NHS Long Term Plan
Public engagement report
Healthwatch Oxfordshire findings

what would you do?
It’s your NHS. Have your say.
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Executive summary

About this report

This report presents a summary of views collected from 155 Oxfordshire residents who responded to the survey about the NHS Long Term Plan in April and May 2019.

This was part of a wider fact-finding exercise which took place across 152 local Healthwatch England-wide, in order to inform implementation of the NHS Long Term Plan, published in January 2019. This was funded by NHS England.

In this region of England, Healthwatch Reading coordinated, analysed and compiled the findings across the health jurisdiction area known as the BOB Integrated Care System1 (BOB ICS), (previously known as the BOB Sustainability and Transformation Partnership (STP)), which covers Oxfordshire and parts of Buckinghamshire and Berkshire. The aim is to ensure patient experience informs the development of the BOB ICS and contribute patient views on how it will implement the Long-Term Plan.

The five local Healthwatch in this area - Buckinghamshire, Oxfordshire, Reading, West Berkshire, and Wokingham, worked across the BOB area to engage with communities in person and online to collect views on the NHS Long Term Plan.

In total:

- 939 responses to a general survey supplied by Healthwatch England (HWE)
- 219 replies to a Healthwatch England 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.

The BOB wide report on these findings can be found here.

In Oxfordshire, Healthwatch Oxfordshire gathered the views of 155 people. This included 121 respondents to a general NHS Long Term Plan questionnaire, 20 respondents to a Long-Term Conditions questionnaire, and 14 participants in two focus groups.

The Oxfordshire Focus Group report on mental health can be found here and the report on the focus group of Asian women can be found by clicking here.

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 owing 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 diverse ethnic groups, in Oxford, Abingdon, Banbury and Reading.

1 https://www.bobstp.org.uk/
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 for Oxfordshire

These findings accentuate what Oxfordshire residents told us and the wider BOB findings can be seen in the main report.

Limitations to study:

It should be noted that 60% of respondents to this research fell into the age group 55 and over. Only two respondents fell into the 18-24 age category, and 30% under 35. The findings of this report should be read with this in mind - in that it presents a picture of the opinions of a certain age group. More research should be undertaken to gauge the views of the younger age group on developments of NHS services.

Communication

People value health professionals who listen, give options, answer questions, have a caring manner

- 90% of Oxfordshire respondents said it was ‘very important’ that professionals listen to them when they speak to them about their health concerns.

Access to healthcare

- 86% of Oxfordshire respondents said it was ‘very important’ to access help and treatment when needed.
- 55% of people with a specific condition said their wait for an initial assessment or diagnosis was ‘slow’ or ‘very slow’.
- People commented on the need for joined-up care, and communication throughout the system.
- Oxfordshire residents expressed concern that service development is not keeping up with housing development.
- Transport to local services was seen as a problem in areas without public transport.
Managing ongoing conditions

✓ Those with long term conditions valued continuity of care, communication across the system, and being supported with information and knowledge to manage their condition.

Mental health care

✓ Comments focused on waiting times for support and treatment for those experiencing mental health issues.
✓ More investment in mental health was a priority.

Healthy lifestyles

✓ People recognise the joint responsibility for keeping healthy but also pointed out barriers to keeping healthy and need for everyone to play their part.
✓ Healthy, equitable, affordable and accessible environments were seen as important for supporting good health.

Care in later life

✓ 81% of respondents said it was ‘very important’ to stay in their own home as long as possible, as long as it is safe to do so.
✓ Communication across the system in support for later life was important with improved links between social care and health.
✓ More options available to older people to be able to live with support in older age, including properly funded care, carers and alternative housing options.

Digital technology

✓ Respondents are happy for digital technology to be used for routine NHS such as appointments but valued face-to-face contact with health professionals when required.
✓ However, comments focused on the need for clear, joined up and accessible information on digital platforms.
✓ A significant group did not use digital technology for a range of reasons, and the NHS must take this into account.

Acknowledgements

Healthwatch Oxfordshire, would like to thank members of the public who took the time to answer the survey, and contribute to the focus groups.

We are also grateful for the voluntary and community groups who gave support and helped spread the word about the project.

