthy lifestyle, and no categories were rated ‘not important at all’. The statement “Access to the help and treatment I need when I want it” was the most popular response (263), closely followed by ‘professionals that listen to me when I talk about my concerns’ (246 respondents), followed by ‘easy access to the information I need to help me make decisions about my health and care.’ This is supported by answers when respondents were asked to only choose one statement that was most important (see Figure 2).

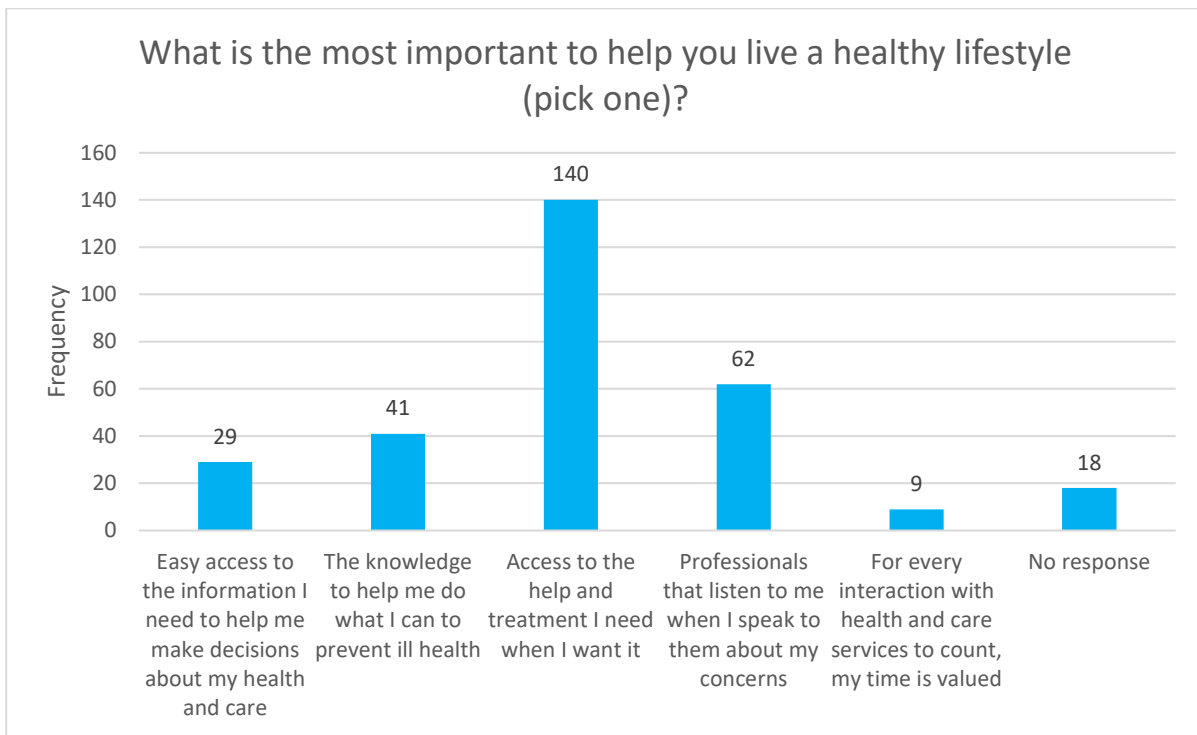


Figure 2: Frequency of Category Selection for Q.7

This ordering suggests access to information comes secondary in importance when compared to access to treatment and professionals.

Comments related to this question focused particularly on the importance of prevention provision in helping people stay healthy, and the importance of access to these services when they are available:

“[There needs to be] more of a focus on mental health and the prevention of mental ill health”

“[A]s a relatively healthy person, regular reviews to help me maintain this status would be helpful, without having to travel around South East to visit hospitals”

“Not proactive enough in asking you come in and prevent ill health. Checking blood sugar levels and cholesterol etc. aren’t consistent area to area...I’ve never been asked to do an annual health check and I’m 70 [years old]”

“I would like my healthcare to focus more on wellness rather than illness”

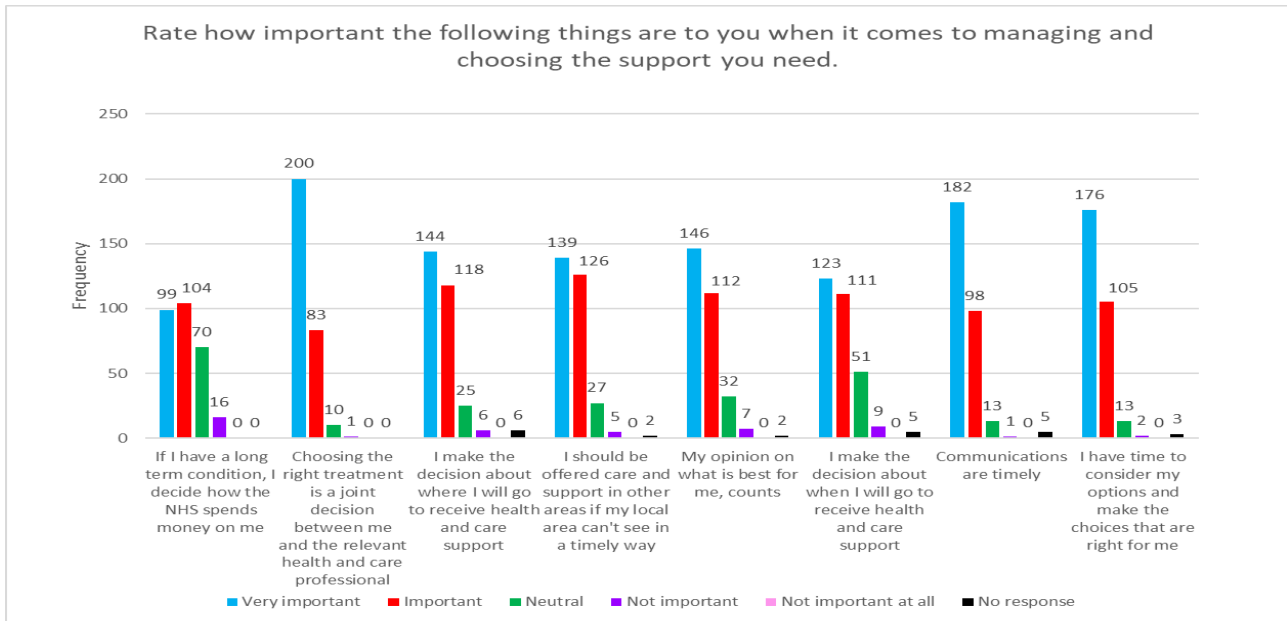


Figure 3: Frequency of Category Selection for Q.4a

As conveyed in Figure 3, the statement “Choosing the right treatment is a joint decision between me and the relevant health and care professional” was the most significant with 200 participants rating this category as “Very Important” when it came to managing and choosing the support they need. This is supported by answers when respondents were asked to only choose one statement that was most important (131 participants chose this option). Closely following this statement was “communications are timely” (182 respondents) and “I have time to consider my options and make the choices that are right by me” (176 respondents).

