

NHS Long Term Plan

Engagement Report

Healthwatch Bexley

wh  **t**
would you do?
It's your NHS. Have your say.

Contents

What is Healthwatch?.....	3
Introduction.....	4
Methodology	5
Executive summary	6
General Survey Findings.....	9
Mental Health.....	14
Learning disabilities	17
Next steps	19
General survey demographics	20

What is Healthwatch?

There are 152 local Healthwatch organisations that were established throughout England in 2013, under the provisions of the Health and Social Care Act 2012. The dual role of local Healthwatch is to champion the rights of users of health and social care services and to hold the system to account for how well it engages with the public.

The remit of local Healthwatch as an independent health and social care watchdog is to be the voice of local people and ensure that health and social care services are safe, effective and designed to meet the needs of patients, social care users and carers.

Healthwatch gives children, young people and adults in their local areas a stronger voice to influence and challenge how health and social care services are purchased, provided and reviewed within the borough.

Healthwatch's core functions are:

1. Gathering the views and experiences of service users, carers, and the wider community,
2. Making people's views known,
3. Involving locals in the commissioning process for health and social care services, and process for their continual scrutiny,
4. Referring providers of concern to Healthwatch England, or the CQC, to investigate,
5. Providing information about which services are available to access and signposting,
6. Collecting views and experiences and communicating them to Healthwatch England,
7. Working with the Health and Wellbeing board in their local areas on the Joint Strategic Needs Assessment and Joint Health and Wellbeing strategy (which will influence the commissioning process).

Introduction

Aim of the research

The aim of the research was to obtain views and experiences of South East London residents which included Bexley residents to support local implementation of the NHS Long Term Plan. Healthwatch Bexley and the other 5 SEL boroughs (Bromley, Greenwich, Lambeth, Lewisham & Southwark) carried out local engagement and enabled people - including seldom heard communities - to have their say in how the NHS can better take care of them and how the care they receive can be improved. The engagement undertaken was part of a wider engagement coordinated by Healthwatch England. The findings will be shared with Our Healthier South East London (OHSEL), south east London's Integrated Care System to help shape the local plan and support OHSEL's own engagement. This report highlights the findings of Bexley residents that fed into the overall SEL report.

What is the NHS Long Term Plan?

The NHS has been asked by the government to write the NHS Long Term Plan. The plan shows how the NHS will spend additional funding in the next ten years.

The plan is based on the views of NHS staff and the public on what the NHS needs. It covers the following key areas:

- Helping more people to stay well and tackling health inequalities.
- Improving how the NHS works so that people can get help more easily and closer to home.
- More money invested in technology.
- Making care better. The NHS wants to get better at looking after people with cancer, lung and heart diseases, mental illness, dementia, learning disabilities, and autism.

What is Our Healthier South East London?

The NHS has set up Integrated Care Systems. These are ways for NHS organisations and local councils to work together further to improve health and care for residents. OHSEL is an Integrated Care System. It is made up of managers and clinicians from the NHS, local councils, charities and other community organisations. The aim of OHSEL is to improve the health of people in south east London, reduce health inequalities and deliver a healthcare system which ensures a sustainable future for local NHS services.

Methodology

Research was carried out across south east London, including the London Boroughs of Bexley, Bromley, Greenwich, Lambeth, Lewisham and Southwark. Each local Healthwatch carried out individual engagement in their own borough and the findings below are a collation of the feedback gathered across the **London Borough of Bexley**. A two-pronged approach of surveys and focus groups was used to gather feedback and were broken down into the following areas:

Focus groups

- Mental health - **28 Carers**
- Learning disabilities and autism - **10 People with lived experience**

The topics of the focus groups for the SEL area were agreed with OHSEL and covered mental health, learning disabilities and autism. In addition, two surveys were filled out by **278** Bexley residents.

Survey

General survey - **243** responses

- Living a healthy life
- Managing and choosing support
- Independence as they get older
- Interaction with local NHS

Specific conditions survey - **35** responses

Executive summary

What matters most to people in Bexley?

Bexley residents identified the following aspects as the most important in the delivery of their local services:

Living a healthy life

Access to the help and treatment I need when I want.

Managing and choosing support

Communications are timely.

Independence as they get older

I want my family to feel supported at the end of life.

Interaction with local NHS

I have absolute confidence that my personal data is managed well and kept secure.

Therefore, it is recommended that OHSEL focus on these areas as priorities to improve local NHS services.

What did you tell Healthwatch?

General survey

Bexley residents were asked what would help them to live a healthier life. Overall, residents were aware they should eat healthily and take regular exercise, but felt monetary constraints and busy lifestyles were barriers to making this a reality. It was also paramount to residents that the link between mental and physical health is made to help them live a healthy life. It should encompass all aspects of life, including community awareness, activities, education and health services. Whilst Bexley residents had a general awareness that exercise and good diet is vital to wellbeing, they would like more in depth information and education. A huge area of concern for all residents was easier and quicker access to GP services.