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

Thanks to Healthwatch Reading for leading on the overall project.
Chapter 1: General survey findings

This section sets out findings to all questions in the general survey, completed by 121 people in Oxfordshire. The pie chart for each question shows the Oxfordshire findings, and a comparison to BOB area wide findings is noted.

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 valued by Oxfordshire respondents was to be listened to. 90% said it was ‘very important’ to have ‘health care professionals listen to me when I speak to them about my concerns’.

“Being able to talk to my GP rather than the receptionist.”

“Be listened to by health care professionals”

“…joined up- including care records, so you do not have to repeat information.”

“To know that the person I am dealing with knows my history, otherwise we spend too much time explaining every time.”

More findings on helping people to live a healthy life

- 86% of Oxfordshire respondents and 84% of people (581) across Buckinghamshire, Oxfordshire and Berkshire West (BOB) say is very important to them, to have ‘access to the help and treatment I need when I want it’.

BOB² area 84% ‘very important’ health care professionals listen to them

Comments received on this theme included a person-centred approach and the need for joined up information and communication, so that people did not need to repeat their story several times.

“A person-centred approach.”

“Very Important” health care professionals listen to them

Very Important 90%
Important 9%
Neutral 1%
BOB figures include Oxfordshire

What would you do? 6
A number of people commented that it was difficult to get GP appointments, without long waits.

“Being able to get a GP appointment.”

“More access to surgeries. i.e. weekends, evenings or early mornings. Also walk in centres to have a GP.”

“Access to NHS services when I need them, not just when my name reaches the top of a list (usually months too late).”

“Decent back treatment. I waited four months for physio and they only drew me exercises, and then waited three months for a follow up.”

- 68% of Oxfordshire respondents and 65% across BOB (609) say is very important to have easy access to the information they need to help them make decisions about their health and care.

People told us they wanted clear, consistent information to help them make decisions. This included the need for timely results. Some commented on lack of joined up information and advice, across departments and areas, meaning that these decisions were difficult to take.

“To stop getting conflicting advice from each different department and clinic.”

“More streamlined online services and information...great deal of information out there but not easy to access.”

“Better and timely results communicated-not just weeks and constant chasing at the doctors”

Decision making was seen as a shared effort, which could be supported with clear information.

“Shared decision making- so you own it as well and are part of it- so more likely to comply.”

“A clearer understanding of the ill effect of making unwise decisions”

“Ability to question information/ diagnosis easily- independent advice.”

“To be able to find out what ‘normal’ procedures are, so if I am diagnosed with x what will happen next, who can I contact etc.”
• 68% in Oxfordshire and 62% (581) in BOB area say it is very important to have the knowledge to help them do what they can to prevent ill health.

Respondents recognised that making healthy choices was their responsibility, along with wanting clear support and information from professionals to enable them to do so. Prevention was seen as important, and skills and knowledge particularly around weight loss, healthy eating, exercise and cooking. However, people wanted a personal approach and support, with understanding of their particular context.

“What down to the person to live a healthy life. They need to do their bit too.”

“More information needed on guidance, particularly nutrition. One size does not fit all and more information should be available on how to figure out what does or does not work for you.”

“A better understanding by professionals of how difficult it is to lose weight being told to lose a shed load of weight to solve the issue is not helpful.”

Some commented on the barriers (such as cost, time, healthy food access and lack of supportive environments) to preventing ill health, even if knowledge was there, it was not always possible to act on it.

“Better work life balance - not having to work quite so hard to earn a decent wage.”

“More affordable access to fitness activities like swimming pools, gyms etc.”

“Being able to cycle in Oxford without risk.”

“Affordable fresh food.”

• 64% in Oxfordshire and 61% in BOB area said it was very important for every interaction with health and care services to count; for their time to be valued.

Here, people told us about the need to recognise and value patient time, particularly when it came to cancelling and arranging appointments, and long waiting times. Last-minute cancellations without clear communication had real impacts.

“Provide timely and accurate information and for me to feel that I can see an expert if I need one. Currently it feels like you are lucky to be referred and there are lots of minor things no longer being offered.”

“I had to constantly chase to find out when changes had been made to appointment dates- I was often told someone would ring me and they never did.”
“If I am expected to set an appointment in advance and ensure I am available, then if it is cancelled last minute, an appointment is rescheduled within a short period (often you are set back months when this happens).”

