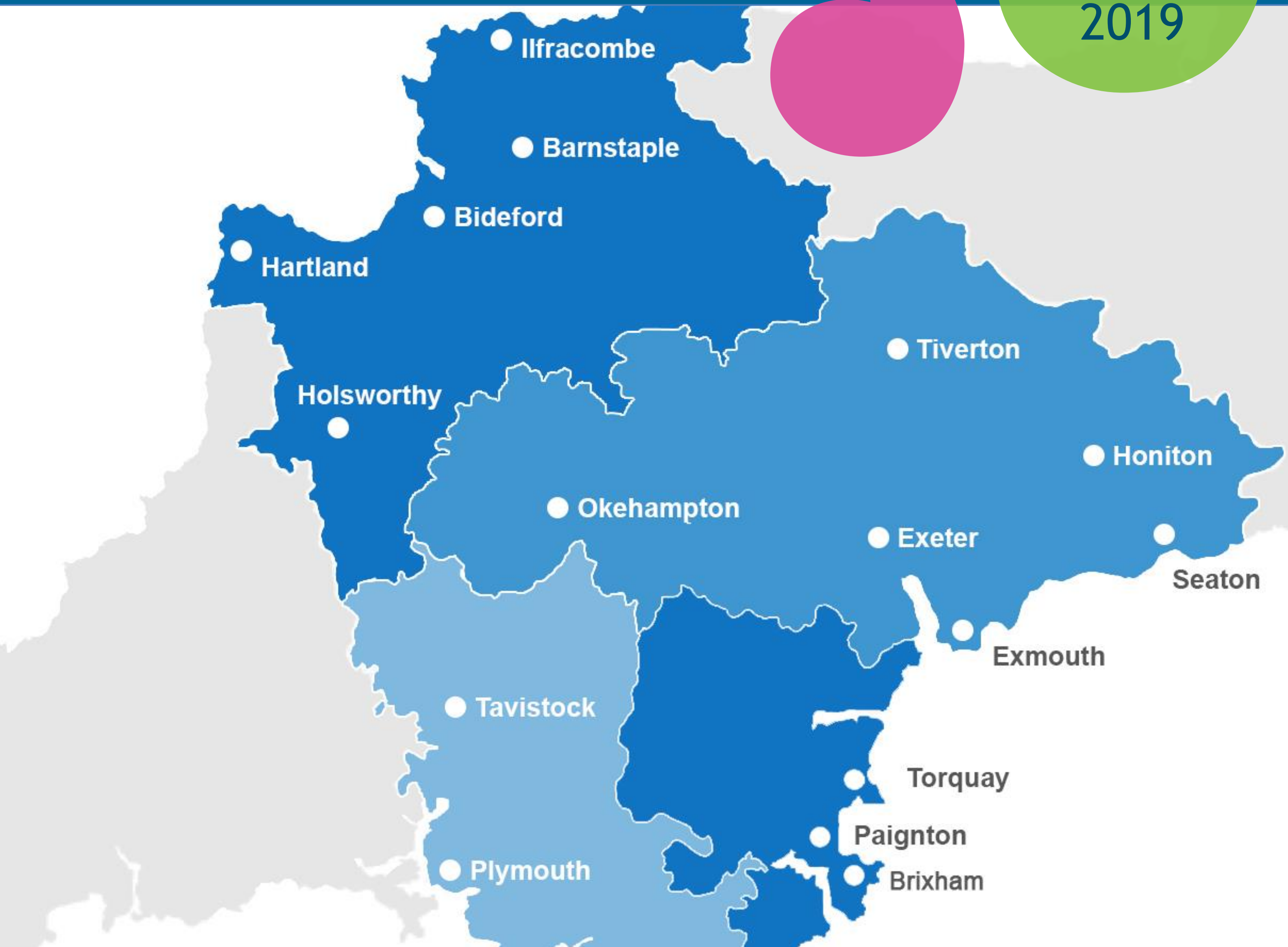
healthwatch Torbay healthwatch Plymouth healthwatch Devon

NHS Long Term Plan
What would you do?

May 2019



Contents

Executive Summary

Healthwatch England (HWE) commissioned local champions Healthwatch Torbay, Plymouth and Devon to engage with our local population and service providers to gather their views about the NHS Long Term Plan.

We used two methods; **focus group workshop sessions** in the local community and two different **surveys** developed nationally by NHSE - a **generalised survey** and a **specific condition survey**.

In total, there were **540** general survey responses, **221** specific condition survey responses, and **170** attendees on the focus group workshops across Devon – **nearly 1,000 people**. Of the survey respondents, the majority (66%) were aged over 55, female (65%) and 'White British' (92%).

The following is a brief summary of the key themes and issues discussed for each of the open-ended questions for both the NHSE surveys and the focus groups, categorised by the three NHSE priority areas for the future: **Prevention**, the **role of the community** and **Technology**.

Prevention

- Respondents would like to see the NHS focus on preventative medicine and early detection of illness.
- Patients in Devon would like to see a reduction in the time they wait to see their GP or receive a referral.
- Patients said they would benefit from greater continuity of care and the opportunity to be treated by the same staff when possible, with many emphasising the importance of building trust and rapport with staff.
- Many respondents felt that the NHS would benefit from better communication between services, allowing a more integrated or holistic approach to their treatment.
- Patients feel that their medical treatment should be a joint decision made in partnership with staff, and that information should be made more easily available in order to support them in making their choices.
- Having access to domiciliary or locally-based care is of high importance to many, however respondents have concerns about the accessibility and quality of care in their area. These concerns are exacerbated by a lack of public transport in areas of Devon.
- Respondents are concerned about the quality and affordability of local residential homes.
- Autism, dementia, and mental health respondents reported the least satisfaction from their experience of care, reporting long waiting times and difficulty accessing support. Overall, cancer respondents reported the shortest waiting times and easiest access to support.

Role of the Community

- Focus group responses of patients with specific conditions (e.g. dementia, heart and lung diseases, and cancer) showed that patients with dementia had a more negative overall experience than those with cancer or heart and lung diseases.

- Focus group participants talked about the importance of mental health awareness and overcoming the stigma of the condition in receiving diagnosis and treatment.
- Many are concerned about access to resources in the local area, with those in rural areas describing difficulties in travelling to GP and hospital appointments.
- Adequate end-of-life planning is important to people in Devon. However, many respondents expressed concerns about the current quality of end-of-life care in the NHS; some mentioned the negative experiences of relatives or spouses.
- Cancer services showed that the emphasis on the responsiveness to their needs have made a significant improvement when compared to other conditions. On the whole Cancer and Heart & Lung experienced effective follow through of care, whereas people with Dementia did not. In this latter category responses were more often provided from a carer perspective.

Technology

- People in Devon would like to see improvements in the use of technology and online services. Many would like to see more of their GP services available online, particularly the ability to view their full, unabridged medical record.
- However, multiple respondents expressed concern that their local services are too reliant on online services, often at the expense of the elderly or those who cannot use or access a computer. It is important to many in Devon that GP services remain accessible to those who have difficulty using the internet.
- Focus group responses of patients with specific conditions (e.g. dementia, heart and lung diseases, and cancer) also expressed anxiety about a future where personal contact is replaced by technology.
- People in Devon consider timely and consistent communication to be very important
- Patients have concerns about the management and security of their personal data.

Other feedback

Most of the key themes covered in this report - such as: waiting times, continuity of care, NHS funding and resources, patient-staff communication, the closure of local services, and promotion of preventative care – are echoed throughout the Appendix feedback. There were also many comments about the quality of the questionnaire itself, with some feeling that it did not give them the opportunity to answer questions fully or honestly.

The views we gather will feed into the development of the NHS’s local plan explaining how they will deliver the priorities set out in the NHS Long Term Plan. This report shows what people have told us. The NHS will explain how they have responded to these views in the plans they produce.

Background

In early 2019, national health & social care consumer champion Healthwatch England (HWE) secured funding from NHS England (NHSE) for local Healthwatch to support public engagement and contribute to local development plans for the 10 Year Forward View. The NHS Long Term Plan is drawn up by frontline staff, patients groups, and national experts to outline how the NHS will move forward to meet the changing health & wellbeing needs of the population over the next 10 years.

Healthwatch England (HWE) commissioned local champions Healthwatch Torbay, Plymouth and Devon to engage with our local population and service providers to gather their views about the NHS Long Term Plan. There are nearly 1.2 million people living in our region, with an estimated average age of 43.5 years, higher than the national average (40).

In addition to the main engagement work, Healthwatch Torbay was also commissioned by HWE to be the coordinating local Healthwatch (for Torbay, Plymouth and Devon) in our local Sustainability and Transformation Partnership (STP) area. We worked in collaboration with our neighbouring Healthwatch and our STP Engagement Leads to ensure effective engagement in the wider Devon area. This included planning group meetings to review the NHSE Surveys, plan engagement, media and marketing activities and to identify and agree on the priority areas within the Devon STP footprint.

Our aim was to give people the opportunity to have their say on how the national plan is delivered locally in the future. The views we gather will feed into the development of the NHS's local plan explaining how they will deliver the priorities set out in the NHS Long Term Plan. This report shows what people have told us. The NHS will explain how they have responded to these views in the plans they produce.

Please note: For the purposes of this report, 'Devon' refers to feedback gathered from all three local Healthwatch - Torbay, Plymouth and Devon.

Methodology

To find out what local people thought about the NHS Long Term Plan and to enable us to feed this back to HWE, our local STP and NHS England (NHSE), we used two methods; **focus group workshop sessions** in the local community and **surveys** developed nationally by NHSE. The surveys included both a **generalised survey** asking what the NHS could do to help ‘you and your community stay well and provide better support’ and a **specific condition survey** asking what the NHS could do better to support people with specific conditions such as cancer, heart and lung diseases, and long-term conditions.

It was mutually agreed that the ‘specific condition’ workshops should focus on heart & lung and cancer services. Our STP Leads then provided further funding for all three local Healthwatch to undertake an additional focussed workshop in each area on dementia. These focus areas were decided by the STP because of the lack of recent engagement in these areas and the acute services review were in the next stage of the engagement for the STP process. To provide a coordinated response, the planning group agreed a framework to use across the Devon STP area, which focussed on the NHSE priority areas for the future: **Prevention**, the **role of the community** and **Technology**.

NHSE surveys and focus group workshop dates were shared via social media, e-news, Healthwatch websites, local newsletters, plus carers and community networks to ensure the community had an opportunity to share their views.

Detailed General Survey Analysis *(Appendix 2)*

The national Healthwatch England general survey was promoted across Devon to give an indication of the thoughts and experience of people of all ages across the county. As the survey was of a substantial size, we are especially grateful to those who responded to share their views and stories of managing their life with a chronic health condition.

In total, there were 540 general survey responses. The survey consisted of both multiple-choice questions (respondents presented with statements and asked to rate their level of agreement) and open-ended questions which allowed respondents to elaborate on their answers.

Demographics of general survey respondents *(Appendix 5)*

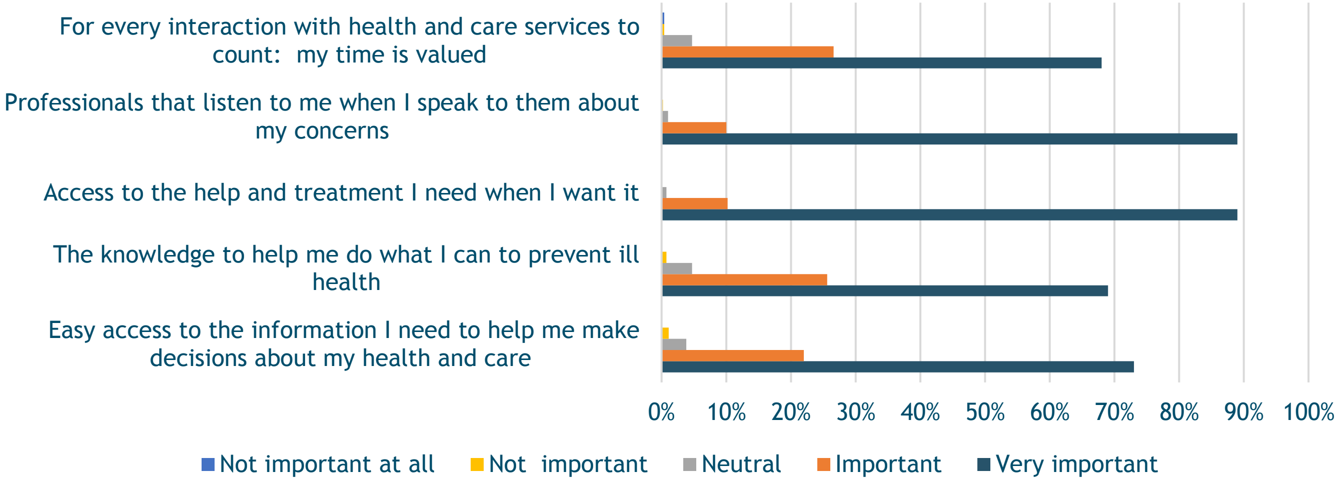
- The significant majority of respondents (70%) were aged over 55
- 93% classed themselves as 'White British'
- 63% of respondents were female and 33% male
- 29% of respondents considered themselves to have a disability
- 56% said they had one or more long term health condition

The following section of the report will discuss the questions and responses in detail.

What matters to you to live a healthy life? (Questions 3a, 3b & 7)

A series of "I" statements were presented, these were questions designed to focus individuals on their own personal needs and requirements (e.g. Having what I need to live a healthy life), and how important they rated each. Overwhelmingly **all were rated as either 'Very Important' or 'Important' for around 90% of responses**.

Question 3a. Having what I need to live a healthy life

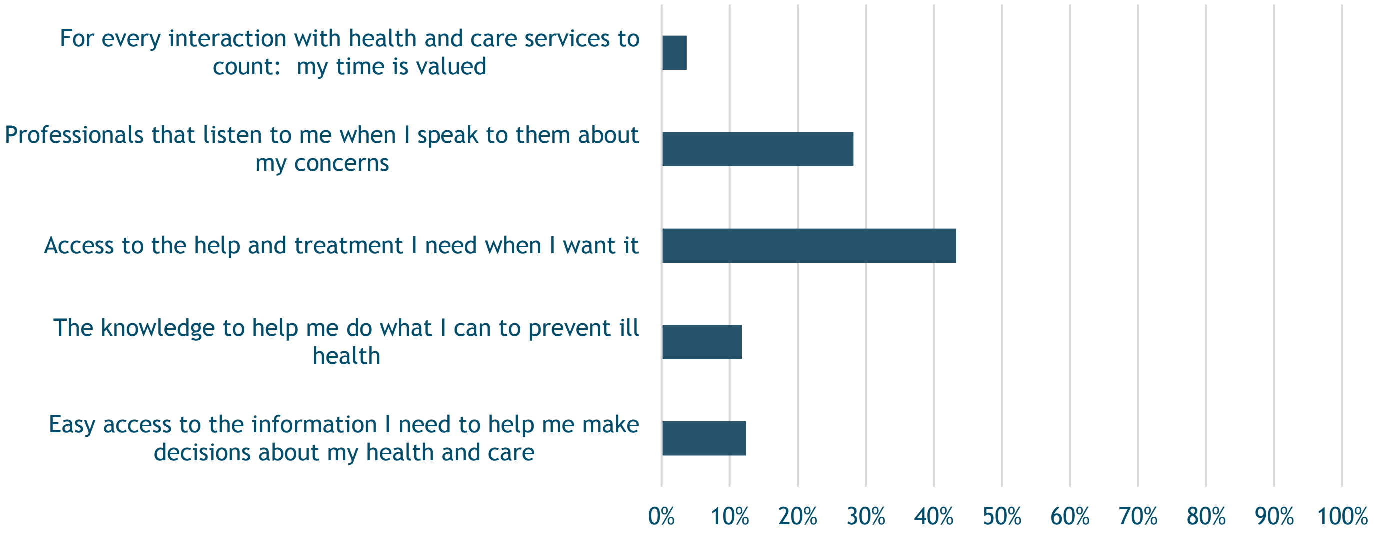


In order of "very important" the choices are: *(in order)*

- Access to the help and treatment I need when I want it – 89%
- Professionals that listen to me when I speak to them about my concerns – 89%
- Easy Access to the information I need to help me make decisions about my health and care – 73%
- The knowledge to help me do what I can to prevent ill health – 69%
- For every interaction with health and care services to count: my time is valued – 68%

This outcome was confirmed when asked to pick only one as the 'most important':

Question 7. What is most important to you to help you live a healthy life?



In order of "very important" the choices are: *(in order)*

- Access to the help and treatment I need when I want it – 43.3%
- Professionals that listen to me when I speak to them about my concerns – 28.2%
- Easy Access to the information I need to help me make decisions about my health and care – 12.4%
- The knowledge to help me do what I can to prevent ill health – 11.8%
- For every interaction with health and care services to count: my time is valued – 3.7%

When asked to offer any other key success factor the following suggestions were made:

(Question 3b – free text question)

Preventative medicine

Respondents feel that the NHS and patients would benefit from emphasis on preventative measures and early detection of illnesses. Patients sometimes feel they are wasting doctors' time when they seek advice on preventative measures. Multiple respondents suggested that there should be annual general health check-ups.

Continuity of care and integration of services

Patients feel they would benefit from greater continuity in their care, better communication and integration between services that treat them, and taking a more holistic approach to health issues (e.g. considering other factors that may aggravate a health issue, such as mental health and lifestyle factors). Respondents feel that healthcare services should be "singing from the same sheet" (#255.)

Intermediate medical care

Patients may need advice from a medical professional even when an issue does not warrant a GP appointment. One respondent says they would like to speak to someone not "trained to read a tick list" and feels this would reduce the need for unnecessary appointments (#193). Patients wish it was easier to contact staff for advice.

Waiting times and access

Many respondents say they struggle to access the services they need (rural areas, lack of transport, services being closed/defunded) and often deal with long waiting times. Multiple respondents mentioned issues with referrals and felt they would benefit from self-referral services.

Resources, staffing, and funding

Respondents feel that services are underfunded and understaffed and some feel they would benefit from having more local services – not having to travel to Exeter, for example. Multiple respondents from North Devon mentioned the inconvenience of travelling to Exeter for treatment.

Staff attitudes

Some respondents feel that they are not listened to or believed when they report health issues or seek advice.

Food and diet

Respondents felt that there could be better information available about nutrition and healthy eating, and that the food industry could be better regulated so the public are more aware of the health impact of eating processed, refined, and unhealthy foods. Respondents felt their health would improve if healthy eating was easier and more convenient.

Education, information, and advice

Respondents feel they would benefit from more information and advice about health and wellbeing.

Transport and travel

Respondents feel they would benefit from travelling less by car and by walking or cycling more often; respondents wish there were more cycle and footpaths. Other respondents also commented that fewer cars on the road would lead to less pollution and better air quality.

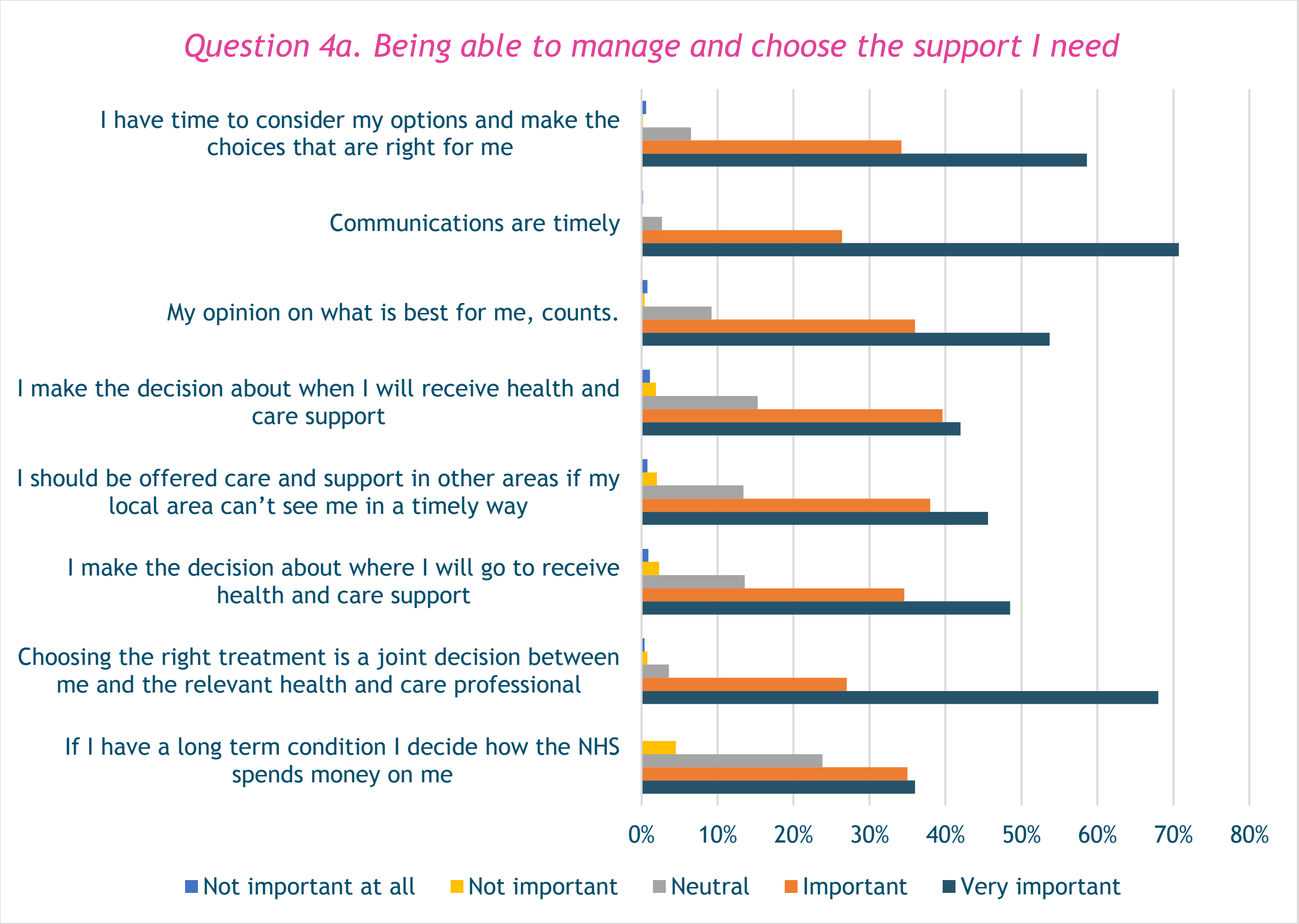
Community support

Multiple respondents felt they would benefit from services and support from their local community. More than one respondent mentioned "social prescribing."

What matters to you to manage and choose support? *(Questions 4a, 4b & 8)*

A series of "I" statements were presented to clarify priorities. **Over 80% consider all these statements as 'important' or 'very important'** but with less certainty in stating "very important".

There is less concern about having a personal decision on funding. Choosing treatment in partnership with the professional and timely communication has the highest level of confirmation. Overall there is less certainty about the individual taking the lead decision.



In order of "very important" the choices are:

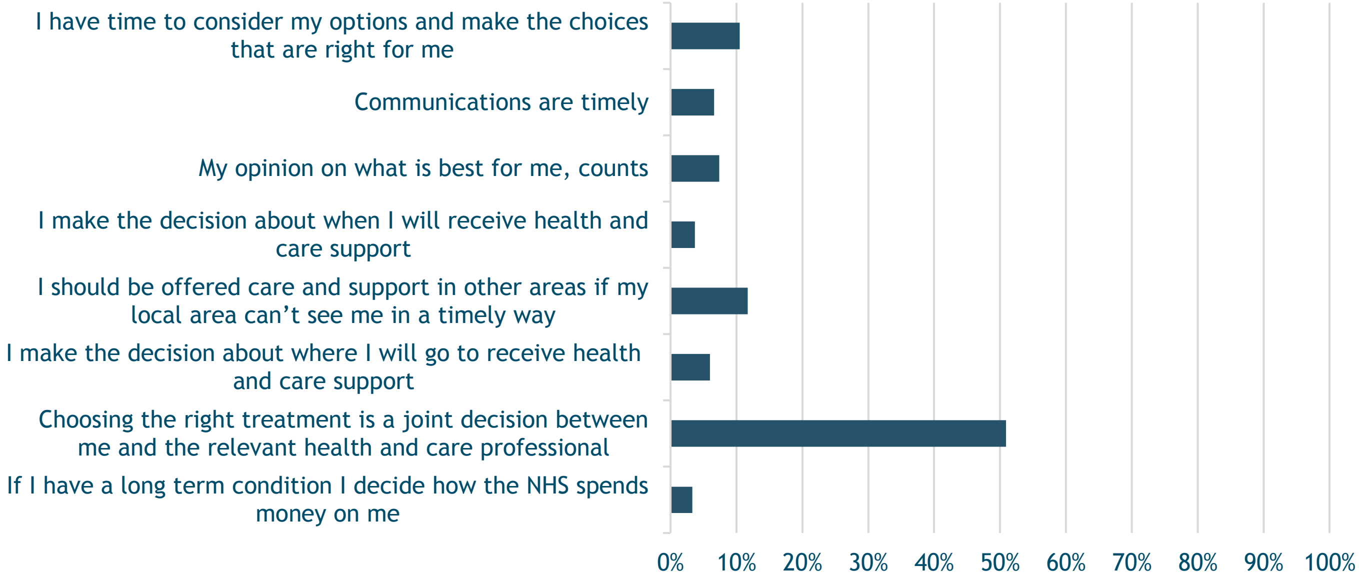
- Communications are timely – 70.7%
- Choosing the right treatment is a joint decision between me and the relevant health and care professional – 68%
- I have time to consider my options and make the choices that are right for me – 58.6%
- My opinion on what is best for me, counts – 53.7%
- I make the decision about where I will go to receive health and care support – 48.5%
- I should be offered care and support in other areas if my local area can't see me in a timely way – 45.6%
- I make the decision about when I will receive health and care support – 42%
- If I have a long term condition I decide how the NHS spends money on me – 36%.

When respondents were asked to select which factor was most important, there was a clear preference for the "I" statement **"Choosing the right treatment is a joint decision between me and the relevant health and care professional,"** which was rated most important by 50.9% of respondents.

This was followed by "I should be offered care and support in other areas if my local area can't see me in a timely way", which received 11.7% of all votes. **The lowest rated statement was "If I have a long term condition I decide how the NHS spends money on me"**, which received 3.3% of the votes.

When asked to pick one, only a similar picture was presented, again with *'how to spend funding'* the least relevant. This may reflect lack of knowledge about the question presumably being relevant to an increase in the use of Personal Budgets.

Question 8. What is most important to you to be able to manage and choose the support you need?



When asked to offer one more thing that would help in managing and choosing support, 'resources and funding' came forwards in the discussion. Responses covered:

(Question 4b – free text question)

Resources, funding, and local access

Many respondents feel they would benefit from having access to more resources in their local area. Many also feel that NHS funding is an issue.

Communication with patients

Respondents mention that they would like better and more efficient communication between patients and healthcare staff.

Information

Multiple respondents wished that the NHS made more information publically available about health, treatment, and healthcare options.

Continuity of care/integration and communication between services

Respondents mentioned that they would like to see their regular or named GP more often, and that the NHS would benefit from better integration and communication between different services and departments.

Waiting times and access

Many respondents said they felt waiting times could be shorter and that they would like to have quicker and easier access to their GP or specialist services.

Staff attitudes

Some respondents felt that staff are dismissive of their concerns or have bad attitudes towards patients.

Preventative medicine

Multiple respondents felt they would benefit from preventative measures and treatments.

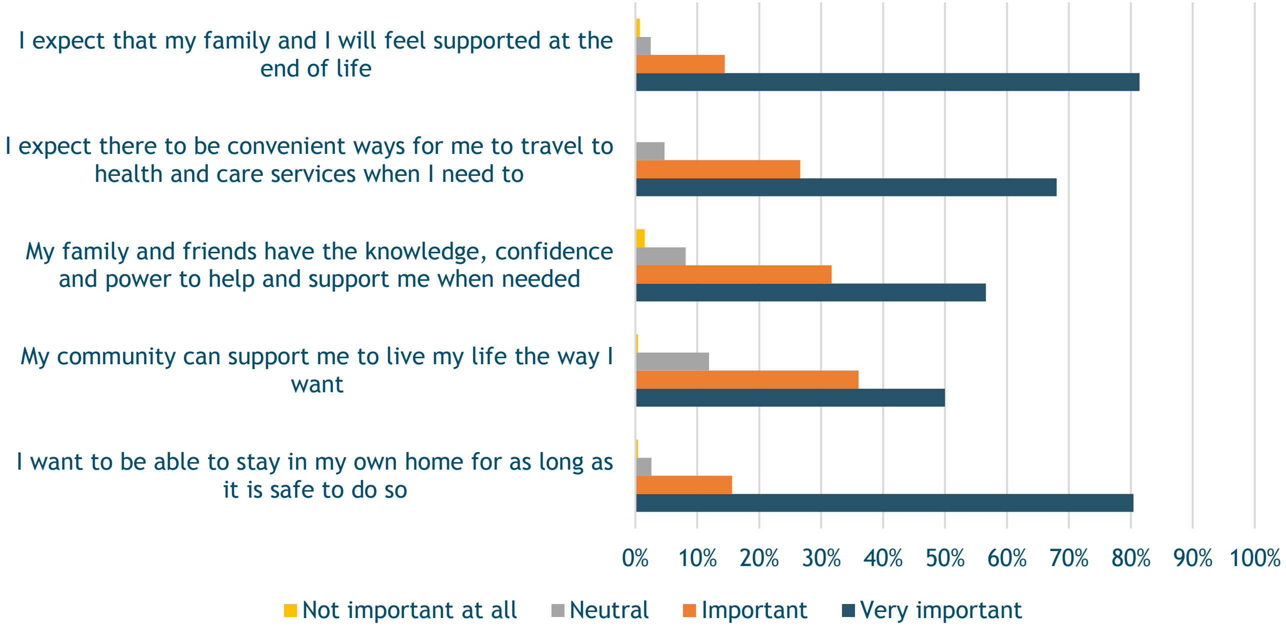
The help I need to keep my independence and stay healthy as I get older

(Questions 5a, 5b)

Over 80% rated all the offered “I want” statements to be ‘important’ or ‘very important’. **Staying at home for as long as it is safe to do so and my family being supported at the end of life has the highest importance.** Apparent reliance on family and friends was less certain.