Bexley residents were asked what would help them manage and choose support. Once again, residents highlighted the need to be able to access local services in a timely manner. This is a clear priority throughout the region. Poor administration and communication at services, including the approach of staff, were barriers to receiving appropriate support. More integrated NHS services would improve the experiences of patients. Residents also wanted to be listened to by professionals and have their opinions respected when decisions were made about their health care. Improved collaboration between NHS staff and patients would help residents manage their health better.

Residents were asked how the NHS can support them to retain their independence as they grow older. Bexley residents wanted support to stay in their home as long as it is safe to do so, through community based support and better social care. Likewise, availability of home services such as good quality care workers are imperative to retain independence. Residents value support to maintain mobility, including good transport systems and links. Access to support

services, day centres, activities, social groups, GPs and specialist health services are vital to support residents as they get older.

Finally, Bexley residents were asked how they would like to interact with the NHS. The subject of digital appointments had mixed feedback. Mainly, residents who objected were concerned that technology would override the current channels to make appointments and access services. Therefore, residents would like the option to make appointments through digital formats, but should still have the option to speak to staff either face to face or on the phone. Likewise, information sharing and record keeping had mixed responses from residents. Residents raised important concerns such as data security. If records are shared with patients and across services, this must be done in a safe and secure way. Residents hope that technology will improve communication between themselves and services, and also across NHS services.

Mental health

Early access and prevention was a significant theme for those with lived experience of mental health issues and parents/carers. Barriers to early access to services included individuals acknowledging they made need help, fear of the possibility of being sectioned after asking for help, carers not being included in decisions, not being listened to, a lack of face to face assessments and poor communication between departments. Participants suggested speed of response, access to mental health professionals and annual health checks would help.

Having sufficient support to stay well (mentally and physically) was also important, with participants describing barriers such as a lack of outdoor activities, access to good quality care coordinators, fear of trying activities and poor information on services. It was suggested that safe community spaces, home strategies, befriending services, continuity of care, healthy budget eating education, and support for carers would help them to stay well.

Quick and easy access to services is vital for people with ill mental health, who currently face barriers such as thresholds to accessing support, long wait times, limited information and a lack of crisis support. Participants' examples of good practice included a service directory, concise information, including service users in the design of services, person-centred care, service availability at a range of times and quicker access to low level support.

Experiences of poor treatment was another significant theme. Examples included services being too quick to prescribe medication, mind and body not being treated together, long waiting times when in crisis, individuals not being involved in their own care, GPs unwilling or ill-equipped to help, trust issues as a barrier for group therapy and more support for dual diagnosis. Good practice examples included collaboration, more mental health education for GPs, suitable environments and person-centred treatment.

Lastly, health inequalities prevented participants from accessing resources. These included ongoing issues with the Department for Work and Pensions, financial difficulties and a lack of understanding for cultural-specific issues. Participants suggested paid sheltered employment, reduced stigma and education to improve their own social circumstances would help to tackle these inequalities.

Learning disabilities and autism

Adults with learning disabilities and/or autism and parents/carers described a number of barriers to accessing appointments. These included not being able to book over the phone, long wait times to see the same doctor, approach of staff, having check-ups across multiple days and difficulties with travel. It was suggested that support for booking and remembering appointments, options for the appointments and good signage would be helpful.

Preventions and staying well was a significant issue for this group, with barriers including limited physical exercise, poor diet, expensive and busy exercise facilities and a reliance on relatives or

support workers. Friendships, empowering parents, therapies like mindfulness, Easy Read information, creative activities and community groups were given as examples of best practice.

Multiple negative examples of outpatients' services were given, such as GPs not understanding carers' needs, long waits that left individuals feeling anxious, struggles getting the correct medication from pharmacies, professionals underestimating them, hospital appointment information not in easy-read format, doctors using unfamiliar language and a lack of thorough explanations of health tests. Participants suggested staff calling patients by their name, friendly staff supporting them during procedures, better communication, specialised nurses, carers being able to represent the patients and clear communication would improve their care.

Professional's knowledge was also seen as an issue, with negative experiences given including staff not having awareness of disabilities and unclear explanations of procedures given to children with learning difficulties. Purple Star Strategy, training for professionals and ongoing support were all given as examples of good practice.

Lastly, negative experiences around screening were shared, including not knowing if the doctor would be male or female at breast screening appointments, not given adequate appointments for cancer screenings, not being given test results, fear around the word "screening" and difficulties carrying out tests. Participants suggested being told the sex of the health professional, education about what the screening is for, expectations being set about the procedure for screenings and education from community organisations would be helpful.

General Survey Findings

Living a Healthy Life

Respondents to the general survey were asked to rate how important the following things are to them when it comes to living a healthy life, on a scale of “Very Important” to “Not important at all”:

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

Bexley residents ranked the following statements “Very Important” (as did the other SEL boroughs)

1. Access to the help and treatment I need when I want it (90%)
2. Professionals that listen to me when I speak to them about my concerns (86%)
3. Easy access to the information I need to help me make decisions about my health and care (76%)

Access

A huge area of concern for residents was access to services. Easier and quicker access to GP appointments was of great importance for people in helping them live healthy life. Patients did not feel confident that they would have prompt access to local GP services if they felt unwell.