“No more significant delays in waiting rooms. At times had to spend two days waiting for treatment because there were not enough resources. After travelling for over an hour to get an early start the treatment was postponed to the very end of the day- a whole day wasted!”

For some with mental health issues, this feeling of interaction being valued was critical, especially in a crisis.

“I was told I’d be rung back by a crisis team at Warneford Hospital- they never rang me back. This is life threatening and frankly an unacceptable level of care.”

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

Respondents in Oxfordshire were asked to rate the importance of eight separate statements in helping them to manage and choose support from the NHS. Replies showed that most valued the ability to work with healthcare professionals to jointly decide the best course of action. Timely communications from services were also very important (68% for both statements in Oxfordshire compared to BOB overall 67% and 66% respectively).

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’ and pitch information in an accessible way.
“Luckily I am good at advocating for myself—but many people with mental health problems find this difficult to do.”

“When health changes are made, patient would like to be consulted.”

“That information about decisions are pitched at the right level—too often information is ‘dumbed down’ to an extent that information required to make choices is not adequate.”

Timely support was also important, particularly when making decisions about future care and support.

“Being given advice at an earlier point in life about making suitable living arrangements in a timely fashion, so that the NHS doesn’t have to pick up the pieces later on.”

“Early diagnosis for life changing conditions and early support.”

More findings on people managing and choosing their support

- 68% respondents from Oxfordshire and 66% of people (612) in BOB area as a whole say is very important that communications are timely

As seen in previous comments, people described frustration with administrative delays, and appointment cancellations. They wanted the NHS to be better at communicating with them, especially across the parts of the ‘system’ through which patients’ journey.

“To achieve this there must be greater cohesion between NHS and social services.”

“I want to be able to access my results in a timely way.”

“One system across the whole NHS so that communication is quicker and easier.”

Answers to other questions, indicate in order of importance, opinions on making decisions about managing and choosing care.

- 54% Oxfordshire respondents said it was very important to have time to consider and make the choices right for them
- 47% Oxfordshire and 48% (444) BOB respondents said it was 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
- 38% Oxfordshire and 39% (394) BOB said it was very important that they can decide when receive health and care support
- 36% Oxfordshire and 50% (466) BOB respondents said it was very important that “my opinion on what is best for me”, counts.
30% Oxfordshire and 38% BOB respondents said it was very important that, if they have a long-term condition, they decide how the NHS spends money on them.

18% Oxfordshire and 47% (436) BOB respondents said it was very important that they decide to where to go for care/treatment.

Comments indicated that while people valued local services, they also wanted the best treatment for their condition. A number of people felt the health professional were the experts and would make the most informed choices.

“Give me local support where, if appropriate I will feel safe and secure in my community.”

“Enough resources to ensure that local services are available when I need them.”

“Being clearer about understanding the constraints on the NHS...managing expectations as a whole.”

“That professionals know best, not me. Will go where they say to go. Want to see people in the 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 81% of Oxfordshire and 77% BOB respondents.

People told us this was dependent on access to high quality, affordable social care in the home, and support for family and friends that will or do care for them.

Some also expressed need for better choice, design and provision of appropriate housing for older age.

“More supported living rather than care homes. Flats with front doors but with care packages available and escalated as you get older.”

“Better and more responsive social care provision.”

“Not having to sell everything including house to pay for care.”

Good public transport is also important, particularly or those in rural areas.
What would you do?

74% Oxfordshire and 76% (707) BOB respondents said was very important that they and their family feel supported at the end of the person’s life.

“The NHS gave me and the rest of our family great support at the end of mum’s life.”

“To ensure my wishes were listened and adhered to.”

“The ability to decide when to terminate my life if I want to—rather than vegetate in a care home waiting to die”

74% Oxfordshire and 69% (639) BOB area say it is very important to have convenient ways to travel to services.

“Reinstatement of buses to villages.”

“Improved patient transport in rural areas—where people are at a financial disadvantage compared to those who live near major hospitals.”

13% Oxfordshire residents said it was ‘very important’ and 76% ‘important’ that their family had knowledge to support them. 59% (543) BOB respondents say it is very important.

