# healthwatch

# NHS Long Term Plan
# Public engagement report

Buckinghamshire, Oxfordshire, and Berkshire West (Reading, West Berkshire and Wokingham)

## what
## would you do?
### It's your NHS. Have your say.

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# Contents

# Executive summary

**About this report**

This report presents a summary of views collected from nearly 1,250 people living in the Buckinghamshire, Oxfordshire and Berkshire West (BOB) NHS area, in April and May 2019.

This project was part of a simultaneous exercise by all 152 local Healthwatch in England, to inform implementation of the NHS Long Term Plan published in January 2019.

The five local Healthwatch within BOB - Buckinghamshire, Oxfordshire, Reading, West Berkshire, and Wokingham, engaged with communities in person and online to collect:

- 938 responses to a general survey supplied by Healthwatch England (HWE)
- 219 replies to a HWE-supplied survey about care of specific conditions such as cancer
- In-depth views of 87 people via 10 focus groups (four on adult mental health, and one each on learning disabilities, older people, Asian women, young onset adult dementia, young carers, and people living in a neighbourhood with high deprivation.

Healthwatch Reading acted as the coordinator, analysing and compiling the BOB-wide findings and submitting them to the BOB Integrated Care System (ICS), previously known as the BOB Sustainability and Transformation Partnership. The aim is to ensure patient experience informs an upcoming BOB ICS report on how it will implement the Long-Term Plan. The five Healthwatch will also publish findings on their own websites.

**About BOB and the local population**

Around 1.8m people live across BOB, in a mix of urban centres in Aylesbury, Oxford and Reading, as well as market towns, villages and more rural areas. The general population is expected to significantly increase due to waves of new homes being built, and the number of over-75s who need more health and care support will also grow. There are also significant pockets of deprivation, and ethnically diverse populations, in Oxford and Reading.

Three NHS trusts run major hospitals across BOB (John Radcliffe, Royal Berkshire and Stoke Mandeville), while two other trusts provide community and mental health services, and a single trust provides ambulance services. However, for most people, their main contact with the NHS is with a GP: 18,000 patients are seen every day by the 175 GP surgeries across BOB.

Funding and planning of health and care is undertaken by multiple bodies across BOB:
- the BOB ICS sets strategy on workforce and NHS buildings, allocates some NHS funds, and holds organisations to account on cancer, maternity, mental health, urgent and emergency care, primary care and digital developments;
- seven, GP-led clinical commissioning groups (CCGs) spend NHS budgets and plan care for their local populations;
- 14 local authorities fund social care and public health services for their residents; elected councillors also scrutinise local decisions on health and care services
- two integrated systems in Berkshire West, and Buckinghamshire, involve partnership working between CCGs and healthcare providers.

### Key themes and findings

#### Access to healthcare

**The public's number one priority is getting healthcare when needed, without delay.**

→ 85% of people say it is 'very important' to access help and treatment when needed
→ 54% say it is more important to see any available health professional when first seeking help, rather than waiting longer to see a professional they know
→ 47% of people with a specific condition, said the wait for their initial assessment or diagnosis was 'slow or very slow'

#### Communication

**People value health professionals who listen, give options, answer questions, have a caring manner, and adapt communication methods for those with extra needs.**

→ 84% of people say it was 'very important' that professionals listen when they speak to them about health concerns
→ 67% say it was 'very important' that choosing the right treatment is a joint decision between them and the health professional
→ People with learning disabilities told us they need professionals to explain things simply and be patient with them
→ Some people with mental health needs want professionals to show more empathy
→ People want to be offered interpreters if they cannot speak English

#### Managing ongoing conditions

**People with conditions value the relationship they have with expert teams as it helps them better manage their care and stops them having to repeat their story.**

→ For long-term support, 62% of people would prefer to wait to see a health professional they know, than to see an available health professional more quickly

#### Mental health care

**Mental health services need urgent investment and improvement.**

→ The largest number of negative comments collected in our project was on this topic

#### Healthy lifestyles

**People want personalised goals from the NHS to become or stay healthy but also think government, business, schools and councils should also play a part.**

#### Care in later life

**People want to keep their independence for as long as possible.**

→ 77% say it is 'very important' to stay at home for as long as it is safe to do so.
→ People told us they want access to high quality, and affordable, or free, social care

#### Digital technology

**People who are happy with digital technology want it more widely used by the NHS, while those who can't use it (due to lack of skills or equipment, or poor broadband coverage) don't want to become 'second-class' NHS citizens.**

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# Chapter 1: General survey findings

This section sets out findings to all questions in the general survey, completed by 938 people. The pie chart for each question shows the BOB ICS-wide findings and a breakdown is also given for the top finding for each of the five local authority/Healthwatch areas, and for the Berkshire West area (Reading, West Berkshire and Wokingham combined), to specifically inform the commissioners and providers who work together as a system there.

## Question 1: What is important to people to help them live a healthy life?

Respondents were asked to rate the importance of five separate statements. Most people said it was very important to have access to help and treatment they needed, when they wanted it, followed by wanting health care professionals to listen to them.

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

129 (14%)

799 (85%)

- Very important
- Important
- Neutral
- Not important
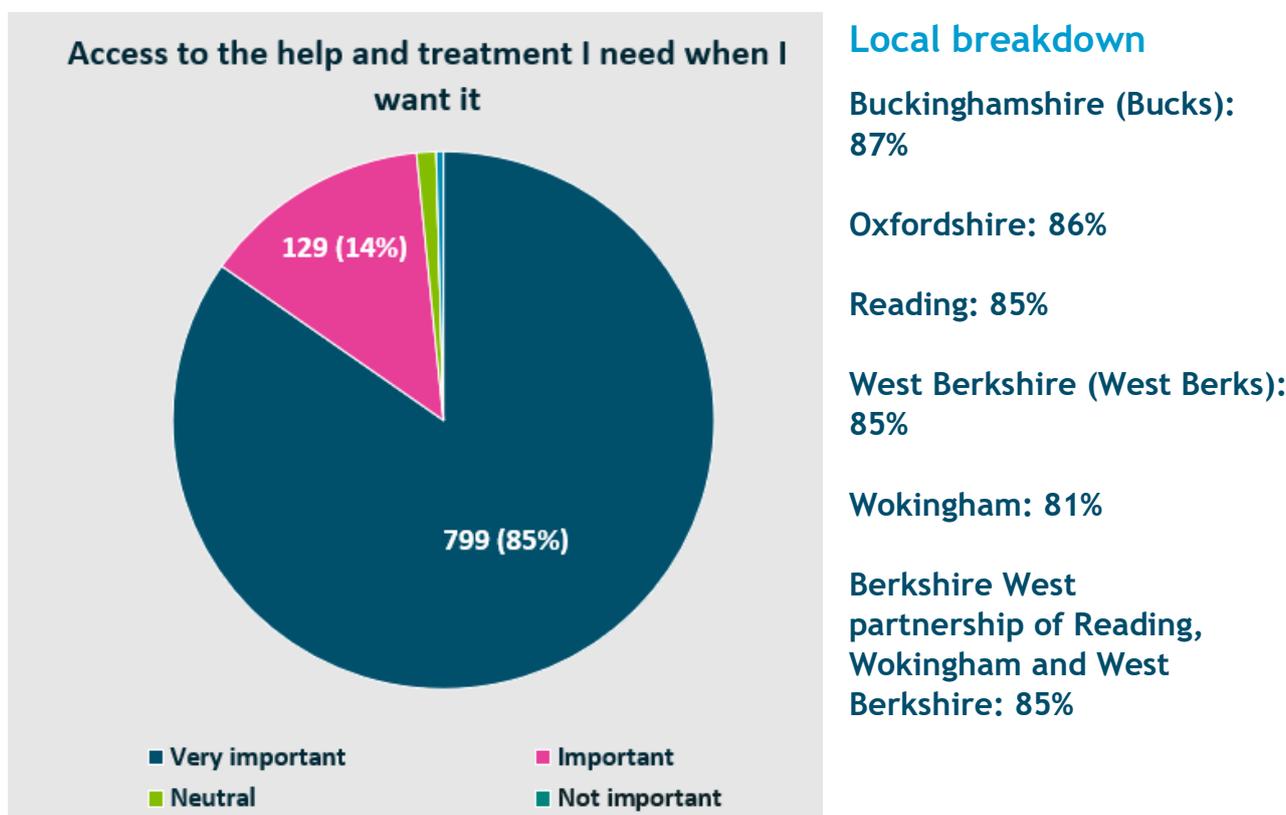
*BOB-wide finding on access to care*

### Local breakdown

**Buckinghamshire (Bucks): 87%**

**Oxfordshire: 86%**

**Reading: 85%**

**West Berkshire (West Berks): 85%**

**Wokingham: 81%**

**Berkshire West partnership of Reading, Wokingham and West Berkshire: 85%**

Many of the comments we received on the theme of access were about difficulties in contacting their doctor's surgery or getting timely appointments with GPs:

"Not having to spend ages on the phone trying to get through to my GP surgery – most online appointments are for weeks in advance so you still have to ring if it's urgent."

"Make it possible to see my own GP in less than four weeks as it is at the moment."

"GP open in the evening and weekend for people who work Mon-Fri."

## More findings on helping people to live a healthy life

- **84% of people (788) across Buckinghamshire, Oxfordshire and Berkshire West (BOB) say is very important to them, that professionals 'listen to me when I speak to them about my concerns'**
  Local breakdown:
  Bucks: 85%                    Oxfordshire: 90%              Reading:85%
  West Berks: 84%              Wokingham: 79%                Berkshire West: 83%

People told us they wanted professionals to hear them fully rather than 'jump in' and make assumptions or be dismissive. People told us they were aware of the pressure that professionals were under and that consultation times were often too short.

**"To be listened to and taken seriously."**

**"The time limit on my GP appointment was too short to talk about my concerns."**

**"When I first went to see my GP to talk to someone about my diminishing mental health, I was dismissed. After repeated visits to no avail, I saw a different GP who signposted to me to Talking Therapies."**

**"I had to go to the GP two times before they listened to me about what I thought was wrong. I know my body so when I was told it was a just a muscular problem, I knew that was incorrect."**

- **65% of people (609) say it is very important to have easy access to the information they need to help them make decisions about their health and care**
  Local breakdown:
  Bucks: 58%                    Oxfordshire: 68%              Reading:71%
  West Berks: 67%              Wokingham: 67%                Berkshire West: 66%

People told us they want to feel that professionals or services are not trying to withhold information from them about potential care options. They also want easy access to up-to-date information they can look up about themselves.

