

Sharing the views of the Patient and Public Voice - COVID-19 Patient and Public Input into 6 April 2021 SAGE Report

Key Statement from Patient and Public Voice:

- Structural barriers to vaccine uptake need to be addressed instead of focusing on stated intent as a barrier
- Improved messaging to young people around the risks of COVID-19 as well as vaccine safety are vital
- There needs to be comprehensive and accessible information for the public on long COVID, particularly around the development of a tool outlining risk factors for developing long COVID.



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

Surveillance and epidemiology

- The Byrne, *et al* paper on C-19 vaccination provides important insights to work towards reducing disparities in vaccine uptake, particularly by identifying:
 - structural barriers are more likely to be underpinning poor uptake in ethnic groups or those from more deprived areas than is stated intention to have (structural barriers include geography, culturally appropriate appointment times, appropriate times for shift workers, workers on contracts without leave, those with dependants)
 - lower vaccine uptake in younger people who tend to perceive their risk of illness to be low and have concerns about vaccine safety may limit the UK vaccine programme's ability to suppress community transmission. This is based on international evidence of older people in places such as Israel and Chile being well vaccinated and instead younger people are becoming more susceptible and ill with C-19 and variants.

Recommendations:

- *public health messaging to improve vaccine uptake in younger age groups needs to focus on safety and effectiveness of the vaccines rather than risk of contracting illness*
- *make local vaccine access possible such as local place of worship*

Longitudinal health and wellbeing

- It is encouraging to see emerging evidence, on long COVID. As these findings are from studies that are small and/or use non-probability sampling, access to data that allow identification of people who have tested positive and have continuing symptoms of C-19, especially those who have not been able to return to work, is likely to be required in order to influence policy especially around changes to health service provision.
- As studies emerge of the risks of long COVID, a coordinated approach to inform and engage the public on this issue is paramount. An opportunity to lead this work could be explored by HDR UK.
- It is important to take into account individuals who fell ill in March 2020 but were unable to be tested for C-19 and therefore are not being assessed for long COVID. This could end up very detrimental and needs to be addressed.

Status of COVID-19 projects

- The three mentioned in this report will help to provide the much needed inclusion criteria of what symptoms and clinical observations can be classified as Long Covid, vaccine uptake, efficacy and safety and further understanding of differences of COVID impact in men and women.

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



3 members of the HDR UK COVID-19 Patient and Public Involvement and Engagement Group 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.