Although travel convenience is important the response showed acceptance that this was not going to happen at all times. Reliance on the local community was not rated highly and may reflect the variation in community support from local organisations across the county.

Question 5a. Keeping my independence as I get older



In order of “very important” the choices are:

- I expect that my family and I will feel supported at the end of life – 81.4%
- I want to be able to stay in my own home for as long as it is safe to do so – 80.4%
- I expect there to be convenient ways for me to travel to health and care services when I need to – 68%
- My family and friends have the knowledge, confidence and power to help and support me when needed – 56.6%
- My community can support me to live my life the way I want – 50%

When asked to choose one their most important statement similar priorities were given.

When asked to offer one more thing that would help in keeping independent and living healthily for as long as possible the following suggestions were made:

(Question 5b – free text question)

Local/home care and support

A large number of respondents felt they would benefit from domiciliary and locally-based care. Many expressed concerns about the accessibility and quality of care and support in their local area. Having access to services locally is of high importance to many respondents. Respondents also expressed concerns about the quality and cost of retirement/nursing homes.

Transport

For many respondents, concerns about lack of local care and support are exacerbated by a lack of accessible public transport. Many respondents said that better access to transport would help them live healthily and independently, prevent loneliness, and enable them to access many of the services they need.

End of life care

Multiple respondents believe that end-of-life planning would give them peace of mind. Many were concerned about the current quality of end-of-life care in the NHS. Many respondents who mention end-of-life care imply or outright state that they would like the option of legally assisted suicide.

Socialising and combatting loneliness

There was considerable concern that loneliness generates ill health.

Resources, funding

Responses reflected the belief that the NHS and social care is underfunded.

Communication with healthcare professionals

This included the value give to talking to “real people” and the frustration of apparent un-coordination of information about the individual.

Information, advice, and guidance

These responses confirmed the diversity in information sources and the lack of co-ordination.

Carers

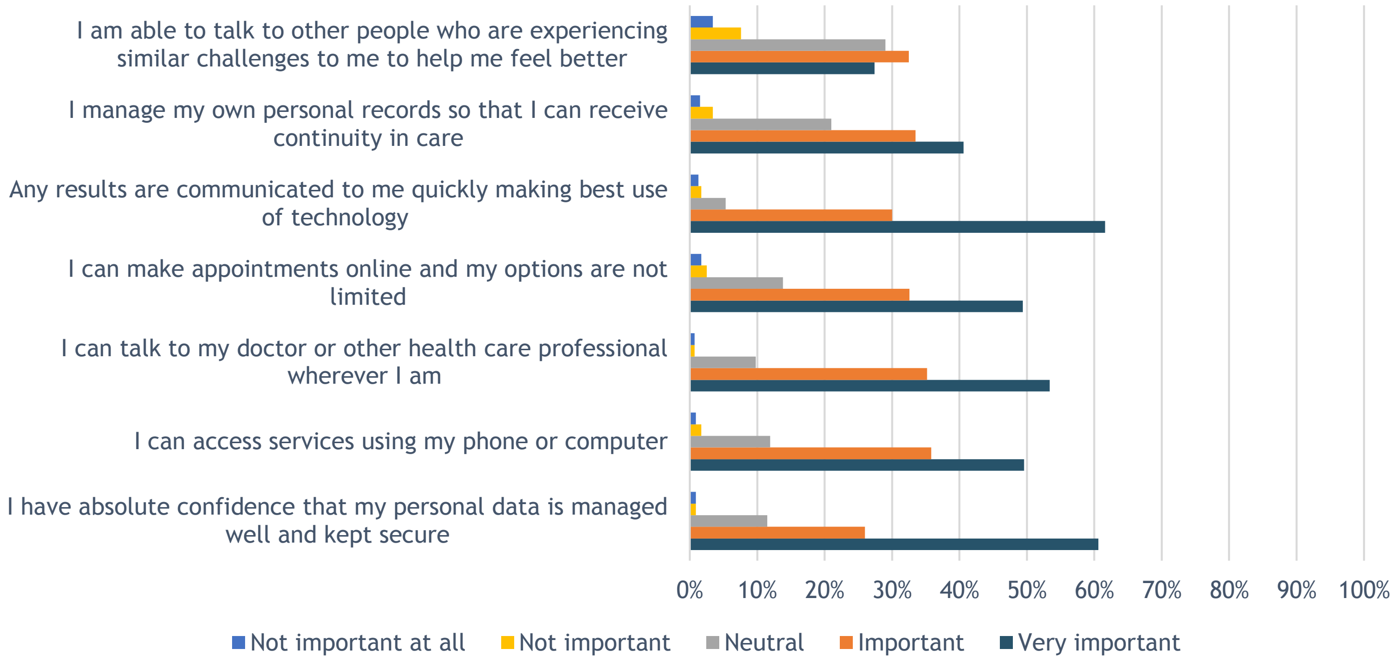
These responses clearly recognised the value of family and friends as carers to support independence, but by doing so recognised the impact of caring stress on that person.

How you interact with your local NHS: How important when it comes to keeping your independence and ageing healthily? (Questions 6a, 6b, 10 & 11)

Although all but one of the "I" statements are above 70% in total importance, **the responses are acknowledging lack of confidence in the areas explored especially in the use of information technology to support health and wellbeing.**

The weakest response is willingness to speak to other people with similar challenges. As we have noted that self-help condition specific support groups tend to discourage sharing of condition related experience, this may point to the need for an increase in use of professionally led Peer support groups in the community.

Question 6a. Interactions with my local NHS



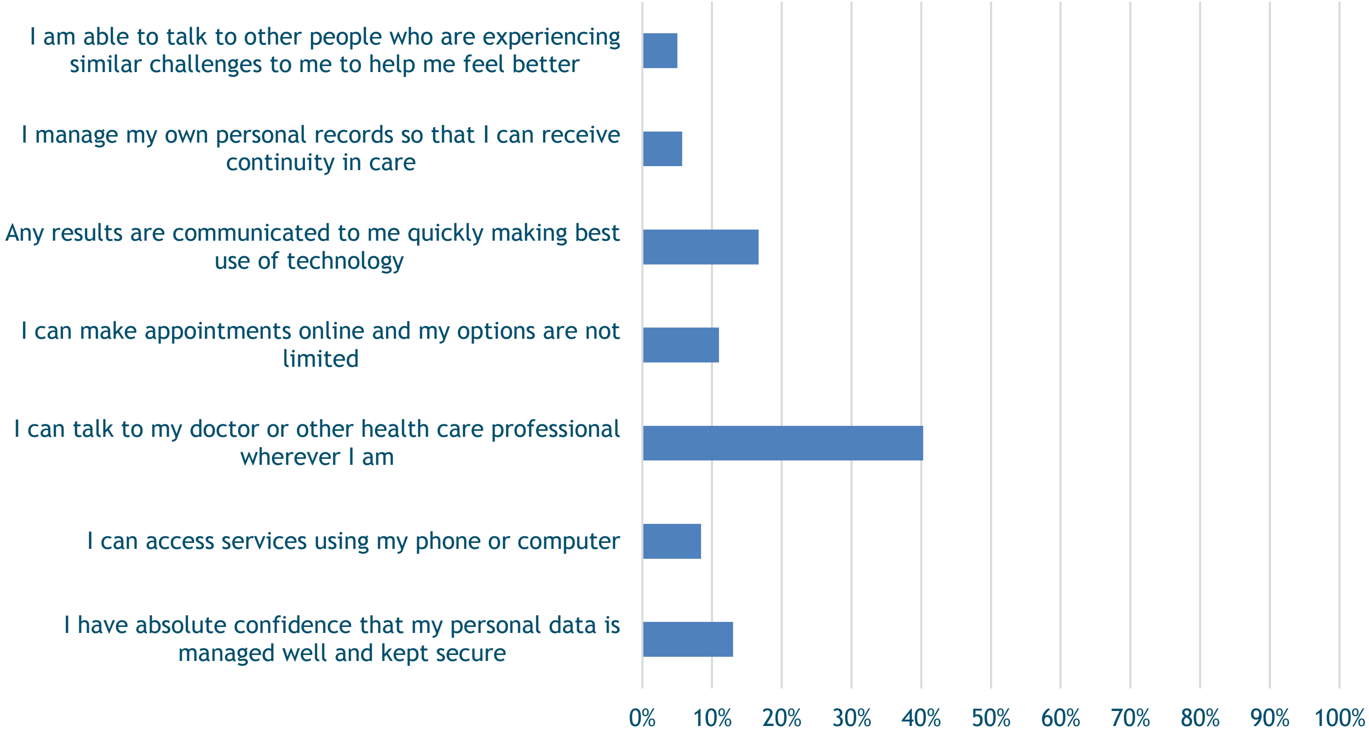
The order of responses stating "very important" for the "I" statements are:

- Any results are communicated to me quickly making best use of technology – 61.6%
- I have absolute confidence that my personal data is managed well and kept secure – 60.6%
- I can talk to my doctor or other health care professional wherever I am – 53.4%
- I can access services using my phone or computer – 49.6%
- I can make appointments online and my options are not limited – 49.4%
- I manage my own personal records so that I can receive continuity in care – 40.6%
- I am able to talk to other people who are experiencing similar challenges to me to help me feel better – 27.4%

When asked which single statement was most important to them, similar results were found. The top three rated statements remained the same, although "I can talk to my doctor or other health care professional wherever I am" received the highest rating by far, at 40.3%.

By contrast, the quick communication of results and confidence in the security of personal data received 16.7% and 13% of votes respectively. Consistent with the previous results, the lowest rated statement was "I am able to talk to other people who are experiencing similar challenges to me to help me feel better," which received 7% of votes.

Question 11. What is most important to you when interacting with the NHS?



When asked to add one more thing to help you to successfully manage your health and care responses included: *(Question 6b – free text question)*

Improvements in online services & technology

Many respondents said they would like to see more of their GP services available online, such as the ability to view their medical history. However, some are also concerned that their local services are too reliant on online services, at the expense of the elderly or those without consistent access to the internet. For many, it is important that GP services remain accessible for those who cannot use online services. One respondent (#88) described difficulty in accessing online services without a valid photo ID.

Waiting times & access to GP services

Multiple respondents said they would like shorter waiting times, particularly for GP appointments. Many said that struggle to see their GP when they would like.

Continuity of care

Respondents felt that communication between different services and departments could be improved, and that there should be greater integration between services; some respondents said that they have to explain their medical history every time they see a new doctor or nurse. Many said they would like to see the GP more often.

Access to medical records

Many respondents felt they would benefit from having online access to their medical records. Some respondents who already have this access said that they would like to see their full record, and not an edited version. However, one respondent (#505) expressed concern that the sharing of unabridged medical records may lead to unnecessary anxiety for patients who are not trained to interpret the results, putting further strain on GP practices.

Specific Conditions Survey Analysis

(Appendix 3 & 4)

In total, there 221 specific condition survey responses. The survey consisted of both multiple-choice questions (respondents presented with statements and asked to rate their level of agreement) and open-ended questions which allowed respondents to elaborate on their answers.

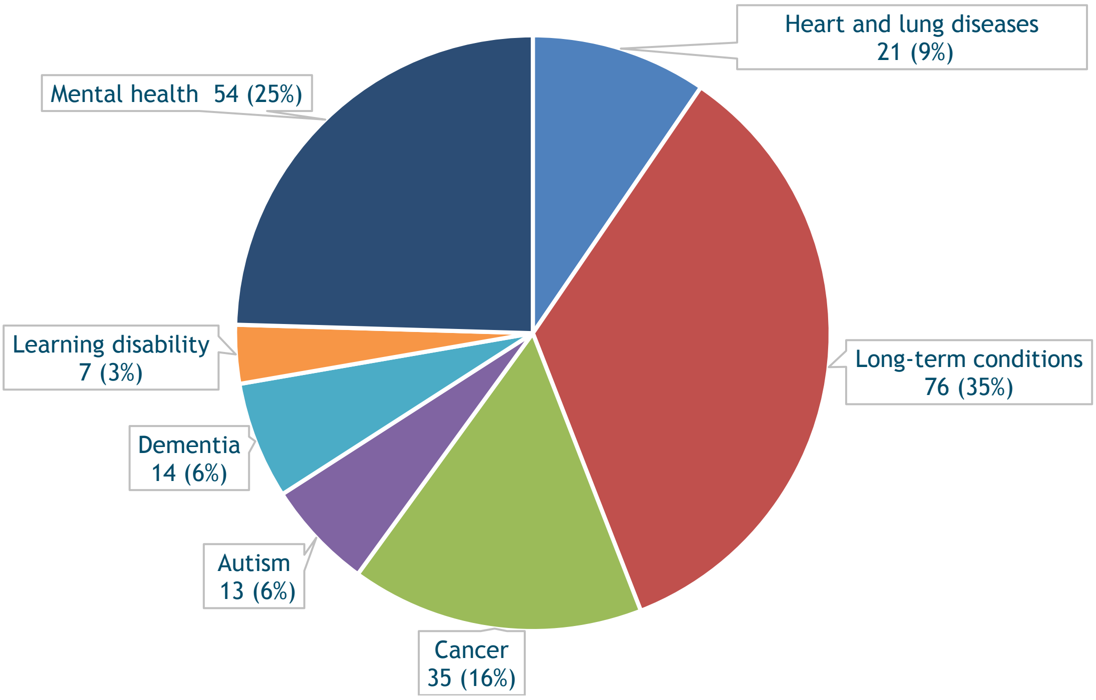
Demographics of specific condition survey respondents *(Appendix 5)*

- The majority of respondents (55%) were aged over 55
- 87% classed themselves as 'White British'
- 68% of respondents were female and 24% male
- 52% of respondents considered themselves to have a disability
- 27% said they were a carer

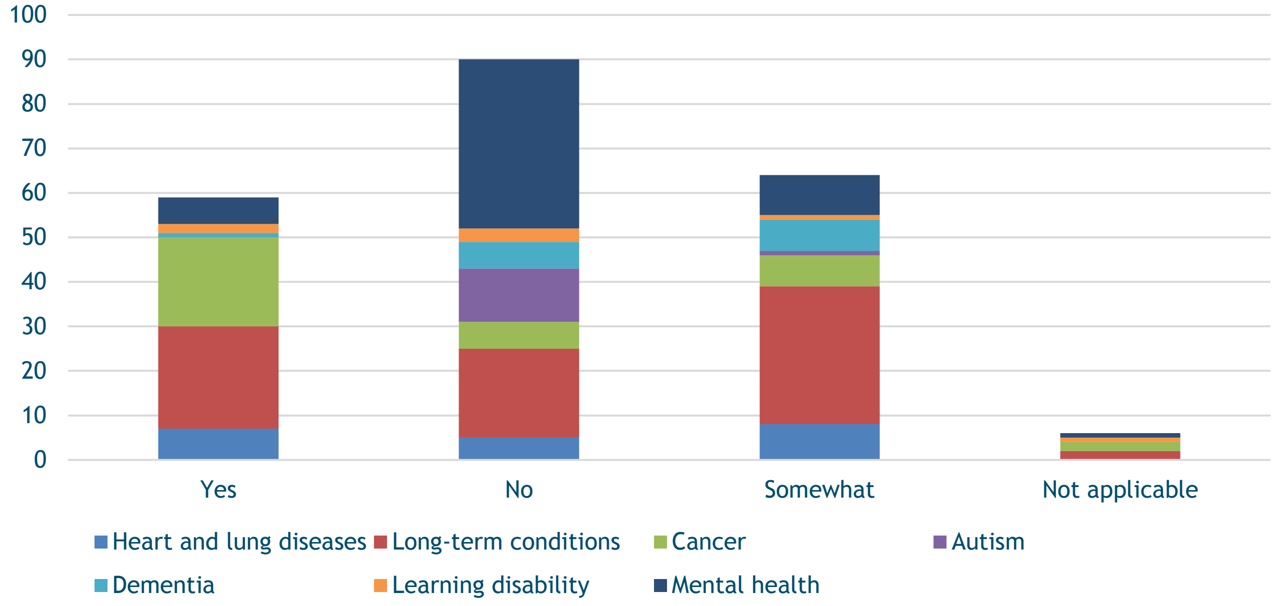
The following section of the report will discuss the questions and responses in detail.

Please select the condition you would like to tell us about *(Question 3)*

220 people answered this question. Those with long-term conditions comprised the largest group of respondents at 76 (35% of respondents). The second largest group was those with mental health conditions, with 54 respondents (21%). This was followed by heart and lung diseases (21 respondents, 9%), dementia (14 respondents, 6%), and autism (13 respondents, 6%). Those with learning disabilities comprised the small group, with 7 respondents (3%).



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



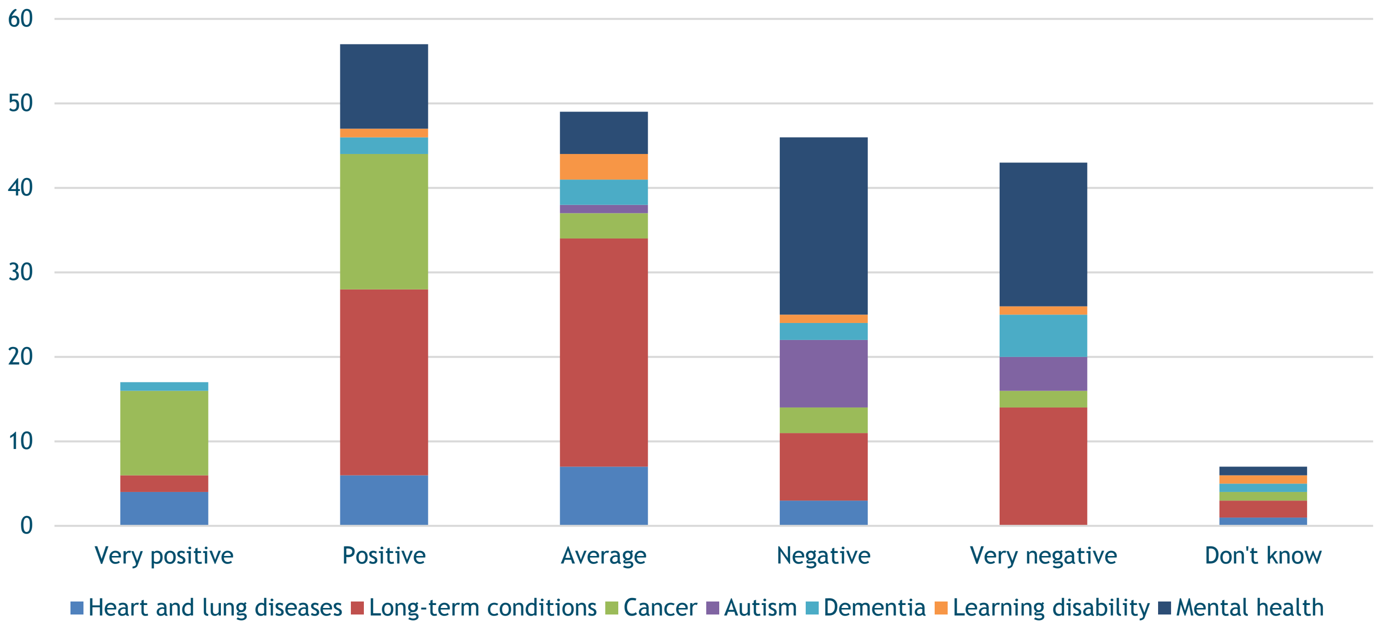
41.4% of respondents answered “no” to this question; this was the most common answer.

The group with the highest proportion of “no” responses were those with autism at 92.3%, followed by those with mental health conditions at 70.4%. This was followed by dementia (42.9%), learning disabilities (42.9%), long-term conditions (26.3%), and heart and lung diseases (25%). The group with the lowest proportion of “no” responses were those with cancer, at 17.1%.

26.9% of respondents answered “yes” to this question, and this was the least common response after “not applicable.” The group with the highest proportion of “yes” responses were those with cancer at 57.1%, followed by those with heart and lung diseases at 35% and those with long-term conditions at 30.3%. The lowest proportion of “yes” responses came from those with autism (0%), dementia (7.1%), and mental health conditions (11.1%).

29.2% of respondents answered “somewhat.” The highest rate of “somewhat” responses came from those with dementia (50%), followed by those with long-term conditions (40.8%), heart and lung diseases (40%), cancer (20%), mental health conditions (16.7%), learning disabilities (14.3%), and autism (7.7%).

How would you describe your overall experience of getting help? (Question 7)



Respondents with cancer reported the most positive experience overall; 74.3% of those with cancer described their experience as “positive” or “very positive,” 8.6% described their experience as “average” and 14.3% described it as “negative” or “very negative.” This was followed by those with heart and lung diseases; 47.6% of those in this category reported a positive experience, 33.3% reported an average experience, and 14.3% described a negative experience.

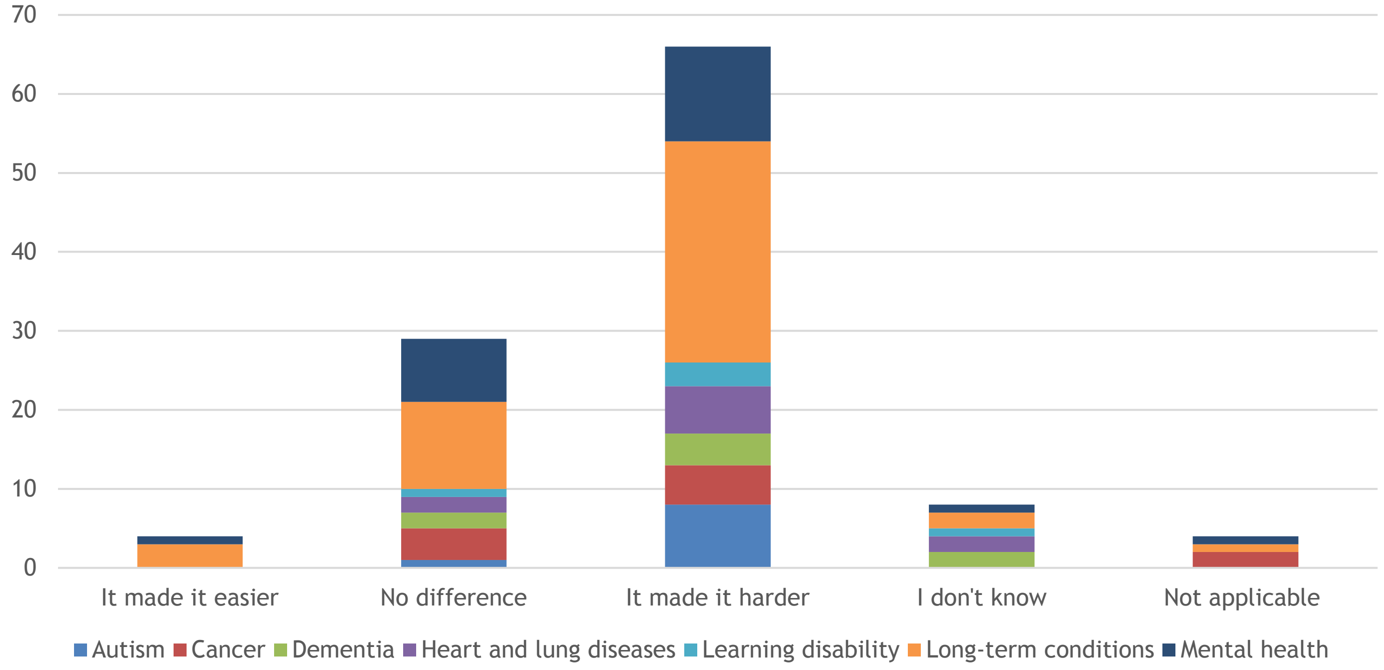
The most negative experiences were reported by those with mental health conditions and autism. 92.3% of those with autism described their experience as “negative” or “very negative,” 7.7% described their experience as “average,” and none reported a positive experience. 70.4% of those with mental health conditions reported a negative experience, 9.3% reported an average experience and 18.5% reported a positive experience.

Those with learning disabilities had the second lowest rate of positive responses (14.3%) but the highest rate of “average” responses (42.9%).

50% of those with dementia reported a negative experience compared to 21.4% who reported a positive experience.

Those with long-term conditions had the most mixed views; 36% reported an average experience, 32% reported a positive experience, and 29.3% reported a negative experience.

How would you describe your experience of seeking support for more than one condition at a time? (Question 9)



111 respondents answered this question (50.7%). **59.5% said that having more than one condition made it harder to get support.**

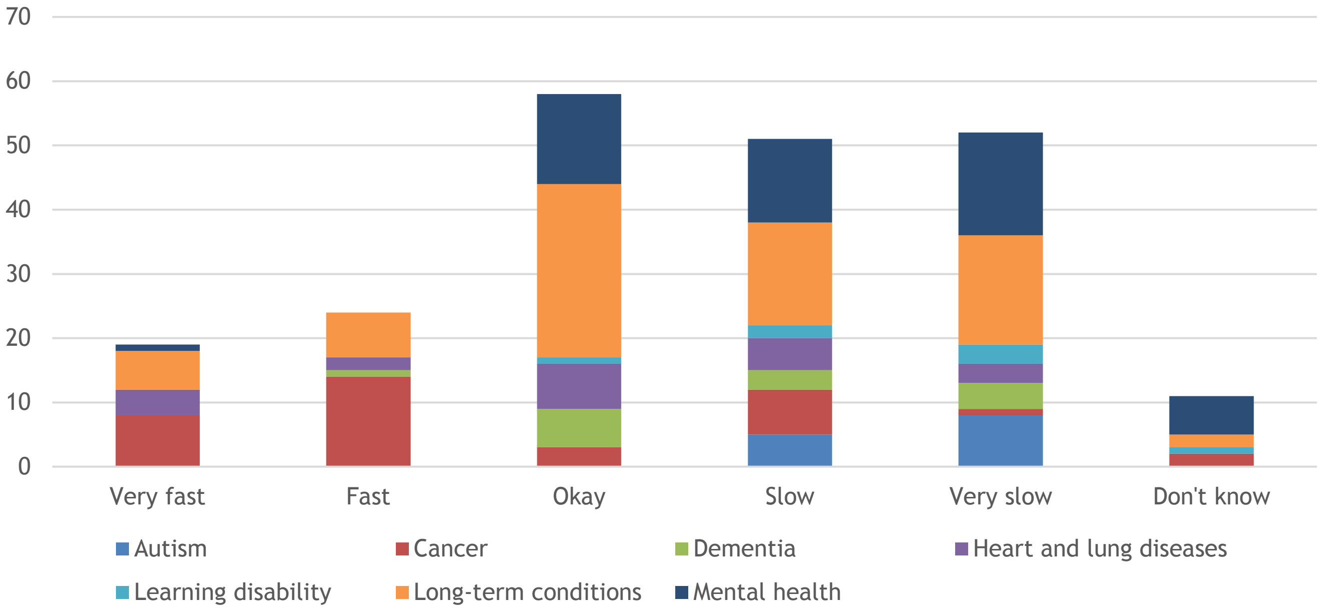
This included 88.9% of those with autism, 62.2% of those with long-term conditions, and 60% of those with heart & lung diseases and those with learning disabilities.

Only 3.6% of respondents said that having more than one condition made it easier to get support; this included 6.7% of those with long-term conditions and 4.3% of those with mental health conditions.

None of the respondents with autism, cancer, dementia, learning disabilities or heart and lung diseases gave this response.

26.1% of respondents said having more than one condition made no difference in seeking support; this included 36.4% of those with cancer, 34.8% of those with mental health conditions, 25% of those with dementia and 24.4% of those with long-term conditions.

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



Those with autism, learning disabilities, dementia and mental health conditions reported the longest waits.

100% of those with autism described their wait as “slow” or “very slow.”

This was followed by those with learning disabilities; 71.4% described their wait as “slow” or “very slow,” 14.3% described their wait as “okay” and none described their wait as “fast” or “very fast.”

58% of respondents with mental health conditions gave “slow/very slow” responses and only 2% gave “fast/very fast” responses.

50% of those with dementia reported a “slow/very slow” wait, 42.9% reported an “okay” wait and 7.1% described a “fast/very fast” wait.