Bexley residents shared the following examples of barriers to accessing services:

- Long waiting times for appointments. *‘Being able to get an appointment with a GP the same day rather than a week later’.*
- Better communication between patients and the service provider (GP, Hospital or other health and social care professionals). Greater levels of co-ordination between services locally. *‘My older sons have autism, often doctors don’t know this until I tell them, I think it is important that something can be put on the system so they are aware of their autism and I am not explaining each time, as it does affect how they are treated’.*
- Appointment booking systems need improvement. A large number of people still use the telephone as their preferred booking method, however it does not always work well. Residents felt GP practices should recognise that people have commitments such as work or school run, which prevents them from spending long periods of time on the phone early in the morning. *‘Being able to easily book an appointment on the day (not using app or only at 8am - clashes with school run)’.*

Knowledge

Bexley residents suggested that further information around the following areas would help them live a healthier life:

- Advice around nutrition and information on how to maintain good health, without relying on medication. Information should be clear, accessible and from a trustworthy source.
- Greater awareness of the impact that certain foods or lifestyles can have on your health later on, starting as early as primary school level.

- Regular reminders of how and what we can do to keep healthy.

Lifestyle / Environment

Many Bexley residents focused on the need for easier access to healthy food at an affordable price and also cheaper access to sport and exercise facilities. They described the following barriers to making this a reality:

- Time, ability and confidence to shop for more healthy choices.
- The cost of ready-made, highly processed, instant meals that were often cheaper than buying more healthy alternatives. *'Healthy foods such as fresh fruit, vegetables, meat and fish can often be more expensive than convenience foods and as a pensioner I have to be careful with expenses'*.
- The large number of takeaway shops compared with the much smaller number of places to buy fresh fruit and vegetables. *'Why is coke cheaper than water?'*
- The high cost of gym memberships and exercise classes. There needs to be easier access to 'free' or 'affordable' exercise facilities.
- More access to women only and disability friendly exercise sessions. *'Make it easier to go swimming. Special times for people with learning disabilities when it's not so busy'*.
- The negative impact that low quality ambient air can have on a population's health.

Mental health

The need to link good mental health with good physical health was also considered important to Bexley residents, with the following suggestions being made to improve people's wellbeing;

- More understanding about mental health issues by professionals.
- Education on mental health from an early age.
- Prompt access to mental health services is vital.

Managing and choosing support

Respondents to the general survey were asked to rate how important the following things are to them when it comes to managing and choosing support, on a scale of "Very Important" to "Not important at all":

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

Bexley residents ranked the following statements "Very important" (as did the other SEL boroughs).

1. Communications are timely (68%)
2. Choosing the right treatment is a joint decision between me and the relevant health and care professional (66%)
3. I have time to consider my options and make the choices that are right for me (64%)

Accessible, timely services

Throughout their responses to the survey, Bexley residents stressed the importance of easier and quicker access to services.

- Access their GP services when and where they need them.
- There should be a consistent booking system across all GP services.
- Availability of experts in one building.
- Some did not know where or who to go to for help when they were unwell and found services difficult to navigate. *'Person centred care is very important to me but for me to make decisions I need information to enable me to make the right decisions. Information has to be easy to read and understand'*.
- Shorter waiting times to see specialists.

Decision making

Many people did not feel listened to when discussing health and care options with professionals and care and treatment was not always tailored to the needs and experience of the user, even when direct requests were made.

- Improved collaboration between NHS staff and patients. Bexley residents wanted reassurance that staff *'will listen to all of their issues'*, treat them with dignity and respect and take their views into account when making decisions. *'Not to be talked to in a condescending way and for my opinion to be listened to on what I feel is best for me. This should be a big part of the decisions taken about my treatment/medication'*.
- Use simple language and present results and information in "layman's terms". The Accessible Information Standard should be embedded in information given to a patient. *'Person centred care is very important to me but for me to make decisions I need information to enable me to make the right decisions. Information has to be easy to read and understand'*.
- GPs to know about local services to appropriately enable choice. *'Information about multiple options available - not just one thing (e.g. they often just prescribe medication when other treatment like counselling or chiropractor would be more beneficial)'*.
- The ability to choose a health professional and continuity of care are equally important.

Independence as they get older

Respondents to the general survey were asked to rate how important the following things are to them when it comes to retaining independence as they get older, on a scale of "Very Important" to "Not important at all":

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

Bexley residents ranked the following statements “Very important” (The other SEL boroughs agreed with points 1&2, but ranked ‘convenient ways to travel to health & care services’ as priority number 3)

1. I want my family to feel supported at the end of life (85%).
2. I want to be able to stay in my own home for as long as it is safe to do so (84%).
3. I want my family and friends to have the knowledge to help and support me when needed (69%).

Social care and home services

For residents in Bexley, it was important that their family felt supported at the end of their life and that they were able to stay in their own home for as long as it is safe to do so.

- More community based support. *‘In an ideal world I would want to stay in my home for as long as possible. Therefore community care would be useful - i.e. district nurse, doctor home visits, care support and meals on wheels, services for elderly that are required to enable them to stay at their own home’.*
- More availability of care workers. Carers are often rushed, running late or do not turn up. *‘My care needs are not restricted by the availability of the care staff’.*
- The needs of disabled people, including those with learning disabilities, must be accounted for when providing support at home and in care homes.
- More information about options. Not everyone has family and people are unaware of what social care is available to them.

