

# Health and Social Care Scrutiny Commission

Wednesday 13 November 2024  
7.00 pm  
160, Tooley Street, SE1 2QH

## Membership

Councillor Suzanne Abachor (Chair)  
Councillor Maria Linforth-Hall (Vice-Chair)  
Councillor Esme Dobson  
Councillor Sandra Rhule  
Councillor Nick Johnson  
Councillor Jason Ochere  
Councillor Charlie Smith

## Reserves

Councillor Victor Chamberlain  
Councillor Dora Dixon-Fyle MBE  
Councillor Sam Foster  
Councillor Emily Hickson  
Councillor Leo Pollak  
Councillor Joseph Vambe  
Councillor David Watson

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## INFORMATION FOR MEMBERS OF THE PUBLIC

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**Access to information** You have the right to request to inspect copies of minutes and reports on this agenda as well as the background documents used in the preparation of these reports.

**Babysitting/Carers allowances** If you are a resident of the borough and have paid someone to look after your children, an elderly dependant or a dependant with disabilities so that you could attend this meeting, you may claim an allowance from the council. Please collect a claim form at the meeting.

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### Contact

Julie Timbrell on 020 7525 0514 or email: [Julie.Timbrell@southwark.gov.uk](mailto:Julie.Timbrell@southwark.gov.uk)

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Members of the committee are summoned to attend this meeting

**Althea Loderick**

Chief Executive

Date: 5 November 2024



## Health and Social Care Scrutiny Commission

Wednesday 13 November 2024  
7.00 pm  
160, Tooley Street, SE1 2QH

### Order of Business

Item No.	Title	Page No.
	<b>PART A - OPEN BUSINESS</b>	
1.	<b>APOLOGIES</b>	
	To receive any apologies for absence.	
2.	<b>NOTIFICATION OF ANY ITEMS OF BUSINESS WHICH THE CHAIR DEEMS URGENT</b>	
	In special circumstances, an item of business may be added to an agenda within five clear working days of the meeting.	
3.	<b>DISCLOSURE OF INTERESTS AND DISPENSATIONS</b>	
	Members to declare any interests and dispensations in respect of any item of business to be considered at this meeting.	
4.	<b>MINUTES</b>	
	To approve as a correct record the Minutes of the open section of the meeting on 21 October 2024, to follow.	
5.	<b>TOPIC: CANCER PREVENTION AND EARLY DIAGNOSIS</b>	1 - 9
6.	<b>PRIMARY CARE ACCESS</b>	10 - 13
7.	<b>CABINET MEMBER FOR HEALTH AND WELL-BEING - ANNUAL INTERVIEW</b>	

Cllr Evelyn Akoto's portfolio includes supporting carers, improving health services and adult social care, as well as public health.

<b>Item No.</b>	<b>Title</b>	<b>Page No.</b>
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- |           |  |         |
|-----------|--|---------|
| <b>8.</b> | <b>HEALTHWATCH SOUTHWARK - ANNUAL REPORT</b> | 14 - 37 |
|-----------|--|---------|

Healthwatch Southwark's Annual report 2023 -24 is enclosed.

Rhyana Ebanks-Babb, Healthwatch Southwark Manager, will present.

- |           |  |         |
|-----------|--|---------|
| <b>9.</b> | <b>HEALTHWATCH SOUTHWARK : EMPOWERING VOICES</b> | 38 - 98 |
|-----------|--|---------|

Healthwatch Southwark's report on Empowering Voices: Examining Healthcare Access for Adults with Learning Disabilities and Autistic Adults is enclosed.

Rhyana Ebanks-Babb, Healthwatch Southwark Manager, will present.

- |            |                       |  |
|------------|-----------------------|--|
| <b>10.</b> | <b>WORK PROGRAMME</b> |  |
|------------|-----------------------|--|

**DISCUSSION OF ANY OTHER OPEN ITEMS AS NOTIFIED AT THE START OF THE MEETING.**

**BLANK**

Date: 5 November 2024

**EXCLUSION OF PRESS AND PUBLIC**

The following motion should be moved, seconded and approved if the sub-committee wishes to exclude the press and public to deal with reports revealing exempt information:

“That the public be excluded from the meeting for the following items of business on the grounds that they involve the likely disclosure of exempt information as defined in paragraphs 1-7, Access to Information Procedure rules of the Constitution.”

# **SEL Cancer Prevention and Early Diagnosis – Focus on Southwark**

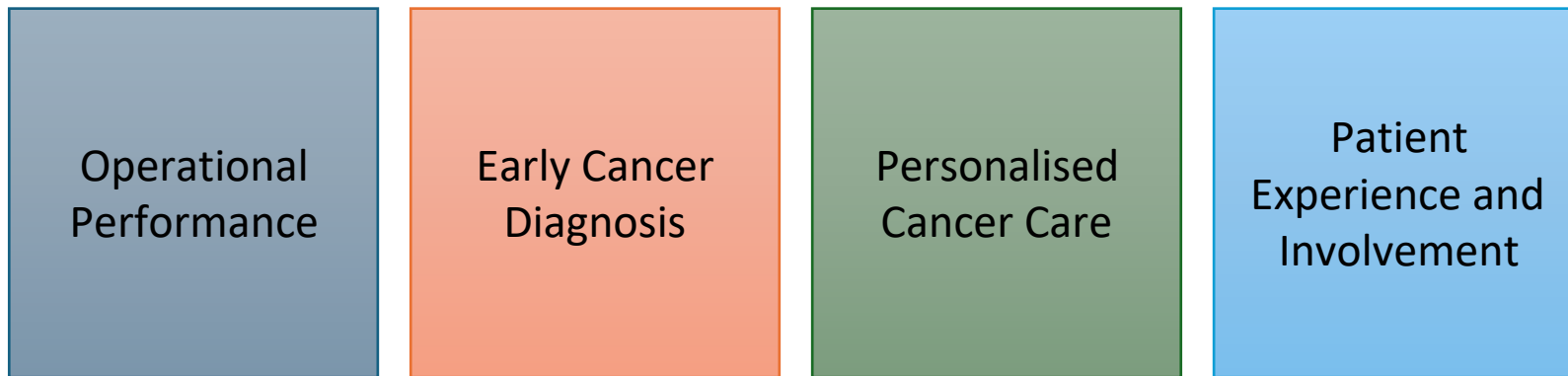
South East London Cancer Alliance and SEL ICB

Samantha Lewis & Nikki McFarlane/Dr Nancy Küchemann

1. The role of South East London Cancer Alliance (SELCA) within SEL Integrated Care System
2. SELCA Early Cancer Diagnosis Programme
3. Cancer Screening Data – Southwark
4. Examples of workstreams in Southwark
  - Completed Projects
  - Planned Projects

- England is broken into 20 Cancer Alliances, 4 of them covering London.
- **South East London Cancer Alliance (SELCA) serves the population within SEL ICS.**
- Cancer Alliances, commissioned by NHS England, are considered to be the primary vehicle for **supporting delivery of the NHS Long Term Plan commitments for Cancer.**
- SELCA work across all 6 boroughs of South East London to **bring together partners across the Integrated Care System (ICS)** including NHS partners, Local Authority, third sector and of course with the public that we serve to support improvement in Cancer services.
- **Planning guidance** is provided by the NHS Cancer Programme each year and **used to build a local delivery plan** with stakeholders across the ICS.

Our core programme areas are:



**In Primary Care, SELCA work in close partnership with:**

- ICB Central Cancer & Planned Care Team
- Cancer Clinical Leads, Public Health and Operational Cancer leads at a Borough level

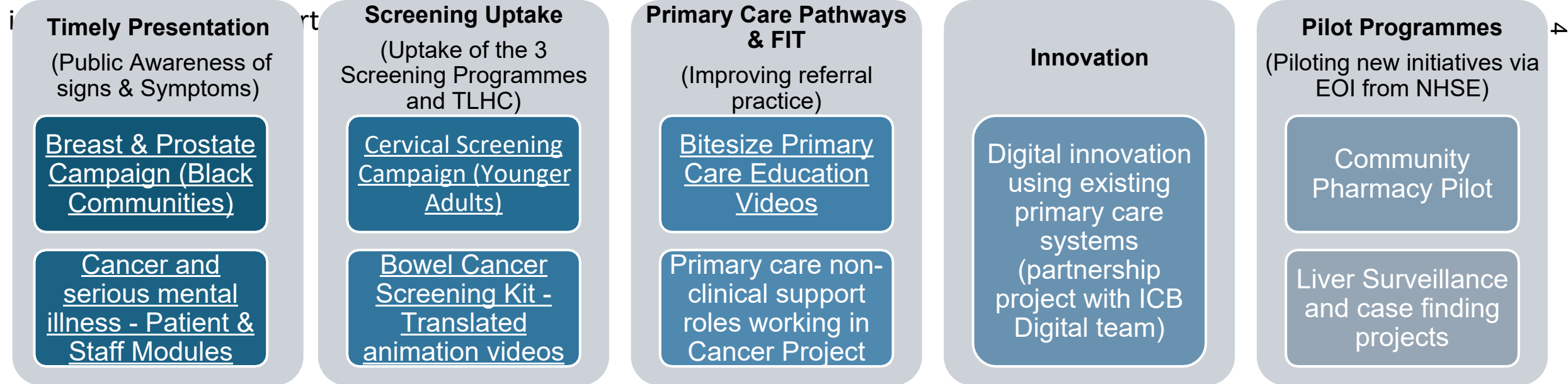


To build our 2024/25 Delivery Plan we have carried out wide stakeholder engagement with partners across SEL, based on what data is telling us.

Workstreams are developed at three different levels:

1. SELCA-led Projects – these may be system-wide or focussed to an area of high need (based on data insights).
2. Borough-level Projects
3. PCN-level projects

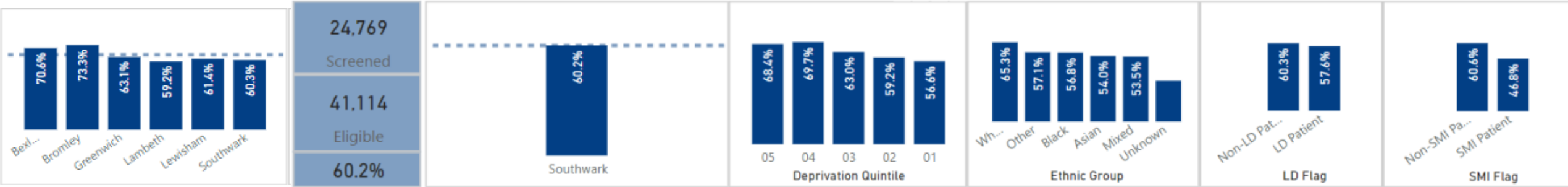
SELCA funding is non-recurrent funding and therefore projects funded at a Borough or PCN level are typically to test new



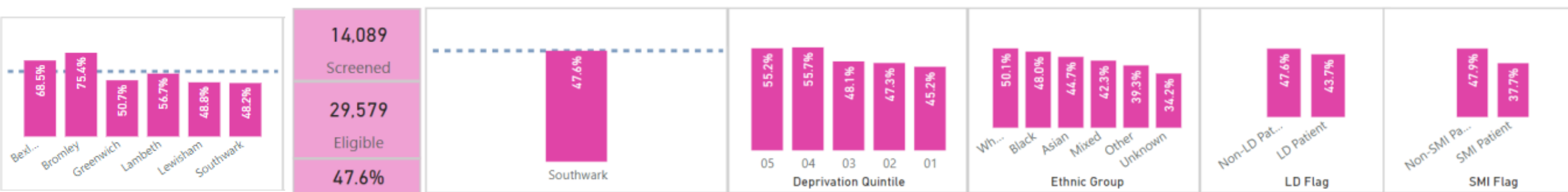
This is **not an exhaustive list**, these are a few examples. There are over 50 workstreams currently ongoing in the SELCA Early Diagnosis programme (across SELCA, Borough and PCN)

\*Please note this is an **estimated** view on cancer screening coverage in Southwark, and relies heavily on accurate & up to date coding in primary care.\* (Official screening data is available separately, but it will not provide the demographic detail). Having this information allows us to understand which groups are facing inequalities so that we can design targeted interventions to reduce these inequalities and improve screening participation.

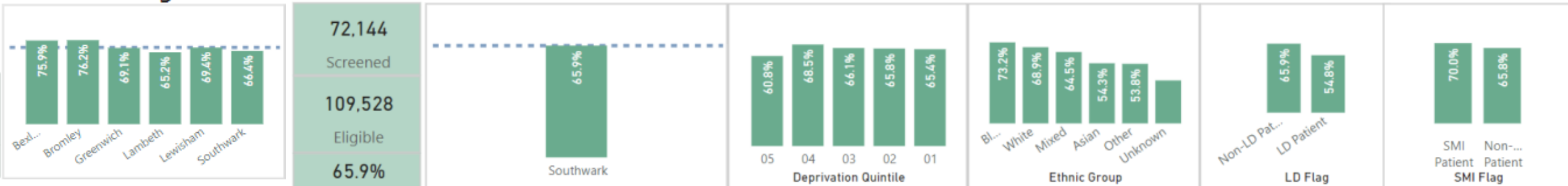
## Bowel Cancer Screening



## Breast Cancer Screening



## Cervical Cancer Screening





- We know that **screening is an important and effective way of detecting cancer early** and in bowel & cervical screening it can also **prevent cancers developing**. Unfortunately as we can see from local data on the previous slide not enough people take up their invitation for screening, particularly in certain groups.
- We also know that some groups experience more **barriers** to accessing healthcare and these people are more likely to present with late stage cancers, through routes such as A&E rather than presenting to their GP. Therefore it is essential that we take a facilitative approach to addressing this through working with practices but also with local people and voluntary & community organisations.
- A bi-monthly **Southwark cancer working group** meeting helps share information with PCN leads to ensure they understand their current position on cancer screening, alongside other cancer metrics.
- A new Cancer Facilitator role was created 2 years ago and they offer support via individual practice resource packs plus the offer of **practice engagement sessions** to provide **education and support for staff** including how to improve on cancer screening participation and **reduce inequalities**, e.g. by providing easy-read format or multi-language resources, and providing signposting information for people who may need to attend specialist services for screening such as CliniQ which provides cervical screening for trans/non-binary people with cervixes. They also provide best practice tips for use of different cancer pathways to help ensure patients are diagnosed (or cancer is ruled out) as early as possible.

Collaborative working between colleagues in Partnership Southwark, SEL ICB, Southwark Public Health and South East London Cancer Alliance (SELCA) has led to successful outcomes.

**Below are a few high impact examples of work undertaken, but please note this is not an exhaustive list. There are numerous examples of work to raise awareness of cancer and improve earlier diagnosis across a range of organisations and partners:**

- **Southwark produced a series of animated videos to promote breast screening in Black African women**, co-produced with London College of Communications. These videos have been used in multiple proactive campaigns, including on GP waiting room screens and being text to breast screening non-responders.
- **A comprehensive campaign was undertaken to text ALL breast screening non-responders in Southwark**, providing advice and support for breast cancer screening and how to participate, this resulted in the screening service reporting a spike in phone calls from Southwark residents.
- **Southwark was a part of an SEL wide initiative to proactively contact men at higher risk of prostate cancer a risk checker**. Black men over 45, and anyone with a family history of prostate cancer over 45, were sent the [PCUK Risk Checker](#) which offers counsels on the pros and cons of PSA testing, after which a test can be requested without needing an appointment by reply to the test. **In Southwark 10,300 men were text with the risk checker, 1,645 PSA tests were carried out, 55 referrals for suspected cancer which resulted in 11 men being diagnosed with prostate cancer.**
- **All eligible individuals in Southwark have been invited to participate in the Targeted Lung Health Check (TLHC) programme**, for which Southwark was one of the first boroughs in SEL to go live. People aged 55 to 74 years old, who have ever smoked, are invited for a free NHS lung health check to screen for lung cancer. This programme is part of an ongoing evaluation by the NHS to develop a national lung cancer screening programme to detect lung cancer earlier, before symptoms develop, and when it is more treatable. Those who participate are also offered support from smoking cessation services if they wish. There will be a drive to contact more of the non-responders from Spring'25, and a new advertising campaign from SELCA will go live soon.

There are numerous planned workstreams in Southwark to continue to support cancer awareness and early diagnosis of cancer. This is not an exhaustive list, but a selection of higher impact actions.

- **Ongoing work with Indo-American Refugee and Migrant Organisation (IRMO)** to raise awareness of cancer and screening in Latin American population, including developing translated materials. This is a collaboration with Lambeth borough.
- **Cancer awareness project with Southwark Traveller Action Group** aiming to promote cancer screening and cancer prevention, and reduce inequalities in this group who are known to experience worse health outcomes and face many barriers to accessing healthcare.
- Improving the **breast & cervical screening experience for the Trans/Non Binary/gender nonconforming population.**
- A comprehensive social media campaign to **promote Cervical Screening for younger patients** who have a lower screening rate.
- **South East London Cancer Alliance (SELCA) have commissioned the [Eve Appeal Charity](#)**, to deliver education sessions to members of the public (older women post-menopausal age and above, from Black and South Asian communities), to raise awareness of endometrial (womb) cancer signs and symptoms & encourage attendance at their GP if they have any. The work is based on the [You Need to Know campaign](#). Some workshops have already been held in Southwark & more are planned.
- **[Increasing earlier diagnosis of Breast and Prostate Cancer amongst our Black African and Caribbean communities](#)**. A SELCA led campaign building on Campaign activity in January 2024. Launching in November 2024 the campaign will focus on reaching communities via places of worship this will include an event at Old Kent Road Mosque & House of Bread Church.
- **Continuous work from the Cancer Facilitator to engage with practices on how they can improve screening participation and increase cancer symptom awareness.** This will include supporting practices who wish to hold cancer awareness events for their patients. Several events are already planned.