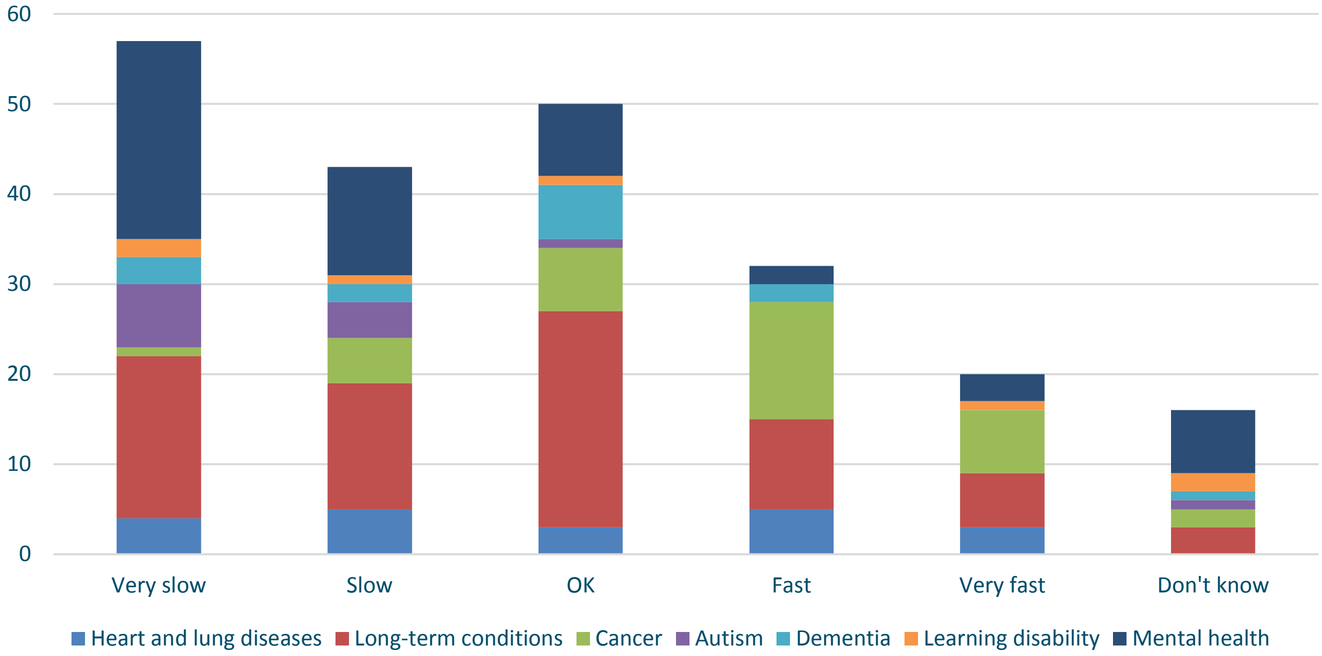
Overall, 47.9% of respondents described their wait as “slow/very slow.”

20% of respondents described their wait as “fast” or “very fast.” Those with cancer reported the shortest waits overall; 62.9% gave a “fast/very fast” response and 8.6% answered “okay.”

Those with heart and lung diseases had the most mixed experiences; 28.6% reported a “fast/very fast” wait, 33.3% described an “okay” wait and 38.1% described a “slow/very slow” wait.

Those with long-term conditions also reported mixed experiences which were overall more negative; 44% said their wait was “slow/very slow,” 36% said it was “okay” and 17.3% said it was “fast/very fast.”

How would you describe the time you had to wait between your initial assessment /diagnosis and receiving treatment? (Question 13)



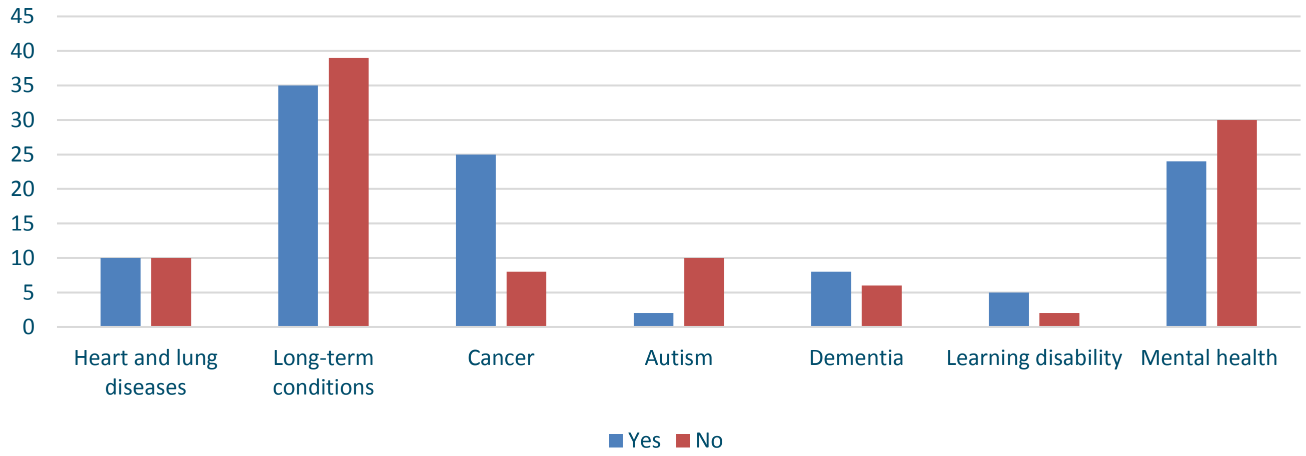
The most popular answer to this question was "very slow," which received 26.1% of votes.

The next most popular answer was "okay," which received 22.9% of votes. 19.7% of respondents described their wait as "slow." 14.7% described their wait as "fast" and 9.2% characterised it as "very fast." In total, 45.9% described their weight as "slow" or "very slow" compared to 23.9% who described it as "fast" or "very fast." 7.3% of respondents replied "don't know" to this question.

Those in the autism and mental health categories reported the longest waits, with 84.6% of respondents in the autism category and 63% of respondents in the mental health category describing their wait as "slow" or "very slow." None of the respondents in the autism category and only 9.3% of respondents with mental health conditions described their wait as "fast" or "very fast."

Respondents in the cancer category reported the shortest waiting times, with 57.1% describing their wait as "fast" or "very fast," and 17.1% describing their wait as "slow" or "very slow."

After being diagnosed or assessed, were you offered access to further health and care support? (Question 14)

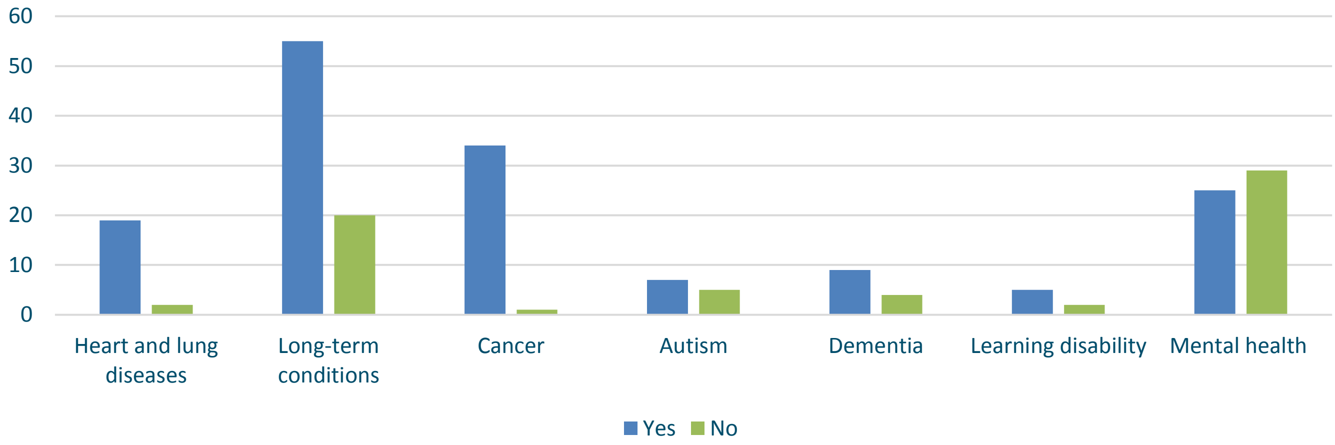


50.9% of respondents answered "yes" to this question and 49.1% answered "no."

The highest proportion of "yes" responses came from those with cancer (75.8%), followed by those with learning disabilities (71.4%), dementia (57.1%).

The lowest proportion of "yes" responses came from those with autism (16.7%), followed by mental health conditions (44.4%), and those with long-term conditions (47.3%).

Were you referred to a specialist? (Question 17)

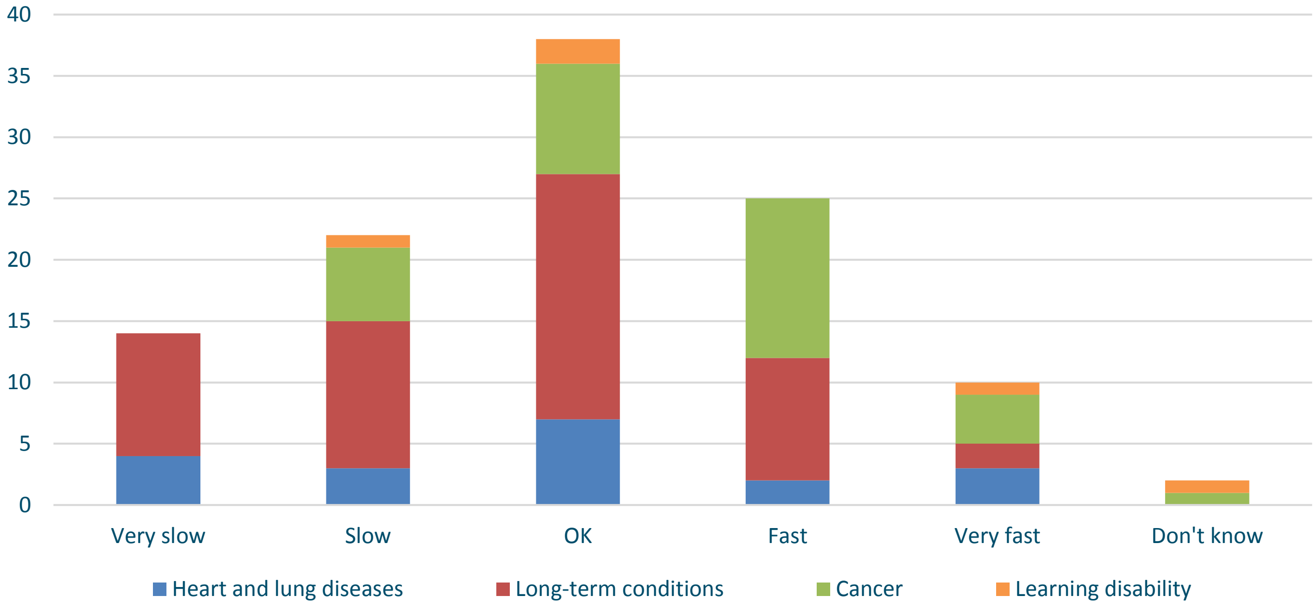


71% of respondents answered "yes" to this question and 29% answered "no."

The highest proportion of "yes" responses came from those with cancer (97.1%), followed by heart and lung diseases (90.5%), those with long term conditions (73.3%), those with learning disabilities (71.4%), and those with dementia (69.2%).

The lowest proportion of "yes" responses came from mental health conditions (46.3%), followed by those with autism (58.3%).

How would you describe the time you had to wait between the initial appointment and seeing the specialist? (Question 18)



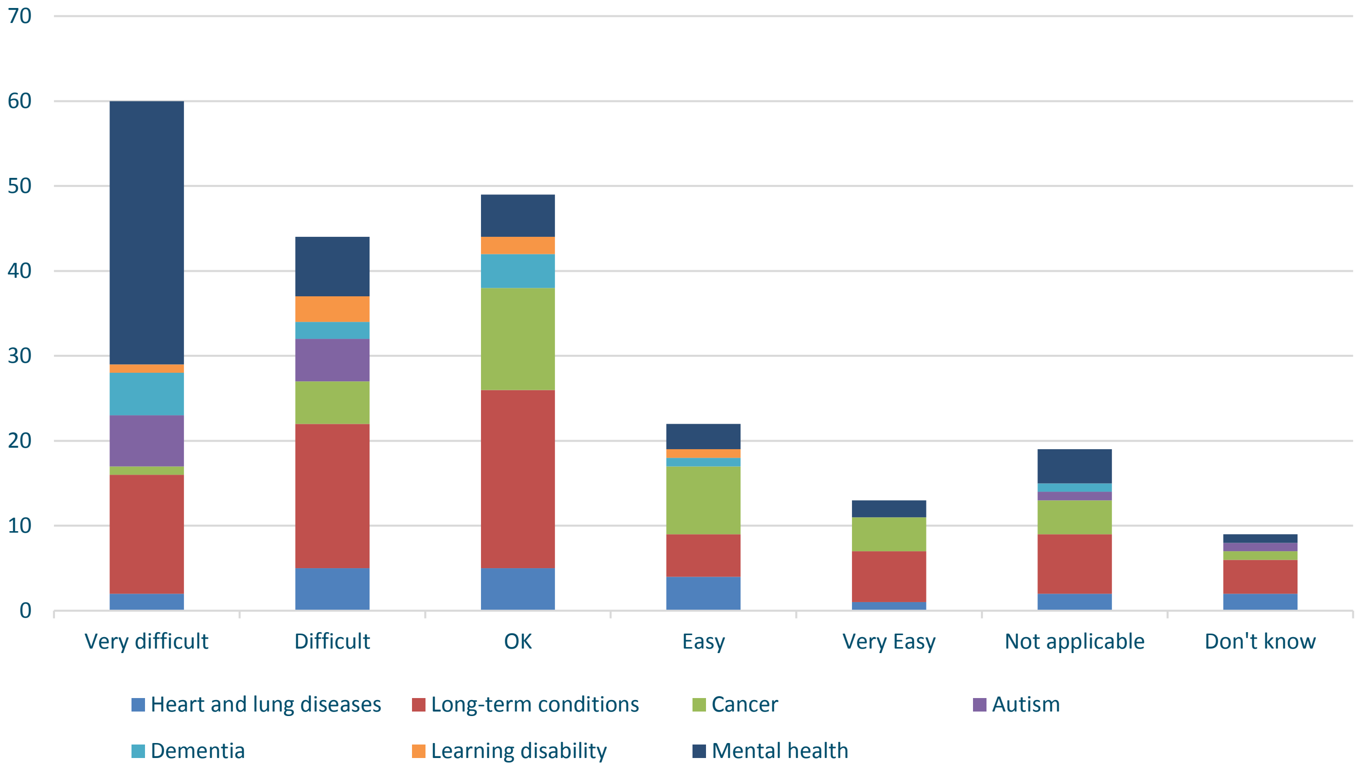
42.1% of responses described their wait as "slow" or "very slow," compared to 27.6% who described their wait as "fast" or "very fast."

28.9% described their wait as "okay." **Respondents with autism and mental health conditions reported the longest waits**, with 85.7% of those with autism and 76% of those with mental health conditions characterising their wait as "slow" or "very slow." None of the respondents with autism described their wait as as "fast" or "very fast."

Respondents with cancer reported the shortest waits, with 51.5% describing their waits as "fast" or "very fast."

In contrast, 26.3% of respondents with heart and lung diseases, 22.2% of those with dementia and long-term conditions, and 20% of those with mental health conditions and learning disabilities described their waits as "fast" or "very fast."

If you needed it, how easy did you find it to access ongoing support after you were diagnosed or assessed? (Question 20)



The most popular answer in this category was "very difficult," which comprised 27.8% of all responses to this question.

In total, 48.1% of respondents described obtaining access to support as "difficult" or "very difficult;" in contrast, 16.2% of respondents described gaining access as "easy" or "very easy."

Consistent with the findings of previous questions, **those with autism and mental health conditions reported the most difficulty in obtaining support.** 84.6% of those with autism and 71.7% of those with mental health conditions found it "difficult" or "very difficult" to access support, and none of the respondents in the autism category described accessing support as "easy" or "very easy."

Those with cancer reported the most positive experiences; 34.3% described support as "easy" or "very easy" to access and only 17.1% described access as "difficult" or "very difficult." This is also consistent with the findings of previous questions. 2.7% of respondents answered "okay" to this question and 8.8% answered with "not applicable."

Specific conditions focus groups feedback *(Appendix 1)*

Using the national survey data, we extracted data for three key conditions of relevance to the development of the Sustainable Transformation Partnership (STP) for Devon. The Systems lead Director of Communication and Engagement for the Devon STP asked the three local Healthwatch of Devon (Devon, Plymouth and Torbay) to carry out supplementary focus groups for these three conditions. These were Cancer, Heart & Lung, and Dementia. These focus areas were decided by the STP because of the lack of recent engagement in these areas and the acute services review were in the next stage of the engagement for the STP process.

The basis of engagement was *what could be done to make a difference in living well with the specific condition?* The focus groups had a total of 170 attendees.

The number of respondents for this section was low, so these findings may not be representative of the whole population. They do give an indication of the experiences of those who did respond and are included (in the appendix) to give a flavour and to confirm our value in their contribution. Also in the appendix is the contribution of patient experience by their own description. The summaries of the focus groups which gave better insight into what is not working well or could be done better is in the following section.

The focus group conversations were directed across 3 themes, common to each Healthwatch. These were framed around:

- What works?
- What could be done better?
- What is missing?

The areas of conversation were focussed on the NHSE priority areas for the future:

- Prevention and early diagnosis
- The role of community support (Shifting the Centre of Gravity)
- Assistive Technology now and in the future as a means of support

The following section is a summary of the key themes and issues discussed in the focus group conversations, categorised by the three NHSE priority areas above:

Focus group findings (Appendix 1)

Prevention and early diagnosis

- Prevention and early detection through screening has lost its priority in the order of importance to the public. Media adverse stories have not been counteracted sufficiently.
- Dementia combined with other long-term conditions feels the least supported and with challenges to the mental health of those who care for individuals

- Overcoming the perceived stigma of the specific condition. This prevents early diagnosis, actively seeking out information and in some cases a reluctance to learn from the positive experiences of others.
- Mental health awareness alongside physical health. This could be linked to the condition e.g. panic attacks, but includes the potential for fear of the condition to generate loneliness. The condition may precipitate new family stress in caring or changing roles.
- Fear of adverse outcomes from health checks, whether related to lack of understanding of the value of vaccination to promote immunisation to protect the whole population and to protect themselves from what may become an emergency. Or to obtain early detection of oncoming conditions.

The role of community support

- The value of the co-relationship between professional, the individual and their family or primary carer and the anxiety about its loss.
- "Shifting the Centre of Gravity" from acute focus to community support and individual resilience is not a model which is well understood by the public, especially as some of the key components are not in place in the voluntary sector
- Being alone without a clear understanding of opportunities for self-help and how to take advantage of support from the community. Especially as approaches differ across Devon.

Assistive technology

- Older people are apprehensive of a future healthcare system which is more inclusive of technology; some describing themselves as "phobic." Where there is group support this can overcome the anxiety. At this time, individuals have no examples of how technology may improve their experience of care, although they do share examples of how it has become part of their life e.g. shopping on-line. Many have internet connectivity but do not use it for themselves.
- Fear of a future where personal contact is replaced by technology. Especially where current consistency in having a known professional team is valued.

Comment from local Healthwatch

“Most of the key themes covered in this report - such as: waiting times, continuity of care, NHS funding and resources, patient-staff communication, the closure of local services, and promotion of preventative care – are echoed throughout the Appendix feedback. There were also many comments about the quality of the questionnaire itself, with some feeling that it did not give them the opportunity to answer questions fully or honestly.

If this consultation process were to be repeated, we would hope to see significant patient involvement in the production process for the questionnaire itself, in order to ensure that the surveys are as easy to understand as possible for the public and wider community.”

Comment from NHS Devon Clinical Commissioning Group

‘We would like to thank Healthwatch for the work they did to gather the views and experiences of local people about the future of health and care services in Devon. This information is extremely important as we start to shape our Long Term Plans for the future. Healthwatch help us reach a wide range of people to gather feedback and that is a priority for the NHS.

‘We have learned a great deal from this work which we believe will help us do things better in the future. In terms of the engagement, having the flexibility to do things that suit local systems is important. We already understand a lot about our local populations and how they like to access information and engage with NHS organisations. Aligning national resources with local knowledge will certainly create a better outcome for all.’

Final Thank You from Healthwatch

“We would like to take this opportunity to thank all the local groups and stakeholders supporting this survey and to the individuals who contributed their thoughts to the wider consultation throughout Devon.”

Appendices

Appendix 1

Individual focus groups for Cancer, Dementia and Heart & Lung

Overview across the STP footprint for Devon

Context

The Systems lead Director of Communication and Engagement for the Devon STP (Sustainable Transformation Plan) asked the Healthwatch of Devon (Devon, Plymouth and Torbay) to carry out supplementary focus groups for three conditions. These were Cancer, Heart & Lung and Dementia. The basis of engagement was *what could be done to make a difference in living well with the specific condition?*

This work was carried out during the same period of activity as the national Healthwatch England survey “What would you do?” which was also promoted by the 3 Healthwatch and included in this compilation report. Achieving substantial focus group recruitment was difficult in the time frame but all took the opportunity to work with those with lived experience of the conditions, where groups met and if they met during the investigation period. This had the advantage of obtaining good personal contact to provide individual experience. The outcome could not be considered to be the full picture as the responders were a self-selected group with small numbers. It did produce some insightful information, even if at times from few individuals. It also provided the opportunity to hear, directly, the voice of the individual which can be more meaningful than generalised surveys.

The focus group conversations were directed across 3 themes, common to each Healthwatch. These were framed around:

- What works?
- What could be done better?
- What is missing?

The areas of conversation were:

- Prevention and early diagnosis
- The role of community support (Shifting the Centre of Gravity)
- Assistive Technology now and in the future as a means of support

Cross cutting themes for Devon STP

What is not working well or could be done better:

- Overcoming the perceived stigma of the specific condition. This prevents early diagnosis, actively seeking out information and in some cases a reluctance to learn from the positive experiences of others.
- Mental health awareness alongside physical health. This could be linked to the condition e.g. panic attacks, but includes the potential for fear of the condition to generate loneliness. The condition may precipitate new family stress in caring or changing roles.
- Fear of adverse outcomes from health checks, whether related to lack of understanding of the value of vaccination to promote immunisation to protect the whole population and to protect themselves from what may become an emergency. Or to obtain early detection of oncoming conditions.
- Being alone without a clear understanding of opportunities for self-help and how to take advantage of support from the community. Especially as approaches differ across Devon.
- Anxiety about technology (digital), some describing themselves as “phobic”. Where there is group support this can overcome the anxiety. At this time individuals have no examples of how technology may improve their experience of care, although they do share examples of how it has become part of their life e.g. shopping on-line. Many have internet connectivity but do not use it for themselves.
- Fear of a future where personal contact is replaced by technology. Especially where current consistency in having a known professional team is valued.

Suggestions for the future:

Prevention and early diagnosis

- Significant levels of investment to overcome reluctance for screening and immunisation. Non-participation for Individuals is falling back on adverse media stories and received wisdom generated in the community.

- Nudge maybe a way forward e.g. making it easy by giving an appointment slot in advance, taking into account working conditions (e.g. shift work) and mobility.

Assistive technology

- Promotion of positive stories about success in the use of technology at home (see Sarcoidosis sufferer case study)
- Promotion and acceptance of the use of technology at home to monitor vital signs and feel "in control".
- Demonstrating how assistive technology can improve the partnership between individual and professional

Investing in ways to work together (individual, family friends and community with professional support)

- Increased Community based Peer support groups, which includes professional advice, known to help people feel more knowledgeable, confident and happy, and less isolated and alone. (National Voices, Nesta May 2015)
- Recognising the strengths or lack of knowledge and understanding in the person and those who care for them as a component of individualised care.
- Not ignoring or avoiding preparation for the end of a person's life and the effect on carers and life partners.

Consistency and continuity

- Working in similar ways across Devon to provide consistency. This includes use and promotion of validated information from a single source and appropriate for the "reluctant reader".
- Having a named team for the care pathway from GP to outpatients, including key contact, explained in non-technical terminology. This is especially valid for those with dementia and memory loss and their family carer who may live at a distance.

Attachments: Full reports from each Healthwatch

HW Devon

Notes gathered from focus group participates by Healthwatch Devon, as part of the #whatwouldyoudo campaign in May 2019.

1. Axminster and Lyme Cancer Support Group

Monday 29th April

Abby Read- Healthwatch Devon

4 participants

Prevention

- Embarrassment about attending a smear - Awareness needs to increase
- Awareness of melanoma
- People felt pressurised into feeling they have to make certain life choices to prevent future cancer where they feel there is no evidence that this is necessary
- Ignorance in men about men's health and testing so they don't attend
- Currently looking into nutrition but there is nothing around here to help

Role of the Community

- Lack of knowledge about funding available
- Lost community beds, now have hospice at home
- Local support service is in Exeter, nothing local which is why the group was set up
- Carers need more support
- Funding should be put in local groups that already exist
- Lack of complementary therapies
- Arranged a Blokes' Brunch to try to encourage men to share stories and feel comfortable to ask for help
- Men prefer to speak to men

Technology

- Anti—technology - things need to be done face to face
- Happy with booking appointments online
- No communication pan-County so treatment between 2 hospitals is not ideal. One hospital had no idea what medicines had been prescribed by the other hospital, would be easy to link this via technology?
- Older generation not always able to access technology
- Technology not very personal which is what people need when they are going through something like this

General health

- Simple things missing, counselling thin on the ground - only have Ark around here but they aren't here for that
- Information needs to come from a more reliable service
- Treatment was quick following diagnosis but there was a lack of explanation of the whole process and how it would affect the person

- Chemo and Radio was good albeit exhausting and there is too long a drive for someone with cancer
- Excellent support for breast cancer before and after surgery at the RD&E. Had a personal nurse and the Oncologist was always on hand
- No one spoke about possibly having a stoma
- Everything comes as a bit of a shock
- Extremely important to see own GP who you trust, not any other GP
- Sharing good stories is important to help recovery
- Continuity for treatment not good
- It is an hour to the nearest major hospital so feel very isolated
- Things weren't broken down to be easily understood by the common lay person, I was only fortunate to understand due to having a medical background

Transport

- Have to drive to Poole for a lot of things
- Poor transport - hospital links take a whole day
- People have to travel far to visit relatives in hospital
- It is a shame that the local hospital has closed so that there are no in-patient beds
- Expense of petrol

2. Focus Group Notes

Barnstaple Wednesday 1st May

10 participants

Abby Read- Healthwatch Devon

Dawn Eckhart- Devon Communities Together

(all notes are taken exactly from attendees notes)

Cancer-

Prevention and early intervention

- Quick diagnosis for pancreatic cancer
- Stoma nurse was always available
- Follow up treatment was always good- chemo and radio
- Information was available but had to as for it- some people don't ask
- The carer needs to be involved at every stage of the journey

- Feeling as a patient that you are being listened to is really important Diagnosis and treatment
- As soon as cancer was identified treatment was quickly started
- Bedside manner is really important- professionals need to be sympathetic
- Speed of referral to scans and then back to specialist- it is much quicker in Germany for example
- Information needs to be shared with family/professional carers to ensure messages/appointments are not missed
- Grossly unfair to expect seriously ill patients to travel daily to Exeter from North Devon
- Need to utilise latest technology/medical practices/research
- Initial diagnosis is dependent on GP
- Two week wait for start of treatment which should be kept after
- Better information could be shared at the beginning of treatment
- Sharing of good practice around the country needs to happen more
- Want treatment at home eg self administered chemo
- Services should be bought together when people have cross-over conditions
- Medication for one condition can affect another and there is no link up sometimes

Ongoing care and support

- Oncologist follow up went on for 1 year after radiotherapy was over
- Positive mindset- studies show value of this in improving quality of life while undergoing treatment as well as extended life
- Use common sense, human input over computer eg scans on same day if possible especially if patient is travelling far
- Support groups in community need funding to enable groups- not many in Devon
- There was no referral into Force- not everyone is aware of it so something could be done
- Inconsistency between GPs and their knowledge- some refer to hospice and some don’t
- Need to take a holistic approach to patient
- Listening to patient needs and taking shared approach is important
- Bedside manner is important
- Options for end of life care need to be given- just because support at home is more difficult/expensive, it must still be offered as a choice

- Hospital discharges- more provision required to bridge gap before social care can be put in place
- Mental health- support referral through Macmillan counselling service at NDDH is excellent
- Force in Exeter is great
- Some support services eg Force/Macmillan- better highlighting and communication of these
- Nurse specialists at RDE for support/communication- though not time sensitive nurses often cannot be contacted
- Good support from North Devon Hospice

Heart and Lung-

Prevention and early intervention

- More regular health checks
- Better education
- Education on eating
- Should leave things alone if they are working fine- ie don't change medication
- Provide access to CPR training- clubs, schools, public
- Improve public awareness
- Advertise consultation exercises in future healthcare plans
- Advice could be advertised more publicly eg in shops, cafes, public transport
- Surgeries could send regular reminders to at risk patients on what services are available
- Increase public health spending
- Post cardiac event management of long term consequences
- More surgeries
- Improve public transports to allow access to H/care
- Increase diagnostic access in north devon
- Regular health checks- patients called in for these rather then waiting to become ill
- More public awareness of warning signs
- We need a change to the economic model so that public healthcare is seen as an integral part rather then a burden on some

Diagnosis and Treatment

- Good CCU at NDDH- explanation/rehab referral

- Treatment in RD+E amazing- futuristic, staff explained everything well, very supportive- watching what was going on inside was great
- Response from ambulance service diagnosis was great and in a strange way reassuring
- Dr Anika-Fremington- clear prognosis, very sympathetic with delivery of news and involved ongoing care
- Dr moody, Dr Hans- consultants who show care and support
- Craedo team- dedicated and professional, the oxygen nurse was support and professional
- Listen to patients needs better
- Should appoint a lead clinician/advocate when patient is receiving treatment from multiple teams/specialists
- They should try to link up appointments to the same clinic for the same day ie breathing test and consultant
- Lack of oxygen cylinders keeps me housebound when exercise is recommended
- If medication works then don't change it as it makes lungs worse
- Improve primary care funding for coronary care OOH
- Improve workforce training and recruit expertise if lacking
- Improve cardiac rehab funding for local access of comprehensive rehab (meds, exercise, nutrition, lifestyle, relationships)
- Improve access to cardiac physicians in north Devon (reduce stress)
- A more local service would have reduced stress levels for myself and my family- especially my children
- Multiple disciplinary meetings
- Need extra staff for the respiratory team
- Air liquid- this service needs improving and more user friendly
- Recruit more doctors and nurses on affordable wages

Ongoing Care and Support

- Recruit and train existing nurses and allied health professionals to manage cardiac care in north devon
- More accessible health centres
- With gym equipment and support staff rehab could have been so much better
- Poor oxygen supply keeps us stuck at home and potentially makes one housebound and unable to exercise
- Care should be received in professional surroundings (not home!)