**"A one-stop-shop type service where I can find all the info I need at the click of a button."**

**"My experience of asking for information is 'we know better, you don't need to know'."**

**"More information at the time, about long-term effects and options for treatments."**

## More findings on helping people to live a healthy life

- **62% of people (581) say it is very important to have the knowledge to help them do what they can to prevent ill health**
Local breakdown:

| | | |
|---|---|---|
| Bucks: 60% | Oxfordshire: 68% | Reading:64% |
| West Berks: 59% | Wokingham: 63% | Berkshire West: 62% |

People want specific goals tailored to them as individuals, rather than just blanket public health messages, in a way that is simple to understand, potentially backed up by short courses that give them any new skills they need on managing their own health, recognising symptoms and changing their lifestyle. Ongoing encouragement is also important.

**"The NHS is big on giving 'knowledge' but often this is full of jargon and not personalised. Many people need support to gain skills to change."**

**"Told in layman's terms."**

**"Information about eating healthier that's easy to understand. Advice on exercise I can do on my own. Appointments with a nurse to talk over difficulties."**

**"Advice sessions re diet and exercise. Possible sessions for groups to meet and discuss needs with professionals."**

- **61% say it is very important for every interaction with health and care services to count; for their time to be valued**
Local breakdown:

| | | |
|---|---|---|
| Bucks: 58% | Oxfordshire: 64% | Reading:63% |
| West Berks: 61% | Wokingham: 57% | Berkshire West: 61% |

People told us they want health care professionals to be enabled to give enough time during appointments and they also want services to do more to prevent the hospital appointments or operations being changed at the last minute.

**"Important to have time to talk and listen to healthcare professionals so that I can make a considered choice re my care."**

**"Health care professionals need time to offer and discuss treatment options and not be rushed by appointment times."**

**"I think consultants should be trained on the effects of changing appointments to a patient's mental health."**

## Question 2: What is important to people when it comes to managing and choosing support?

Respondents were asked to rate the importance of eight separate statements in helping them to manage and choose support. Replies showed that most people across the BOB ICS valued the ability to work with healthcare professionals to jointly decide the best course of action. Timely communications from services were also very important.



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

266 (28%)
630 (67%)

- Very important
- Important
- Neutral
- Not important
- Not important at all
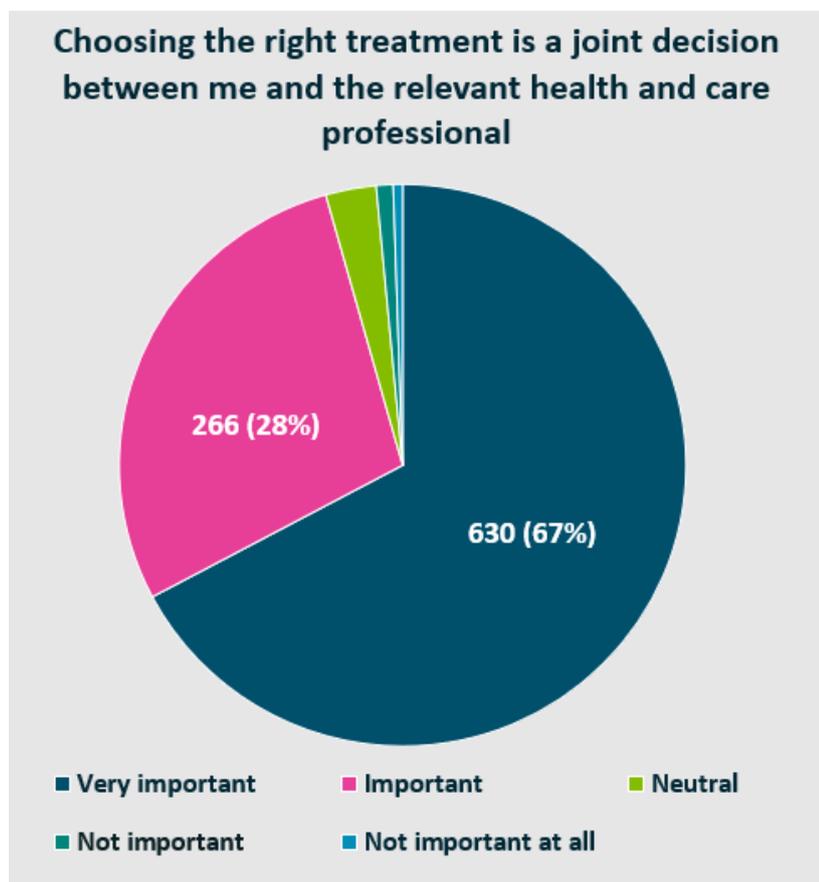
*BOB-wide finding on decision-making*

**Local breakdown**

**Bucks: 68%**
**Oxfordshire: 68%**
**Reading: 68%**
**West Berks: 70%**
**Wokingham: 57%**
**Berkshire West:67%**

People told us they wanted health care professionals who discussed their options, rather than just told them what to do. They also wanted doctors to see the 'whole person'.

**"More transparent and honest information and doctors and consultants that speak to me like an educated, informed human – who don't patronise, and who treat me like an equal."**

**"That all available options are explained, including advantages and disadvantages."**

**"Nowadays there is so much online that patients know more about their condition and they know their own bodies better than doctors.…I believe in order to manage a condition, health care professionals and patients need to start working together."**

**"Common sense seems to be severely rationed and the sight of grey hair reduces most people to baby talk. The most effective consultant I have met recently took a look at me, a look at test results on her computer screen, correctly diagnosed that I was all right and the tests were wrong. She looked at the person – not the screen – retesting proved her right."**

## More findings on people managing and choosing their support

- **66% of people (612) say it is very important that communications are timely**
  Local breakdown:
  Bucks: 58%                Oxfordshire: 68%              Reading:68%
  West Berks: 69%           Wokingham: 66%                Berkshire West: 68%

People described their frustration at administration delays or hold-ups, and of having to be proactive in chasing up information themselves and wanting the NHS to become more efficient in getting back to people.

**"Information being added to NHS systems in a timely manner by consultants and admin staff, and communications sent to patients in a timely manner and when promised – in any other business it is not acceptable to wait 3-4 weeks for an 'urgent' letter."**

- **54% of people (496) say it is very important that they have time to consider their options and make the choices that are right for them.**
  Local breakdown:
  Bucks: 48%                Oxfordshire: 55%              Reading:58%
  West Berks: 58%           Wokingham: 43%                Berkshire West: 55%

Extra time was particularly important for people with learning disabilities:

**"Talking to other people such as my support workers to help me understand what my options are. I need extra time to decide."**

Answers to other questions, showed around 50 per cent of respondents or fewer found it vital to be in total control of decisions about managing and choosing care. In extra comments they gave, they said it was important that the NHS was transparent about what treatments or operations were available and funded in their local area, that professionals helped guide them on which consultant or hospital had a good reputation and that professionals were honest about waiting times.

- **50% (466) say it is very important, their opinion on what's best for them, counts**
- **48% (444) say it is very important that they should be offered care and support in other areas if their local area can't see them in a timely way**
- **47% (436) say it is very important they decide where to go for care/treatment**
- **42% (394) say it is very important that they decide when they receive health and care support**
- **38% of people say it is very important that, if they have a long-term condition, they decide how the NHS spends money on them**
- **38% of people say it is very important that, if they have a long-term condition, they decide how the NHS spends money on them**

**"Knowing what care and treatment is truly funded in my area, rather than a NICE guideline that says one thing, then finding out my GP can't refer because 'we don't fund that in our area'."**

## Question 3: What is important to people to help them keep their independence and stay healthy as they get older?

Respondents were asked to rate the importance of five separate statements about their health as they get older. Staying in their own home for as long as possible was very important for more than three-quarters of respondents. People told us this was dependent on access to high quality social care in the home, and support for family and friends that will or do care for them. Good public transport is also important.



*BOB-wide findings on remaining at home*
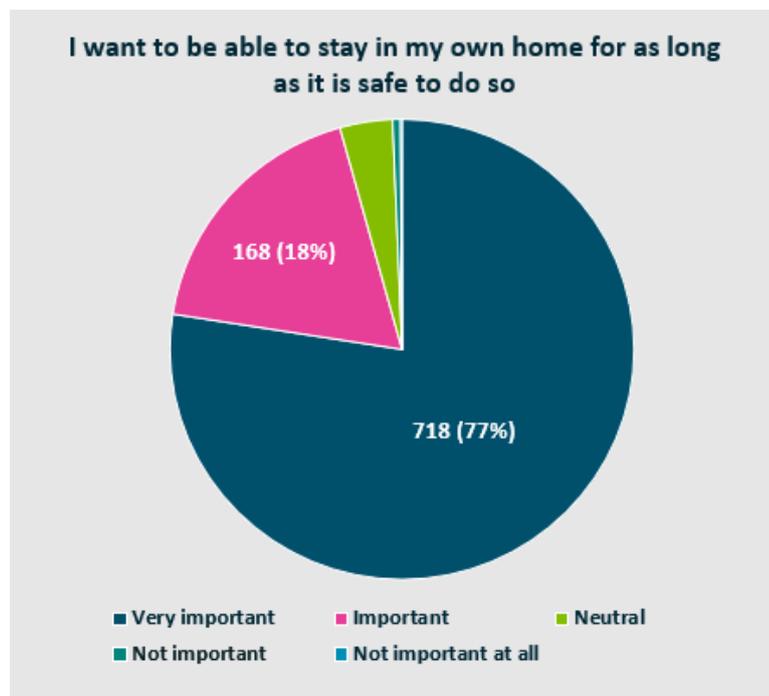
### Local breakdown

**Bucks: 78%**
**Oxfordshire: 81%**
**Reading: 77%**
**West Berks: 74%**
**Wokingham: 79%**
**Berkshire West: 76%**

*"Reliable care workers who are allowed enough time to ensure I have what I need without it being rushed."*

- **76% (707) say it is very important that they and their family feel supported at the end of the person's life**
  Local breakdown:
  Bucks: 75%          Oxfordshire: 74%          Reading: 81%
  West Berks: 75%     Wokingham: 72%            Berkshire West: 77%

- **69% 639) say it is very important to have convenient ways to travel to services**
  Local breakdown:
  Bucks: 66%          Oxfordshire: 74%          Reading: 71%
  West Berks: 68%     Wokingham: 67%            Berkshire West: 69%

- **59% (543) say it is very important their family has knowledge to support them**
  Local breakdown:
  Bucks: 52%          Oxfordshire: 47%          Reading: 65%
  West Berks: 64%     Wokingham: 53%            Berkshire West: 62%

- **50% of people (459) say it is very important for their community to support them**
  Local breakdown:
  Bucks: 45%          Oxfordshire: 52%          Reading: 56%
  West Berks: 48%     Wokingham: 40%            Berkshire West: 50%

## Question 4: What is important to people when they are interacting with the local NHS?

Respondents were asked to rate the importance of seven separate statements about communication between themselves and health services. For most people, receiving any results related to their health in a timely way, was very important.