52% Oxfordshire and 50% (459) BOB respondents said it was very important for their community to support them.
“Bring back day centres in Oxfordshire as they help to stop carer burden thereby enabling older people to live in their homes longer.”

“I want to feel I am part of my community by having local health facilities like local hospitalisation in time of need, to be close to family and friends, and being looked after by local people who understand local issues for patients.”

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 NHS services. For most Oxfordshire respondents, having absolute confidence in their data being kept safely and securely was the most important.

Other findings on how people interact with the NHS

➢ 51% Oxfordshire and 63% of people (578) of BOB respondents said it was very important that any results are communicated quickly making the best use of technology.

➢ 48% Oxfordshire and 52% (476) BOB respondents said it was very important to be able to talk to their doctor or other health care professional, wherever the patient is.

➢ 45% Oxfordshire and 51% (470) BOB respondents say it is very important that they could make appointments online and for their options not to be limited.
“Health systems that are clear and easy to navigate, joined up including care records so you don’t have to repeat information.”

Some expressed reservations and concerns about equity of access.

“I think it is important to note that not everyone is able to use the internet or have a mobile phone so it is important to keep sending out paper appointment letters and correspondence.”

More findings on how people interact with the NHS

➢ 44% Oxfordshire and 48% (450) BOB respondents said it was very important that they could access services using their phone or computer.

“If we are to use technology (I assume that it is considered that this will be more efficient and cost less) ensuring that online services are simple and work well especially the first time they are accessed.”

➢ People had mixed feelings about managing their own personal records: Of Oxfordshire respondents 32% stated it was ‘very important’ 23% ‘important’ and 27% ‘neutral’ on this point. Overall BOB, 37% (343) think it is very important to manage their own personal records so they can receive continuity in care.

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

“Medical reports to be written in layman’s terms!”

“Full medical records should be able to be accessed online.”

➢ In Oxfordshire 22% respondents said it was ‘very important’ and 32% ‘important’ to be able to talk to others who are experiencing similar health challenges.

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.
44% Oxfordshire and 49% (433) respondents across the BOB STP said that access to care and treatment was the single most important thing to help them live a healthy life.

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

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

**Healthy environments**

For Oxfordshire Healthy environments featured strongly in comments, to support healthier lifestyles. Spatial and joined up healthy planning was seen to have a role to play in creating healthier environments.

“Cleaner air that is without pollution from model fossil fuel burning machines.”

“More joined-up thinking in transport planning so cycling, walking and using public transport become the practical choice. We need less traffic where people breathe. This would then improve air quality as well as help to get exercise. Instead of funding carparks- subsidise buses so they are more frequent.”

“To not have to travel from Banbury to Oxford every time I have an appointment.”
Concern was also expressed at the rate of development and additional housebuilding taking place in the county, with fears of not enough infrastructure to support new communities.

“For the provision of healthcare services to match the development of my town, thousands of new homes going up without any increase in hospital beds or access to GPs.”

Healthy eating

“Affordable fruit and vegetables.”

“Time and opportunity to eat well, cook healthily.”

“Better access to healthy food and eating advice.”

Exercise advice and facilities

“Cheaper access to gym and sporting facilities, could be made tax free to encourage people to be more active.”

Strong leadership from central government

“Salt consumption- more information and awareness about salt. More emphasis needed, like sugar.”

“Government committed to reducing inequalities in health.”

“Make cigarettes illegal to sell.”

“Work in a well-funded NHS.”

Health checks

“Annual health MOT check-up with doctor or other health professional. It would remind me to visit doctor at least once a year”

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.
In Oxfordshire 46% and BOB 49% (436) said that working jointly with a health professional to make the right decision about their treatment, was the single most important factor, followed by making the decision about when to receive care appointments.

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

- Clear, consistent streamlined information online and elsewhere;
- Communication in accessible and easy to understand information;
- More integration and communication between health and social care.

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

**Clear, expert advice**

“Important medical professions are supported by NHS England and listened to…professionals who know what support is needed.”

**Continuity of care and options**

“I need to be able to source the help I need from local people and not be told (as often happens) that because of lack of finances, you have an agency come in, and have different people at different times of the day, with no continuity.”
Integrated services

“NHS is doing well, but overall the system can be let down between professionals and across services and boundaries.”

