



# Access to the annual health check programme and the Covid-19 vaccine:

The experiences of people with mental health needs, learning disabilities and autism

# Access to annual health checks and COVID-19 vaccine





# About Healthwatch Lambeth

Healthwatch Lambeth is your health and social care champion. We are here to listen to your experiences of using local health and care services and to hear about the issues that really matter to you. As an independent statutory body, we have the power to make sure NHS leaders and other decision makers listen to your feedback and improve standards of care. We can also help you find reliable and trustworthy information and advice that helps you get the care and support you need.



# Contents

Executive summary	3
Introduction	5
Background	5
Vaccine Confidence	6
Health Checks	7
The Lambeth context	8
Project scope	8
Strengths and limitations	9
Methodology	10
Recruitment and ethics	10
What did we talk to people about?	11
How we analysed their feedback	11
Who took part in the interviews?	11
Our findings	13
Experiences of engaging with the health check programme	13
Views about coronavirus and the vaccines	16
The views of health professionals	22
Summary and discussion	25
Conclusions and key recommendations	26
Next steps	27
Acknowledgements	27
References	28



# **Executive summary**

During the pandemic, people with severe mental illness (SMI), learning disabilities (LD), and autism experienced some of the worst outcomes from the virus itself. Measures to slow the spread of the disease exacerbated existing health inequalities including access to care and premature mortality. In Lambeth, uptake of annual health checks and COVID-19 vaccines is lower compared to national average statistics, particularly amongst people from these groups.

In June 2021, Healthwatch Lambeth were approached by Lambeth Council to talk to people from these groups about their experiences of engaging with physical health, particularly health checks and vaccination programmes.

The aim of this project was to gain a better insight into people's experiences of accessing health checks and COVID-19 vaccines, and to identify strategies that might help the council commission interventions to improve access to these and future physical health and vaccine campaigns.

We worked closely with local support organisations to carry out semi-structured interviews with a total of 12 people and/or their carers or support workers. Interviews included six people with severe mental illness and six with learning disabilities and/or autism. Five people had experience of accessing a health check and nine had accessed the COVID-19 vaccine.

Our findings indicated that people varied in their understanding of what a health check was, were unclear about whether they had received it and were not always clear on their entitlements to it. The role of support networks and proactive approaches by GP surgery staff were key facilitators to access. In relation to the COVID-19 virus and vaccines, whilst most of our participants had been vaccinated, they varied in how they described the virus. Understanding the symptoms, restrictions and seriousness of the virus did not act as barriers to accessing the vaccines.



Personal perceptions of risk, and experience of the virus itself, through knowing others who had contracted it, were factors which influenced trust in the vaccines. Key facilitators to access included social context and, in particular, the role of trusted family members and friends in acting as role models, providing space for different points of views and countering misinformation surrounding the virus and vaccines.

Services, particularly support staff in local organisations and trusted health professionals, also played a key role in reinforcing messages about the vaccine campaign and creating a culture of acceptance. One barrier affecting those with learning disabilities and/or autism concerned vaccine settings, particularly those that were busy and noisy, as well as distances to travel to centres which were seen as stressful and challenging to navigate.

Suggested strategies to improve access to these interventions included working closely with trusted family members and carers to support decision making and access, encouraging peer-to-peer conversations, holding non-judgemental discussions with community leaders, bringing interventions into trusted spaces within the community, time, persistent encouragement and the provision of reliable information.

Our recommendations include increasing awareness through a local information campaign, proactive approaches to reminding people to attend annual health checks; and sharing positive stories and/or encouraging peer-to-peer and nonjudgemental conversations with adults and young people where relevant.



# Introduction

In June 2021, representatives from Lambeth Council and NHS South-East London CCG (Lambeth) approached us to help them gain a better understanding into why people with severe mental illness, learning disabilities and autism were not receiving the COVID-19 vaccines and/or their annual health checks.

This report presents our findings about how people from these groups engaged with healthcare and health checks and how well they understood the COVID-19 virus and vaccine programme. We identified barriers and key facilitators to enable the council to commission interventions that might improve access to these and future physical health and vaccine campaigns.

# Background

The COVID-19 pandemic has had a profound impact on people's health, their livelihoods and on health and social care systems in the UK.<sup>1</sup> Despite measures to control the virus and protect the nation, by March 2021 the pandemic had already resulted in 119,000 excess deaths in the UK.<sup>2</sup> It had also become increasingly clear that some population groups experienced worse outcomes from the virus itself and, as a result of measures taken to slow the spread of the disease, experienced exacerbation of pre-existing inequalities.<sup>3</sup>

Increasing evidence suggests that people with severe mental illnesses (SMI) including schizophrenia spectrum disorders, bipolar disorder (BD), major depressive disorder (MDD), and those with intellectual disabilities are at higher risk of dying from COVID-19 and deaths from other causes compared to the general population, <sup>4-6</sup> with similar risks in relation to ethnicity.<sup>2</sup> Even before the pandemic, people with severe mental illness (SMI), learning disabilities (LD) and autism were more likely to die younger compared to the general population, either through an unavoidable medical cause or a preventable physical health condition.