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

578 (63%)

276 (30%)

- Very important
- Important
- Neutral
- Not important
- Not important at all
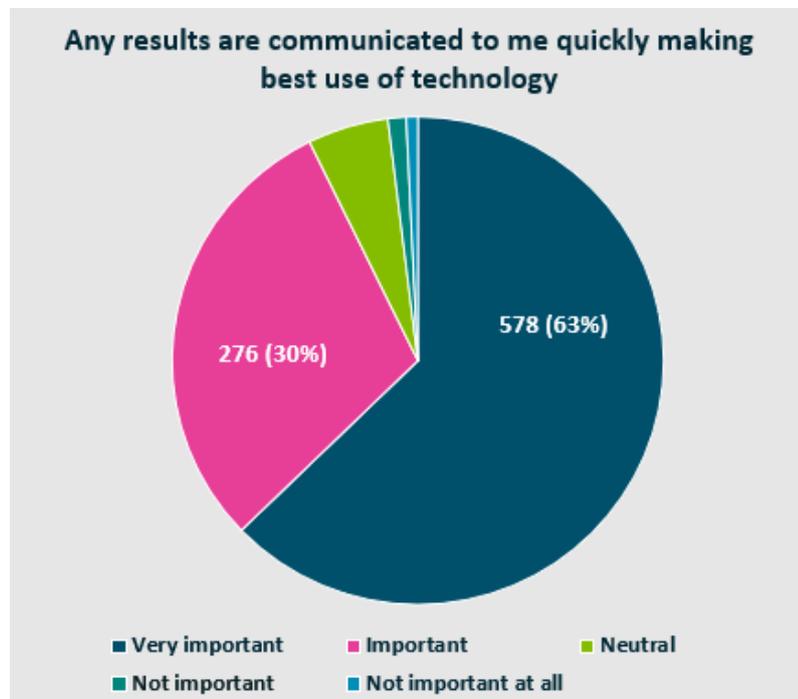
*BOB-wide findings on receiving results*

### Local breakdown

**Bucks: 57%**
**Oxfordshire: 51%**
**Reading: 69%**
**West Berks: 64%**
**Wokingham: 64%**
**Berkshire West:  66%**

*"The NHS needs to make use of digital resources such as sharing blood results…online."*

## Other findings on how people interact with the NHS

- **59% of people (543) say it is very important to have absolute confidence that their personal data is managed well and kept secure**
  Local breakdown:
  Bucks: 52%          Oxfordshire:  59%          Reading: 63%
  West Berks: 61%          Wokingham:  62%          Berkshire West: 61%

- **52% of people (476) say it is very important to be able to talk to their doctor or other health care professional, wherever the patient is.**
  Local breakdown:
  Bucks: 48%          Oxfordshire:  48%          Reading: 58%
  West Berks: 52%          Wokingham:  46%          Berkshire West:  54%

- **51% of people (470) say it is very important that they can make appointments online and for their options not to be limited**
  Local breakdown:
  Bucks: 57%          Oxfordshire:  45%          Reading: 48%
  West Berks: 56%          Wokingham:  55%          Berkshire West: 53%

*"Please make online booking of appointments…available to the local HIV clinic."*

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## More findings on how people interact with the NHS

- **48% of people (450) say it is very important that they can access services using their phone or computer**
  Local breakdown:
  Bucks: 45%          Oxfordshire: 44%          Reading: 50%
  West Berks: 50%          Wokingham:  52%          Berkshire West: 50%

- **People had mixed feelings about managing their own personal records: 37% (343) think it is very important to manage their own personal records so they can receive continuity in care; while 34% (309) say it is important and 23% say they are neutral on this point.**

  If records are made more widely available online, people want to know that they will be presented in a way that they can understand:

  **"To be able to have my records online and easily readable in easy terms as well as medical terms."**

- **32% of people (297) say it is important to be able to talk to others who are experiencing similar health challenges; 31% feel neutral, and 28%, very important**

  **"Following a recent total knee replacement…I would have felt better being in a support group with other people instead of feeling isolated at times when progress was initially slow and painful."**

## Question 5: What is *most* important to people to help them live a healthy life?

**Respondents were asked to choose *only one* of the following five options:**

- Access to the help and treatment when they need it
- Easy access to the information to help them make decisions about their health and care
- For every interaction with health and care services to count and for their time to be valued
- Professionals that listen to them when they speak to them about their concerns
- The knowledge to help them do what they can to prevent ill health

Nearly half of all people (433) across the BOB ICS say access to care and treatment is the single most important thing to help them live a healthy life



Local breakdown, for top finding of access to care:
Bucks: 57%
Oxfordshire: 44%
Reading: 49%
West Berks: 49%
Wokingham: 42%
Berkshire West: 48%
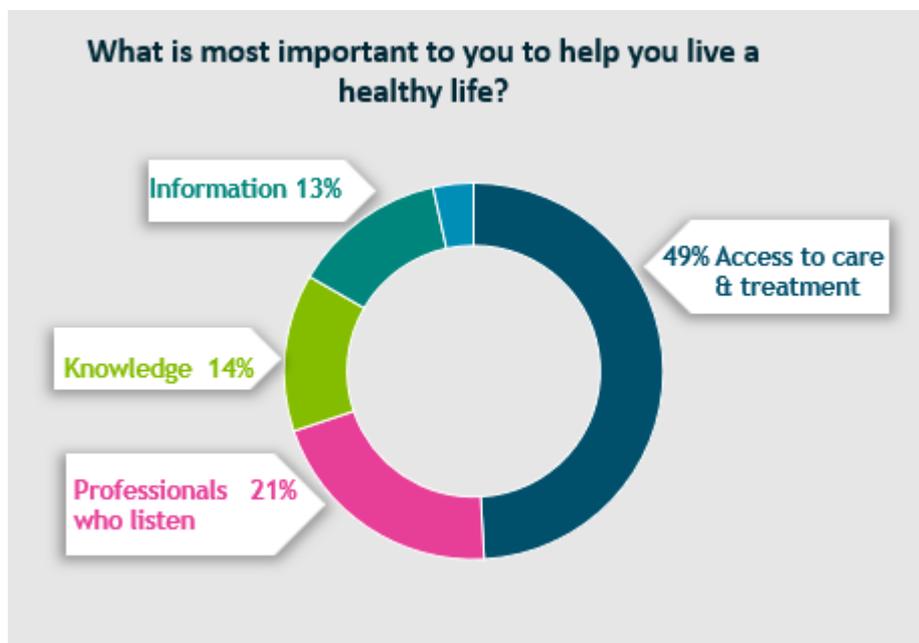
*BOB-wide ranking on healthy living*

As well as many comments from people wanting easier and quicker access to GP appointments, many people called for services to remove access barriers for people who have physical impairments and learning disabilities.

**"Text phone numbers for Deaf BSL users to access GPs."**

**"For interpreters to be accessible for GP appointments and other health service appointments and not to have to wait two weeks for an interpreter to be available."**

**"Budgets provided for care agencies to be trained in BSL to care for deaf patients after they leave hospital – there are none in this area!"**

When people were also asked to suggest *one more thing* that would help them live a healthy life, they suggested a variety of personal, NHS, community and state-led solutions.

**People's ideas for healthy living:**

**Healthy eating**

"Let someone come up with a good grow-your-own incentive. Make better use of allotment sites. Schools could grow veg and have a weekly market stall and earn income; corporates could have roof gardens where staff could grow fruit and veg – good for team building, stress relief, mental and physical health. Housing development companies should be made to include such a space on their development sites – perhaps one metre square per household, at least. Parents could grow veg whilst watching children in the plan area, instead of just… flicking through social media."

"Having companies like Gousto or HelloFresh, perhaps subsidised in a way to make it more affordable for busy, working people to have access to good, organic, fresh, healthy food."

"Cheaper fruit and vegetables."

**Healthy environments**

"Less traffic, so I could feel safe to cycle with my children around our neighbourhood."

"General reduction in pollution, especially from cars."

**State intervention**

"Cigarettes should be outlawed and irresponsible alcohol usage should be discouraged more robustly."

"The NHS should be proactive in tackling causes and treating conditions rather than relying on long-term ill health, dependence on medication and accepting declining quality of life."

"Why is public health funding being cut?"

**Social interaction**

"That as part of any treatment involving medicines and pills – or better still, instead of – patients are encouraged to join a group, club or activity relevant to their condition. I suspect that a good proportion of conditions presented stem from a lack of social interaction or activity."

"More support for lonely people."

## Health checks

"Since my wife passed away...my health has deteriorated as I am far more reluctant to contact my GP when not feeling well – basically I am suffering from the lack of a concerned 'nag' factor. I suspect that the health system needs to get ahead of the curve by proactively keeping an eye on my health, possibly by a proper annual...check-up."

"Regular full check-ups and advice. The so-called 'MOT'."

"More early preventative checks on possible inherited conditions."

## Exercise advice and facilities

"Easy, low cost access to exercise facilities for the over-60s. Gyms often appear to be promoted towards the fit and active younger set."

"Exercise for disabled and people who have long-term conditions."

"More affordable facilities."

"For exercising to be more fun.  I already exercise a lot (swimming, running) and build in exercise to daily activities (cycle to town rather than drive) but often exercise is a slog.  This is not particularly a request for help from statutory authorities: it's up to me to find fun ways to exercise but if I feel like that, others may too, so it may be worth thinking of ways to encourage more fun exercise.  That could be coming up with different ways of doing it (accepting that a lot already exists, from sports clubs to the use of electronic trackers) and helping local people come up with new arrangements.  So perhaps some research, information dissemination and some local facilitation."

"Free gym memberships."

more group (mixed ability) sport sessions organised and available on a drop-in basis

"Free, self-guided walks all around [our town] that we could download and follow. But they would need to be extensive, i.e.no more than a few minutes from everyone's house so those of us who are disabled/poorly/overweight etc could do them."

## Education

"Education from nursery age, simple healthy life messages that can build through the years."

## Question 6: What is *most* important to people to enable them to manage and choose the support they need?

Respondents were asked to select just one of the following eight options:

- Choosing the right treatment is a joint decision between me and the relevant health and care professional
- Communications are timely
- I have time to consider my options and make the choices that are right for me
- I make the decision about when I will receive health and care support
- 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
- If I have a long-term condition, I decide how the NHS spends money on me
- My opinion on what is best for me, counts

Nearly half of people (436) said that working jointly with a health professional to make the right decision about their treatment, was the single most important factor.



