

Sharing the views of the Patient and Public Voice

COVID-19 Patient and Public Input into 23 February 2021 SAGE Report

Key Statement from Patient and Public Voice:

As we move towards an easing of restrictions, key areas of research that need to be prioritised include:

- Use and analysis of vaccine programme data continues to be of great public interest and remains of the utmost importance. Urgent research is needed to increase understanding and inform decisions in key areas including ways to overcome vaccine hesitancy and low vaccine coverage as well as impact of the vaccine programme on transmission.
- Additionally, with an emphasis on testing and as we grow our understanding of the virus, further work is needed to understand how presentation of COVID-19 symptoms may vary between different groups and populations. This will ensure the list of symptoms that trigger a COVID test are as accurate as possible and therefore help monitor and reduce transmission rates.

Input reiterated key recommendations from previous reports whilst also suggesting new areas of work and directions to consider:

- General
 - Appears to be a very welcome step-change in data having been made useable, linkable and accessible for answering priority COVID-19 research questions. It is also heartening to witness recently developed COVID-19 policy having been derived from this hard work.
 - It is important that trustworthiness continues to be demonstrated and communicated, especially in the linking of NHS data with non-health data e.g., occupation data.
- Immunity
 - The emerging evidence on real-world efficacy of the vaccines is most encouraging. The public will now want to see further research into the effects of the various vaccines on transmission rates.
 - There continues to be an urgent need to understand the factors influencing vaccination uptake, looking in particular at regional variations and variations between socio-economic and ethnic groups.
 - This includes an evaluation of initiatives to overcome vaccine hesitancy and low vaccine coverage which is essential if we are to avoid further disproportional detrimental impacts on these populations.
 - A number of studies are exploring the efficacy of the vaccines and whether it will stop COVID-19 and its severity. However, until we have clearer answers, research is needed to explore whether the vaccines could affect the type of symptoms presented as this could influence transmission rates.

HDRUK
Health Data Research UK

Office for
National Statistics

63 members of the COVID-19 Patient and Public Involvement and Engagement Group available to support researchers to provide patient and public input into the development, running, interpretation and dissemination of their research



7 members of the HDR UK COVID-19 Patient and Public Involvement and Engagement Group and Public Advisory Board reviewed and provided additional feedback into the development of this report



Ongoing requisite from HDR UK Public Advisory Board that the public and patients should be involved in these priority areas. In addition to building public trust, incorporating lived experiences and views, could generate further valuable research questions.

Sharing the views of the Patient and Public Voice

COVID-19 Patient and Public Input into 23 February 2021 SAGE Report

Input reiterated key recommendations from previous reports whilst also suggesting new areas of work and directions to consider (contd):

- Surveillance and Epidemiology
 - Some emerging evidence from Israel has shown there to have been an increase in hospitalisation in younger age groups. Some have suggested this could be due to an effect of older people being vaccinated first.
 - Urgent further research is needed to look at the data to better understand whether this could also be in the case in the UK as more and more priority groups become vaccinated and help healthcare systems be better prepared.
 - This could help influence policy decisions if there are unforeseen impacts from the vaccine rollout programme.
 - Dependent on outcomes and future research, there is a question as to whether there is a need to extend surveillance in younger populations, including those under 18 years.
 - Further work and research is needed to understand how presentation of COVID-19 symptoms may vary between different groups and populations.
 - Outcomes from such research is needed to explore and ensure the list of symptoms that trigger a COVID test are as accurate as possible.
 - Additionally, those who are diagnosed with variants of the virus may not typically present with the same symptoms and this needs to be urgently accounted for to reduce transmission.
 - Whilst positive to see there was a reduction in COVID 19 mortality for most ethnic groups in Wave 2, those from South Asian backgrounds have continued to have higher mortality rates and further urgent research is needed to understand why the severity of the virus is disproportionately impacted in this population group (as well as others too).
 - With an emphasis on testing, further research is needed to compare the accuracy of self-administered PCR testing and those administered by healthcare professionals.
- Longitudinal Health and Wellbeing
 - Would recommend research that could help determine whether previously unsuspected underlying conditions have been diagnosed (revealed) by a COVID-19 infection.
 - There has been some anecdotal evidence, and this could be an unexpected boost for public health, if handled effectively.
 - Welcome the news that metformin does not influence COVID-19 severity or mortality as this is a hugely important drug for those with diabetes. Further research is urgently needed to explore other vital drugs for other underlying health conditions, particularly those that put individuals at a higher risk of COVID-19.
- Transmission and Environment
 - With schools re-opening (albeit at different timescales across the UK), it is essential that the different approaches across the 4 nations, with respect to school opening, are monitored very closely in terms of impact on community transmission.
 - Additionally, whilst studies in England and Wales have shown no increased risk, further research on a large scale is needed to add to the evidence base around whether or not teachers and education professionals are more likely to test positive for COVID-19.



63 members of the COVID-19 Patient and Public Involvement and Engagement Group available to support researchers to provide patient and public input into the development, running, interpretation and dissemination of their research



7 members of the HDR UK COVID-19 Patient and Public Involvement and Engagement Group and Public Advisory Board reviewed and provided additional feedback into the development of this report



Ongoing requisite from HDR UK Public Advisory Board that the public and patients should be involved in these priority areas. In addition to building public trust, incorporating lived experiences and views, could generate further valuable research questions.