- Cardio rehab was very poor
- Litchdon medical centre- good ongoing management of cardiac conditions, excellent GP support and follow up
- Need more access to local professionals
- Support from GP service could not be faulted
- Hospital consultants very helpful
- Oxygen nurse in NDDH very diligent and good at her job
- North Devon Creado team all friendly and helpful

Feedback below covers both areas

Prevention

- Children should be taught at school about conditions
- People need to be more aware of themselves and how you feel
- Utilise chemists
- Taxes on food/smoking
- Promoting exercise to reduce heart/lung disease
- Men are less likely to go to doctors- stigma/embarrassment needs to be removed
- Education from a young age
    - on lifestyle/health and wellbeing
    - management of health crisis (CPR/first aid)
    - stress- life values
- Workforce
    - Paid education (bursary for healthcare students (eg nurses/O.T/physio/medics)
- Management of funding according to need, not restricted by budget

Technology

- Lots of information can be found online, however there are scare stories which can prevent people attending check-ups, getting jabs etc
- Can have negative impact from self diagnosis
- Using technology to get repeat prescriptions is ok, but annoying that you have to go into GP to register for online use
- Think its great getting a text reminder for appointments
- Would rather travel far to see a specialist/consultant face to face than skype appointment

- There should be one place where records are kept so that all hospitals/GPs etc can access them when having to attend multiple places for appointments
- Often a legal barrier around technology
- Need broadband access across rural Devon
- Training on new technology for older people/special needs
- Maintain alternative communication for people without access to internet
- Investment in technology in north Devon healthcare system- diagnosis and communication
- Investment in research and development in North Devon.

Role of Community

- Oxygen nurse is available everyday- would have to go to A+E if I needed oxygen, Gp cannot order it in. Cannot understand why we cant pick it up at the local hospital, or a local supplier
- Community communication and contact
- Co-operate with healthcare professionals (attend appointments/respond to diagnostic test requests/treatment (bowel cancer/flu jabs)
- Volunteers are overwhelmed by professional expectations- need recognition/support/training and payment if taking on skilled roles
- Neighbourly support

3. Focus Group Notes

Exeter Wednesday 8th May

7 participants

Jessica Crowley- Healthwatch Devon

Dawn Eckhart- Devon Communities Together

(all notes are taken exactly from attendees notes)

Cancer

Prevention and early intervention

- Early treatment following diagnosis; “once I knew I didn’t want to have to wait 6 weeks or more for treatment to begin” (5 votes for this as a top priority)
- Can just about see a Doctor on a daily basis, if you can get past the receptionist
- My current GP pushes her chair back and looks at you
- More phones lines needed – always too often engaged – (1 vote as a top priority)
- More triage nurses (1 vote as a top priority)
- Must save cottage hospitals – part of the system (5 votes for this as a top priority)

- If you are old you can simply die of old age, not some actual statistic
- Early screening e.g. cervical cancer
- Everyone over 50 years should have a full check up

General comments

- Difficulty getting appointments with GP
- Cottage hospital experience for hernia op, memorable for treatment and staff care
- Human touch more important than pushing buttons (Doctors looking at the screen avidly rather than weighing up the patient before them).

Diagnosis and treatment

- Health and wellbeing meeting was excellent (2 votes for this as a top priority)
- Clinical Nurse Specialists (1 vots for this as a top priority)
- Retention of quality cancer consultants (Mr A Moors – spelling not clear here)
- Consultant was interested and easy to talk to
- RD&E, Jenny Forrest Consultant, excellent, spoke to us all
- Medication;lack of pain management control (client spoke to me and explained that prior to the cancer diagnosis and chemotherapy staff at the NHS were unable to control the pain)
- Support for patient – consultant/staff always available and have a named nurse
- Fantastic -have a named nurse once you are in the system
- Referral to Force – made a big difference
- And continuation, beginning of treatment
- Diagnosis
- Support for family

General comments

- Hospital treatment (In-patient) first – Outpatient for injuries very good
- More information on the problem and treatment proposed

Ongoing care and support

- V Good support at home: visits, treatment as necessary, during and following treatment (2 votes for this as a top priority)
- Day care nurses made treatment easier, by explaining
- Referral to Force or Hospiscare nurses – patient and family
- Can speak to staff on ward 24/7 if needed
- Support for family (1 vote for this as a top priority)

- Focused investment at the sharp end
- More staff on day case unit
- Wellbeing support to motivate more staff
- Increase in PAYE contribution (1% or 2%)
- Not listening to my concerns
- Waiting much too long for appointments

General comments

- Parking at hospital very stressful
- Still waiting to be recalled for check up following eye appointment in 2017
- Post Hospital aftercare much desired

Heart and Lung

Prevention and early intervention

- Everyone over 50 should have a full check up (1 vote for this as a top priority)
- Communication (lack of)
- More help with weight management. I know the fact I was overweight contributed to my condition.

Diagnosis and Treatment

- When the treatment works great
- When my mother tool ill over here both Torquay and Derriford were brilliant
- Mr Dalrymple-Hay performed my surgery. I will always be grateful
- Professor Bellinger was kind and considerate throughout my treatment
- The actual surgery (2 votes for this as a top priority)
- For the elderly with heart surgery they need rehabilitation in community hospitals (1 vote for this as a top priority)
- Needs greater communication between hospitals and GPs, GPs do need to listen to instructions
- On the occasion I didn’t pay to see my cardiologist his assistant could not even access my test results
- While I was waiting to be admitted to Derriford several people waited all day and were turned away because there were no beds
- Communications (lack of)
- A young man who had epilepsy was occupying an acute cardio bed because there was no housing for him

Ongoing Care and Support

- My current GP pushes her chair back and turns to face you – it makes such a difference
- The NHS Counselling I was offered for anxiety was totally ineffective, it was computer based!
- Dr Reid at Sidmouth surgery was totally disinterested, fortunately he has just retired
- Torbay Hydro unit was brilliant
- Physio department e.g. Teignmouth Hospital
- Availability of physio is vital for patients. Elderly need community hospitals
- My mother had open heart surgery in France (emergency) she had amazing care. She was elderly. She had the surgery in the general hospital and rehab in a LARGE community hospital. The tops beds were for the elderly and bottom wards were for the young. They had a physio unit (gym), hydro unit and garden.
- A cardiac trained nurse who could advise patients following surgery (1 vote for this as a top priority)
- Exercise and rehab classes. I know this happens in some areas of the country (1 vote for this as a top priority)
- No after care following surgery
- I kept visiting the Doctor and asking for rehab. By the time he referred me we were told it was too late

Feedback below covers both areas

Prevention

- More resources needed
- Greater diagnostic testing
- More awareness needed of the importance of poor diet and obesity
- Better communication needed within the NHS and improved staff management e.g. a client travelling a long distance needed two scans, a request was made for them to be done on the same day and administration said it wasn't possible, yet on the day of the first scan it wasn't a problem for the Radiologists to conduct both scans.
- The art of science is an accurate diagnosis, client felt this has been lost by GPs and therefore it takes a long time for diagnosis

Technology

- Improve diagnostic blood tests etc
- Online prescription services is not reliable – often the prescriptions do not come through
- Delays in forwarding patient information when moving to a new GP surgery
- Sharing good practice, using national database such as Basecamp used by ACRE
- Quicker diagnosis

Role of Community

- Volunteering in health needs more funding: FORCE, Hospiscare, ELF (Exeter Leukaemia Fund)and other Independent charities need more funding
- Most individuals cannot afford private personal care. More funding needed for NHS to provide more carers etc
- Weight loss groups e.g. Slimming World, for improved health and wellbeing
- To change the thinking of clinical commissioning groups - to act as a Watchdog
- For there to be synergy between NHS and various other organisation, to share best practice from each other

End note

The focus group acknowledged the significance of staff, their wellbeing and how well they are resourced as contributing factors to all the above. They are interested to learn more about the NHS workforce strategy running in parallel with the #whatyouwoulddo campaign and would like to know what is happening and will there be an opportunity to be consulted on the NHS business model?

4. Heart and Lung Long Term Plan

Individual Feedback – 2 cases

Abby Read- Healthwatch Devon

Client 1

- GP relationship- haven't seen a GP for nearly a year, has to try to communicate via receptionist. Had letter which GP was copied into but they had no record of it.
- No communication
- Lack of continuity
- Sometimes wait 6 months for appointment, sometimes even had to remind hospital that they were on the waiting list
- Helplines should be bought into local hospitals, human on the phone, a bit like 111 but speak to someone with more experience
- Grumpy receptionists

- Variety of conditions makes cross over hard and delays things
- Doctors don't communicate
- Has to photocopy things herself to take along to appointments- tiring doing admin with a chronic disease
- Lack of continuity between doctors
- Too many people involved
- Jobs aren't done properly
- Have to travel to London for special Sarcoidosis treatment, would prefer specialist in area. This is expensive and tiring.
- Would prefer advice about claiming- package of info about PIP and where to claim

Client 2

- Trouble is lack of awareness, she herself didn't know about it
- Found out when she was 40, had infection, took 7 visits to the GP until she was sent for a chest x-ray
- Had to go in for blood tests, she was unclear about why, this was poor communication
- Doctor told her in waiting room that she either had sarcoidosis or cancer
- She had never heard of sarcoidosis and needed more information
- Frustrated that it took several visits, even senior doctors didn't help
- GPs need to be more aware
- Had referral to heart and lung specialist, had breathing tests and specific exercises
- Found out through another forum that she would be highly likely to have another condition
- Regular check ups stopped, no advice or ongoing support was given, specifically around exercise and nutrition
- Found that a lot of people weren't knowledgeable about condition
- She went to an osteopath who actually treated sarcoidosis in horses so used some of the same techniques and found it really benefitted her. Gave her exercises and acupuncture which she thinks should be better referred into
- Would be good to have future check ups. In the first instance they are seen but has now been left in the dark

Prevention

- Lack of awareness- GPS not interested or don't learn about conditions even when invited to talks
- Adequate care not received
- Lack of awareness from general public
- Rare disease

- 6.4 years for diagnosis
- Tests could be done early to help and initiate treatment
- Early diagnosis is key, mental state isn't good when it drags out
- Thinks people should be sent for chest x-ray sooner instead of being over questioned and made to feel stupid
- More information about long term issues with conditions would help people prepare
- No information about who to turn to or support groups

Community

- Funding from Lupus UK would be great if had NHS funding for local groups
- Meeting would then increase awareness
- GPs should social prescribe more, for example CBT for clients
- Need to be made more aware of conditions
- Gps more proactive in sourcing information
- Useful for community to be made more aware
- Can have a huge impact on employment, people need to be made aware of their condition and employee rights
- Insurance/PIP- where to get this
- Lack of support groups in North/Mid/Exeter
- Doctors should be better at signposting into the community

Technology

- Doesn't want more technology
- Hacking is a worry
- Appointments and data can be lost
- A lot of the older generation aren't able to use internet
- Rural community limits access to internet
- Doesn't use technology for healthcare only for booking appointments
- Finds typing tiring
- Would prefer video call appointments to reduce travel time
- Uses internet to book appointments and phone call checks up and finds this works well

5.Social Media Analytics

Jessica Crowley

The following stats represent social media engagement relating to #whatwouldyoudo campaign – 16 April to 10 May 2019.

Twitter

Retweets	Likes	Mentions	Clicks	Potential
26	15	1	2593	190000

Top Tweet

★ TOP TWEET

What do you think needs to be improved to health services for your family in #Devon ? Tell us in our survey: https://buff.ly/2tPCqLA @NHSDevonCCG @RDEhospitals @MaternityRde @WellbeingExeter @livewellsw @WMNNews @ExpressandEcho @BBCDevon @DevonCC @DevComsTogether

APR, 17TH AT 18:00 (BST) via Web

2 Retweets

0 Likes

0 Mentions

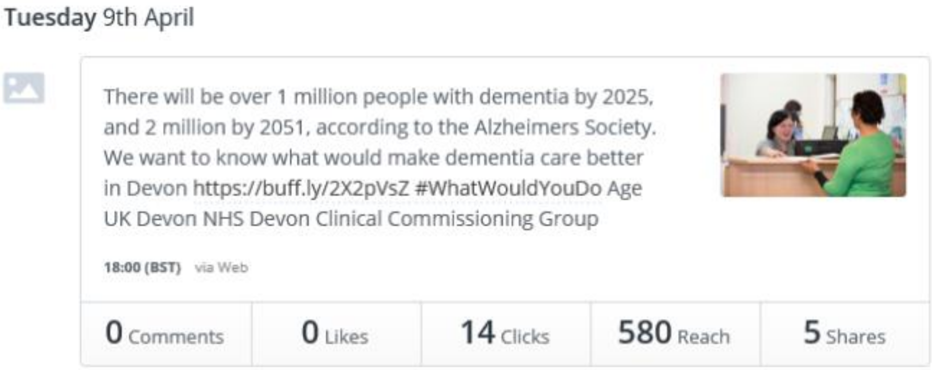
93 Clicks *

50.1k Potential

Facebook

Comments	Likes	Clicks	Reach	Share(s)
6	18	34	2033	34

Post with highest reach and most shares



Tuesday 9th April

There will be over 1 million people with dementia by 2025, and 2 million by 2051, according to the Alzheimers Society. We want to know what would make dementia care better in Devon https://buff.ly/2X2pVsZ #WhatWouldYouDo Age UK Devon NHS Devon Clinical Commissioning Group

18:00 (BST) via Web

0 Comments

0 Likes

14 Clicks

580 Reach

5 Shares

Insight

The most popular posts were those mentioning dementia care, mental health and heart and lung disease.

Mailchimp Campaigns

24 Apr Public Consultation, circa 3,314/727 opens

25 Apr Public Consultation circa 3,314/694 opens

29 Apr Newsletter, leading with #Whatwouldyoudocampaign, circa 3,278/676 opens

Also promoted in Healthwatch Voices magazine circa 7400 (4000 print and 3,278 digital)

HW Plymouth

HWP talk to Bladder Cancer Support Group - Derriford Mustard Tree

10th April 2019 – 8 individuals

Cancer Focus Group - supported by Di Charlton from McMillan

15th April 2019 – 1 individual

Cancer Focus Group - Plymouth Area Cancer Support Network

30th April 2019 – 5 individuals

Prevention

- Need more information on the early warning signs of disease (e.g. getting up several times in the night for or potential bladder cancer).
- Was expecting to learn from others experience, but support group members not encouraged to go into clinical detail.
- Promotion of the value of healthy eating and exercise in prevention of certain conditions. Discounted Gym membership?
- Information on preventative screening programmes/tests and when and how to access including age information.
- If screening is only routinely done up to an upper age, making sure individuals know that they can still access tests and are not debarred from doing so because they are above the upper age limit.
- Promoting Well Woman/Well Man health checks and making sure that capacity is in the system to be able to offer and conduct.
- Looking for more information on how to prevent ongoing development of the cancer.
- Preventative services, especially those that involve a period of exercise, need to be long enough to become habit forming.
- Text message reminders to attend appointments both with GP and Hospital Outpatients – message needs to include location, particularly if appointment is at a different GP venue than the one the patient is registered with.

- Early testing and diagnosis not taken up due to cultural/faith, gender and generational issues around personal /private investigations.
- There is also a low uptake of remote and private FIT tests.
- Development of more tests that are less invasive.
- People don't want to know what the reality might be. Perspectives on the treatment options and success rates are out of date.
- Issue of individual having multiple conditions and diseases and the need for holistic treatment. This the case even with in each cancer type, e.g. breast cancer patients have to see multiple different professionals with different appointment and locations. Other e.g sarcoidosis with multiple and varying symptoms and presentations.

"Men don't want a finger up their bum, or a camera up their willy"

"I'm not going into hospital; I might never come out!"

"Treatment is too NHS work force focused"

Role of the Community

- Yes find community and group support groups useful, is a member of several, health and other community groups.
- Would like peer to peer support but needs individuals with the skills, leadership, and confidence.
- Macmillan mention of Asset Based Community Development (ABCD), seeing people as the sum of their assets not their Deficits. E.g. not to identified as solely a cancer sufferer.
- Bladder Support Group - issues around maintaining membership numbers, some meeting dates there are no attendees. Maybe need a meeting and greeting role
- Sometimes break down between support group and Health Service. MacMillan looking to develop Support Group Memorandum of Understanding.
- Having national links helps a local group develop.
- Clinicians need to promote benefits of support groups.
- Use of care homes in supporting community network development.

Digital

- Age dependent, young people respond more to digital processes.
- Wealth and resources can also restrict access to privately sourced technology. Spent £1,500 on specific digital aids.
- Use of software programmes/apps to communicate with Health Professionals i.e. Skype/Facetime/WhatsApp.
- Access to digital devices and broadband coverage will vary e.g. blackspots, cost of connectivity.

"Pick up the phone and talk to me, otherwise I do not want to know"

AOB

- Hereditary issue of learning coping mechanisms from earlier generations. Equally informing and supporting future generations.
- Reflections on change of individual role (i.e. mother) from provider of care to recipient of care as symptoms develop.
- Family caring and support capacity changes with social norms and families being more dispersed.
- Clinicians being able to use the same IT system to communicate i.e. acute to primary care.
- Terminology is an issue, don't you think? Probably because questionnaires are put together by medical staff familiar with the terms as patients often are not. The Cancer Nurse Specialists for example are often called CNSs but if you are not used to either term and preoccupied by your diagnosis you might not realise that this is your main link or ‘key worker’. Definitely a challenge for questionnaire devisors.

Dementia Feedback - Happy Go Luckies Dementia Group in Moments Cafe

26th April 2019 - 9 Individuals (all Dementia Suffers)

Dementia Feedback - Carers

10th May 2019 - 2 Individuals

Dementia Feedback - Central Library Memory Cafe

13th May 2019 - 2 Individuals - group facilitors

Prevention

- Important to eat well, exercise/keep fit, use memory games, think creatively, talk and give opinions.
- Difficult to identify at what point it should start.
- “Railway track” existence, avoiding diagnosis – What is the trigger point for acceptance of the condition?
- Prevention pathways dependent on cause of Dementia – more research required.
- Education to identify signs of Dementia onset.
- Information key especially about worse case, but it must be easily accessible, correct and up to date.
- Healthy living promotion, but must be backed up by realistic food prices, otherwise nothing will change.
- Less active, more solitary life after their alzheimers.

- Learning new skills, language, musical instrument.
- Reading books

“Sufferers already in crisis before diagnosis so always playing catch up”

Role of the Community

- Do puzzles crosswords.
- We are all going through the same thing.
- Understand each other.
- All of a generational age.
- Family important but don’t always live close by.
- Residential Care is viewed as modern day workhouses.
- Continuity of care environment/routine/carers important.
- Dementia sufferers gradually lose rights due to the nature of the condition, possibly ending up in a care home that do not have the right to fight for them.
- Properly funded respite care at capacity would be better than more generic short-term care in the community – ultimately keeping individuals at home with family longer.
- Day Centres delivery of service – is it fit for purpose?
- Was anti-social but now getting more involved.
- One time when one member didn’t arrive everyone was asking after them.
- Nice experiment combining dementia club and toddler group- really enjoyed by both groups.

“In the group you have someone to talk to, If I miss one it makes me feel sad”

“Don’t feel so isolated by being in a group”

“Looking after a Dementia Sufferer is like having a new baby - a support network is needed as it’s 24/7”

“This group has been great for me”

“Made new friends”

Digital

- Technology is the future, but some are petrified and scared of it.
- Use of speech technology (i.e. Alexa), however barriers…. don’t have internet, security risk.
- Access to technology is inconsistent as is the ability to use.
- Communication needs to be timely and accurate and uses various means.
- Individual with dementia taking a basic computing course, kept forgetting skills every week.
- Reminders etc. on carers phone
- Use of fall alarms, issue of false alarms causes problems.

"Information should be full, frank and complete to allow carers to understand, be prepared and empowered."

Notes from Co-ordinator of Happy Go Luckies:

- Where our groups allow, we try and get out for a walk during the day.
- We know that some of our groups benefit from the latest technology (i.e. Alexa, Google dot) to enable them to live well at home.
- Others live well at home without internet connection, we are working on a bid to investigate this further..
- The groups enjoy using iPads, we will bring to Plymouth for the group to try.
- We provide Livewell sessions, which help people set goals on drinking enough /introducing the MIND diet and other goals set around the 6 pillars of brain health.

Heart and Lung Disease – HWP engagement at Derriford Chest Clinic (Outpatients)

23rd April 2019

Heart and Lung Disease - Heartbeat Gym Cardio session

24th April 2019 – 19 individuals

Heart and Lung Disease - Pulmonary Fibrosis

10th May 2019 – 1 individual (Chair of local Action for Pulmonary Fibrosis Group)

Prevention

- Had been in the Marines and was fit so didn't anticipate problems. After retirement put on weight and suffered Diabetes and had a heart attack
- I had all the information but didn't act on it.
- Had picked up the background message on healthy living but was very fit prior to 2 heart attacks. Now does exercise for cardio and all over body fitness.
- I don't have a flu jab, I wasn't well after I had one and put me off, the GP told me it wasn't anything to do with the jab, but it still put me off.
- Don't always have the availability for pain management.
- I access all screening available to me, bowel, breast, Flu vaccines.
- Here to lose weight and stay healthy.
- Had no awareness of prevention message prior to his bypass.
- I have a high BP and a family history of heart disease. My doctor recommended exercise and a change of diet, both he and I are pleased with the results.
- Support for weight loss important.
- Having positive mind set supports to aging well, people must take responsibility for own health.

- **Sarcoidosis sufferer** – Hard condition to prevent as can affect all different parts of body at different times. Some ethnic / genetical related factors, e.g. African and Norwegians have a higher % incidence.
- Symptoms (persistent cough, breathlessness) could be misdiagnosed, can take 2-3 years and is diagnosed with CT scan, not x-ray.
- There is no clear pathway or specific screening for Pulmonary Fibrosis. GP refers to Chest Physician, who may be aware of Pulmonary Fibrosis.
- Clinicians need to be more aware of Pulmonary Fibrosis, often assume it's like COPD.

"I wish I had some of the health prevention messages that are been given now"

"Diet and exercise or die early"

"No bending over to pick up things off the floor"

"We all get told about it"

"I was in hospital for a year with my grandchildren crying at my bedside - that changed my perspective"

"I didn't listen, drank 10 pints a day"

Role of the Community

- Has been attending the 'cardiology' group for 12 years, enjoys the mutual support and chat
- Really valued the community and social element of the rehab process, even waiting together for their medical tests.
- Encouraged to return to the gym sessions by fellow group members
- Has known members of the group for a long time, swapping stories around health and operations.
- Sports Students from Majons also support individuals through their exercises
- Regular social activities help to bond the group e.g. Christmas Lunch
- Enjoy exercising in a group setting, find it very sociable, we learn from each other and share problems with people who are experiencing the same things.
- It can be a long wait to get Doctor's appointment and this can delay ongoing treatment.
- Within community groups it is important to have someone knowledgeable to coordinate the groups.
- Wolseley Trust offers a lot of services, they are very good.
- Peer support is beneficial.
- More support from specialist nurses would help, they would ensure I am receiving best treatment for my condition.
- Long wait from have tests to seeing consultant and getting a diagnosis, stressful waiting, I want continuity and to be seen close to where I live.
- Difficulty getting appointment to see GP, you need to be motivated and take responsibility to act on getting care needed.
- I would like a gym like this closer to where I live.
- Safe place, sense of community.

- Cheaper than mainstream gyms.
- It is having the knowledge of what’s available and where to go for information, a gym for people with mental illness would be useful.
- I live in an area where my neighbours are supportive and make me feel less isolated.
- A good bus service is essential.
- Very friendly, chat with other people, I love it.
- Provides a space to get rid of stress and not always look to family for support.
- I started off a as a user, then was asked onto the committee, now I’m the Chairman.
- People attend from across Plymouth and beyond.
- There should be more help after a stroke, I only had 6 weeks rehab.
- Enjoy the social element, especially after being told that I wouldn’t walk or talk again.
- Uses social media and voice generator on phone to aid communication.
- Nice mixture from all walks of Life.
- Nice non-commercial gym with no mirrors...
- Living in a rural location and having other conditions, would be easier if Specialist services was closer to home or have access to patient transport to go to secondary care.
- Increased support at home, e.g. district nurse, carers, depending upon need.
- Useful if appointments could be coordinated to stop constant trips to Derriford and for them to communicate with each other, to be aware of other treatment being received and patient’s medical history.
- Focus care in the community, closer to home rather than in hospital, will help with parking.
- **Sarcoidosis sufferer** – Until recently suffers felt very isolated and unheard as the condition was rare and under diagnosed. Social events held regularly.
- A good relationship with the GP is extremely beneficial.
- Support groups incredibly helpful, including telephone support as well as Facebook Groups.
- Support for the carers is also important.

“We’ve got each other’s back”

“Rehab lifted her spirits, and the social side was as important as the medical support”

“If I was away too long people would ask, where are you?”

“This gym is just what I need”

“Hearing other’s health stories encourages me to keep fit”

“it was a weight lifted off me having someone to talk to who is living with the condition”

Digital

- Regular user of the Blood Pressure monitors and keep record before and after every session.

- Julie the coordinator keeps an eye on BP records, and steps in to do manual blood pressure readings for AF – which doesn't show on machine reading.
- Wears Fit bit, measures BP, O2 levels, number of steps etc. Uses scales with extra digital analysis options.
- I do access the internet, however, would need training to use technology.
- Good to access information online but need to know recommended sites to go on.
- Has own BP monitor at home as well as Wrist monitoring device. Also has diabetic blood monitoring tab that send results to phone.
- Gym has a defibrillator.
- Not interested!
- Gym has specialised equipment for physically disabled and special needs users.
- Gym has a body fat indicator machine, monitoring weight, and % water.
- Investigating more flexible and convenient health monitoring systems. Potentially linking in to mental health support situations.
- Technology is 1st step these days, as difficult to get to see GP, but not accessible for all, particularly older generation.
- **Sarcoidosis sufferer -** Dispersed group across the region use social media and Facebook page to keep in touch and share information and activities.
- Technology important but is dependent upon connectivity, security issues, available Apps and usefulness.

AOB

- Private screening companies offer a lot but costs, this should be offered by GP.
- Appreciate specialist support for condition, staff generally more knowledgeable than practice staff, they cannot be specialists in everything.
- General comments about wait to see GP, which can impact on referrals for ongoing care.
- Specialist services would be useful rather than the surgery.
- More money needs to go into GP practice, they need to assess people for ongoing treatment.
- Need more beds to move patients out of ED, better discharge planning, access to meds to take home, have staff other than Doctors and nurses to do this, takes their time up when they should be caring for patients.
- Different referral process for Devon and Cornwall, taking more time than it used to.

HW Torbay

Summary of Cancer focus group (Torbay)

Responders came from a day treatment ward visit, individuals were spoken to and then asked to respond via freepost, (7 written responses returned) plus a small multidisciplinary mixed focus group (6) of healthcare professionals, carers and volunteer with lived experience.

- Indicative themes verbatim comments are included below.

Prevention and living a healthy life

In general attenders on the ward rated physical activity, eating well and oral hygiene, to remain healthy, higher than mental activity (reading, hobbies, social media) with social media having the lowest value.

Comments:

- Learn to cook if you know what goes into a dish it is easier to know whether it is healthy or not
- More organised activities for other teenagers particularly in inner city areas

When asked about living well themselves, physical activity was still rated highest, but mental health activity was rated less helpful e.g. joining a hobby club, social media. There was ambivalence to meeting up with friends with cancer so only considered helpful to some extent not important.

- Not everyone's reaction to treatment is the same
- Other people's experience may help you find a solution to something you are struggling with

Half of the responders considered that the reason for non-attendence for health checks and vaccination was lack of understanding of the purpose. Forgetting to make an appointment and belief that they caused illness was only relevant to some extent but not necessarily the reason.

The role of community in helping to remain independent

There was complete lack of knowledge from the day ward written responses. During the session questions were asked so the volunteer researcher was able to share her knowledge as a volunteer in a cancer drop-in centre. This information was very well received and appreciated, especially by the accompanying carer. They appreciated the direct approach of the knowledgeable volunteer who had lived experience to contribute to the conversation. It is likely that the information would be shared by the ward, as treatment progressed, as a leaflet was available. But as this stage the comment was made that “We don’t know what we want!”

Use of assistive technology now and in the future

Day ward attenders had internet at home but did not report actively using apps or on-line resources to support their health. 4 (of 6) in the group did not consider that technology had improved their lives in any way and only 2 requested medication repeats on-line.

Comments:

- Too much technology is not always a good thing

- I find the reminder function on my mobile invaluable

What more is needed?