- **Breast Screening:** [It's In Your Hands](#), [Speak up](#), [Say No To Cancer](#), [Together](#)
- **Prostate Cancer:** [Why us Black men?](#); [Let's talk about prostate cancer](#); [Don't wait. The earlier you speak to your GP the better](#); [Prostate cancer runs in my family](#); [Prostate cancer: We pretend it doesn't exist](#).
- **Cervical Screening:** [We're in a race to eliminate Cervical Cancer](#) (co-produced by SELCA and the other London Cancer Alliances).
- **Bowel Screening:** [How to use the bowel cancer screening FIT kit](#) (produced by South East London Cancer Alliance and available in **top 23 languages** for South East London).
- **Symptomatic Bowel FIT Test:** [FIT testing for patients presenting with bowel symptoms](#) (this is only for people presenting to their GP **with symptoms** that could be suggestive of bowel cancer, not for generic bowel screening - produced by South East London Cancer Alliance and available in **top 23 languages** for South East London).
- **Targeted Lung Health Checks:** [What is an NHS Lung Health Check?](#) (produced by SELCA).

Meeting Name	Health and Social Care Scrutiny Commission
Date	13 November 2024
Report Title	Primary Care Access
Report Author	Kate Kavanagh, Associate Director of Community Based Care

## Introduction and context

Access to general practice care is an ongoing concern for the general public and NHS England (NHSE) and patients report difficulties getting appointments in a timely way, and in seeing their preferred healthcare professional when they do attend. In the report ‘What Matters to You? Healthwatch Southwark’s Priorities Survey 2024-25’, [1] GP access (registering, booking and waiting for appointments) was ranked as the highest healthcare concern by the respondents.

Whilst nationally general practice is delivering a million appointments every day and half a million more every week than pre-COVID-19, [2] we know the pandemic changed the healthcare landscape, and the increase in practice capacity needs to keep pace with growing demand.

The purpose of this paper is to update the committee on what Southwark borough are doing to address this locally.

## Background

In order to improve access to primary care services, and the perception of access, in 2022, NHS England (NHSE) launched the ‘Primary Care Access Recovery Programme {3} (PCARP). The main priority was to ‘tackle the 8am rush’, making it easier and quicker for patients to get the help they need.

The programme includes implementing ‘Modern General Practice’, with the aim of allowing patients to know on the day they make contact, how their request will be handled. This should be based on clinical need and continue to respect their individual preference for a phone call, face-to-face, or online message.

In Southwark, the following improvements have been implemented:

### Cloud-based Telephony

100% of practices have been supported to move onto a cloud-based telephony solution, which provides a ‘call back’ function, so patients don’t have to wait in a lengthy queue. Once patients speak to the practice, they will know on the day how their request will be managed:

1. If their need is clinically urgent it should be assessed on the same day by a telephone or face-to-face appointment. If the patient contacts their practice in the afternoon they may be assessed on the next day, where clinically appropriate.
2. If their need is not urgent, but it requires a telephone or face-to-face appointment, this should be scheduled within two weeks.
3. Where appropriate, patients will be signposted to self-care or other local services (eg community pharmacy or self-referral services).
4. The general practice workforce has evolved to include a number of new roles, including Clinical Pharmacist, Health and Well-being Coach, Dietician, Paramedic, First-contact Physiotherapist and Mental Health Practitioner. This means that by providing a little more information at the point of

contact, patients can be directed to the most appropriate healthcare member first time, speeding up their pathway and reducing the number of unnecessary GP appointments.

### **Pharmacy First and Pharmacy First Plus**

The Pharmacy First (PF) scheme means local Pharmacists can carry out consultations and issue antibiotics for one of the seven conditions below, directly to patients when appropriate. Patients can access the service by walking straight into a chemist. They can also be referred by NHS 111, urgent treatment centres, emergency departments or their GP. Those who are not registered with a GP can still access the service.

The seven common conditions managed by the clinical pathways are:

- Uncomplicated UTI
- Shingles
- Impetigo
- Infected insect bites
- Sinusitis
- Sore throat
- Acute otitis media (middle ear infection)

Patients who need more specialist or follow-up care are referred onwards. The aim is to make it easier for people to get the help quickly when they need it, as well as free up millions of GP appointments for patients with greater need and long terms condition management.

There are 57 community pharmacies in Southwark, of those, 51 have already signed up to the scheme. In addition to the conditions above, 45 are signed up to provide hypertension screening and 36 to offer contraceptive services.

Pharmacy First Plus is a locally commissioned service and is provided by Southwark community pharmacists to enable people that don't pay prescription charges to get medicines 'free' from their local pharmacy without needing to visit a GP. A pharmacist can offer quick and local access to advice and treatment about common illnesses without needing an appointment. There is a long list of minor illness conditions from athletes foot to threadworm. Everyone can get free advice from any pharmacist but to be able to get free medicines they need to:

- Sign up to the service at the pharmacy
- Be registered with a Southwark GP
- On low income and entitled to free prescriptions (show their exemption certificate)

There are currently 34 community pharmacies providing this service in Southwark and work continues to encourage the remaining pharmacies to sign up to deliver the scheme.

Benefits include:

- Pharmacists are highly qualified health care professionals who are experts in medicines. They can give the same advice and treatment for common illnesses as GPs.
- Many pharmacies open late during the week and on Saturdays and Sundays.
- It is often quicker to see a pharmacist than wait for a GP appointment.

- No appointment is necessary

### **Enhanced Access and Extended Primary Care Service.**

The Enhanced Access (EA) service in Southwark is a key component of the nationally commissioned Primary Care Network (PCN) Direct Enhanced Service and refers to hours delivered on top of core General Practice Hours (Mon-Fri 08:00-18:30).

**The Extended Primary Care Service (EPCS)** is delivered via hubs from the Tessa Jowell Health Centre in the south and Bermondsey Spa in the north of the Borough. Care is delivered by GPs, Advanced Nurse Practitioners, Nurses, and other health care professionals. Appointments are for same or next day primary care access, are pre-bookable and are predominantly face to face, with some online and telephone appointments available.

Southwark commissions this additional capacity from the two GP Federations, which provides approximately 16,000 additional appointments per annum. The service offers appointments 8am-8pm Monday to Saturday, as well as 8am-4pm Sunday's and Bank Holidays. Patients are offered the option to be booked into one of these hubs if they are unable to secure an appointment at their registered practice which also offers the flexibility of evening, weekend and bank-holiday appointments.

In addition to routine GP appointments, the weekend service includes all age immunisations and clinics for women's health / cervical screening, two areas of focus for reducing inequalities, whilst enabling access for women with children who otherwise cannot access these services during core GP hours due to work patterns.

### **The NHS App**

There has been strong focus on increasing utilisation of the NHS App within Southwark via promotional SMS campaigns, recommendations shared with practices and more recently the NHS App Week in October 2024. The latest data available shows the percentage of NHS App registered patients has increased from 53.8% in September 2023 to 58.6% in September 2024. The number of total registrations in September 2024 was 187,453 and there has been a gradual trend of higher NHS App registrations every month during the same period.

'NHS App Week', which ran 14<sup>th</sup> October -18<sup>th</sup> October 2024 and practice and patient engagement was encouraging.

- 17 GP surgeries across the Southwark borough participated. Each Practice had a visit from the digital team which involved an in-depth introduction to the NHS App to teams, with further training on Proxy access and the patient verification process. Posters and flyers were distributed across the board, with a handy QR code for ease of download.
- The visits also involved direct introduction of the NHS App features to patients. There was further assistance provided to patients for downloading and navigating through the NHS App, in some instances for the first time, to experience the benefits of their NHS records at their fingertips.

### **GP Practice Websites**

The SEL Digital Team has recently collaborated with Borough Change Managers and GP practices to improve the standardisation of practice websites. The Digital Change Manager has been working

closely with each practice to ensure their websites are fully functional and accessible. 18 out of 32 Southwark practices are 100% compliant with the NHSE National Benchmarking toolkit and work is ongoing to reach all practices by the end of the year

### **Latin American Communities in Southwark**

In response to Healthwatch Southwark's 'Access to Health and Social Care services for Latin American Communities in Southwark' [4], SEL ICB Southwark developed an action plan to respond to the 11 recommendations set out in the report. This included improving access to interpreters, providing information on health care services available, liaising with Latin American community organisations to disseminate information and providing information about migrants' entitlements to health and social care in Spanish and Portuguese. The borough team continue to address and monitor improvements in this regard.

### **Access improvements**

Between April and September 2024, Southwark GPs carried out 692,681 appointments. This represents an additional 5228 appointments, or a 0.75% increase compared to the same period in 2023.

### **Collective Action**

Following changes to the GP Contract for 2024/25 by the previous Government, the British Medical Association (BMA) called upon GP partners/contractors to take collective action, which included 10 actions, including 'limit daily patient consultations', 'withdraw permission for data sharing agreements' and 'stop rationing referrals, investigations and to name a few.

No issues have been raised locally in Southwark or disruption to direct patient outward facing care identified. However, we continue to monitor the situation.

### **References:**

1. [What Matters to You? Healthwatch Southwark's Priorities Survey 2024-25](#)
2. [Appointments in General Practice, January 2023 - NHS England Digital](#)
3. [NHS England » Delivery plan for recovering access to primary care](#)
4. [Access to Health and Social Care Services for Latin American Communities in Southwark Report | Healthwatch Southwark](#)



# The value of listening

Healthwatch Southwark  
Annual Report 2023-2024



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**"Over the last year, local Healthwatch have shown what happens when people speak up about their care, and services listen. They are helping the NHS unlock the power of people's views and experiences, especially those facing the most serious health inequalities."**

Louise Ansari, Chief Executive at Healthwatch England



# Message from our Chair

This year has been a year of change for Healthwatch Southwark, whereby we have successfully developed and embedded a new Healthwatch Southwark strategy 2023- 2026 to support our efforts in the local community, the team have firmly put in place a holding to account process which encourages service providers to make informed improvements for the betterment of people who use their services and the team will also be holding a Listening Tour across the Southwark borough to ensure all voices in the community have access to us and are heard. It has been a very busy period for us, but a period that has been worthwhile and that has been full of organisational growth.

Over 4500 people made contact with us online and in person. It is our hope that through our collaborations with other local Healthwatches, we believe we have made a positive impact and have been able to influence decisions for the betterment of the local community at the Southeast London Integrated Care System level. The work of the Healthwatch Southwark team has not gone unnoticed amongst Advisory Board members, nor the Southwark Mayor Michael Situ 2023/24 who provided the team with a letter of commendation for all their hard work. On behalf of the Advisory Board, I would like to publicly thank the Healthwatch Southwark team again for their efforts.

**“This is my last year as the Chair of the Healthwatch Southwark Advisory Board, it has been an absolute privilege serving and representing the people in the London Borough of Southwark. I am very pleased to welcome our new Chair to take the reigns and lead us on to better and improved opportunities for the benefit of local people, but at the same time ensuring quality over quantity remains our focus within our community work.”**

Sheona St Hilaire – London region



## Introducing our new Chair

**Firstly, it is an honour to be nominated as Chair, and to serve my community. I hope to continue to advocate for improving patients' experiences, promoting health equity and to support the overall objectives of Healthwatch Southwark. It means a great deal to me to represent the voice of the residents and to work collaboratively in empowering them to get involved in order to bring about positive change for the future.**

Charlene Young - London Region



# About us

## Healthwatch Southwark is your local health and social care champion.

From London Bridge to Dulwich and everywhere in between, we make sure NHS leaders and decision-makers hear your voice and use your feedback to improve care. We can also help you to find reliable and trustworthy information and advice.

### Our vision

A world where we can all get the health and care we need.



### Our mission

To make sure people's experiences help make health and care better.



### Our values are:

- **Listening** to people and making sure their voices are heard.
- **Including** everyone in the conversation – especially those who don't always have their voice heard.
- **Analysing** different people's experiences to learn how to improve care.
- **Acting** on feedback and driving change.
- **Partnering** with care providers, Government, and the voluntary sector – serving as the public's independent advocate.



# Year in review

## Reaching out:

**4,792 people**



Engaged with us either through sharing their experiences of health and social care services or via community events and outreach – online and in person – which has helped us to raise awareness of issues and continue working with services to improve care.

**115 people**

came to us for clear advice and information about topics such as support with finding services, how to raise a complaint, advocacy services and the cost-of-living crisis support.

## Making a difference to care:

We published

**1 report in September 2023**



We have continued to present, promote findings and gain responses to our report:

### **'Access to Health and Social Care Services for Latin American Communities in Southwark'**

which highlighted the accessibility of health information for Latin American communities. Our report was included in a Joint Strategic Needs Assessment to explore improvements with local services in Southwark.

## We are working on 1 report

Looking into the experiences of adults with learning disabilities and autistic adults in accessing health and social care services

## Health and social care that works for you:

We're lucky to have

**181**

outstanding volunteers, a combination of Advisory Board members, Community Health Ambassadors and core Healthwatch Southwark volunteers who gave up

**2,044 hours**

to make care better for our community.

We're funded by our local authority.  
In 2023 - 24 we received

**£152,643**

which is the same as the previous year.

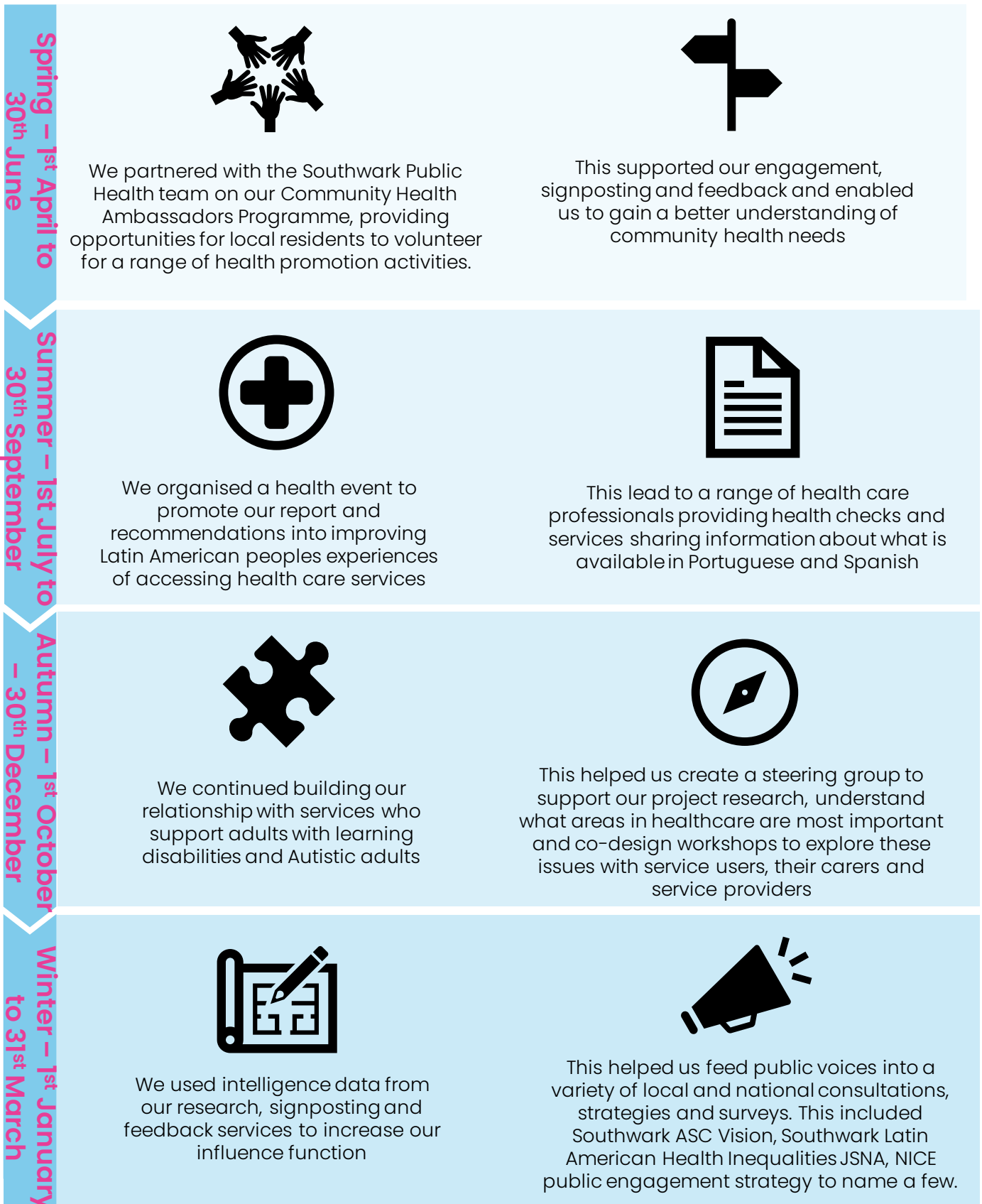
We currently employ

**4 staff**

who help us carry out our work.