# healthwatch

Delays impacting access to testing and care for the COVID-19 infection,<sup>8</sup> poor quality healthcare, barriers, or disruption to access to routine healthcare<sup>7,9-11</sup> may have also contributed to the disproportionate impact on these population groups. The vaccination programme has been crucial in reducing the spread of the virus and preventing deaths and hospitalisations, with over 70 million doses of the vaccine given by 12 June 2021.<sup>12</sup> Despite this, there continue to be emerging differences between population groups accessing the vaccine.<sup>2</sup>

# Vaccine Confidence

Willingness to take vaccines has long been a topic of research in public health and has become especially significant in the context of the COVID-19 pandemic. In one study, vaccine acceptance was shown to be closely bound to recognition of the collective importance of taking the vaccine. This includes an awareness of the importance of saving lives, helping the community and having an understanding that it will not be dangerous to be vaccinated.

Conspiracy beliefs, lack of awareness of the public health benefits of the vaccine and behavioural influences (including perceptions of personal risk) can lower trust in the efficacy of the vaccine.<sup>13-14</sup> Confidence and acceptance of the COVID-19 vaccine has also been associated in part with the social determinants of health, including socioeconomic and healthcare inequalities and demographic factors such as younger age and Black or Black British ethnic background.<sup>15-18</sup>Concerns about side effects and the long-term effects on health have affected lack of trust in vaccines, particularly among black respondents.<sup>15,19-20</sup>

There is a scarcity of evidence exploring vaccine acceptance amongst people with severe mental illness. Existing evidence suggests mental disorders that are particularly vulnerable to the fear of vaccines are anxiety, panic attacks and certain phobias including trypanophobia (fear of needles) agoraphobia (fear of open spaces and leaving home) and obsessive-compulsive disorder.<sup>21</sup>

6

# healthwatch

These fears might further exacerbate anxiety about receiving the COVID-19 vaccine. Patients with SMI may also experience barriers to accessing vaccines including a lack of knowledge and awareness, accessibility problems and lack of contact with health care professionals who could raise awareness.<sup>22.</sup> Mistrust and misinformation may further fuel paranoia and increase anxiety, resulting in vaccine hesitancy and avoidance.<sup>23-24</sup>

Evidence about vaccine acceptance amongst people with intellectual disabilities and autism is also limited. There is some evidence that people with LD can be fearful of a range of medical procedures including needle phobia.<sup>25-26</sup>

In the context of the COVID-19 pandemic, vaccine acceptance or willingness was associated with white ethnicity, having already had a flu vaccine, gaining information about COVID-19 from television (but not from social media), knowing COVID-19 social restrictions and/or rules and being close to someone who had died due to having the virus.<sup>27</sup>

## Health Checks

Annual and physical health checks were introduced with the aim of reducing premature mortality and improving the physical health and mental health of people with SMI, LD and autism. Evidence suggests that health checks are effective in identifying unmet health needs and lead to treatment of health conditions which may be serious or life threatening.

They can also be seen as one way to support public health interventions (vaccine campaigns, for example) and further engagement in physical health. However, uptake of health checks amongst these groups is poor. National data indicates that approximately 58% of people with a learning disability had an annual health check in 2019-2020 <sup>29</sup> and 43% of people on GP SMI registers were in receipt of all six elements of the physical health check in the 12 months to the end of 2021.<sup>30</sup>



Whilst the NHS Long Term Plan makes a renewed commitment to reducing these inequalities and ensuring these groups receive timely and appropriate health checks, uptake continues to be an issue.<sup>31-34</sup>

Evidence suggests annual health check uptake and/or acceptance amongst those with chronic illness and learning disabilities is affected by levels of awareness of the health check programme and process; understanding of what a health check entails; its purpose and, finally, access to health check appointments, which includes communication and support from carers to attend as well as physical barriers including distance to travel to appointments. <sup>35-40</sup>

# The Lambeth context

In Lambeth, uptake of COVID-19 vaccine and annual health checks is lower compared with the national average. <sup>12,41</sup> There is also a disparity of vaccine uptake amongst people with SMI, LD and autism in the borough. Unpublished data provided by Lambeth Council in June 2021 indicated that 29% of people on the SMI and 32% on the LD register had not received their first dose of the vaccine. In this context, understanding vaccine and annual health check experiences among people within these groups is crucial to inform initiatives to improve uptake.

# **Project scope**

Healthwatch Lambeth were approached by the local council to talk to people with SMI, LD and autism about their experiences of accessing the COVID-19 vaccine and health checks. The main aims of this research were to:

- Understand the perspectives of people with SMI, LD, and autism regarding their experiences of engaging with physical health, accessing health checks and the COVID-19 vaccine.
- Explore the views of healthcare professionals on their experiences of engaging with specified groups.



• Using insights, identify barriers and facilitators to access and strategies that might help to increase awareness and uptake.

# Strengths and limitations

The main strengths of this community engagement project are:

- People had an opportunity to talk to us in a space that was comfortable, appropriate and supportive.
- We were able to include participants with limited psychological capability and, although this resulted in a varied level of understanding of our questions, we were able to gather their insights (sometimes with support).
- We were able to talk to people from the specified groups at a point in the pandemic when most services were cautious in their level of face-to-face engagement.
- We worked with local organisations and had input from support staff to engage with people from the specified groups.
- Given the highly interpretative nature of comments made during interviews, we decided to include a team of engagement officers/researchers in data gathering and held a series of meetings to analyse the data and reduce the risk of introducing bias to the results.