Local breakdown for the top finding, of choosing treatment jointly with professionals:

Bucks: 49%
Oxfordshire: 43%
Reading: 46%
West Berks: 55%
Wokingham: 45%
Berkshire West: 49%
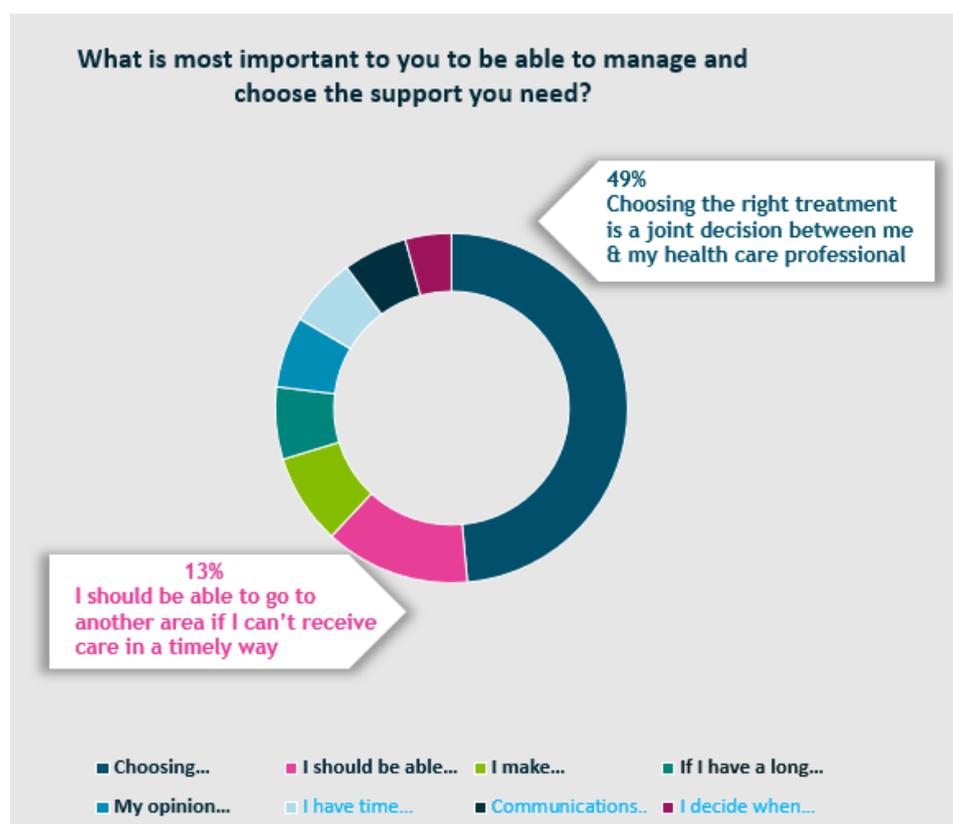
*BOB-wide ranking on managing and choosing support*

When people were also asked to suggest *one more thing* that would help them manage and choose how the NHS supports them, they suggested:

- Being given clear information on symptoms, diagnosis and options
- Being given consistent advice by different health professionals
- Better communication with people with extra needs such as learning disabilities
- Having consistency of clinician at follow-up appointments
- Involve carers/family or advocates when someone lacks mental capacity
- Services that are integrated

**People's ideas for managing and choosing their own support:**

**Clear, expert advice**

"That I am provided with support/advice by multi-disciplinary staff who are skilled and trained on, prevention, behaviour changes where necessary and have knowledge of other wrap-around services."

"Frank talks with my GP or healthcare professional."

**Consistency of care and options**

"Being able to speak to the same doctor consistently."

"A more consistent approach to treatments as opposed to where you live and if a consultant has a different approach to other consultants."

**Integrated services**

"Single point of contact, person or centre which has all the relevant information about me and my health rather than the confusing different channels which don't join up – GP, physio, nurse, pharmacist, outpatients' clinics."

"Being able to have treatment across borders with sharing of information. Cross border issues for Newbury and outlying areas is a real problem.  E.g. if I have treatment at North Hampshire, I cannot get blood test or follow up appointments locally."

**Accessible information**

"Information that is easily understandable, particularly for people whose first language is not English."

"The NHS should not expect everybody to be able to read – 'tell' people about it as well."

"Ensure there is an advocate who can communicate in BSL to explain and discuss options."

"Easy read information. Talk to my family so they can help me understand what my choices are."

**Involvement of carers**

"Let family and carers be involved in discussions and decisions for people who lack mental capacity."

"Medics should accept that family carers know patients and what is their 'normal' healthy state."

## Question 7: What is *most* important to people to help them keep their independence and stay healthy as they get older?

Respondents were asked to select only one of the following five options:

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



*BOB-wide ranking on keeping independence and staying healthy as you get older*

Local breakdown
Bucks: 54%          Oxfordshire: 54%          Reading: 57%
West Berks: 55%     Wokingham: 70%            Berkshire West: 58%

Many suggestions were given by people when asked what else could support them:

- Not becoming a financial or personal burden to relatives
- Cheaper or free social care
- Opportunities to stay mobile as long as possible via support from physios and OTs
- Cheap or free transport, and/or bus services restored to small villages
- Adaptations/technology and high-quality home care workers to stay safe at home
- A care coordinator to fully join up health and social care
- The ability to choose when to end their life, through assisted dying

**People's ideas for staying independent and healthy as they get older**

**Support to stay mobile**

"Maintaining my health and mobility, if I could have other types of treatment like hydra therapy pool, assisted exercise machines. That would help keep me healthier and remain mobile for longer, which in the long term be less of a burden for the NHS."

"Access to appropriate exercise classes or physio-led exercise close to where I live."

"More needs to be done to get elderly people moving when they have broken something, otherwise they end up not being able to move and might not be able to move back to their house."

**Access to social care**

"I don't want my family to have to give up their quality of life to support me. Having paid my taxes, I feel the state should pay for my care."

"Make access to information more readily available. For example, I had no knowledge that I could remain at home with live-in care home rather than a care home. I now know from a few friends…this is possible with live-in Care supported by the district nurses and MacMillan nurses all working in a co-productive fashion."

"To have home care integrated with healthcare provision and provided by central funding."

**Care closer to home**

"Having supported neighbours, it is blatantly obvious that Wycombe, and other areas, needs something like an elderly overnight care facility for the elderly with conditions like COPD.  A&E at Stoke Mandeville is clogged up…and it is such a difficult journey driving back from Stoke at 2am (I have done it on several occasions to support a neighbour)."

"Bring back day centres in Oxfordshire as they help to stop carer burden thereby enabling older people to live in their homes longer."

"Regarding end of life, it would be appropriate to have a hospice locally."

## Greater support for carers

"Family members who spend more time with elderly relatives than social workers, should be listened to. Mine were ignored with regards to my dementia-suffering grandmother and she was left in a 3-bed house too long suffering so they could save money."

"Support for those around me if I choose to stay at home for end of life."

## Better transport

"If you need to go to a medical appointment you do not want to be jolted around the area for a couple of hours and have to change buses. There is no direct bus from Winnersh to RBH [Royal Berkshire Hospital]."

"Organise a park-and-ride from the Madejski Stadium to the RBH [Royal Berkshire Hospital]."

"NHS was great, all tests done and treatment provided but having to travel large distances to get to the Royal Berks and the lack of parking, meant long bus journeys both ways, which, when you're having chemo is not a great experience. Taxis cost £70. Unsustainable."

"Better transport in rural areas, especially when getting to doctors' surgeries and hospitals. It is also important to have transport that enables people to visit people when they are in hospital, which can help them remain positive and so aid their recovery."

"Better local transport for when driving is no longer safe."

## Care coordination

"One person, a key worker who is responsible for taking a holistic view and who can coordinate agencies to provide thorough care from a medical and social model, a bit like a EHC plan that is put in place for SEN [special education needs] children but is a plan for elderly provision."

## Changes to the law

"I would strongly support provisions for dignity in dying including a right to choose when to die in the event serious terminal illness."

"The ability to decide when to die."

## Question 8: What is *most* important to people when they are interacting with the NHS?

Respondents were asked to choose only one of seven options most important to them:

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

There was a spread of opinion about which factor was most important:
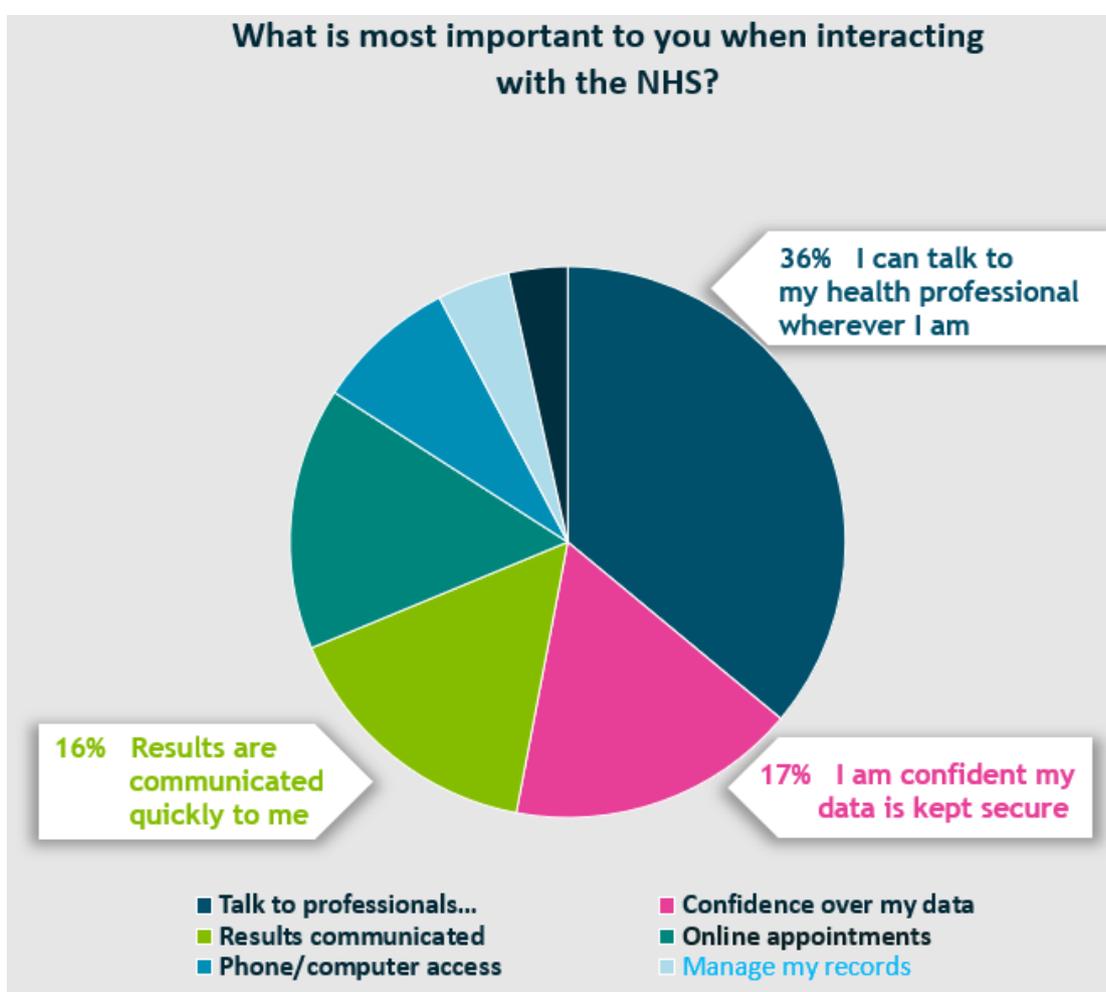


*BOB-wide ranking on interaction with the NHS*

Local breakdown, for the top finding of being able to talk to health professionals:
Bucks: 43%          Oxfordshire: 30%          Reading: 29%
West Berks: 43%     Wokingham: 32%            Berkshire West: 35%

**Respondents' views on the role of technology in the NHS:**

**Use technology to its fullest capability**

"I have to have regular blood tests - why can't I book these online?"