“There must be greater cohesion between NHS and social services.”

Other comments included thoughts on support for healthy living, advice and lifestyle courses, more available GP appointments and more NHS staff.

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 to be able to stay at home as long as it is safe to do so;
- 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 to travel to health and care services

54% Oxfordshire respondents chose to be able to stay in their own home as most important followed by 22% choosing convenient travel to healthcare services. For BOB area 57% chose ‘stay in own home’ followed by 13% ‘knowledge to support me’.

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

- Affordable transport, and/or bus services restored to small villages;
- Adaptations/technology to stay safe at home;
- High-quality home carers and some financial support for social care to remain at home;
- Increased housing options for older people to remain independent;
- A care coordinator to support and navigate joined 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

**Maintaining healthy lifestyles**

“Access to gyms and physical activity.”

“Strong community with access to friends and activities.”

“Why not have coaching specialists who can help advise in a more imaginative, holistic way on options on lifestyles that might chime more positively with the current health and aspirations of senior citizens.”

**Access to social care**

“Better and more responsive social care provision.”

“Properly funded social care.”

“Being able to afford and find care to keep me in my home.”

**Care closer to home**

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

**Better transport**

“More practical and low-cost public transport.”

**Care coordination**

“Health care professional to navigate and support my elderly relative to join up the dots.”

**Changes to the law and debate about end of life**

“Legal support for assisted dying.”

**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 of my computer;
- I can make appointments online and my options are not limited;
- I can talk to my doctor or other professional where-ever am 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:

- **Personal data secure**: 31%
- **Talk to doctor from wherever I am**: 27%
- **Results communicated quickly**: 20%
- **Make appointments online**: 11%
- **Talk to others with similar challenges**: 7%
- **Phone computer access**: 2%
- **Manage own records**: 2%
- **Talk to doctor from wherever I am**: 2%

For Oxfordshire respondents, just under 31% chose the statement that it is important to be able to talk to doctor from wherever they were, 27% said confidence in data security, and getting results quickly 20%. For BOB area as a whole, these results were echoed.

**Oxfordshire respondents’ views on the role of technology in the NHS:**

**Use technology to its fullest capability**

“Needs to be digital as default. Very frustrating trying to find a practice’s email or phone number and it not being available on the website.”

“Smart watch helps”

“Services to communicate with each other-digitally.”

“Enabling the messaging function in the patient access App.”

**Using technology to promote independence**

“Using technology that helps me stay at home for as long as possible.”
Technology has its limitations

A number of people expressed concerns about the emphasis on digital communications and interactions with NHS professionals. While many understood the value of booking appointments and routine administration using computers or phone, others voiced that they valued human interaction and support.

“I want to SEE my Doctor or healthcare professional when necessary...not just a telephone conversation or video conference.”

“There is a danger that the NHS is going to rely on technology too much. The personal touch is very important.”

“I greatly worry that increasingly accessing services requires the use of computer...I personally prefer to speak directly to people.”

“Increases impersonalisation of services.”

Others, both younger and older, commented on ‘digital exclusion’.

“Not everyone is able to use the internet or use a mobile phone.”

“Don’t have a computer or mobile phone, just a house phone.”

Valuing the NHS

Many people we spoke to valued the NHS and the professional and compassionate care of its staff.

“Love the NHS - get an excellent service.”

Chapter 2: Specific conditions survey findings

We received 20 responses to the second survey Healthwatch England supplied for this engagement project.

This second survey aimed 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
The findings show that 52% of respondents said their condition had started within the last three years. We heard from people with the following conditions: autism (1), dementia (1), heart and lung disease (2), mental health (9) and long-term conditions (7).

The key themes and findings were that:

- People wanted joined up support across the ‘system’;
- Consistent communication both with themselves and across health professionals;
- More investment in mental health (child and adult) and less time waiting for treatment.

This chapter summarises key responses and then focuses on comments and experiences of those with conditions highlighted. Full findings for the specific condition survey can be found in Appendix 3, on pages 32 of this report.
Key findings from the specific conditions survey

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

- 30% said it was very slow
- 25% said it was slow
- 25% said it was okay.
- 15% said it was fast
- 10% didn’t know
- 5% didn’t know

What was most important to you....