The limitations are:

- We were not able to get a broad sample of individuals who had not accessed the vaccine and/or health checks. Therefore, whether their views are representative of a larger group of people who do not access these interventions is not known. We mitigated this by talking to people who had been vaccinated and/or accessed health checks, to learn from their experiences and share valuable insight into what influenced their decisions.
- We had a relatively small sample of individuals we were able to talk to. Whilst partners showed enthusiasm at the beginning of the project to



support our efforts to engage with the specified groups, service pressures affected this and recruitment was not a priority for them.

# Methodology

# **Recruitment and ethics**

We worked on this project, actively engaging people with SMI, LD and autism between August 2021 and February 2022. We worked closely with local support organisations to promote this project. These included:

- A voluntary organisation offering learning and wellbeing support for adults with LD, autism, physical disabilities, and mental health needs.
- An organisation supporting people living with mental health conditions.
- An organisation that provides personalised support for people with LD, autism, and mental health needs.

We also emailed flyers to local community and voluntary organisations who in turn promoted the project via their own regular newsletters. The project was also promoted via our website and social media channels and through our regular newsletter.

Individuals who expressed interest in participating were provided with an information sheet about the project alongside a verbal description of the project and asked to sign a consent form. Support workers within these organisations also assisted with recruitment and in explaining the project to potential participants. At the start of the interviews, participants were asked to reconfirm their understanding of the purpose of the project and their consent to take part.

The semi-structured interviews were conducted face to face in a private space with individuals from the specified groups and via zoom/telephone with health professionals. Interviews lasted between 20 and 45 minutes. The researcher took



verbatim notes during the interviews. All data was anonymised and stored on the secure Healthwatch Lambeth drive.

## What did we talk to people about?

We wanted to understand what helped or acted as a barrier to people in accessing health checks and vaccines. We also wanted to hear the views of carers and health professionals. The interview topic guide included broad questions which addressed:

- People's knowledge and experiences of the NHS health check programme
- People's understanding of the COVID-19 virus and their experiences of accessing the vaccines

## How we analysed their feedback

Anonymised verbatim interview data were independently read by the team involved in the project. The feedback was summarised and coded into a framework matrix to enable us to compare across the different groups of participants; those with SMI, those with LD and those with autism. Patterns and themes were identified and, where data was sufficient, comparisons were made across groups to identify key factors that facilitated or acted as barriers to accessing health checks and the vaccine.

## Who took part in the interviews?

A total of 14 people expressed an interest in talking to us about their experiences and of these 12 people were successfully followed up and took part in interviews. These included six people with SMI, three people with LD, two parents/carers of people with both LD and autism and one person with autism.

The sample included one mental health support worker. One interview was conducted with both the carer and the person with autism.

Six participants described themselves as female and five described themselves as male. Five participants described themselves as being of White ethnicity, five



identified as Black Caribbean, Mixed African and Asian and Mixed African and White. Four participants were aged between 50 and 64 years old.

Please note that some participants were unable to tell us about their demographic background. Those with SMI had a range of conditions including schizoaffective disorder, sarcoidosis, anxiety, depression, and obsessive-compulsive disorder.

Five participants indicated that they had previously accessed an annual health check although for several there was uncertainty. The majority of participants (9) indicated that they had been vaccinated, two participants had not, and for one participant information about their vaccination status was not given (See Table 1).



# **Our findings**

This section summarises the findings of our interviews with people with Serious Mental Illness (SMI), Learning Disabilities (LD) and Autism. We start by presenting people's perspectives of their engagement with healthcare and their experiences of health checks. We then present people's views and experiences of the COVID-19 virus and vaccines. Themes in Tables 2 and 3 demonstrate how people perceived and understood annual health checks and COVID-19 vaccines and highlight the salience of factors that may facilitate or act as barriers to uptake and engagement. We also present our findings from discussions with health professionals.

# Experiences of engaging with the health check programme

The feedback from groups regarding health checks was mixed, with some describing their experiences of attending, while for others it was less clear. Two themes describe participant's experiences and understanding of the health check and highlight the factors that facilitate or act as barriers to engagement (see Table 1).

Themes	Sub-themes
Understanding health checks	Awareness and knowledge
Access to the health check	Healthcare provision
programme	The role of support networks

## Table 1: Summary of themes - health checks

## Understanding of health checks

## Awareness and knowledge

There was significant variation between the participants in terms of their understanding of what an annual health check was, its purpose and their



entitlement to it. During the interviews, some participants required further prompting and explanation on the topic of annual health checks. Comments indicated that there was a lack of clarity. They frequently described situations that suggested they had attended GP appointments for treatment or tests, had surgery or collected prescriptions.

"I went in person to the GP to have my blood pressure taken. They gave me medicine and I picked it up at the chemist." (Female with LD-not accessed a check)

"I never know about this annual health check. I did not have it but had a test and was diagnosed as pre-diabetic." (Male with SMI-not accessed a check)

Others, who appeared to be more aware of the health check programme, talked about the key elements of it or described their experience of it as challenging.

"I got a health check. I had it for my sugar levels and I got a blood sample taken." (Female with LD-accessed a check)

"The health check was really hard because they asked a lot of questions, some easy and some hard to understand." (Female with LD-accessed a check)

## Access to the health check programme

The two final themes that were identified from comments about the health check programme related to setting-specific barriers and social context related facilitators to access.

#### Healthcare provision

The healthcare environment was seen as central to facilitating engagement with healthcare and access to health checks. Some participants with an SMI reported that an AHC had not been offered to them and they were not clear about the reasons.