"Ensure every professional interacting with me has access to my full health records (at least the current situation and data for 2 years) and every aspect of my health management. I do not want to repeat everything to each professional I see."

"Enable the messaging function [to GP] in the Patient Access App."

"As a patient with myeloma (a blood cancer) I would like to be able to access my blood results online and not have to wait for clinic appointments. It can be an anxious wait at crucial times in my disease."

"Make it easier to book online.  At the moment it is difficult to register - you have to have lots of information and go to the surgery first.  Then when you do book a GP appointment online you are given one slot on one day with one doctor, which isn't your own doctor.  There is no choice, no other slots."

"Patient Access [for booking GP appointments] is a waste of time. Had to drive 4 miles to book an appointment as nothing available on Patient Access this morning."

**Technology helps those with extra needs**

"Access via my computer is important to me, because I am hearing impaired and the telephone is very difficult for me."

"Text phone numbers. Deaf and hard of hearing people cannot use telephones. Minicoms are not used anymore."

**Technology has its limitations**

"Face to face still important as cannot hide true feelings/symptoms."

"There are many places in Bucks where you can't get a good signal /adequate broadband so people could miss vital information."

"Personal interaction between patient and practitioner is vital."

"It is no help to the NHS, its staff or patients if the healthiest patients who rarely see a GP are given a high tech video link GP service which leads to less money being available to their previous GP surgery to manage the needs of the patients who need more  frequent care."

# Chapter 2: Specific conditions survey findings

We received 219 responses to the second survey Healthwatch England supplied for this engagement project, to obtain people's experiences of conditions that are set out as priorities in the NHS Long-Term Plan. These seven conditions are:

- Autism
- Cancer
- Dementia
- Heart & lung disease
- Learning disabilities
- Long-term conditions (like diabetes or arthritis)
- Mental health

## Breakdown of respondents by condition

- 40% Long-term condition
- 21% Mental health
- 15% Cancer
- 11% Heart & lung

Legend:
- Long-term conditions
- Mental health
- Cancer
- Heart & lung disease
- Autism
- Dementia
- Learning disabilities

*BOB breakdown of survey 2 respondents by specific conditions*

The findings show that 45% of respondents said their condition had started within the last three years.

The key themes and findings were that:

- The wait to get an initial assessment or diagnosis was too slow
- Continuity of care from a known professional for ongoing follow-ups was important in helping people manage their condition
- People who had multiple conditions found it harder to get the support they needed
- People had mixed experiences of receiving support they needed and consistent communications

The largest number of free text comments we received were about mental health care, mostly negative.

The rest of this chapter highlights some key statistics and then focuses on each of the seven conditions and the experiences that people shared with us. Full findings for the specific condition survey can be found in Appendix 3, on pages 41-42 of this report.

Due to the smaller sample size of this second survey, we have not provided a breakdown of findings for the five local areas.
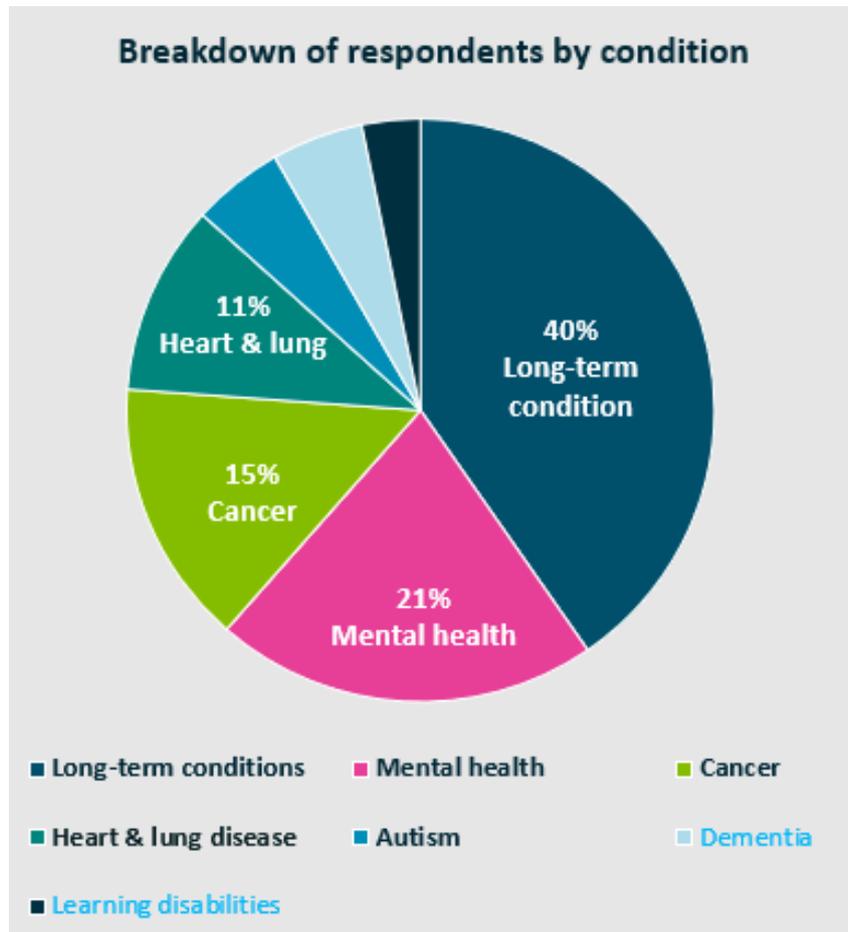
**healthwatch**

## Key findings from the specific conditions survey

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

- Very slow 22%
- Slow (25%)
- Very fast 6%
- Fast 18%
- Okay 26%

## What was most important to you when......

### First seeking help?

- 16% Don't mind
- 31% Waiting longer to see a health professional you know
- 54% Seeing any health professional immediately

### During your long-term support?

- 11% Don't mind
- 27% Seeing any health professional immediately
- 62% Waiting longer to see a health professional you know

**healthwatch**
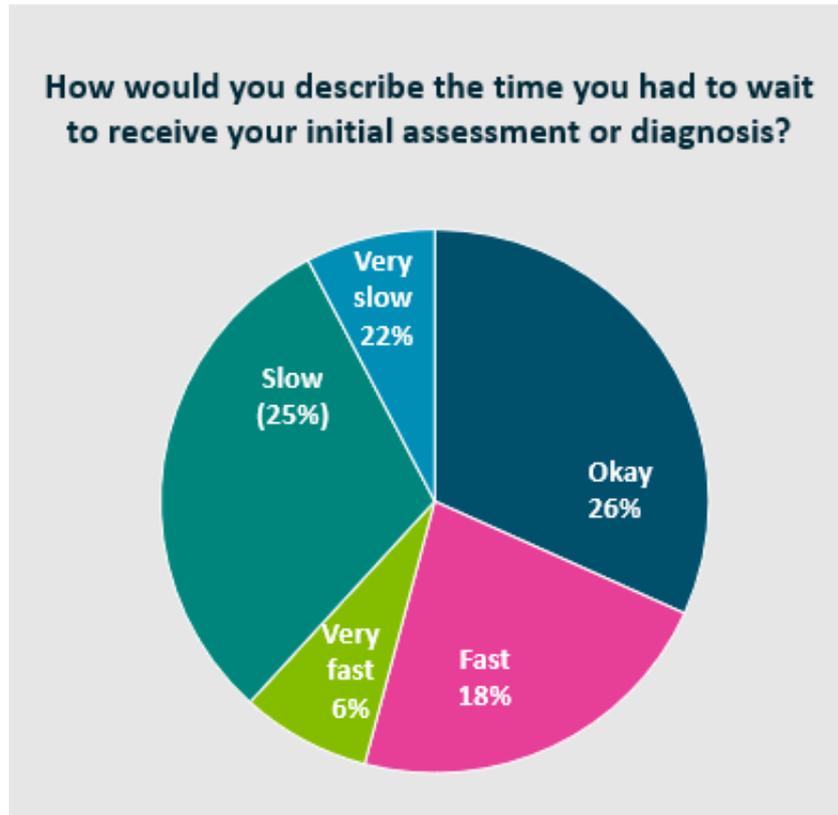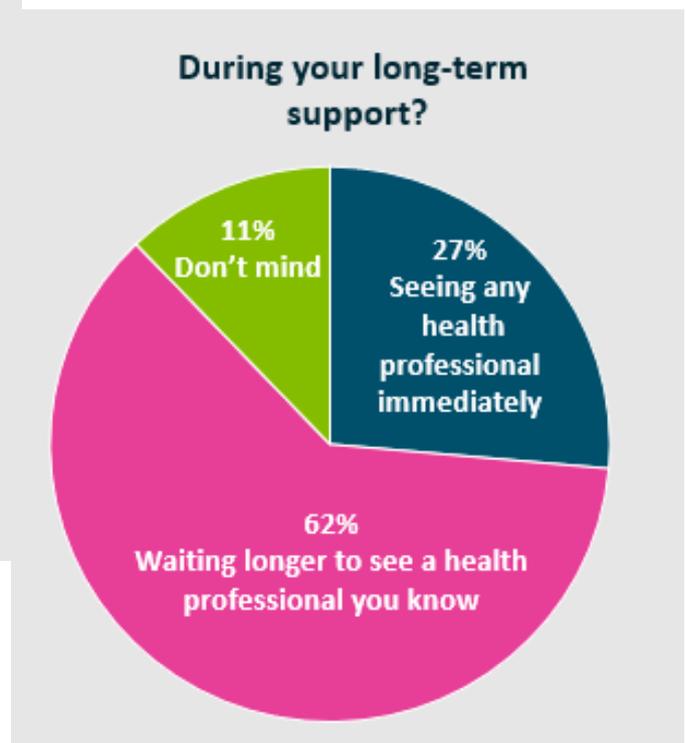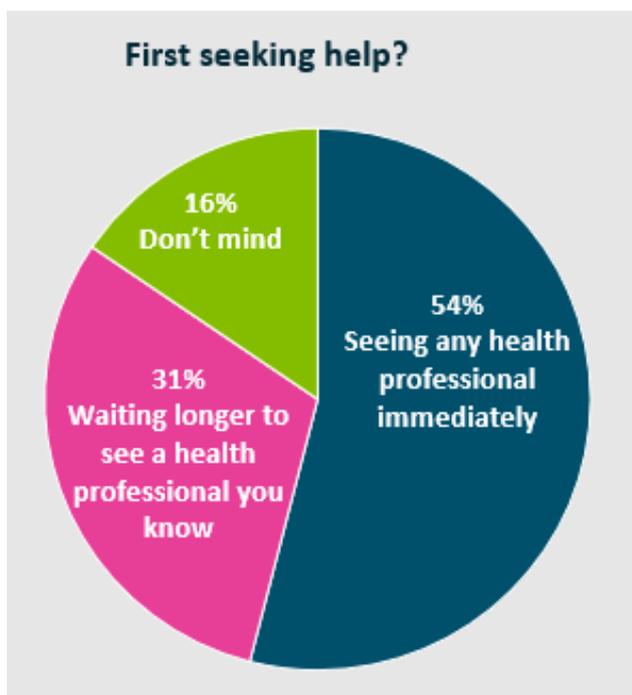
## More key findings from the specific conditions survey