# How we've made a difference this year -



# Your voice heard at a wider level

**We collaborate with other Healthwatch organisations to ensure the experiences of people in Southwark influence decisions made about services at South East London Integrated Care System (ICS) level.**

This year we've worked with the other five Healthwatch across south east London to:



Feed in people's experiences to identify, shape, and develop the six South East London Integrated Care System priorities, the principles that underpin them and the ICS Integrated Care Strategy. We also provided support for this programme's community engagement.

Provide representation on 16 ICS and ICB Boards, Committees, and Groups. Through this participation, we ensured an independent voice for the public, and highlighted the insight and intelligence gathered by SEL Healthwatch to decision makers and health providers.



Develop south east London Healthwatch webpages, bringing together key Healthwatch reports in one place to facilitate health commissioners' access to people's views, experiences, stories, and recommended solutions.

Champion digital inclusion across south east London programmes and services so that as technology use becomes more widespread, the reality of digital exclusion, which many people face, is mitigated.





# Listening to your experiences

**Services can't make improvements without hearing your views. That's why, over the last year, we have made listening to feedback from all areas of the community a priority. This allows us to understand the full picture, and feed this back to services and help them improve.**



# Three ways we have made a difference in the community

Throughout our work we gather information about health inequalities by speaking to people whose experiences aren't often heard.

## Letter of Commendation from Southwark Mayor

We at Healthwatch Southwark are pleased to share the letter of commendation from Mayor Michael Situ for our work in the community supporting residents to address barriers to health and social services.

We acknowledge and appreciate everyone who has supported our work and look forward to reaching more Southwark residents each year!

**You can read the letter of commendation here: [Letter from the Mayor of Southwark](#)**



## Getting services to involve the public

**Services need to understand the benefits of involving local people to help improve care for everyone.**

During the engagement phase of our healthcare barriers project for adults with learning disabilities and autistic individuals, we actively incorporated feedback from service users and their caregivers. They expressed a desire for World Café-style conversations to involve service providers, allowing them to directly address the challenges they were encountering. This allowed the community to hear directly what provisions and barriers service providers were experiencing and created a welcoming and non-judgemental space for co-designed solutions which we will include in our report.

“

*Conversations in my group among participants that offered support for each other. Two of them exchanged contact details and arranged to meet outside a GP surgery to go together and ask for help with an ASFD assessment for their child.*

## Improving care over time

**Change takes time. We often work behind the scenes with services to consistently raise issues and bring about change.**

Since the end of our Latin American Project looking into access issues for this community, we have been piloting our holding to account process which includes holding 6 and 12 month progress reviews with public services. We will ensure we feedback to the steering group and members of the Latin American community. So far we have held one meeting with a local hospital and have booked several other review meetings where summary reports will be completed. This will take some time to refine but we hope this shows historically under-represented communities that we are serious about advocating for the changes they want to see and feel.



There's a summary of other outcomes we've achieved this year in the Statutory Statements section at the end of this report.



# Hearing from all communities

**Over the past year, we have worked hard to make sure we hear from everyone within our local area. We consider it important to reach out to the communities we hear from less frequently to gather their feedback and make sure their voice is heard, and services meet their needs.**

**This year we have reached different communities by:**

- Strengthening our relationship with our Community Health Ambassadors by attending more events organised by them
- Attending clinics that are addressing social determinants of health such as people struggling with socio-economic deprivation by the cost of living crisis.
- Ensure we are understanding, capturing and reporting issues using the [QualityAlert](#) reporting system and liaising with key stakeholders and decision makers to drive change
- Using our data to identify who we haven't heard from and targeting future engagement to include those groups e.g. our engagement with service users, carers and professionals using a café conversation method

# Championing health through the Community Health Ambassadors Programme

**In 2022–23, Healthwatch Southwark has continued to partner with the Public Health team at Southwark Council to support our Community Health Ambassadors Network. The network supports Southwark residents to protect themselves and their communities.**

Over the last year, Ambassadors have been instrumental in a range of health promotion and prevention activities, a few of which include:

- A review of the Doctors of the World “Safe Surgeries” programme where local GP surgeries who have signed up, were audited against their commitment to this programme.
- Supported The Health Roadshow Van and static Health Kiosks which provides free Vital 5 health checks to local residents
- Participate in the Long COVID Health Management workshops created and delivered by Guys and St Thomas Hospital and share vital health information within their communities.
- Attend The London-wide Community Champions Development Programme which honoured Southwark Health Ambassadors at the House of Lords
- Organise a range of community-led events, capacity building activities, training in areas that support the local community to build confidence, enhance wellbeing and increase community cohesion.

The Community Health Ambassadors programme has been influential in getting key health messages out to residents, gather insights about the barriers being experienced, help us and Public Health understand health behaviours and connect people to services in Southwark.



**“I feel very happy, satisfied and encouraged seeing the result and impact of what I do in my community. Initially, I was volunteering as manager of our food bank. Due to trainings and networking meeting, I found better ways to improve the quality of life of the people coming to us for support. I began to identify their needs and using a research training skill I acquired, I conducted a focus group discussion and the outcome of that focus group made me introduce a Saturday breakfast meeting where every Saturday, the people had a singing and fellowship session, an exercise class, full English breakfast (hot meal) and finally they go home with their food parcel. This has greatly improved the physical and mental well-being of the people. ”**

Franklin Akpomuvwe - Community Health Ambassador

# Championing health through the Community Health Ambassadors Programme

## What difference did this make?

- Through the collaborations with the Public Health outreach van, there was increased opportunities for people to get the Vital 5 health checks within faith settings which includes advice and information on health eating, blood pressure, mental health, smoking and alcohol dependency.
- Community activities such as Dance Therapy health workshops and sewing workshops positively impacted attendees mood, reduced stress levels, and increased feelings of empowerment and self-confidence. Some began making their own clothes or expressed interest in starting their own businesses through the use of these new skills, in addition to increased self-expression, and community connection to lead healthier, more fulfilling lives.



## Do you feel inspired?

We are always looking for new Ambassadors, so please get in touch today. Sign up [here](#) to become a Community Health Ambassador



**“In my year as a part-time ambassador, I’ve witnessed first-hand the power of advocacy and community engagement in driving positive change. Through dedicated efforts and collaboration, I’ve had the privilege of contributing to impactful initiatives aimed at promoting health and well-being including tackling health inequality. From empowering individuals with vital skills to fostering strategic partnerships, every interaction has reinforced the importance of collective action in advancing our shared goals. As I reflect on my journey, I am inspired by the resilience and passion of those I’ve had the honour of working alongside. Moving forward, I am committed to leveraging these learnings and experiences to continue making a meaningful difference in my role as a health ambassador Champion.”**

Saidat Oketunde - Community Health Ambassador

## Supporting those waiting for appointments

**From our signposting and feedback data, we found out that many people are experiencing long waiting times to receive an appointment from their GP, dentist or hospital**

“My son cannot access dental treatment. He's been referred by the GP (Dulwich Medical Centre) three times, I haven't received any letters, the GP said the referral has definitely gone through, but Lister dentist say they have not received it. I was told anyone with an NHS email can make a referral. (My son) has many cavities and is in pain. It has been over a year. My other son (who has SEN) was seen within a month.” Quote via outreach event.

### **As a result of what was shared with us:**

We handled it by following up with the individual and signposted them to POhWER as well as escalating directly to PALS. We have since reached out to London Dental Confederation and Community Dental Services to establish a route for feedback and escalation for future cases.

## Engaging organisations that assist people during the cost of living crisis.

**Share The Cost Global hosted our coffee morning which invited local residents, other community organisations and public bodies to learn more about the services each other offer, build relationships and understand collaborative ways of working.**

From this we have:

- Been strengthening our relationship with the team at Share The Cost Global
- Understood their services and promote the support on offer to local residents, businesses and stakeholders
- Established a referral pathway for non-statutory advocacy support, to ensure local residents do not slip through the net



Healthwatch Southwark's relationship with Share The Cost Global has enabled us to seek advice for a specific case where a mother had given feedback about multiple issues she was experiencing, such as financial issues, concerns she has raised about her adult child with additional needs and overcrowding in her small home that she shares with her 4 children.

After hearing the difficulties this mother was experiencing we signposted her to Share The Cost Global, a range of financial aid services, housing advice, health and social care services in addition to practical support to help with form filling.



## Advice and information

If you feel lost and don't know where to turn, Healthwatch is here for you. In times of worry or stress, we can provide confidential support and free information to help you understand your options and get the help you need. Whether it's finding an NHS dentist, making a complaint or choosing a good care home for a loved one – you can count on us.

**This year we've helped people by:**

- Providing up-to-date information from sources that people can trust
- Helping people access the services they need the most such as practical help to fill in forms
- Build relationships with local services by understanding their remit and referral pathways
- Supporting people to look after their health during the cost-of-living crisis

## Challenging digital-first services for older people

**It's essential that people have clear, accurate communication about their care and can choose the method of communication that best suits them and their needs.**

Thanks to the efforts of Healthwatch Southwark, a GP surgery have reviewed their telephone prompts to enable patients to request an appointment over the phone which reduced digital exclusion for many patients on their register. Healthwatch Southwark will encourage more primary care providers to implement this where the option to book an appointment over the phone is not available.

Digital platforms are becoming more common in healthcare for tasks like booking appointments, especially after the pandemic prompted a review of phone prompts and appointment request options. However, there's a risk of excluding those who are not comfortable with or can't access these services. Healthwatch Southwark heard from 90-year-old Jane\*, who has several physical and mental health issues, and couldn't book an appointment for her emotional needs over the phone. Jane\* has limited mobility, little family support, and does not have or want to use a smartphone.

She has been passed between mental health services and faced another barrier, feeling distressed by the unwelcoming phone prompts. Jane\* called Healthwatch Southwark to report her difficulties, stating that she had called the surgery multiple times and eventually left a voicemail for the GP/practice manager. Healthwatch Southwark raised her concerns with the practice.

\*Names changed

I just wanted to thank you for your support. On checking the GP surgery's introductory message, I was pleased and relieved to hear an option to speak to make an appointment. The Practice did not get back to me to tell me this, so I was about to launch another attack... but glad I had the wit to check first.

## Making informed decisions with signposting advice and guidance

**Challenging a decision regarding your health can be done with equipping individuals with the correct information**

Since the COVID-19 pandemic and vaccination program, more people suspecting poor health from vaccines have become aware of the Vaccine Damage Payment. We received a request for information about this government scheme from a man providing feedback about someone he cares for.

**Healthwatch Southwark wanted to make sure he could get the information he needed and support from services that help with form filling.**

- We provided him with trusted sources on the Gov.UK website about the Vaccine Damage Payment programme
- As well as providing him with a variety of local services that provide the practical support he needed, this was accompanied by information about how to make a formal NHS complaint and how he can access local advocacy services



# Volunteering

**We're supported by a team of amazing volunteers who are at the heart of what we do. Thanks to their efforts in the community, we're able to understand what is working and what needs improving.**

## **This year our volunteers:**

- Visited communities to promote their local Healthwatch and what we have to offer
- Collected experiences and supported their communities to share their views
- Shared key health messages to communities who may not always receive the information they need to better their health choices
- Supported us with our project engagement work





**My time at Healthwatch Southwark has been worthwhile and looking back to when I started only brings back good memories. I first joined Healthwatch Southwark as a public health master's student. I have always been passionate about health and the ways in which we can address health inequalities.**

**I also wanted to gain a practical insight into how we address health concerns in my community.**

**My team at Healthwatch Southwark have been so supportive and were amazing in allowing me to showcase my skills and participate in chosen projects. I was also fortunate to be selected to receive an award for my efforts.**

**From speaking to the public as part of community engagement, to delivering presentations at stakeholder meetings, Healthwatch Southwark will always have a special place in my heart.**

**I have grown so much in confidence and I know that all the skills I have gained during my time there would be beneficial for when I transition into my new role as Patient Engagement Facilitator.**

**I would like to give a special thanks to the entire team. I am truly grateful and I appreciate you all.**

**Elishia –  
Healthwatch Southwark Volunteer /  
Community Health Ambassador**



## **Community engagement and project research volunteer**

### **Do you feel inspired?**



We are always on the lookout for new volunteers, so please get in touch today.

 [www.healthwatchsouthwark.org](http://www.healthwatchsouthwark.org)

 0203 848 6546

 [info@healthwatchsouthwark.org](mailto:info@healthwatchsouthwark.org)



This project has not only been important on a personal level, it has also been important for the community in general. The presentations that were made in various places with different authorities and representatives of organizations saw for the first time the need and support that the Latino community needs.

This project opened the doors to other organizations to integrate the Latin community more and we have more information in Spanish language now.

Not only did it show us the problem of the language barrier in the Latin community but also in all immigrants, from that came the idea of putting up a flag of origin next to the name of the NHS workers, to try to have better communication.

Personally and as Health Ambassador gave me a voice and made me realize the passion I have for the health inequalities, and with the help of Healthwatch making this survey showed how important it is to try to improve this barrier so that we all try to live in harmony and receive the necessary help to improve our health.

Thanks to Healthwatch for the dedication and effort in carrying out this project.

**Patricia Cuenca** –  
Healthwatch Southwark Volunteer /  
Community Health Ambassador



**Project volunteer for Access to Health and Social Care Services for Latin American Communities in Southwark.**

Read the report [here](#).

## Do you feel inspired?



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# Finance and future priorities

To help us carry out our work we receive funding from our local authority under the Health and Social Care Act 2012.

## Our income and expenditure

Income		Expenditure	
Annual grant from Government	£150,720.34	Expenditure on pay	£120,644.01
		Non-pay expenditure	£3,592.76
		Office and management fees	£12,166.04
<b>Total income</b>	<b>£150,720.34</b>	<b>Total expenditure</b>	<b>£136,402.81</b>

**Additional income is broken down by:**

- £2,000 received from Healthwatch England for work on a project.
- £2,000 received from the local ICS for joint work on a project.
- £800 funding received from a local charity to support their project.

**ICS funding**

Healthwatch across south east London also receives funding from our Integrated Care System (ICS) to support new areas of collaborative work at this level, including:

Purpose of ICS funding	Amount
a. SEL ICS posts x2 (1.2 fte)	£ 91,500.00
b. South East London Healthwatch Reference Group	
c. Organisational on costs	
	£
	£

**Next steps**

**Over the next year, we will keep reaching out to every part of society, especially people in the most deprived areas, so that those in power hear their views and experiences.**

We will also work together with partners and our local Integrated Care System to help develop an NHS culture where, at every level, staff strive to listen and learn from patients to make care better.

**Our top three priorities for the next year are:**

1. Completing previous years project work and ensure the reports receive 100% formal responses from decision makers in health and social care
2. Using information gathered from our priorities survey, listening tour, themes from liaison meetings and other intelligence to inform our community-led research and projects
3. Increase community engagement, with particular focus on historically underrepresented communities in Southwark and promote the work we have done and will do over 2024-25



# Statutory statements

**Healthwatch Southwark 11 Market Place, Bermondsey, London, SE16 3UQ**

**Healthwatch Southwark is hosted by Community Southwark**

**Healthwatch Southwark uses the Healthwatch Trademark when undertaking our statutory activities as covered by the licence agreement.**

## The way we work

### Involvement of volunteers and lay people in our governance and decision-making

Our Healthwatch Board consists of 8 members who work on a voluntary basis to provide direction, oversight and scrutiny of our activities. Our Board ensures that decisions about priority areas of work reflect the concerns and interests of our diverse local community.

Throughout 2023/24, the Board met 4 times and made decisions on matters such as the new Healthwatch Southwark strategy for 2023–26 and project direction for our Latin American access to health services. We ensure wider public involvement in deciding our work priorities through our annual survey, feedback and signposting themes and trends and stakeholder intelligence.

### Methods and systems used across the year to obtain people's experiences

We use a wide range of approaches to ensure that as many people as possible can provide us with insight into their experience of using services. During 2023/24, we have been available by phone, email, web form on our website and social media. This is in addition to attending meetings of influence within statutory services, alongside community groups and forums.

We ensure that this annual report is made available to as many members of the public and partner organisations as possible. We will publish it on our website, share with our statutory and community stakeholders in our newsletters and on the [South East London Healthwatch](#) webpage.

### Responses to recommendations

100% of providers responded to our requests for information or recommendations, therefore we did not have to escalate any concerns to the Healthwatch England Committee.

### Taking people's experiences to decision-makers

We ensure that people who can make decisions about services hear about the insights and experiences that have been shared with us. In our local authority area, for example, we take information to the Southwark Health and Wellbeing Board, Overview and Scrutiny Committee and local commissioners where we presented concerns about receiving formal responses to our research reports.

We also take insight and experiences to decision-makers in the South East London Integrated Care System. For example, we produce an integrated report of all SEL Healthwatch reports published every quarter, which is shared widely. In addition, we provide updates on Healthwatch activity to the ICB Engagement Assurance Committee and to the System and Concerns Group. Our SEL Healthwatch Reference Group has influenced the Digital Strategy and the Anchor System Programme engagement. We also share our data with Healthwatch England to help address health and care issues at a national level.

## Enter and view

This year, we did not make any Enter and View visits due to several changes to staff and our priorities. We aim to re-start our Enter and View programme and re-train representatives during 2024-25.

## Healthwatch representatives

Healthwatch Southwark is represented on the Southwark Health and Wellbeing Board by Sheona St Hilaire, Chair of the Healthwatch Southwark Advisory Board. During 2023/24 our representative has effectively carried out this role by sharing important updates with the core Healthwatch Southwark team, sharing best practice information and health related information that our ambassadors can provide to their communities.

