

The NHS Long Term Plan

Black Country and West Birmingham

what
would you do?

It's your NHS. Have your say.

A Healthwatch report for the Black Country
and West Birmingham Sustainability and
Transformation Partnership

June 2019

healthwatch
Dudley

healthwatch
Sandwell

healthwatch
Walsall

healthwatch
Wolverhampton

healthwatch
Birmingham



Contents

Page	Section
3	1 Executive Summary
3	1.1 Background
3	1.2 General Questionnaire
3	1.3 Health Conditions Questionnaire
4	1.4 Focus Groups
4	1.5 Next Steps
5	2 Background
5	2.1 NHS Long Term Plan
5	2.2 Healthwatch England Brief
5	2.3 Healthwatch in the Black Country and West Birmingham
6	2.4 Sustainability and Transformation Partnership
6	2.5 Engagement Methodology
7	3 Questionnaire Analysis
7	3.1 General Questionnaire Feedback
9	3.2 General Questionnaire Trends
9	3.3 Health Conditions Questionnaire Feedback
11	3.4 Health Conditions Trends
12	4 Focus Group Analysis
13	4.1 Feedback
13	4.2 Question 1, What Does Being Well Mean To You?
13	4.3 Question 2, What Do You Do To Stay Well?
14	4.4 Question 3, What Are The Barriers To You Helping Yourself To Stay Well?
14	4.5 Question 4, How Would You Prefer To Access Help, Support or Information?
15	4.6 Question 5, How Would You Like To Continue To Be Involved?
16	5 Recommendations and Next Steps
16	5.1 Recommendations
17	5.2 Next Steps
17	Appendices
18	A General Questionnaire
27	B Health Conditions Questionnaire
34	C Focus Group Questions



1 Executive Summary

1.1 Background

This report presents a succinct overview of the findings from community engagement undertaken by Healthwatch in the Black Country and West Birmingham, for the Black Country and West Birmingham Sustainability and Transformation Partnership. It relates to Healthwatch England's request to local Healthwatch organisations to gain insight into how people view local healthcare services, and use the findings to shape local action to support delivery of the overarching NHS England Long Term Plan.

To ensure a thorough range of feedback was gained two electronic questionnaires (a General Questionnaire, and a Health Conditions Questionnaire) and several focus groups were used.

1.2 General Questionnaire

Over 1,000 questionnaires were returned. Emerging trends indicate that people have a preference for:

- 1 Control over their medical records and healthcare
- 2 Easy access to information that helps with healthcare
- 3 Easy access to healthcare professionals to get advice and help
- 4 Easy access to healthcare services when needed
- 5 Every contact with a healthcare professional to make a difference
- 6 Their views on health and next steps to be taken seriously
- 7 Time to consider healthcare options and make decisions
- 8 Being able to decide where they go to get care
- 9 Communications that are timely, helpful and work for them
- 10 Knowledge that helps them to care for themselves and the community, family and friends to help where they can

1.3 Health Conditions Questionnaire

290 questionnaires were returned. Feedback indicates that people have a preference for:

- 1 Seeing any appropriate healthcare professional initially and to get a diagnosis
- 2 But, a significant number would prefer to see someone they know
- 3 A majority would prefer to see someone they know for longer-term support
- 4 Most would prefer not to travel too far to get healthcare help

In addition, there may be the opportunity to enable more people to report on:

- 1 Their healthcare needs are met when they seek help
- 2 A positive overall experience of getting healthcare help
- 3 Quickly getting an initial medical assessment or diagnosis
- 4 Getting easy access to support after getting healthcare help
- 5 Getting access to healthcare support that meets their expectations



1.4 Focus Groups

The focus groups included five key questions, with key feedback including:

Question 1 “What Does Being Well Mean To You?” received a number of diverse response:

- 1 Being able to take care of yourself
- 2 Mental wellbeing
- 3 No pain and being comfortable
- 4 Getting the right work life balance

Question 2 “What Do You Do To Stay Well?” returned feedback such as:

- 1 Not sitting at home deteriorating
- 2 Listening to music
- 3 Seeing friends
- 4 Having a GP that listens to me

Question 3 “What Are The Barriers To You Helping Yourself To Stay Well?” received:

- 1 Difficulties with timings of access to services
- 2 There aren't enough Talking Therapies
- 3 GP having more time to listen and give full attention
- 4 Not really knowing what questions to ask the GP

Question 4 “How Would You Prefer To Access Help, Support or Information” gained:

- 1 Online consultations
- 2 There is confusion over roles of who to access and when
- 3 Voluntary sector to provide info, posters are NOT ok
- 4 Could we use email to communicate with professionals?

