

NHS Long Term Plan

Engagement Report

South east London

whot

would you do?

It's your NHS. Have your say.

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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 to support local implementation of the NHS Long Term Plan. Each borough 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.

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.

What does south east London look like?

The following areas have been broken down by borough to contextualise the findings:

- Population size
- Key health services
- Income equality
- Life/healthy life expectancy

The table below provides a breakdown of the south east London population and key health services available.

Borough	Population size ¹	Key health services ²
Bexley	247,258	<p><i>Local hospitals</i></p> <ul style="list-style-type: none"> • Queen Elizabeth Hospital • Princess Royal University Hospital • Darent Valley Hospital <p><i>Mental health trusts</i></p> <ul style="list-style-type: none"> • Oxleas NHS Foundation Trust • South London and Maudsley NHS Trust <p><i>Number of GP Practices</i></p> <ul style="list-style-type: none"> • 23
Bromley	331,096	<p><i>Local hospitals</i></p> <ul style="list-style-type: none"> • Princess Royal University Hospital <p><i>Mental health trust</i></p> <ul style="list-style-type: none"> • Oxleas NHS Foundation Trust <p><i>Number of GP Practices</i></p> <ul style="list-style-type: none"> • 45
Greenwich	286,186	<p><i>Local hospitals</i></p> <ul style="list-style-type: none"> • Queen Elizabeth Hospital • Princess Royal University Hospital • University Hospital Lewisham <p><i>Mental health trust</i></p> <ul style="list-style-type: none"> • Oxleas NHS Foundation Trust <p><i>Number of GP Practices</i></p> <ul style="list-style-type: none"> • 46
Lambeth	325,917	<p><i>Local hospitals</i></p> <ul style="list-style-type: none"> • King's College Hospital • Guys' & St Thomas' NHS Foundation Trust • University Hospital Lewisham <p><i>Mental health trust</i></p> <ul style="list-style-type: none"> • South London and Maudsley NHS Trust <p><i>Number of GP Practices</i></p> <ul style="list-style-type: none"> • 43
Lewisham	303,536	<p><i>Local hospitals</i></p> <ul style="list-style-type: none"> • University Hospital Lewisham • King's College Hospital

¹ "Estimates of the population for the UK", *Office for National Statistics*, 26 June 2019, <https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland>

² Information found on local CCG and NHS websites.

		<p><i>Mental health trust</i></p> <ul style="list-style-type: none"> • South London and Maudsley NHS Trust <p><i>Number of GP Practices</i></p> <ul style="list-style-type: none"> • 38
Southwark	317,256	<p><i>Local hospitals</i></p> <ul style="list-style-type: none"> • Guys’ & St Thomas’ NHS Foundation Trust • King’s College Hospital <p><i>Mental health trust</i></p> <ul style="list-style-type: none"> • South London and Maudsley NHS Trust <p><i>Number of GP Practices</i></p> <ul style="list-style-type: none"> • 49
Total	1,811,249	

Income equality in south east London

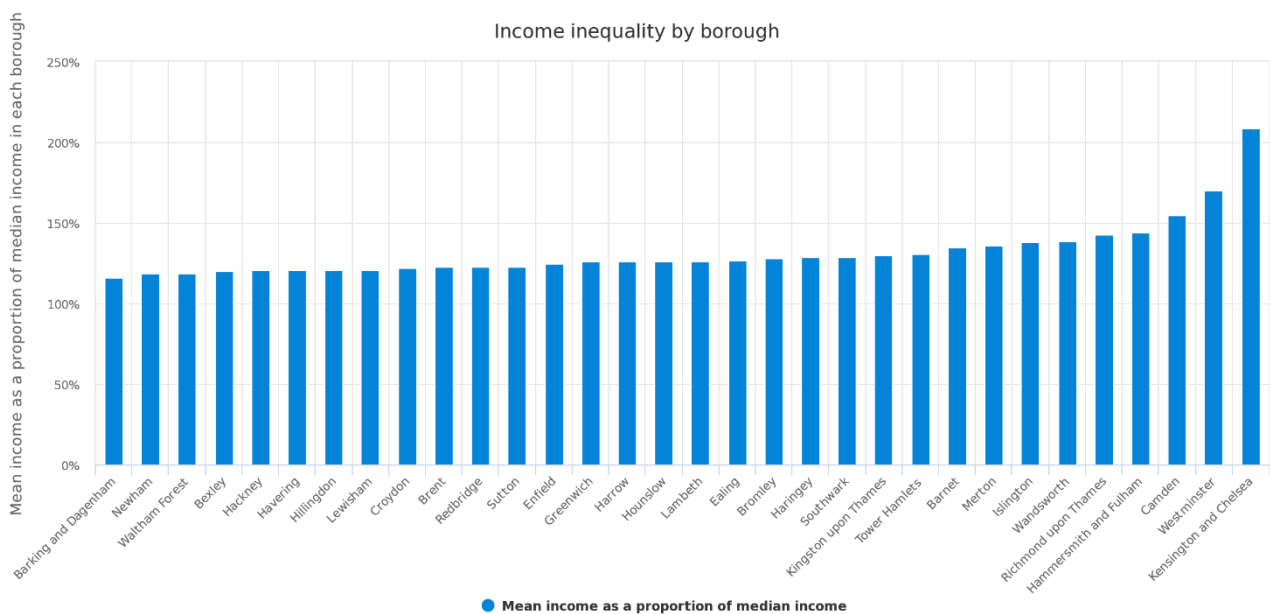


Figure one: “Income equality by borough”, The Trust for London, <https://www.trustforlondon.org.uk/data/income-inequality-borough/>

Figure one compares income inequality across London boroughs. Kensington and Chelsea placed 1st on the above chart and overall is the wealthiest borough. Barking and Dagenham placed 32nd and is the most deprived borough. South east London boroughs ranked as follows:

- Southwark - 12th
- Bromley - 13th
- Lambeth - 15th
- Greenwich - 18th
- Lewisham - 24th
- Bexley - 28th

Life/healthy life expectancy

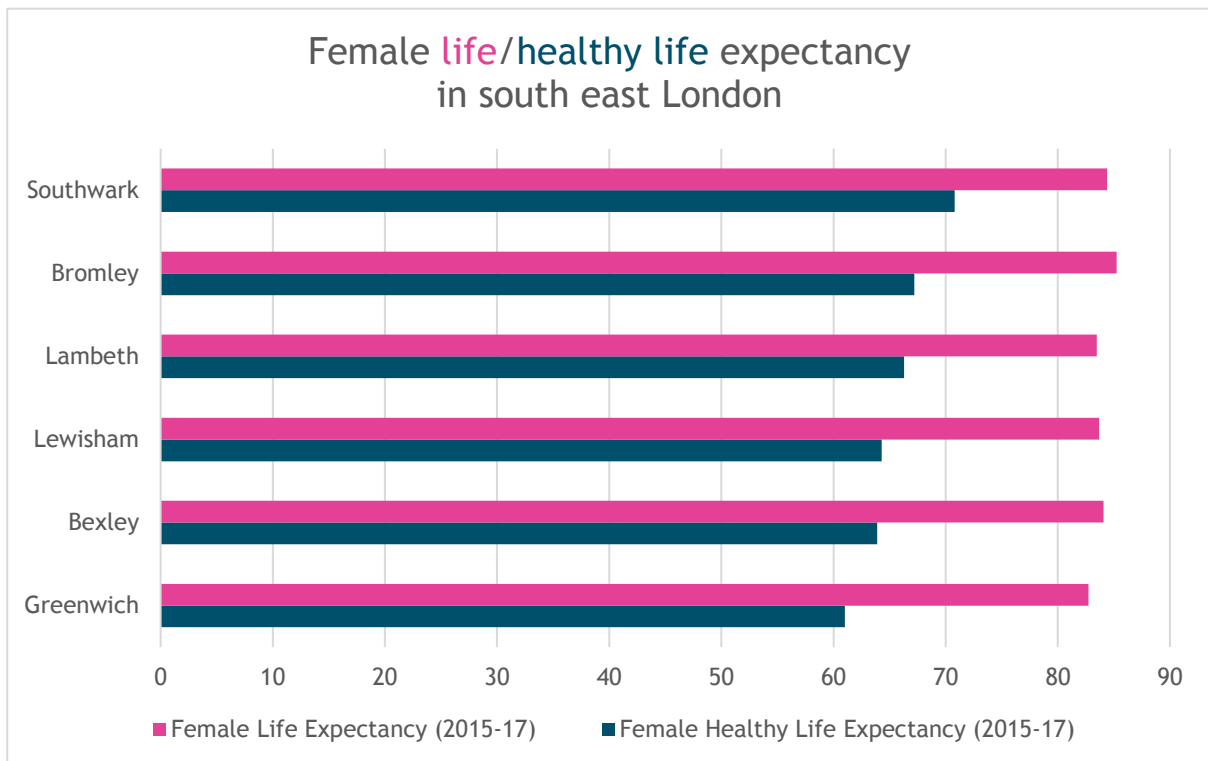


Figure two: 'Female life/healthy life expectancy in south east London', Office for National Statistics.

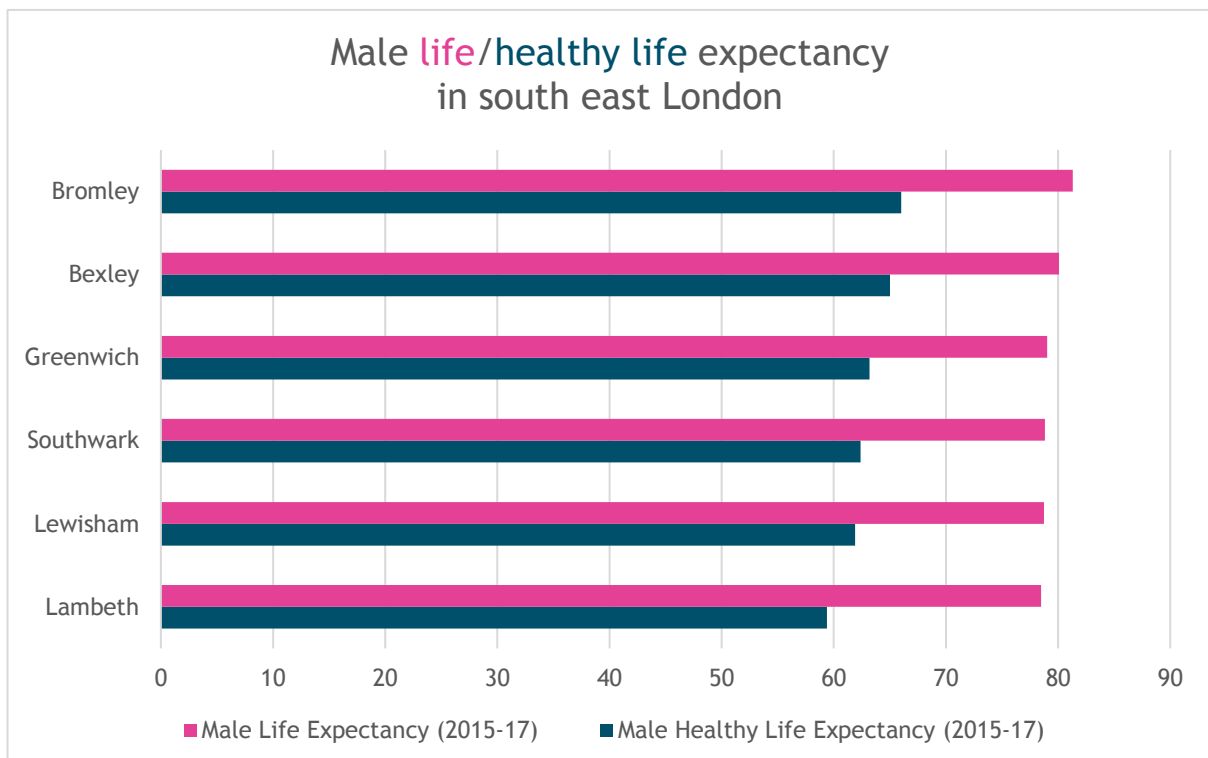


Figure three: 'Male life/healthy life expectancy in south east London', Office for National Statistics.