"The GP did not call me to have an annual health check." (Female SMI-not accessed a check)



For some parents of young people with learning disabilities and/or autism, a lack of continuity between health providers affected access to annual health checks. This left some families feeling invisible and unclear about entitlements.

"He (the son) became eligible at 14. What I did was to call the GP to check if he is on the register and he was not. There is no record of him... The GP cannot put him on the register until there is an annual health assessment by the GP and CAMHS. They don't work in partnership." (Female parent of son with LD, ASD and ADHD-not accessed a check)

"On annual health checks, I feel like my daughter is invisible in the system and doesn't get offered things like this... I don't believe anybody knows she's got it outside of the GP." (Female parent of daughter with LD and autism-not accessed a check)

#### The role of support networks

Participant responses also suggested that their families, carers or support workers played a key role in giving them opportunities to access care in general, which interventions they received and how frequently, as well as providing direct support to attend appointments. The impact of the pandemic also made them more reliant on this support.

"My mum booked my appointment. I gave a sample. They weighed me. We had to phone first. It was easy for her to get it. We sat in a chair and our name came up." Female with LD-accessed a check)

"In the past I used to receive a letter about the annual health check to check you out but did not get one during Covid. Someone (a worker) from Mosaic 'forced' the doctor to see me, as I needed help." (Male with SMI-not accessed a check)

"The support worker from Mosaic helped me with appointments by downloading the GP App on my phone so I could order my prescription online because patients were not allowed to go to the surgery." (Female with SMI - Sarcoidosis, anxiety & depression - not accessed a check)



## Views about coronavirus and the vaccines

Throughout our interviews, it appeared that most of our participants (n=9) had accessed the COVID-19 vaccine. Several themes emerged in discussions about experiences, demonstrating how participants perceived and understood COVID-19 and the vaccines and highlighting factors that may facilitate or act as barriers to access (see Table 2). Quotes in this section are labelled with the participant's gender or role i.e., parent or carer, specified group i.e., SMI, LD or LD/autism and whether not they have had the vaccine.

Themes	Sub-themes or descriptions
Understanding	Description of symptoms and measures to control the spread
the virus	
Vaccine	Perception of risk and the efficacy of the vaccines
confidence	Personal experience; knowing friends and family members who
	had it
The social	The role of family members and friends
context	The role of trusted staff from support services
Access to the	Concerns about vaccine settings and difficulties with booking
vaccine	appointments
programme	

### Table 2. Summary of themes-coronavirus and the vaccines

## Understanding the virus

Though the participants demonstrated some understanding of the virus, this understanding and how they articulated it varied. Some participants mentioned the importance of wearing masks and maintaining distance, whereas others



focused more on symptoms with descriptions such as "like flu" or "hay fever" and how it could be contracted.

"When I got the letter to self-isolate, I was really confused about how to catch it. Was it through touching? Then we realised it was through the air... you cough, you feel like having flu, pain, lose sense of smell but may not have any symptoms." (Female-SMI sarcoidosis, anxiety, and depression).

"I know you can catch it because it's spread through the air. It will spread if people sneeze or cough." (Male-SMI)

"It's important to wear a mask, wash hands and not to be too close to people. If you catch the virus, you get better by staying at home." (Female-LD)

Understanding of the seriousness of the virus did not act as a barrier to decisions about getting vaccinated.

"The virus does not kill people, it just spreads. Other viruses also kill you. You see it wasn't as deadly as they told us it would be. People get hysterical about it." (Male-SMI-vaccinated)

#### Vaccine confidence

#### Perception of risk

Participant comments indicated that they understood the potential risk of contracting Covid 19 and in doing so they perceived themselves to be at risk. In this context, for the majority of participants, the vaccine was seen as efficacious in reducing that risk, providing protection, and preventing the spread of the virus.

"It is important to be vaccinated because I believe it gives protection and reduces the spread. If there's another booster, I will put my name down." (Female-SMIvaccinated)



*"It's important to get vaccinated so you don't catch Covid and stay strong."* (Male-SMI-vaccinated)

"I had two (doses of the vaccine). It's important for me to have two because of COVID." (Female LD-vaccinated)

### Personal experience

Knowing someone who had previously had the virus and/or died as a result was also a factor influencing decisions about getting vaccinated. This was noticeable in comments made by those with LD/autism and/or their parents.

"My auntie was not well. She had COVID and went to hospital. She had the vaccine. I know people who have had the jab. My nan died of COVID." (Female-LD vaccinated)

*"His dad has long COVID and this swayed him to think to get vaccinated."* (Female Parent of son with Autism/LD)

#### The social context

The social context was also important in relation to how people perceived the vaccine and their decisions to be vaccinated. The role of family members, friends and staff from support services were key themes in participants' comments concerning access to the vaccine.

#### The role of family members and friends

The influence of family members and friends were an important motivating factor in deciding to be vaccinated. Trust was frequently mentioned in comments.

"Trusting someone helps you. I asked a friend, "Did you have the vaccine"? She had it, so I did. Everything runs on trust." (Male, SMI- vaccinated)



In cases where misinformation around COVID-19 was mentioned from peers or from other sources such as the views of 'antivaxxers,' it was clear that the role of parent or carer was key to correcting this.

"He (the son) asks about what he hears from other young people and on the street, especially from the anti-vax people. At first, he was fearful of what he heard but we discussed this at home and he trusts us, his parents." (Father of a young male with LDvaccinated).