Question 5 “How Would You Like To Continue To Be Involved”, returned feedback such as:

- 1 Talking to others via social media
- 2 Deaf and Visually impaired representatives at CCGs, and other groups
- 3 Give access to personal medical records
- 4 People should be offered the opportunity to be able to share their views

1.5 Next Steps

A series of recommendations for potential improvements to delivery of health support have been included, as well as three key next steps that it would be strategically beneficial for the STP to provide to Healthwatch:

- 1 How will the STP consider the Healthwatch findings?
- 2 How will the STP feedback to Healthwatch?
- 3 What further conversations will there be around how to engage with the public?



2 Background

2.1 NHS Long Term Plan

In January 2019, NHS England published its Long Term Plan (LTP); setting out its ambition to get healthcare services to work better for people to help them stay well and get the best care when they need it. The implementation of the LTP will occur over at least a ten year period.

The LTP contains significant detail on healthcare issues and how healthcare services need to change to make the most of existing and new technologies, deal with increased levels of demand for care, and provide help for those people who are living longer, often with one or more chronic conditions. At the same time, the political and social context in which this change is expected to happen is challenging, given a long period of fiscal austerity, growing inequalities and, for many, stagnating life expectancy.

2.2 Healthwatch England Brief

Healthwatch England is the independent national champion for people who are using, or will use, health and social care services. It works to ensure government and organisations providing services put people at the heart of care. It has a specific driver to increase professional's and relevant other's understanding of the experiences and concerns of people using services.

Given the pressures facing implementation of the LTP, NHS England asked Healthwatch England to engage the support of local Healthwatch organisations to undertake public engagement. The focus of this activity was to gain insight into how people view local healthcare services, and use the findings to shape local action to support delivery of the overarching LTP.

2.3 Healthwatch in the Black Country and West Birmingham

There is a local Healthwatch organisation in each of the Black Country borough areas; Dudley, Sandwell, Walsall and Wolverhampton. Healthwatch Dudley took on the lead responsibility for the Healthwatch England brief for the LTP engagement activity, working closely with the other three local Healthwatch organisations in the Black Country.

In reference to West Birmingham, their views of this population are included in the Birmingham and Solihull STP report produced by Healthwatch Birmingham. We are committed to working together to cross-reference the engagement findings from Healthwatch Birmingham, to provide a comprehensive representation of local people's views spanning the Black Country and West Birmingham.



2.4 Sustainability and Transformation Partnership

The Black Country and West Birmingham Sustainability and Transformation Partnership (STP) is formed of several organisations. To deliver these plans NHS providers, Clinical Commissioning Groups (CCGs), Local Authorities, and other health and care services have come together; providing primary care, community care, social care, mental health, acute and specialised services. They retain their individual responsibilities but recognise the potential benefits of collaborative working to help manage the way services are delivered and find solutions to complex and cross-cutting healthcare problems.

Acknowledging this, the STP is the primary audience for this report that is intended to assist the STP understand how health and social care systems can be improved to help with the delivery of the LTP objectives.

2.5 Engagement Methodology

To ensure a thorough range of feedback was gained a mixed approach was adopted that involved two electronic questionnaires, as well as several focus groups:

- **General Questionnaire**

To gain a mixture of qualitative and quantitative feedback on respondent's generic views on their own health and the quality of service they required. This included some 24 open and closed questions, with a copy included in Appendix A.

- **Health Conditions Questionnaire**

A more focused survey for those individuals with specific conditions (cancer, dementia, autism etc). This included some 35 open and closed questions, with a copy included in Appendix B.

- **Focus Groups**

Focus groups were delivered with community groups and people who attended different public events. Each focus group included the same five questions to ensure feedback would be standardised across the Black Country, with the questions included in Appendix C.



3 Questionnaire Analysis

3.1 General Questionnaire Feedback

Over 1,000 General Questionnaires were returned with summarised feedback and key trends indicated below:

The four main thematic areas within the survey received the following feedback:

1. Having what I need to live a healthy life		
Easy access to the information I need to help me make decisions about my health and care	98%	Rated this as "Very Important" or "Important"
The knowledge to help me do what I can to prevent ill health	97%	
For every interaction with health and care services to count; my time is valued	95%	

2. Being able to manage and choose the support I need		
If I have a long term condition I decide how the NHS spends money on	76%	Rated this as "Very Important" or "Important"
Choosing the right treatment is a joint decision between me and the relevant health and care professional	97%	
I make the decision about where I will go to receive health and care support	87%	
I should be offered care and support in other areas if my local area can't see me in a timely way	91%	
My opinion on what is best for me counts.	88%	
Communications are timely	97%	
I have time to consider my options and make the choices that are right for me	95%	



3. The help to keep my independence and stay healthy as I get older		
I want to be able to stay in my own home for as long as it is safe to do so	97%	Rated this as "Very Important" or "Important"
I want my community to be able to support me to live my life the way I want	88%	
I want my family and friends to have the knowledge to help and support me when needed	95%	
I want there to be convenient ways for me to travel to health and care services when I need to	96%	
I want my family to feel supported at the end of life	96%	