Healthwatch Southwark is represented on the South East London Integrated Care Partnership, ICS Information Governance Group, ICS Quality and Performance Committee, ICS System Quality Group, and ICS Digital Board by Folake Segun, Director, South East London Healthwatch. Folake Segun and Graham Head, Vice Chair Healthwatch Southwark, represent the Healthwatch in south east London on the CS Data Usage Committee.

## 2023 – 2024 Outcomes

Project/activity	Outcomes achieved
Black mental health	We have begun re-engaging the community and steering group to review the project scope
Holding to account process	We have refined our holding to account process to ensure health and social care services implement the recommendations from our findings through facilitating 6 and 12 month reviews with community members and statutory services. We have had good feedback from services who have piloted the process so far
Re-establishing our connection with Social Care	This has enabled us to have regular liaison meetings to provide our insights and intelligence relating to feedback we receive about adult and child social care services
Rebuilding our connection with Primary Care Network	This has enabled us to join regular liaison meetings to provide our insights and intelligence relating to feedback we receive about primary care services

# healthwatch

## Southwark



Healthwatch Southwark

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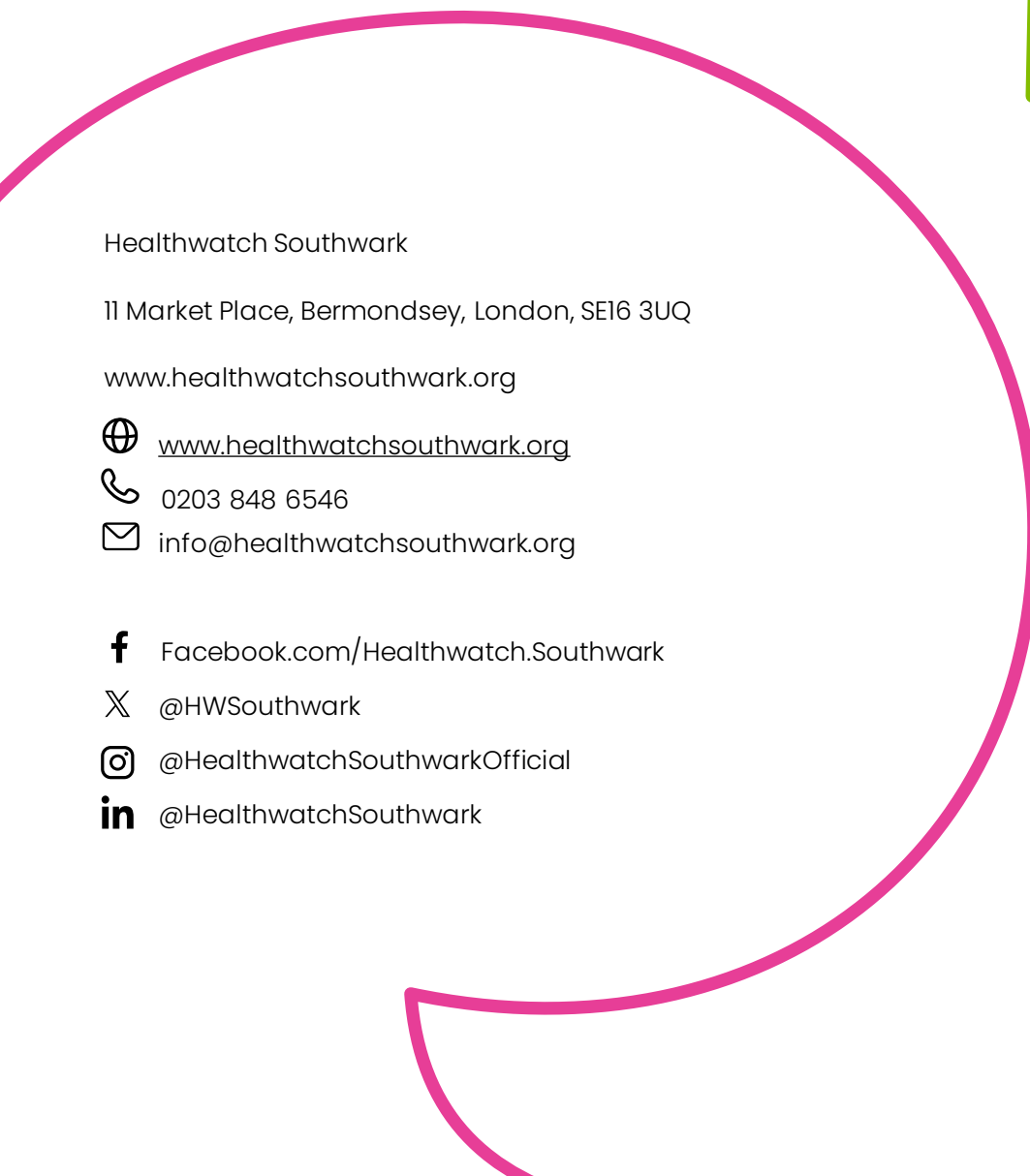
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# **Empowering Voices:** **Examining Healthcare Access for **Adults with** **Learning Disabilities and Autistic Adults in** **Southwark****

**Healthwatch Southwark**  
**June 2024**



## Acknowledgements

We are grateful to everyone who took part in this research, including our respondents, steering group members and volunteers at Healthwatch Southwark: Jacqueline Jan, Elishia Rankin and Janet Morris.

We would like to thank the incredible staff and clients at Autism Voice, Bede House Day Centre, and Cherry Gardens Day Centre.

If you have any questions or comments on the report or any of the issues raised, please contact Ruman Kallar (Healthwatch Southwark Research & Projects Officer) at [ruman@healthwatchsouthwark.org](mailto:ruman@healthwatchsouthwark.org)

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# 1. Executive Summary

This project examines the accessibility of healthcare services for adults with learning disabilities and autistic adults in Southwark. It was prompted by evidence that adults with learning disabilities face notably poorer health outcomes compared to adults who do not have a learning disability (Southwark Council 2018; Learning from Lives and Deaths 2021; Office of National Statistics 2022; Healthwatch England 2022).

The research involved a written survey capturing the experiences of service users, carers, and service providers regarding healthcare access across Southwark. We held three Café Conversations events to gather in-depth insights and collaboratively brainstorm solutions. In total, 104 individuals participated.

The people we spoke to did not believe there was consistent equity of access to local healthcare services. Our findings reveal widespread barriers to healthcare, particularly within mainstream services including GPs and A&E. The most common obstacles identified **include encounters with unkind or impatient staff, communication difficulties with healthcare professionals, and a lack of reasonable adjustments for individual needs**. These challenges appear to stem predominantly from healthcare staff's limited understanding of learning disabilities and autism, as well as inadequate practice systems to accommodate individual needs.

Moreover, the **absence of a centralised directory of services and information** for adults with learning disabilities and autistic adults in Southwark hinders coordinated healthcare provision and leaves service users and carers uncertain about where to access support.

In response to these findings, we worked with respondents to develop a set of recommendations for care providers. These include providing **training** on learning disabilities and autism for healthcare staff, facilitating **information-sharing** between services, and implementing changes to **practice systems** to ensure that reasonable adjustments are consistently made available. Further details are provided in section 4 of the report.

## 1.1. Key findings

Our findings indicate that the majority of respondents have experienced barriers to accessing healthcare services. These barriers include:

### Staff-Related Issues

- Poor staff attitude towards service users and carers, e.g. being rude, dismissive, and patronising.
- Staff failing to support service users to communicate and understand during appointments, e.g. use of complex language, not giving service users enough time.
- Staff having little understanding of learning disabilities and autism.



### Patient-Centred Issues

- Feelings of fear and anxiety towards healthcare services.
- Service users and carers are uninformed about health promotion initiatives and adjustments such as double appointments.
- Unsuitable and inaccessible locations for appointments, e.g. bright and noisy waiting rooms, no lifts.



### Operational Issues

- Inconsistent implementation of reasonable adjustments within and across healthcare services.
- Limited options to contact services outside of appointments, telephones are not always answered, and the use of withheld numbers to contact patients is off-putting.
- Lack of flexibility for the date, time, location, and structure of appointments.
- Lack of aftercare or follow-up care for adults with learning disabilities and autistic adults; caused by poor co-ordination between care providers and the reduction of services from child to adult care.



- Diagnosis of a learning disability or autism is required to access specialist services and adjustments. Long waiting times and unclear pathways for diagnostic services.
- Excluding service users from being involved in and informed about their own care.
- Excluding carers from being involved in and informed about service users' care, particularly after transition to adult services.
- Frequent staff rotation disrupting care.

### Social Factors

- Financial hardship adversely impacting health and causing service users to deprioritise healthcare.
- Social isolation adversely impacting health and making it harder for service users to access healthcare.
- Lack of provision for service users who do not have carers to support them.
- Lack of support for carers, e.g. respite services.
- Systemic racial and ethnic inequalities preventing people from accessing suitable services until crisis point.



## 1.2. Summary of Recommendations

This research makes a series of recommendations to improve healthcare access for adults with learning disabilities and autistic adults. The complete set of recommendations is contained in section 4 of this report. However, our recommendations can be summed into four core categories:



**1. Training.** Provide training about learning disabilities and autism to all patient-facing staff delivering healthcare services.



**2. Sharing Information.** Facilitate and promote sharing information about services and support available for adults with learning disabilities and autistic adults. This should include voluntary and community sector support, and adult social care.



**3. Communications.** Healthcare services should audit and improve the accessibility of their communications with service users and carers.



**4. Operational Issues.** Implement measures to deliver a consistent standard of care across healthcare services that adheres to the Accessible Information Act 2016.



## 2. Introduction

Adults with learning disabilities are known to have significantly poorer health outcomes compared to adults who do not have a learning disability (Southwark Council 2018; Learning from Lives and Deaths (LeDeR) 2021; Office of National Statistics, 2022). These outcomes are influenced by factors such as access to health and care services, a higher burden of disease, and social factors such as poverty and poor housing.

In recognition of this, improving healthcare services available for people with learning disabilities and autistic people has been identified as a priority area at the national and local level. Both the NHS Long Term Plan (NHS England 2022) and Southwark's Joint Strategic Needs Assessment on Learning Disabilities in Southwark (Southwark Council 2018) set out actions to understand and help healthcare professionals respond to people's needs.

This project aims to contribute to this work by gathering feedback from adults with learning disabilities and autistic adults, their carers and healthcare professionals who provide general and specialist services for this group, about their experiences of using and delivering healthcare services in Southwark.

This project sets out to identify the barriers to healthcare access for adults with learning disabilities and autistic adults, and co-produce targeted recommendations to make healthcare services more accessible to this group.

### **What is a learning disability?**

NHS England (2019) defines a learning disability as "a lifelong condition; it is not an illness and cannot be cured. The term learning disability is used in relation to people who have the following characteristics:

- A significantly reduced ability to understand complex information or learn new skills.

- A reduced ability to cope independently.
- A condition which started before adulthood and has a lasting effect.”

## What is autism?

National Autistic Society defines autism as “a lifelong developmental disability which affects how people communicate and interact with the world. Autism is a spectrum condition and affects people in different ways” (National Autistic Society 2024).

Autistic spectrum conditions are not classed as a learning disability in themselves; however, approximately 20–30% of people with a learning disability also have autism (NHS England 2019).

## 2.1. Background Research

### National findings

The life expectancy of adults with learning disabilities and autistic adults is up to 20 years shorter than adults who do not have a learning disability and are not autistic (Healthwatch England 2019). Worse still, the life expectancy of people with a learning disability who are from ethnic minority backgrounds is just over half the life expectancy of their white counterparts (Race Equality Foundation 2023).

Mencap, a charity that supports people with a learning disability, argues that health inequalities experienced by people with learning disabilities are not inevitable, but are the result of “poor quality healthcare causing avoidable deaths” (2023).

Research identifies key challenges in accessing healthcare services, including timely identification of needs, accessing appropriate services, and quality interactions during consultations. Barriers include long waiting lists, short consultation slots, insufficient joint working between healthcare and social care services, limitations on carer participation, and inadequate

transport links (Mencap 2023; Care Quality Commission (CQC) 2022; Blair 2016; Sakellariou and Rotarou 2017).

While fewer studies focus on autistic individuals accessing healthcare, reports suggest failings in identifying autistic individuals who do not have learning disabilities and a lack of staff knowledge to provide suitable care (CQC 2022).

From an intersectional perspective, individuals from ethnic minority backgrounds with learning disabilities encounter additional problems such as language barriers, cultural insensitivity, and racial discrimination from healthcare providers (Race Equality Foundation 2023).

Recommendations to address these disparities include holding providers accountable for service standards, involving individuals with communication needs in service design, and implementing existing policies related to learning disabilities (Healthwatch Southwark 2022; Race Equality Foundation 2023).

### **Local findings**

At the local level, Southwark's Joint Strategic Needs Assessment (JSNA) on Learning Disabilities revealed low uptake of seasonal flu immunisation and lower rates of cancer screening among individuals with learning disabilities (Southwark Council 2018). The JSNA recommended efforts to promote greater participation in annual health checks and emphasised the need for formal engagement with individuals with learning disabilities, carers, and service providers to improve service provision.

Additionally, a 'Have Your Say' event was held by Southwark's Health Ambassadors in August 2022, gathering feedback from 34 participants, including 17 service users with learning disabilities and/or autism (Advocacy in Greenwich 2022). The event highlighted several barriers to healthcare access, including digital exclusion, poor communication with patients, and overwhelming medical environments. However, deeper engagement with service users and carers is necessary to fully understand the issues identified during this event.

## 2.2. Aims

Our project aims to build upon and help deliver the recommendations identified in existing work. To achieve this, we set out to:

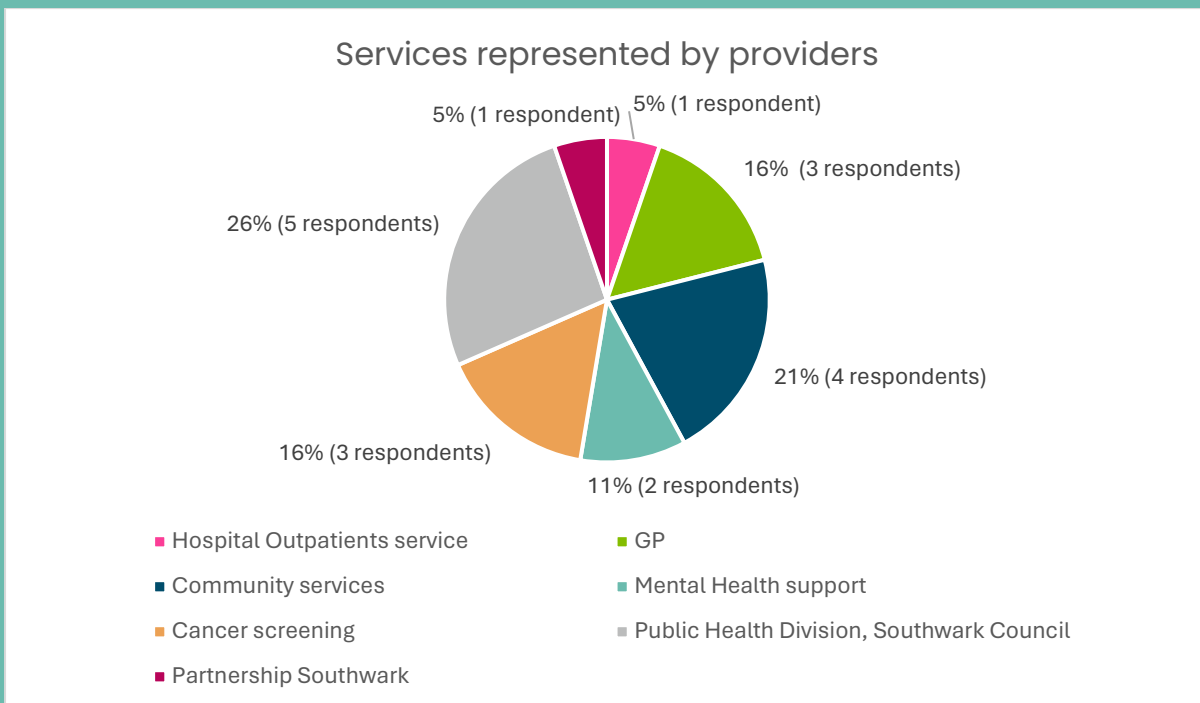
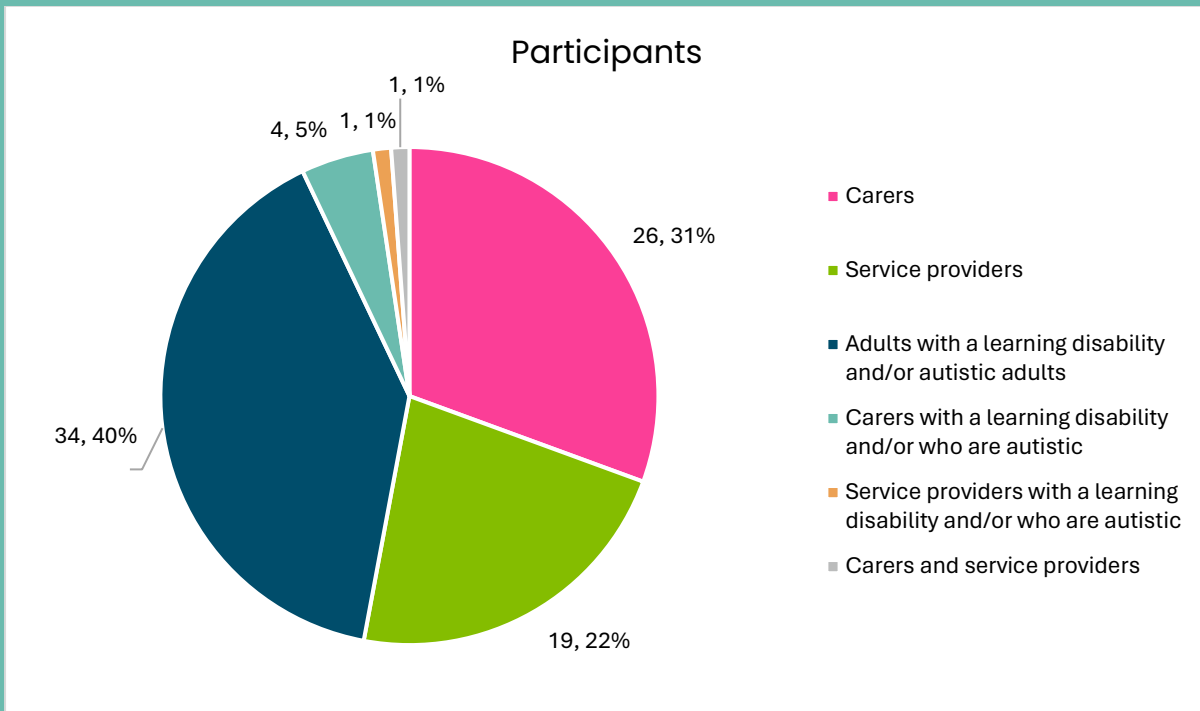


We prioritised the engagement of service users and carers from ethnic minority backgrounds, recognising the additional disparities in health outcomes between people with learning disabilities and autistic people from ethnic minority backgrounds and those from white ethnic backgrounds (Race Equality Foundation 2023).