Figures two and three show a breakdown of female and male life and healthy life expectancy in south east London.

Methodology

The 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. The findings below are a collation of the results, summarising the themes across the region.

A two-pronged approach of surveys and focus groups was used to gather feedback, broken down into the following areas:

- **Survey**
 - *General survey*
 - Living a healthy life
 - Managing and choosing support
 - Independence as they get older
 - Interaction with local NHS
 - *Specific conditions survey*
- **Focus groups**
 - Mental health
 - Learning disabilities and autism

The topics of the focus groups were agreed with OHSEL and covered mental health and learning disabilities and autism. In addition, two surveys were filled out by nearly 1000 residents and covered themes within the NHS Long Term Plan. A breakdown of equality and diversity data can be found in an attached appendix.

The table below gives a breakdown of the number of residents engaged with in each borough.

Borough	General Survey	Specific Survey	Mental health focus group	Learning disabilities and autism focus group
Bexley	243	35	People with lived experience (0) Carers (28)	People with lived experience (10) Carers (0)
Bromley	127	0	People with lived experience (12) Carers (0)	People with lived experience (12) Carers (0)
Greenwich	94	39	People with lived experience (12) Carers (0)	N/A
Lambeth	84	26	People with lived experience (17) Carers (3)	People with lived experience (15) Carers (3)
Lewisham	241	11	People with lived experience (12) Carers (1)	People with lived experience (20) Carers (1)
Southwark	72	25	People with lived experience (3) Carers (0)	People with lived experience (6) Carers (0)

Total	861	136	People with lived experience (56) Carers (32)	People with lived experience (63) Carers (4)
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Executive summary

What matters most to people in south east London?

South east London 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 they tell Healthwatch?

General survey

South east London residents were asked what would help live a healthier life. Overall, residents were aware that they should eat healthily and take regular exercise, but felt that access to clean green spaces, 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 south east London 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 in all boroughs was easier and quicker access to GP services. South east London residents do not have confidence they can access primary care services promptly if they feel unwell.

In addition, South east London 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 at services such as approach of staff and communication 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 opinion respected during the decision making of their health care. Improved collaboration between NHS staff and patients would help residents manage their health better.

Also, residents were asked how the NHS can support them to retain their independence as they grow older. South east Londoners 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, south east London 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 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' name, friendly staff who support 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 such as 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.

Recommendations

OHSEL are focussing on six areas to improve the NHS until August 2019 as priorities, outlined in the table below. The suggestions to improve NHS services in south east London and examples of good practices shared by our residents have been categorised by colour throughout the report to reflect the six topics OHSEL is focussing on. These form the recommendations of the report.

Topics	Why are OHSEL focussing on this?	For example...
1: Getting the best start in life	<ul style="list-style-type: none"> How healthy children are isn't just about the NHS It's also about their schools, homes, food and more. This means working together. 	<ul style="list-style-type: none"> How much time should the NHS spend working with primary schools?
2: Young people's mental health	<ul style="list-style-type: none"> Half of all mental health problems are established by the age of 14. This means helping early can have lifelong effects. 	<ul style="list-style-type: none"> Should GPs be trained to help young people in using social media?
3: Daytime hospital appointments	<ul style="list-style-type: none"> We only want people to go to hospital if they have to. This means more care outside hospital, and more use of telephone appointments. 	<ul style="list-style-type: none"> When would you like the hospital doctor to give you a ring?
4: Accessing care	<ul style="list-style-type: none"> We want to make it easier to get care in the right place. This means making it easier to get GP appointments, including in emergencies. 	<ul style="list-style-type: none"> Which services are better than A&E?
5: Social isolation and charities	<ul style="list-style-type: none"> Loneliness is as bad for your health as smoking 15 cigarettes a day. The best help often comes from the community. 	<ul style="list-style-type: none"> What services in the community should we prioritise?
6: Services working together	<ul style="list-style-type: none"> We are working together because we want the best health for our area. This means we need to think about removing barriers. 	<ul style="list-style-type: none"> How much difference should there be between health and social care budgets?

NHS Long Term Plan

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*

The table below shows a breakdown of the statements ranked “Very Important” in each south east London borough:

Borough	Statements ranked “Very Important”
Bexley	<ol style="list-style-type: none"> 1. <i>Access to the help and treatment I need when I want it (90%)</i> 2. <i>Professionals that listen to me when I speak to them about my concerns (86%)</i> 3. <i>Easy access to the information I need to help me make decisions about my health and care (76%)</i>
Bromley	<ol style="list-style-type: none"> 1. <i>Access to the help and treatment I need when I want it (89%)</i> 2. <i>Professionals that listen to me when I speak to them about my concerns (78%)</i> 3. <i>Easy access to the information I need to help me make decisions about my health and care (73%)</i>
Greenwich	<ol style="list-style-type: none"> 1. <i>Access to the help and treatment I need when I want it (83%)</i> 2. <i>Easy access to the information I need to help me make decisions about my health and care (82%)</i> 3. <i>The knowledge to help me do what I can to prevent ill health (76%)</i>
Lambeth	<ol style="list-style-type: none"> 1. <i>Easy access to the information I need to help me make decisions about my health and care (80%)</i> 2. <i>Access to the help and treatment I need when I want it (79%)</i> 3. <i>Professionals that listen to me when I speak to them about my concerns (79%)</i>
Lewisham	<ol style="list-style-type: none"> 1. <i>Access to the help and treatment I need when I want it (85%)</i> 2. <i>Professionals that listen to me when I speak to them about my concerns (79%)</i> 3. <i>Easy access to the information I need to help me make decisions about my health and care (73%)</i>
Southwark	<ol style="list-style-type: none"> 1. <i>Professionals that listen to me when I speak to them about my concerns (88%)</i> 2. <i>Access to the help and treatment I need when I want it (85%)</i> 3. <i>The knowledge to help me do what I can to prevent ill health (74%)</i>

Overall, South East London residents ranked the following as the top three ‘Very Important’ aspects for them to live a healthy life:

1. *Access to the help and treatment I need when I want*
2. *Professionals that listen to me when I speak to them about my concerns*
3. *Easy access to the information I need to help me make decisions about my health and care*

South East London residents provided the following comments on what would help them live a healthier life through the free text section of the survey, which have been broken down into themes.

Access

A huge area of concern for South east London 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.

Residents shared the following examples of barriers to accessing services:

- Long waiting times for appointments. One resident told us about her experience of being in an automated queuing system for her GP surgery and being told she was 21st in line to be answered. She did not wait and took her daughter to A&E instead. Other patients also stated they used urgent care facilities if they could not get a GP appointment.
- Quicker follow up appointments after initial diagnosis. *‘Being able to get important appointments - I have been waiting 6 months for an initial physiotherapy assessment for my disabling arthritis.’*
- 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.
- A number of people were unsure of the options available to them when they felt unwell. Going to the GP or Emergency Department is not always the right solution.



Residents made the following suggestions to improve access to services and shared examples of good practice:

✓	<ul style="list-style-type: none"> • Alternative easy booking methods for appointments. The use of more digital technology would be welcomed by some. They would like the option to book appointments and receive prescriptions via mobile phone apps. Also, they would like to be able to email or text concerns and have consultations via telephone or Skype. However, a large number of people wish to continue to use the telephone as their preferred booking method.
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✓	<ul style="list-style-type: none"> More consultation time which is time consuming initially, but saves time in the long run. <i>'I don't get enough time with the health professional to sort out my multiple health needs.'</i>, <i>'Only 10 minutes per appointment is not enough.'</i>
✓ ✓	<ul style="list-style-type: none"> An effective transport infrastructure is necessary to support access to health care services, as well as other amenities vital to independent and healthy living, such as shops social activities and fitness centres. This is especially important for those who are less mobile or have a disability.
✓	<ul style="list-style-type: none"> If patients need to access treatment that they have to pay for, it should be affordable.
✓	<ul style="list-style-type: none"> 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.
✓	<ul style="list-style-type: none"> GP services should be able to offer tests such as bloods and other tests.
✓	<ul style="list-style-type: none"> Residents that had access to the GP hub service in their borough praised the additional access to selected surgeries, including appointment availability until 8.00pm. However, some felt that they are still not enough available appointments and that receptionists at their regular practice ought to be able to book appointments at extended services for them.
✓ ✓ ✓	<ul style="list-style-type: none"> There should be a wider societal view of health rather than focus on medication, illness, and disease. People said that they would benefit from being referred (not signposted) to a holistic lifestyle service to support in successfully making life changes.
✓	<ul style="list-style-type: none"> Many people are aware of the pressure that health and social care services are under, with considerable pressures on staff. It is desirable that future changes are equitable for staff and service users alike, with good levels of support available to all.
✓	<ul style="list-style-type: none"> Many people are happy to see a different health or care professional (not their regular one) to reduce waiting time.

'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.'

'More support accessing hospital transport. Shocked to hear that I wouldn't be attending my appointment because they couldn't cope with numbers.'

The survey asked respondents to highlight areas that needed improvement in the delivery of NHS and what was most important to people locally. However, some respondents also shared positive feedback about the quality of services, once they were able to access them.

'I have every confidence in my local GP surgery and the hospitals to which I have recently been referred. Despite financial constraints and the growing population, I have received high quality care, the NHS at its very best, for which I am extremely grateful.'