4. How you interact with your local NHS		
I have absolute confidence that my personal data is managed well and kept secure	89%	Rated this as "Very Important" or "Important"
I can access services using my phone or computer	84%	
I can talk to my doctor or other health care professional wherever I am	91%	
I can make appointments online and my options are not limited	77%	
Any results are communicated to me quickly making best use of technology	91%	
I manage my own personal records so that I can receive continuity in care	76%	
I am able to talk to other people who are experiencing similar challenges to me to help me feel better	80%	



3.2 General Questionnaire Trends

Key Trends - General Questionnaire

Feedback indicates that people have a preference for:

- 1 Control over their medical records and healthcare
- 2 Easy access to information that helps with healthcare
- 3 Easy access to healthcare professionals to get advice and help
- 4 Easy access to healthcare services when needed
- 5 Every contact with a healthcare professional to make a difference
- 6 Their views on health and next steps to be taken seriously
- 7 Time to consider healthcare options and make decisions
- 8 Being able to decide where they go to get care
- 9 Communications that are timely, helpful and work for them
- 10 Knowledge that helps them to care for themselves and the community, family and friends to help where they can

3.3 Health Conditions Questionnaire Feedback

A total of 290 Health Conditions Questionnaires were returned with summarised feedback and key trends indicated below. The specific conditions predefined in the survey were; cancer, heart and lung disease, mental health problems, dementia, learning disabilities, autism and long-term conditions, such as diabetes or arthritis.

The main thematic areas within the survey received the following feedback:

Needs and Options		
Needs were met when first trying to get help	38%	Yes
	31%	No
Support options met your expectations	32%	Yes
	30%	No



Your experience of getting help and support		
Overall experience of getting help	42%	Very positive or positive
	32%	Very negative or negative
Time to initial assessment or diagnosis	26%	Very fast or fast
	41%	Very slow or slow
Time from assessment or diagnosis to treatment	25%	Very fast or fast
	42%	Very slow or slow
Accessing ongoing support after assessment or diagnosis	26%	Very easy or easy
	38%	Very difficult or difficult

Time willing to travel for a quick diagnosis	
Less than 30 minutes	28%
30 minutes to 1 hour	54%
1 to 2 hours	6%
More than 2 hours	12%

Your expectations at each stage of your care		
Most important when first seeking help	58%	Seeing any medically appropriate health professional who is free immediately
	34%	Seeing a health professional normally seen but maybe having to wait
Most important when getting a diagnosis or explanation of treatment	52%	Seeing any medically appropriate health professional who is free immediately
	39%	Seeing a health professional normally seen but maybe having to wait
Most important for long term support	39%	Seeing any medically appropriate health professional who is free immediately
	59%	Seeing a health professional normally seen but maybe having to wait



3.4 Health Conditions Questionnaire Trends

Key Trends - Health Conditions Questionnaire

In summary, feedback indicates that people have a preference for:

- 1 Seeing any appropriate healthcare professional initially and to get a diagnosis
- 2 But, a significant number would prefer to see someone they know
- 3 A majority would prefer to see someone they know for longer-term support
- 4 Most would prefer not to travel too far to get healthcare help

In addition, there may be the opportunity to enable more people to report on:

- 1 Their healthcare needs are met when they seek help
- 2 A positive overall experience of getting healthcare help
- 3 Quickly getting an initial medical assessment or diagnosis
- 4 Getting easy access to support after getting healthcare help
- 5 Getting access to healthcare support that meets their expectations



4 Focus Group Analysis

4.1 Feedback

A total of 156 people attended focus groups in a variety of settings across the Black Country, being able to provide their views on their health and wellbeing as well as regarding their experiences of using healthcare services.

Full summaries of the focus groups are available as stand-alone reports, and a summary from the five standardised questions is considered below.

4.2 Question 1, What Does Being Well Mean To You?

Indicative comments from attendees included:

“Being able to access good healthcare when you need it”

“We need to know [about] coping mechanisms and how to self-manage”

“Being positive, thinking positive and being able to do what you want when you want”

“Just surviving isn’t living, if people are living longer they need a [good] quality of life”

Key trends from wider discussions indicate that “being well” means a variety of things to different people, including:

- 1 Being able to take care of yourself
- 2 Mental wellbeing
- 3 Not being let down
- 4 No pain and being comfortable
- 5 Getting the right work life balance
- 6 Money, stability
- 7 Managing stress
- 8 Being supported to avoid complications to medical conditions
- 9 Going for a walk
- 10 Family, exercise, eating good food
- 11 Being well in body and mind
- 12 Mental and physical health
- 13 Getting referred to the right people at the right time when I need help

4.3 Question 2, What Do You Do To Stay Well?

Indicative comments from attendees included:



"I try to eat well, plenty of fruit and veg, drink water. For my mental health I try to relax. I do like to work, I'd go bonkers if I didn't work. It's important to get a balance"