Mobility

- Provision of support services to help people with their mobility and transport. it is important to ensure that appropriate transport infrastructure is in place or accessible. *‘I have recently seen my elderly parents struggle massively with attending hospital appointments - driving was virtually impossible due to parking, ambulance was not available, public transport difficult. Parents had to rely on relatives taking time off work (unpaid) to take them to and from hospital. Putting pressure on parents and family’.*

Community based services

- Access to activities, social groups and community support is vital in helping people to be less lonely and thus improving their wellbeing. *‘Investment in the voluntary sector - they do lots of free or low cost groups/activities and have volunteers who can support people but the lack of funding means they cannot help as many people as they would like to or groups are shut down’.*
- Free, person centred activities.

Interaction with local NHS

Respondents to the general survey were asked to rate how important the following things are to them when it comes to how they want to interact with their local NHS, on a scale of “Very Important” to “Not important at all”:

- I have absolute confidence that my personal data is managed well and kept secure
- I can access services using my phone or computer □ I can talk to my doctor or other health care professional wherever I am
- I can make appointments online and my options are not limited
- Any results are communicated to me quickly making best use of technology

- I manage my own personal records so that I can receive continuity in care
- I am able to talk to other people who are experiencing similar challenges to me to help me feel better

Bexley residents ranked the following statements “Very important” (as did the other SEL boroughs).

1. I have absolute confidence that my personal data is managed well and kept secure (70%)
2. Any results are communicated to me quickly making best use of technology (64%)
3. I can talk to my doctor or other health care professional wherever I am (58%)

Respondents had mixed views on digital appointments. Many felt that digital access that is consistent and up to date with technological advancements would help people maintain their health. For others, the increasing use of technology was viewed as a barrier to accessing advice and treatment. They highlighted the following issues:

- Ensure equality of access for those who do not use technology and prefer other methods of communication. *'Less dependence on IT communications. There are certain people across the spectrum that are not confident with the technology'*.
- Improve communication with patients including responding to patient's queries (phone and email) and providing information about test results promptly, using the best use of technology. *'Results need to be explained more. Patients being told that the blood test is satisfactory but last time it was Good - what does this mean? GP will not offer advice or support unless the bloods are unsatisfactory but patient should be informed about they they can do to improve and what this actually means'*.

NHS Long Term Plan

Specific condition related findings

Below is a table showing the specific conditions that Bexley residents told us about. Of the 35 surveys completed, 23 people responded on their own behalf and 12 for someone else and for 66% of respondents they had lived with this condition for more than 3 years.

Autism	1	3%
Cancer	3	9%
Dementia	2	6%
Heart and lung diseases	5	14%
Learning disability	1	3%
Long term conditions e.g. diabetes, arthritis	6	17%
Mental health	17	49%

Grand Total	35
--------------------	-----------

Mental Health

Through focus groups and the specific conditions survey, Bexley residents shared their experiences of using mental health services, which have been broken down into themes. 28 parents and/or carers took part in these focus groups.

Early access and prevention

Participants of the Bexley mental health focus groups felt that early access to help was vital for people living with mental health issues.

- The problem many carers face is getting the person with the problem to acknowledge they need help and getting them to access help early. If they access help early the group felt it was very beneficial. Many of those cared for were scared to ask for help as they were worried about losing control and being sectioned, this is often due to past experiences of how they were treated and affects all aspects of treatment. As a result they often left it until reaching rock bottom before asking or seeking help.
- Offering help on how to prevent MH issues escalating/prevention is important as many described the person they care for being in denial and not getting help until it is too late and not placing value on preventative strategies.
- They felt there was a lack of communication between different professionals, hospitals, community care etc., and the person they cared for (who may not understand fully what's happening) and carers"

"Mental health prevents them accessing services"

"They are in denial and hide the problems.....they have to be ready to get help"

"They don't look at prevention as they think they can cope and are in denial"

“We can’t force or make them go but it would help if they got help sooner...how do you persuade someone?”

“Who knows their child better than their mother? Carers are not recognised and taken seriously as experts on their children” Carers felt that they were often not included enough or their concerns taken seriously by the professionals making decisions about those they care for.”

“They often don’t face up to problems so won’t get preventive help, that’s why it gets to crisis. They then ask for help when it’s too late”

Participants of the focus groups made suggestions to improve prevention and early access and gave examples of good practice:

- Annual health checks were suggested if people could be persuaded to attend. The appointments should be available immediately without a long wait for an appointment as mental health can change quickly. They should be local and carried out by someone that they already had a relationship with and know i.e. their own GP.
- There should be immediate access to someone people could talk with instead of being prescribed medication. Many felt that it would be beneficial to have a mental health professional/ psychiatrist or psychologist people could speak to in GPs or other community settings. Prescription is not an answer.
- Carers felt speed is really important as if the person they care for agrees to get help and attends an initial appointment. If consecutive treatment has a long wait they may worsen or change their mind about getting help. People should get help the first time they ask. *‘It takes a lot of courage to seek help’* and asking for help is not easy for many people, especially men.