**Did the support options you were offered, after initial assessment or diagnosis, meet your expectations?**
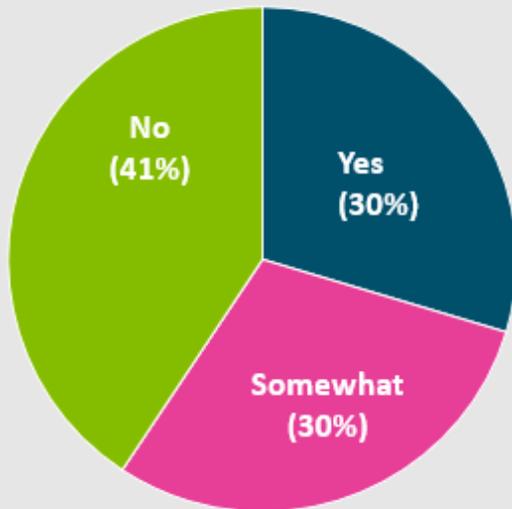
No (41%)
Yes (30%)
Somewhat (30%)

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

No (37%)
Yes (29%)
Somewhat (34%)
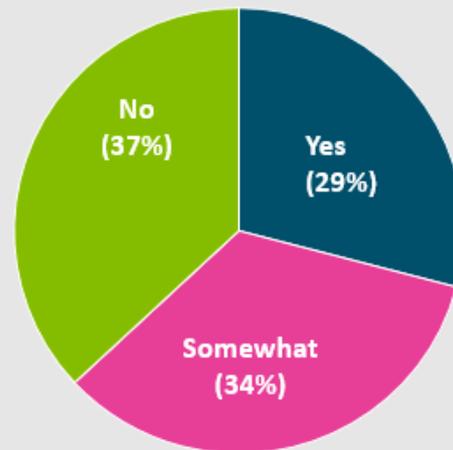
**How much time would you be willing to travel for a quick and accurate diagnosis?**

18% Less than 30 mins
18% 1-2 hours
53% 30 minutes-1 hour

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

23% 1-2 hours
15% Over 2 hours
48% 30 minutes-1 hour

# People's experiences about the specific conditions

## Autism

**Feedback themes:**

- Long wait to get children diagnosed
- Little support for adults with autism
- Health professionals and teachers need training on supporting people with autism
- Delays in mental health referrals due to professionals only seeing autism needs

"The child...should have been diagnosed and statemented for school earlier and without having to write to all parties to get this as he got lost in the system. Once diagnosed...extra help was provided to keep him in mainstream education."

"I am an Adult with Autism. There is no support available...there is no Community Adult Autism Team and the Adult Community Learning Disability Team excludes people with Autism."

"Access to mental health help extremely slow and often issues bounced back to autism."

## Cancer

**Feedback themes:**

- Medical care for cancer praised
- People really value the support of specialist cancer nurses
- Some said improvements were needed to after care or emotional support

"The cancer nurses were brilliant."

My friend...is having to travel...to Oxford for treatment that cannot be delivered in Reading which is adding more pressure to both him, his wife and...children. The charity Maggie's is in place at Churchill Hospital and they often travel to Oxford when they need support. It appears there is nothing of a similar nature in the area and is something that would benefit patients, families and friends enormously in so many ways."

"I am happy that my oncology department are giving me the best treatment. I feel a more holistic approach to living with Stage 4 cancer would be better, as the emotional issues in my case were huge. I did get support from a psychologist who is excellent, but this is for a limited number of sessions. When it is finished, I feel I have no ongoing support other than my GP. There are a team of specialist nurses, but you are not allocated one person, so it is difficult to build the relationship of trust and understanding that would be useful in my situation - so I do not use them other than for very practical issues."

## Dementia

**Feedback themes:**

- Delays in getting diagnosis
- Family feel their evidence about relatives' behaviour is not always taken into account

**"I struggled to get GP to understand the issue with my mother and her dementia and this severely delayed referral."**

**"Took months to get the help needed for my mother's dementia."**

## Heart and lung disease

**Feedback themes:**

- Praise for medical care
- People value support and advice from heart failure nurses
- Some people want better follow-up care
- Society should make adjustments for people with lung conditions in the same way as disabilities

**"The heart failure nurses are brilliant."**

**"Great heart failure team and amazing GP."**

**"I do not have a disability, but my quality of life is affected by my Arthritis, Bronchiectasis and Asthma.   I think being classed as 'disabled' should not be the only measure of how your life is affected by your health. Being able to park in disabled spaces when being admitted and discharged [at the Royal Berkshire Hospital] would have helped enormously as I was in considerable pain and had limited mobility (I needed a wheelchair to reach my car).  Is there a short-term disabled permit that could be issued?"**

**"Great to start with, but now just left to get on with it. More access to a heart consultant to discuss medication would be helpful."**

## Learning disabilities

**Feedback themes**

- Health care professionals need training on learning disabilities, including communication
- Relatives want health professionals to take their views into account

**"Understanding of disability and learning difficulties, communication difficulties, by staff at all levels, particularly GPs as first point of call."**

**"They need to be patient and explain things easier to me."**

**"Not to assume, if nonverbal, unable to feel pain or communicate."**

# Long-term conditions

**Feedback themes**

- Some people had experienced long delays in getting a diagnosis and/or treatment
- It is important to have continuity of care from the same team of professionals
- Services should be aware of the fatigue, stress and financial burden of conditions

## Delays

"I was originally diagnosed as having migraine; however, years later, after moving into a new area and going to a new surgery, I got the correct diagnosis [of epilepsy], and treatment that could help me."

"Initially I seemed to get lost in the system and was left having been given some terrible news about a long-term condition with an appointment three months down the line and absolutely no support. I had to fight to get some answers…"

"For my arthritis I was left waiting a long time from referral to treatment. Referral was in April… treatment [the following] January - however this was partly due to intervening diagnosis of [another condition] but included a delay due to last minute cancellation."

## Consistency of care

"I have to get regular appointments at the GP, but am not allowed to book in advance, [only] on the day; this makes it hard to see my [own] GP and penalises me for having a long-term condition."

"I have had lupus for [many years] and even though I live in Reading I still make the appointments at Guys in London as I feel my consultants know the history but also have taken the time to get to know me as a person. I always know that they are an email or a phone call away and have received great treatment."

## Accessibility

"Long-term conditions make it difficult to get around without feeling tired all the time. More telephone support would be useful."

"I cannot keep taking off time from my job to travel, find parking, pay for parking and then to walk all the way through the hospital to the blood clinic each month."

## Care costs

"Make inhalers for asthmatics free."

"I was offered four physiotherapy sessions but told I needed many more. I since paid thousands of pounds on treatment."

# Mental health

We received more comments about mental health care than any other specific condition

**Feedback themes:**

- Delays in diagnosis or treatment
- Inadequate or limited care options for ongoing symptoms
- Inadequate support in a crisis situation
- Professionals who are overworked, and/or not empathetic
- Not getting the same level of support as for physical conditions

## Delays

"I kept going to see my GP about my symptoms and was wrongly diagnosed with depression and anxiety. After two years and nearly committing suicide - my GP finally listened. I was sent to a psychiatrist and waited a month and was diagnosed with PTSD and then discharged from the mental health team. I've struggled for over 2.5 years now with PTSD but the mental health team and my GP won't help me."

"I had to wait nine months to see a therapist to start CBT. When you are struggling to get through each day this is a horrendous wait. It's very hard to pluck up the courage to ask for help and then to be left in limbo for so long is not right. There needs to be more funding for mental health services to reduce waiting times."

"I received very basic support. GP couldn't help. Took them months to get through to mental health services and even then, I had to wait longer for help. Took about eight months and they weren't very understanding, spoke over me a lot and I felt they didn't listen."

"I took a friend to A&E as she was having suicidal thoughts and had the resources to carry the action out.  I tried to contact the crisis centres and various other organisations and was eventually told to take her to A&E - we waited for 4 hours in the waiting room, another 1-2hrs in a second waiting room and then she told the mental health consultant what she'd already told me, she was then advised to go to her GP surgery the next day - I could've told her that myself."

"After a serious suicide attempt and subsequent referral to the home crisis team, it took six weeks to be seen by a psychiatrist."

"When she turned 18, she then had to register with the adult mental health team, which took a while, then moving to...university she had to see a psychiatrist all over again before getting counselling, when it is supposed to be a NATIONAL health service. The wait was too long there, and she had another suicide attempt, so we paid for private treatment."

## Attitude of NHS staff

"Medics treat anyone with mental health issues like a nuisance and I've fought 2.5 years for a correct diagnosis and it led to me nearly committing suicide before anyone actually listened to me. It also makes me getting help for my asthma extremely difficult as the GP blames my mental health for it."