"Trying not to be in a rut and getting onto a treadmill"

"Walk each week and swim once a week, and I keep busy with many different activities and groups"

"Being fit and healthy, able to look after yourself, and completing all your daily routines"

"Small group that goes walking every month, going to different places, two to three miles, sometimes up to five miles, we all enjoy ourselves"

Key feedback from wider discussions identified that staying well can include:

- 1 Mentally staying fit
- 2 Not sitting at home deteriorating
- 3 Ensure I'm up to date with vaccinations
- 4 NHS offers courses to help you stay well and look after yourself, but they're not always easy to access, or deaf friendly.
- 5 Listening to music
- 6 Seeing friends
- 7 Socialising in small groups
- 8 Having a GP that listens to me
- 9 'Mom knows best'
- 10 Go to local leisure and social facilities

4.4 Question 3, What Are The Barriers To You Helping Yourself To Stay Well?

Indicative comments from attendees included:

"Unfortunately, many GPs ... don't have the knowledge about what is available locally around self-care [and] condition management"

"Please can GPs talk a little more of our problems when we are ill, they only give us two minutes to speak, it's not good enough".

"Loneliness is a real issue, it can be hard to make friends; people just stare and I think they don't like me, so I keep myself to myself"



“When I’m stressed, I feel the need to buy clothes or unhealthy food, it gives me comfort but then I feel worse afterwards as I don’t have enough money anyway and also the cheap food is rubbish. I can’t break the cycle.”

“GP reluctance to help when I first lost my sight”

“Lack of knowledge of newly diagnosed long term conditions”

“The benefit system and having to fight, their starting point is not to believe you. People who stop benefits get bonuses so it’s an incentive for them not to help”

Key trends from wider discussions indicate that barriers to staying well can encompass:

- 1 The benefits system and fighting it
- 2 Neighbours not feeling safe due to local crime levels
- 3 Access to services (having knowledge of)
- 4 Difficulties with timings of access to services
- 5 GP’s more supportive in knowing about local activities and groups
- 6 There aren’t enough Talking Therapies
- 7 GP having more time to listen and give full attention
- 8 Not really knowing what questions to ask the GP

4.5 Question 4, How Would You Prefer To Access Help, Support or Information?

Indicative comments from attendees included:

“When my wife came out of hospital we didn’t know anything about how to manage. By coming to Cancer Support people who have been through the same thing as me and who understand really help”

“The internet, it does not always help, for example, it can just increase hypochondria”

“Google can be useful but for diagnosis we must be careful”

“More use of pharmacists ... we don’t utilise pharmacists enough”

“Through contact with the GP that I have built up a relationship and get continuity of care”



Key feedback from wider discussions indicates that people may prefer:

- 1 Online consultations
- 2 A variety of methods of access depending upon need, and knowledge of the variety
- 3 Apps
- 4 There is confusion over roles of who to access and when
- 5 Voluntary sector to provide info, posters are NOT ok
- 6 Could we use email to communicate with professionals?
- 7 A preference to see the same GP that people are comfortable with and who knows a person's history
- 8 Preference for online communications...plain English not clinical jargon that's not understood nor explained
- 9 Having choices is always best as people's needs and wants are different and varied

4.6 Question 5, How Would You Like To Continue To Be Involved?

Indicative comments from attendees included:

"Families, parents, carers and people who access services to regularly come together with front line staff and clinicians to highlight issues, gaps in service, and find solutions and solve problems together ... It's not about being confrontational, we have got valuable experience and if we are listened to can help to improve things. The NHS belongs to everyone, we don't want to feel 'done to' we want to be part of it"

"I don't think I'm at the centre of my healthcare, decisions are made for me, there is a pre-set plan ... I don't feel confident enough to challenge healthcare professionals"

"I would love to have access to my own health records - I like the fact that my doctor will show me my x-rays and talk me through them and involve me"

Key trends from wider discussions highlighted that people may wish to have continued involvement through:

- 1 Talking to others via social media
- 2 PPG's to be more effective
- 3 Forums/Sessions
- 4 Deaf and Visually impaired representatives at CCGs, and other groups
- 5 Give access to personal medical records
- 6 Educational activities and information at College
- 7 People should be offered the opportunity to be able to share their views
- 8 People don't really know that there is much opportunity to be involved??
- 9 More information out there about how to be involved.