## 2.3. Methodology

Between September 2023 and February 2024, we engaged with 104 participants through a survey and three Café Conversations events. Although we offered to hold individual interviews, none were requested.

Respondents included adults with learning disabilities and autistic adults (40% or 34 individuals), carers (31% or 26 individuals), and healthcare professionals who provide services for this group (22% or 19 individuals). Six respondents (7%) belonged to more than one of these categories. We aimed to include service providers, as this perspective has previously been underrepresented. Additionally, 66% of respondents (69 individuals) identified as being from ethnic minority backgrounds. We collaborated with voluntary and community sector organisations supporting adults with learning disabilities and autistic adults to reach our target groups effectively.



## Survey

Our survey employed a branching structure tailored for three distinct participant groups (service users, carers, and service providers), with slightly different sets of questions to capture the different perspective of each group. Those identifying with multiple groups were directed along one survey branch and offered the opportunity to provide additional feedback directly. Bede House Day Centre piloted the survey draft with 20 service users to assess the accessibility and efficacy of the questions.<sup>1</sup>

The final survey included a mix of closed and open questions to gather detailed personal experiences. It was distributed online and promoted by voluntary and community sector groups (VCS), Southwark Council, and care providers' internal and external communications. We also circulated physical copies at Bede House and Cherry Gardens Day Centres. We obtained 51 responses, yielding both quantitative and qualitative data. While this study relies predominantly on qualitative analysis for narrative capture, quantitative data is useful for identifying service usage patterns and feedback trends.

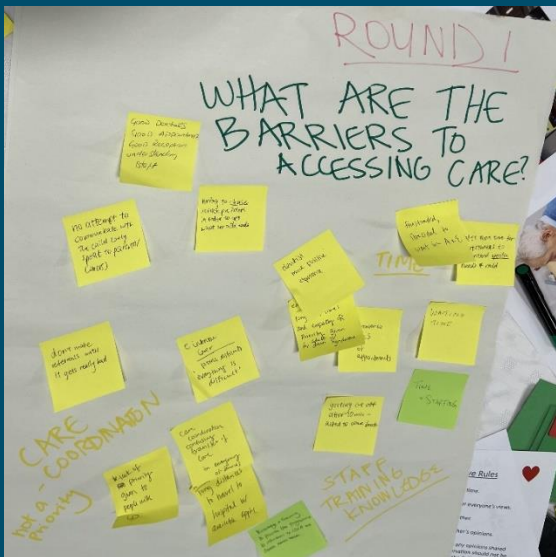
## Café Conversations

We organised three events, utilising the World Café workshop methodology to facilitate deeper, richer engagement. Service users, carers, and providers were brought together to discuss three rounds of questions, culminating in an opportunity to brainstorm solutions for how to improve healthcare access. These events, facilitated by local voluntary and community sector groups- Autism Voice, Bede House Day Centre, and Cherry Gardens Day Centre- provided familiar settings for respondents. In total, 53 people attended these events.

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<sup>1</sup> We followed guidance from Mencap (2023) and South East London Integrated Care System (2022) on involving people with a learning disability in research and consulted the project steering group for insight into appropriate methods and topics to include for this group, e.g. health promotion initiatives.

# Photographs from Café Conversations.



## 2.4. Analysis

We used thematic analysis to process our qualitative data, focusing on how people described their experiences and what this revealed about healthcare services. We employed an inductive approach to let the data shape our themes.

Initially, we coded the data to describe expressed ideas, then grouped codes to form broader themes. These themes were reviewed across the dataset to ensure they provide comprehensive and accurate representations of recurring issues and key ideas.

## 2.5. Challenges

We received feedback from service providers that the project aims were too general to produce focused outcomes. Based on this feedback, we polled a shortlist of more specific topics that had been flagged as priority areas by providers. However, VCS groups and carers responded that it was difficult to choose one priority area, as service users experience barriers to accessing services across the entire healthcare system.

This presented a challenge, as the narrowing requested by service providers reflects the way that organisational improvements are actioned but does not align with community feedback about a whole-system issue.

The decision was made to maintain the project's broad focus to better understand service users' and carers' perspectives on improving access to healthcare services. This approach aligns with recommendations from Healthwatch England (2022) and Healthwatch Sheffield (2016) to establish a foundational understanding of the communication, information, and access needs for people with learning disabilities and autistic adults.

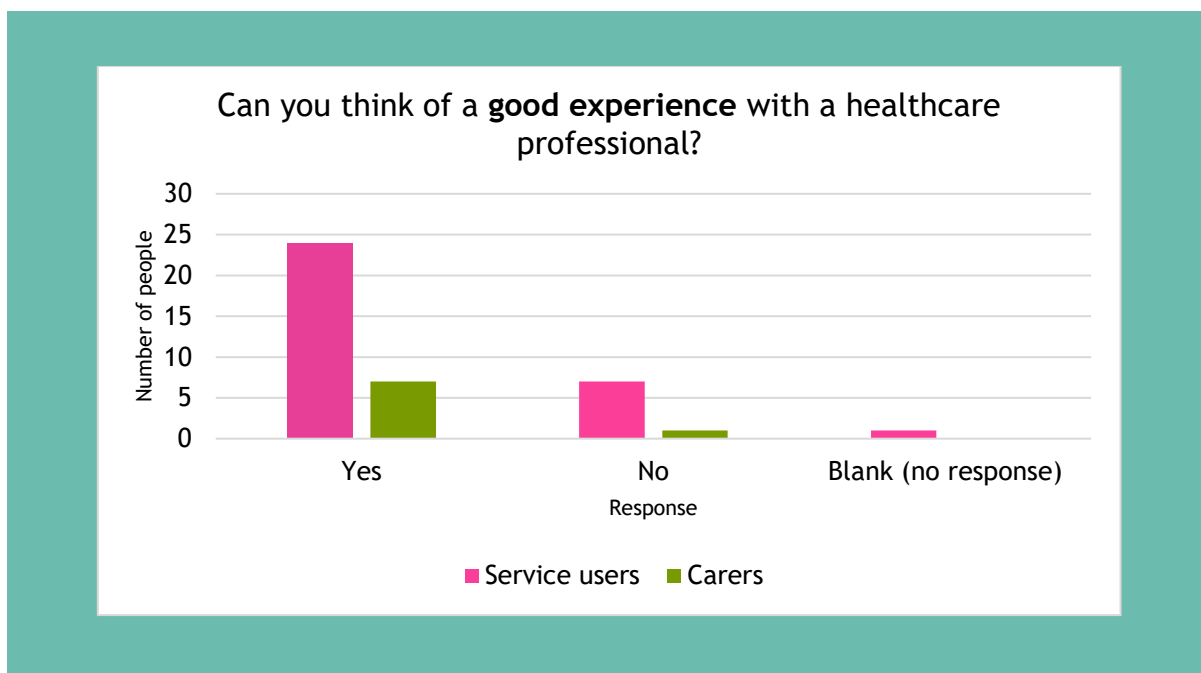


### 3. Findings

We asked service users and carers about their experiences of accessing healthcare services. **78%** of service users and carers (31 individuals) we spoke to said they have had at least one **good experience** with healthcare professionals. These experiences included kind and helpful staff, timely appointments, and good continuity of care.



“There is a national shortage for my treatment and the GP was fantastic in finding a solution. I was very anxious and catastrophising and assumed nothing would happen, but my GP was very attentive, kind, and took steps to remedy the situation including engaging with the local chemist.”

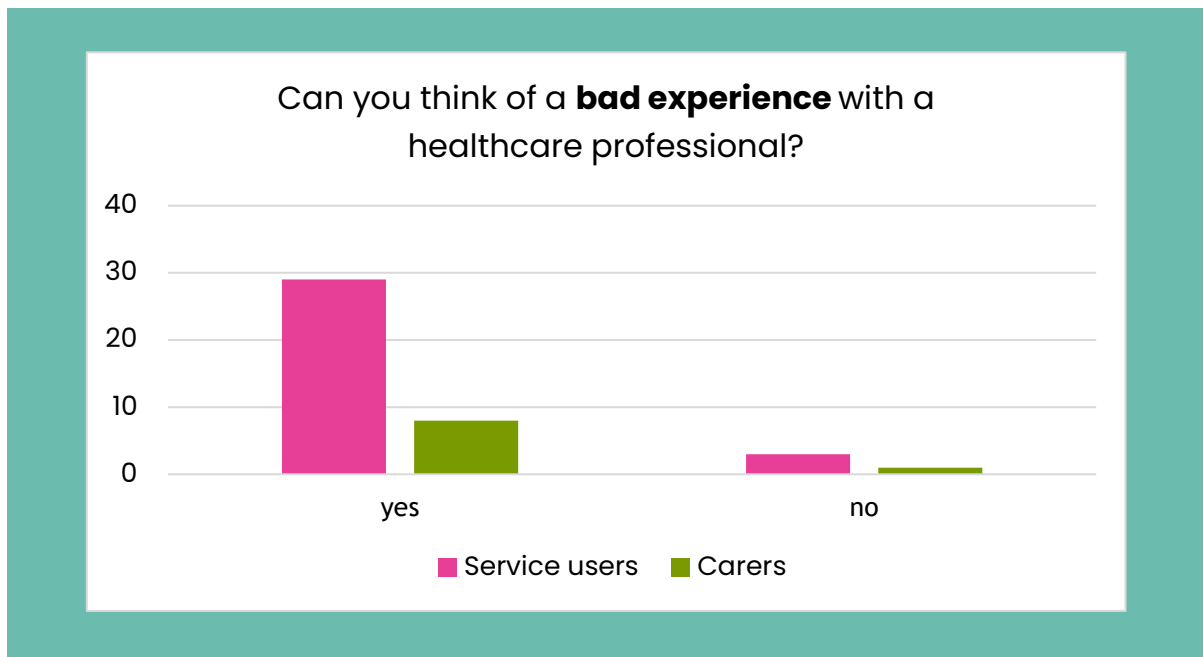


However, **90%** of service users and carers (37 individuals) said they have had at least one **bad experience** with healthcare professionals. The reasons given were wide-ranging, including rude staff, inaccessible buildings, and a lack of follow-up care.

“I’m constantly having bad experiences, constantly not being followed up with the specialist.”



“I’ve had too many to share, unfortunately. I expect the worst, perhaps a trauma response now. Sometimes when professionals know I’m autistic they treat me like a child or don’t expand upon my questions. Others previously have dismissed my concerns and not followed through for me – they say one thing, but subsequent actions do not match.”



We asked follow-up questions to understand what is currently working well for this group and to pinpoint areas that require improvement.

We grouped the barriers identified by respondents into four themes to make our findings more accessible to all audiences. However, we recognise that there is substantial overlap between themes.

## Staff-Related Issues



### 3.1. Staff Attitude

Most of the feedback we received centred around the attitudes of healthcare staff, particularly how staff communicated with service users and carers, and made them feel.

Positive feedback included,



“My doctor is funny and likes football.”

“Our GP is very engaged and treats our daughter with care and respect.”

Respondents emphasised the importance of friendly conversation with healthcare professionals to facilitate access to healthcare; building rapport during appointments creates trust and can foster a positive association with healthcare services.



However, the volume of negative feedback we received regarding staff attitude was far greater, with service users and carers describing feeling ignored, rushed, and patronised when communicating with healthcare professionals. This feedback was regarding doctors, nurses and receptionists.

“When I was in hospital, they didn’t talk to me, I was left alone, and the nurses were horrible...I never want to go to hospital again.”



The sentiments expressed here recurred throughout our data, with several service users explaining that the feelings induced by negative interactions with healthcare professionals make them reluctant to return to services for support.

alone horrible dismissed confused  
 patronising frustrated  
 overwhelmed challenged stressful  
 rude upset  
 ashamed rushed misunderstood  
 lost ignored anxious

### 3.2. Communication During Appointments

Adults with learning disabilities and autistic adults often find it challenging to communicate with healthcare professionals during appointments, particularly in mainstream services. Barriers to communication include the use of complex language and medical jargon, and not being given enough time and support to understand.



"I didn't understand what was going on. The doctor didn't give me time to speak."



One carer said that staff did not explain why her son's medication was being changed and ignored her questions. She described feeling "like the staff were blaming me."

This can be particularly challenging for people with multiple disabilities, who may experience greater difficulty with communicating and understanding.



For example, a service user who has a learning disability and a hearing impairment said, "I've given up. They don't do anything for me, they don't listen to me because of my hearing."

Whilst two service providers said they find the use of visual communication methods such as Picture Exchange Communication System (PECS) or Makaton to be effective during appointments with adults with learning disabilities and autistic adults, they acknowledged that these methods are

not available in all services, particularly mainstream services such as primary care.

### 3.3. Staff Knowledge and Understanding

Service users and carers expressed concerns about the limited understanding that healthcare professionals' have of learning disabilities and autism, especially in primary care and emergency services. They felt this lack of understanding led to poor quality care, with instances of misdiagnosis and incorrect medication.

One carer felt that her autistic son had been overmedicated due to the inability of healthcare professionals to identify his needs and provide appropriate support. This aligns with the national STOMP campaign, aimed at stopping the overmedication of people with a learning disability, autism, or both with psychotropic medications.

“Staff do not recognise people with autism as their own person. They act like all autism is the same when it is not.”

“For any vaccines (my son) receives, there is no understanding on how to deal with learning disability.”



While **70%** of service providers (7 individuals) reported receiving sufficient training to support adults with learning disabilities and autistic adults, they acknowledged that the level of training provided differs across services.

“Yes (I have received sufficient training), but I work in a specialist service, I do not think that is the case for mainstream mental health or physical health services.”



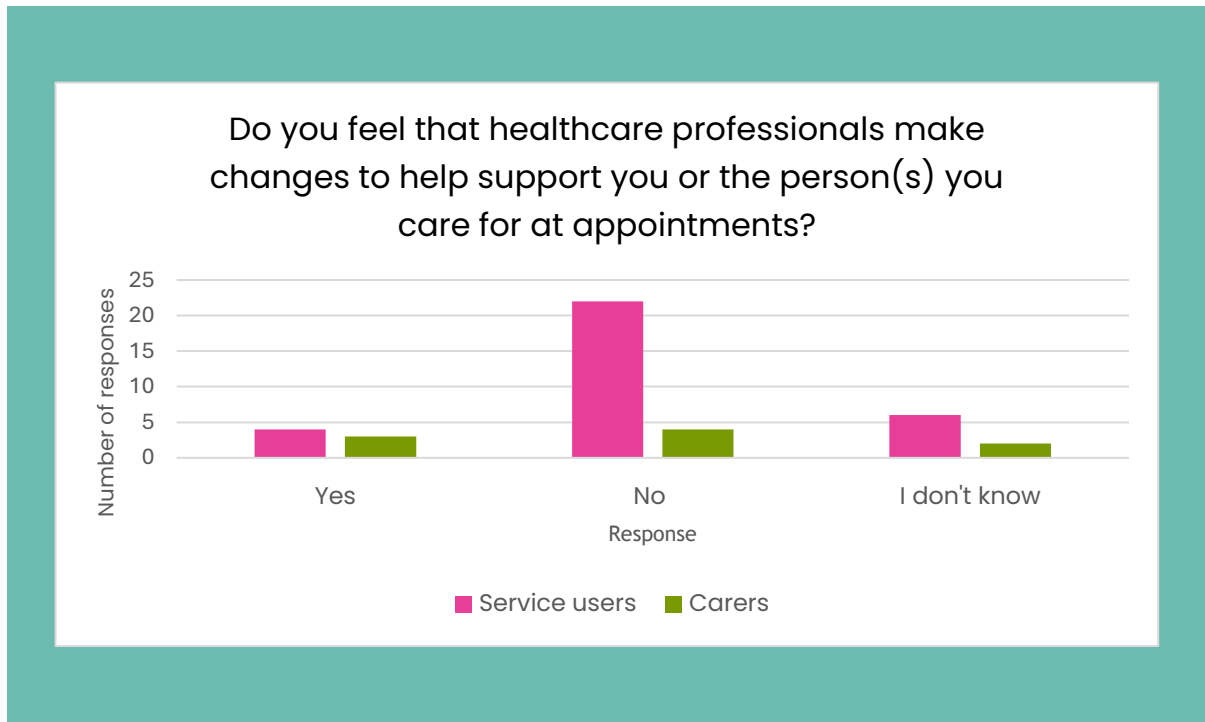
One response highlighted the value of lived experience in meeting the needs of this group,

“Yes, but I am autistic myself and my information is based on my own research and experiences which help me to understand the different support needs or services which may help autistic adults.”