A substantial amount of information came from the workshop, where professionals including public health and individuals shared information. Responses showed a deep understanding of what could be done better and have an impact. Although still only a small sample themes were:

Prevention and self-help to live a healthy life:

- Not having a one stop shop approach makes it hard to know where to go for support
- We (patients) don't know what we don't know including information to reduce risk of Ca development – need right information at the right time.
- Good clear communication and information to support a person's understanding (personalised)
- Signposting to be clearer
- Pathways to be clearer
- Health and wellbeing for carers – a whole family approach not just the individual
- No door should be wrong door
- Focus on how to stay well
- Prepare people to manage dying and losing someone
- Normalise healthy behaviour e.g. slimming well with knowledge
- Managing the stress with a negative cancer diagnosis, not knowing the actual diagnosis and putting the individual back on a waiting list

Community – shifting the centre of gravity

The group recognised the challenges to "shifting the centre of gravity" normalising cancer support in the community and the aspirations for care being personal. These started with reducing the stigma of cancer diagnosis and recognising where information could be used to good effect.

- Why is travel insurance more expensive? - Normal life after cancer
- What can employers do – do we need supportive employers?
- Eating well, community support to give confidence, prevention belongs to community
- There is fear of upsetting the patients
- Information provision is inconsistent – neutral place needed for information i.e. in the library, good use for volunteers. Needs a communications strategy on Living with Cancer. Identify the financial aspects of support and its impact on the patients.

- Community needs to [have knowledge] to change the experience of cancer
- Supporting people wanting to die at home – using bespoke partnership and supporting choice, taking services out to the community.

Use of assistive technology now and in the future

Technology was considered to be both a blessing and a curse. This included included

- Experiences where technology had become outdated but still locked into the system.
- There could be benefits for improved communication and interaction with the patient including monitoring which would improve the independence of the patient
- There may be stress for paying bills on-line when the main account holder is no longer able to use systems

Summary of Dementia feedback (Torbay)

Dementia feedback Torbay: 2 Memory clinics (Brixham and Newton Abbot)

Approx 25 representatives in each one both family carers and individuals. Aims to provide friendship and fun together with professional or experienced advice and support.

Prevention and living a healthy life

When asked about sharing advice with young people to encourage a health life: considered that social media likely to have greatest risk to health; concern that healthy food messages keep changing and challenges if young people go to school hungry.

When asked about themselves: all understood about healthy lifestyle and the benefit of meeting people on a regular basis. They enjoyed meeting up with the same people and looked forward to attending the memory cafe, but memory cafes are only once a month and would like more. Social media and talking to friends was not considered to have as much benefit as exercise and physical health.

When asked why routine health checks and vaccinations were not taken up it was considered that

- the reason for having them was not understood, (this was the major reason given)
- some gave examples of adverse reaction to the 'flu vaccination that had meant future refusal
- some considered that making the appointment presented a barrier as an excuse for ignoring

suggestions were:

- bringing the vaccination to the individual and to the groups e.g. having it at the Memory Cafe

- increasing the number of reminders and offering appointments, sharing reminders with carers (my son makes my appointment for me)
- a dementia friendly dentist

The role of community support

Discussion showed how the need for support both for the individual and the family carers increased as the disease progressed and with increase in age and frailty. With an extended family, care was shared, either across siblings or moving to live with “my daughter and her family”

Discussion included the stresses on families and how to overcome problems. When the main family support lived away there was discussion on how this remote support worked for the individual. Family carers had not taken up the full range of what was on offer and did not know of existing services when the time for them happened:

Comments:

- I have not had the time to have my Carer’s assessment yet
- We have only just applied for the attendance allowance

Voluntary support, help from neighbours and charitable organisations were valued but not always available.

- Brixham Does Care is wonderful and should be in every town. They are so helpful with form filling etc and its a meeting place for senior citizens
- Neighbour helps with calls due to sight impairment, Brixham Does Care, Oracle in Brixham, information and meeting. The Edge - food (meals) and take care of you (know where you should be). Careline is very good. Dementia Bay walks in Brixham, new service, good neighbours - helping with scooter if brakes down
- Landlord (Riviera Housing Trust) could listen more as tripped going down the stairs and needs a hand-rail on both sides. Having to look after inside of property e.g. new carpet, chairs rather than outside. Looks run down which makes you feel bad
- Need someone to do ironing.
- Not able to get out for a walk at all. Family too busy.
- Memory loss means it is difficult to remember appointment. I am still able to go shopping on my own.
- A widowed lady said the worst thing is she is so lonely and this doesn't help her memory loss. She finds days so long and not able to get out on her own. Has ready meals - no cooking at all.
- Lives with her daughter: spoken to GP about panic attacks. Had panic attacks before she left the house today. Has to have a taxi or friend to get to appointments.

- Husband drives and looks after his wife. GP good and no difficulties to get appointment. Forgotten how many grandchildren she has. Husband very deaf but is her carer. This is 2nd visit [to Memory Cafe] and enjoyed it. Husband (carer) has found it difficult to communicate as very deaf, so relies on his wife to hear on the ‘phone, but this has become more difficult with her memory loss, no computer so not able to skype etc. phone calls becoming difficult.

Technology and its future role

Individuals were not heavy users of personal technology, mostly because they found it too complex to remember, not necessarily because they were against it, although this was voiced. Over half had tried to engage with using tablets and mobile phones but memory and the lack of sustained support had become barriers. When technology such as fall alarms had failed, this was remembered, not the times when it worked well. The groups had no insight to the potential of assistive technology and only a third of individuals were on-line. The poor response was due to not being interested or consider it a risk e.g. bank account fraud.

- I have Broadband for the grandchildren and my son. I do not use it. I have had it explained but I forgot. I had a tablet but it has gone from my memory on how to us it. Need it to be instant. Press a button, they make it complicated I like to be shown not just told.
- Husband (carer) has found it difficult to communicate as very deaf, so relies on his wife to hear on the ‘phone, but this has become more difficult with her memory loss, no computer so not able to skype etc. phone calls becoming difficult.

But there were success stories, especially for wife or husband as carer who may be a similar age to the individual and with their own health issues:

  - Great to skype to New Zealand
  - Shopping on-line to supermarkets – especially where food was put away.
  - Help with medication
  - If new technology becomes available to me I will use it
  - We have a tracker in Mum’s bag as she gets lost

What more is needed?

- Lack of information about cared for condition – dementia and to manage their change in condition, knowing what to expect.
- Need a consistent approach will all aspects of supporting someone with dementia as the person with dementia does not like change.
- Help with some relief for the carer if attending the group
- GP too busy to spend time to discuss your actual issues
- More outdoor activities

- More exercise classes
- Organised holidays for both carer and cared for with trained support (they would be happy to pay)
- what would improve life: more thing like the memory clinic as life is so lonely and I find people find it difficult to accept my dementia

Heart and Lung Feedback: Torbay

Summary of Heart and Lung focus group (Torbay)

Responders came from a community self-help support group and outpatients waiting sessions.

46 written responses returned – indicative themes verbatim comments are included below.

Prevention and living a healthy life

To lead a healthy life priorities are

- Keeping physically healthy (fresh air exercise, eating well) topped the list above meeting up with friends and participating in social media, reading or sharing a hobby with friends
- Mental health is as important as physical health
- When appointments for health checks and vaccinations are ignored it is because people do not understand the reason for them. In some cases it is considered that vaccinations cause problems. To some extent forgetting to make an appointment is the reason for non-attendance

Comments:

- Gaps include better provision for people with mental health, depression, ensuring all people that have physical health needs are getting the same care as those without especially if they have anxiety issues
- Appointment with doctor, make family/friends know how you feel, its not easy to "open up" you feel "a mess", mental breakdowns are hard
- Where possible physiotherapy (fresh air). A balanced diet is important
- Most definitely talking is very good (help when not coping well)
- More information given, times of vaccination clinics to be accessible to all walks of life - e.g. someone who works night shift. Currently I am having investigation to see if I have COPD/asthma
- Improve technology for reminder appointments
- Use media to emphasise the benefits
- Keep advertising the importance of this (health checks). Make it easier for people to get quicker appointments by phone

- More information given beforehand - you cannot force people to do these things
- Make them compulsory
- Make it more easy to understand (use of language, easy read)

The role of community in helping to remain independent

Community support was considered to be an important component of self-help. It was also a component of carer/partner resilience and support after the death of the person cared for.

Comments:

- I moved down to Devon to be nearer family which is very important for me as it gives me peace of mind. Things can always be better but it is often down to resources in all areas. Help is there if you look for it and want it
- The support of friends with transport and shopping helps us to cope during the recovery period
- We encourage the person left after the death of the husband to continue being part of the group (Heartbeaters)

It is not always known what community and voluntary support is available. Transport, availability and ease of making appointments continue to be issues important to effective coping.

Comments:

- This lady and gentleman have to travel from Teignmouth (by car as not able to walk) so always get to Paignton Hospital 1 and a half hours before due appointment time due to lack of parking especially for disabled people
- A few years after a diagnosis of COPD I was having difficulties walking any distance and was granted a Blue Badge enabling me to park closer to my destination
- My husband had a heart attack, without our club I don't know how I would have got on. He then had a tumour and the club (Heartbeaters) was my biggest help. We are completely on our own we have no help from healthcare.
- We have lost our connection with professional physiotherapy support for the group

Use of assistive technology now and in the future

Only a quarter of those responding used health related Apps to any extent. Although two-thirds of individuals have internet at home, less than a quarter of responders use this for health related reasons e.g. ordering medication. Nearly half did agree that technology had or would improved their lives to some extent if made easy to use. There was the repeated concern that assistive technology might replaced contact with professional people.

Comments:

- It's been my change in lifestyle under the supervision of health professional which has improved my life the most not technology
- I don't think any should rely on technology but [use]advice from health professionals
- Not into computers or other means
- My last year or so before retiring I used a computer, although I managed to produce letters on it, I hated using it and never wanted one, I am now "tehno-phobic”
- Prefer the personal touch and going to surgery or ringing the doctor
- Because of my age I find help with technology difficult to find, wish there were more classes etc for keeping up with technology
- Need to be aware that older people do not have knowledge or access
- Easier technology for my age group (76)

What more is needed?

Comments confirmed that they appreciated the quality of hospital care. General Practice was not mentioned other than need for appointments. Outpatients were considered to work well other than recurrence of transport issues. There is recognition that care is a partnership between, professional, family carer and community and the individual.

Comments and helpful suggestions:

- Getting housebound people involved somewhere especially [preventing] isolation
- Letter from hospital in medical terms it would be easier to understand if in plain language. I have never had any problems with treatment at Torbay Hospital
- Help when needed "not" when available. More interaction between people and not mobile phones etc. Not enough NHS dentists.
- Have problems with appointments. Doctors appointments easier if possible
- Having to come all the way to Torbay Hospital from Brixham when I have agoraphobia and anxiety is not good
- Oxygen supply is complex.
- Knowing your limitations, RNIB support and offered house cleaning 2hrs fortnightly, paid. Would like more but not available. Have family support which would work well [in partnership] with professional support through Torbay Hospital and GP surgery.

Appendix 2:

General survey detailed results

3a. Having what I need to live a healthy life

534 responses maximum	Very important	Important	Neutral	Not important	Not important at all
Easy Access to the information I need to help me make decisions about my health and care	73%	22%	3.8%	1.1%	0
The knowledge to help me do what I can to prevent ill health	69%	25.6%	4.7%	0.75%	0
Access to the help and treatment I need when I want it	89%	10.2%	0.74%	0%	0
Professionals that listen to me when I speak to them about my concerns	89%	10%	1%	0.2%	0
For every interaction with health and care services to count: my time is valued	68%	26.6%	4.7%	0.4%	0.4%

All "I" statements overwhelmingly (around 90%) confirmed as either Very Important or Important

4a Being able to manage and choose the support I need

	Very important	Important	Neutral	Not important	Not important at all
If I have a long term condition I decide how the NHS spends money on me	36%	35%	23.8%	4.5%	0%
Choosing the right treatment is a joint decision between me and the relevant health and care professional	68%	27%	3.6%	0.75%	0.4%

I make the decision about where I will go to receive health and care support	48.5%	34.6%	13.6%	2.3%	0.9%
I should be offered care and support in other areas if my local area can't see me in a timely way	45.6%	38%	13.4%	2%	0.75%
I make the decision about when I will receive health and care support	42%	39.6%	15.3%	1.9%	1.1%
My opinion on what is best for me, counts.	53.7%	36%	9.2%	0.4%	0.75%
Communications are timely	70.7%	26.4%	2.7%	-	0.2%
I have time to consider my options and make the choices that are right for me	58.6%	34.2%	6.5%	0.2%	0.6%

Over 80% consider all these statement as important or very important. There is less concern about having a personal decision on funding. Choosing treatment in partnership with the professional and timely communication has the highest level of confirmation. Overall there is less certainty about the individual taking the lead decision.

The help I need to keep my independence and stay healthy as I get older

5a How important to you when it comes to keeping your independence and ageing healthily

	Very important	Important	Neutral	Not important at all
I want to be able to stay in my own home for as long as it is safe to do so	80.4%	15.6%	2.6%	0.4%
My community can support me to live my life the way I want	50%	36%	11.9%	0.4%

My family and friends have the knowledge, confidence and power to help and support me when needed	56.6%	31.7%	8.1%	1.5%
I expect there to be convenient ways for me to travel to health and care services when I need to	68%	26.6%	4.7%	0
I expect that my family and I will feel supported at the end of life	81.4%	14.4%	2.5%	0.75%

Over 80% considered all these statements to be important or very important. Staying at home for as long as it is safe to do so and my family being supported at the end of life has the highest importance. Apparent reliance on family and friends was less certain. Although travel convenience is important the response showed acceptance that this was not going to happen at all times. Reliance on the local community was not rated highly.

How you interact with your local NHS

6a How important when it comes to keeping your independence and ageing healthily

	Very important	Important	Neutral	Not important	Not important at all
I have absolute confidence that my personal data is managed well and kept secure	60.6%	26%	11.5%	0.9%	0.9%
I can access services using my phone or computer	49.6%	35.8%	11.9%	1.7%	0.9%
I can talk to my doctor or other health care professional wherever I am	53.4%	35.2%	9.8%	0.7%	0.7%

I can make appointments online and my options are not limited	49.4%	32.6%	13.8%	2.5%	1.7%
Any results are communicated to me quickly making best use of technology	61.6%	30%	5.3%	1.7%	1.3%
I manage my own personal records so that I can receive continuity in care	40.6%	33.5%	21%	3.4%	1.5%
I am able to talk to other people who are experiencing similar challenges to me to help me feel better	27.4%	32.5%	29%	7.6%	3.4%

Although all but one of the "I" statements are above 70% in total importance responders are acknowledging their lack of confidence with the use of information technology. The weakest response is willingness to speak to other people with similar challenges. As we have noted that self-help conditions specific groups tend to discourage sharing of condition related experience, this may reflect lack of experience in sharing and may point to the need for an increase in use of professionally led Peer support groups in the community.

7. What is most important to you to help you live a healthy life? (pick one)

Easy access to the information I need to help me make decisions about my health and care	12.4%	3rd
The knowledge to help me do what I can to prevent ill health	11.8%	4th
Access to the help and treatment I need when I want it	43.3%	1st
Professionals that listen to me when I speak to them about my concerns	28.2%	2nd

For every interaction with health and care services to count: my time is valued	3.7%	5th

The most popular (access to the help and treatment I need when I want it) has 2 interpretations i.e. the patient makes the choice or alternatively, treatment is available without waiting, so it is unclear what the choice might be. Professional communication is next. Making every contact count is not understood by the patient, reflected in the low choice

8. What is most important to you to be able to manage and choose the support you need? (pick one)

If I have a long term condition I decide how the NHS spends money on me	3.3%	8th
Choosing the right treatment is a joint decision between me and the relevant health and care professional	50.9%	1st
I make the decision about where I will go to receive health and care support	6%	6th
I should be offered care and support in other areas if my local area can't see me in a timely way	11.7%	2nd
I make the decision about when I will receive health and care support	3.7%	7th
My opinion on what is best for me, counts	7.4%	4th
Communications are timely	6.6%	5th
I have time to consider my options and make the choices that are right for me	10.5%	3rd

Highest priority was given to treatment being a joint decision showing support for co-desgn of their care. The lowest being the need to have control of funding in a complex environment. As with the question above the responders were aware that organising good care is complex and not something they would wish to control directly

10. What is most important to you to help you keep your independence and stay healthy as you get older? (pick one)

512 responders

I want to be able to stay in my own home for as long as it is safe to do so	58.4%	1st
My community can support me to live my life the way I want	11.1%	2nd =
My family and friends have the knowledge, confidence and power to help and support me when needed	10.2%	4th
I expect there to be convenient ways for me to travel to health and care services when I need to	11.1%	2nd =
I expect that my family and I will feel supported at the end of life	9%	5th

Over 50% consider home is the best bed. The remaining choices are not significantly different in their value as first choice.

11.What is most important to you when interacting with the NHS?

510 responders

I have absolute confidence that my personal data is managed well and kept secure	13%	3rd
I can access services using my phone or computer	8.4%	5th
I can talk to my doctor or other health care professional wherever I am	40.3%	1st

I can make appointments online and my options are not limited	11%	4th
Any results are communicated to me quickly making best use of technology	16.7%	2nd
I manage my own personal records so that I can receive continuity in care	5.7%	6th
I am able to talk to other people who are experiencing similar challenges to me to help me feel better	5%	7th

Responders identified good communication with their health care professionals as being key to quality interaction. Some considered that use of technology would add to effectiveness of this interaction and that data would be secure. Talking to others experiencing similar challenges was not considered especially helpful to quality interaction with the NHS.

“If there was one more thing that would help you live a healthy life, what would it be?” - Free text responses

NHS themes

Preventative medicine: Respondents feel that the NHS and patients would benefit from emphasis on preventative measures and early detection of illnesses. Patients sometimes feel they are wasting doctors’ time when they seek advice on preventative measures. Multiple respondents suggested that there should be annual general health check-ups.

- #60: “GP appointments under so much pressure that I feel it is unreasonable to book an appointment to discuss niggles, or prevention (strong family history of osteoporosis, I am approaching menopause - I know that now is the time for me to be assessed and potentially start treatment, but it doesn't seem reasonable to take a slot when I can wait 10 days for an urgent appointment if one of the children is ill)”
- #288: “a more preventative approach to my health that could reduce the need for more intensive and invasive care later on.”
- #348: “Annual ‘well person’ check up with age appropriate blood work checks to attempt to identify any health issues before they become too established to treat readily.”
- #364: “an annual health MOT with general blood tests for a range of illnesses.”
- #410: “Annual check-ups, even if I feel well and am asymptomatic. Hidden issues can be detected by professionals and subtle changes become more obvious if baseline values are monitored. As an over 70 person with a chronic medical

condition, I am amazed my GP has never asked me in for routine blood work after being in the practice for 6+ years."

- #475: "Being able to go to the doctor for a "check up" and not being made to feel like I'm wasting time...prevention is far cheaper and better than cure"
- #490: "A thorough and more lengthy medical examination every now and then"
- #537: "For so many of us, it's not just our own health that concerns us; we are also beginning to be carers of another family member with deteriorating health but which is not yet at the stage of needing official outside support"

Continuity of care and integration of services: patients feel they would benefit from greater continuity in their care, better communication and integration between services that treat them, and taking a more holistic approach to health issues (e.g. considering other factors that may aggravate a health issue, such as mental health and lifestyle factors). Respondents feel that healthcare services should be "singing from the same sheet" (#255.)

- #87: "easier access to my own family doctor."
- #89: "access to my named GP when I need to see a GP"
- #120: "To be able to speak to the same doctor at each appointment to guarantee continuity of care"
- #141: "the opportunity for continued care from the same GP"
- #299: "Seeing the same doctor or at least someone aware of my normal health and any issues"
- #305: "Making sure all involved were on the same page, and actually after meetings went off and did what was required as quickly as possible."
- #362: "Tighten communication between patient and healthcare provider so that those who are known to be good self-managers of their care can assist. For example, I need a replacement drug which hasn't appeared on my repeat prescription since transferring my care. Despite repeated efforts the only way I can obtain it is to make an unnecessary appointment blocking the system for others."
- #376: "Continuity of care is really important – building a trusting relationship with professionals."
- #463: "A more holistic approach. I have complex health problems and am seen by a few different consultants/departments but they never seem to communicate with each other. I need to be dealt with as a whole person rather than a set of separate conditions that don't overlap or effect each other - they do. Contra- indications, side-effects and several serious issues have been overlooked and they rarely work together to actually help/treat me. In fact, there seems to be a competitive attitude with a degree of rivalry between specialist consultants and I am regularly stuck in the middle having to sort/balance everything. All this has been very detrimental to both my physical and mental health. It has caused me serious permanent damage."

- #466: “Consistent nurses visiting the home. It becomes difficult to understand what to do when various health workers have different ideas which are often conflicting”

Intermediate medical care: patients may need advice from a medical professional even when an issue does not warrant a GP appointment. One respondent says they would like to speak to someone not “trained to read a tick list” and feels this would reduce the need for unnecessary appointments (#193). Patients wish it was easier to contact staff for advice.

- #60: “I feel it is unreasonable to book an appointment to discuss niggles, or prevention… it doesn’t seem reasonable to take a slot”
- #107: “health advice drop-in sessions e.g. healthy eating, exercise for good health etc.”
- #168: “more appointments available, even if it means not always seeing a doctor, as long as they can give the right information, then if important be passed over to a doctor for further investigation”
- #193: “Be able to have online conversations with health professionals (not a person trained to read a tick list). To reduce the need for unnecessary appointments.”
- #203: “More readily obtainable information about how I can live a healthy life without bothering a doctor”

Waiting times and access: many respondents say they struggle to access the services they need (rural areas, lack of transport, services being closed/defunded) and often deal with long waiting times. Multiple respondents mentioned issues with referrals and felt they would benefit from self-referral services.

- #33: “Easier access to prompt GP appointments”
- #47: “Being able to access timely GP support on the few occasions I actually need it.”
- #308: “shorter wait times to get the help I need”
- #318: “knowing the length of time I should expect to wait for referrals”
- #326: “Self-referral to professionals, e.g physiotherapists has been of great value. The same kind of self-referral for hearing and occupational therapists would be helpful.”
- #488: “Shorter waiting lists for surgery and more intensive care beds. I almost died eighteen months ago because I had to wait six months for heart surgery, which was postponed three times due to emergency procedures taking precedence (rightly so)”
- #493: “Quicker access to NHS services such as physiotherapy”

Resources, staffing, and funding: respondents feel that services are underfunded and understaffed and some feel they would benefit from having more local services – not having to travel to Exeter, for example. Multiple respondents from North Devon mentioned the inconvenience of travelling to Exeter for treatment.

- #78: “more medical & nursing frontline NHS staff.”

- #160: “I live over 20 miles from Exeter hospital, with no direct public transport link. Taxis are over £50.00 each way. There is a very elderly population in this area of East Devon. The in-patient beds have been closed at the 2 local hospitals, and it is a problem trying to visit patients in Exeter. More appointments should be able to be made at Axminster and Seaton hospitals. Why are people from Dorset and Somerset also coming there, when East Devon need them?”
- #293: “Health service provision to meet my needs in my locality”
- #282: “Access to better equipment at the North Devon Hospital so that repetitive up to 4 hour exhausting trips to Exeter is no longer necessary.”
- #205: “Better local provision of rural health services.”
- #297: “My postcode is EX21 5RU, and had a village GP for over 100 years. The practice was taken over by a group practice 10 miles away, and then closed our Surgery, as it "was not economically viable". Ten miles is a twenty minutes car journey for those of us that can drive, if you are infirm or unable to drive you are screwed as there is no suitable bus or other transport service available.”
- #302: “local care as I live in a rural place.”
- #333: “Access to healthcare services close to North Devon. No travelling 70 minutes away to Exeter.”
- #341: “Having enough staff to provide all services. Services to be local to me.”
- #342: “That any help I need is available and properly funded.”

Staff attitudes: some respondents feel that they are not listened to or believed when they report health issues or seek advice

- #16: “Being able to be open with a health professional without the feeling of being judged.”
- #52: “Help when we ask for it. Not being called a liar.”
- #122: “having a GP that does not tell me I have middle-age spread when I have a serious disease and taking 2 years to take me seriously”
- #148: “Not only listen to users but to believe what they are saying after all it's their body.”
- #316: “Professionals to have a caring nature and not to just think about rushing treatment or profit.”
- #317: “I sincerely wish that Doctors amend their attitude towards patients. They have the tendency to "talk down" to patients”
- #537: “It would be good if NHS were gentle with us rather than scolding and finger wagging when our loved ones are being difficult over keeping to the guidelines.”

Other themes

Food and diet: respondents felt that there could be better information available about nutrition and healthy eating, and that the food industry could be better regulated so the public are more aware of the health impact of eating processed, refined, and unhealthy foods. Respondents felt their health would improve if healthy eating was easier and more convenient.

- #191: “More education about the role of nutrition, fresh local food and cooking from fresh ingredients, including a wide variety of vegetables unrefined carbohydrates and good quality protein, both animal, poultry, fish, dairy and plant based. Too many people are ignorant about the health hazards posed by over processed, refined foods, fast food and junk food, not to mention carbonated drinks containing sugar and sweeteners. Too many people lack cooking skills or the confidence to cook from scratch.”
- #218: “government action required to ensure foods don’t contain hidden salt and sugar.”
- #248: “in bold we might see low fat but the products are in fact high in sugar which has hardly any prominence - there are many examples of misleading packaging in our food industry”
- #292: “a reduction in the price of healthy foodstuffs.”
- “#199: “Government taking on the food lobby to regulate for improved labelling and more regulation about excess/unnecessary additives, including sugar and salt, in food, so that we actually know what we're eating”
- #334: “There are so any diets/articles/books/apps about having the right diet… Most of the population are confused or are unable to stick to good quality basic diets… We need more specialists in nutrition to spread basic good quality information about diet & nutrition.”
- #351: “Ability to buy fruit and vegetables at work”
- #375: “Access to up to date results of large scale evidence based studies about nutrition, exercise, breathing techniques, stress busting techniques”
- #478: “Cheaper fresh fruit and vegetables”
- #490: “control of what is allowed in food at source”
- #526: “Provision of fresh vegetable shops available in Torquay, not just in Paignton”

Education, information, and advice: respondents feel they would benefit from more information and advice about health and wellbeing

- Some respondents suggested that there should be better information about alternative and natural treatments – “not just given pills” (#236). Another respondent (#177) said they would like “access to more advice, including natural therapies, other than those advocated by the Pharmaceutical chemical giants.” Respondent #320 said they would like a “more personally tailored approach, taking a holistic overview and not pooh-poohing alternative and complementary medicine simply through lack of knowledge."

- #224: "Having true information about keeping healthy not media/trivia information not based on fact"
- #250 – "prevent conflicting advice from companies trying to sell products."
- #203: "More readily obtainable information about how I can live a healthy life without bothering a doctor"
- #356: "Knowing what happens when one ages (I am 68). So what is normal (for example aches and pains or lumps) and what one should go to my GP about."
- #495: "More health education aimed at younger 16 to 25 year olds regarding health and diet. Never forget when I reached middle age and the bones started to creek. I wished I would have looked after myself better when younger? Education should also include burn out as well as overdoing physical sport and exercise and the future ramifications of overdoing physical exercise later in life."

Transport and travel: respondents feel they would benefit from travelling less by car and by walking or cycling more often; respondents wish there were more cycle and footpaths. Other respondents also commented that fewer cars on the road would lead to less pollution and better air quality.

- #265: "More cycleways & footpaths away from traffic - less pollution, less traffic generally"
- #319: "More provision for cycle lanes and walking paths that are traffic free, for safer and more enjoyable commute to work/ shops. Improved and cheaper public transport would also help reduce traffic and pollution."
- #332: "a decent daily bus service."
- #478: "Better bus service which is affordable allowing people to socialize"

Exercise: many respondents said they would benefit from easier and more affordable access to activities and exercise. Multiple respondents said they felt local gyms and exercise classes were not suitable or welcoming for older people.

- #197: "As per many countries being able to attend more exercising venues allowing people to be in charge of their bodies, make it more affordable. I am a member of our local swimming pool which is not cheap."
- #284: "cheaper sessions at local leisure centres."
- #246: "affordable exercise facilities that are accessible."
- #293: "Access to some kind of exercise equipment suited to over 70s that is local and free and available all day, every day. (Not a lesson at 10am, or walk at 10am, as I am not ready then, nor on certain days only.)"
- #313: "Access to a healthy lifestyle e.g. leisure centres, WW, no matter what your financial background."

- #349: “Help with reduced cost exercise classes and adapt them for disabled people.”
- #357: “More time! Working parents or lone parents accessing fitness venues in evenings where children can also be accommodated or employers providing onsite facilities and time to attend say a gym session in the working day. This has been a major issue for me, I want to exercise but unless you have a baby sitter what are you to do? There is only so much exercise you can do with a child in tow, not everyone has family and or friend support.”
- #465: “Easy access to local exercise routines (Pilates, Yoga, mobility exercise). I am 75 and know my mobility is deteriorating and although I walk a lot, I struggle to tie shoelaces, trim toenails or pick things up. Local gyms are expensive and seem to be full of vigorous young people who I can't keep up with. I don't know where to find out about facilities or services reasonably local to me.”
- #486: “More opportunity to exercise in community based groups. All the local gyms are focused on the young and beautiful - which I am NOT.”
- #506: “Afternoon fitness activities particularly for older persons. Too many activities are am or evenings”
- #519: “More exercise classes for older people”

Community support: multiple respondents felt they would benefit from services and support from their local community. More than one respondent mentioned “social prescribing.”