5 Recommendations and Next Steps

5.1 Recommendations

Given the engagement undertaken and the feedback gained, to increase the efficacy and impact across the Black Country it is recommended that:

- A deeper analysis of feedback is undertaken, especially open questions from the questionnaires, to provide greater insight and ability to inform future service modelling
- Offer patients a greater choice in how they are communicated with
- Although NHS offers courses to help people stay well and look after themselves, these need to be deaf friendly
- Offer greater opportunity for accessing information and services
- Make leaflets and communications in plain English so they are understandable
- Leaflets aren't specific to a person, so people prefer a person to explain matters and answer questions about their concerns, face to face
- Set up a Black Country Group for Visual Impairment, Deaf/Hard of Hearing and other long term conditions, so that information and peer support can be shared
- Look at the mechanisms to listening to people - offer more and better opportunities to engage with people and listen to their experiences
- Consider the use of language by medical professionals - "*plain English please*"
- People would like a 'one stop shop' approach to receiving Health and Social Care support, from GP's to Community support etc. A joined up/holistic approach to their health and care needs is required
- Find better ways of ensuring vulnerable people stay up to date with vaccinations



5.2 Next Steps

Further to the recommendations, it would be strategically beneficial for the STP to provide to Healthwatch a position statement that addresses:

- 1 How will the STP consider the Healthwatch findings?
“These will be considered at the STP partnership on the 25th July and included within the Long Term Plan engagement report which will be completed at the end of July to inform the STP plan for the Autumn”.

- 2 How will the STP feedback to Healthwatch?

“The Black Country and West Birmingham Sustainability and Transformation Partnership (STP) received this report at our July Partnership Meeting

We are committed to understanding and acting upon what matters to people. We recognise that part of the solution to the challenges we face rest in our ability to create the right environment for people to have more choice and control in their own health, this report will help us to do just that.

We would like to extend our thanks, not only to the Black Country Healthwatch teams who have worked collaboratively to produce this report but also to our neighbouring Healthwatch in Birmingham. Your collective effort to represent the views of local people will be key to informing our Long Term Plan. Our thanks also go out to local people who took time to express their views, whose experiences have provided these useful insights”.

- 3 What further conversations will there be around how to engage with the public?

“The STP Communications and Engagement Work stream are developing a strategy to support the implementation of the Long Term Plan and to take the STP/ ICS to the next phase of development. This will be published in November with a workshop in September to start to create the plan. Your recommendations are very helpful in that regard and we would like to extend an invitation to you to be part of that workshop to develop the strategy”.

Appendices

- A General Questionnaire
- B Health Conditions Questionnaire
- C Focus Group Questions



Appendix A - General Questionnaire

General survey - what's it about?

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

The Government is investing an extra £20bn a year in the NHS. The NHS has produced a Long Term Plan, setting out all the things it wants health services to do better for people across the country. Now your local NHS needs to hear from you about what those changes should look like in your community.

The Long Term Plan sets out what the NHS wants to do better, including making it easier for people to access support closer to home and via technology, doing more to help people stay well, and providing better support for people with cancer, mental health conditions, heart and lung diseases, long-term conditions, such as diabetes and arthritis, learning disabilities and autism, and for people as they get older and experience conditions such as dementia.

Your local NHS needs to hear from you about what it should do to make care better for your community.

- How would you help people live healthier lives?
- What would make health services better?
- How would you make it easier for people to take control of their own health and wellbeing?
- What would you do to make support better for people with long-term conditions?

Share your views and help make care better.

Healthwatch is your independent voice for health and care. We are working in partnership with other local Healthwatch organisations and Healthwatch England, to gather people's views and experiences on health and care.

- What you tell us will be reported back to people who can change and improve local services.
- We will not use your name and your answers will remain anonymous in our final report.
- You do not have to answer a question if you don't want to and you can stop at any time.
- Please ask us if you have got any further questions before continuing:

Survey 1 - people's general experiences of health and care services

1. Do you consent to Healthwatch using your responses?

Yes

No (thank you - end survey)

2. What is the area / borough that best describes where you live

2a) Who are you responding on behalf of?

Yourself

Someone else

Having what I need to live a healthy life

The NHS isn't just there to help you when you're ill, but to support you to live a healthy life too. Tell us what you think local services could do to help you stay well.

3a) Rate how important the following things are to you when it comes to living a healthy life:

	Very important	Important	Neutral	Not important	Not important at all
<i>Easy access to the information I need to help me make decisions about my health and care</i>					
<i>The knowledge to help me do what I can to prevent ill health</i>					
<i>Access to the help and treatment I need when I want it</i>					
<i>Professionals that listen to me when I speak to them about my concerns</i>					
<i>For every interaction with health and care services to count; my time is valued</i>					

3b) If there was one more thing that would help you live a healthy life, what would it be?

Being able to manage and choose the support I need

When you are unwell and need support or treatment for your condition you need to be properly informed to make choices about what works best for you. Tell us what local services need to do to make this a reality.

4a) Rate how important the following things are to you when it comes to managing and choosing the support you need:

	Very important	Important	Neutral	Not important	Not important at all
<i>If I have a long term condition I decide how the NHS spends money on</i>					
<i>Choosing the right treatment is a joint decision between me and the relevant health and care professional</i>					
<i>I make the decision about where I will go to receive health and care support</i>					
<i>I should be offered care and support in other areas if my local area can't see me in a timely way</i>					
<i>I make the decision about when I will receive health and care support</i>					
<i>My opinion on what is best for me, counts.</i>					
<i>Communications are timely</i>					
<i>I have time to consider my options and make the choices that are right for me</i>					

4b) If there was one more thing that would help you to manage and choose how the NHS supports you, what would it be?