Knowledge

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

✓	<ul style="list-style-type: none"> Advice around nutrition and information on how to maintain good health, without relying on medication. Information should be clear, accessible and from a
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✓	trustworthy source. <i>‘More accessible and clearer information given on treatment and support in managing health conditions.’</i>
✓	<ul style="list-style-type: none"> Greater awareness of the impact that certain foods or lifestyles can have on your health later on, starting as early as primary school level.
✓	<ul style="list-style-type: none"> Also, early education about menstruation and how diet and exercise can have a positive/negative impact on a female’s health. Some said that not all families are comfortable talking about this topic at home, and so general awareness raising would help.
✓ ✓	<ul style="list-style-type: none"> Regular reminders of how and what we can do to keep healthy. The extensive advertising and marketing campaigns of food manufacturers was compared to how often information on more healthy choices and lifestyles were seen. <i>‘Regular information on healthy and good living.’</i>
✓ ✓	<ul style="list-style-type: none"> Improvements of public health messages that can be “bland” and “basic”, such as, “sugar is always bad” would be beneficial. Messages should be relevant and clear, for example, “diet of too much sugar puts you at risk of developing diabetes because of the strain you put on your insulin production.”

‘There are too many options and I am not sure what is right for me.’

Lifestyle

- **Healthy, affordable food**

Many south east London residents focused on the need for easier access to healthy food at an affordable price. They described the following barriers to making this a reality:

- Time, ability and confidence to shop for more healthy choices and then cook from “scratch”.
- The cost of ready-made, highly processed, instant meals that were often cheaper than buying more healthy alternatives.
- The large number of take-away shops was compared with the much smaller number of places to buy fresh fruit and vegetables and that, as a result, it was much easier to find and buy a takeaway than a bag of fruit and veg. *‘Why is coke cheaper than water? Why is fried chicken cheaper than salad?’*

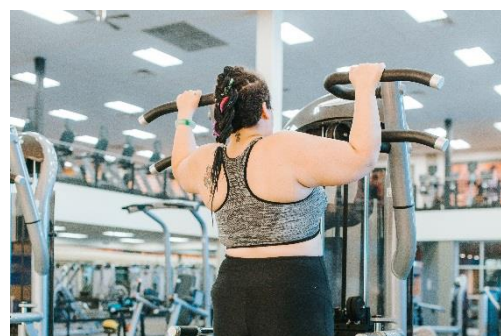
Awareness of what foods were healthy was clear to most, however, people also stressed the importance of access to consistent advice about health lifestyles. The practical means to make changes to lifestyles was also limited.

‘Consistent advice about healthy lifestyles [is needed] - there is so much out there in the media it is hard to know what is right.’

- **Exercise**

South east London residents considered access to sport and exercise facilities as vital to help people stay well, including people with mental health issues. Residents emphasised the following barriers to taking regular exercise:

- The high cost of gym memberships and exercise classes. They wanted easier access to “free” or “affordable”.



- Some residents did not feel they have enough time to focus on their health.
- Accessing green spaces could also be difficult if not nearby. Having to cross busy roads to access parks and gardens raised the issues of air pollution.

Residents made the following suggestions for uptake of exercise in south east London:

✓	<ul style="list-style-type: none"> • They wanted to take part in activities such as swimming, cycling and gym workouts. Other suggestions also included having a walking companion for country walks.
✓	<ul style="list-style-type: none"> • People felt it was essential to provide “gentle” exercises to suit those with reduced mobility.
✓	<ul style="list-style-type: none"> • Respondents also expressed their desire for women only and disability friendly sessions.
✓	<ul style="list-style-type: none"> • Some residents wanted further information on how they can lose weight or keep fit.

Awareness of the need to be more physically active was apparent, but the means of doing so were limited.

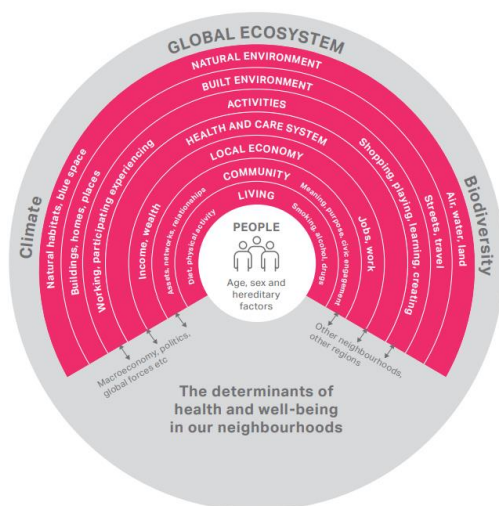
‘Free gym membership or subsidised gym membership for young adults to help them prevent illness.’

- **Health inequalities**

For some South East London residents, wider social issues impacted on their wellbeing.

‘Some of my benefits were stopped because I was getting myself more mobile and this is detrimental to my wellbeing.’

‘To be blunt, I think for many people the thing that would help them retain their independence and live healthily for as long as possible might simply be MONEY - being able to buy in the help you need rather than having to rely on what the state might provide.’



Adapted from Dalghren and Whitehead (1991); Barton and Grant (2006)

Figure four demonstrates the determinants of health and wellbeing, including social security and financial inequality.

The breakdown of wealth in south east London in figure one showed Bexley, Lewisham and Greenwich to be the most deprived boroughs.

Females had the lowest healthy life expectancies in Greenwich, Bexley and Lewisham. This seems to reveal a clear link between wealth and female healthy life expectancy in these areas.

Males had the lowest healthy life expectancies in Lambeth, Lewisham and Southwark. Interestingly, Southwark and Lambeth were two of the wealthiest London boroughs.

Figure four: “The determinants of health and well-being in our neighbourhoods”, *The London Health Inequalities Strategy*, September 2018.

Environment

South east London residents felt that improvements could be made to the environment to help them live a healthier life. They described the following issues with the current environment:

- They stressed the negative impact that low quality ambient air can have on a population’s health.
- People felt smoking in public spaces (including at bus stops) remains an issue and affects those with respiratory problems such as COPD. It was felt that smokers would benefit from greater support to help them quit.

Residents made the following suggestions to improve pollution levels in south east London:

 	<ul style="list-style-type: none"> • Planting more trees
 	<ul style="list-style-type: none"> • Lower speed limits

Changes to the physical environment should not have a detrimental impact on access to public transport.

‘The area that concerns me is that over which I have least control and that is the quality of the environment and the pollution that is high in my area.’

Mental health

The need to link good mental health with good physical health was also considered important to south east London residents. The following suggestions were made to improve people’s wellbeing:

 	<ul style="list-style-type: none"> • Being outside and accessing nature was suggested as an opportunity to link both mental health and physical health, particularly through group activities.
 	<ul style="list-style-type: none"> • A chance to make friends or meet neighbours and others in the local community while taking part in some form of physical activity would be welcomed.
 	<ul style="list-style-type: none"> • More understanding about mental health issues by professionals.
 	<ul style="list-style-type: none"> • Education on mental health from an early age.

✓ ✓	<ul style="list-style-type: none"> • Prompt access to mental health services was also stressed as vital.
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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*

The table below shows a breakdown of the statements ranked “Very Important” in each south east London borough:

Borough	Statements ranked “Very Important”
Bexley	<ol style="list-style-type: none"> 1. <i>Communications are timely (68%)</i> 2. <i>Choosing the right treatment is a joint decision between me and the relevant health and care professional (66%)</i> 3. <i>I have time to consider my options and make the choices that are right for me (64%)</i>
Bromley	<ol style="list-style-type: none"> 1. <i>Communications are timely (69%)</i> 2. <i>Choosing the right treatment is a joint decision between me and the relevant health and care professional (61%)</i> 3. <i>I have time to consider my options and make the choices that are right for me (54%)</i>
Greenwich	<ol style="list-style-type: none"> 1. <i>Choosing the right treatment is a joint decision between me and the relevant health and care professional (70%)</i> 2. <i>Communications are timely (69%)</i> 3. <i>My opinion on what is best for me, counts (60%)</i>
Lambeth	<ol style="list-style-type: none"> 1. <i>Choosing the right treatment is a joint decision between me and the relevant health and care professional (65%)</i> 2. <i>I have time to consider my options and make the choices that are right for me (61%)</i> 3. <i>Communications are timely (60%)</i>
Lewisham	<ol style="list-style-type: none"> 1. <i>Communications are timely (65%)</i> 2. <i>Choosing the right treatment is a joint decision between me and the relevant health and care professional (62%)</i>

	3. <i>I should be offered care and support in other areas if my local area can't see me in a timely way (60%)</i>
Southwark	<ol style="list-style-type: none"> 1. <i>Communications are timely (72%)</i> 2. <i>Choosing the right treatment is a joint decision between me and the relevant health and care professional (61%)</i> 3. <i>I have time to consider my options and make the choices that are right for me (56%)</i>

Overall, South East London residents ranked the following as the top three ‘Very Important’ aspects for them to manage and choose support:

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

South East London residents provided the following comments on what would help them manage and choose support through the free text section of the survey, which have been broken down into themes.

Accessible, timely services

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

Residents outlined similar issues to those made above, that create barriers to living a healthier life and managing and choosing support:

- Access their GP services when and where they need them.

Residents made the following suggestions to improve access to services and gave examples of good practice:

 	<ul style="list-style-type: none"> • Alternative ways of improving mental and physical health, such as exercise, could be made more accessible through NHS contact for those who might not be able to access due to confidence, mobility, and finance.
 	<ul style="list-style-type: none"> • Patients should be offered care and support at other local services, if they cannot be seen in a timely way at their registered practice. Some surgeries have access to a Pharmacist who takes appointments for patients with medication issues/problems, freeing up some time for the doctors to see more patients.
	<ul style="list-style-type: none"> • GP appointments that can be booked on different days and times, and can be booked in advance.
 	<ul style="list-style-type: none"> • Some want to access blood test service in the nearest hospital. Those who also have tests would appreciate discussing the results with the GP who referred them for tests.
 	<ul style="list-style-type: none"> • More investment in evidence-based talking therapies. Patients wanted the ability to access CBT without waiting for months and to receive it for as long as needed within reason (current time limits are too tight and inflexible).