Access to services

Access to services is vital for people with ill mental health. Quick access to good quality care and appropriate support is key to managing mental health. Participants in the Bexley focus groups raised the following barriers to accessing services:

- Accessing and receiving help from adult services was flagged as a significant problem. The necessary criteria to access support has become harder to meet.
- Many felt that access to specialist services such as Community Mental Health Teams (CMHTs) and care coordinators is very difficult. They said that they have to wait for a long time before they can access any support.
- People with lived experience felt there was a move towards telephone assessments which was not a good idea, as the people they support can hold it together for a phone call. They felt face to face was better as body language and appearance were important in diagnosing. They explained how *‘a brave face could be put on over the phone which could be misleading’*.

Ongoing support was an important aspect to keeping well after an onset of ill mental health and hospitalisation. Those who were left without support or follow up felt anxious because they were unsure about how to best care for themselves.

Individuals and carers described the following barriers to staying well:

- Participants felt there was a lack of outdoor activities available to people with mental health conditions.
- Accessing services and activities can be daunting for people with ill mental health. *‘The person I care for is terrified of change so wouldn’t engage in activities.’ ‘My son won’t*

travel on the bus so he can't get to things.' 'They assume we can just use [sports] services like everyone else.'

- Many participants of the focus groups felt that there is lack of clear and accessible information and this creates a significant barrier to accessing services. Not all had access to internet services or felt they did not have the skills to find information this way. Putting more information online maybe helpful for some but for others it may create a barrier. Others may need support and help to understand online information. Some patients noted Mind as a useful source of information, but did not know where to get help other than Mind. 'This can only work if all information was available in the format that meets the needs of the patient.'
- There should be, safe, community, spaces where people with mental health issues can come together to help and support each other, such as community café and/or peer support groups.
- There needs to be a holistic, person-centred, tailored approach to mental health rather than a "best-practice/one size fits all" process that many had experienced. They asked for flexibility in care packages.
- Carers must receive support to improve their quality of life, as well as the people they care for. Several carers were suffering from stress anxiety and their own mental health issues. It is important that the needs of carers are considered at the same time of those of the person with mental ill health to prevent carers becoming ill themselves. 'Carers and those they cared for should have free bus travel to encourage them to get out and about.' 'No one asked if I was ok. The focus was on my husband.'

Treatment

Participants of the focus groups described and made the following suggestions to improve treatment and gave examples of good practice:

- Treatment options should be discussed and agreed with the patient. 'Many people know what helps them. It should be a joint decision.'
- Staff at services, especially GP practices and A&E, would benefit from more education on how to best support patients with mental health.
- People feel grateful if they've spoken with someone quickly even if it's with Primary Care.
- People would like recognition that ill mental health can affect their physical health.
- Environments should be appropriate for people going through a mental health crisis. 'The Crisis Café looks like an office, it is too bright and confusing.'
- The local Crisis Café has been used by carers and those they care for to deescalate problems, especially those who don't like to admit they have a problem. Many said the people they care for had used it instead of going to A&E.
- Treatment should be person-centred. 'Treatment should be personalised to be effective, not one size fits all.'

Learning disabilities

Through focus groups and the specific conditions survey, Bexley residents shared their experiences of learning disabilities, which have been broken down into themes. 10 adults with learning disabilities took part in these focus groups.

Access to appointments

- Participants said they may have to wait longer to see the same doctor. It is hard not seeing the same doctor for all appointments. Most would prefer to see the same doctor for every appointment because they are aware of the patient's medical history and understand the patient's needs. Some described difficulties with individual doctors such as accents or not enough eye contact.
- Reception staff were often not very helpful at their GP.
- Having check-ups on different days can be stressful, for example, hearing and dental. It can be difficult for carers to arrange, and can make some people with learning disabilities feel anxious because they don't like going to hospital. They would value being offered different checks in one day/appointment. They said that professionals should coordinate the services because people with LD will be unable to ask for it.
- Travel to and from hospitals can be difficult. Taxis are expensive and you can have trouble parking.

Prevention and staying well

Participants of the Bexley focus groups described the barriers to staying well and gave some examples of good practice:

- For some, it is a struggle to achieve five fruits and vegetables a day. It is much easier to eat takeaway/convenience foods. Finances were also an issue for, for example, some people cut out meals to save money.
- Accessing facilities to exercise can be expensive and some would prefer to go to specially arranged sessions when it was quieter.
- Knowledge varied between participants of healthy diet. Some did not equate health with sugar intake, and would add sugar to their tea.
- More information provided in easy read.
- Most participants rely heavily on the help of their relatives/family and support workers and would struggle to stay well on their own.
- Participants of the group were aware of the importance of a healthy balanced diet and healthy lifestyle, including eating five a day, exercising, not smoking and drinking less alcohol. Their key workers, family and carers play a key role in encouraging and supporting them to change their eating habits and improve their wellbeing. Participants were encouraged to lose weight by health professionals/or carers. Some accessed help of a dietician which they found helpful.
- Community organisations that organise fitness sessions, discussion groups and information sharing are valued, and financial help in running these groups would be really helpful. Participants had learnt about being safe, sex and relationships, losing weight, current events and travelling safely through community groups. They had also been introduced to new hobbies.