- #53: “Availability of local, disease specific self-help groups.”
- #96: “access to volunteer groups where peer support is available.”
- #123: “more group-led activities in the local area”
- #220: “Local services that help me to engage in those diets and activities that promote my health”

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

Resources, funding, and local access: Many respondents feel they would benefit from having access to more resources in their local area. Many also feel that NHS funding is an issue.

- #59: “increased resources available to the NHS”
- #84: “Expert opinions based on outcomes not funding etc”
- #88: “Have sufficient qualified staff so we can see someone before a small health issue turns into a major problem, which in turn will be more costly for the NHS.”
- #96: “Have access to talk to Commissioners about where we think money should be spent to help local services.”

- #98: “Better funding – refuse to believe that good health care can be delivered on the cheap.”
- #104: “a walk-in centre in Paignton.”
- #113: “Removing administrative boundaries, particularly in rural areas, so that care can be received at the point most convenient by geography rather than having to travel to provision further away because it is your CCGs local hospital. (For instance people who live in the Plymouth travel to work area, but administratively in Cornwall so some services are only available at Treliske despite it being much further away than Derriford.”
- #117: “Not to be told ‘of course such a treatment or line of action would be most beneficial but as it cost too much we will try something else/cheaper first’”
- #125: “More funding for the NHS.”
- #160: “No-one considers that East Devon NHS is important.”
- #178: “Offer me services which are local so they are easy to get to for me and my family/friends.”
- #292: “I’d like the opportunity to be registered with a female GP.”
- #310: “Enough NHS personnel to help me make a decision, and enough staff to support the services.”
- #333: “That I don't need to go to "other areas" if my area can't support me. My area SHOULD support me.”
- #463: “Realisation that in a more rural, smaller area we have very few choices at all. Most of the time there is no reasonable choice at all. We already have to travel for most services and even the closest can take an hour to get to. Even when I have been advised to see a Specialist outside my Area, this has not happened because of funding and/or a willingness to even consider it. It is usually a case that I have to wait months and then be seen at the nearest local level first. Again, this has caused permanent, irreversible damage.”

Communication with patients: Respondents mention that they would like better and more efficient communication between patients and healthcare staff.

- #23: “good communication between services”
- #36: “more face to face opportunities but a more reliable online option to streamline the bureaucratic aspects of health care”
- #41: “I believe consistent and timely communication is important”
- #49: “an online communication tool (such as Patient Knows Best) to allow two way conversation around my healthcare, and of course consultants who support the use of such tools.”
- #76: “reminders of appointments via email/text” and #61: “health reminders”
- #82: “Open communication including realistic timescales for access to healthcare professionals.”

- #94: “Online or digital access & consultations”
- #131: “That the treatment is explained to me in an appropriate manner (I have a science background) so that I can weigh up risks and benefits.”
- #294: “My doctor recently sent a prescription straight through to the pharmacy. When it was delivered I read the information leaflet. It stated 1 in 10 people were likely to develop a condition I had had to call the emergency doctors in the middle of the night a couple of months previously. As it was obvious this prescription was not suitable for me, I read on. There were other contra indications and at the end of the leaflet I was informed the product was made from the ovaries of hamsters. I have been a strict vegetarian for 40 years. This pre filled syringe cost the NHS $990. As it had left the pharmacy I could not return it for use. It had to be destroyed. If the doctor, who was not my usual one had told me the name of what he had sent through I would have looked it up and never collected it from the pharmacy, but he did not. I am a retired senior nurse and have a BNF on my bookshelf. However, even if I had no previous medical experience I should have been informed of what was being ordered in my name.”
- #362: “Pass on and store messages, there seems to be lots of mishaps with messages not getting through from patients, GPs and hospital staff.”
- #392: “A closer liaison between my GP and the local hospital(s) and the timely communication of relevant information to me e.g. I recently broke my wrist and had no communication from my GP after the referral which was handled wrongly by the hospital leaving me in an inappropriate cast for eight weeks.”
- #481: “Easier communications between professionals/ patients. Waiting on the phone for hours on end is of no use to anyone especially if you are unwell.”
- #492: “Consultations via Skype or such. Email or Twitter access to GP”
- #510: “Bring back the Auxiliary nurses, they help with the actual nursing, leaving the more trained staff to deal with the more medical side of things. This would help people on the wards, maybe, to eat or be fed, help with walking - just after surgery, dressings, temperatures and blood pressure, all at present being done by a nurse, who has done a university degree. These may be classed as 'menial jobs', but, nevertheless important, but the staff wouldn't have to be university trained. Generally being on the ward and not in a side office.”

Information: Multiple respondents wished that the NHS made more information publically available about health, treatment, and healthcare options.

- #39: “understanding all options available so informed choices can be made as well as having the opinion of a doctor”
- #57: “Provision of impartial information about all potential care providers within the area, to include wait times and results tables to enable an informed choice. This should also include parking availability and cost between centres.”
- #74: “accessibility to information”

- #80: “policies open to public or published online”
- #136: “more information to be available”
- #143: “Accessible and relevant information, in accordance with the principles of the Care Act”
- #161: “Too much choice is not good if not enough info is available to decide eg which hospital do you want to go to? Choice is important when the decision is important e.g. Do I have this hip replacement or not”
- #163: “As I get older (I'm 71) I'd like help to understand the differences that are happening to me as far as my brain function is concerned”
- #300: “Early information so that I can plan for the future.”
- #334: “More community support to inform everyone on maintaining good health. Films, talks, quality information not endless jargon. If we sort this, there will be less need for secondary care.”
- #507: “A list of all services available and in other areas with a ranking system of best outcomes - so I can choose which is best and weigh up travelling with quality etc.”

Continuity of care/integration and communication between services: Respondents mentioned that they would like to see their regular or named GP more often, and that the NHS would benefit from better integration and communication between different services and departments.

- #42: “more efficient communication between different health professionals and departments to speed up referral and diagnosis processes.”
- #51: “to be able to see the same doctor for continuity”
- #73: “to have a GP who is a permanent position in my surgery (not a locum).”
- #90: “I have Primary Biliary and an Underactive Thyroid. I generally have to remind Doctors of this when I see them on other issues to make sure treatment suits. I think it should be obvious on my notes so they can’t take it into account without my reminders.”
- #122: “Accurate Communication between hospitals, District Nurses, GPs and their computers. My GP told a department I had a completely incorrect disease. It started with the same letter but that was all they had in common.”
- #128: “to be able to see the GP of my choice much quicker”
- #465: “I have three separate health problems which are dealt with by three separate treatment paths arranged by my GP. I feel it would be more effective if all three were dealt with holistically - I don't know if I would benefit from a more joined up approach.”
- #474: “All information shared with all relevant professionals electronically”
- #502: “That communication between social services and family members improves”

Waiting times and access: Many respondents said they felt waiting times could be shorter and that they would like to have quicker and easier access to their GP or specialist services.

- #62: “shorter waiting times for results and appointments”
- #64: “to be able to book an appointment when I need it”
- #67: “easier access to see the doctor of my choice”
- #128: “to be able to see the GP of my choice much quicker”
- #134: “having the best facilities available quickly”
- #157: “When it takes up to 3-4 weeks to see a GP, 1-2 weeks to see a nurse. When it takes 12-18 weeks to get a hospital appointment, then wait another 12 weeks before you can see a consultant. I would say this is not acceptable.”
- #336: “When there was an urgent referral made, it should be within two weeks, I have waited longer, just to see a specialist. If it is urgent, then it should be within a week.”
- #348: “Ability to discuss more than one concern at a time with GP. Also not always wanting to be seen by nurses who are not always able to diagnose more complicated issues.”

Staff attitudes: some respondents felt that staff are dismissive of their concerns or have bad attitudes towards patients.

- #83: “To be listened to as if I am a living human being with feelings and a life and family. That I am not just a statistic, I have feelings, I need to be heard and know that I am cared for and that after living with this condition for many years, that I might just know what I'm talking about when it comes to my medication and welfare!!!!”
- #166: “Being made to feel that I am being taken seriously would help.”

Preventative medicine: multiple respondents felt they would benefit from preventative measures and treatments.

- #88: “Have sufficient qualified staff so we can see someone before a small health issue turns into a major problem, which in turn will be more costly for the NHS.”
- #153: “Spend more time/money on prevention advice and support. Services are loaded to the time after illness.”
- #156: “More tests and preventative care for post 65”
- #490: “Opportunity to have a detailed assessment of my health periodically.”

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

Local/home care and support

A large number of respondents felt they would benefit from domiciliary and locally-based care. Many expressed concerns about the accessibility and quality of care and support in their local area. Having access to services locally is of high importance to many respondents. Respondents also expressed concerns about the quality and cost of retirement/nursing homes.

- #7: “Good, reliable domiciliary care with choices.”
- #23: “More visits to the home, to assess if people are coping well.”
- #29: “High quality and affordable home care and support.”
- #68: “Increased help to stay independent”
- #76: “Easy home adaptations.”
- #84: “More focus on community healthcare and less on acute hospitals.”
- #92: “An alarm system should I be able to reach the phone.”
- #110: “A joined up system of support for the elderly in their own homes.”
- #124: “Care homes are awful, even more so if you cannot ‘self-fund.’ I cannot think of anything worse than having to go into one.”
- #139: “Warden assisted accommodation. Home helps who can do food shopping and cleaning.”
- #145: “Live-in care in my home.”
- #148: “To have care facilities in the local community, not miles away.”
- #157: “There is very poor support when you want to live in your own home.”
- #160: “None of the trustees of Healthcare Devon, state where they live. No-one ever comes from this area, so no-one ever understand the problems of having to get to Exeter.”
- #163: “travelling to Torbay Hospital by public transport from Brixham takes a long time and is very tiring. Could some diagnostic tests be carried out more locally?”
- #166: “Access to domestic help/carer if needed.”
- #168: “More care workers available for those who want to remain in their own home till the end, unless seriously ill, then be able to go into a nursing home of their choice, and without having to worry about cost”
- #173: “Good options for community support and availability of the kind of supported accommodation that I’d actually enjoy being alive in.”
- #178: “Provide local home care services and get them the time to attend to me properly.”
- #199: “Reinstate and properly fund care and support services within local communities.”
- #203: “Access to medical services at a local level. No more closures of small community hospitals and returning services to those hospitals that have lost them.”

- #215: “good effective community care – that isn’t the case currently.”
- #262: “locally available check-ups for people to avoid very long travel times.”

Transport

For many respondents, concerns about lack of local care and support are exacerbated by a lack of accessible public transport. Many respondents said that better access to transport would help them live healthily and independently, prevent loneliness, and enable them to access many of the services they need.

- #41: “Places to meet locally and transport to these places to meet with other people socially.”
- #43: “Better public transport in the more rural areas to prevent isolation”
- #82: “Good access to facilities e.g. shopping for basic needs.”
- #143: “Public transport! I live in an area where the bus is being axed, resulting in many people with health needs being isolated and excluded from participating in their community.”
- #163: “I don’t drive and travelling to Torbay Hospital by public transport from Brixham takes a long time and is very tiring.”
- #185: “Heavily subsidised transport to appointments.”
- #202: “Help getting to medical services if I am unable to take myself.”
- #264: “Having confidence within public transport, knowing it will continue to run at between the hours of 0600 – 2300 Monday to Sunday.”
- #271: “Design neighbourhoods to support all people, including those who are becoming frail and less able to cope, to access open space, shops, friends, and services, via healthy active methods (e.g. walking) as long as possible.”
- #294: “I moved to the South West from the Highlands due to poor health… I was excited as I saw there was a station and a bus stop, but no one informed me that there was no public transport between West Devon and East Cornwall. I am 25 miles from my son… who I have had to ask to stay (on doctors orders) twice during the night, but he has to drive… I still drive, but one day I might not be able to. It is not an actual health issue, but I know other people who cannot visit or be visited by relatives for the very same reason. Health services need to ensure that transport is available.”
- #296: “Maintain public transport in rural areas – affects access to all services.”
- #297: “we had a truly rural community practice, now we are obliged to travel 10 miles with no public transport, just to see a GP. Efficient it maybe, but screw the patients who are unable to travel that distance under their own steam.”
- #337: “A better public transport system. Currently there is one bus per week on a Friday.”

End of life care

Multiple respondents believe that end-of-life planning would give them peace of mind. Many were concerned about the current quality of end-of-life care in the NHS. Many respondents who mention end-of-life care imply or outright state that they would like the option of legally assisted suicide.

- #39: “greater education about end of life planning from an early age, understanding death is part of life and not fearing the end - being able to choose comfort and dignity. More understanding and opportunity towards euthanasia for those that have progressive degenerative diseases.”
- #56: “Knowing that I would have a good death. And having witnessed the current End of Life care this sadly is just not the case. Knowing you will have the best end of life care IS the way to enjoy your later years without fear… And once again, disjointed services, different care teams, some who breeze in and say 'right sit in the chair' to a dying man, going a few days with no care team available, unanswered phones, told to phone out of hours doctors”
- #60: “we do far too much to very old, frail patients who frequently haven't had their options honestly communicated to them. It takes much more time to set up a package of end of life care, than to arrange an ambulance/admission. Community engagement and raising the profile of end of life care, and reducing unrealistic expectations about likely outcomes for aggressive treatments in the very frail and elderly is urgently needed.”
- #87: “Have easy access 24 hours a day to medical help at the end of life.”
- #105: “I think the subject of end of life can be a difficult one however this to me is a really important. Family support at the time of death at the moment can be very varied depending on the area one lives, so a good co-ordinated approach should be adopted.”
- #119: “The knowledge that if I became incapable through dementia the state would not keep me alive in a care facility. I want to be able to give a written instruction while having all my faculties that should I lose them and no longer know who I am, where I am etc. then the medical profession will be able to put me out of my misery. The current scenario is obscenely cruel and economically unsustainable.”
- #120: “My husband was let down during his end of life care. The whole family feel that is true and I would not wish to suffer the same fate.”
- #126: “I think end of life care should be as comfortable & pain free as possible. Respect for the elderly and infirm.”
- #165: “Accept that it might be better not to live as long as possible at all costs, but to live as well as possible. Sometimes it’s OK to die when the quality of life no longer exists.”
- #212: “Choice on when to end life”
- #288: “I want to retain my independence until the end and choose the time of my death”

- #311: “To know that if I become severally impaired and unable to look after myself I could end my life peacefully with dignity. This would give me great comfort having watched my father die a horrendous death as a Parkinson's victim.”

Socialising and combatting loneliness

- #41: “Places to meet locally and transport to these places to meet with other people socially.”
- #59: “More available to keep older people active and well-nourished with some social interaction.”
- #142: “Loneliness is a huge issue in today’s society and encouraging solutions to that will help enormously.”
- #303: “Good social networks with good exercise opportunities.”
- #334: “Interaction with others as loneliness is a killer.”

Resources, funding

- #21: “confidence in the system that support will be available when required. Due to cut backs a lack of resources, this is not always the case.”
- #51: “To know there are local care homes and facilities here in Brixham and not miles away”
- #67: “More doctor and nursing staff - too long to wait”
- #115: “more money put into adult social care”
- #125: “improved social services funding”
- #143: “Pooling budgets that are not short term and do not rely on lottery funding and charitable events.”
- #150: “Necessary funding to extend palliative care service awareness on the part of the local population and practice”
- #322: “Social Care provision is very important and needs to be funded properly, there should be no distinction between health and social care. There needs to be adequate respite care and rehabilitation provision. The closure of beds has caused a worsening crisis in the acute hospitals because the Sustainability and transformation project has been instigated the wrong way round. Properly organised Social care provision would prevent a lot of hospital admissions as people would not become debilitated and sick because they do not have anyone checking on them. We live in an area of higher than average life expectancy coupled with the fact that many people do not have family living local to them. This is because families have had to leave the South West for work, or older people have moved here for retirement leaving their friends and family in their original domicile.”
- #333: “Integrated social care and healthcare. National Social care needs to be funded by NHS with proper care, NOT tendered out to private services. With integrated social and healthcare this would help me have quality of life.”

Communication with healthcare professionals

- #114: “Local medical centre access by phone.”
- #153: “111 and online resources help, but nothing beats getting reassurance or advice from real people face to face. Elderly relatives are often lonely and need time face to face with a professional to feel reassured”
- #326: “Easier access to discuss problems, e.g. Skype or telephone.”
- #466: “One person who could collate all the different advice from various departments and discuss and advise on what to do.”

Information, advice, and guidance

- #69: “Support and education from health professionals”
- #131: “There should be guidance on what type of accommodation is appropriate for me at different stages in my life. I don’t want to get too old to move.”
- #156: “information on:- how to make homes safe and dementia friendly, how to make memory books and encouragement to do them soon, regular medication checks to ensure only what’s needed is prescribed and that medication does not add to difficulties, introduction/provision of activities for elderly and carer, knowledge to help make elderly feel secure and not worry about selling home/depleting financial resources to pay for care, to ensure known faces are the points of contact, how to see the specialist team early to form the needed relationships.”
- #200: “Easily obtainable advice and help given before you need it”
- #286: “Fast access to advice and anything needed practically to to support independent living.”
- #303: “When needed good information and advice services like Citizens Advice and why not locate this in libraries?”
- #477: “More education regarding palliative care”
- #507: “More information on NHS websites. I often use American sites as I find they have more detailed information.”

Carers

- #31: “Financial support for carers”
- #101: “Someone to live in when I get older so I can stay in my home.”
- #188: “Money given to carers for myself, e.g. family. You have to jump through hoops to receive anything at the moment.”
- #191: “Better recognition for carers, better training and better pay commensurate with the service they provide.   Maybe a professional qualification”

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

Improvements in online services & technology

Many respondents said they would like to see more of their GP services available online, such as the ability to view their medical history. However, some are also concerned that their local services are too reliant on online services, at the expense of the elderly or those without consistent access to the internet. For many, it is important that GP services remain accessible for those who cannot use online services. One respondent (#88) described difficulty in accessing online services without a valid photo ID.

- #12: “Greater use of technology/computer records.”
- #18: “Make it easier to go on line for appointments etc., it won’t accept the password that was given to me I have tried 3 times. It wasn’t a good idea to stop patients making appointments at the desk”
- #25: “Seeing professional in person not via a device”
- #30: “Better GP online services”
- #31: “I cannot hear well so phones are difficult, and I am partly blind, so computers are difficult too. There must be other types of technology, like texting only large phone screens linked to a keyboard. The people who need the most help are like me, old and frail, and rely on carers to use technology for us, we cannot.”
- #51: “Be able to access online appointments which we cannot at St Luke’s in Brixham due to lack of doctors”
- #56: “A lot of these questions are about technology. And yes, a lot more people are using different means of communicating with their health professionals. Apart from being able to communicate much quicker with a GP and receive a quicker response none of the other questions are of particular interest to me. I know many people use technology now but that might isolate the poor and the elderly...”
- #57: “Provision of a patient portal that provides access to services across all sectors from GP bookings to referrals to the acute sector. Ability to book appointments, review requested tests and results, acknowledge receipt of diagnostic results. The portal should provide the patient with transparency of all interaction, apart from when deemed not in the interests of the patient due to exceptional circumstances (validated by more than one authority).”
- #67: “More people to talk to – not everyone has a PC”
- #84: “Better online services and easier access to notes.”
- #88: “My local GP service is currently changing their systems and are encouraging us to use 'Patient Access' which I am quite happy to do, however to gain access I need to have photo ID and 2 proofs of address. I have neither, due to health reasons I am living back with parents, so the household bills are addressed to them. If I get a passport for the photo ID, I will have to ask my GP to sign the photographs to say it is me, to then use the passport as proof of identity at the surgery! I am happy to make the best use of technology but it needs to be accessible to all. I am also all for being able to speak to others with

similar health issues, however I feel those of us who have rare and complicated health issues will lose out.

- #114: “to be able to reorder medication & make appointments by phone, not just online”
- #139: “Email communication with GP. Online GP appointment booking.”
- #143: “Contacting GP practices has become highly problematic - only within certain times, constantly engaged, being held in big queues. Although I enjoy using IT, some people don't. My GP practice expects people to go online for results, which excludes people unable to do this.”
- #199: “Overall making the best use of technology that is accessible and effective - but so far integrated IT health systems have been expensive failures.”

Waiting times & access to GP services

Multiple respondents said they would like shorter waiting times, particularly for GP appointments. Many said that struggle to see their GP when they would like.

- #15: “Getting timely appointments”
- #23: “less waiting times on appointments”
- #55: “GP appointments are extremely difficult to access - especially when you want to see a particular GP. There should be no more GP surgery closures and the ones we have should have more room and more support”
- #64: “Being able to see my GP when I need to”
- #69: “Better access to doctors’ appointments”
- #85: “Easier access to see a GP and not a paramedic or nurse”
- #93: “Only thing would be is having an appointment as soon as possible instead of waiting”
- #97: “To be able to speak to someone when needed”
- #204: “Access to the over worked consultants who deal with eye care. My appointment has been delayed for over a year because hospital clinics are too busy and understaffed”

Continuity of care

Respondents felt that communication between different services and departments could be improved, and that there should be greater integration between services; some respondents said that they have to explain their medical history every time they see a new doctor or nurse. Many said they would like to see the GP more often.

- #24: “Constant communication where possible with the same GP or consultant and that they have the ability to be able to have access to patient's records so that they have complete knowledge of the history. This will give confidence to the patient as they will not have to repeat their history over and over again.”

- #43: “Integrated IT across all aspects of the NHS (not the independent providers - they are less robust and I don't trust them as much with my data given prior experience)”
- #59: “More holistic/integrated approach to NHS IT solutions.”
- #87: “Have continuity of care within my doctor’s surgery.”
- #90: “To be able to see just one doctor who knows you and your situation and a relationship of trust is built up like in the past not seeing an ongoing array of new faces. As you get older more embarrassing ailments occur it is really hard to buck up courage to seek help if it is a stranger”
- #101: “Being able to see the same GP each time I go to the surgery, but so many work part time and I can only go on certain days at certain times.”
- #117: “Not having to fill in endless questionnaires and checklists all asking the same thing every time I engage with or use different NHS services”
- #120: “To have the same doctor treating me throughout. It is very tiring having to explain my condition and how it affects me, so having the same person each visit is a great help!”
- #131: “Personal contact with a designated NHS professional who knows me and my needs.”
- #145: “proper records so that you don't have to repeat yourself over and over again. Secure records that are not sold off to insurance companies, or other interested parties.”
- #177: “Contact with named individuals who would be consistently available and contactable, within reason.”
- #203: “Quicker access to the Dr whose patient I am so that there is continuity of care.”

Access to medical records

Many respondents felt they would benefit from having online access to their medical records. Some respondents who already have this access said that they would like to see their full record, and not an edited version. However, one respondent (#505) expressed concern that the sharing of unabridged medical records may lead to unnecessary anxiety for patients who are not trained to interpret the results, putting further strain on GP practices.

- #84: “Better online services and easier access to notes.”
- #165: “I would like to be able to access ALL of my health care records, for ANY reason.”
- #168: “Make all personal health records available, not just those the local surgery think you should see.”
- #171: “Access to blood test results online”

- #212: “Full access to records not coded records - i.e. being able to see EVERYTHING that is written by any health professional onto my records. And being able to get these corrected when inaccurate.”
- #469: “Easy access to my test results using technology”
- #505: “Holding our own records can also cause problems unless it is a summary only as we cannot be expected to interpret all the results etc. Once again this adds to GP workload as concerns lead to unnecessary consultations to explain what terminology or results mean.”
- #540: “All medical records online and available to me”

“If you have any further comments, please write them below”

Most of the responses to this question echoed the themes that have already been covered in this report, such as: waiting times, continuity of care, NHS funding and resources, patient-staff communication, the closure of local services, and preventative healthcare. The rest of the respondents had comments about the quality of this questionnaire, with some feeling that it did not give them the opportunity to answer questions fully or honestly.

- #24: “In this part of the survey the questions are impossible to answer as some of the points would be equally important.”
- #25: “I don't agree with how this is worded you are not giving any other non-digital options; a total stitch up just like the consultation I attended regarding day services”
- #88: “It is good that you want to know which statement is the most important to us but really it should not be a choice between professionals who listen to me and easy access for information!”
- #98: “Sorry I can't do this. I can't make these statements into priorities because they are all priorities. It doesn't make sense to me to choose in the way you are asking.”
- #150: “Who decides the form of the above questions? Where might this information be found? Which medical consultants if any are involved in shaping these questions?”
- #170: “The whole slant of this questionnaire is wrong.”
- #173: “When interacting with the NHS, pretty much the only thing that is important is a good quality interaction which is likely to lead towards the best possible outcome. I do not think this survey is structured very well.”
- #205: “This set of questions seem very similar as to those on page 1. Why?”
- #218: “Most of these questions are 'leading' questions. They are designed to achieve a specific outcome.”

- #421: “This is rather ambiguous. It asks some questions that are obviously going to be agreed with, then asks you 1 out of 5 all of which are important.”
- #425: “all points are important so is unfair to ask to pick just one”
- #463: “With this last question, NONE of the choices are the most important things when interacting with the NHS - they are important to a degree in their own ways but I am more concerned with getting a timely referral to the right person and then to get the best, timely treatment. Seeing a healthcare professional face to face is better than by phone or via computer etc.”

Appendix 3

Specific conditions survey detailed results **(including free text responses) for Cancer, Dementia, Heart & Lung**

Survey 2 - NHS support for specific conditions across Devon

Overview

The response numbers do not give a high level of reliability in this section, especially as it is unknown what numbers of individuals are receiving treatment across the county. The responses, though, could be considered as indicators for further exploration.

Throughout the responses:

- Dementia conditions reported the least satisfaction for their experience of care.
- Cancer services showed that the emphasis on the responsiveness to their needs have made a significant improvement when compared to other conditions
- Heart and Lung conditions tend to be at an acceptable level of experience
- Expectation of the outcome of care seems to vary across conditions, but as this term is not well described in the survey, responses may be reflecting the person as well as the condition.
- On the whole Cancer and Heart & Lung experienced effective follow through of care, whereas people with Dementia did not. In this latter category responses were more often provided from a carer perspective.

Your experience of getting help and support

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

	Cancer (34)	Dementia (14)	Heart & Lung (20)
No	18%	43%	25%

Not applicable	6%	nil	nil
Somewhat	22%	50%	40%
Yes	56%	7%	35%

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

	Cancer (35)	Dementia (14)	Heart & Lung (20)
Very positive	34%	7%	20%
Positive	45%	2%	30%
Average	8.6%	21.4%	35%
Negative	8.6%	2%	15%
Very negative	nil	36%	nil
Don’t know	0.03%	7%	5%

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

	Cancer (33)	Dementia (13)	Heart & Lung (21)
Yes	33.3%	61.5%	47.6%
No	66.7%	38.5%	52.4%

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

	Cancer (11)	Dementia (8)	Heart & Lung (10)

It made getting support easier	nil	nil	nil
No difference	36.4%	25%	20%
It made getting support harder	45.5%	50%	60%
I don’t know	nil	25%	20%
Not applicable	18%	nil	nil

The health and care support you received after initially seeking help

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

	Cancer (35)	Dementia (14)	Heart & Lung (21)
Very slow	3%	28.5%	14.2%
Slow	20%	21.4%	23.8%
OK	8.8%	42.8%	33.3%
Fast	40%	7%	9.5%
Very fast	22.8%	nil	19%
Don’t know	5.7%	nil	nil

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

	Cancer (35)	Dementia (14)	Heart & Lung (20)
Very slow	2.8%	21.4%	20%

Slow	14.3%	14.3%	25%
OK	20%	42.8%	30%
Fast	37%	14.3%	10%
Very fast	20%	nil	15%
Don’t know	5.7%	7%	nil

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

	Cancer (25)	Dementia (14)	Heart & Lung (20)
Yes	68%	57.1%	45%
No	32%	42.9%	55%

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

	Cancer (38)	Dementia (13)	Heart & Lung (21)
Yes	97%	69%	90.4%
No	3%	31%	9.6%

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

	Cancer (33)	Dementia (9)	Heart & Lung (19)
Very slow	nil	33.3%	15.8%
Slow	18%	11%	15.8%

OK	27.3%	44%	36.8%
Fast	39%	11%	10.5%
Very fast	12%	nil	15.8%
Don't know	3%	nil	nil

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

	Cancer (35)	Dementia (13)	Heart & Lung (21)
Very easy	11.4%	nil	4.8%
Easy	22.9%	7.7%	19%
OK	34.3%	30.8%	23.8%
Difficult	14.3%	15.4%	nil
Very difficult	2.9%	38%	9.5%
Don't know	2.9%	nil	4.8%
Not applicable	11.4%	7.7%	9.5%

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

	Cancer (33)	Dementia (13)	Heart & Lung (19)
Yes	63.6%	15.4%	21%
No	9%	61.5%	47.3%
Somewhat	27.3%	23%	31.6%

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

	Cancer (33)	Dementia (12)	Heart & Lung (20)
Yes	48.5%	8%	40%
No	27.3%	66.7%	35%
Somewhat	24.2%	25%	25%

Time spent travelling to access support and care

20. What is your main means of transport?

	Cancer (35)	Dementia (12)	Heart & Lung (21)
Own car	63%	58%	66.7%
Another person's car (lift)	17%	42%	14.3%
Bus	11.4%	nil	4.7&
Train	2.8%	nil	4.7%
Bicycle	nil	nil	nil
Taxi	2.8%	nil	9.5%
Other	2.8%	nil	nil

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

	Cancer (35)	Dementia (12)	Heart & Lung (21)

Less than 30 min	14.3%	16.7%	14.3%
30 min-1hr	51.4%	33.3%	57%
1-2hrs	8.6%	25%	19%
Over 2hrs	25.7%	25%	9.5%

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

	Cancer (35)	Dementia (12)	Heart & Lung (21)
Less than 30 mins	17%	33.3%	9.5%
30 min-1hr	34%	16.7%	47.6%
1-2hrs	20%	25%	23.8%
More than 2 hrs	29%	25%	19%

Your expectations at each stage of your care

23. What is most important to you?

When first seeking help:

	Cancer (33)	Dementia (9)	Heart & Lung
Seeing a health professional you normally see but you may have to wait	18%	33.3%	22.2%
Seeing any medically appropriate health	42.4%	33.3%	33.3%

professional who is free immediately			
Don’t mind	9%	33.3%	44.5%

When you first received a diagnosis and explanation of treatment or support options

	Cancer (34)	Dementia (9)	Heart & Lung (19)
Seeing a health professional you normally see but you may have to wait	41%	33.3%	21%
Seeing any medically appropriate health professional who is free immediately	53%	44.4%	58%
Don’t mind	6%	22.2%	21%

During your initial treatment or support

	Cancer (33)	Dementia (9)	Heart & Lung (17)
Seeing a health professional you normally see but you may have to wait	54.5%	44%	76.5%
Seeing any medically appropriate health professional who is free immediately	39.4%	33.3%	11.8%
Don’t mind	6%	22.2%	11.8%

During your long term support

	Cancer (31)	Dementia (10)	Heart & Lung (17)
Seeing a health professional you normally see but you may have to wait	51.6%	80%	76.5%
Seeing any medically appropriate health professional who is free immediately	35.5%	10%	11.8%
Don’t mind	12.9%	10%	11.8%

Supporting you to have more control over your own care

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

	Cancer (35)	Dementia (11)	Heart & Lung (21)
A lot of support	20%	63.7%	9.5%
Some support	68.5%	27.3%	81%
I don’t need support	6%	9%	9.5%
Don’t know	6%	nil	nil

Specific conditions survey - free text responses

7. Tell us whether the support met your needs and how it could be improved.

Heart and lung diseases: There were no responses to this question.