### 3.4. Reasonable Adjustments

When we asked service users and carers if healthcare professionals made changes to support them or the person they care for during appointments, **63%** of respondents (26 individuals) said no.



Examples of positive experiences where professionals made adjustments for patients include:



“My GP is really good and has in the past offered additional resources like easy read leaflets.”



“They understood that I have a lot of anxiety around hospitals. Letting me take my dog to the appointment helped.”

More frequently, service users and carers reported mixed experiences, stating that the support they received differed depending on the healthcare professional or service they encountered.



“It depends. Sometimes they do (make changes), sometimes they don’t. Most of the time they don’t though.”



Referring to a lanyard used to indicate a hidden disability, "When my child had an accident and ended up in A&E, the flower lanyard and 'I'm autistic' badge meant nothing."



Two individuals reported that despite requesting adjustments, none were made, "I have expressed during my x-ray that I prefer to have only one person in the room which the nurse said she would make a note of but I've yet to receive any accommodations following my autism diagnosis."

Service providers noted that patients often struggle to access reasonable adjustments in non-specialist services, explaining that "mainstream services are not set up to offer reasonable adjustments." For example, some GPs offer home visits whilst others do not due to lack of capacity.



"Not every surgery is the same, some are better prepared and aware of care needed."

## Patient-Centred Issues



### 3.5. Feelings and Anxiety

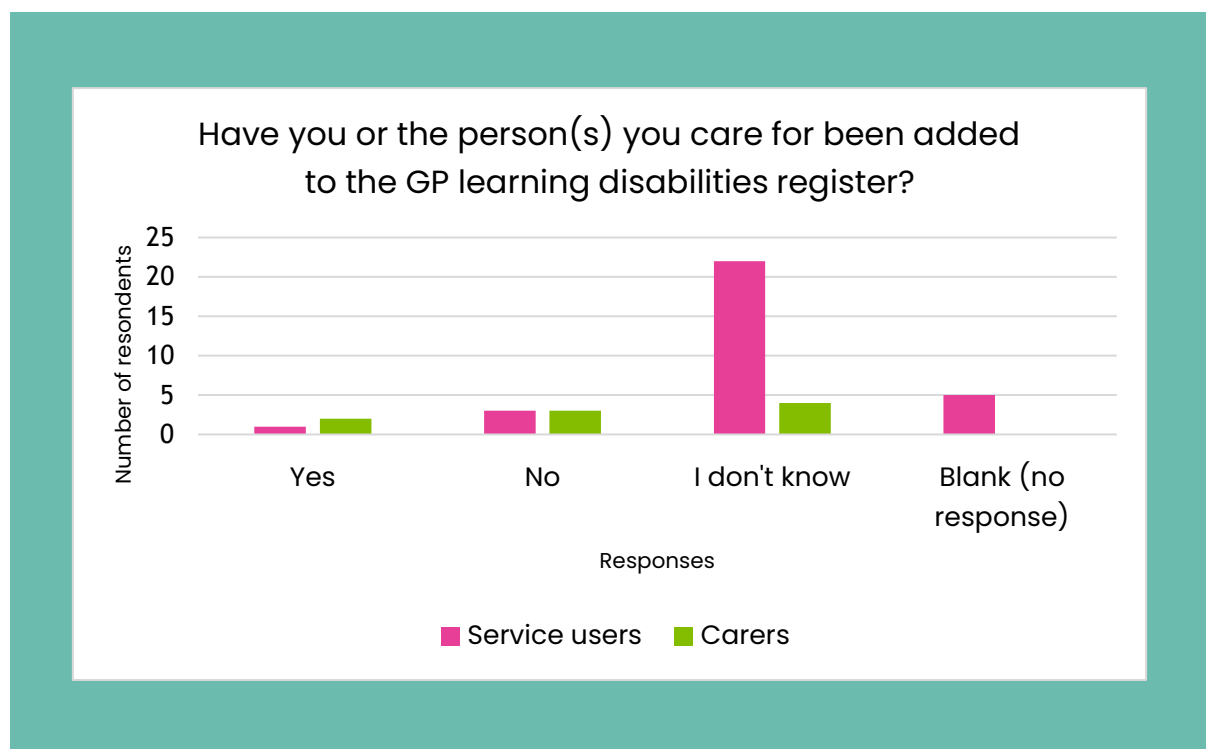
Many service users expressed fear and anxiety about accessing healthcare services, especially for routine procedures like dental checks or vaccinations. This can stem from past negative experiences, fear of pain, aversion to touch, and sensory sensitivities. As discussed, lack of communication from service providers intensifies these feelings. Dental appointments were specifically highlighted as challenging, despite the availability of specialised support from community dental services for people with learning disabilities and autistic people. Respondents described feeling overwhelmed and frightened during these appointments.

"The dentist is really scary. I don't like to open my mouth... It's scary."



### 3.6. Service User and Carer Knowledge

Despite national and local reports indicating increased uptake of health promotion initiatives for adults with learning disabilities and autistic adults (NHS Digital 2019; Southwark Council 2018), our findings revealed that many service users were unaware of these initiatives. For instance, individuals must be added to their GP Learning Disability Register to access initiatives like annual health checks and flu vaccinations, yet **65%** of service users and carers (26 individuals) did not know their registration status.<sup>2</sup>

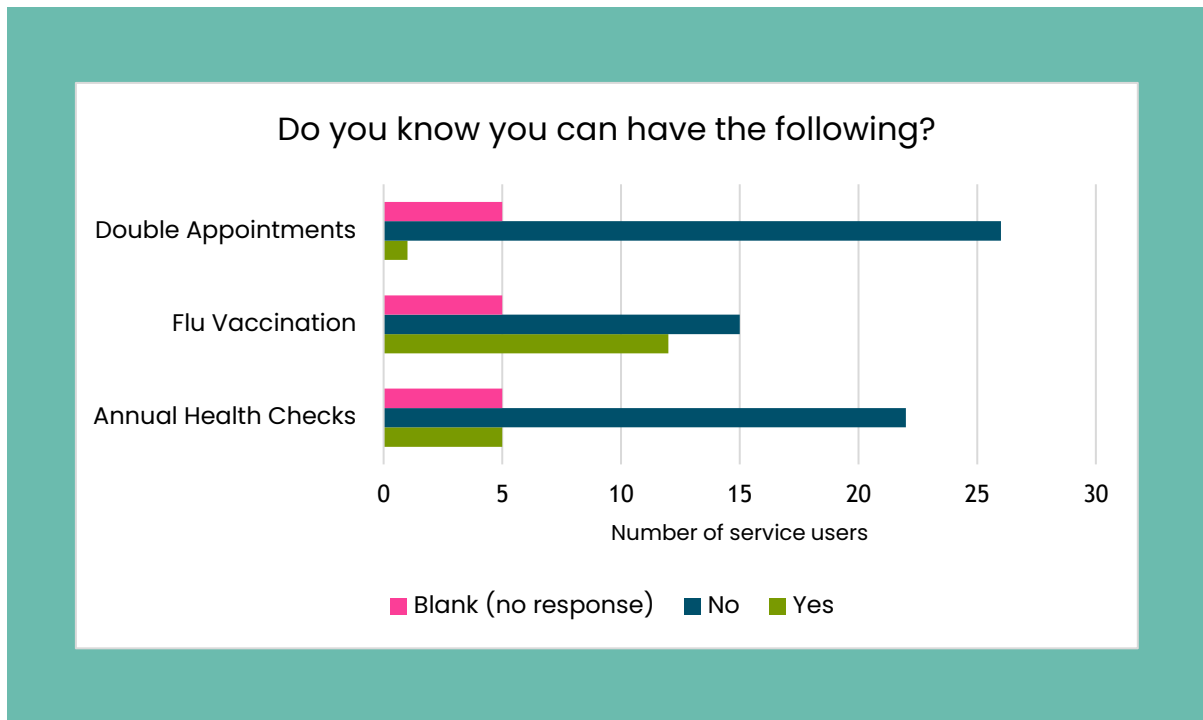


Furthermore, when asked about entitlements such as double appointments, annual flu vaccinations, and health checks, a significant proportion of service users were unaware of their rights. For example, **81%** (26 individuals) were unaware of their entitlement to double appointments, despite time constraints being identified as a major barrier to healthcare access.

<sup>2</sup> This question was only asked to people with learning disabilities and people who care for someone with a learning disability, as autistic people who do not have a learning disability are not included on GP Learning Disability Registers.



Similarly, **69%** (22 individuals) did not know they were entitled to annual health checks, indicating a lack of information about the care they receive.<sup>3</sup> This suggests that whilst measures are in place to improve access to healthcare services for people with learning disabilities, they are not widely understood by service users.



Service users and carers emphasised the need for clearer information about available services and adjustments, expressing frustration with the lack of accessible resources. While a local offer exists for young people with

<sup>3</sup> Feedback we received on the quality of annual health checks was mixed, "Good experience. Consultant at Guy's & St Thomas's made sure to cover all areas of health in annual review."  
 "GP annual health checks are not great. They keep asking the same questions and irrelevant questions e.g. if my son smokes or drinks when he has severe disabilities! They have 20 years of notes in his files from many doctors, yet I have to sit for an hour answering questions about his health history."  
 However, as the majority of respondents did not know what the annual health check was, this feedback was limited.

special educational needs, there is no comprehensive equivalent for adults.<sup>4</sup>



“There should be more information in accessible formats, not just ‘go online’.”



“Services would be better if information was more transparent and accessible. More flyers, brochures etc. in easy read formats.”

### 3.7. Exclusion from Patient Care

Some service users felt uninformed and excluded from decision-making about their own care, as healthcare professionals only communicate with their carers, depriving them of independence and privacy.

“They speak about me, not to me.”



Conversely, some carers felt marginalised in decision-making about the health of the person they care for, despite their expertise relating to the individual's needs.

“Doctors need to listen more to what carers say, because while they are medical experts, we are the ones who live with them day-to-day and know them better.”



Thus, the extent to which carers should be involved in healthcare varies depending on the individual's needs and preferences, underscoring the importance of tailored care.

### 3.8. Medical Environments

We received feedback indicating that the busy and unfamiliar environments of healthcare facilities can be distressing for adults with learning disabilities and autistic adults due to overstimulation. Respondents described feeling anxious and overwhelmed by loud noises, bright lights,

<sup>4</sup> The Local Offer is provided by Southwark Information Advice and Support Team (SIAS) which offers a directory of services for young people aged 0-25 who have special educational needs, as well as advice on how to navigate SEND services for families of young people.

and crowded waiting areas. Additionally, the lack of privacy in waiting areas can be distressing for carers who feel conscious of disturbing other patients.

“I don’t like the ambulance sirens. They annoy me, they are really scary.”



“They made me wait for ages in a really busy area that was so anxiety provoking, and I was not allowed to make noise.”

Furthermore, individuals with co-existing physical disabilities highlighted additional challenges with accessing care due to a lack of wheelchair access in some facilities. This can lead to patients being seen in unsuitable locations, causing further distress and discomfort.



For example, one respondent described feeling “traumatised” after having their blood pressure checked in the hallway of their GP practice. “The check was not in a private, reasonable space.”



“There is no lift in my local GP surgery, only a stair lift which my son can’t access.”

## Operational Issues



### 3.9. Communication Outside of Appointments

Service users and carers reported difficulties contacting healthcare services when needed, hindering appointment bookings, follow-ups, and access to patient records. Limited communication options, primarily by telephone, fail to accommodate diverse needs. Additionally, services using withheld telephone numbers and email addresses that discourage replies or are not clearly identifiable can be off-putting for service users and carers, making it “hard to trust” who is contacting them.

One service provider stated, “Many hospital departments do not allow booking via email or web form. They always seem to insist that one phones or expects a call back from a ‘private number’.”



Carers also shared that staff frequently do not answer phone calls and it can be difficult to find the correct telephone number for services.

“I can never get through to staff if I have a problem. I was meant to receive a call from the hospital but it didn’t happen, though I was waiting with my phone by my side all day. Then I received a missed call from a private number and no voicemail was left.”



### 3.10. Inflexible Appointments

Lack of flexibility around the times, locations, and structure of appointments poses a significant barrier for adults with learning disabilities and autistic adults seeking healthcare. Appointments scheduled during typical working hours can be challenging for carers to attend and disrupt the daily routines of service users, causing emotional distress.

For example, one service user expressed reluctance to go to the hospital because it meant missing activities at the day centre he attends. He suggested that having a nurse visit the day centre instead would be more convenient, allowing him to receive treatment without leaving his familiar environment and staying with his friends and day centre staff.



“It is important to be flexible and not disrupt routines with appointments. Make things convenient. Come to the community centre, spaces where people feel comfortable.”

Moreover, limitations on appointment duration and the number of issues that can be addressed per appointment further prevent access to healthcare, particularly with GPs. One respondent recounted waiting a year for an appointment where all their concerns had to be addressed in a single session.



“The appointment times are too short (to discuss everything), especially when you have to explain your problems to someone who isn’t familiar with your medical history.”

### 3.11. Poor Care Continuity

Several respondents reported a lack of follow-up or aftercare following appointments. This was attributed to poor communication within and between services, leading to uncertainty about who is responsible for patient care. For example, one service user described being referred to a community dental practice by their GP in 2019 but had not received any further communication.

Others highlighted issues with the support received post-diagnosis.

One service user described feeling abandoned, “They simply gave a diagnosis and that is it. No support for my child once he was diagnosed, especially (transitioning to adult services), there was no follow up care.”



Moreover, several service users faced challenges in accessing medication due to coordination issues between doctors and pharmacists. Problems with repeat prescriptions resulted in interruption to treatment, causing distress for those reliant on long-term medication.

Carers also noted a significant reduction in support for service users after they transition from child to adult services, despite service users’ needs remaining the same. With no Local Offer tailored for adults with learning disabilities and autistic adults, service users, carers, and service providers found it challenging to locate appropriate support from healthcare services and within the voluntary and community sector (VCS). Service providers echoed the need for a more personalised approach to the transition to adult care, emphasising the importance of addressing individual needs.

### 3.12. Diagnosis


Access to specialised services and reasonable adjustments often requires service users to meet eligibility criteria or “thresholds” such as having a formal diagnosis of a learning disability or autism.

Receiving a diagnosis can be challenging due to factors such as long waiting times to access diagnostic services, individual differences in

presentation, and reluctance to pursue or accept a diagnosis from service users and carers due to culture, belief, lack of information or stigmatisation.

There are also gendered implications to the requirement for diagnosis to access services, as women are less likely to be diagnosed with autism than men due to gender biases (Brickhill et al., 2023).

Without a diagnosis, service users are forced to seek support from services that are ill-suited to their needs, which can lead to poor treatment outcomes and negative experiences with healthcare interventions. This cycle may deter them from seeking healthcare again in the future.

 As highlighted by one individual's experience, "My autism was diagnosed very late and was a battle." Moreover, a service provider noted, "The referral pathway to access an ASD [autism spectrum disorder assessment] is particularly unclear in Southwark."

### 3.13. Staff Turnover

We received feedback indicating that consistent interaction with the same service providers significantly improves the experiences of adults with learning disabilities and autistic adults, and their carers, when accessing healthcare services, as it fosters trust and understanding between staff and patients.

One service user explained, "I like to see the same GP, my preferred GP accommodates me. I feel listened to and heard."



As mentioned previously, service users often find that the quality of care varies depending on the healthcare professional they encounter. Staff turnover during treatment can be distressing for adults with learning disabilities and autistic adults, as they may struggle to repeatedly explain their history and preferences to different healthcare professionals. This contributes to feeling overwhelmed and disenchanted about service providers, as patients are unable to build rapport with staff.

“It’s too confusing seeing different people every time. A lot of explaining to staff although they have notes on the system. It’s draining.”



## Social Factors

Wider determinants of health including socioeconomic status, race, and ethnicity impact health outcomes for everyone. However, when combined with the additional challenges that adults with learning disabilities and autistic adults experience in their daily lives, these factors can severely limit their ability to access the healthcare they need.



### 3.14. Financial Hardship

Respondents noted that the inability to afford essentials negatively affects both their overall health and wellbeing, as well as their ability to access healthcare services.



“When there are other demands on daily life, health is deprioritised.”