Although these categories were important to respondents when thinking about how services should look, the qualitative data gathered indicated that people do not feel this always happens at present:

“Good conversation between health professionals on how best to manage care”

“My opinion should matter but it doesn’t”

“Above all, I would like to be listened to, understood and given time and options for my health choices.

“Less red tape, better communication between healthcare professionals. If they say they are referring you, be honest and tell you how long it will take, make referrals letters be sent within a set time scale to avoid patient getting sicker, then further stressed having to chase up letters with phone calls etc. It just wastes staff time constantly answering calls.”

“Communications in my experience are not timely”

“Wanted to know what had happened following an operation which caused partial blindness. GP didn’t seem interested - I had to find out myself what had happened”

“[I’d like] quicker diagnosis of results especially for cancer and heart problems”

“I’d like clearer explanations from GP as to medication being prescribed and details of possible side effects.”

In comparison, the category “*If I have a long term condition, I decide how the NHS spends money on me*” was the least popular response with 99 participants considering this statement “Very Important” and 70 rating it as ‘neutral’. This could partly be because the majority of participants who completed the survey did not have a long term condition so the statement was inapplicable or less important to them. But also partly because respondents felt unskilled or unable to make these decisions on behalf of the NHS telling us “They [the NHS] are paid to make decisions about how money is spent, and are better informed than me.”

Making it easier for people to take control of their own health: Accessing Support & Maintaining Independence

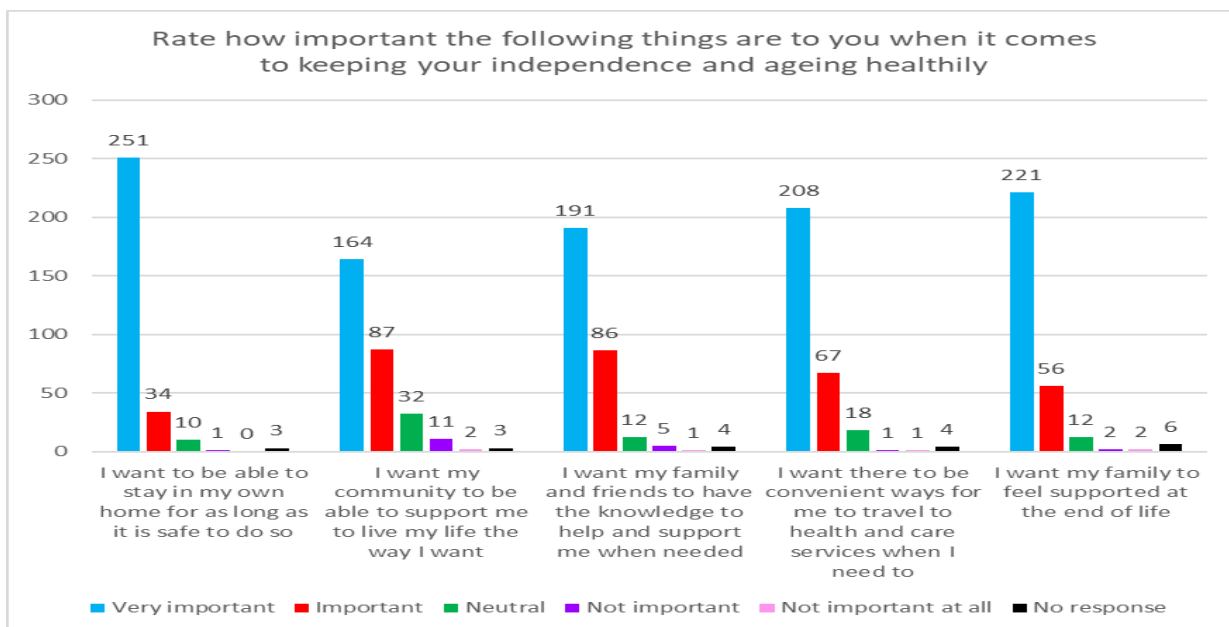


Figure 4. Frequency of Category Selection for Q.5a.

As figure 4 shows, all the categories were considered “Very Important” by respondents, but the category “*I want to be able to stay in my own home for as long as it is safe to do so*” was the most common response with 251 participants identifying this as a very important factor in keeping their independence and ageing healthily. This is supported by answers when respondents were asked to only choose one statement that was most important (180 respondents).

The least popular response was “*I want my community to be able to support me to live my life the way I want*” with 164 respondents considering this “Very Important.” The qualitative data suggests that this because patients are less aware of the services and facilities available in the community to help support them, or would prefer support from health and social care providers in the first instance:

“I’ve just been through end of life. I was very lucky to have a large family as I don’t think the support is there.”

“I’d like another person to help me go to my appointments.”

“I don’t feel supported by health professionals”

“I don’t feel that there is enough support currently for bereavement - especially for young children who have lost their parents. I also feel that mental health support for children and young adults needs to be better”

“I’d like someone I could ask questions [to], not necessarily a doctor but caring person.”