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

Our ageing population is placing greater demands on the NHS. We know that people want to be able to look after themselves for longer, and the NHS wants to help you do so.

5a) Rate how important the following things are to you when it comes to keeping your independence and ageing healthily:

	Very important	Important	Neutral	Not important	Not important at all
<i>I want to be able to stay in my own home for as long as it is safe to do so</i>					
<i>I want my community to be able to support me to live my life the way I want</i>					
<i>I want my family and friends to have the knowledge to help and support me when needed</i>					
<i>I want there to be convenient ways for me to travel to health and care services when I need to</i>					
<i>I want my family to feel supported at the end of life</i>					

5b) 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

How you interact with your local NHS

The NHS wants to adapt to make it easier for people to access support they need, when they need it.

6a) Rate how important the following things are to you when it comes to keeping your independence and ageing healthily:

	Very important	Important	Neutral	Not important	Not important at all
<i>I have absolute confidence that my personal data is managed well and kept secure</i>					
<i>I can access services using my phone or computer</i>					
<i>I can talk to my doctor or other health care professional wherever I am</i>					
<i>I can make appointments online and my options are not limited</i>					
<i>Any results are communicated to me quickly making best use of technology</i>					
<i>I manage my own personal records so that I can receive continuity in care</i>					
<i>I am able to talk to other people who are experiencing similar challenges to me to help me feel better</i>					

6b) If there was one more thing that you think need to change to help you to successfully manage your health and care, what would it be?

Tell us what is most important

Out of the statements below, we want you to pick the one that you feel is most important to you.

7. What is most important to you to help you live a healthy life? **(CHOOSE ONE ONLY)**

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

8. What's most important to you to be able to manage and choose the support you need? **[CHOOSE ONE ONLY]**

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

9. What's most important to you to help you keep your independence and stay healthy as you get older? **[CHOOSE ONE ONLY]**

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

10. What is most important to you when interacting with the NHS **[CHOOSE ONE ONLY]**

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

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

Tell us a bit about you

By telling us more information about yourself, you will help us better understand how people's experiences may differ depending on their personal characteristics. However, if you do not wish to answer these questions you do not have to.

12. Your age

- | | |
|-----------------------------------|---------------------------------|
| <input type="checkbox"/> Under 18 | <input type="checkbox"/> 45-54 |
| <input type="checkbox"/> 18-24 | <input type="checkbox"/> 55 -64 |
| <input type="checkbox"/> 25-34 | <input type="checkbox"/> 65-74 |
| <input type="checkbox"/> 35-44 | <input type="checkbox"/> 75+ |

13. Your ethnicity

- | | |
|---|---|
| <input type="checkbox"/> African | <input type="checkbox"/> Indian |
| <input type="checkbox"/> Arab | <input type="checkbox"/> White British |
| <input type="checkbox"/> Asian British | <input type="checkbox"/> Pakistani |
| <input type="checkbox"/> Bangladeshi | <input type="checkbox"/> Any other white background |
| <input type="checkbox"/> Black British | <input type="checkbox"/> Any other mixed background |
| <input type="checkbox"/> Caribbean | <input type="checkbox"/> Other |
| <input type="checkbox"/> Gypsy or Irish Traveller | |

14. Do you consider yourself to have a disability?

- | | |
|------------------------------|--|
| <input type="checkbox"/> Yes | <input type="checkbox"/> I'd prefer not to say |
| <input type="checkbox"/> No | |

15. Are you a carer?

- | | |
|------------------------------|-----------------------------|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No |
|------------------------------|-----------------------------|

16. Do you have:

- | | |
|--|----------------------------------|
| <input type="checkbox"/> A long term condition | <input type="checkbox"/> Neither |
| <input type="checkbox"/> Multiple conditions | |

17. Which of the following best describes you?

- | | |
|---|------------------------------------|
| <input type="checkbox"/> Heterosexual | <input type="checkbox"/> Asexual |
| <input type="checkbox"/> Gay or lesbian | <input type="checkbox"/> Pansexual |
| <input type="checkbox"/> Bisexual | <input type="checkbox"/> Other |

18. Your gender

- Male
- Female
- Other
- Prefer not to say

19. Your religion

- Buddhist
- Christian
- Hindu
- Jewish
- I'd prefer not to say
- Muslim
- Sikh
- Other
- No religion

Thank you for your time - your views matter!

Healthwatch is your independent voice for health and care. We listen - so that your views and experiences can help shape local services and support for everyone.



Appendix B - Health Conditions Questionnaire

Conditions survey – what's it about?