Cancer

- SID 13053: “"a) I needed Lymphoedema sleeves. When I went to my GP surgery I was allocated to a locum. She told me that there were no Lymphoedema clinics in Devon (which I knew was incorrect) but that she'd try to order me some more sleeves. The prescription she wrote was incorrect and resulted in a male jock strap being ordered. The pharmacist got in touch with the surgery. I was eventually referred into the local hospice which provided excellent assessment and provision for my needs. b) My oncologist had said to request antibiotics if I was ever visiting a place where I would be at risk for insect bites. When I did this at the same surgery as a) above this request was initially questioned resulting in a telephone assessment by a non-medical member of staff to determine whether I could or could not have these antibiotics. This advice, to ask for antibiotics for the reason mentioned is apparently on my medical records, but no one seems to have referred to these notes."
- SID 25481: “Saw GP who quickly referred me to hospital”
- SID 26026: “Yes.”
- SID 26396: “Quality of clinical support from doctors and nurses was mixed depending on who you were allocated - but overall was good. It could have been improved by the doctors reading my notes prior to the visit so I didn't have to keep them informed and correct their understanding. This was more difficult when I was feeling unwell.”

Dementia

- SID 25578: “More specialist equipment and making home safe both inside and outside.”

12. Please tell us more about the length of time you waited [to receive your initial assessment or diagnosis]:

Heart and lung diseases: There were no responses to this question.

Cancer

- SID 13053: “I now can't give you accurate timescales as my experiences relating to a) and b) above are some time ago. I can tell you that trying to 'phone my surgery on one occasion resulted in hanging on for over an hour to speak to a non-medical member of staff. This person said a member of the medical staff would return my call, they never did. The surgery' website, while ok if your concerns/enquiry is straightforward and related to a subject/symptom on their fixed list does not provide access to something not on their pre-determined list or direct your query to a doctor of your choice within the practice.”

Dementia: There were no responses to this question.

15. If you accessed support, what worked well?

Heart and lung diseases

- SID 17824: “ongoing support following heart attack”

Cancer

- SID 26026: “More information/advice/education. Friendly faces. Sympathetic staff.”

Dementia: there were no responses to this question.

16. If you accessed support, what could be improved?

Heart and lung diseases: there were no responses to this question.

Cancer

- SID 26026: “More resources.”

Dementia: there were no responses to this question.

19. Please tell us more about the length of time you waited [between the initial appointment and seeing the specialist]

Heart and lung diseases: there were no responses to this question.

Cancer

- SID 25481: “2 weeks, rare condition required review.”
- SID 26026: “Can’t remember.”

Dementia: there were no responses to this question.

Learning disability: there were no responses to this question.

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

Heart and lung diseases: there were no responses to this question.

Cancer

- SID 13053: “Once I was referred into the local hospice life became much better. The staff there were efficient and effective.”
- SID 26026: “Supportive.”

Dementia

- SID 25578: “Tight time for carers to relieve one to allow appointments shopping and other family activities.”

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

Heart and lung diseases: There were no responses to this question.

Cancer

- SID 13053: “It was basically the pharmacist contacting the GP Practice confirming that an inappropriate script had been sent in that set in train an assessment at the local hospice. In terms of antibiotics I was asked why I wanted them, I explained and recommended that they checked my medical records where they would i) be able to confirm why I was requesting them and ii) when the last request for a prescription had been made (over a year previously).”

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

Heart and lung diseases: there were no responses to this question.

- SID 26431: “My brother will be living with just half a kidney. He may from time to time have questions or concerns which he will need answers to quickly for peace of mind. If he needs investigations, he will need those done quickly too as if the remaining half kidney fails he will encounter serious problems. At the moment I don’t believe he will be supported

Cancer

- SID 13053: “Provide a service/staffing that gives me confidence in the provider’s competence. If I have a medical concern I want someone trained and qualified in medicine to give me their time not a receptionist, no matter how well meaning they may be.”
- SID 25481: “Regular checks”
- SID 26026: “Signposting to local services/resources. Helpful, available staff. Advice and education.”

Dementia

- SID 25578: “Need to stay well for husband who has dementia and lives at home.”

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

Heart and lung diseases: there were no responses to this question.

Cancer

- SID 26396: “"I have a box full of unused medications that will need to be thrown away - seems a waste of money. I have an unused wig that I cannot return - seems a waste. Although my care was good, I understand the funding issues with the NHS and that it needs a complete redesign to be viable in the future. I think it is hugely important that any redesign and all commissioning of services is undertaken by a fully independent organisation that does not employ people on NHS terms and conditions. I believe that currently too many people have a vested interest to maintain the status quo."

Dementia: there were no responses to this question.

Appendix 4 -

Specific conditions survey (all conditions) free text responses

Specific conditions survey – free text responses

7. Tell us whether the support met your needs and how it could be improved.

Heart and lung diseases: There were no responses to this question.

Long-term health condition (e.g. arthritis, diabetes)

- SID 15307: “I initially accessed care by paying privately to get into the system more quickly”
- SID 20869: “X-ray showed severe osteoarthritis below C3 and the exercises caused pain. The NHS physio had nothing else to suggest. I accessed private physio who educated me in what I could reasonably expect, used gentle massage plus heat to alleviate, while stressing any relief would be temporary. However he was excellent about mental attitude on my part, without patronising me. I learned much, and have for years used T'ai Chi and deep relaxation as a result. I do not blame the NHS physio. I felt she was constrained by time and guidelines. I feel we all need to be educated into reasonable expectations, and self-help methods could be made easily available. In the Midlands our amazing GP taught patients who were willing self-hypnosis. This has been a life changing tool in my family.”
- SID 21205: “I paid out of pocket to see an eye specialist rather than be forced to go to an optician or wait for the local hospital to send an appointment.”
- SID 22128: “good access to disability equipment”
- SID 23167: “Housing to meet my needs, NHS being able to give more authority to help”

- SID 26431: “"My brother had blood tests which threw up some results which needed investigating. He was initially told it could be bone cancer. He was referred for a series of tests which led onto others and the process started last June 2018. There was no urgency and each time another test was required, he was put back into the pot and had to wait the same time as anybody having a one off test. He eventually saw a consultant in November 2018 who told him his kidney had completely failed. He had previous history of kidney problems where his OTHER kidney had become diseased after an injury and was repaired when he was seven. We assumed it would be that one which had failed but it was the one we always referred to as his good kidney. He needed more tests and yet again went into the same pot as everybody else which took another couple of months and he received the results in early January. It took another two months for the consultant appointment in March at which point the kidney removal was discussed. He was scheduled for Surgery in early May which was rescheduled for later in the month. The impact this has had on his mental health has been shocking. When they knew there was an issue and they needed to establish the problem, any tests, scans etc. should have been made a priority. They knew there was a problem and what tests were required to establish what it was, he should never have been made to join the queue again and again and the tests should have been expedited by a health coordinator or consultant, it wasn’t as if they didn’t know there was a problem. It has taken almost 12 months to get to the point where he is about to have surgery. In recent weeks, he has experienced pain in his good kidney and approached his GP who didn’t want to know. They discussed a scan on this kidney prior to the surgery as if there is a problem with the good kidney it may possibly affect how the consultant approaches the operation. My brother was asked to self-refer with no supporting evidence and that a scan would be needed before his surgery, he was told he would have to wait up to 8 weeks with no chance of anything before his surgery. Absolutely shocking! This is a really important procedure and if there are likely to be complications I am sure the surgeon would like a heads up but yet again my brother was expected to join the queue. It should not have taken 12 months to get to this point."

Cancer

- SID 13053: “"a) I needed Lymphoedema sleeves. When I went to my GP surgery I was allocated to a locum. She told me that there were no Lymphoedema clinics in Devon (which I knew was incorrect) but that she'd try to order me some more sleeves. The prescription she wrote was incorrect and resulted in a male jock strap being ordered. The pharmacist got in touch with the surgery. I was eventually referred into the local hospice which provided excellent assessment and provision for my needs. b) My oncologist had said to request antibiotics if I was ever visiting a place where I would be at risk for insect bites. When I did this at the same surgery as a) above this request was initially questioned resulting in a telephone assessment by a non-medical member of staff to determine whether I could or could not have these antibiotics. This advice, to ask for antibiotics for the reason mentioned is apparently on my medical records, but no one seems to have referred to these notes."

- SID 25481: “Saw GP who quickly referred me to hospital”
- SID 26026: “Yes.”
- SID 26396: “Quality of clinical support from doctors and nurses was mixed depending on who you were allocated - but overall was good. It could have been improved by the doctors reading my notes prior to the visit so I didn't have to keep them informed and correct their understanding. This was more difficult when I was feeling unwell.”

Autism

- SID 11501: “Improve communication between members of health visiting/nursery nurse team so I don't have to be constantly chasing them. I spent 6+ months waiting for a health visitor to visit my child after a nursery nurse had advised that a joint nursery nurse/health visitor visit would be needed for the 2 year old check. The nursery nurse completed the check alone as the health visitor was unavailable with the understanding that the health visitor would make contact on returning from leave 2 weeks later. That never happened!! I was left with making contact myself and met with the response of 'we don't know who is meant to be visiting you, we'll work it out & get back to you', followed by yet more silence & me having to initiate contact on multiple occasions. When health visitor did eventually arrive she did manage to refer us to paediatrician & speech therapist.”
- SID 16248: “My child was referred to a paediatrician when he was 6-7 he was finally referred for an autism assessment aged 10 he then had to wait 2 years for Austin Assessment finally diagnosed ages 12 years 5 months”
- SID 16285: “The registrar told me that my child was not autistic and I had to complain about him to the consultant to get her assessed. We got the same doctor (by then promoted to consultant) for my next child. He actually said that it was his job to get the waiting list down and refused to assess my next child deciding that she was not autistic. I had to argue the case in a very sweaty meeting to get her assessed. The assessment report from Torbay Hospital was rubbish compared to the one from Great Ormond Street which gave lots of detail about areas of strength and weakness which was useful educationally. The Torbay one just said ‘autism spectrum condition’. The Early Bird + and Cygnet courses were good, but there is no ongoing support and no awareness of comorbid conditions. I think that a paediatrician needs to have an overview of the development of a child with autism, not just diagnose and discharge.”

Dementia

- SID 25578: “More specialist equipment and making home safe both inside and outside.”

Learning disability

- SID 26422: “Existing support for people with mental disabilities does not meet my wife's needs… All the support on offer is group based and she always feels isolated in groups”

Mental health

- SID 7739: “The support did not meet my needs as they offered me CBT which relies on self-assessment which is pointless on people who have no feeling of self-worth”
- SID 10377: “No support as even though he was an urgent CAHMS referral, they said they couldn't come out to see him as he refused to attend his appointment. Home visit would've been beneficial starting point.”
- SID 11603: “I had a mental health assessment. The report came back. It didn't mention the child abuse I spoke about, but DID mention that my parents (the abusers) are "supportive" of me. Didn't mention that I hadn't showered in a week, but DID mention "evidence of acceptable general self-care". Didn't mention the regular self-harm, but DID state that I apparently "haven't self-harmed in a while now" (I hadn't for a week beforehand). Mentioned my active suicide plan, but said my life had improved enough to make me reconsider - which is not at all what I said. Then they labelled me as low risk, didn't diagnose me with anything , discharged me and gave me a bunch of leaflets for programs I can't attend due to my physical illness (which the assessor wrote about in great detail, so they knew about this). Super, super unhelpful and distressing, and has had a really negative impact on my mental health since then; I have declined and now self-harm pretty much every day.”
- SID 21206: “A family member had mental health problems and there was a delay before he was seen by the consultant. By the time he was seen his condition had worsened. As a carer I felt that if he had received the correct help earlier his recovery would have been quicker.”
- SID 25408: “No understanding.”

12. Please tell us more about the length of time you waited [to receive your initial assessment or diagnosis]:

Heart and lung diseases: There were no responses to this question.

Long-term condition

- SID 15307: “I had already been diagnosed abroad so it was an issue of getting into the system here.”
- SID 20869: “Again the physio route was appropriate, but the old within 3 days system has gone. It was two weeks instead”
- SID 21205: “Paying out of pocket sped up the process of the initial assessment in this area of an ongoing condition I have been dealing with for over 13 years.”
- SID 22128: “didn't wait long”
- SID 26431: “June to Mid-November to establish that a kidney had failed. And another 6 months to get to surgery.”

Cancer

- SID 13053: “I now can't give you accurate timescales as my experiences relating to a) and b) above are some time ago. I can tell you that trying to 'phone my surgery on one occasion resulted in hanging on for over an hour to speak to a non-medical member of staff. This person said a member of the medical staff would return my call, they never did. The surgery' website, while ok if your concerns/enquiry is straightforward and related to a subject/symptom on their fixed list does not provide access to something not on their pre-determined list or direct your query to a doctor of your choice within the practice."

- SID 25481: "3 weeks"
- SID 26026: "2 weeks"

Autism

- SID 11501: "WE'RE STILL WAITING!!!!! Having made contact with nursery nurse in March 2017, it took 6+ months to be seen by health visitor (home visit required & had been due in March '17 with nursery nurse) we were then referred to a paediatrician (fairly quickly) who referred us onto the Child Development Centre. Contact made by the CDC was relatively quick after referral from paediatrician (Mar '18), however we were told our son would need a multidisciplinary assessment as the next step & there was at that point a 12 month waiting. So 12 months on from CDC contact & 2 years since initially requesting support, we are still waiting for the assessment, have been told the assessment won't take place until the summer (I have heard via the grapevine of other parents it may now be a 2 year wait). This means our son has been WAITING HALF HIS LIFE for an assessment!!!!! And there is NO SIGN OF AN ASSESSMENT HAPPENING SOON. He is now 4. School are reluctant to do anything until he has received an assessment & beyond that a diagnosis. Professionals along the way have suggested he has autism, he is also completely non-verbal. We have had odd bits of speech therapy but that is the only medical support we have received - nothing autism related. There has been limited/no communication from the CDC informing us of the delay, giving reason for it or asking if we are ok supporting our child. Though helpful when involved in face-to-face contact the silence is deafening in between."
- SID 16248: "Waiting times for Torbay autism assessment team is over 18 months. Once the initial assessment starts it's very quick. It's a long process to get there. At first you need a referral to the autism assessment team that's an even longer process via peads route"
- SID 16285: "About six months on a fast track for one of my children, 15 months (by going out of area) and two years for the third child who was diagnosed with autism. There's no chance of early intervention with delays like that."

Dementia: There were no responses to this question.

Learning disability

- SID 13935: "waiting for multi agency's to work together, slow communication"
- SID 26422: "I was unaware for many years that I qualified for carer's allowance"

Mental health

- SID 7739: "About 6 weeks to see somebody initially"

- SID 11603: “I waited about two months. It's average.”
- SID 21206: “Several weeks to see the consultant. We were lucky to be seen by a nurse and I was offered carer support which I found helpful.”
- SID 25408: “3 months”

15. If you accessed support, what worked well?

Heart and lung diseases

- SID 17824: “ongoing support following heart attack”

Long-term conditions

- SID 21205: “Again I stayed in the private sector paying out of pocket for care.”

Cancer

- SID 26026: “More information/advice/education. Friendly faces. Sympathetic staff.”

Autism

- SID 16248: “Unfortunately there is a waiting list and wait time to access the cygnet course after an autism diagnoses”

Dementia: there were no responses to this question.

Learning disability

- SID 11023: “ROC support in Torbay”

Mental health

- SID 21206: “Support of nurse and carer support”
- SID 25408: “Medication”

16. If you accessed support, what could be improved?

Heart and lung diseases: there were no responses to this question.

Long term conditions

- SID 22121: “time related”
- SID 23167: “Be more local”

Cancer

- SID 26026: “More resources.”

Autism: there were no responses to this question.

Dementia: there were no responses to this question.

Learning disability

- SID 11023: “More free exercise classes and activities”

- SID 26422: “Existing support for people with mental disabilities does not meet my wife's needs… All the support on offer is group based and she always feels isolated in groups”

Mental health

- SID 21206: “Advice on how to handle the patient with mental health issues. It was very bewildering and I found help through a voluntary support group.”
- SID 25408: “Diagnosis”

19. Please tell us more about the length of time you waited [between the initial appointment and seeing the specialist]

Heart and lung diseases: there were no responses to this question.

Long-term conditions

- SID 15307: “Paid privately”
- SID 20869: “4.5 weeks to see next level of physiotherapy”
- SID 21205: “Cannot remember exactly but it was 3+ months”
- SID 22121: “2 and a half months”
- SID 22133: “4 years”
- SID 23167: “3 month wait”
- SID 26418: “selected private”
- SID 26431: “As above......it should have been more joined up.”

Cancer

- SID 25481: “2 weeks, rare condition required review.”
- SID 26026: “Can’t remember.”

Autism: there were no responses to this question.

Dementia: there were no responses to this question.

Learning disability: there were no responses to this question.

Mental health: there were no responses to this question.

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

Heart and lung diseases: there were no responses to this question.

Long-term conditions

- SID 15307: “I received appropriate follow up and ongoing diagnostic tests”
- SID 20869: “I accept that I have been referred to higher level physiotherapy, from where access to consultant can come, but it has taken a long time, and normal life is on hold.”

- SID 22121: “still waiting for assessment”
- SID 22128: “if treatment is closer to home”
- SID 23167: “Sessions moved to different towns that I cannot get to easily. So I could not go.”
- SID 26431: “All of this threw up questions and concerns and each time he had to start from the beginning. It would have helped if people he came into contact with had read his notes and knew and understood the problem he was facing with one dead kidney and half of one which was doing the work of two.”

Cancer

- SID 13053: “Once I was referred into the local hospice life became much better. The staff there were efficient and effective.”
- SID 26026: “Supportive.”

Autism

- SID 16248: “There is not much in the way of support in today for those on the spectrum.”
- SID 16285: “I was horrified by the lack of ongoing support. There’s none, the doctors are pretty much fighting you off.”

Dementia

- SID 25578: “Tight time for carers to relieve one to allow appointments shopping and other family activities.”

Learning disability

- SID 13935: “Not enough nurses who can work well with a person with a learning disability.”
- SID 26422: Existing support for people with mental disabilities does not meet my wife's needs… All the support on offer is group based and she always feels isolated in groups… She needs group support that is proactive in preventing isolation”

Mental health

- SID 7739: “I was not made aware of any options”
- SID 10377: “The only support offered was in the form of leaflets for community-run mental health support groups, which I can't even attend due to physical illness (that the mental health team was aware of).
- SID 21206: “It would have been useful if there was somewhere for the patient to go after diagnosis i.e. a day unit as he stayed in bed a lot of the time.”
- SID 25408: “Deemed fil”

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

Heart and lung diseases: There were no responses to this question.

Long-term condition

- SID 20869: “Individual physiotherapists took time and trouble, but I need to be on a list for hip surgery, and feel that the physio service is being used to slow down the process because of shortage of staff and/or facilities.”
- SID 21205: “Had to call to try and get results of tests and only after 4+ months did I get an appt letter for a specialist without any further explanation.”
- SID 22121: “still waiting”
- SID 26431: “Once they knew my brother had a problem (early days) they should have coordinated a timely approach to establishing the problem and how it would be dealt with. Almost a year from start to finish is unacceptable.”

Cancer

- SID 13053: “It was basically the pharmacist contacting the GP Practice confirming that an inappropriate script had been sent in that set in train an assessment at the local hospice. In terms of antibiotics I was asked why I wanted them, I explained and recommended that they checked my medical records where they would i) be able to confirm why I was requesting them and ii) when the last request for a prescription had been made (over a year previously).”

Autism

- SID 16248: “Better communication in general. Myself had to ring the services to find out what was happening i.e. how long the wait or where my child was on the list. If the paediatrician sent the relevant paperwork.”
- SID 16285: “I can’t remember to be honest.”

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

Heart and lung diseases: there were no responses to this question.

Long-term conditions

- SID 15307: “Timely and regular follow up appts”
- SID 20869: “point me at sources of clear information, plus pathways to any resources I could use.”
- SID 21205: “Earlier intervention”
- SID 22121: “knowledge on how to manage condition”
- SID 22128: “better access to local doctor”
- SID 23167: “To have services available in my local area due to constant pain, unable to drive for long distances.”
- SID 26431: “My brother will be living with just half a kidney. He may from time to time have questions or concerns which he will need answers to quickly for peace of

mind. If he needs investigations, he will need those done quickly too as if the remaining half kidney fails he will encounter serious problems. At the moment I don’t believe he will be supported by the kidney unit and that would be good if he could just pick the phone up if he needs to but no mention has been made.”

Cancer

- SID 13053: “Provide a service/staffing that gives me confidence in the provider’s competence. If I have a medical concern I want someone trained and qualified in medicine to give me their time not a receptionist, no matter how well meaning they may be.”
- SID 25481: “Regular checks”
- SID 26026: “Signposting to local services/resources. Helpful, available staff. Advice and education.”

Autism

- SID 16248: “More health professionals trained in understanding autism learning difficulties and send.”

Dementia

- SID 25578: “Need to stay well for husband who has dementia and lives at home.”

Learning disability

- SID 26422: “More proactive support for mentally disabled”

Mental health

- SID 7739: “Increased funding for mental health in Torbay over in reqsing the funding for addiction which is constantly being increased”
- SID 11603: “Offer me literally any support whatsoever. Not give the impression that they don't listen to anything I say, and don't care about whether I live or not.”
- SID 21206: “I get called in for checks which is useful”

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

Heart and lung diseases: there were no responses to this question.

Long-term conditions

- SID 20869: “I find individual NHS staff, across all areas largely warmly friendly, professional, and prepared to be clear about what is and isn't possible. It is those limitations which I regret for myself, and for vast swathes of the population.”
- SID 21205: “NHS deals with a lot of emergencies but I feel earlier interventions when symptoms arise would reduce the need and number of emergency situations arising if caught earlier.”

Cancer

- SID 26396: “"I have a box full of unused medications that will need to be thrown away - seems a waste of money. I have an unused wig that I cannot return - seems a waste. Although my care was good, I understand the funding issues with the NHS and that it needs a complete redesign to be viable in the future. I think it is hugely important that any redesign and all commissioning of services is undertaken by a fully independent organisation that does not employ people on NHS terms and conditions. I believe that currently too many people have a vested interest to maintain the status quo."

Autism

- SID 11501: Someone who has a child with Down syndrome once said to me that she had been told 'SHE WAS LUCKY TO HAVE A CHILD WITH DOWN SYNDROME'. The friend was slightly confused by this comment but I can fully understand why it was made. A child with DS has an obvious difficulty noticeable from birth & therefore all measure of support is put in place at times prior to issues arising, however a child with autism or similar is ignored and parents made to feel a failure because their child doesn't respond by the correct milestones, they have to fight to get professionals to realise their child is having difficulties often being told 'they may be just a late developer' & then when they do start getting people to listen they're put on a mammoth waiting list with no support or contact. And those children who have parents who are able to use their own initiative to support their child & implement strategies seemed to end up even further down the list as they are viewed to be coping, as the parents have done their own research, put in strategies to reduce meltdowns etc. & support their child's education, all the while the parents are being destroyed financially and emotionally through lack of support from actual medical professionals. We may still be barking up the wrong tree because at the end of the day we're not medical professionals, we're just guessing & hoping for the best & STILL AWAITING a diagnosis.
- SID 16285: “I can’t answer some of the questions - they don’t work on my phone”

Dementia: there were no responses to this question.