When first seeking help?

- 90% Waiting longer to see a health professional you know
- 10% Don’t mind

During your long term support?

- 90% Waiting longer to see a health professional you know
- 10% Don’t mind

“Continuity with specialists for Long Term Care.”
More key findings from the specific conditions survey

Did the support options you were offered after initial assessment or diagnosis, meet your expectations?

- Yes (20%)
- No (40%)
- Somewhat (40%)

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 (15%)
- No (45%)
- Somewhat (40%)

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

- 49%, 30 minutes to one hour
- 37%, less than 30 minutes
- 9%, 1-2 hours
- 5%, over 2 hours

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

- 55%, 30 minutes to one hour
- 25%, 1-2 hours
- 10%, Less than 30 minutes
- 10%, over 2 hours

What would you do?
People’s experiences about the specific conditions

Autism

“More courses for staff in the schools to learn about autism.”

“When I first saw my GP and told her I was self-harming, immediately she asked if I was experiencing any suicidal thoughts and when I said no (because at 15 it had not even crossed my mind) I was seemingly dismissed with an A4 printout moments later, leaving me feeling like my problems were not ‘severe enough’ to be taken seriously.”

Heart and lung disease

Feedback themes:

- Highlighted patient’s need for clear, consistent information to help them manage their condition both at diagnosis and in the longer term.

“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.”

“I wasn’t given as much help as I think I could have been. More time explaining how to gage my attacks would have helped.”

“Very confusing about who should be discussing the condition- the consultant, cardio nurses, GP were all involved. Better access to the consultant would have improved the condition.”

Long-term conditions

Feedback themes:

- Clear communication across the system
- Links to wider support groups needs to be highlighted
- Need for ongoing support to manage condition

“There occasionally seemed to be internal miscommunication amongst members of my care team, however, any official form of communication sent to me was always clear and met my expectations.”

“Never enough time to discuss. Different organisations don’t talk to each other.”

“There was no consistent communication.”

“There are no support groups and limited information online. I can only speak with the consultant who can take a few days to get back to me.”

“It has taken two years of blood tests to establish my current dose of medication. I am still symptomatic, but my blood results show me to be...
“within the range” I am a person, not a predefined range of blood levels. I would like to be optimal, not just in range.”

“The consultant did not inform me of support groups and there is no choice in my area.”

“The pain clinic was ok, but I was discharged and then there was very little support despite having a long term condition.”

**Mental health**

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

**Feedback themes:**

- Delays in diagnosis and access to treatment.
- Awareness of mental health issues among professionals varied.

**Waiting times and access to therapies**

“Waiting times too long.”

“I had to wait 9 months to see a therapist and 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.”

“No access to the specific therapy I needed at the time (EMDR).”

“I was often told someone would ring me and then they never did. Luckily I am good at advocating for myself and calling people to follow up.. Many people with mental health problems find this difficult to do.”

“I felt like I had to fight for everything and when you are very depressed this is not easy.”

“Therapy types offered inadequate and not enough sessions offered. Went private instead. Learned more from COPD groups than my own GP practice.”

“I was in A&E for being suicidal. They made me wait 4 weeks for a psychiatrist assessment because the (wrongly) deemed me ‘lower risk’. Once I was finally put on a waiting list I was told the wait was a year and I would be better to go private.”

“it was too slow- I was off work and it affected my whole life.”
Attitude of NHS staff and quality of ongoing care

“There was an excellent first assessment in the Emergency Department - The nurse and doctor in ED from the mental health team were very good-started medication immediately and referred to mental health team, and gave a safety plan which was really helpful - but the follow-up in the mental health system was really not as good.”

“Dismissed by some doctors. Some doctors got my basic details wrong or said unprofessional things, showed a basic misunderstanding of mental health issues.”

“Staff were poorly trained and lacked basic empathy and understanding of the complexity of mental health issues.”

“No support at all, just sent away with antidepressants-no numbers of people to contact, not help offered, no finding out the root of the problem.”

“CBT was extremely helpful.”

Support for children and young people

“The child at the time should have been diagnosed and statemented for school earlier and without having to write to all parties to get his, as they got lost in the system. Once diagnosed with autism and OCCD extra help was provided to keep them in mainstream education.”