Outpatients

Participants of the focus groups described the following negative examples of outpatients' service:

- Participants commented that letters and leaflets were not being received in easy-read for hospital appointments, so help was required to understand the information being received for appointments. Some had help when attending their appointments.
- Some participants expressed frustration at long waiting periods between diagnosis and treatment.
- Some doctors don't quite understand how to interact with someone with learning disabilities. Doctors often used words that were unfamiliar to patients or that patients did not fully understand. 'Rather than talking in jargon, it would be better if they used pictures.'
- Also, participants felt that doctors do not spend enough time explaining health tests to them. One person was scheduled to have a CT scan at hospital, but was not really sure what it was for. He was really scared as the GP had mentioned that it could be an infection or even a tumour. He prepared himself for the worse. It would have been good if the GP could have spent more time with him, explaining what the scan was for and exactly what would happen during the procedure. The leaflet explaining about CT scans, (that arrived with his appointment letter) was not in easy read and was confusing.

Participants of the Bexley focus groups made the following suggestions for outpatients' and gave examples of good practice:

- Staff calling patients' name and seeing their name on the screen when it is their turn for appointments.
- One hospital has an experienced learning disability nurse present when undertaking blood tests. Another hospital already has a nurse who is experienced in this field. She assists learning disability patients with most things at the hospital. This would help patients with learning disabilities feel less anxious.
- Clearer, jargon free communication supported by pictures would improve people's understanding of their health issues. People would appreciate accessible written information that they could take home and this would help them remember it.

Screening

Participants of the focus groups described the following negative examples of experiences with screening:

- Participants had a mixture of knowledge on screenings. Some felt that they were not as good at being screened as they could be, and that information needs to be better regarding the process for people with learning disabilities. Others knew about screenings and had accessed them.
- Participants had mixed experiences of being offered screening tests. Some women had been invited for a smear test via their GPs, but others said they had not been offered screening.
- Some ignored their screening letters. Bowel cancer is one of the hardest screening test for people with learning disabilities because of the different samples required. It is easier for people with assistance and support at home to carry this test out.

Participants of the focus groups made the following suggestions regarding screening and gave examples of good practice:

- Patients with learning difficulties should be told the sex of the health professional performing the screening.
- Education about the body such as what prostate or bowel is would be helpful in understanding what the screening was for.
- It needs to be made clearer what the tests are, how they are done, how long they will take and if there is any discomfort. They said that they should be informed of what to expect before they go to the hospital or GP. They added that leaflet with flow chart of stages or steps with pictures of what the screening is about to happen at the appointment should be sent to them.
- Organisations such as Mencap are doing some training around screening and this is valuable.

Next steps

Our Healthier South East London provided the following statement in support of the work undertaken:

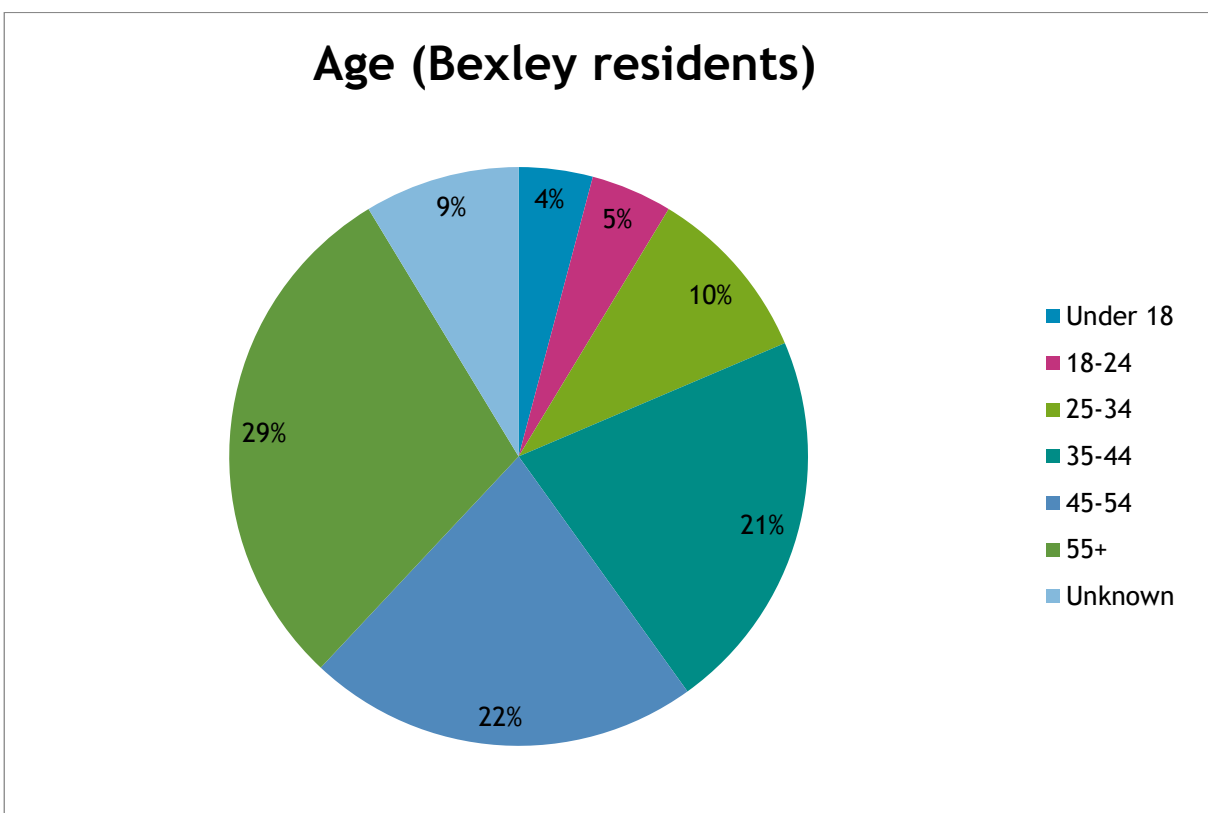
'The feedback we have gathered from this engagement work will now be used in the development of the south east London response to the NHS Long Term Plan. The findings of this report will help to ensure that south east London plans take into account what is important to the local population. All plans have to be submitted to NHS England and Improvement in mid November, after which national plans will be published publicly. Once our plans have been finalised we will provide feedback on how your input helped to shape these.'