Making it easier for people to take control of their own health: Interacting and communicating with my local NHS

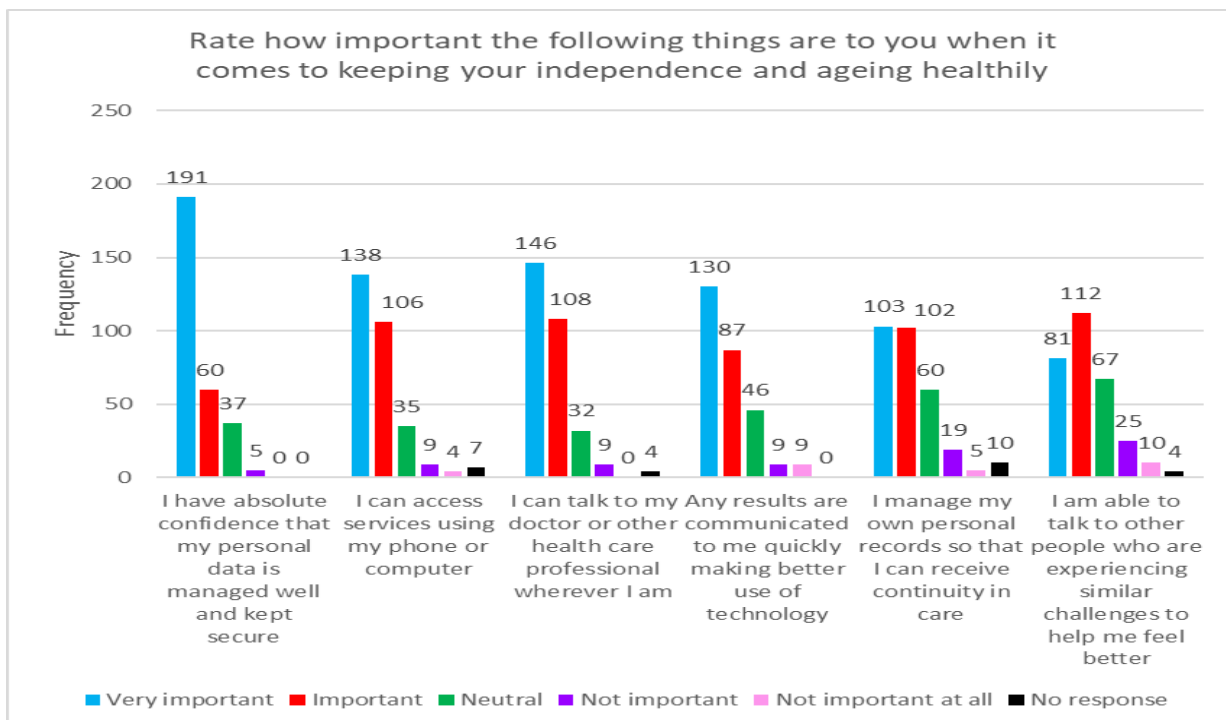


Figure 5. Frequency of Category Selection for Q.6a

As identified in Figure 5, the most popular rated category was “I have absolute confidence that my personal data is managed well and kept secure” with 191 participants considering this “Very Important.” This was contradicted by answers when respondents were asked to only choose one statement that was most important (see Figure 7), the statement they chose in this instance was ‘I can talk to my doctor or other health care professional wherever I am’.

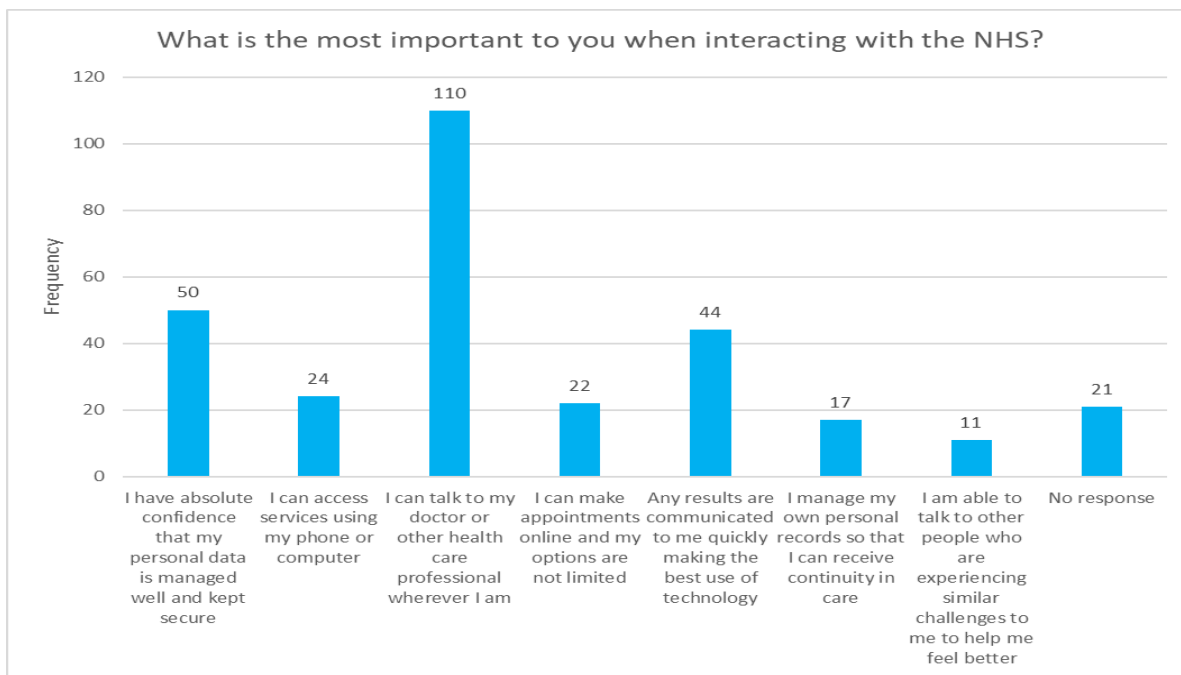


Figure 7: Frequency of Category Selection for Q.9

Linking back to personal data, people were worried that at present their data was not being managed well by the NHS, and felt more information and reassurance could be provided by providers and commissioners:

“GP has lost my data twice, so I don’t feel confident yet!”

“I worry about how data is managed, especially when you hear about how many times data is lost, misplace or given to the wrong person by accident”

“I have no confidence that the NHS keep records secure”

“They [the NHS] haven’t communicated well re data sharing and protection, so I don’t understand what to expect”

“I don’t really know much about how data is handled. The NHS could do more to provide information on this”

In comparison, the least popular response was *“I am able to talk to other people who are experiencing similar challenges to help me feel better”* with 81 respondents believing this to be “Very Important”. One reason for this could be because the majority of participants who completed the survey did not have a long term condition, so require this support less. There were also respondents that noted that their conditions were so rare that support groups and others experiencing similar challenges weren’t available to them. The statement/category was closely followed by *“I manage my own personal records so that I can receive continuity of care”* with only 103 respondents rating this as “Very important”, comments supporting this focused on the individuals wanting easy access to their records, but demonstrated a lack of confidence when being asked to ‘manage’ them:

“I want the professionals to manage my records”

“It should not be my responsibility to manage my own health and care record. However, I should have full access to all the data about me and the ability to have it corrected and to save a copy whenever I choose...”