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

The Government is investing an extra £20bn a year in the NHS. The NHS has produced a Long Term Plan, setting out all the things it wants health services to do better for people across the country. Now your local NHS needs to hear from you about what those changes should look like in your community.

The Long Term Plan sets out what the NHS wants to do better, including making it easier for people to access support closer to home and via technology, doing more to help people stay well, and providing better support for people with cancer, mental health conditions, heart and lung diseases, long-term conditions, such as diabetes and arthritis, learning disabilities and autism, and for people as they get older and experience conditions such as dementia.

Your local NHS needs to hear from you about what it should do to make care better for your community.

- How would you help people live healthier lives?
- What would make health services better?
- How would you make it easier for people to take control of their own health and wellbeing?
- What would you do to make support better for people with long-term conditions?

Share your views and help make care better.

Healthwatch is your independent voice for health and care. We are working in partnership with other local Healthwatch organisations and Healthwatch England, to gather people's views and experiences on health and care.

- What you tell us will be reported back to people who can change and improve local services.
- We will not use your name and your answers will remain anonymous in our final report.
- You do not have to answer a question if you don't want to and you can stop at any time.
- Please ask us if you have got any further questions before continuing:

Survey 2 – NHS support for specific conditions

1. Do you consent to Healthwatch using your responses?

Yes

No (thank you - end survey)

2. What is the area / borough that best describes where you live

3. Please select the condition you would like to tell us about in this questionnaire

(Please choose one only – complete additional surveys for different conditions)

Cancer

Learning disability

Heart and lung diseases

Autism

Mental Health

Long-term condition e.g. diabetes, arthritis

Dementia

4. Who are you responding on behalf of?

Myself

Someone else

5. Has the condition you are telling us about started within the last three years?

Yes

No

Your experience of getting help and support

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

Yes

Somewhat

No

Not applicable

6b) Tell us whether the support met your needs and how it could have been improved

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

Very positive

Negative

Positive

Very negative

Average

Don't know

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

Yes

No

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

It made getting support easier

I don't know

No difference

Not applicable

It made getting support harder

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?

- | | |
|------------------------------------|-------------------------------------|
| <input type="checkbox"/> Very slow | <input type="checkbox"/> Fast |
| <input type="checkbox"/> Slow | <input type="checkbox"/> Very fast |
| <input type="checkbox"/> Ok | <input type="checkbox"/> Don't know |

10b) Please tell us more about the length of time you waited

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

- | | |
|------------------------------------|-------------------------------------|
| <input type="checkbox"/> Very slow | <input type="checkbox"/> Fast |
| <input type="checkbox"/> Slow | <input type="checkbox"/> Very fast |
| <input type="checkbox"/> Ok | <input type="checkbox"/> Don't know |

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

- | | |
|---|--|
| <input type="checkbox"/> Yes (<i>go to Q13</i>) | <input type="checkbox"/> No (<i>go to Q15</i>) |
|---|--|

13. If you accessed support, what aspects worked well?

14. If you accessed support, what aspect could be improved?

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

- | | |
|---|--|
| <input type="checkbox"/> Yes (<i>go to Q16</i>) | <input type="checkbox"/> No (<i>go to Q17</i>) |
|---|--|

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

- | | |
|------------------------------------|-------------------------------------|
| <input type="checkbox"/> Very slow | <input type="checkbox"/> Fast |
| <input type="checkbox"/> Slow | <input type="checkbox"/> Very fast |
| <input type="checkbox"/> Ok | <input type="checkbox"/> Don't know |

16b) Please tell us more about the length of time you waited



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

- | | |
|------------------------------------|---|
| <input type="checkbox"/> Very easy | <input type="checkbox"/> Very difficult |
| <input type="checkbox"/> Easy | <input type="checkbox"/> Don't know |
| <input type="checkbox"/> OK | <input type="checkbox"/> Not applicable |
| <input type="checkbox"/> Difficult | <input type="checkbox"/> |

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

- | | |
|------------------------------|-----------------------------------|
| <input type="checkbox"/> Yes | <input type="checkbox"/> Somewhat |
| <input type="checkbox"/> No | |

18b) Please explain how the care did or did not meet your expectations and how it could have been improved.

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?

- | | |
|------------------------------|-----------------------------------|
| <input type="checkbox"/> Yes | <input type="checkbox"/> Somewhat |
| <input type="checkbox"/> No | <input type="checkbox"/> |

19b) Please explain how the care did or did not meet your expectations and how it could have been improved.