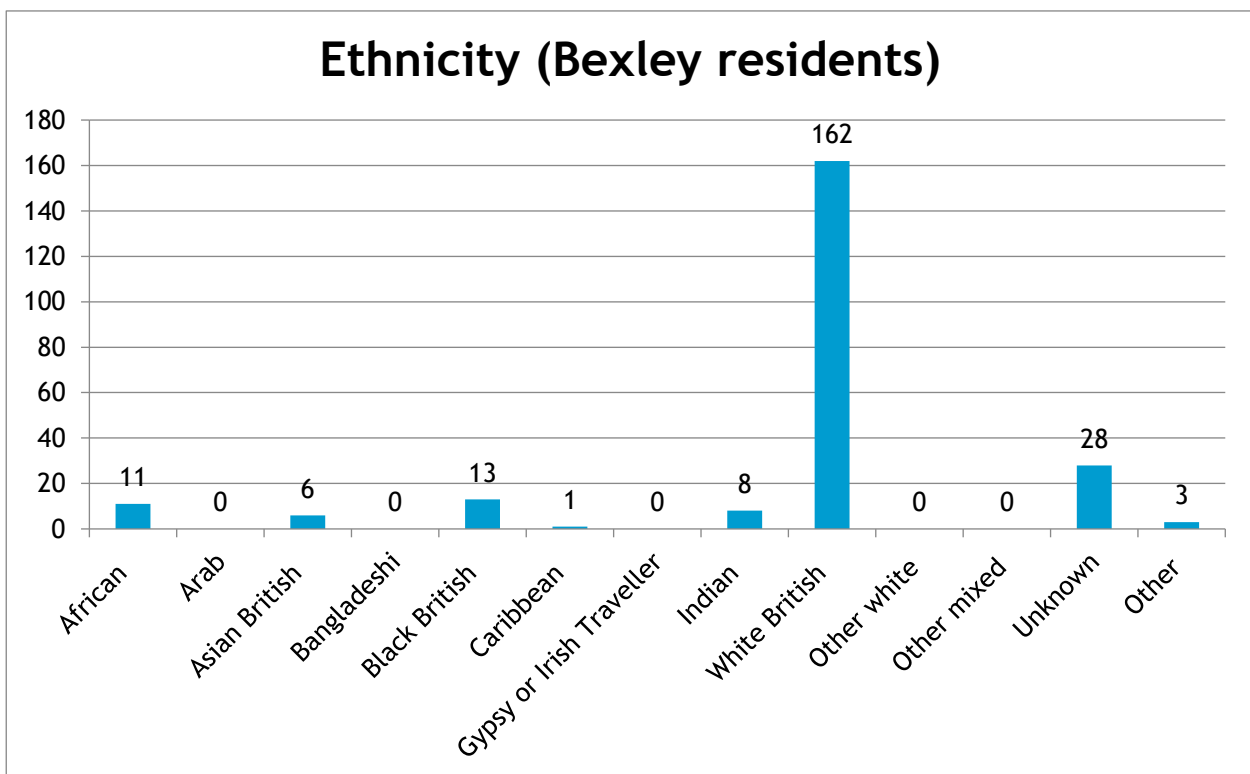
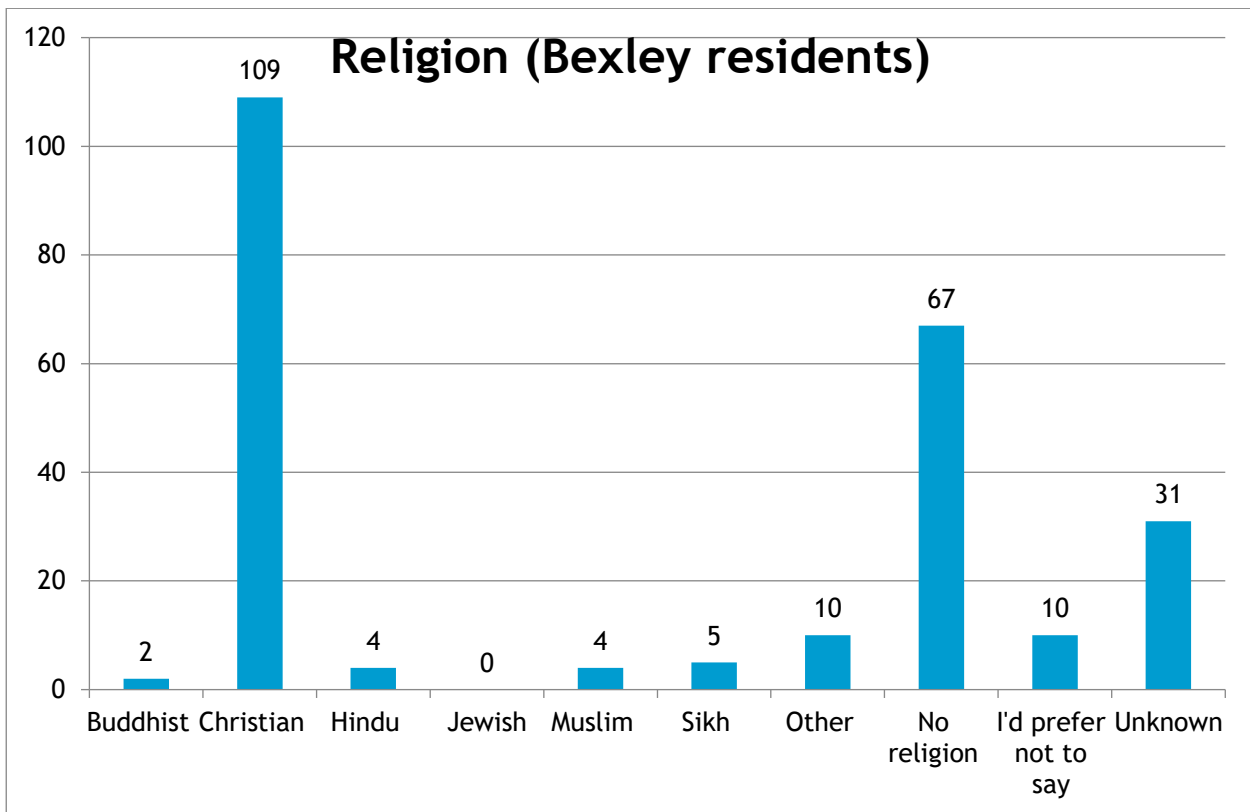
NHS Long Term Plan