“Need the best person suitable looking after your records when you get older”

“I’m unsure about patient records. How would I manage my own records?”

“I want to be able to see my records easily, not manage them”

Conclusions: How the NHS and Social Care Services Could be Better

Respondents to this survey highlighted that to support people in staying well and healthy, they would like to see timely access to help and treatment when needed. They felt that having professionals listen to them was very important, as well as treatment being a joint decision between them and the professional.

Respondents stated that access to information was secondary to accessing treatment and professionals. They also rated statements about the importance of community support networks as less important compared to support from professionals.

People being able to stay in their home for as long as it is safe to do so, was very important when thinking about what ageing well and maintaining independence.

When considering how future services should be accessed and data should be managed, respondents felt it was important for technology to enable people to access health professionals from wherever they are, as well as data to be kept secure. This was something people worried wasn’t the case currently. People also stressed the importance of being able to access and edit their health records, but seemed to lack information and confidence about how to manage their own data.

Conditions Survey: Understanding how care could be improved for people with conditions that the NHS made a national priority.

This section analyses the responses received in relation to improving care for those with the seven health conditions the NHS has listed as a priority-Cancer, Heart and Lung diseases, Mental Health conditions, Dementia, Learning Disability, Autism, and Long term conditions such as diabetes. It looks at access and experience of getting support- specifically whether there was delay in accessing initial and ongoing help and support, whether the support and help received initially met their needs, access to specialist support, whether having more than one condition affected the support they received; communication, travel and time issues. This survey focused on evidencing respondents direct experiences - what currently does or does not work well.

Demographics

The total number of respondents for this survey was 42, of these, 66% (28) of respondents were female and 21% (9) are male. 62% (26) are aged between 18-64 years and 36% (15) were aged 65 years and over. The respondent’s conditions are categorised as follows:

Condition	Frequency
Cancer	7
Heart and lung diseases	3
Mental Health	11
Dementia	3
Learning disability	2
Autism	2
Long term condition e.g. diabetes, arthritis	14

Access and experience of getting help & support

As demonstrated in Figure 5 & 6, the majority of respondents to this survey (30 of 42) did not feel the support they first accessed met all their needs, and also did not rate their overall experience positively - 69% (26 of 42) categorising their experience as ‘average’ to ‘very poor’.

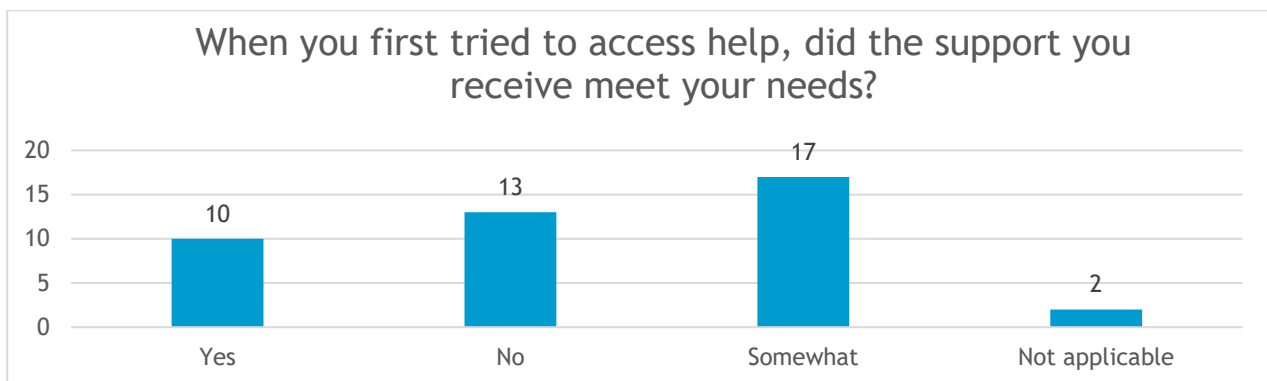


Figure 5. Q.6a, Conditions Survey - All respondents

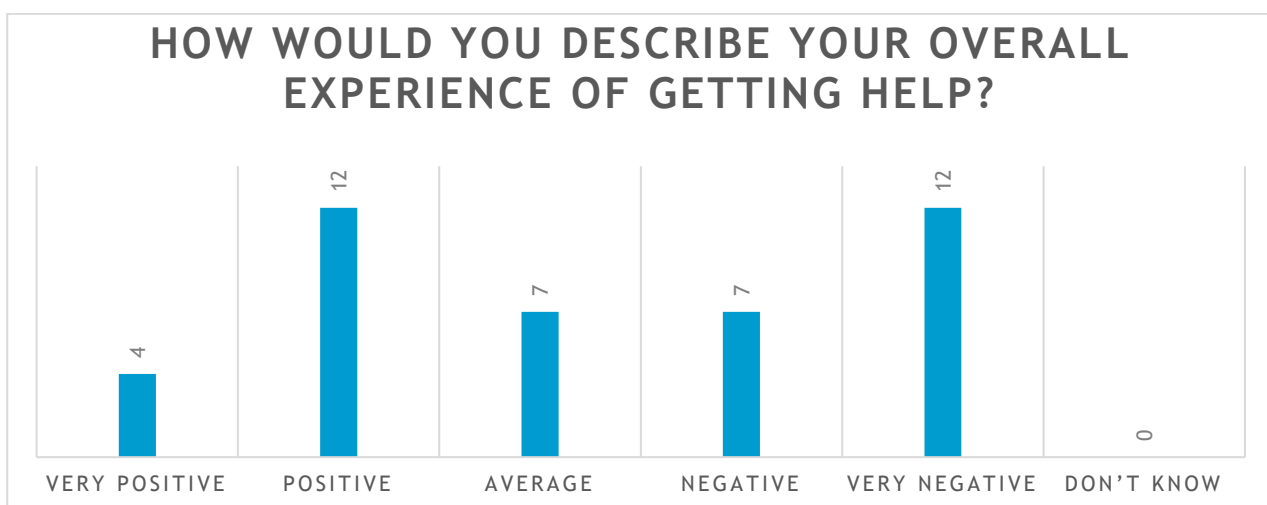


Figure 6. Q7, Conditions Survey - all respondents

When this is broken down by condition (Figures 7 & 8), we see that for the majority of conditions there is a fairly even spread across the support ‘meeting their needs’, the support ‘somewhat meeting their needs’ and the support ‘not meeting their needs’, with the exception of those individuals with a mental health condition. For those with a mental health condition, 10 of 11 participants (90%) felt that the support either only somewhat met their needs or did not meet their needs at all. Additionally, those with mental health conditions more so than those with other conditions did not tend to find their experience of getting help positive, as can be seen in Figure 8 where 82% (9) participants rated their experience as ‘negative’ to ‘very negative’. Only 1 of the mental health participants stated that they had a positive experience, which was in contrast to the participants with a long term condition who generally stated that their experiences had been positive with only 14% (2) participants rating their experience within the ‘negative’ category.