✓	<ul style="list-style-type: none"> • Availability of experts in one building.
✓ ✓	<ul style="list-style-type: none"> • Having regular, annual, health checks was suggested as a useful addition to current provision. “MOT” type check-up for patients that incorporated guidance and advice on how to stay healthy as well as picking up early indications of “something not quite right” where the patient not had yet experienced any worrying symptoms. <i>‘Consultation with doctor on all health problems. 10 mins a problem at time doctor slots means many health concerns are overlooked and never dealt with properly and as prevention is better than cure. I feel a yearly consultation for people with more than one health concern would be beneficial.’</i>
✓	<ul style="list-style-type: none"> • Doctors to get it right the first time and shorter waiting time to see specialists. One respondent said she did not have good support for her mental health condition, which resulted to family stress.
✓ ✓	<ul style="list-style-type: none"> • There should be a consistent booking system across GP services. <i>‘It seems that each practice has very different ways of doing things and you have to get used to each one to make it work for you. This is difficult for someone who doesn't use their GP very often.’</i>
✓ ✓	<ul style="list-style-type: none"> • Some did not know where or who to go to for help when they were unwell and found services difficult to navigate.

Administration

South east London patients shared their frustrations over inefficient administrative processes that create barriers to managing and choosing support.

They gave the following examples of negative experiences:

- Communication from services. *‘It shouldn't take weeks for referrals and prescriptions to be sent via post... especially when external providers are involved.’*
- Ineffective IT/data systems. One resident recently moved to a temporary address to receive additional support and needed to update the records with their GP practice. Despite confirming the details on the receptionist's screen, all communications continued to be sent to their previous address, resulting in the patient have to constantly chase information.
- Poor communication from services. For example, a number of people said that they had to chase follow-up appointments, as these were not coming through automatically. *‘It takes a long time for my doctor to get hospital results and often these are not received prior to my next GP appointment.’*

‘NHS Patient Access has functions for instant messaging, however this is up to the GP practice to “switch that function on” even when I request it, and one response was “we won't switch that function on for you as its more work for us!”

Residents made the following suggestions for to improve administration and gave examples of good practice:

✓	<ul style="list-style-type: none"> • Improved service integration and faster processes to ensure communications are timely.
✓	<ul style="list-style-type: none"> • Health Passports should be routinely used and elevated into a health standard. <i>‘Health Passports aren't always utilised by some medical professionals.’, ‘All medical professionals should be aware/made aware of Health Passports and know to use them.’</i>

✓	<ul style="list-style-type: none"> Improved staff approach and training. People asked for <i>'better attitudes from doctors' receptionists', 'more helpful receptionists. Most are, not all.'</i>
✓	<ul style="list-style-type: none"> People felt that GP practices should tackle the issue of missed appointments, especially in light of current problems around access.

Decision making

Decision making was of particular importance to south east London residents when managing and choosing the best support for them. People highlighted the following areas for improvement:

- Many do not feel listened to when discussing health and care options with professionals. *'Recognise that some patients are experts on their conditions and their actual experience may differ from the text book or even other patients with the same condition, so the support would be to acknowledge their experiences and supplement with their medical experience.'*
- Care and treatment was not always felt to be tailored to the needs and experience of the user, even when direct requests were made. Some residents felt this inflexibility reduced their confidence in their healthcare professionals and made it harder for them to comply with or attend referrals or follow-ups.



Residents made the following suggestions to improve decision-making and gave examples of good practice:

✓	<ul style="list-style-type: none"> Improved collaboration between NHS staff and patients. Residents wanted reassurance that staff <i>'will listen to all of their issues'</i>, treat them with dignity and respect and take their views into account when making decisions.
✓	<ul style="list-style-type: none"> All professionals should be trained to support people with joint decision making. Statutory and voluntary sector should work better together to provide the care, treatment, and support if possible.
✓	<ul style="list-style-type: none"> Patients wish to have time to consider options and make the choices that are right for them. Patients wish to ask questions without being patronised. <i>'I need to be assured that at all times, I would be given sufficient information and then time to make such decisions - including, if necessary, second opinions from professionals.'</i>, <i>'I take research to my doctor and am told it's wrong (from proper sources such as Thyroid UK). I am made to feel paranoid.'</i>
✓	<ul style="list-style-type: none"> Residents sought greater clarity around professionals' diagnosis and why treatments are offered or refused. They wanted detailed, consistent and trustworthy information which would help them explore their options. <i>'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 what they can do to improve and what this actually means.'</i>
✓	<ul style="list-style-type: none"> Patients wished to be valued and treated with respect and dignity. <i>'Every NHS person treating you with respect and dignity and making you feel you matter', 'Staff are not valued, patients are just numbers, doctors need to be more caring instead of staring at a computer screen when being seen.'</i>
✓	<ul style="list-style-type: none"> Full access to joint up records which would allow them to see their entire medical history and have a greater understanding of any health conditions.
✓ ✓	<ul style="list-style-type: none"> Some GPs don't know about local services to appropriately enable choice. Options should be presented in a balanced manner with appropriate information to empower the patient to make their own decisions. However, some patients wanted GPs to know which service would best suit the person and their needs

✓	and be able to advise accordingly. <i>'I have often experienced that doctors/nurses don't have enough time to read our health records and knowledge about my own health condition and treatment plan helped me a lot and the doctors to provide me with the best care.'</i>
✓	<ul style="list-style-type: none"> Using simple language and presenting results and information in "layman's terms" is important to ensure patients' understanding. The Accessible Information Standard should be embedded in information given to a patient. <i>'I am currently deciding whether to have a surgery, and where, but it's hard to find information about likely risks of the surgery, and also which surgeons/hospitals have the best outcomes.'</i>, <i>'I was told verbally what my options were but I could not remember everything, I received nothing in writing.'</i>
✓	<ul style="list-style-type: none"> The ability to choose a health professional and continuity of care are equally important.
✓	<ul style="list-style-type: none"> The option to discuss serious health problems with a family member present. <i>'If serious concerns then it should be discussed with patient and perhaps family member both together if possible.'</i>

'LISTEN to what I am really saying as this would help to know what was wrong and therefore not get so much wrong by presuming, assuming and guessing.'

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*

The table below shows a breakdown of the statements ranked "Very Important" in each south east London borough:

Borough	Statements ranked "Very Important"
Bexley	<ol style="list-style-type: none"> <i>I want my family to feel supported at the end of life (85%)</i> <i>I want to be able to stay in my own home for as long as it is safe to do so (84%)</i> <i>I want my family and friends to have the knowledge to help and support me when needed (69%)</i>
Bromley	<ol style="list-style-type: none"> <i>I want to be able to stay in my own home for as long as it is safe to do so (81%)</i> <i>I want my family to feel supported at the end of life (74%)</i> <i>I want there to be convenient ways for me to travel to health and care services when I need to (69%)</i>
Greenwich	<ol style="list-style-type: none"> <i>I want to be able to stay in my own home for as long as it is safe to do so (76%)</i>

	2. <i>I want my community to be able to support me to live my life the way I want (54%)</i>
Lambeth	<ol style="list-style-type: none"> 1. <i>I want to be able to stay in my own home for as long as it is safe to do so (81%)</i> 2. <i>I want my family to feel supported at the end of life (79%)</i> 3. <i>I want there to be convenient ways for me to travel to health and care services when I need to (68%)</i>
Lewisham	<ol style="list-style-type: none"> 1. <i>I want my family to feel supported at the end of life (84%)</i> 2. <i>I want to be able to stay in my own home for as long as it is safe to do so (77%)</i> 3. <i>I want my family and friends to have the knowledge to help and support me when needed (71%)</i>
Southwark	<ol style="list-style-type: none"> 1. <i>I want to be able to stay in my own home for as long as it is safe to do so (81%)</i> 2. <i>I want my family to feel supported at the end of life (75%)</i> 3. <i>I want there to be convenient ways for me to travel to health and care services when I need to (61%)</i>

Overall, south east London residents ranked the following as the top three ‘Very Important’ aspects for them to retain independence as they get older:

1. *I want my family to feel supported at the end of life*
2. *I want to be able to stay in my own home for as long as it is safe to do so*
3. *I want there to be convenient ways for me to travel to health and care services when I need to*

South east London residents provided the following comments on what would help them to retain their independence as they get older through the free text section of the survey, which have been broken down into themes.

Social care and home services

For south east London residents, it was very important to be able to stay in their own home for as long as it is safe to do so. Availability of social care and home services was important to south east London residents. People highlighted the following areas for improvement:

- Friends and relatives of those needing care in their homes told us that finding care workers was a challenge. For those with care workers, time limitations meant that just getting the basis care tasks was a challenge, often leaving no time for choices in how time was spent, for example, no time to simply sit and have a chat and get to know each other.
- While home care staff are trained to carry-out their duties, people have told us that they will often miss key early symptoms of deteriorating health.
- Some surgeries no longer provide home visits from GPs and health workers which is an issue.

Residents made the following suggestions to improve social care and home services and gave examples of good practice:

✓	<ul style="list-style-type: none"> • More community based support.
✓	<ul style="list-style-type: none"> • Some people wanted the local authority to prioritise investment in domiciliary care.

✓	<ul style="list-style-type: none"> • More availability of care workers.
✓	<ul style="list-style-type: none"> • More information about options. Some respondents who didn't have any family were unaware of what social care is available to them.
✓	<ul style="list-style-type: none"> • The needs of disabled people, including those with learning disabilities, must be accounted for when providing support both at home and in care homes.
✓	<ul style="list-style-type: none"> • Services provided by local councils were valued, however, it was felt they should to be extended. One older resident needed further support from the handyperson service with maintenance tasks such as changing light bulbs or repairing curtains rails, which have become increasingly more difficult.

'It would be essential for me to retain my independence for as long as possible and to know I had rights to receive appropriate care and medical aid in my home if necessary without further charge - this being much more economic than institutional care.'

'Home care services that you can rely on are very important, this also applies to the district nurses.'



Mobility

Respondents considered maintaining mobility to be essential to retaining independence. They highlighted the issues they currently face in maintaining 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. *'Since the start of my mobility issues I find it hard to get around, so I have to rely on dial a ride or taxi to get me to places.'*

Residents made the following suggestions to enable mobility and gave examples of good practice:

✓	<ul style="list-style-type: none"> • Being able to travel freely is important and accessible transport schemes such as the Freedom Pass are valued by older people.
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Community based services

Getting the right community based support was important to south east London residents. They highlighted the issues they currently face in accessing community based services:

- Residents struggle to find and access support services for themselves and, more commonly, for relatives and friends they look after. There is a lack of support groups and day centres. This is issue is particularly difficult for those looking after others with dementia and/or with mental health issues such as depression and loneliness.
- Where provision was available there were sometimes barriers in having the confidence or ability to get to a venue.

Residents made the following suggestions for accessing community based services and gave examples of good practice:

✓	<ul style="list-style-type: none"> • Access to activities, social groups and community support is vital in helping people to be less lonely and thus improving their wellbeing.
✓	<ul style="list-style-type: none"> • Free, person-centred activities. <i>'Free access to a personal trainer to keep my muscles strong and prevent frailty!'</i>

'Social groups/support groups to make me feel independent/support/not lonely'.