“When I first saw my GP I was given an A4 print-out. The next time I went to see her was an entire year later, when I was incredibly suicidal and a danger to myself. My family forced me to go because after the previous experience I didn’t think I would be given the help that I desperately required. During this second appointment I received a diagnosis and was referred to my local CAMHS team urgently.”

“Supervision of medication at school broke down several times, and the child had to be taken home.”

“Treating older children being referred to CAMHS teams more like adults. Many children aged 15/16 will know what the symptoms of conditions like anxiety and will often know their triggers. By having statements on pre-assessment questionnaires such as ‘I get funny feelings in my tummy’ are unhelpful and made me feel like I was going to be treated like a five-year-old with no input into my care before I even walked through the door. Perhaps tailoring such questionnaires to different age groups would be beneficial and an easy thing to do?”
Investment

“There needs to be more funding for mental health services to reduce waiting times.”

“The systems are poor but what is most obvious is the desperate underinvestment in mental health services- all the staff are willing but there are too few of them. There is little access to psychological therapies and long waiting times to see a consultant.”

Chapter 3: Focus group findings

This chapter sets out a summary of the views of people collected during two-focus groups convened by Healthwatch Oxfordshire: one with mental health service users, and one with an Asian Women’s group, a total of 14 people. Focus groups were chosen to reflect voices of ‘seldom heard’ groups, health inequality, or particular areas of interest. The full reports can be found on Healthwatch Oxfordshire website.

The findings summarised below relate to the views expressed at a particular focus group and should not be seen as being representative of the wider population.

Summary of focus group findings

<table>
<thead>
<tr>
<th>Oxfordshire</th>
<th>Mental health focus group</th>
<th>What people said matters most or needs to change</th>
</tr>
</thead>
<tbody>
<tr>
<td>What people said works well</td>
<td>What people said doesn’t work well</td>
<td>Getting more support at the right time</td>
</tr>
<tr>
<td>Holistic support from voluntary sector within Oxfordshire Mental Health Partnership</td>
<td>Some people felt that A&amp;E was the only place to go in a crisis</td>
<td>Expert mental health support based in A&amp;E</td>
</tr>
<tr>
<td>Other social and leisure activities run by charities</td>
<td>Long waits from referral to therapy</td>
<td>More evening or weekend social clubs or activities</td>
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<td></td>
<td>Not enough support after working hours</td>
<td>More training for GPs on recognising key signs of mental health problems</td>
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<tr>
<td></td>
<td>Only crisis support is A&amp;E</td>
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<tr>
<td></td>
<td>GPs don’t always recognise the severity of symptoms</td>
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<td></td>
<td>Potential disparity between services available in city &amp; county</td>
<td></td>
</tr>
</tbody>
</table>

“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.”
<table>
<thead>
<tr>
<th>Oxfordshire</th>
<th>Asian women’s perspectives on GP services, focus group</th>
<th>What people said matters most or needs to change</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>What people said works well</strong></td>
<td><strong>What people said doesn’t work well</strong></td>
<td><strong>What people said matters most or needs to change</strong></td>
</tr>
<tr>
<td>• Showing health promotion videos on the GP surgery waiting room screen (e.g. NHS Sugar Smart)</td>
<td>• Repeatedly asking for help but not getting it</td>
<td>• An outreach talk by a clinician to their group on diabetes would be useful</td>
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<td></td>
<td>• Expectations for medication aren’t met</td>
<td>• Culturally appropriate dietary information</td>
</tr>
<tr>
<td></td>
<td>• Not being offered translators if needed</td>
<td>• GPs need to give information about antibiotics and prescribing in an easy-to-understand manner</td>
</tr>
<tr>
<td></td>
<td>• GPs making assumptions</td>
<td>• Promote the availability of translators at the point you book GP appointments</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Education at school on healthy eating</td>
</tr>
</tbody>
</table>

“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.”
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 main report highlights key messages taken to BOB ICS and responses given.