Condition	When you first tried to get access to help, did the support you received meet your needs?				
	Yes	No	Somewhat	Not applicable	No response
Autism	0	2 (100%)	0	0	0
Cancer	1 (14%)	3 (43%)	2 (29%)	1 (14%)	0
Dementia	0	2 (67%)	1 (33%)	0	0
Heart and Lung Diseases	2 (67%)	0	1 (33%)	0	0
Learning disability	1 (50%)	1(50%)	0	0	0
Long term condition eg diabetes, arthritis	5 (36%)	2 (14%)	6 (43%)	1(7%)	0
Mental Health	1 (10%)	5 (45%)	5 (45%)	0	0

Figure 7. Q.6a, Conditions Survey - frequency of answers by condition/percentage of condition total

Condition	How would you describe your overall experience of getting help?					
	Very positive	Positive	Average	Negative	Very Negative	Don't know
Autism	0	1 (50%)	0	0	1 (50%)	0
Cancer	2 (29%)	0	1 (14%)	2 (29%)	2 (29%)	0
Dementia	0	0	1 (33%)	0	2 (67%)	0
Heart and Lung Diseases	1 (33%)	2 (67%)	0	0	0	0
Learning disability	0	1 (50%)	0	0	1 (50%)	0
Long term condition eg diabetes, arthritis	1 (7%)	7 (50%)	4 (29%)	2 (14%)	0	0
Mental Health	0	1 (9%)	1 (9%)	2 (18%)	7 (64%)	0

Figure 8. Q7, Conditions Survey - frequency of answers by condition/percentage of condition total

Figures 9 and 10 show that 21 participants considered themselves to have additional conditions or disabilities, and highlight whether they found that this impacted on their experience with

seeking support. Over half (57%) felt that having more than one condition made getting support harder. The most noticeable conditions that this effected was autism and mental health, with 2 of 2 individuals with Autism and 4 of 5 mental health patients stating having multiple conditions ‘made getting support harder’.

There were 9 participants that stated having an additional condition either made no difference or made getting support easier.

Condition	Do you have any other/additional conditions including long-term conditions and disabilities?		
	Yes	No	No response
Autism	2	0	0
Cancer	6	1	0
Dementia	0	3	0
Heart and Lung Diseases	0	3	0
Learning disability	2	0	0
Long term condition eg diabetes, arthritis	6	7	1
Mental Health	5	5	1

Figure 9. Q8, Conditions Survey - answer frequency by condition/percentage of condition total

Condition	If so, how would you describe the experience of seeking support for more than one condition at a time?				
	It made getting support easier	No difference	It made getting support harder	I don't know	Not applicable
Autism	0	0	2 (100%)	0	0
Cancer	2 (29%)	1 (14%)	3 (43%)	0	0
Learning disability	0	1 (50%)	1 (50%)	0	0
Long term condition eg diabetes, arthritis	1 (17%)	3 (50%)	2 (33%)	0	0
Mental Health	1 (20%)	0	4 (80%)	0	0

Figure 10. Q9, Conditions Survey - answer frequency by condition

Comments that related to this were:

“Long history of mental health issues. It took a long time to get into the system in the first place...despite being seen by mental health professionals off and on since 2001, it took 16 years before I was even diagnosed with Autism”.

Waiting Times & Further Support

Condition	How would you describe the time you had to wait to receive your initial assessment of diagnosis?						
	Very Fast	Fast	OK	Slow	Very Slow	Don't Know	No response
Autism	0	0	0	0	2 (100%)	0	0
Cancer	2 (29%)	0	2 (29%)	0	3 (42%)	0	0
Dementia	0	0	1 (33%)	1 (33%)	1 (33%)	0	0
Heart and Lung Diseases	0	0	2 (67%)	1 (33%)	0	0	0
Learning disability	0	1 (50%)	0	0	0	0	1 (50%)
Long term condition eg diabetes, arthritis	1 (7%)	2 (14%)	4 (29%)	5 (36%)	1 (7%)	1 (7%)	0

Mental Health	1 (9%)	0	1 (9%)	2 (18%)	5 (45%)	1 (9%)	1 (9%)
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Figure 11. Q10, Conditions Survey - answer frequency by condition/percentage of condition total

Condition	How would you describe the time that you had to wait between your initial assessment and diagnosis and treatment?						
	Very Fast	Fast	OK	Slow	Very Slow	Don't Know	No response
Autism	0	0	0	1 (50%)	0	0	1 (50%)
Cancer	2 (29%)	2 (29%)	0	1 (14%)	2 (29%)	0	0
Dementia	0		0	0	0	0	0
Heart and Lung Diseases	0	1 (33%)	0	0	0	1 (33%)	1 (33%)
Learning disability	0	1 (50%)	0	0	1 (50%)	0	0
Long term condition eg diabetes, arthritis	2 (14%)	1 (7%)	4 (29%)	5 (36%)	2 (14%)	0	0
Mental Health	1 (9%)	0	1 (9%)	4 (36%)	4 (36%)	1 (9%)	0

Figure 12. Q11, Conditions Survey - answer frequency by condition/percentage of condition total

Figure 11 & 12 both summarise the data from questions 10a and 11a in the survey which refer to waiting times. The figures show that overall 50% (21 respondents) described their initial wait for an assessment/diagnosis as ‘slow’ or ‘very slow’, compared to 16% (7 participants) who described their experience as ‘fast’ or ‘very fast’. This supports findings within the general survey relating to access.