Time spent travelling to access support and care

20. What is your main means of transport?

- | | |
|--|----------------------------------|
| <input type="checkbox"/> Own car | <input type="checkbox"/> Bicycle |
| <input type="checkbox"/> Another person's car (getting a lift) | <input type="checkbox"/> Taxi |
| <input type="checkbox"/> Bus | <input type="checkbox"/> Other |
| <input type="checkbox"/> Train | <input type="checkbox"/> |

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

- | | |
|---|---------------------------------------|
| <input type="checkbox"/> Less than 30 minutes | <input type="checkbox"/> 1-2 hours |
| <input type="checkbox"/> 30 minutes to 1 hour | <input type="checkbox"/> Over 2 hours |

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

- | | |
|--|--|
| <input type="checkbox"/> Under 30 minutes | <input type="checkbox"/> More than two hours |
| <input type="checkbox"/> From 20 minutes to one hour | |
| <input type="checkbox"/> From one to two hours | |

Your expectations at each stage of your care

23. What is most important you?

	Seeing a health professional you normally see but you may have to wait	Seeing any medically appropriate health professional who is free immediately	Don't mind
When first seeking help			
When you first received a diagnosis and explanation of treatment or support options			
During your initial treatment or support			
During your long term support			

Supporting you to have more control over your own care

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

- A lot of support
- Some support
- I don't need support
- Don't know
-

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

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

Tell us a bit about you

By telling us more information about yourself, you will help us better understand how people's experiences may differ depending on their personal characteristics. However, if you do not wish to answer these questions you do not have to.

27. Your age

- Under 18
- 18-24
- 25-34
- 35-44
- 45-54
- 55-64
- 65-74
- 75+

28. Your ethnicity

- | | |
|---|---|
| <input type="checkbox"/> African | <input type="checkbox"/> Indian |
| <input type="checkbox"/> Arab | <input type="checkbox"/> White British |
| <input type="checkbox"/> Asian British | <input type="checkbox"/> Pakistani |
| <input type="checkbox"/> Bangladeshi | <input type="checkbox"/> Any other white background |
| <input type="checkbox"/> Black British | <input type="checkbox"/> Any other mixed background |
| <input type="checkbox"/> Caribbean | <input type="checkbox"/> Other |
| <input type="checkbox"/> Gypsy or Irish Traveller | |

29. Do you consider yourself to have a disability?

- | | |
|------------------------------|--|
| <input type="checkbox"/> Yes | <input type="checkbox"/> I'd prefer not to say |
| <input type="checkbox"/> No | |

30. Are you a carer?

- | | |
|------------------------------|-----------------------------|
| <input type="checkbox"/> Yes | <input type="checkbox"/> No |
|------------------------------|-----------------------------|

31. Do you have:

- | | |
|--|----------------------------------|
| <input type="checkbox"/> A long term condition | <input type="checkbox"/> Neither |
| <input type="checkbox"/> Multiple conditions | |

32. Which of the following best describes you?

- | | |
|---|------------------------------------|
| <input type="checkbox"/> Heterosexual | <input type="checkbox"/> Asexual |
| <input type="checkbox"/> Gay or lesbian | <input type="checkbox"/> Pansexual |
| <input type="checkbox"/> Bisexual | <input type="checkbox"/> Other |
| | <input type="checkbox"/> |

33. Your gender

- | | |
|---------------------------------|--|
| <input type="checkbox"/> Male | <input type="checkbox"/> Other |
| <input type="checkbox"/> Female | <input type="checkbox"/> Prefer not to say |

34. Your religion

- | | |
|------------------------------------|--|
| <input type="checkbox"/> Buddhist | <input type="checkbox"/> Sikh |
| <input type="checkbox"/> Christian | <input type="checkbox"/> Other |
| <input type="checkbox"/> Hindu | <input type="checkbox"/> No religion |
| <input type="checkbox"/> Jewish | <input type="checkbox"/> I'd prefer not to say |
| <input type="checkbox"/> Muslim | |

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Appendix C - Focus Group Questions

Topic Area	Main Question	Prompts and Deeper Dives
Being Well - Understanding goals and outcomes for individuals (Benchmark for discussions)	What does 'being well' mean to you?	Physical and Emotional/Mental Health
Current assets/ tactics/ activities individuals use	What do you do to stay well?	If you are unwell, where do you go for information? If you are unwell who do you see? If you are unwell what can you do to help yourself?
Addressing the Barriers	What are the barriers to 'you helping yourself to stay well'?	Are there barriers to helping yourself to stay well? If there are barriers to staying well is there anything that can be done to overcome them? What works for you and your healthcare? Would you like to see anything change to help with your healthcare?
Solutions, opportunities and innovation	How would you prefer to access help, support or information?	Do you look online or use technology? How can online services help with your healthcare? How can technology help with your healthcare? Do you have a preferred way to get access to healthcare information? Do you have a preferred way to get access to healthcare support? How can the most be made of existing building, facilities, and peoples knowledge and skills, to help with people's health and care? How can people have more control over their health and care?
Involvement	How would you like to continue to be involved?	Are you involved in decisions about your healthcare? How would you like to get involved, or continue to be involved, in future decisions about Health and Social Care? What topics are important to you?