"I often felt unimportant during my process with CAMHS. I felt like they believed that my mental health needs were not severe enough to be worth their help and felt concerns were not taken seriously. There was a long wait time and appointments were sporadic at the best of times. The care did not feel person centred and I felt that CAMHS were too desperate to follow the NICE guidelines rather than take into account individual needs. I do think that individual practitioners are not to blame for this and their hands are tied. They are underfunded and overworked."

"Have empathy and understanding."

## Quality of care

"There was an excellent first assessment in the Emergency Department – the nurse and doctor were very good, started medication immediately and gave both me and the patient a safety plan which was very useful. But the follow-up in the mental health system was really not as good."

"The NHS only offers certain types of therapy and CBT online is not effective for someone with severe and enduring mental health problems. I needed face-to- face counselling, not computer course and fortnightly (sometimes monthly) telephone appointments."

"More options for mental health support - medication and CBT is not a one-size-fits-all solution to complex long-term mental health issues."

"You would not half treat cancer or a broken leg, so why half treat mental health conditions."

## Investment

"What is most obvious is the desperate underinvestment in mental health services - all the staff are willing, but there are too few of them and they all seem overstretched and unhappy. There is little access to psychological therapies and long waiting times to see a consultant."

"The NHS should have mental health casualty services just as they have for physical health these services will be the signpost to other support and health and guide people who don't have the capacity at that time to help themselves."

## Chapter 3: Focus group findings

This chapter sets out a summary of the views of 87 people collected during 10 focus groups held by the five local Healthwatch.

Four of the focus groups were with people with experience of mental health needs. This reflects the level of ongoing concerns reported to local Healthwatch about mental health services. The focus group findings build on the extensive library of patient experience that local Healthwatch across BOB have produced, including reports on the experiences of people admitted to acute hospital wards, people who have self-harmed, people who use crisis services, and the mental health needs of young people.

Other focus group topics were chosen by local Healthwatch to allow engagement with seldom heard groups: women from ethnic minority backgrounds, young carers, people with learning disabilities, and carers of adults with young-onset dementia. A further two of the focus groups explored how services and/or neighbourhoods should be designed to meet the needs of older people, or a population in a deprived ward.

The full report on each focus group can be found on the five local Healthwatch websites. (See page 43 of this report for contact details).

The findings summarised in this report only relate to the views expressed by that particular focus group and should not be seen as being representative of the wider population.

### Summary of focus group findings

| Bucks | Mental health focus group | |
|---|---|---|
| What people said works well | What people said doesn't work well | What people said matters most or needs to change |
| • Support from mental health charities<br><br>• Day centre<br><br>• Those GPs that specialise in mental health<br><br>• Police respond well to mental health crisis | • GP appointment times not long enough to talk about mental health<br><br>• Stressful having to tell receptionists symptoms<br><br>• Timely GP appointments not always available<br><br>• Some acute beds are too far away, takes people away from family<br><br>• Feel like you're on your own after discharge from community team | • Need more staff<br><br>• Every GP surgery should have a doctor specialising in mental health<br><br>• Need more information about local community support and activities<br><br>• Need walk-in services like those run by charities |

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| Oxfordshire | Mental health focus group | |
|---|---|---|
| **What people said works well** | **What people said doesn't work well** | **What people said matters most or needs to change** |
| • Holistic support from voluntary sector within Oxfordshire Mental Health Partnership<br><br>• Other social and leisure activities run by charities | • Some people felt that A&E was the only place to go in a crisis<br>• Long waits from referral to therapy<br>• Not enough support after working hours<br>• Only crisis support is A&E<br>• GPs don't always recognise the severity of symptoms<br>• Potential disparity between services available in city & county<br><br>*"I called the Warneford [hospital] trying to make contact with a care coordinator, but no one got back to me. So I had to phone the police. The police are a great help, they take the slack for mental health services."* | • Getting more support at the right time<br><br>• Expert mental health support based in A&E<br><br>• More evening or weekend social clubs or activities<br><br>• More training for GPs on recognising key signs of mental health problems |

| Reading | Mental health focus group | |
|---|---|---|
| **What people said works well** | **What people said doesn't work well** | **What people said matters most or needs to change** |
| • Support from mental health charities | • Mental health needs aren't given the same priority as physical needs<br>• GPs not always skilled on mental health<br>• Long waits after being referred<br>• Negative experiences with community mental health team staff – puts people off seeking help<br><br>*"They deal with crisis much better than they deal with ongoing support and prevention."* | • Need empathetic staff who see the person holistically<br>• Information about available community support needs to be better distributed among professionals<br>• Install a bus stop outside Prospect Park Hospital to make it easier & safer to attend appointments<br>• Invest more in preventative services<br>• More funding of peer-led groups |

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| West Berkshire | Mental health focus group | |
|---|---|---|
| **What people said works well** | **What people said doesn't work well** | **What people said matters most or needs to change** |
| • Support from mental health charities<br>• GP support is generally good despite their workload and funding pressures | • Long waiting time for the NHS mental health crisis helpline to be answered<br>• Waiting times too long from GP referral to see a mental health specialist<br>• Not enough follow-up after hospital discharge<br>• Stress of dealing with council or DWP<br>• Poor transport<br><br>**"For someone who is in a mental health crisis there is not a direct line for them in Newbury. They have a switchboard…and you end up waiting 20 minutes on the phone."** | • Engagement with service users need to be constant and used to make changes<br>• Mental health resilience needs to be taught at school<br>• Need to see the same GP<br>• Locate specialist support nearer people's homes, such as charities/GP's<br>• Make information on local support available offline, too |

| Bucks | Young onset dementia focus group | |
|---|---|---|
| **What people said works well** | **What people said doesn't work well** | **What people said matters most or needs to change** |
| • Help & support from local carers organisation<br>• Some health professionals who proactively make adjustments<br><br>**"We couldn't manage without support from Carers Bucks."** | • Delays in diagnosis due to GPs not considering it in young people<br>• Relatives don't feel their evidence is listened to<br>• Respite service for younger patients closed in 2012<br>• Some professionals who don't know how to communicate with dementia patients<br>• Social services not responsive enough<br>• Not qualifying for CHC | • Carers should be more involved in initial diagnosis process<br>• Use other assessments than just the memory test<br>• Fast-track for support when needed<br>• CPNs should be available<br>• Professionals need more experience of interacting with people with dementia<br>• More information aimed at children of patients<br>• Evening and weekend appointments are better for carers, who often work |

| Oxfordshire | Asian women's perspectives on GP services, focus group | |
|---|---|---|
| **What people said works well** | **What people said doesn't work well** | **What people said matters most or needs to change** |
| • Showing health promotion videos on the GP surgery waiting room screen (e.g. NHS Sugar Smart) | • Repeatedly asking for help but not getting it<br>• Expectations for medication aren't met<br>• Not being offered translators if needed<br>• GPs making assumptions<br><br>*"I went to the GP feeling tired and my hair was falling out. The GP said, 'All Asian people have vitamin D deficiency' and told me to buy vitamins from the chemist. When they finally [checked my blood] my Vitamin D level was [very low] and I needed a high dose only the GP could give, not over the counter."* | • An outreach talk by a clinician to their group on diabetes would be useful<br>• Culturally appropriate dietary information<br>• GPs need to give information about antibiotics and prescribing in an easy-to-understand manner<br>• Promote the availability of translators at the point you book GP appointments<br>• Education at school on healthy eating |
| Reading | Designing a healthy neighbourhood, focus group | |
| **Current issues** | **Questions raised about primary care networks** | **What matters most or needs to change** |
| • Difficult to make a same-day GP appointment unless you can phone at 8am<br>• Some people resort to using Reading Walk-In Centre when they can't get an appointment at own surgery<br>• GP surgeries aren't near other services<br>• Telling people to stop unhealthy habits doesn't work | • Won't the plan for 'digital first' primary care leave behind those not online?<br>• Where will 111 helpline get all the staff needed to do direct GP appointment booking?<br>• Do GPs have time to set up new networks?<br>• Why haven't our surgeries talked to us about primary care networks?<br>• Will the networks just be based on GP business relationships rather than what's best for patients? | • Build on existing community resources like local allotments to tie into healthy eating plans<br>• Create fun activities at the community hub which already has a library, parent & children groups, advice sessions & café<br>• Merge GP surgeries into one, large health centre within community hub<br>• Set up services closer to home for people with poor mobility<br>• Improve public transport<br>• Engage with patients on plans<br><br>*"You've just got to make it enjoyable and sociable - come here learn to cook, all eat together."* |

| West Berkshire | Learning disabilities focus group | |
|---|---|---|
| What people said works well | What people said doesn't work well | What people said matters most or needs to change |
| • When health professionals make reasonable adjustments<br><br>**"He [the dentist] understood that I don't like needles and gave me the choice of going to the RBH [for wisdom teeth extraction] and being knocked out."** | • When services overlook a person's written care plan as vital communication tool, and risk their safety<br>• When people use jargon, acronyms and terminology that they can't understand | • Health professionals need to communicate in a way people understand<br>• Accessible transport is needed to and from appointments (most people with LDs do not drive, have limited income for paying support staff or have restrictions on bus pass times)<br>• Make sure follow-up letters are in Easy Read format<br>• Women want to see female doctors/nurses<br>• People want to be honestly told if treatment will hurt<br>• People want to feel safe at the service they are attending |

| Wokingham | Young carers focus group | |
|---|---|---|
| What people said works well | What people said doesn't work well | What people said matters most or needs to change |
| • GPs are caring, empathetic, listen, focus on them as individuals and understood the pressure of being a young carer<br>• A&E staff are kind, compassionate and explain things clearly | • 10 minutes isn't enough time for GP appointments<br>• They didn't always feel heard by CAMHS professionals – or too much time was spent talking with the parent<br>• Things weren't always explained clearly by hospital staff (outside of A&E)<br><br>**"Why did my parents get a letter and not me? This is my issue, my treatment. If they have to send a letter to my parents, then okay, but send one to me as well."** | • Young people want to feel heard<br>• Young people want to be treated as individuals<br>• Young people want to feel like their opinions are valued<br>• Young people want information about treatment, before, during and after<br>• Young people want to be asked views on current or new services and be told later how these have shaped changes |

| Wokingham | Older people ageing healthily, focus group | |
|---|---|---|
| What people said works well | What people said doesn't work well | What people said matters most or needs to change |
| <ul><li>GPs listen and are caring</li><li>Referrals for diseases like cancer or heart disease are swift</li><li>Treatment from cancer and heart specialist teams was excellent</li><li>MacMillan staff were exemplary</li></ul> | <ul><li>Two week waits for GP appointments</li><li>Having to visit hospitals can cause anxiety about driving into city centres, lack of parking or walking around large buildings</li><li>There hasn't been enough engagement with public about previous changes to local NHS services</li></ul> | <ul><li>A community healthspace of various services would be welcome</li><li>The excellent cancer care from doctors or nurses should be replicated for other diseases/conditions</li><li>Carers want quick access to GPs, fall services & nurses</li><li>Carers don't want to have transport unwell relatives to far away services</li></ul><br>**"I've used the Brants Bridge Healthspace in Bracknell, it's excellent at providing services, we need something like that in the Wokingham area."** |