Getting older

Towards the end of life, it was very important to south east London residents that their families feel supported. It was also important to know how to stay healthy to prevent ill health when they are older. They made the following suggestions to achieve this:

✓	<ul style="list-style-type: none"> • Quick access to high quality GPs
✓	<ul style="list-style-type: none"> • Improvement to access and quality of other services such as palliative care and specialist dementia services.

'I would like to think that my family will be supported when I die but I have not heard any good examples of this happening.'

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*

The table below shows a breakdown of the statements ranked “Very Important” in each south east London borough:

Borough	Statements ranked “Very Important”
Bexley	<ol style="list-style-type: none"> 1. <i>I have absolute confidence that my personal data is managed well and kept secure (70%)</i> 2. <i>Any results are communicated to me quickly making best use of technology (64%)</i> 3. <i>I can talk to my doctor or other health care professional wherever I am (58%)</i>
Bromley	<ol style="list-style-type: none"> 1. <i>Any results are communicated to me quickly making best use of technology (63%)</i> 2. <i>I can access services using my phone or computer (57%)</i> 3. <i>I have absolute confidence that my personal data is managed well and kept secure (55%)</i>

Greenwich	<ol style="list-style-type: none"> 1. <i>I have absolute confidence that my personal data is managed well and kept secure (68%)</i> 2. <i>I can talk to my doctor or other health care professional wherever I am (65%)</i>
Lambeth	<ol style="list-style-type: none"> 1. <i>I have absolute confidence that my personal data is managed well and kept secure (70%)</i> 2. <i>Any results are communicated to me quickly making best use of technology (52%)</i> 3. <i>I can access services using my phone or computer (48%)</i>
Lewisham	<ol style="list-style-type: none"> 1. <i>I have absolute confidence that my personal data is managed well and kept secure (69%)</i> 2. <i>Any results are communicated to me quickly making best use of technology (64%)</i> 3. <i>I can talk to my doctor or other health care professional wherever I am (59%)</i>
Southwark	<ol style="list-style-type: none"> 1. <i>I have absolute confidence that my personal data is managed well and kept secure (58%)</i> 2. <i>Any results are communicated to me quickly making best use of technology (53%)</i> 3. <i>I can access services using my phone or computer (51%)</i>

Overall, south east London residents ranked the following as the top three ‘Very Important’ aspects for their interaction with local NHS:

1. *I have absolute confidence that my personal data is managed well and kept secure*
2. *Any results are communicated to me quickly making best use of technology*
3. *I can talk to my doctor or other health care professional wherever I am
I can access services using my phone or computer*

South east London residents provided the following comments on how they would like to interact with the NHS through the free text section of the survey, which have been broken down into themes.

Digital appointments

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:

- The use of technology was a concern for those who were not fluent English speakers and for those who did not have, or want to have, the skills to use digital technology. This includes elderly people and those with reduced dexterity or with additional communication needs. Amongst the latter group, the increasing use of technology was felt to be a way of saving money rather than a way of addressing demand for services.

‘I don’t have a new phone that can do everything and I don’t have a computer. How does this work for me?’

Residents made the following suggestions for use of digital appointments and gave examples of good practice:

✓	<ul style="list-style-type: none"> Ensure equality of access for those who do not use technology and prefer other methods of communication. Those who expressed this view were concerned that they may be excluded as a result. <i>'I need to receive information by phone or letter.'</i> One patient requested: <i>'That there will always be a human to speak with, in regards to my health matter, and that it would not be only a data/digital process.'</i>
✓	<ul style="list-style-type: none"> It was important that patients were able to book online appointment, in particular with their GPs and manage access to their online record in a reliable way. Some residents wanted primary care services to offer "online chat" access to doctors. <i>'Our GP surgery is supposed to have on-line option to make appointments but despite signing up for this, the service is unavailable when I try to use it.'</i>

Information sharing and record keeping

Residents suggested that services could utilise technology to streamline information sharing and record keeping, leading to better continuity of care.

Residents highlighted the issues they have with information sharing and record keeping:

- Security. *'Can computer data really be secure?'*
- Current records available to patients is limited.

Residents made the following suggestions for better information sharing and record keeping and gave examples of good practice:

✓	<ul style="list-style-type: none"> 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. <i>'Better use of technology across the NHS. There should much more that is standardised / mandated. Linked systems allowing access to patient records.'</i>, <i>'Better communication of my care between hospital and community services.'</i>
✓	<ul style="list-style-type: none"> Secure, integrated access to records. <i>'All information on my health and care is held in one data file which is accessible by authorised professionals.'</i>

'Integrated services (e.g. my GP to have access to my hospital records and vice-versa. The hospital shouldn't have to be writing and sending letters with blood test exams to my GP! That's what computers are for! Save everyone some time please.'

NHS Long Term Plan

Specific condition

related findings

Mental Health

Through focus groups and the specific conditions survey, south east London residents shared their experiences of using mental health services, which have been broken down into themes. 56 adults with lived experience of mental health issues and 32 parents and/or carers took part in the focus groups. 136 south east London residents completed the specific conditions survey.

Early access and prevention

Participants of the mental health focus groups felt that early access to help was vital for people living with mental health issues. Offering help on how to prevent MH issues escalating/prevention is important. Many carers described the person they care for being in denial, not getting help until it is too late and not placing value on preventative strategies.

People with lived experience and parents/carers described the following barriers to accessing early help:

- The problem many carers face is getting the person with the problem to acknowledge they need help and getting them to access help early. Some had accessed their local crisis café rather than A&E to deescalate problems, especially those who don't like to admit they have a problem. *'Mental health prevents them accessing services.'* *'They are in denial and hide the problems.....they have to be ready to get help.'*
- 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.
- Difficulty expressing themselves. Those with learning difficulties found it difficult to express themselves in ten minute appointments and were presented with information that was not in easy read. People with lived experience of mental health without carers or someone to advocate on their behalf found it difficult to access early help.
- Carers felt that they were often not included enough or their concerns taken seriously by the professionals making decisions about those they care for. *'Who knows their child better than their mother? Carers are not recognised and taken seriously as experts on their children.'* *'They hide their illness so take notice of carers who are more aware of what is actually happening.'*
- Not being listened to or referred for further help may discourage people from asking again. A participant with chronic mental health problems said *'When I stick my hand out, and asked for help. No one did anything.'*
- 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.'*
- Carers also cited 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. *'Including carers in discharge decisions as they are the ones that have to cope when it goes wrong.'*



- Ill mental health and lack of early support has a domino effect on other aspects of life for an individual such as their ability to sustain employment, risk of losing housing, relationship and family breakdown and social life.
- They also said that when their situation changes, the system doesn't respond very well.






'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'

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

'I got chucked on tablets at 16 and it took 2 years to get a CAHMS appointment. I was very disappointed with the service and their suggestions on how to make me feel ok'

'I have been on the waiting list for counselling for a couple of years, I need one to one so my needs have not been met yet.'

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

 	<ul style="list-style-type: none"> • 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. <i>'It takes a lot courage to seek help'</i> and asking for help is not easy for many people, especially men.
 	<ul style="list-style-type: none"> • 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. <i>'They may get the first appointment (with GP) and be referred fast but if they have to wait 6 months after that lots could have changed.'</i>
	<ul style="list-style-type: none"> • 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.

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 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.
- Those in Greenwich with long-term mental health problems felt there was a lack of long-term support in the borough.
- Timely access to talking therapies is also a big issue. Some are still waiting for their calls, and it has been over three months since they were told that they would be called for an appointment. One person described waiting 10 to 15 weeks to see a psychiatrist.

- Making an appointment with the GP or other medical practitioner takes a degree of self-worth. Also if you don't turn up for an appointment you are deemed to not need your appointment.
- People with MH conditions said that they receive limited information and rely heavily on a voluntary sector groups to help them access support.
- Access to crisis services is vital. In Greenwich, it was felt there was a lack of crisis support services. Those needing pre-crisis support who said they were about to have relapses could not find services welcoming enough with people who understand where they are coming from. It is also difficult to get an appointment with a GP. They are unaware of the Home Treatment Team and so will wait for their Community Mental Health Team or to go to the A&E.

Participants in the focus groups suggested the following changes for people with mental health issues to access services and gave examples of good practice:

✓	<ul style="list-style-type: none"> • A map, flow-chart or directory, for service users, to help them understand, navigate and effectively use services. Knowing who and where to go to, for what, would reduce time spent and frustrations when trying to access services. This would also increase efficiencies for services with a reduction in time spent with patients who have (inadvertently/inappropriately) turned to them. We were given examples of service users going to the “wrong” service because they did not know who they should go to and feeling upset/angry/irritated because this service could not meet their needs.
✓	<ul style="list-style-type: none"> • Information should be short and written on a one-page paper with information on how to access them. They also mentioned the libraries as a good place to do things such as reading the paper, having access to the internet, and to find out what things are happening.
✓	<ul style="list-style-type: none"> • Carers suggested that GP should be the point of contact to access services and provide information.
✓	<ul style="list-style-type: none"> • Service users should be fully engaged and central to the planning process before any changes are made.
✓	<ul style="list-style-type: none"> • It is extremely important to have access to a named person as a care coordinator. The coordinator should know them well and the relationship they build should be helpful. <i>‘Not having a named person who really knows you just makes me more anxious.’</i>
✓	<ul style="list-style-type: none"> • There should be a more personalised approach where things are included in their care plan. Some would prefer that the information is tailored to their need because not everyone wants the same things.
✓	<ul style="list-style-type: none"> • Services should be available at a variety of times, to reflect people’s differing schedules. <i>‘Services at different times as life not 9-5, I work long hours and often weekends.’</i>
✓	<ul style="list-style-type: none"> • Some said that they had difficulty accessing their GPs and felt that people with mental health conditions should be given priority.
✓	<ul style="list-style-type: none"> • Quick access to low level support services such as IAPT would help patients recover quicker. More thorough assessments at these services would assist in ensuring the right support and treatment is given to help recovery.
✓	<ul style="list-style-type: none"> • For others, more in-depth treatments are necessary for recovery. Thorough assessment was address this issue if service users can be referred to more specialist services.