When breaking experiences of waiting times down by condition, the majority of those with autism (2 of 2), mental health (7 of 11) and dementia (2 of 3) described their wait for an initial diagnosis as either ‘slow’ or ‘very slow’. In comparison, those with a long term condition (7 of 14) and those with cancer (4 of 7) rated their wait for an initial assessment/diagnosis as ‘very fast’ ‘fast’ or ‘ok’.

When looking at how patients described their wait times between their initial assessment and their treatment starting, Figure 12 shows that 42% of all respondents stated this was ‘slow’ or ‘very slow’. When broken down by condition, cancer patients were split almost evenly between ‘very fast - fast’ and ‘very slow- slow’, mental health patients (8 of 11) mostly rated their wait as ‘slow’ and ‘very slow’, and those with long term conditions had a mixed experience:

“I was diagnosed with ovarian cancer and had to wait for many weeks before my operation, even though in the meantime I had to go to A&E because of bleeding. The mass had broken up by the time they got it out. This led to another mass and a further up two years later which in turn led to me being fitted with a stoma and two holes in my bladder which in turn led to another operation to repair my bladder. So two unnecessary operations which could have been avoided if treatment had been quicker. [There] definitely there should be faster response times after diagnosis.”

“Waiting times for my 53 year old daughter to access help and support have been far too long. Without my constant monitoring I really believe she would have taken her own life before she got help from mental health services.”

I'm still waiting for Palliative referral"

Specialist Support

Just over two thirds (69%) of the respondents to this survey were referred to a specialist. The table below breaks this down by condition.

Condition	Were you referred to a specialist? For example, a hospital consultant, psychiatrist or physiotherapist		
	Yes	No	No response
Autism	1	1	0
Cancer	6	0	1
Dementia	1	2	0
Heart and Lung Diseases	3	0	0
Learning disability	1	1	0
Long term condition eg diabetes, arthritis	12	2	
Mental Health	5	6	0

Figure 13. Q15, Conditions Survey - answer frequency by condition

As seen below in Figure 14, the majority of participants referred to a specialist within cancer, heart and Lung disease and long term condition services rated their wait as 'ok' 'fast' and 'very fast'. For those who responded with a mental health condition 2 of 5 could not answer and 2 of 5 described their wait as 'slow' or 'very slow'.

Condition	How would you describe the time you had to wait between initial appointment and seeing the specialist?					
	Very Fast	Fast	OK	Slow	Very Slow	Don't Know
Autism	0	0	1 (100%)	0	0	0
Cancer	2 (33%)	1 (17%)	1 (17%)	2 (33%)	0	0
Dementia	0	0	0	0	0	1 (100%)
Heart and Lung Diseases	0	2 (67%)	1 (33%)	0	0	0
Learning disability	0	1 (100%)	0	0	0	0
Long term condition eg diabetes, arthritis	1 (8%)	2 (17%)	5 (42%)	2 (17%)	2 (17%)	0
Mental Health	0	0	1 (20%)	1 (20%)	1 (20%)	2 (40%)

Figure 14. Q16a, Conditions Survey - answer frequency y condition/percentage of condition total

Ongoing Support & Communication

Figures 15 & 16 below refer to the respondent's experiences of ongoing support and communication. As you can see from these figures overall, 21% (9 of 42 participants) found accessing ongoing support as 'very easy' or 'easy' compared to 38% (16 of 42 participants) who found this either 'difficult' or 'very difficult'.

Respondents with mental health conditions consistently rate the ease of seeking support and the support offered as 'very difficult - difficult' (8 of 11 participants) or not meeting expectations (9 of 11 participants). Additionally, those with a mental health condition most often said that they did not always receive timely communications (10 of 11 participants). In contrast, those with long term conditions more commonly stated that they did receive timely communications or they somewhat received them.

Overall 69% (29 of 42 participants) stated that they either did not or only somewhat received timely and consistent communication from all of the services they came into contact with.

Timely communication was also factor highlighted as important in the general survey findings. Respondents noted that timely communications, and being able to talk to a professional from wherever you are were key enablers which help to maintain independence and age well.

Condition	If you needed it, how easy did you find it to access ongoing support after you were diagnosed or assessed?						
	Very Easy	Easy	OK	Difficult	Very difficult	Don't know	Not applicable
Autism	0	0	0	1 (50%)	1 (50%)	0	0
Cancer	1 (14%)	2 (29%)	2 (29%)	0	1 (14%)	1 (14%)	0
Dementia	0	0	2 (67%)	0	0	0	1 (33%)
Heart and Lung Diseases	0	1 (33%)	0	1 (33%)	0	1 (33%)	0
Learning disability	1 (50%)	0	0	0	1 (50%)	0	0
Long term condition eg diabetes, arthritis	0	2 (14%)	6 (43%)	3 (21%)	2 (14%)	1 (7%)	1 (7%)
Mental Health	1 (9%)	1 (9%)	0	3 (27%)	5 (45%)	1 (9%)	0

Figure 15.

Condition	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?			
	Yes	No	Somewhat	No response
Autism	0	1 (50%)	0	1 (50%)
Cancer	2 (29%)	2 (29%)	3 (43%)	0
Dementia	0	3 (100%)	0	0
Heart and Lung Diseases	0		3 (100%)	0
Learning disability	1 (50%)	1 (50%)	0	0
Long term condition eg diabetes, arthritis	7 (50%)	4 (29%)	2 (14%)	1 (7%)
Mental Health	1 (9%)	7 (64%)	3 (27%)	0

Figure 16.

Travel & time spent to access support and care

As seen below in Figure 18 & 19, the majority of respondent's stated their main form of transport is by car (27 of 42), and 64% (27 of 42) stated they are willing to travel between 30 minutes and 1-2 hours to receive a 'quick and accurate diagnosis'.

When the figures are broken down by condition we see that individuals with a mental health condition are more likely to travel via public transport or via 'other' means than to use a car, and would be prepared to travel less time compared to those with a long term condition or cancer who tended to travel by car. For those with a mental health condition, the reluctance to travel over an hour did not change when it was to see a specialist, whereas again those with a long term condition, such as diabetes, or those with cancer were more willing to travel long distances, sometimes even over 2 hours to receive specialist treatment or support.