### 3.15. Isolation

Individuals who lack local connections, such as friends, family, community support, or social care links may be less likely to engage with healthcare providers, despite being more likely to face mental health issues. Service users reiterated the importance of friends and family to their overall wellbeing and ability to access care.

### 3.16. Role of Carers

Service users explained that they rely on their carers to help them book, attend, and communicate during appointments, as well as providing emotional support and managing medication. This poses a significant challenge to those who do not have full-time carers or whose carers are disabled.

**Case Study:** Staff at a day centre shared that one of their clients, an individual who is non-verbal and has a physical disability, was sent home from A&E without receiving treatment. The individual's carer was too old (90 years of age) to go to the hospital and advocate on his behalf.

"He wouldn't cooperate when they (healthcare professionals) saw him, because he didn't understand what they wanted or why – so they sent him home. They wanted to do an X-Ray with him in his wheelchair... you can't do that. So, they just sent him home."



This case study highlights how multiple barriers intersect to prevent access to suitable healthcare. This individual was not provided with reasonable adjustments and did not have the support of a carer to advocate for him.

Carers also highlighted the need for better support for carers, as age and the demands of caregiving can diminish their capacity over time. As asked by one respondent, "who cares for carers?"

### 3.17. Racial Inequalities

There is an overrepresentation of young Black men (18-24) in Southwark Learning Disability services, particularly in crisis services such as the Intensive Support Team (IST) (Davonport et al., 2023). Service providers noted that Black men with learning disabilities tend to access mental health services at crisis point or via adverse pathways such as police intervention, indicating systemic barriers to accessing timely support. Reports suggest that apprehension or distrust in healthcare professionals, stemming from personal experiences or community mistreatment, contribute to these barriers for young Black men with learning disabilities (Devonport et al., 2022 cited in Davonport et al., 2023).



### 3. Recommendations

We asked respondents for suggestions on how to make healthcare services more accessible to adults with learning disabilities and autistic adults in Southwark. Based on their responses, as well as our own analysis of the findings, we have compiled a summary of targeted recommendations set out below.

We will share this with local stakeholders and work collaboratively to implement these recommendations.

#### Training

1. Provide and monitor the delivery of training for clinical and non-clinical healthcare staff about learning disabilities and autism. The Oliver McGowan Mandatory Training on Learning Disability and Autism should be prioritised as a baseline for all service providers. However, additional training such as guidance on Picture Exchange Communication System (PECS) or Makaton should also be considered if requested by staff or indicated in service user feedback.
2. Training should take an intersectional approach, acknowledging the overlap between learning disabilities, autism, physical and mental disabilities, as well as health inequalities between people with learning disabilities from ethnic minority backgrounds and those from white ethnic backgrounds.
3. Appoint an LDA Champion in each service who has completed or will receive additional training on learning disabilities and autism. The Champion should identify barriers and best practice within their service and represent learning disabilities and autism in patient experience and public participation groups. This could involve establishing a network of Champions across services to promote information-sharing.

#### Sharing Information

4. Facilitate or join events about learning disabilities and autism to promote information-sharing across services and sectors, including social care and the voluntary and community sector (VCS). Similar “information day” events should be held for the public in accessible spaces.
5. Specialist learning disability and autism services should liaise with mainstream services to share learnings and help implement adjustments. This could be through direct training or learning resources.
6. Implement a centralised system across services to record gaps in provision. For example, if a patient cannot access home visits at their GP, the case could be flagged for the primary care network to refer that patient to another GP within the network.
7. Promote and encourage carers to access carer’s support and request a Carer’s Assessment under the Care Act 2014.
8. Southwark Council should expand the Local Offer and Southwark Information and Advice Support Team (SIAS) to include services for adults over 25 with learning disabilities and autistic adults.<sup>5</sup>

## **Communications**

9. Carry out a self-audit of service information and contact details to ensure they are up to date and accessible to service users both on and offline, in accordance with the five mandatory actions set out in the Accessible Information Standard 2016.
10. Offer multiple methods of communication for patients to contact services e.g. email/website and telephone. Services should avoid using withheld telephone number systems to contact patients.
11. Provide information about health promotion initiatives, adjustments and support such as companion services that are available to

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<sup>5</sup> The Local Offer is provided by Southwark Council’s Information Advice and Support Team (SIAS) which offers a directory of services and up-to-date information for young people aged 0-25 who have special educational needs and disabilities (SEND), as well as advice on how to navigate SEND services for families of young people. [Southwark Information Advice and Support Team \(SIAS\) – Southwark Council](#)

service users and carers both online and in hard copies such as leaflets. Liaise with VCS groups to ensure that these resources reach service users and carers, and that resources about VCS support are available at healthcare sites.

12. Establish a standard easy read format to ensure consistency in the appearance of information across documents and services.





### **Operational Issues**

13. Configure services to recognise the overlap between learning disabilities and autism, as well as learning disabilities and physical disabilities. This could involve a duty for providers to collaborate on an individual's care and share interventions across services.
14. Register with NHS England for connection to the DAPB4019: Reasonable Adjustments Digital Flag asset to ensure that reasonable adjustments are known across services in line with the Equality Act 2010.
15. Improve staff continuity and handovers to streamline referrals. Staff should be encouraged to read case notes ahead of appointments to ensure that adjustments are made.
16. Conduct an NHS Equality Delivery System (EDS2) review of areas that are utilised by patients, where service users, carers, and VCS groups can review and recommend improvements.
17. Provide suitable patient environments that are accessible to people with physical disabilities and reduce the impact of sensory sensitivities, e.g. a quiet waiting area. Home visits and visits to day centres should be facilitated where possible to reduce disruption to routine.
18. Health and adult social care services should collect feedback from service users and carers to evaluate quality against the Accessible Information Standard 2016. This could involve facilitating focus groups, which would serve a double function of preventing social isolation and potentially encouraging more people to access support before crisis point.

19. Conduct an equality impact assessment (EIA) to identify disparities and mitigate discrimination for service users, particularly adults with learning disabilities and autistic adults who are from ethnic minority backgrounds. Develop an EIA action plan to improve equality of access while ensuring compliance with duties under the Equality Act 2010.

## Findings and Recommendations chart

Key:

	Staff-related Issues
	Patient-centred Issues
	Operational Issues
	Social Factors

Barrier	Recommendation(s)
Staff Attitude	1, 2
Communication During Appointments	1, 2, 3
Staff Knowledge and Understanding	1, 2, 3, 4, 5, 8
Reasonable Adjustments	1, 5, 6, 14, 15, 16
Feelings and Anxiety	1
Service User and Carer Knowledge	4, 8, 11, 12
Exclusion from Patient Care	1, 2
Medical Environments	17, 18
Communication Outside of Appointments	9, 10
Inflexible Appointments	13, 18
Poor Care Continuity	6
Diagnosis	6, 16
Staff Turnover	16
Financial Hardship	11
Isolation	11, 18
Role of Carers	7, 11
Racial Inequalities	18, 19

## 4. Conclusion

In conclusion, this report provides further evidence of the barriers that prevent adults with learning disabilities and autistic adults from accessing healthcare. Our findings align with and expand upon existing research that identifies a link between poorer health outcomes and a lack of suitable healthcare provision for individuals from these groups (Mencap 2023; CQC 2022; Blair 2016; Sakellariou and Rotarou 2017; Healthwatch England 2022). For example, our respondents corroborate Healthwatch England's findings that the statutory duty to meet the information and communication needs of service users with learning disabilities is being compromised (Healthwatch England 2022).

However, we also offer an alternative perspective to Southwark Council's (2018) reporting that the uptake of annual health checks in Southwark is increasing in line with the national picture. Our findings suggests that service users are not aware whether they are receiving health checks, indicating a need to move beyond the current means of impact evaluation which monitors the number of health checks performed, rather than the quality of health checks experienced by patients.

We worked with service users, carers, and service providers to develop recommendations that promote a comprehensive, intersectional approach to achieving equitable access to healthcare for adults with learning disabilities and autistic adults. We encourage providers and partners to work together to form responses and action plans, as many of the issues highlighted are system-wide.

### 5.1. Limitations and Opportunities for Future Research

This report prioritises in-depth engagement with a small number of respondents to generate quality feedback from historically

underrepresented groups. Future research should therefore expand upon the number of respondents and explore the views of men, as they remain underrepresented within this study.

Furthermore, research into the quality of health promotion initiatives such as annual health checks would offer valuable insights into how these initiatives are perceived and utilised by individuals, and could inform strategies to enhance their effectiveness.

A similar analysis of adult social care services would be useful to understand the broader support needs of adults with learning disabilities and autistic adults, and enable policymakers and service providers to develop joined-up support systems.

## 5.2. Next Steps

We will present this report back to the community and to key stakeholders including:

- Partnership Southwark Strategic Board Meeting
- Partnership Southwark/ Southwark Council Engagement Advisory Group
- Southwark Council Health and Wellbeing Board
- Southwark Council Health Scrutiny Committee
- King's College Hospital, Guy's & St Thomas' and South London & Maudsley – including trust liaison meetings
- King's Community and Health Research Board
- SEL ICB LDA Collaboration Meeting
- Southeast London Healthwatch Staff Network
- Southwark Adult Social Care
- Southwark Primary Care Network
- Local Dental Committee (Southwark)

In addition to presenting the report, healthcare providers will be asked to provide formal responses to the report and its recommendations. The report and providers' responses will be available to view on Healthwatch Southwark's website.

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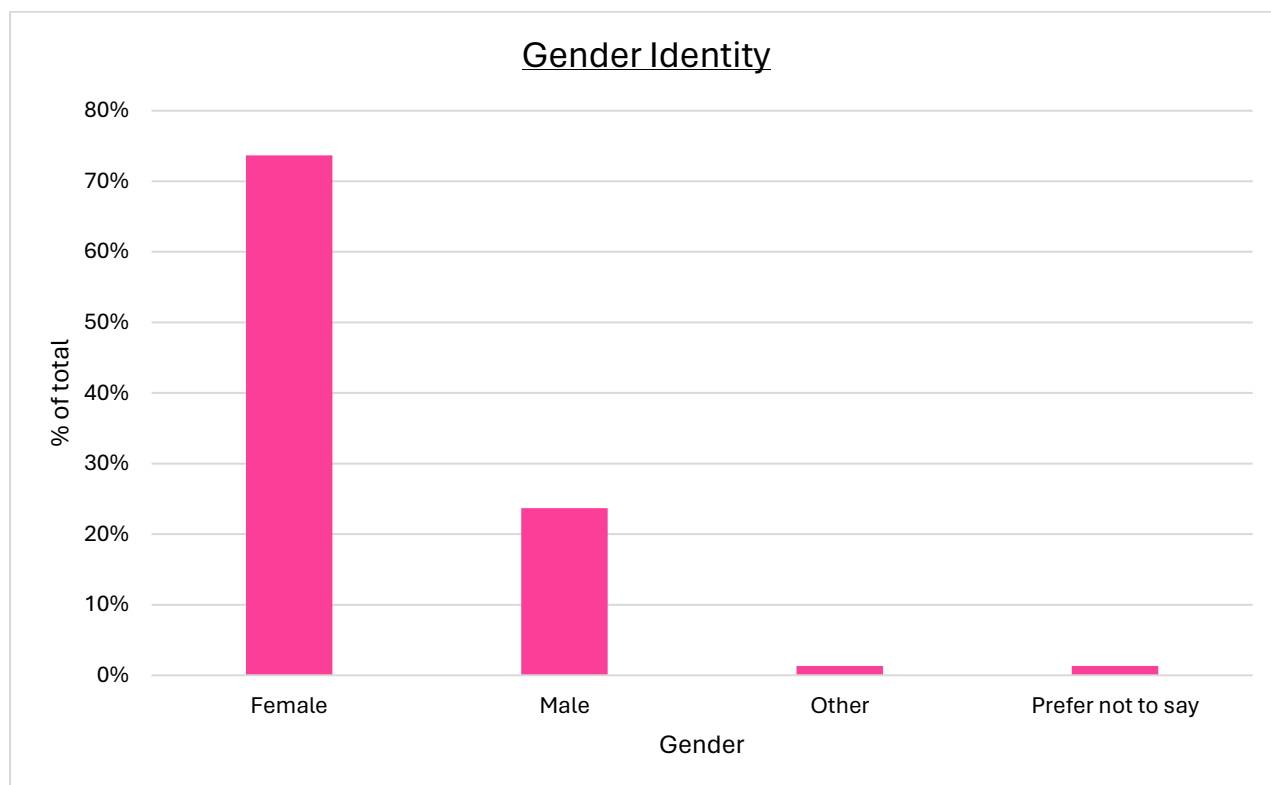
## Appendices

### Appendix 1- Equalities Data

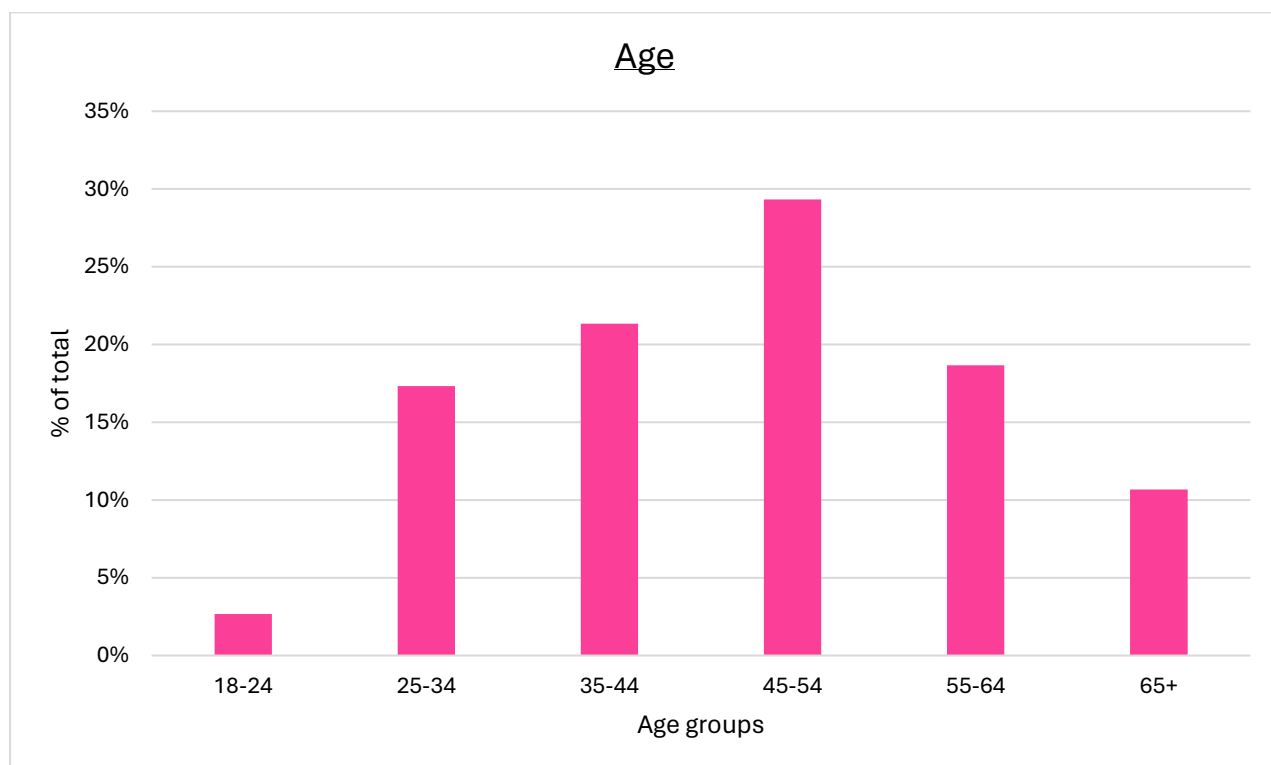
#### Ethnicity

Ethnicity	% of total
Arab/ Arab British	1%
Asian/ Asian British - Bangladeshi	1%
Asian/ Asian British - Japanese	1%
Asian/ Asian British - Pakistani	4%
Asian/ Asian British- Chinese	2%
Black - other	1%
Black/ Black British - African	23%
Black/ Black British - Caribbean	20%
Mixed - Black African and White	1%
Mixed - Black Caribbean and White	4%
Other - Kurdish	4%
Other	4%
Prefer not to say	1%
White British/ English/ Scottish/ Welsh/ Northern Irish	32%
White European	1%
White Traveller/ Irish Traveller/ Gypsy	1%