“One stop shop for all mental health treatment as its confusing trying to navigate the system”

Support to stay well

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.
- A good care coordinator plays a pivotal role in supporting people with ongoing mental health issues. Participants shared both positive experiences of exceptional coordinators and others shared negative experiences. Those who provided positive experience felt their care coordinator continued to have a positive impact on their wellbeing. Others said that the lack of frequency of contact can be difficult. One participant is only seen once every three months by the community mental health team and said that this is not helpful.
- Regardless of how long ago diagnosed, there should be better access to physical and emotional support. There was a feeling that priority was given to those newly diagnosed and those who had been diagnosed for some time did not get the same level of access to support.
- Participants felt they would struggle to take more control of their own health and wellbeing. Some felt they would not be able to manage on their own. It would *‘take a great deal of courage, it would be difficult. I would not know where to start.’*
- 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.’*
- Carers also talked of their difficulty caring for the person with mental health problems when they were discharged from hospitals, saying they did not get help and no one came to assess their needs.
- People with lived experiences in Greenwich felt there was a long wait time between referrals, assessments and diagnosis.



Participants of the south east London focus groups made suggestions to support them to stay well and gave examples of good practice:

✓	<ul style="list-style-type: none"> • Health care professionals and the wider community to acknowledge that they are in pain: <i>‘it’s like a roller-coaster that you can’t get off’.</i>
✓	<ul style="list-style-type: none"> • People with lived experiences felt that consistent support from care workers and health professionals that could be trusted and who were empathetic was key.
✓	

✓ ✓	<ul style="list-style-type: none"> Also for some, frequently and timely communication with clinics and receiving appropriate care and treatment soon after diagnosis was important.
✓	<ul style="list-style-type: none"> 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.
✓	<ul style="list-style-type: none"> Participants would appreciate access to outdoor activities. Other activities such as Mindfulness can be very helpful, but sometimes are not available or difficult to access.
✓ ✓	<ul style="list-style-type: none"> Strategies to use to cope at home would be useful, especially to those who hear voices and may experience triggers. Others said they need support for anxiety and help self-management of symptoms.
✓	<ul style="list-style-type: none"> Many felt they would benefit from having someone to talk to. They suggested something to bring people together as a group, build confidence and do things together, such as a befriending service. <i>‘Everyday life triggers anxiety but there is nowhere to go when you need it’.</i>
✓ ✓	<ul style="list-style-type: none"> Also, others felt that education about the conditions, triggers and self-management was vital to stay well.
✓ ✓	<ul style="list-style-type: none"> People appreciated support from organisations such as Quo Vadis Trust and other national mental health charities. They felt they are an excellent way of feeling listened to and supported in their recovery. They also valued mental health cafes.
✓	<ul style="list-style-type: none"> 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.
✓ ✓	<ul style="list-style-type: none"> Continuity of care and seeing the same person was important, but also choice of who they see was important. If they don’t connect with those offering help or the community team worker assigned to them then they don’t attend, don’t improve or may refuse help.
✓ ✓	<ul style="list-style-type: none"> Good sleep and diet are valued, but are not always possible if symptoms are active and money is tight. Sessions on healthy eating and cooking on a budget would be valued. Some did not realise that exercise and healthy diet could help improve health.
✓ ✓	<ul style="list-style-type: none"> 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. <i>‘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.’</i>
✓ ✓	<ul style="list-style-type: none"> Greater awareness of services people with ill mental health are eligible to access, especially after discharge from hospital. <i>‘It’s fixed, off you go!’ ‘You hope for the best’</i>

‘We are left to manage our own thoughts far too much’.

Treatment

Participants of the focus groups described the following experiences of poor treatment:

- Medication was an issue that many have raised. Many felt that the services are quick to prescribe without looking at patient's holistic needs. Access to additional support in the form of therapy or activities (sport, mindfulness, learning, hobbies) help them manage their mental wellbeing. *'They don't look for the cause only treat the symptoms.'*
- Some pointed out that their mental health has not been taken into account when they accessed services through A&E. Mind and body are not treated together. One patient who attended A&E as a result of self-harming was only treated for physical injuries, although his injuries were a result of his ill mental health. His mental health was overlooked and he was discharged after his physical health improved.
- Participants also complained about long waiting times at hospital. One patient shared his experience of accessing A&E. He felt he was in *'turmoil'*, yet was asked to wait for a couple of hours. He eventually left without being seen and as a result was admitted to a mental health hospital soon after.
- Some participants were not involved in decisions about their own care. One participant complained about his GP stopping his medication without his knowledge. This was only discovered by the participant's key worker after realising he was not taking his medication.
- Other participants had experiences of GPs who were either unable to did not want to help them with their mental health. One participant said that his GP told him *'We don't deal with your mental health issues'*. Another participant said that a GP had told her daughter *'[y]ou're young and fit what I have you got to worry about?'* The daughter had described symptoms and said that she was raped, the GP was unable to deal with this situation.
- Some felt their GP does not have enough expertise regarding mental health medication.
- People feel that they are in a system where they are required to repeat their story to numbers of different health professionals. *'Apparently you can only bring up one issue with your GP per appointment.'* *'This isn't good enough for me with my multiple conditions.'* *'It means that when I make a next appointment I am not seeing the same person.'*
- Not all mental health patients were in receipt of a care plan from their psychologist. This has led to poor monitoring of medications both regular and newly prescribed.
- In conversation with the Department for Work and Pensions and Jobcentre Plus there is agreement that people should do voluntary work as this is good for mental health. However tribunal teams - over which there is no jurisdiction - may assess the person is more capable than they really are and change benefits in a way that doesn't support their recovery. GPs may encourage patients to do physical activity to help with their well-being, but this might be seen, or is seen, by the DWP as evidence that the person does not need to be on the benefits that are on, therefore there is a disincentive to lead healthier lifestyles.
- Some people with trust issues and anxiety find it hard to take part in group therapy or build relationships with others.
- Mental health and addiction services need to work together more to be effective. Wards don't support people with dual diagnosis. They are told it's a substance use issue so they are discharged. *'Need to be clean and sober to get help, but drinks due to mental health problems which are not sorted so it's an endless circle'*.



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

✓	<ul style="list-style-type: none"> Treatment options should be discussed and agreed with the patient. <i>'Many people know what helps them. It should be a joint decision.'</i>
✓	<ul style="list-style-type: none"> Staff at services, especially GP practices and A&E, would benefit from more education on how to best support patients with mental health.
✓	<ul style="list-style-type: none"> People feel grateful if they've spoken with someone quickly even if it's with Primary Care.
✓	<ul style="list-style-type: none"> People would like recognition that ill mental health can affect their physical health.
✓	<ul style="list-style-type: none"> Environments should be appropriate for people going through a mental health crisis. <i>'The Crisis Café looks like an office, it is too bright and confusing.'</i>
✓	<ul style="list-style-type: none"> Treatment should be person-centred. <i>'Treatment should be personalised to be effective, not one size fits all.'</i>

"Hospital and A&E often discharge too early, they don't talk to the carers and services are not joined up. It's an endless circle of the same things happening resulting in repeated hospital visits as the cause is not addressed. People are not interested"

Health inequalities

The participants described inequalities that prevent them from accessing resources and looking after their mental health.

Participants of the focus groups described the following experiences of health inequalities:

- Participants with chronic illness or disabilities reported ongoing difficulties with the Department for Work and Pensions (DWP) which caused them a great deal of stress and financial difficulty, making it doubly difficult for them to access support. Having housing and financial problems was a key factor having a major impact on their physical and mental health. *'The agencies employed by the DWP [should] operate more fairly. I have had two work capability assessments ... after a lot of struggle and stress, including having my benefit stopped unfairly...It also puts additional pressure on the NHS as its costs the consultants and GPs time to send in reports that are no different to the last time.'*
- Participants said that they don't have enough money to live on, even to meet the very basic. This makes it incredibly difficult to stay well.
- Residents from BAME communities using mental health services often found that professionals lacked knowledge and understanding of cultural- specific issues affecting their mental health, leaving them feeling unsupported. *"I think the BME people...need more professionals in the mental health services with own background to understand our specific problems beyond the mainstream services."*

Participants of the focus groups made suggestions to tackle health inequalities and gave examples of good practice of this:

✓	<ul style="list-style-type: none"> Some suggested paid sheltered employment, mentioning SRA as a positive example. For most of them, having something meaningful to do is important and it is not only about work. <i>'More supported housing.'</i>
✓	<ul style="list-style-type: none"> Carers said that they try to be fit and healthy but prefer not to be dependent on services. They said that they should be enabled to make their own arrangements,

	e.g. for respite care. <i>'Social media/computer training for carers to use internet and email to increase connectivity.'</i>
✓	<ul style="list-style-type: none">• Increased awareness of mental health in communities. <i>'Continued visibility about mental health problems to decrease stigma.'</i>
✓	<ul style="list-style-type: none">• Education to improve social circumstances. <i>'Budget management for those with MH issues.'</i>

Learning disabilities and autism

Through focus groups and the specific conditions survey, south east London residents shared their experiences of learning disabilities and autism, which have been broken down into themes. 63 adults with learning disabilities and/or autism and 3 parents and/or carers took part in the focus groups. 136 south east London residents completed the specific conditions survey.

Access to appointments

Participants of the focus groups described the following barriers to accessing appointments:

- Participants said that they cannot book appointments with their GP over the phone or through any means and this must be done by their family/relative or carer. They are frustrated by spending significant amounts of time waiting on hold, to either not get through or to be only able to book appointments two weeks away. This results in some patients going to walk in clinics, however, they may have to wait a long time to be seen.
- 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.

Participants of the focus groups made the following suggestions for accessing appointments and gave examples of good practice:

✓	<ul style="list-style-type: none"> • Clear explanations and support booking appointments would be valued. Some participants said that they receive letter reminding them of their appointments. One group member told us that they had missed several appointments, because she doesn’t remember them. Participants said they would prefer health services to provide text or phone call reminders about their appointments. It was suggested that practices could also issue tickets which would contain full appointment details, like those provided by dental practices.
✓	<ul style="list-style-type: none"> • Appointment processes should always be in easy-read format, including online appointments. <i>“Can’t get through to my doctor. Always on the answer phone, never call me back. Don’t know how to book online.”</i>
✓ ✓	<ul style="list-style-type: none"> • Those who are given options for appointments value them. For example, having the option for home visits is valued. Also, being able to choose which hospital to attend is important. To make sure they have enough time with the doctor, participants wanted the option of a double appointment. They also wanted to be given the option to take someone to their appointments. <i>“Sometimes it is easy, sometimes difficult. Depending on the times it can make it difficult. More difficult if an appointment is early.”</i>
✓	<ul style="list-style-type: none"> • Good signage is important to people with learning disabilities. For example, colour-coded signs like those on underground trains and big letters are helpful. Participants would appreciate support to inform them it’s their turn for an appointment. Some find it difficult to read the current signage.
✓	<ul style="list-style-type: none"> • At one hospital, all staff including the cleaner had been trained to be able to help give directions. This was especially helpful.