"He (son) has tunnel vision and can easily be manipulated by peers. As a parent you give your opinion but try not to push your opinion. We (parents) explain to him using factual information." (Mother of young male with LD/autism-not vaccinated)

Parents of young people with LD/autism also offered suggestions to counter misinformation and improve understanding of the virus and risks, including peer-to-peer conversations, spaces to talk about fears without feeling judged and contacting community leaders.

"Children listen to children, and I feel they need to be given the platform. Use examples of all illnesses that were already wiped out for example polio. Also use diseases that have been wiped out because of the vaccine." (Mother of son with LD/Autism - not vaccinated).

"There are also fake news and people should have the space to ask. It's not about judging but about having open communication and understanding their fears. Find community leaders and spend time to understand their resistance." (Parent of young person with LD vaccinated)

Some participants talked about close family members who had not had the COVID-19 vaccine whilst confirming that they themselves had. Comments suggest that hesitancy on the part of parents or carers would not necessarily prevent individuals from actively ensuring those they were caring for had the vaccine.



"My mum said she wasn't having the vaccine, but she booked my appointment." (Female LD- vaccinated).

Comments also indicated that some parents had a high level of control with regards to deciding whether their child with LD/autism would have the vaccine. In the quote below, despite feeling ambivalent about the vaccine, issues around risk were a clear priority for this parent.

"Now that he is eligible for the vaccine programme, part of me feels he needs the vaccine as evidence suggests you get protection. I research everything. I don't listen to fake news. I respect their opinions but for my son, I would vaccinate him." (Female Parent of son with ASD & ADHD - not vaccinated).

### The role of trusted services

Support and advice from trusted services and support staff as well as the nature of interactions with health professionals were also considered very important in making decisions about the vaccine.

"Trusting doctors and talking to the family is important, as well as older generations talking to the younger generations to exchange life experience and discuss the benefit of getting the vaccine. Also, attending an event where there are people you can trust. If it's [name of organisation] event, I would take part because they have helped me. If I got a letter from Lambeth Council, to get the vaccine, I would not do it because I waited to get care from them for so long." (Male-SMI-vaccinated)

"The doctors did a session at [name of organisation] and I watched someone have the vaccine. I trust the people at [name of organisation]." (Female LD-vaccinated).

There are a lot of people who are saying it is unsafe and there is a lot of inaccurate information being spread but I would rely on putting trust to the system." (Female carers of young person with LD/ASD)



## Access to the vaccine programme

Barriers to accessing the vaccine programme were related less to understanding of the virus or beliefs about the vaccine efficacy or safety but more to settingspecific barriers to attendance. These included concerns about vaccine settings and difficulties with booking vaccine appointments.

### Concern about vaccine programme settings

Among those parents or carers of young people with LD/autism, there were concerns regarding the setting of the vaccine programme and in particular the busy environment of vaccination centres and hospitals which were seen as stressful and challenging for young people to navigate. This acted as a barrier to accessing the vaccine.

"With autism, it's very difficult for her to go in a waiting room to be treated anonymously like that. She can't cope with the noise. She is quite capable of going but she can't cope. For her, (daughter) it would have taken all her energy for the day to get vaccinated. That would be all that she could manage to do for that day. She got an appointment but it was at the hospital, so she has to go to London which is a big deal for her. And then go into a busy place which she can't. She finds it very nerve-wracking going into new spaces with waiting rooms... It takes so much of her energy." (Female care of a young autistic person - not yet vaccinated)

In this context, one parent suggested strategies to make access to the vaccine easier; for example, bringing the vaccine into community groups.

"Bring the vaccine to groups of people where they are and make it physically easy for them to get the jab." (Parent of young person with LD vaccinated)



### Difficulty booking appointments

Another reason cited for not accessing the vaccine included difficulties with booking an appointment. One parent talked about the difficulty of using the online booking system and obtaining an appointment in the general practice setting.

"We struggle to get the vaccine. Make the online systems work and we were put on hold for 45 minutes by the GP practice. I was hoping schools would offer the vaccination like in the past." (Mother of young son with LD/autism - not vaccinated)

## The views of health professionals

We interviewed three GPs working within Lambeth to explore their experiences of engaging with people with SMI and LD and their thoughts about annual health checks and access to the vaccines. The barriers to uptake appeared to be more generalised and not specifically related to target groups of this exploration.

## The importance of the health check and the issues affecting access

Professionals commenting specifically on the annual health check for LD patients indicated that although the appointments might not always be clinically necessary, they played an important role in the patient's wellbeing by strengthening the support network and opening up space for longer conversations in which clinical outcomes were not the sole focus.

"If they've got a severe learning disability, they're usually under the hospital teams and so the health check doesn't pick up anything new. It's more for the carer to be supportive."

"LD health check is unusual - checking is significantly longer and open-ended... it is about opening a conversation to see if there are issues. It is 40 minutes to an hour, undivided attention to bring up any issue you have. Brilliant opportunity."



Some service-user interviews indicate uncertainty over what the annual health check was, the purpose and whether they were eligible. Evidence from the health professionals support the uncertainty experienced by service users. This suggests that confusion and uncertainty around what the annual health check is would not necessarily prevent patients from having it in every situation. GPs also commented that patients might not remember or might misunderstand the circumstances of the appointment.