From the Oxfordshire respondents, key messages support the wider BOB area findings as follows:

- **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.**
- **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.**
- **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.**
- **Mental health services are in urgent need of investment and improvement.**
- **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.**

And specific themes that respondents commented on for Oxfordshire:

- **People value consistent communication with different health professionals and across the system as a whole.**
- **Concern about rapid housing and population expansion and need for services and infrastructure to keep up with this.**
- **Waiting times for mental health support can be long.**
Appendix 1: Methodology

For full methodology see the main report for BOB findings as a whole.

For Oxfordshire: questionnaires were provided online and in paper form. Staff outreach enabled forms to be filled in face to face.

Two focus groups were held as described.

Analysis of entire BOB findings and area data was carried out by Healthwatch West Berkshire, with further Oxfordshire specific analysis by Healthwatch Oxfordshire.

Appendix 2: Demographics

General survey respondents Oxfordshire:

Total: 121 respondents

Age: The biggest age group (26%) was 65-74; followed by 45-54 (20%), 55-64 (17%), 74+ (14%), 35-44 (11%), 25-34 (10%) and two respondents between the age of 18-24.

Gender: 56% of respondents were women, 42% men and 4 people said they preferred not to say.

Ethnicity: White British 86%; Any other white background 8%; Asian British 2%; Indian 1%; Other 3%.

Sexual orientation: Of those who answered this question 91% of people said they were heterosexual, 5% preferred not to say, 2% identified as gay/lesbian and 1% identified as Pan-sexual and 1% as Asexual.

Long Term Conditions Survey Oxfordshire:

Total: 20 respondents

Gender: Of those who answered this question, 66% of respondents were woman, 34% were male.

Ethnicity: 85% of respondents were White British and 15% were from Any Other White Background.

Age: Of those that answered this question the biggest age groups were 35-44 (28%) and 45-54 (28%), followed by 65-74 (23%), 18-24 (11%), 25-34 (11%) and one respondent between the age of 55-64.
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: 30%  Somewhat: 30%  No: 40%

Q2: How would you describe your overall experience of getting help?
Very positive: 15%  Positive: 30%  Average: 30%
Negative: 15%  Very negative: 10%

Q3: Do you have any other/additional conditions including long term conditions or disabilities?
Yes: 40%  No: 55%

Q4: If so, how would you describe the experience of seeking support for more than one condition at a time?
It made it easier: 1  No difference: 3  It made it harder: 4

Q5: How would you describe the time you had to wait to receive your initial assessment or diagnosis?
Very fast: 0%  Fast: 15%  Okay: 25%
Slow: 25%  Very slow: 30%

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%  (NB. all mental health)

Q7: After being diagnosed or assessed, were you offered access to further health and care support?
Yes: 60%  No: 40%

Q8: Were you referred to a specialist? For example, a hospital consultant, psychiatrist or physiotherapist
Yes: 65%  No: 35%

Q10: How would you describe the time you had to wait between initial appointment and seeing the specialist?
Don’t know: 8%  Fast: 15%  Okay: 15%
Slow: 31%  Very slow: 31%

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

Don’t know: 10%  Easy: 25%  Okay: 5%
Difficult: 40%  Very difficult: 15%  N/A: 5%

Q12: Did the support options you were offered meet your expectations?
Yes: 20%  Somewhat: 40%  No: 40%

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: 15%  Somewhat: 40%  No: 45%

Q14: What is your main means of transport?
Another person’s car: 5%  Bus: 20%  Own car: 75%

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: 10%  1-2 hours: 25%  30 mins-1 hr: 55%  Less than 30 mins: 10%

Q17: What is most important to you....
When first seeking help?
Seeing a health professional, you normally see but you may have to wait: 25%
Seeing any medically appropriate health professional who is free immediately: 65%
Don’t mind: 10%

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: 35%
Seeing any medically appropriate health professional who is free immediately: 50%
Don’t mind: 15%

During your initial treatment or support?
Seeing a health professional, you normally see but you may have to wait: 30%
Seeing any medically appropriate health professional who is free immediately: 35%
Don’t mind: 10%

During your long-term support?
Seeing a health professional, you normally see but you may have to wait: 60%
Seeing any medically appropriate health professional who is free immediately: 30%
Don’t mind: 10%

What level of support do you want the NHS to provide to help you stay healthy?
A lot: 15%  Some: 70%  I don’t need support: 10%  Don’t know: 5%
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