✓	<ul style="list-style-type: none"> Participants were unaware of the GP Extended Access service available in some boroughs. A participant received a text message about the service but did not understand the content. They felt it would have been easier for a doctor to explain the message.
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“Find it easier to go into practice to book an appointment. Staff are friendly and sometimes send letter reminders.”

Prevention and staying well

Participants of the focus groups described the following barriers to staying well:

- Parents of children with LD and autism said that they value good physical health for their children, but often physical exercise is limited.
- 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. *‘Gym sessions for people with autism, less crowded, quiet changing rooms dim lighting etc.’*
- Knowledge varied between participants of healthy diet. Some did not equate health with sugar intake, and would add sugar to their tea.
- 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 focus groups made the following suggestions for staying well and gave examples of good practice:

✓	<ul style="list-style-type: none"> They talked of the value of friendship and how having friends is good to encourage people to attend appointments and give advice on how to stay well. They said that when they are sad, they talk to their support workers or friends. Support of key workers, friends and carers was vital to wellbeing. They are not aware of places where they can get information and so they ask their support workers if they need to know about places or services.
✓	<ul style="list-style-type: none"> Parents should be empowered to ask questions and to have the confidence to navigate the system. Where this is not possible, for example for parents who themselves have autism or learning disability, information should be readily available and accessible.
✓	<ul style="list-style-type: none"> Parents of children and young people with LD/autism said that introducing more play time and more physical activities in school is beneficial and helps children sleep better.
✓	<ul style="list-style-type: none"> Alongside physical exercise, participants valued some therapies like mindfulness. One parent talked about her child who is very violent and said that therapy talking has helped her a lot.
✓	<ul style="list-style-type: none"> Parents of children with LD/Autism said that therapies should be offered in different ways such as face to face or online. One mother said that she wants online therapies where she can dip and out depending on her availability.
✓	<ul style="list-style-type: none"> More information provided in Easy read about where to find good NHS dentists, with easy access and you know they are going to treat you fairly.
✓	<ul style="list-style-type: none"> 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.
✓	<ul style="list-style-type: none"> The importance of exercise was appreciated with many participants giving examples of a variety of physical activities they take part in including walking, swimming, Zumba, dance class, Taekwondo and the gym. Some used weights at home and others had completed the Couch to 5K scheme. People who were exercising felt empowered and happy. One participant who uses a wheelchair and Zimmer frame felt a sense of achievement after being supported by a physiotherapist and staff at a home he lives in.
✓	<ul style="list-style-type: none"> Participants also valued access to other activities such as painting that promote good mental health.
✓	<ul style="list-style-type: none"> 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.
✓	<ul style="list-style-type: none"> Many participants said that they prefer to receive information via post.

Outpatients

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

- Many carers stated that GPs don't understand carers' situation. GPs have assumed that carers can cope but, in reality, some carers are also suffering from depression and need of counselling. Carers expected their GP to be more supportive and knowledgeable of other services they can be signposted to.
- Participants described experiences of GPs not asking enough questions about the issue the patient wants to discuss, and focussing on other health problems instead.
- Participants were frustrated by long waits, and would often feel anxious whilst waiting. *'My appointment is always last; I need to regularly talk to staff to ask why.'* *'Get there especially early and still have to sit for over an hour. You only get 10 minutes to chat. Long queues for reception desk. Sick and tired of it, people would turn up way after me and get seen before me. I've changed doctors because of it.'*
- Participants described struggles to get the correct medication from their pharmacies. Lack of communication between services had caused patients to unnecessarily visit their pharmacy to pick up a prescription when the medication was unavailable. *'We shouldn't have to fight for medication, I know there is so many people, but the people should get the treatment they need.'*
- Participants felt that health professionals often underestimated people with learning disabilities. *'Staff don't think you can do it, so don't suggest certain things, they make an assumption. Just give us a chance to put a foot in the door, give me a chance to share my views.'*
- 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 focus groups made the following suggestions for outpatients' and gave examples of good practice:

✓	<ul style="list-style-type: none"> Staff calling patients' name and seeing their name on the screen when it is their turn for appointments.
✓	<ul style="list-style-type: none"> When accessing health services, participants appreciate being clearly explained who they will see and why. This would help them to be reassured and improve their experience. Participants appreciate it when staff are friendly and when they are seen quickly. <i>'I went to Accident and Emergency department because my iron was low. I was taken to Ambulatory care. They book you for an appointment quickly. Staff were nice and explained everything.'</i>
✓	<ul style="list-style-type: none"> Some felt that communication during treatment at hospitals could be improved. <i>'Doctors in hospital need to explain what they are doing better. During my last visit, they stuck a needle in my arm, and I don't know why? It was painful.'</i> Having injections was described <i>'scary'</i> for many patients and extra support and reassurance during procedures requiring injections would be beneficial.
✓	<ul style="list-style-type: none"> It is helpful to have someone or a family member to support them when going to appointments. One participant was frustrated that his stepdad wasn't allowed to ride in the ambulance with him.
✓	<ul style="list-style-type: none"> 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.
✓	<ul style="list-style-type: none"> Carers would appreciate having the option to communicate on behalf of the person they care for. Occasionally people with learning disabilities are unable to understand the doctor.
✓	<ul style="list-style-type: none"> 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.

Professionals' knowledge

Participants of the focus groups described the following negative examples of professionals' knowledge:

- People with learning difficulties felt that the awareness of hospital staff of disability is low. One carer shared her experience how she accompanies her sister with down syndrome to A&E and the sister was transferred to a wrong ward because the nurse that assessed her sister did not have the skills to identify a Down's Syndrome patient. Parents of young people with autism said that the doctor dismissed the symptoms of autism and instead prescribed him paracetamol. *'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.'*
- Parents of children with learning difficulties described negative experiences of blood tests. One health professional lied to a parent's child saying no blood would be taken and they would just check his muscles. Another parent had similar experience of her child

being restrained so they could get blood. The parent recommended not to restrain children, but to model blood taking is done.

- Participants said that their experience with their GPs were ok in terms of quality of care, but that they wished they would talk to them. They said that doctors talk only to their support workers or relatives. They said that it would be nice if doctors would also speak with them and explain about their health. More importantly, they also felt that doctors don't listen to them.



Participants of the focus groups made the following suggestions for improve professionals' knowledge and gave examples of good practice:

✓	<ul style="list-style-type: none"> • There should be a system that could easily identify patients wherever they present themselves to avoid confusion and misunderstanding. When asked what can be used to flag learning disability, they suggested to using the Purple Star Strategy. This is a system that has been developed to award health services that work really hard to give the best help to people with learning disabilities.
✓	<ul style="list-style-type: none"> • Parents of children with learning disabilities said that all health professionals should be trained on how to deal with children with autism and learning disability. They should also work with parents to understand the needs of the child.
✓	<ul style="list-style-type: none"> • Support should be ongoing for people with autism and their carers. <i>'Autism is for life and help is only short term, this needs to be addressed.'</i>

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.
- Carers described difficulties helping their children to attend breast screening appointments because the letter they received did not state if it was a female or male doctor at the appointment.
- Some participants felt that people with learning disabilities are not adequately given appointment for cancer screening.
- Lack of test results was an issue raised by several participants. *'If everyone just communicated in the NHS, we wouldn't have these issues. Everyone should get letters; we shouldn't have to chase them for our results.'*
- Many participants were scared of the word screening.
- Participants had mixed experiences of being offered screening tests. Some women had been invited for a smear tests 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.

- Some participants were confused about how and when they would receive their screening results. *‘Uncomfortable but it is good to know what is going on in my body. Doctors will get my results, but I can’t remember if they told me if I’d get them.’*

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

✓	<ul style="list-style-type: none"> • Patients with learning difficulties should be told the sex of the health professional performing the screening.
✓	<ul style="list-style-type: none"> • Education about the body such as what prostate or bowel is would be helpful in understanding what the screening was for.
✓ ✓	<ul style="list-style-type: none"> • 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.
✓	<ul style="list-style-type: none"> • 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.'

The findings of the work undertaken align with existing insight of local Healthwatch. For example, Healthwatch Lewisham's 2018-19 Annual Report cites the following common examples of change residents want to see:

- *'Make it easier to see a doctor or nurse quickly'*
- *'Improved access to mental health services'*
- *'Increased awareness around self-care for seldom heard communities'*
- *'Services should provide clear, accessible information so that everyone can make informed decisions'*

Further insight and existing data for individual boroughs can be found at the following local Healthwatch websites:

- <http://www.healthwatchbexley.co.uk/home>
- <https://healthwatchbromley.co.uk/>
- <https://healthwatchgreenwich.co.uk/>
- <http://www.healthwatchlambeth.org.uk/>
- <https://www.healthwatchlewisham.co.uk/>
- <https://healthwatchesouthwark.co.uk/>

Local Healthwatch look forward to further working with OHSEL to improve local health and social care services for our residents, and would welcome any opportunity to support the region's work.

Acknowledgements

Local Healthwatch would like to say thank you to all charities, organisations, GPs and volunteers who supported this project and committed time to gathering south east London residents' feedback. In particular, we would like to acknowledge:

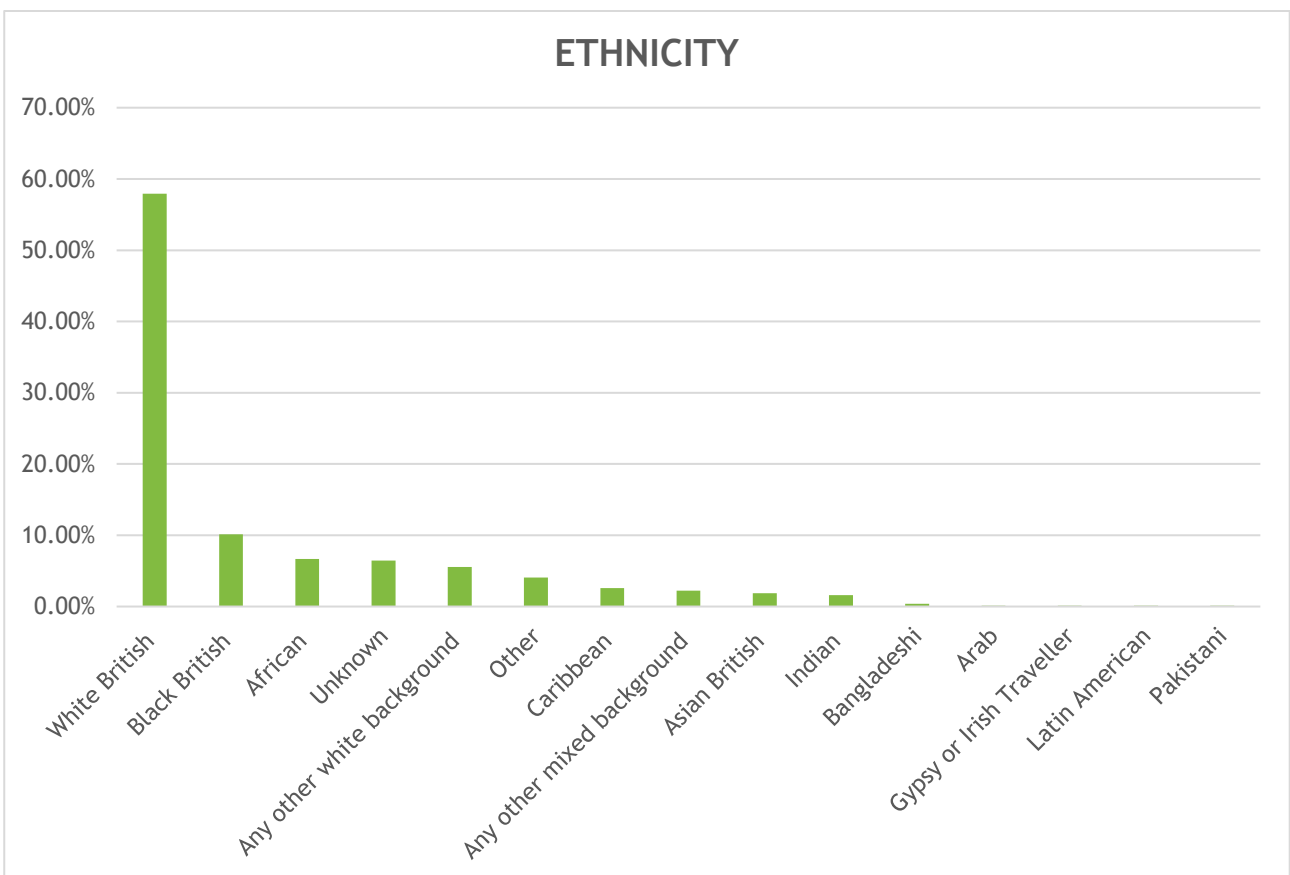
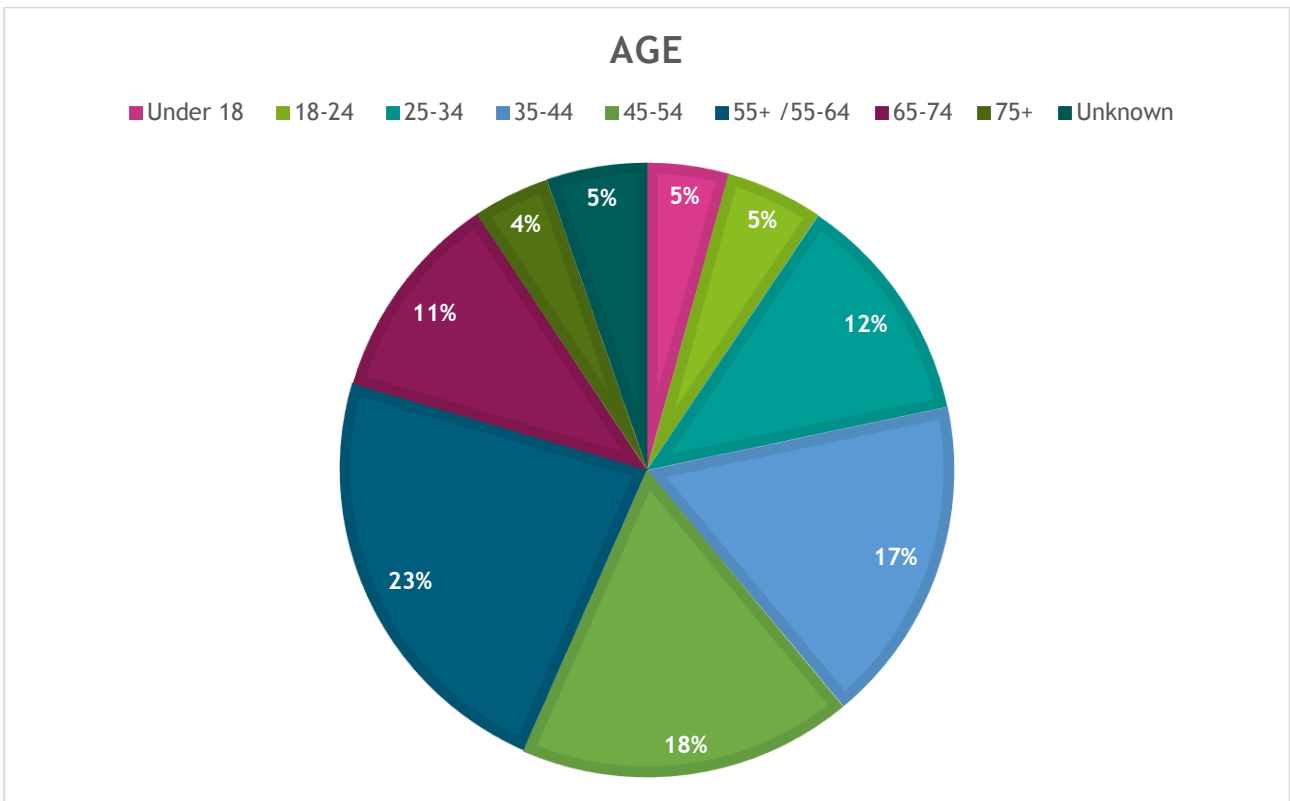
- Oxleas ResearchNet
- Bromley Well
- Bromley Mencap
- Bromley, Lewisham & Greenwich Mind
- Advocacy For All
- Lewisham Speaking Up
- Quo Vadis Trust
- Mind in Bexley Carers Groups
- Bexley Mencap
- Carlton Centre (Sidcup)
- Hearing Voices Group

NHS Long Term Plan

Equality and

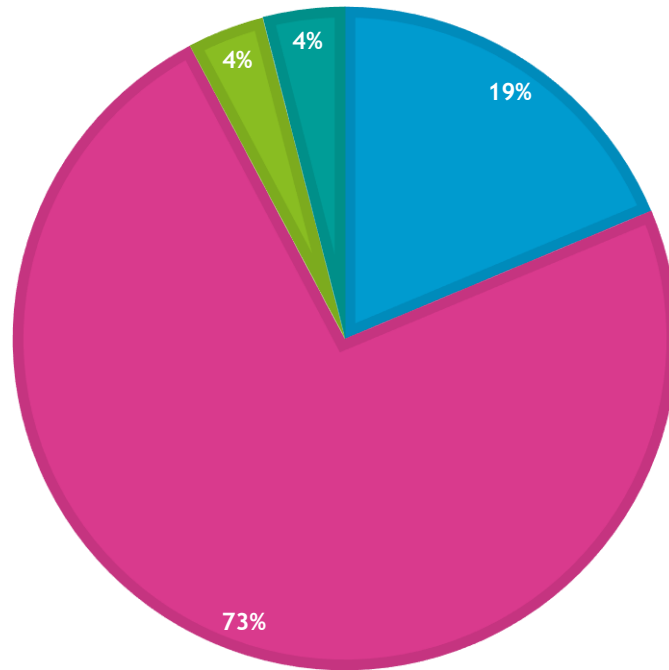
diversity data

General survey demographics



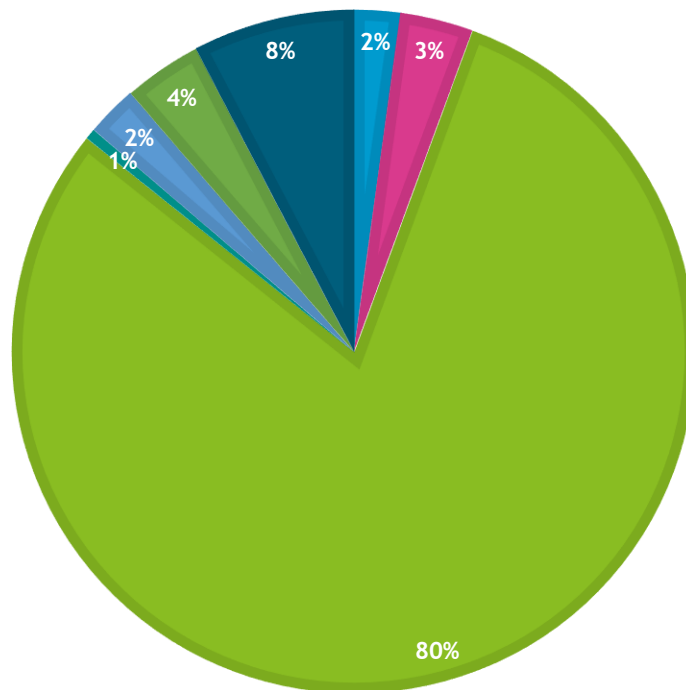
DO YOU CONSIDER YOURSELF TO HAVE A DISABILITY?

■ Yes ■ No ■ I'd prefer not to say ■ Unknown



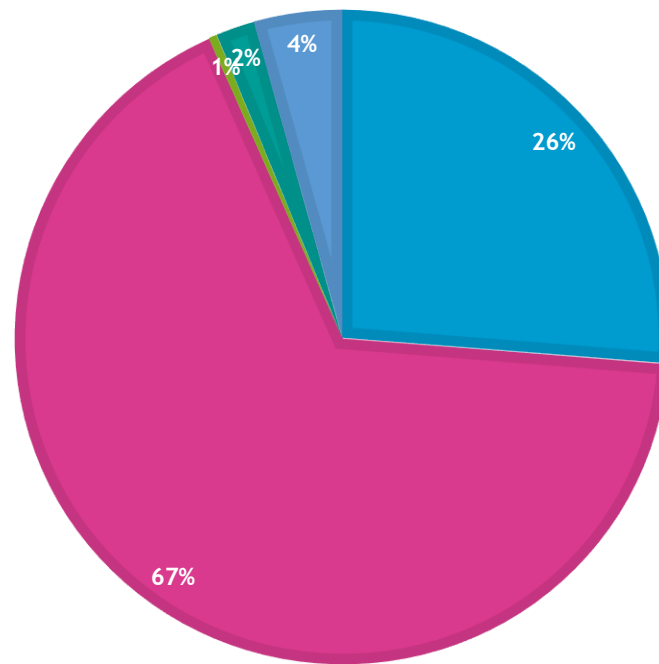
WHICH OF THE FOLLOWING BEST DESCRIBES YOU?

■ Bisexual ■ Gay or Lesbian ■ Heterosexual ■ Pansexual ■ I'd prefer not to say ■ Other ■ Unknown



WHAT GENDER DO YOU IDENTIFY AS?

■ Male ■ Female ■ Other ■ I'd prefer not to say ■ Unknown



RELIGION