# Next steps

This major public engagement exercise has collected a substantial amount of views from people in communities across Buckinghamshire, Oxfordshire and Berkshire West. The key messages that we urge commissioners and providers within BOB STP to consider, are:

- *The public's top priority is to access healthcare when needed, without delay*

- *People can choose and manage their support when they have access to professionals who truly listen, set out options and answer their questions*

- *A caring and empathetic manner in health care professionals is as important as medical skills and knowledge*

- *Health professionals must use a variety of communication methods, particularly with people with disabilities, and those who do not speak English as a first language, so these people can be fully involved and informed about their care and kept safe*

- *People who care for those who are vulnerable, such as people with dementia, want to be seen as 'experts' on their needs and be fully consulted about their options*

- *People with long-term conditions value relationships with trusted, familiar health professionals; it helps them manage conditions and stops them repeating their story*

- *People who are happy to use technology, want the NHS to enable it to its full extent (such as making all GP appointment slots bookable online)*

- *People who can't or don't want to use online services, do not want to become 'second-class citizens' in terms of accessing NHS services*

- *People want personalised goals from the NHS to stay or become healthy, but they also call for more action by government, industry, schools and local authorities*

- *People are keen on health hubs that bring together multiple services closer to home*

- *Transport can be a major barrier to accessing services, if village bus routes are closed, hospital carparks are expensive or full, and if people have limited mobility*

- *At the end of life, people's main wish is to stay at home; they need help beyond the NHS to do this, in the form of affordable (or free), high quality social care*

- *Mental health services are in urgent need of investment and improvement, not least to stop people feeling they need to be contemplating suicide before they get help.*

We asked the BOB ICS to respond to our report. On June 24 2019 it sent us a statement:

*"We welcome the work carried out by Healthwatch and are grateful to those who took the time to talk about their experiences, concerns and priorities. All of the feedback provided will be carefully considered by colleagues and leaders working to plan for and implement the ambitions of the NHS Long Term Plan.*

*"It has been helpful to see that the issues raised chime with those areas that we have identified as our priorities, through our work in recent months to analyse local health and care needs and reflect on what communities tell us about what matters to them.*

*"The Healthwatch survey and focus groups both complement and supplement the on-going engagement and conversations continuing in local health and care systems and more locally still in neighbourhoods. In addition to this on-going work, we expect to do further engagement work specific to our strategy for BOB and the Long Term Plan.  The timeline and next steps for this will be informed by national guidance, which we expect to be published in the coming weeks."*

# Appendix 1: Methodology

Representatives of five local Healthwatch met at the beginning of the project with the BOB ICS lead on communications and engagement, to discuss the aims of the survey:

- To survey up to 250 people per local Healthwatch area, using two Healthwatch England-supplied surveys (one for the general public and one for people with specific conditions)

- To run two focus groups of up to 10 people per local Healthwatch

- To compile the findings on a BOB-wide basis to inform the BOB ICS response to the NHS Long-Term Plan

From the beginning of April 2019, all five local Healthwatch promoted the surveys, which people could complete online on the Healthwatch England site.

However, all the local Healthwatch found that good response rates relied more on printing and bringing out paper copies of the surveys to community groups and organisations, hospitals, and GP waiting rooms. Local Healthwatch then input the findings into the online survey form.

Healthwatch England supplied Excel files of the raw survey data back to the coordinating Healthwatch (Reading) to analyse fully.

All survey responses were anonymous.

For the focus groups, local Healthwatch in most cases worked in partnership with local voluntary groups or support services to set up and run sessions, ranging from one to several hours.

Participants signed consent forms to confirm their anonymous views could be used.

In some cases, people were thanked for their time in taking part, with a small gift voucher and/or lunch and refreshments.

# Appendix 2: Demographics

**General survey respondents:**

**Total:** 938 people

**Gender:** 69% of respondents were women, 30% men, two people said 'other' and 10 people said they preferred not to say

**Age:** The biggest age group (26%) was 65-74; followed by 55-64 (20%), 75+ (18%), 45-54 (16%), 35-44 (10%), 25-34 (8%), 18-24 (3%) and five respondents aged under 18

**Ethnicity:** Most people (89%) said they were White British, followed by Any Other White Background (4%), and 'Other' (2%). Nine people said they were from Any Other Mixed Background; 8, Asian British; 7, Indian; 4, African; 3 each for Arab, Bangladeshi and Black British, 2 Pakistani, and 1, Caribbean. 41 people left this question unanswered

**Disability:** 21% of people said they considered themselves to have a disability; 75% said no, 4% said they preferred not to say; and 37 people left this unanswered.

**Carer:** 12% of people said they were a carer, 88% said no, 53 left this unanswered.

**Sexual orientation:** 89% of people said they were heterosexual; 2% said 'Other', 1% said Gay or Lesbian, 1% said Bisexual; two people said they were Asexual, two Pan-Sexual, and 6% said they preferred not to say.

**Religion:** 51% of people said they were Christian; 36% said No Religion; 7% said they preferred not to say; 23 people said 'Other', 11 said Muslim, 7, Hindu; 6, Buddhist; 4, Jewish; 2, Sikh.

**Specific conditions survey:**

**Total:** 219

**Gender:** 66% of respondents were women, 32% men, three people said 'other' and one person said they preferred not to say

**Age:** The biggest age group (22%) was 55-64; followed by 45-54 (20%), 65-74 (19%), 35-44 (14%), 75+ (12%), 25-34 (7%), 18-24 (4%) and five respondents aged under 18

**Ethnicity:** Most people (86%) said they were White British, followed by Any Other White Background (12 people), Asian British (6 people), Any Other Mixed Background (5 people), Caribbean (3 people), 'Other' (3 people), African (1 person), Indian (1 Person), and four people left this question unanswered

**Disability:** 41% of people said they considered themselves to have a disability; 56% said no; 8 people said they preferred not to say; and 7 people left this unanswered.

**Carer:** 15% of people said they were a carer, 85% said no and 8 people left this unanswered.

**Sexual orientation:** 87% of people said they were heterosexual; 8% said they preferred not to say, followed by 3 who said they Bisexual; 3 people said they were Asexual, 2 people who said 'Other', 2 said Gay or Lesbian.

**Religion:** 47% of people said they were Christian; 36% said No Religion; 10% said they preferred not to say; 11% people said 'Other', 4 people said Hindu; 2 said Buddhist, 1 said Muslim.

# Appendix three: Full findings of the specific conditions survey

**Q1: When you first tried to access help, did the support you received meet your needs?**

**Yes:** 33%　　　　　**Somewhat:** 29%　　　　　**No:** 32%

**Q2: How would you describe your overall experience of getting help?**

**Very positive:** 17%　　**Positive:** 27%　　**Average:** 25%
**Negative:** 17%　　**Very negative:** 10%

**Q3: Do you have any other/additional conditions including long term conditions or disabilities?**

**Yes:** 56%　　　　　**No:** 44%

**Q4: If so, how would you describe the experience of seeking support for more than one condition at a time?**

**It made it easier:** 8%　　**No difference:** 38%　　**It made it harder:** 46%

**Q5: How would you describe the time you had to wait to receive your initial assessment or diagnosis?**

**Very fast:** 6%　　**Fast:** 18%　　**Okay:** 26%
**Slow:** 25%　　**Very slow:** 22%

**Q6: How would you describe the time you had to wait between your initial assessment/diagnosis and receiving treatment?**

**Very fast:** 28%　　**Fast:** 18%　　**Okay:** 27%
**Slow:** 22%　　**Very slow:** 20%

**Q7: After being diagnosed or assessed, were you offered access to further health and care support?**

**Yes:** 56%　　　　　**No:** 44%

**Q8: Were you referred to a specialist? For example, a hospital consultant, psychiatrist or physiotherapist**

**Yes:** 73%　　　　　**No:** 27%

**Q10: How would you describe the time you had to wait between initial appointment and seeing the specialist?**

**Very fast:** 5%　　**Fast:** 19%　　**Okay:** 29%
**Slow:** 26%　　**Very slow:** 17%

**Q11: If you needed it, how easy did you find it to access ongoing support after you were diagnosed or assessed?**

**Very Easy:** 5%          **Easy:** 13%          **Okay:** 30%
**Difficult:** 23%          **Very difficult:** 17%

**Q12: Did the support options you were offered meet your expectations?**

**Yes:** 30%          **Somewhat:** 30%          **No:** 41%

**Q13: During your whole experience of getting support did you receive timely and consistent communication from all of the services that you came into contact with?**

**Yes:** 29%          **Somewhat:** 34%          **No:** 37%

**Q14: What is your main means of transport?**

**Another person's car:** 15%          **Bus:** 10%          **Own car:** 67%

**Q15: How much time would you be willing to travel to receive a quick and accurate diagnosis?**

**Over 2 hours:** 4%     **1-2 hours:** 18%     **30 mins-1 hr:** 53%     **Less than 30 mins:** 18%

**Q16: How much time would you be willing to travel to receive specialist treatment or support?**

**Over 2 hours:** 15%     **1-2 hours:** 23%     **30 mins-1 hr:** 48%     **Less than 30 mins:** 14%

**Q17: What is most important to you….**

**When first seeking help?**

Seeing a health professional you normally see but you may have to wait: 31%
Seeing any medically appropriate health professional who is free immediately: 54%
Don't mind: 16%

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

Seeing a health professional you normally see but you may have to wait: 40%
Seeing any medically appropriate health professional who is free immediately: 47%
Don't mind: 13%

**During your initial treatment or support?**

Seeing a health professional you normally see but you may have to wait: 42%
Seeing any medically appropriate health professional who is free immediately: 46%
Don't mind: 12%

**During your long-term support?**

Seeing a health professional you normally see but you may have to wait: 62%
Seeing any medically appropriate health professional who is free immediately: 27%
Don't mind: 11%

**What level of support do you want the NHS to provide to help you stay healthy?**
**A lot:** 22%          **Some:** 63%          **I don't need support:** 10%          **Don't know:** 5%

# Acknowledgements

Local Healthwatch in Buckinghamshire, Oxfordshire, Reading, West Berkshire, and Wokingham would like to thank members of the public who took the time to answer the survey.

We are also grateful for the voluntary and community groups who allowed us to come and speak with their service users and who helped spread the word about the project.

Lastly, we thank our volunteers who helped us to undertake the surveys.

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