Condition	What is your main means of transport?						
	Own Car	Another Person's car	Bus	Train	Bicycle	Taxi	Other
Autism	1	0	1	0	0	0	0
Cancer	6	0	0	0	0	0	1
Dementia	3	0	0	0	0	0	0
Heart and Lung Diseases	1	1	1	0	0	0	0
Learning disability	1	1	0	0	0	0	0
Long term condition eg diabetes, arthritis	8	2	2	0	0	0	1
Mental Health	1	2	4	0	0	1	3

Figure 18

Condition	How much time would you be willing to travel for to receive a quick and accurate diagnosis?			
	Less than 30 minutes	30 minutes to an hour	1-2 hours	Over 2 hours
Autism	0	1 (50%)	1 (50%)	0
Cancer	2 (29%)	1 (14%)	2 (29%)	2 (29%)
Dementia	2 (67%)	0	0	1 (33%)
Heart and Lung Diseases	0	1 (33%)	2 (67%)	0
Learning disability	1 (50%)	1 (50%)	0	0
Long term condition eg diabetes, arthritis	3 (21%)	5 (36%)	5 (36%)	1 (7%)
Mental Health	3 (27%)	7 (64%)	0	1 (9%)

Figure 19

Conclusions: Understanding how care could be improved for people with conditions that the NHS made a national priority

The findings from this survey echoed themes highlighted in the general survey - the want and need for greater access to treatment and supported when needed, as well as the importance of timely communications and being able to talk to and access a professional easily. However, looked more in depth at the similarities and differences of experiences across conditions.

The 'conditions survey' found that overall those with heart and lung diseases and long term conditions had a more positive experience with the help and support received meeting their needs. However, all respondents across all conditions, felt there was significant delay both in getting initial assessment, and treatment and ongoing support after initial assessment.

Those with mental health conditions disclosed negative experiences with the health and support received not meeting their needs across all questions.

Generally, respondents except those with mental health conditions, were willing and able to travel up to 2 hours to access help and support as they have access to a car, whereas those with mental health conditions tended to use public transport and therefore unable/unwilling to travel as far. This may reflect socio-economic factors.

Co-production workshop: Experiences of Personalised care and what future provision should look like

To support the surveys in gathering more in- depth feedback, we ran a workshop bringing together 14 people with personal or carer’s experiences to discuss personalised care (a key priority of the long term plan), to investigate how personalised care works currently, and how participants would like it to work in the future.

As part of this workshop, we invited a representative from our local Sustainable Transformation Plan (STP) to jointly present with HwH on the Long Term Plan (LTP) and the Comprehensive Model for Personalised Care. This presentation focused on knowledge building and providing the participants with an understanding of what personalised care is. The second part of the session focused on understanding how personalised care actually worked in practice through sharing personal experiences, and the final exercise concentrated on working together to produce a vision for how personalised care should work locally.

Personal Experiences of Personalised Care: Key Themes

Participants shared their views and experiences of personalised care and person centred care, which can be broken down into the following themes:

- Lack of choice, flexibility and enablement of independence e.g. an example of a male care worker provided to support an elderly female bathing, when the individual requested a female

“Unfortunately we have a lot of the girls leaving because the organisation [they work for] is so bad. This morning the girl said “I’ve got a gap here, a gap there. I come to work for 8 hours a day, I don’t only want to get paid for five hours. They’re not giving me enough jobs”. And then you lose them. They give up. The good ones go, which is an awful shame. You get to know them, like them, and they know you and know what to do.”
- Lack of overall co-ordination and management of care

“the person holding the care plan is expected to organise, co-ordinate and chase when things go wrong. [we] should have someone who manages the process, like a project manager to help make things happen, the care happen”
- A feeling that organisations aren’t as patient focused as they could be

“When they send my doctor something, I get copied in. Why? This is my medical report, this is my assessment!”
- Lack of staff, ongoing support and information

“Need more information. The GP will give a diagnosis and then just send you on your way.”
- Lack of sharing and being able to access health records, meaning patients have to repeat their story and can have long waits for diagnosis and treatment

“It took them 5 years to diagnose my initial mental [health] condition, then it was 2 years after that before I got a treatment plan. Now, I have a treatment plan and it’s working really well - I’m seeing a therapist on a weekly basis, I am on medication, but it was a huge struggle and it just turns people off.”
- Experience of an organisation not sharing patient information across services and this meaning patient had to have tests which weren’t needed.

- Experience of seeing the same mental health therapist only twice for a total of 8 years. Individual would often have to repeat their problems to each new person they met as they could not access their medical notes. Only after making a complaint they finally got to regularly see the same therapist
- Requests from all members that the NHS and Social Care services work in a more integrated way

“[I]t would be great if Health and Social Care systems were not so fragmented, and they all worked together. Social Care needs to work with the NHS in order to make the Long Term Plan work”

What Does Good Personalised Care and Support Planning mean to you?

For this exercise we asked participants to split into three groups and assess 12 statements on personalised care and support planning created by Think Local Act Personal (TLAP) National Co-production Advisory Group. The groups were asked to rank their top 3-5 statements that best described what good personalised care and support planning looked like. Each group was then asked to frame their discussion around what local future provision should look like based on the statements they had chosen as most important. Each group focused on a different stage of care (a) prevention and early intervention (b) assessment, diagnosis and treatment (c) ongoing care and support.

Group 1: Prevention and Early Intervention

Ranked TLAP statements:

1. I have all the information I need to plan - when I need it, in an accessible way, including signposting to what is available locally
2. My care and support plan is a about the whole of my life, not just assessed needs or money.
3. My review is person-centered, focused on me and my life, my outcomes and what is working and not working - not just the money.

Future provision discussion:

Group one felt strongly that patients and the public should have the information and knowledge they need not only to plan their care, but to also help with prevention and manage wellbeing.

Personal responsibility was seen as important, but the group stressed that unless you have information going to the right audience, it's difficult to expect people to change their behaviour. They also noted that there is a lot of information and misinformation available to public - *“it contradicts itself, so it's difficult to know what to trust and follow.” “[It's] a whole life-skill understanding what is a fact and what is opinion. When personally researching on the internet, I can get really confused”*.

One member of the group talked about their experiences of mental health, and highlighted the importance of personal responsibility being met with adequate professional support - *“with mental health, you need to know yourself if you have a problem. You need information to be able to say I've got a problem and I need to get it sorted. That's where it starts. It's the same with ordinary illness.”*

Group 2: Assessment, Diagnosis and Treatment

Ranked TLAP statements:

1. People do what they say they will do.
2. If I need help to plan, I can choose who supports me and who will help put the plan into practice.
3. I can involve friends and family in the process if I choose.
4. People who support me to plan, have a flexible, open, honest, positive, solution-focused attitude.
5. My review is person-centred, focused on me and my life, my outcomes and what is working and not working - not just the money.