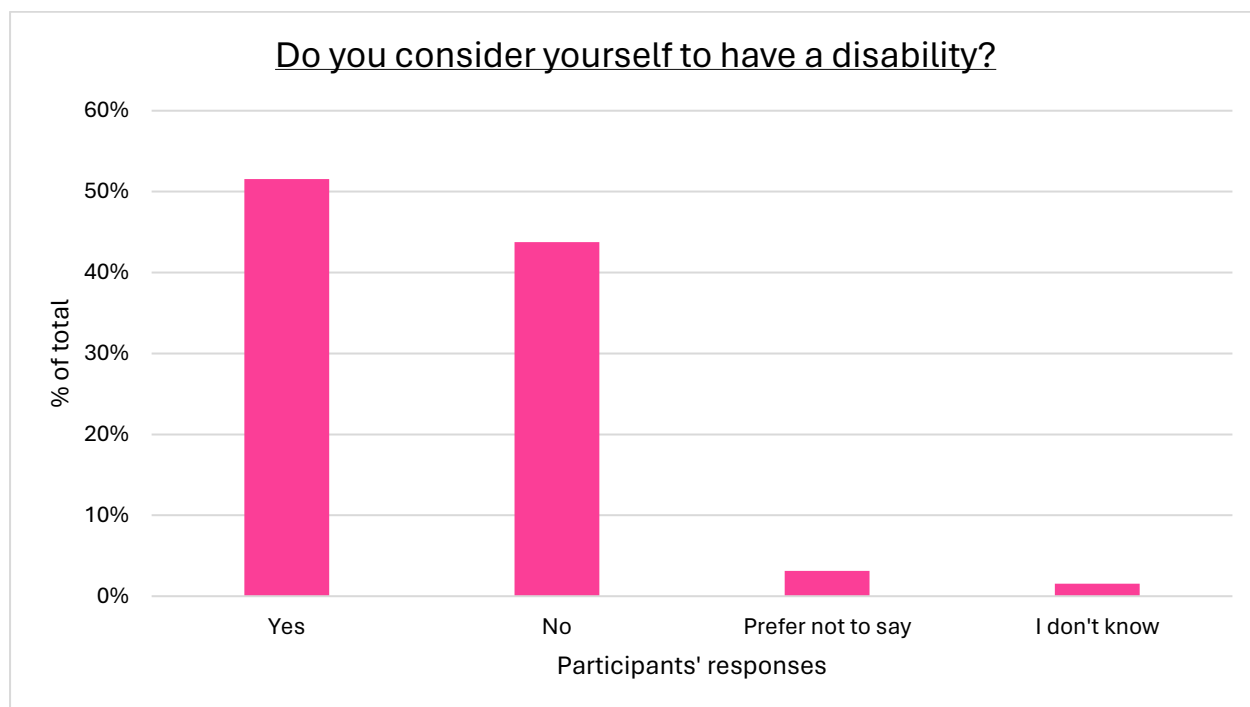
## Gender



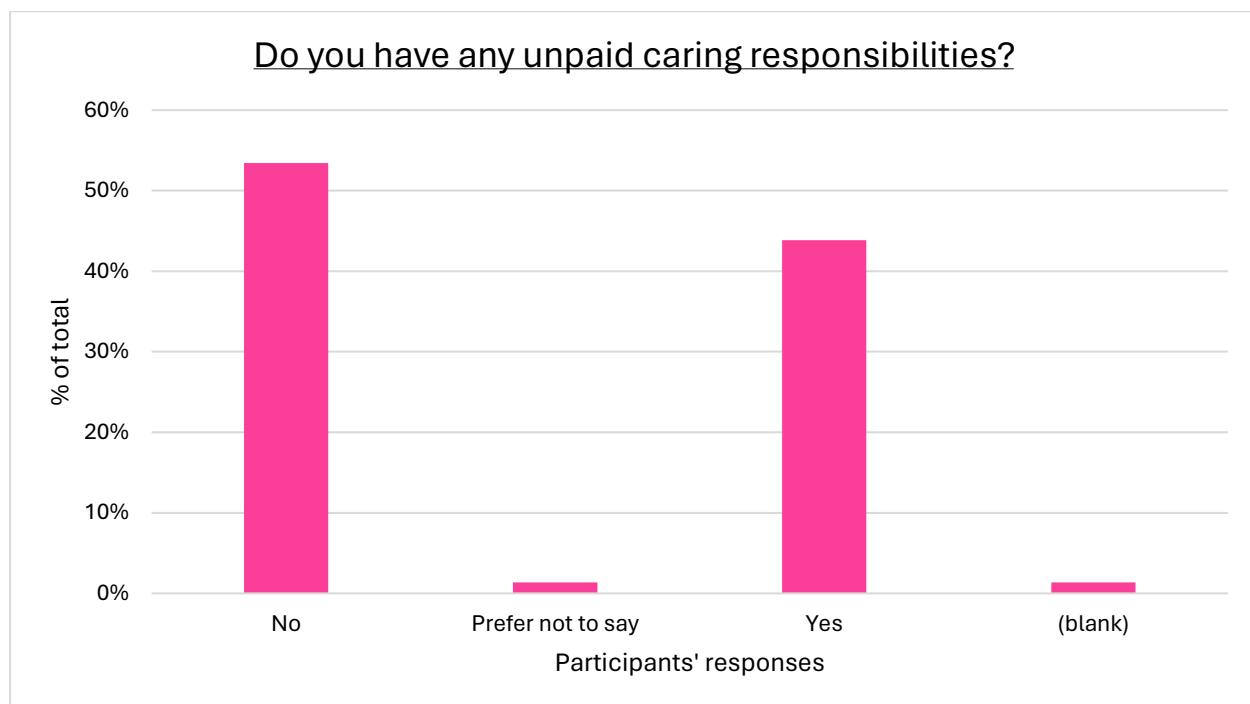
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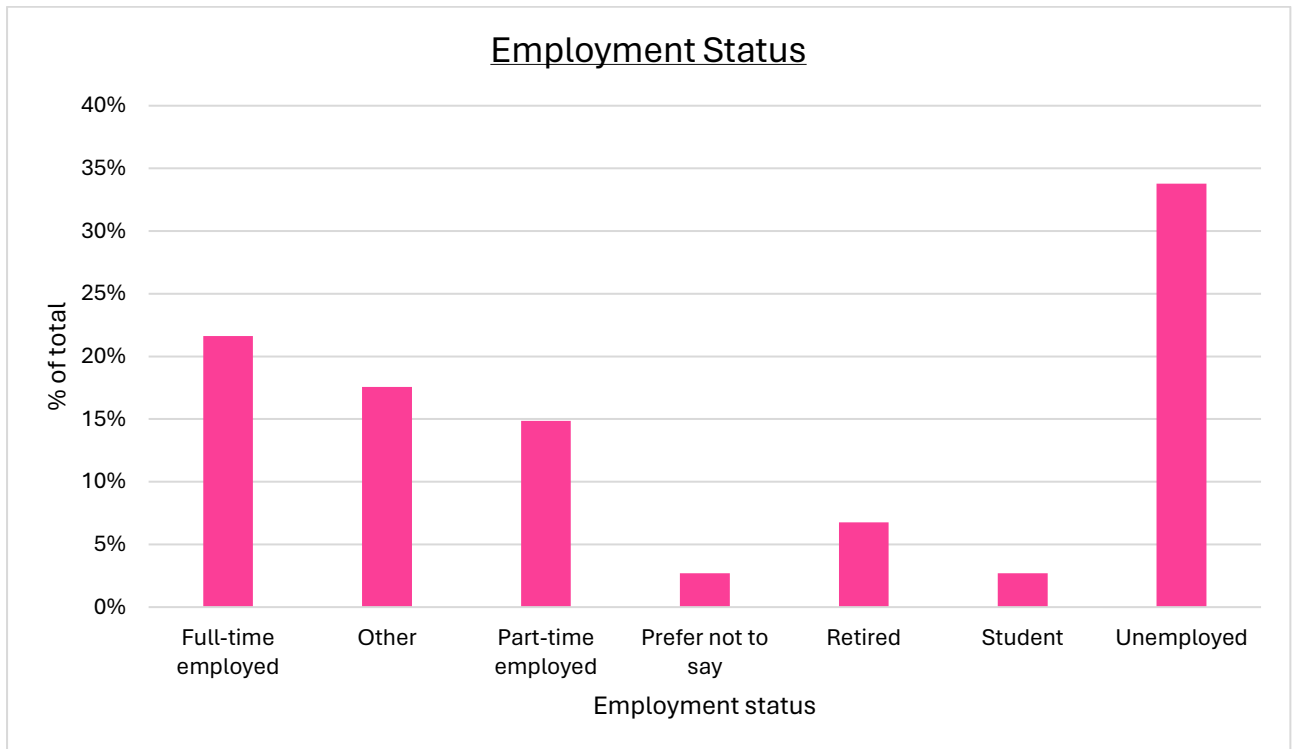
## Disability



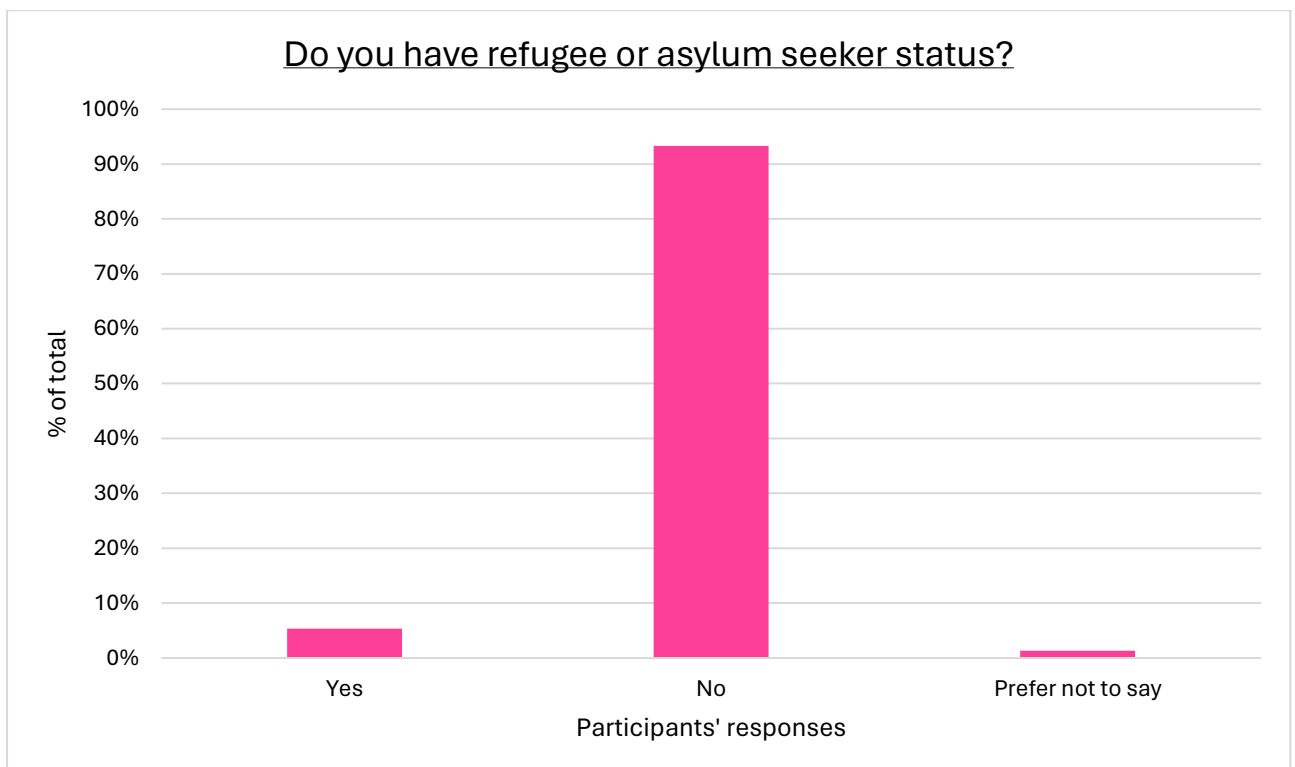
## Carer status



## Employment Status



## Refugee or Asylum Seeker Status



## Appendix 2- Survey



Start

**Healthwatch Southwark is your independent health and social care champion. We listen to local people about what matters to them and help decision-makers understand what they need to do to make things better so everyone finds healthcare services easier to use.**

**We are carrying out research to understand what changes need to be made to improve healthcare access for adults with learning disabilities and autistic adults.**

**If you would prefer to speak to us on the phone or in-person, please contact [ruman@healthwatchsouthwark.org](mailto:ruman@healthwatchsouthwark.org) or 07599653479**

**We will make sure that your data is confidential and treated securely. Please refer to our [Privacy Statement](#) here.**

1. Tell us who you are

We know that some people might fit into more than one of these groups. For example, you may be a carer who has a learning disability. If this describes you, please select one group and write the other in the comments box.

For example, select 'I am a carer' and write below 'I am a carer with a learning disability'

- I am an adult with a learning disability and/or autism
- I am a carer
- I am a service provider

Comments

## healthwatch Southwark

### Service Users

**These questions are for adults with a learning disability and/or autism.**

2. Are you autistic?



Yes



No



I don't know

3. Do you have a learning disability?



Yes



No



I don't know





4. Have you been added to your **GP learning disabilities register**?

The GP learning disability register is a list of all the people with a learning disability that your GP looks after. It helps GPs know what support people need.



Yes



No

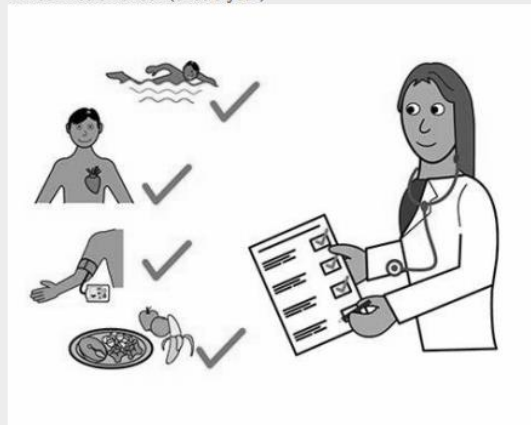


I don't know

5. Do you know you can have the following?

Yes  No

Annual Health Check (once a year)



Annual Flu Vaccination



Double-Appointments (when the doctor gives you extra time during an appointment)



6. Have you had an **annual health check** in the past 12 months?

Annual health checks gives people who are on their GP learning disabilities register an appointment with a doctor once a year to talk about anything that is worrying them.



Yes



No



I don't know

7. Can you think of a **good** experience with healthcare professionals? For example, at the GP, dentist or hospital?



Yes

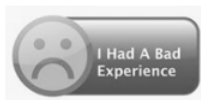


No

If yes, what made it good?

8. Can you think of a **bad** experience with healthcare professionals?

Healthcare professionals are people like doctors, nurses and receptionists at the GP or the hospital.



Yes



No

If yes, what made it bad?

9. Do you feel that healthcare professionals **make changes to help support you** at appointments?

For example, does your GP give you easy read leaflets, more time, or see you first?

Healthcare professionals are people like doctors, nurses and receptionists at the GP or the hospital.



Yes



No



I don't know

Any other comments (optional)

10. What should healthcare professionals do to **make it easier** for you to get help?

For example, should they use pictures to help you understand what they mean?

Healthcare professionals are people doctors, nurses and receptionists at the GP and hospital.



## healthwatch Southwark

### Carers

**These questions are intended for people who regularly look after one or more adults with a learning disability and/or autism.**

11. Has the person(s) you care for been added to the **GP learning disabilities register**?

The GP learning disability register is a list of all the people with a learning disability that your GP looks after. It helps GPs know what support people need.



Yes



No



I don't know

12. Has the person(s) you care for had an **annual health check** in the last year?

Annual health checks give people who have a learning disability an appointment with a doctor once a year to talk about anything that is worrying them.

 Yes

 No

 I don't know

If no, why has this not taken place?

13. Can you think of a **good** experience with a healthcare professional?

Healthcare professionals are people like doctors, nurses and receptionists at the GP or hospital.

 Yes

 No

If yes, what made it good?

14. Can you think of a **bad** experience with a healthcare professional?

Healthcare professionals are people like doctors, nurses and receptionists at the GP or hospital.



Yes



No

If yes, what made it bad?

15. Have you experienced **barriers or challenges** when accessing healthcare services for the person you care for? For example: staff communication, loud waiting rooms.



Yes



No



I don't know

If yes, can you describe these barriers or challenges?



16. Do you feel healthcare professionals **make sufficient changes** to support the needs of the person you care for during appointments?

For example, does the GP provide easy to read leaflets, longer appointments, or see you first.

 Yes

 No

 I don't know

Any other comments (optional)

17. If you are experiencing issues with the health of the person you care for, **do you know where to go to access the right help?**

For example, do you know how to book a hearing test or get their feet checked?

 Yes

 No

 Sometimes

Any other comments (optional)

18. If you could change something about the healthcare services in Southwark to better support the person you care for, **what would you change?**



### Service Providers

**These questions are intended for staff who deliver healthcare services for adults with learning disabilities and autistic adults.**

19. What type of healthcare service do you work for?

- GP
- Hospital Inpatients service
- Hospital Outpatients service
- Dentist
- Mental Health support
- Accident and Emergency Care
- Community services
- Other (please specify)

20. How would you describe the **quality of care** that adults with learning disabilities and autistic adults experience within your service?

Quality of care is the degree to which health services for individuals and populations increase the likelihood of desired health outcomes.

- Very good
- Good
- Neither good nor bad
- Bad
- Very bad

Please give a reason for your choice (optional)

21. What do you think are the **most significant barriers** to accessing healthcare for adults with learning disabilities and autistic adults?

22. Do you think you are provided with **sufficient training and resources** to support adults with learning disabilities and autistic adults?

- Yes
- No
- I don't know

Please give a reason for your choice (optional)

23. Do you have any suggestions to **make services more accessible** for adults with learning disabilities and autistic adults?

For example, changing the type of communications used.




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## Health & Social Care Scrutiny Commission

**MUNICIPAL YEAR 2024-25**

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Councillor Sam Foster			
Councillor Dora Dixon Fyle			
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		<b>Total: 12</b>	
		<b>Dated: July 2024</b>	