



Ensuring uptake of COVID-19 vaccinations among people with severe mental illness – barriers, enablers and recommendations

1. Introduction

The Joint Committee on Vaccination and Immunisation (JCVI) has placed people with severe mental illness (defined in this case as “*Individuals with schizophrenia or bipolar disorder, or any mental illness that causes severe functional impairment*”) in [priority group 6](#) to receive the vaccine. Under current plans, this means that people with living with severe mental illness (SMI) should begin receiving the first dose of the vaccine at the end of February.

Rethink Mental Illness was pleased with the decision by the JCVI to include those with severe mental illness within priority group 6. We also warmly welcomed the announcement and delivery of £4.5 million for STPs to support outreach to increase take up of the vaccine, alongside physical health checks.

We created a COVID-19 vaccine [advice page](#) to support our beneficiaries, and it became our most viewed page in January, receiving over 10,000 page views in the week beginning the 18th January 2021. This prompted us to create a survey to find out more about how our beneficiaries felt about being in a priority group for the vaccine, if they planned on getting it and what the barriers and enablers were to this.

2. Methodology

The survey was created online and sent out via social media and through Rethink Mental Illness’ lived experience networks, as well as those of the NHS England/Improvement Adult Mental Health Team and Equally Well UK. It included a mixture of open ended and multiple choice questions and was open for two weeks. 390 people with SMI and carers of people with SMI filled out the survey. 10% were screened out for not being in a priority group for the vaccine.

It important to outline the limitations of our sample. When asked, 92.3% of respondents identified themselves as being from a white background and 78.1% of respondents described their gender as female. As far as is possible, we wanted to include black, Asian and ethnic minority (BAME) voices in this summary of results, however low overall numbers mean we have to accept limitations to the extrapolation of this data.

3. Motivations for getting the vaccine

3.1 Protect their own health

Three quarters (75.4%) of respondents said they were certain (62.2%) or very likely to get the vaccine (13.2%). Only 6.2% were certain not (3.6%) or very unlikely (2.6%) to.

Key motivational factors for getting vaccinated included to protect their own health (77.5%), protect people they know by not passing the virus on (73.6%) and to play their part in controlling the pandemic (69.7%).

These factors are mirrored in BAME respondents in slightly lower numbers. Protecting people they know was the most important factor (63.2%), followed by protecting their own health (57.9%) and playing their part in controlling the pandemic (42.1%).

3.2 Trusted sources of information

Peer-reviewed research and other academic sources were cited as trusted sources of information about the vaccine, highlighting the importance of this kind of material being communicated to people in an accessible way.

It may be advisable to deliver information through GPs and charitable organisations (such as Rethink Mental Illness) as they were cited as people or organisations that people would trust to provide them with information about the vaccine, among both overall respondents (77.6% and 46.7%) and those “not sure” or “unlikely” to get the vaccine (43.6% and 30.8%). For some people, information from VCSE organisations could help to address apparent mistrust of medical professionals.

Media and social media received low scores across the board in terms of trusted information.

4. Barriers to getting the vaccine

4.1 Distrust of vaccine

Concerns about side effects (41%) and medical risks of getting the vaccine (36%) stood out as factors respondents said would make them less likely to get the vaccine.

Troublingly, this scepticism was higher among BAME respondents to our survey, who were also less likely to say that they were certain (40%) or very likely (15%) to get the vaccine. Over half (57.9%) of all BAME respondents stated that they were worried about the medical risks of the vaccine, while half (52.6%) were worried about side effects. BAME respondents were also twice as likely (42.1% versus 21% of overall respondents) to cite a lack of trust in the process of developing and approving the vaccine.

“I would want guarantees the vaccine is safe and thoroughly tested...

“...then I could operate on the basis of informed consent rather than blind faith.”

“Have had allergic reactions, and am worried it may trigger a reaction”

Concerns were expressed regarding the impact of the vaccine on those with pre-existing health conditions. This is supported by related data, showing that just under one third (29%) of respondents were concerned about the impact on their current medication. This was notably higher among those stating they were “not sure” or “unlikely” to get the vaccine (43.6%).

“Our rights are waived re vaccine injury. How do people with multiple other health issues know they will be safe from side effects.”

A small number of respondents expressed distrust of medical professionals following previous experiences of care via write-in responses.

“I lost my trust after psychiatric assault.”

“I do not trust medications or healthcare professionals so I cannot take medication and haven’t been registered with a GP for many years.”

4.2 Travelling to vaccination centres and receiving the vaccine

Less than half (46.9%) of respondents were sure that they would be able to travel to a vaccination centre on their own. Mental health-related factors may be among the reasons that people are unable or uncertain as to whether they could travel to a vaccination centre. Concerns that mental health would make it hard to get to a vaccination centre was cited by over a third (39.2%) of respondents.

Respondents from BAME communities were more likely to say (60%) that they would rely on public transport to get to a vaccination centre if it was more than walking distance from their home, but the figure was also relatively high (44.8%) in the overall response. This is potentially an area of concern, given possible limitations on available public transport (particularly outside of urban areas) and potential concerns as to the safety of taking public transport during the pandemic – although only a small number (15.2%) of people said that they were worried about catching COVID-19 whilst receiving the vaccine.

Smaller but notable numbers of people said that they did not like the idea of an unfamiliar medical professional administering the vaccine (15.2%) or were scared of needles (12.4%).

Some comments revealed other, mental health-focused barriers:

“May be too anxious to leave house”

“I can't ignore my paranoia that the vaccine is to control us in some way”

“Son with Schizophrenia may not want the vaccine on the day... will need gentle persuasion”

4.3 Managing appointments

Around a third (31%) said that they struggle to keep on top of letters and emails meaning that they may miss the appointment notification, particularly given that two appointments are necessary to receive both doses.

This figure was similar (30.1%) among those who said they were certain or very likely to get the vaccine.

5. Recommendations

We welcome all the actions taken by NHSE/I and DHSC to provide guidance to the system and ensure outreach is taking place to increase uptake of the COVID vaccine. The following are further recommendations that could be taken based on our survey analysis:

BAME groups: The Department for Health and Social Care should commission urgent further research with BAME people with SMI through local VCSE organisations and leaders to identify the barriers and enablers to vaccination.

Information and communication: DHSC or NHSE/I could work with groups such as Equally Well and experts by experience to co-produce an information sheet aimed at people with SMI and carers

outlining who is eligible, the evidence around efficacy, safety and side effects, including on how the vaccine interacts with existing medications, if at all.

- This could be supported with communications highlighting the positive factors people in our survey noted would make them likely to take up the vaccine.
- Communication channels to reach people with SMI could include GPs, Royal Colleges, mental health professionals and the VCSE sector. It is vital everyone is using the same co-produced information to enable trust.

Guidance to the NHS: Clear guidance on who is eligible for the vaccine should be shared with health professionals, in particular to highlight the expanded definition of SMI, and that it is wider than the GP SMI register. This guidance should also outline the need for outreach for those who do not respond to invitations and advice on how to enable culturally aware and psychologically safe discussions about the vaccine.

Outreach funding: We strongly support the extension of the outreach funding to STPs into the financial year 2021/2. Part of this funding will be important to go towards the following to increase vaccination take up:

- Primary care must follow up with people who have received an invite for a vaccination but not taken it up to understand what the barriers are and if they can help overcome e.g. booking transport or re-booking an appointment closer to home.
- GPs will need to provide opportunities for some people with SMI to receive the vaccine in their own home, as is happening with other groups.

For more information about this briefing, please contact Gabriella Hasham - Senior Project Officer, email: gabriella.hasham@rethink.org.