Future provision discussion:

Group two described what characteristics they would like to see from a staff member providing good personalised care. They stated these as

- Compassionate;
- Knowledgeable and fully informed;
- Focused on the individual's personal needs;
- Flexible around individual's life and interests;
- Willing to discuss what individual would like to achieve;
- Considers the individual's social circumstances (e.g. isolated).

Some members highlighted that the above isn't always what they experience. When group members were asked how they thought these characteristics could be achieved, they suggested training, learning from feedback such as complaints and increased capacity/numbers of staff.

When thinking about choice and control, the group highlighted the need to have real choices, rather than just two choices - which some members described they had experienced in the past. Group members felt that there needed to be a 'reality check' on what is truly possible as a choice, not just now but in the future, and that the NHS needs to be more transparent in this.

When asked if they were willing to travel long distances to receive a diagnosis or treatment, the majority of the group would for better care.

Group 3: Ongoing Care & Support

Ranked TLAP statements

1. My care and support plan is about the whole of my life, not just about assessed needs and money.
2. I have all the information I need to plan - when I need it in an accessible way, including signposting to what is available locally.
3. My review is person centred, focused on me and my life, my outcomes and what is working and not working
4. The process from assessment through to review is transparent and clear. I know what to expect and when to expect it
5. Through my review I can contribute my views to improving the system well.

Future provision discussion:

Group three felt that the most important statement was 'people do what they say they will do', but felt that this should be a given, though it was highlighted that some members had personal experiences of this not always happening.

For this group the statements as a whole were missing support roles like carers, family and friends. The group highlighted that good personalised care should include a person's loved one if that was what they wanted.

The group also highlighted what they felt was a disparity between services and therefore people's experiences, echoing the findings in the 'conditions survey'. One group member highlighted their recent positive experience of using cancer services, they described the ongoing support as "fantastic" and stated that their named contact (a Macmillan Nurse) was always contactable; whereas another described their experience of using community mental health services as the opposite - "it makes you question if the NHS thinks one condition is more important than another, as I haven't had that type of service."

When asked about travel and location of services, for most participants they were happy to travel if needed, however one participant stressed that they could not drive due to their mental health condition, so having good local services was really important to them. Again, this statement was supported by the findings in the 'conditions survey'.

Conclusions: Experiences of Personalised care and what future provision should look like

Participants felt that future service provision should give choice, flexibility of care and enable independence. When thinking particularly about choice, the group felt that choice needed to be real and 'transparent'. The group also highlighted the difficulty in evaluating messages and requested the NHS does more to provide reliable information.

Whilst some participants recognised the significance of personal responsibility, the group stressed the importance of this being met with adequate professional support. Some participants also highlighted a possible disparity in ongoing care and support provided by services such as cancer and mental health. It was also noted that different conditions may impact on the willingness/ability of individuals to travel further afield for care, so local provision needs to be made for those who can't travel. These statements supported findings from the earlier surveys.

The group felt that there needed to be an individual who coordinates and manages care plans once people are out in the community, as this type of community support is currently missing.

Lastly, the group stressed the need for NHS and Social Care services to work in a more integrated way, which again they felt was not happening currently. There were numerous examples of participants recounting having to repeat their story over and over due to lack of continuity and sharing of health records.

Conclusions

The findings from this work broadly align with the aims of the local STP in terms of assisting people to make the right choices about their health and to have services integrated so that all the needs of the individual are considered together.

Respondents to the survey on how the NHS and social care services can be better, highlight the need for timely access to help and treatment, joint decision making between the individual and health care professionals and a sense of being listened to. Services should enable them to stay in their own home if it is safe to do so.

Technology should enable individuals to access health care professionals from any location and patient's data should be securely held. It was important for Individuals to access and edit their own records but there was lack of confidence in managing their data in other ways.

In response to the survey on specific conditions, some, mainly those with heart and lung disease and long term physical conditions, had positive experiences with the help and support meeting their needs; but those with mental health conditions felt the help and support available did not meet their needs. There was significant delay in initial assessment, treatment and ongoing support across all conditions.

Participants in the focus group supported the findings of the surveys, highlighting disparity in experiences depending on medical diagnosis. Participants also felt that future service provisions should give real and transparent choices, flexibility in care provisions, and support from health care professionals to be independent and stay healthy.

Overall, there was an overriding theme for the integration of health and social care needs to ensure continuity of care.

Limitations

Although the general survey received a large number of responses, the majority of respondents were of similar demographic when it came to ethnicity and religion. Therefore, comparing the results by these characteristics provided little insight. When comparing data by gender or age, there were no significant differences to note.

It is also worth noting, that the surveys collected data on the County people lived in, but not which town or city, so the results cannot be looked at specifically in this way. Lastly the timescales of the project presented its own challenges, particularly with hearing from seldom heard groups through focus groups settings.

Response from STP

“We very much welcome the findings of the Healthwatch report, which raises a number of issues that are critically important to people’s experiences of health and social care in Hertfordshire and west Essex. To secure a healthier future for residents and develop high quality, sustainable services, we must work in partnership with the people we serve. We will ensure that the report is shared with the clinicians and professionals responsible for transforming services across our area and ask them to respond to its findings and conclusions.”

Beverley Flowers, Joint STP Lead Officer

“We can’t successfully transform health and care services without involving the people who use them.

We continue to work together with patient and Healthwatch representatives across many areas of health and social care delivery including the development of the ‘Personalisation’ agenda - an approach which seeks to focus services around the aims and goals of individuals.

The recent establishment of Primary Care Networks (PCNs) has been a major step forward to improve local services. By encouraging GP practices to work more closely together in groups,

together with other health and care staff in their local area, PCNs will be able to provide more proactive, personalised, coordinated and joined-up health and social care.

We all have our part to play in turning around the focus of the health service and social care from ‘rescuing’ us when we are ill or become dependent to supporting and encouraging us to stay well and maintain our independence. As individuals, we need to do whatever we can to take responsibility for our health and wellbeing whenever we can, supporting our friends and families to do the same.”

Denise Boardman, STP Director Lead for Primary Care

Acknowledgements

We would like to say a big thank you to the public and participants who provided their views, comments and experiences. As well to all our partners who supported us by sharing the surveys, and helping us to recruit for the focus group. Also, thank you to the STP for their ongoing commitment to the project and to hearing the views of the public.