# "Over 20 years, we managed to continually have [AHC] done but they still forget that they have it every year."

GPs indicated that several issues needed to be addressed, including the need for annual health check reminders to book appointments, support for service users to attend and the role of proactive action on the part of surgery staff in achieving improved uptake.

"We ring them up, we book them in, and we achieve every year over 80% coverage."

#### "One of our nurses calls and tracks patients. We have a pretty good uptake."

For those patients who had not had the AHC, professionals thought it was important to explore the barriers they encountered in more depth. Arranging a public campaign, open days and/or evenings to give information were all regarded as good ways to engage with them.

# "You need to do public targeting the people who have not had it and explore and talk to them in more detail of what stops them."

#### **COVID-19 vaccine beliefs**

While most of the service users we spoke to had had the vaccine, the GPs we spoke to were more focused on the reasons their patients had given them for not doing so and therefore comments tended to be unrelated to specific population groups. Factors such as religious beliefs, previous negative experiences with health



authorities and the belief that the vaccine trials were too rushed with the vaccine being introduced too quickly were all discussed.

"It's a whole range. Ranging from religious beliefs to what they've read about bad experiments... and sometimes its historical and sometimes it's distrust with authorities."

Professionals who were able to talk about a shift in their patient's views in favour of deciding to have the vaccine emphasised the importance of a person-centred approach and giving patients encouragement and time, with the understanding that a conversation about the COVID-19 vaccine wasn't going to be a one-off in every case.

"We have to give them time, encourage them and support with all information and then mention it again. I ask them again whether they thought more about what I've said."

#### Access to the vaccine

GPs echoed the concerns around access raised by patients, describing practical barriers to receiving vaccine services and suggestions for reducing these, including bringing the vaccine to spaces where people meet without the complexities of booking online.

# "Offer it in places where patients are. Make it easier for them to access it instead of having to book online."

Professionals suggested dispelling myths through using the relationship between the GP and patient to improve trust.

"We responded by email, telephone, and personal contact 'knowing that it is your doctor who knows you."

"Offer it in places where patients are. Make it easier for them to access it instead of having to book online."



# Summary and discussion

This project aimed to understand the perspectives of people with SMI, LD and autism regarding their experiences of the NHS health check programme, COVID-19 and the vaccines. We also included the views of health professionals on their experiences of engaging with these groups.

The results of this qualitative study indicate that our interviewees with SMI, LD and/or autism varied in their understanding of what the annual health check was, were unclear about whether they had received it and were not always clear on its purpose or their entitlement to it. This finding was echoed in the views of health professionals. The role of support networks and proactive approaches by GP surgery staff are key to facilitating access, as is providing more information about what health checks entail and why they are important. Our findings support existing evidence which suggests that health check uptake is affected by levels of awareness of the health programme and the process as well as communication and support to attend appointments from carers. <sup>35-40</sup>

In relation to COVID-19 and the vaccines, we found that most of our respondents had been vaccinated but their level of knowledge about COVID-19 and their understanding varied in how they articulated it, with most talking about symptoms and restrictions. Understanding these and the seriousness of the disease did not act as a barrier to being vaccinated, as has been shown in previous evidence.<sup>27</sup> Personal perceptions of risk and experience of the virus itself were factors which influenced trust in the vaccines in terms of providing protection and reducing the spread of the disease, which supports previous evidence on the role of risk perception and vaccine efficacy.<sup>13-14</sup>

A key facilitator identified from discussions about COVID-19 and the vaccines was the social context and in particular the role of trusted family and friends in acting as role models, providing space for different points of view and countering misinformation. This was the case for people with SMI and LD/autism. Services and

25



professionals played a role in reinforcing messages about the vaccine campaign and creating a culture of acceptance.

A barrier affecting experiences of those with LD/autism concerns vaccine programme settings, put forward by parents/carers. In particular, the busy and noisy environments and distances to travel were seen as stressful and challenging to navigate. Lack of accessibility of COVID-19 related services has been found to affect uptake in previous research.<sup>11</sup>

Suggested strategies to improve access include encouraging peer-to-peer conversations; linking up community leaders to provide opportunities; nonjudgemental discussions and bringing interventions into trusted spaces within the community. The healthcare professionals we interviewed highlighted the importance of trust, time and persistent encouragement as well as providing reliable information and improving physical access as key strategies to encouraging vaccine uptake. Drawing on insights from health professionals, the success of annual health check and vaccine programmes could be facilitated by health professionals having space for discussions with patients from these groups about their health and wellbeing where clinical outcomes are not the sole focus.

# Conclusions and key recommendations

Our insights from people with SMI, LD and autism has highlighted what has encouraged uptake for them and therefore what could work well in terms of public health interventions in the future including annual health checks and other health or vaccination programmes.

Drawing insight from the specified groups and professionals about what could encourage uptake we recommend that local decision makers can adopt the following approaches:



- Initiatives that involve working closely with trusted family members and carers to support decision making and access to annual health checks and the vaccine.
- A local information campaign aimed at increasing awareness of the annual health check, conducted in tandem with grass roots community organisations in the borough that support individuals with SMI and LD and/or autism.
- More consistent, proactive approaches to reminding people to attend annual health checks.
- Campaigns which involve sharing positive stories or which encourage peerto-peer and non-judgemental conversations with adults and children or young people where relevant.
- Align education and awareness strategies with other preventative health strategies, for example, general health and wellbeing sessions or building in more time for conversations during health appointments with trusted health professionals.
- Practical help to access interventions for people with LD/autism including bringing these into spaces with which they are familiar, don't require complex booking and are easy to reach.