Equality and diversity data

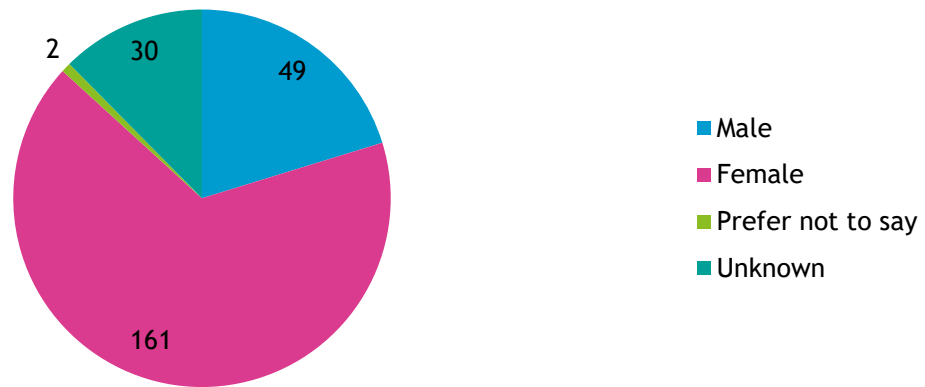
General survey demographics

Completing the demographic section of the survey was optional and not completed by all respondents.

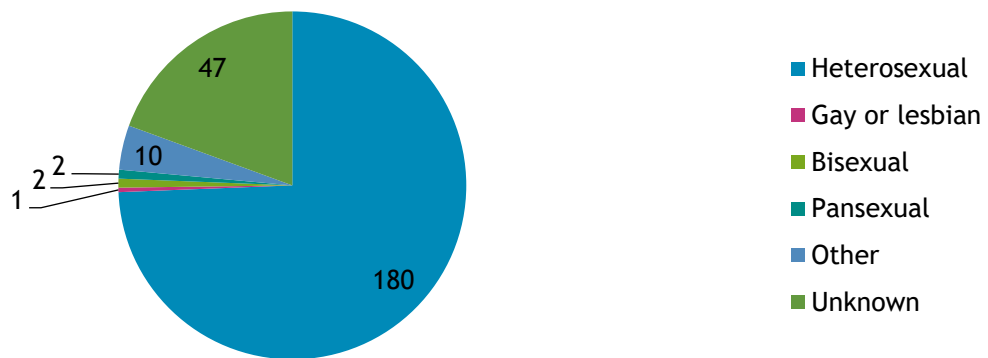




Gender (Bexley residents)



Which of the following best describes you? (Bexley residents)



Do you consider yourself to have a disability? (Bexley residents)