Learning disability

- SID 26422: “Increase taxes to get more money into the system”

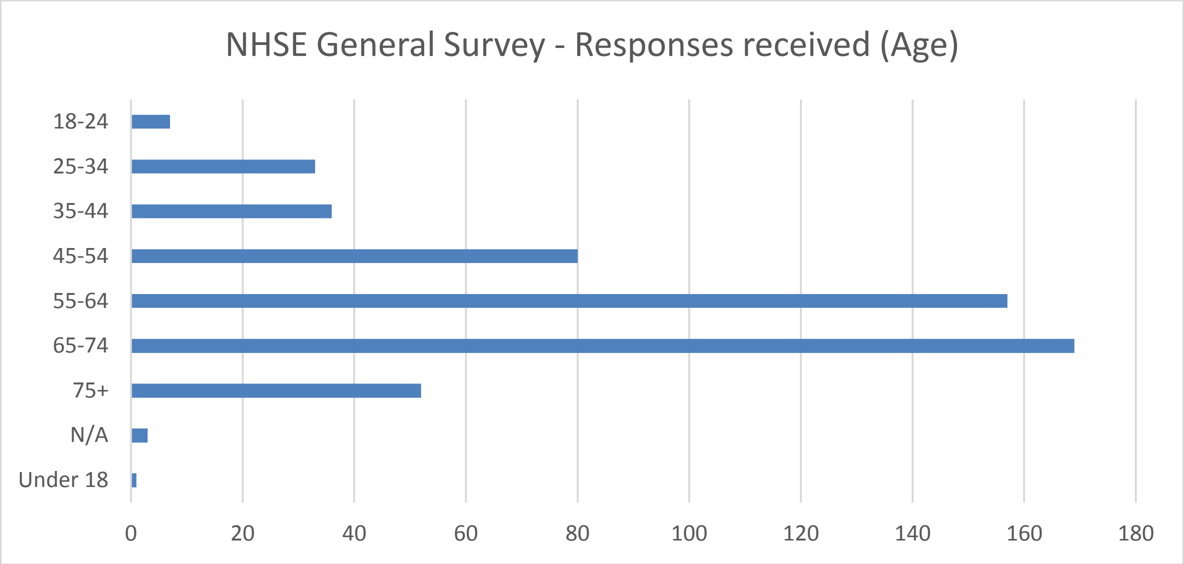
Mental health

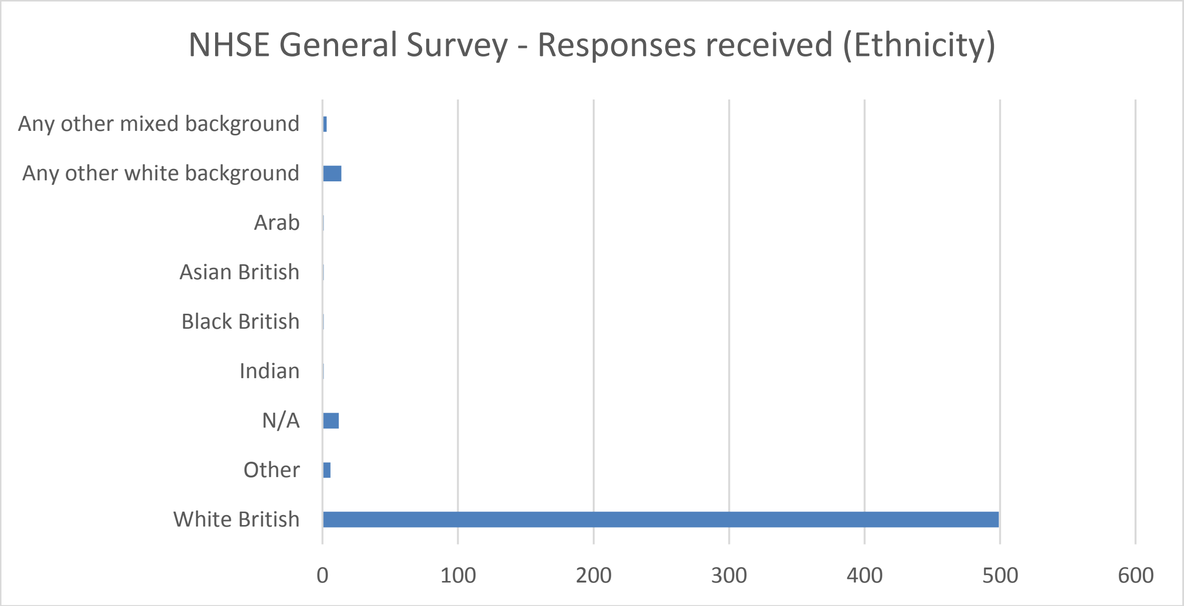
- SID 7739: “The state of mental health care in Torbay is pathetic as the budget has been cut so much they have reduced services to a level just above non-existent”
- SID 10377: “The problem he had was with CAHMS, his GP has been fantastic once he was ready to seek help.”
- SID 21206: “I was a carer but not anymore”

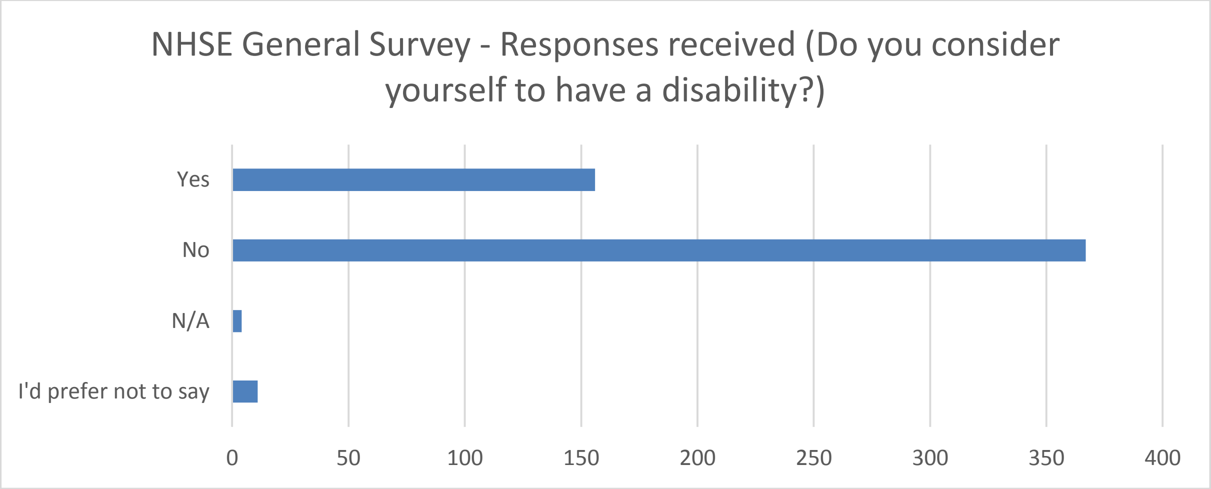
Appendix 5

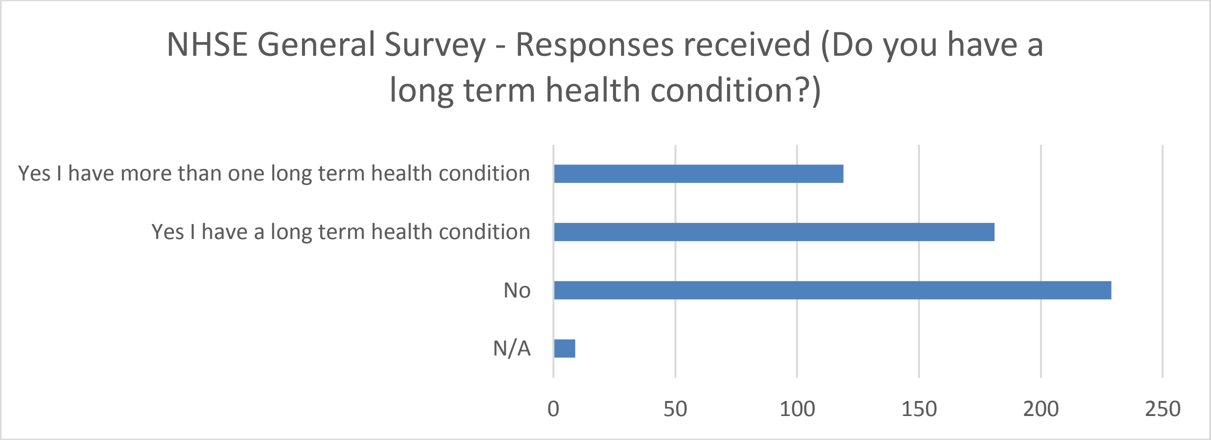
Demographics

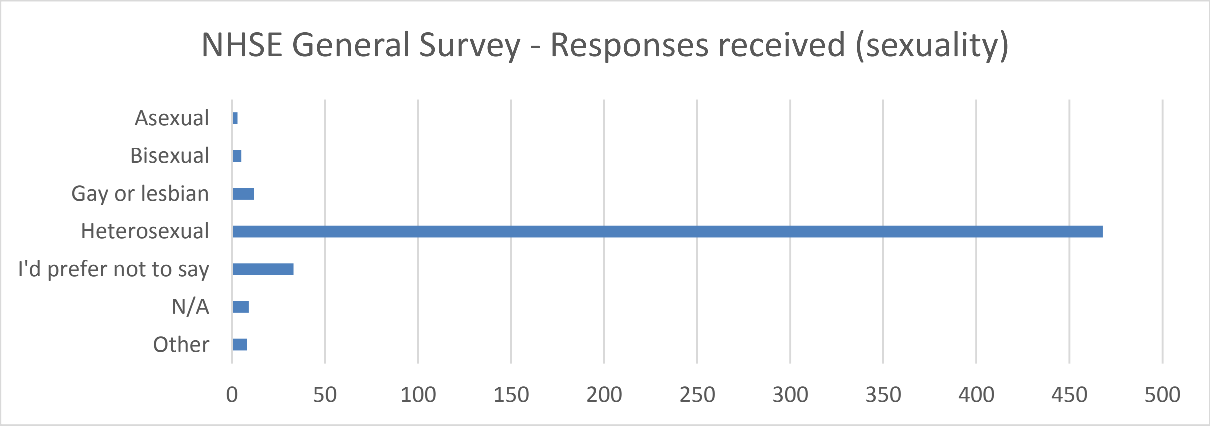
General Survey – 538 responses received

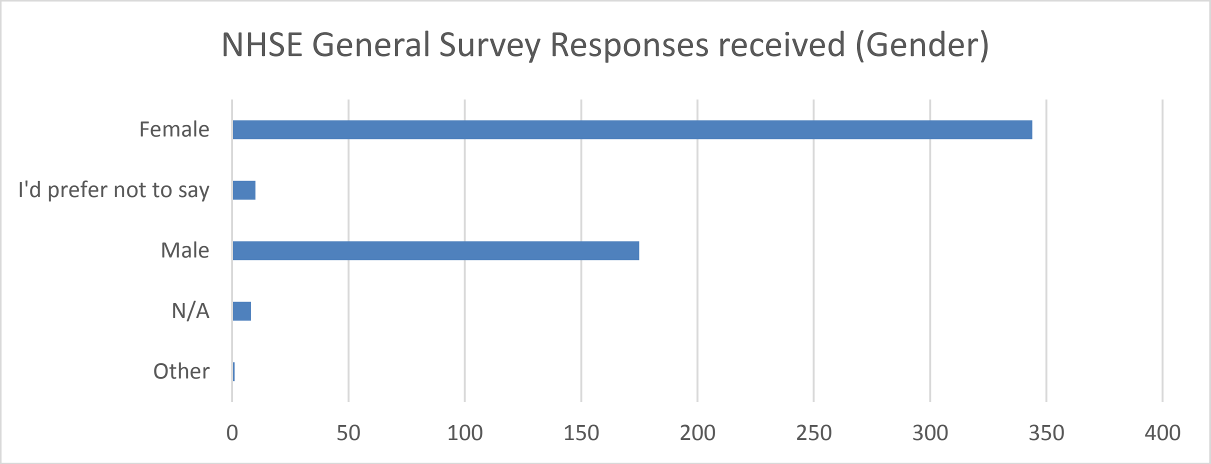


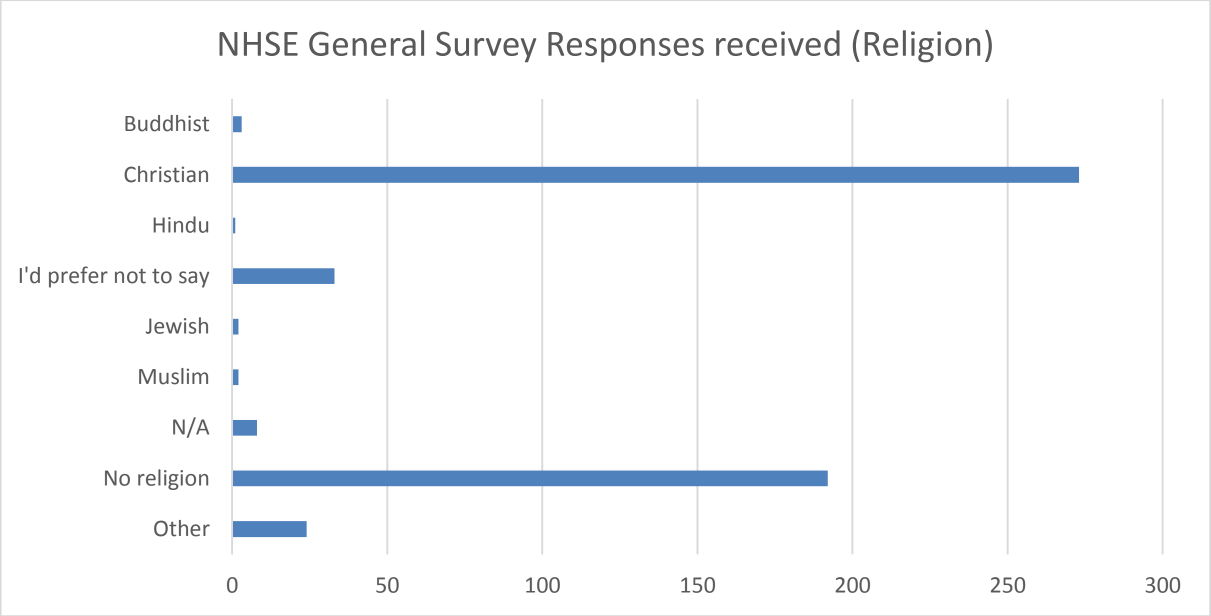



NHSE General Survey - Responses received (Do you consider yourself to have a disability?)
Yes
No
N/A
I'd prefer not to say
0
50
100
150
200
250
300
350
400

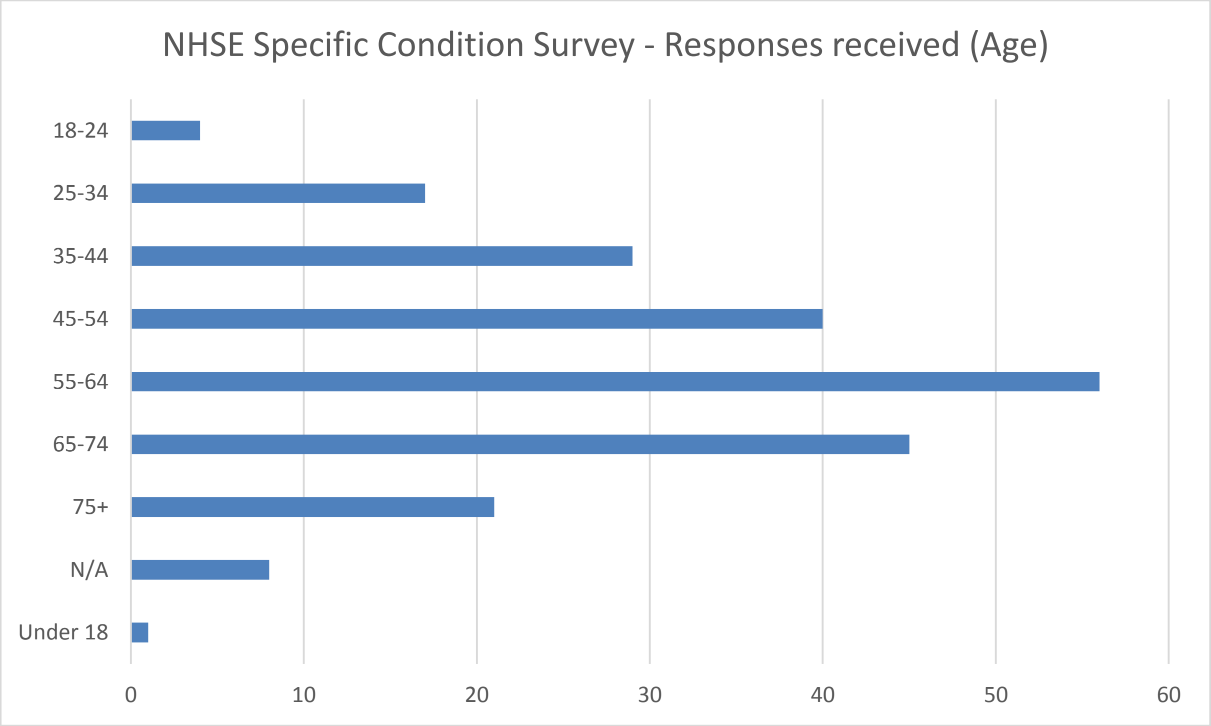

NHSE General Survey - Responses received (Do you have a long term health condition?)
Yes I have more than one long term health condition
Yes I have a long term health condition
No
N/A
0
50
100
150
200
250

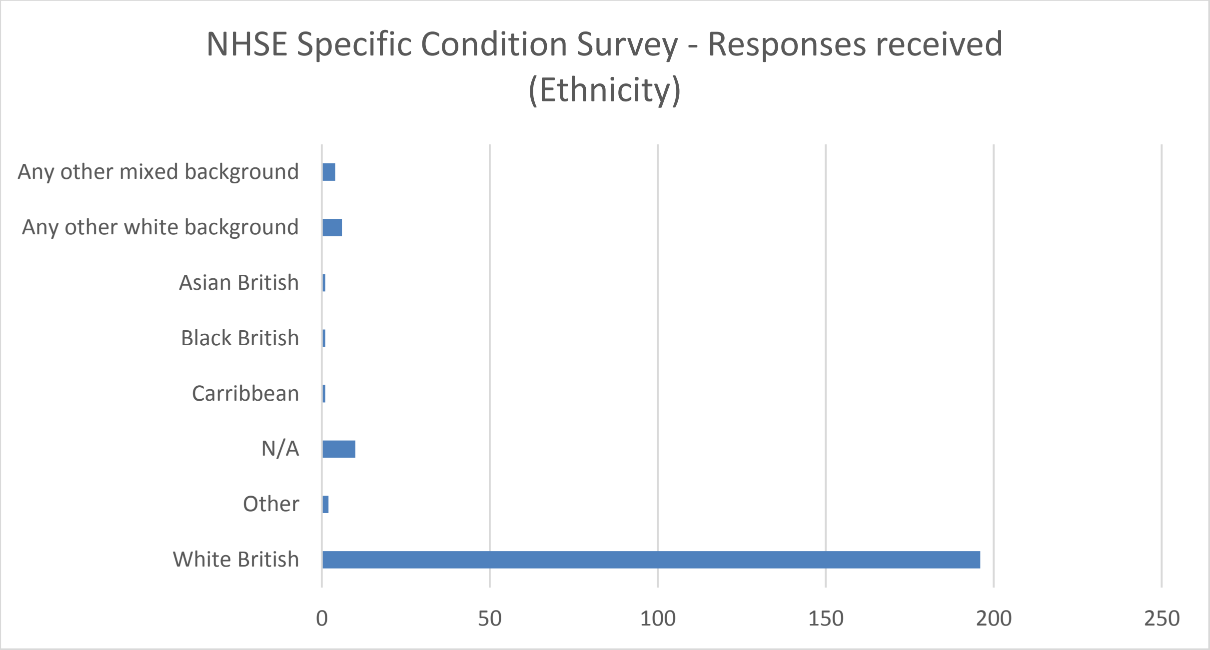

NHSE General Survey - Responses received (sexuality)
Asexual
Bisexual
Gay or lesbian
Heterosexual
I'd prefer not to say
N/A
Other
0
50
100
150
200
250
300
350
400
450
500

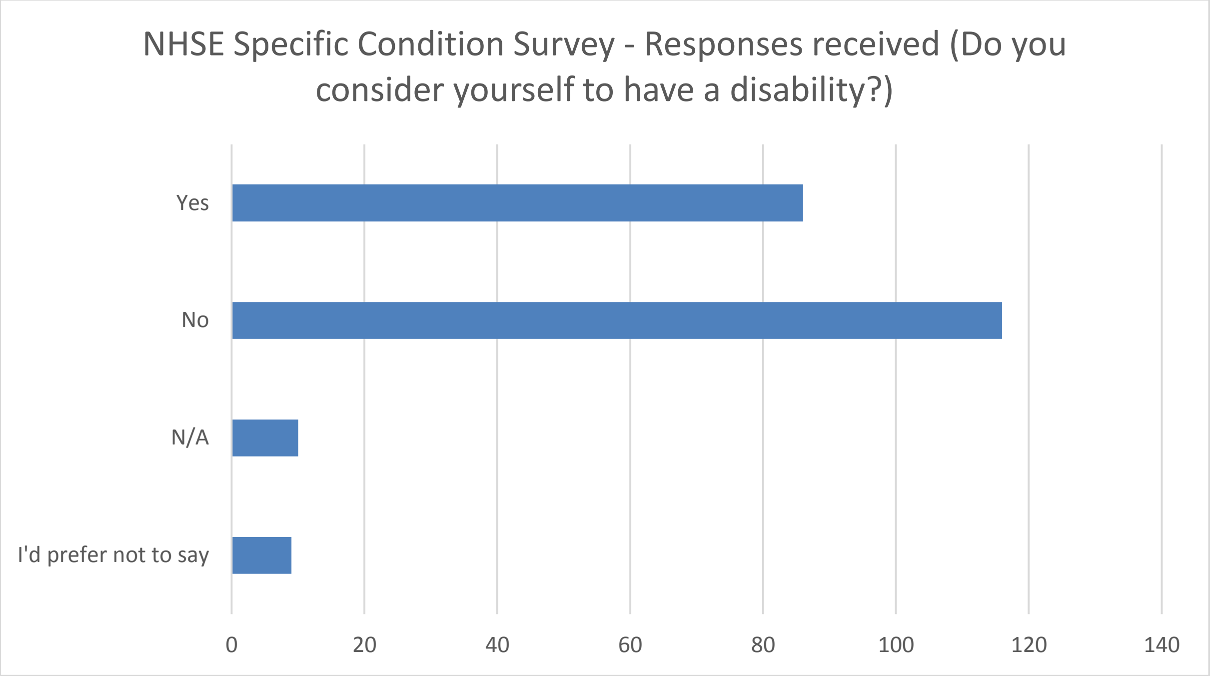


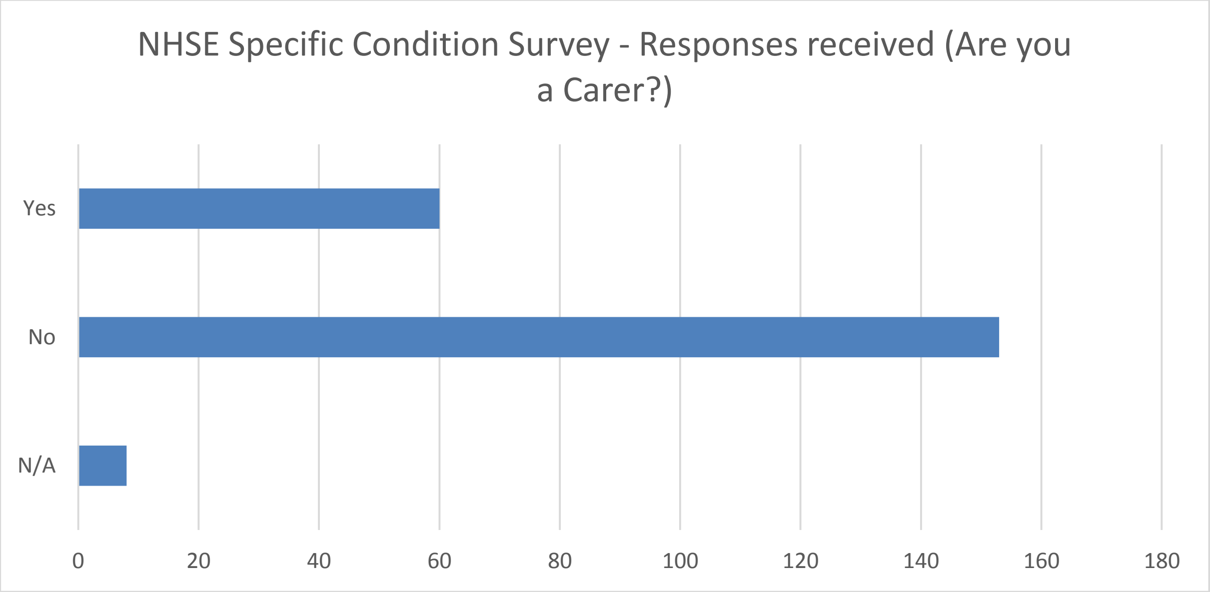


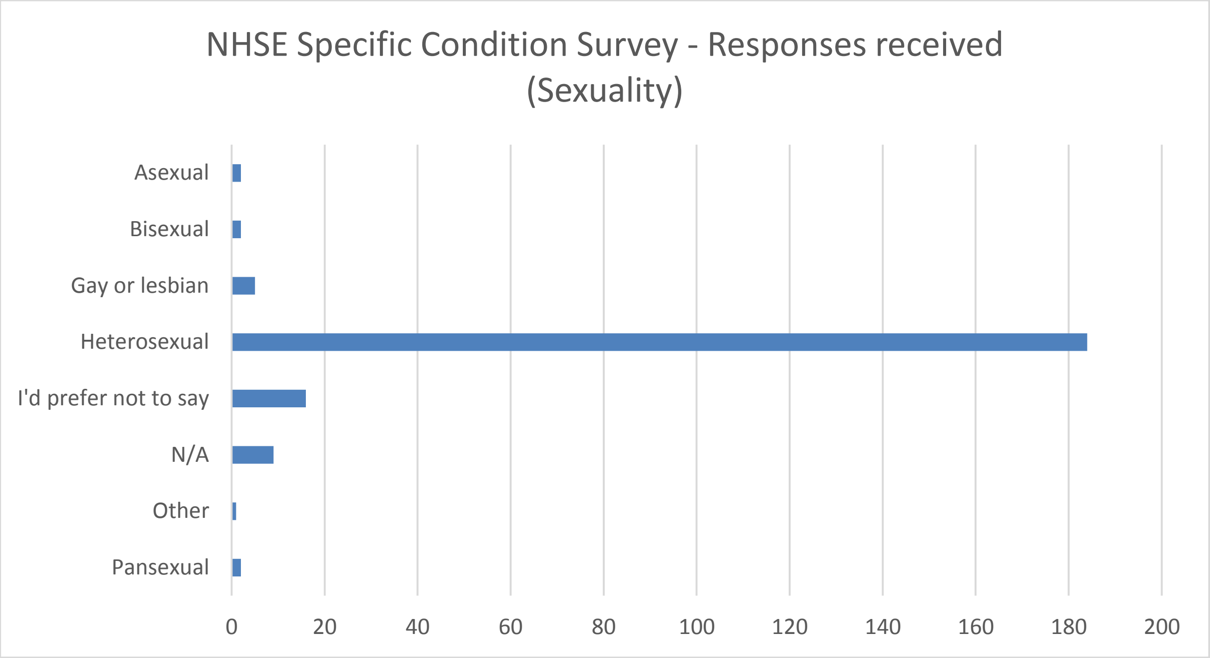
Specific Condition Survey - 221 responses received

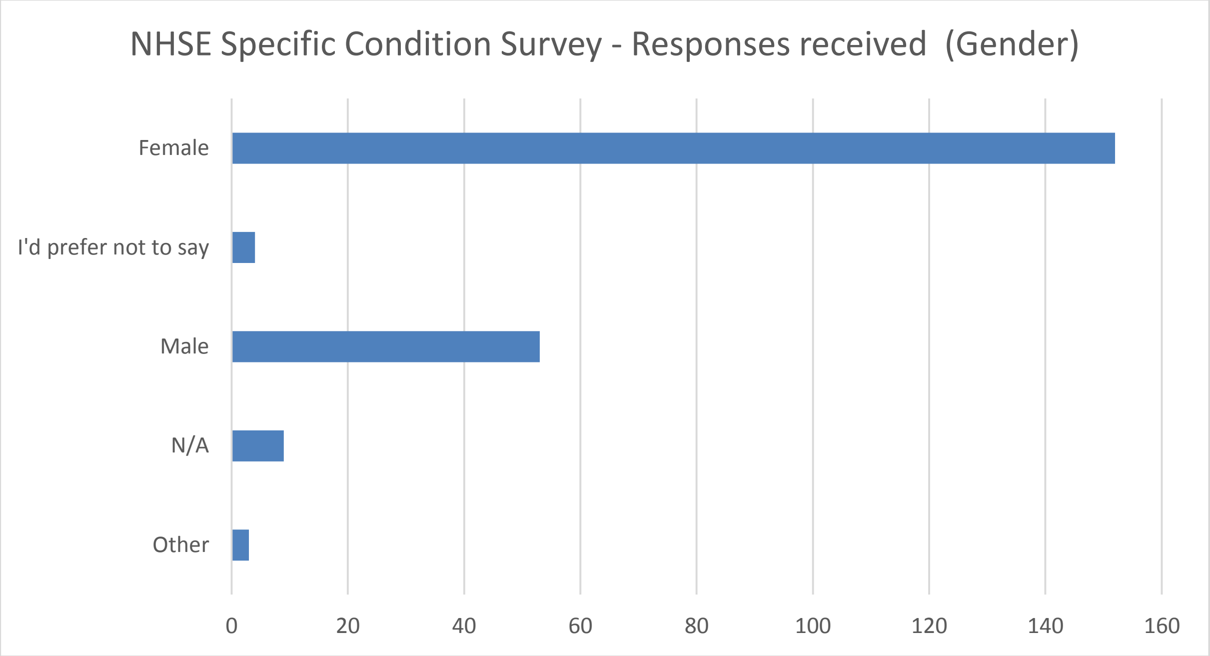


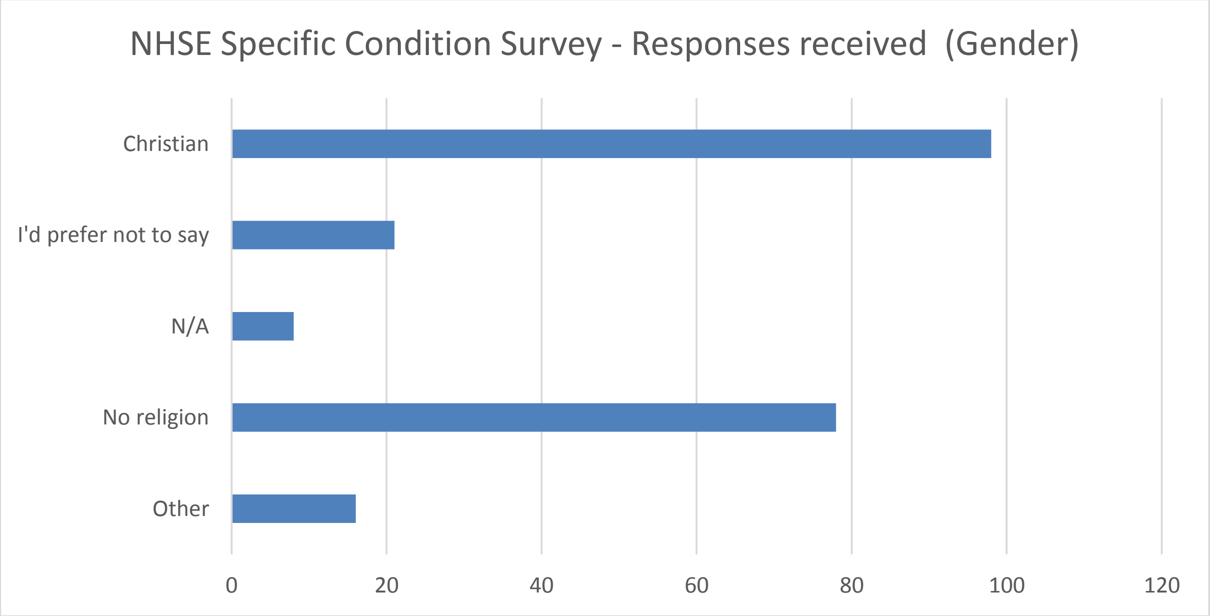

NHSE Specific Condition Survey - Responses received (Ethnicity)
Any other mixed background
Any other white background
Asian British
Black British
Carribbean
N/A
Other
White British
0
50
100
150
200
250


NHSE Specific Condition Survey - Responses received (Do you consider yourself to have a disability?)
Yes
No
N/A
I'd prefer not to say
0
20
40
60
80
100
120
140


NHSE Specific Condition Survey - Responses received (Are you a Carer?)
Yes
No
N/A
0
20
40
60
80
100
120
140
160
180


NHSE Specific Condition Survey - Responses received (Sexuality)
Asexual
Bisexual
Gay or lesbian
Heterosexual
I'd prefer not to say
N/A
Other
Pansexual
0
20
40
60
80
100
120
140
160
180
200


NHSE Specific Condition Survey - Responses received (Gender)
Female
I'd prefer not to say
Male
N/A
Other
0
20
40
60
80
100
120
140
160


NHSE Specific Condition Survey - Responses received (Gender)
Christian
I'd prefer not to say
N/A
No religion
Other
0
20
40
60
80
100
120

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FINAL VERSION 5