# Next steps

We shared our findings and recommendations with representatives of Lambeth Council in January 2022. Our insight is being used to support their efforts to engage with these groups more effectively and commission interventions that might improve access to these and future physical health and vaccine campaigns.

# Acknowledgements

We would like to thank our interviewees along with their carers who shared their experiences with us. Without you we would not be able to do the work that we do. A special thanks to staff at Share Community, Mosaic and Certitude for supporting



us with recruitment and facilitating interviews with service users. Thank you also to healthcare professionals for their contributions and partners at Lambeth Council and the South East London CCG for their support of this work.

# References

- Department of Health and Social Care (DHSC) Office for National Statistics (ONS) 2021. Direct and indirect impacts of COVID-19 in England. Accessed January 2022: <u>https://assets.publishing.service.gov.uk/government/uploads/system/uploads/ attachment\_data/file/1018698/S1373\_Direct\_and\_Indirect\_Health\_Impacts\_of\_ C19\_Detailed\_Paper\_.pdf
  </u>
- Suleman M, Sonthalia S, Webb C, Tinson A, Kane M, Bunbury S, Finch D, Bibby J. Unequal pandemic, fairer recovery The COVID-19 impact inquiry report. The Health Foundation July 2021; Accessed January 2022. <u>Unequal Pandemic, Fairer</u> <u>Recovery</u>
- 3. NHS Confederation. The unequal impact of COVID-19 Investigating the effect on people with certain protected characteristics. June 2022; Accessed July 2022. <u>Unequal-impact-of-COVID-19-protected-characteristics.pdf</u>
- 4. De Hert M, Mazereel V, Detraux J, Van Assche K. Prioritizing COVID-19 vaccination for people with severe mental illness. World Psychiatr. Published online November 1, 2020. doi:10.1002/wps.20826
- 5. Mazereel V, Van Assche K, Detraux J, De Hert D. COVID-19 vaccination for people with severe mental illness: why, what, how? 2021 Lancet Psychiatry https://doi.org/10.1016/S2215-0366(20)30564-2
- Das Munshia J, Changa CK, Bakolisf I, Broadbent M, Dregana A, Hotopfa M, Morgane C, Stewart R. All-cause and cause-specific mortality in people with mental disorders and intellectual disabilities, before and during the COVID-19 pandemic: cohort study. The Lancet Regional Health - Europe 11 (2021) 100228; Accessed January 2022



- Weir E, Allison C, Warrier V, Baron-Cohen, S. Increased prevalence of noncommunicable physical health conditions among autistic adults. Autism. 2020; 25 (3):681-94
- Livingston G, et al. Prevalence, management, and outcomes of SARS-CoV-2infections in older people and those with dementia in mental health wards in London, UK: a retrospective observational study. Lancet Psychiatry 2020;7:1054-63.
- 9. Kontopantelis E, et al. Excess mortality in England and Wales during the first wave of the COVID-19 pandemic. J Epidemiol Community Health 2021;75:213.
- 10.NICE Impact. People with a learning disability. November 2021. Learning disability impact report.pdf
- 11. Oakley B, Tillman J, Ruigrok A, et al. COVID-19 health and social care access for autistic people: European policy review. BMJ 2021. <u>bmjopen-2020-045341</u>
- 12. UK Government. Vaccinations in the United Kingdom. Accessed June 2022. <u>Vaccinations in the UK | Coronavirus in the UK (data.gov.uk)</u>
- 13. Freeman D, Los BS, Chadwick A et al. COVID-19 vaccine hesitancy in the UK: the Oxford coronavirus explanations, attitudes, and narratives survey (OCEANS)11. Psychol Med 2020. Published online Dec 11. https://doi.org/10.1017/S0033291720005188
- 14. Hertfordshire County Council Behaviour Change Unit: COVID-19 Vaccination: Reducing vaccine hesitancy Review & Recommendations. December 2020; <u>Covid-19 Vaccination: Reducing vaccine hesitancy (bsphn.org.uk)</u>Accessed January 2022
- 15. Chaudhuri K, Chakrabarti A, Chandan JS, Bandyopadhyay S COVID-19 vaccine hesitancy in the UK: a longitudinal household cross-sectional study. BMC Public Health 2022 22:104
- 16. Opinions and Lifestyle Survey (OPN) -Coronavirus and vaccine hesitancy GB 9<sup>th</sup> August 2021) Accessed May 2022 <u>Coronavirus and vaccine hesitancy, Great</u> <u>Britain - Office for National Statistics (ons.gov.uk)</u>



- 17. Razia MS, Chaudhry UAR, Doerholt K, Bauld L, and Majeed A. COVID-19 vaccine hesitancy. BMJ 2021; 373 n1138. <u>Covid-19 vaccination hesitancy | The BMJ</u>
- Razia MS, Osama T, McKechnie DGJ, and Majeed A. COVID-19 vaccine hesitancy among ethnic minority groups. BMJ 2021; 372 <u>Covid-19 vaccine hesitancy among</u> <u>ethnic minority groups | The BMJ</u>
- 19. Razai MS, Kankam HKN, Majeed A, Esmail A, and Williams DR. Mitigating ethnic disparities in covid-19 and beyond. BMJ 2021; 372:m4921 <u>Mitigating ethnic</u> <u>disparities in covid-19 and beyond | The BMJ</u>
- 20. Robertson E, Reeve KS, Niedzwiedz CL, et al. Predictors of COVID-19 vaccine hesitancy in the UK Household Longitudinal Study. Brain, Behaviour and Immunity 2021; 94: 41-50. <u>Predictors of COVID-19 vaccine hesitancy in the UK</u> household longitudinal study - ScienceDirect

21. COVID vaccine hesitancy: Help for panic attacks, anxiety & fear [Internet]. Psycom.net. Available from: https://www.psycom.net/covid19-vaccine-hesita ncy-mental-health. [cited Jan 22].

22.Miles LW, Williams N, Luthy KE, Eden L. Adult vaccination rates in the mentally ill population: an outpatient improvement project. J Am Psychiatr Nurses Assoc. 2020;26(2):172-80. <u>https://doi.org/10.1177/1078390319831763</u>.

23. Ebrahim Payberah E, Payberah D, Sarangi A, Gude j. COVID-19 vaccine hesitancy in patients with mental illness: strategies to overcome barriers—a review: Journal of the Egyptian Public Health Association (2022) 97:5 https://doi.org/10.1186/s42506-022-00102-8

24. SPI:B: COVID-19 vaccination uptake in those with severe mental illness, 11 March 2021

25. Marriott A. (2017) Blood Tests for People with Learning Disabilities: Making Reasonable Adjustments. Public Health England, London.

26. Kupzyk S. & Allen K. A. (2019) A review of strategies to increase comfort and compliance with medical/dental routines in persons with intellectual and



developmental disabilities. Journal of Developmental and Physical Disabilities 31, 231-49

27. Hatton C, Bailey T, Bradshaw J et al. The willingness of UK adults with intellectual disabilities to take COVID-19 vaccines. Journal of Intellectual Disability Research 2021 doi: 10.1111/jir.12884

28. Goin-Kochel R. P., Fombonne E., Mire S. S., Minard C. G., Shani L. C., Cunningham R. M. et al. (2020) Beliefs about causes of autism and vaccine hesitancy among parents of children with autism spectrum disorder. Vaccine 40, 6327-33.

29. Health and Care of People with Learning Disabilities. Experimental Statistics 2019 to 2020. <u>https://digital.nhs.uk/data-and-</u> information/publications/statistical/health-and-care-of-people-with-learningdisabilities/experimental-statistics-2019-to-2020

30.Statistical press notice - Physical Health Checks for People with Severe Mental Illness May 22: https://www.england.nhs.uk/statistics/wpcontent/uploads/sites/2/2022/05/Physical-Health-Checks-SMI-Statistical-Press-Notice-2021-22-Q4.pdf

31. Improving the uptake and quality of annual Health checks for people with LD. June 2021 <u>https://www.england.nhs.uk/wp-content/uploads/2021/06/C0962-i-annual-health-check-in-secondary-care-context-document.pdf</u>

32.NHS Long term plan - Learning disability and autism: <u>https://www.longtermplan.nhs.uk/online-version/chapter-3-further-progress-on-</u> <u>care-quality-and-outcomes/a-strong-start-in-life-for-children-and-young-</u> <u>people/learning-disability-and-autism/</u>

33.Delivery of annual health checks for people with severe mental illness and or learning disability; January 2022. <u>B1268-letter-delivery-of-annual-health-checks-for-people-with-severe-mental-illnesses-and-or-learning-disabili.pdf</u>

34. NICE Impact Mental Health 2019. https://www.nice.org.uk/media/default/about/what-we-do/intopractice/measuring-uptake/niceimpact-mental-health.pdf



35. Coronavirus (COVID-19) in the UK

https://coronavirus.data.gov.uk/details/vaccinations?areaType=ltla&areaName=La mbeth

36.\_Healthwatch Hertfordshire. (August 2020) <u>Experiences of Annual Health</u> <u>Checks: Voices from the Learning Disability Community. HwH-Annual-Health-</u> <u>Checks-Report-FINAL.pdf (healthwatchhertfordshire.co.uk)</u>

37. Boyle J and Powell C. (2017) G505(P) Qualitative audit of GP learning disability annual health checks for young people *Archives of Disease in Childhood* 2017;**102:**A200.

38. Harte E, Maclure C, Martin A et al. (2018) Reasons why people do not attend NHS Health Checks: a systematic review and qualitative analysis. British Journal of General Practice 2018; 68 (666): e28e35. DOI: https://doi.org/10.3399/bjgp17X693929

39. Burgess C, Wright AJ, Forster AS, et al. (2015) Influences on individuals' decisions to take up the offer of a health check: a qualitative study. Heal Expect **18**(6):2437-2448.

40. Tyson M, McElduff S, Pawlyn J. et al. 2016. The Views of Carers with Intellectual Disabilities on Annual Health Checks. Report published 2016 carers' <u>Survey about Annual Health Checks for Adults with Learning disabilities</u> (basw.co.uk)

41. Covid-19 stats | Lambeth Council



#### Healthwatch Lambeth

336 Brixton Road London, SW9 7AA Tel 020 7274 8522 Text 07545 211 283 info@healthwatchlambeth.org.uk www.healthwatchlambeth.org.uk/enterandview

Registered charity no: 1153444 Registered company in England and Wales no: 8430436

