

Sharing the views of the Patient and Public Voice - COVID-19 Patient and Public Input into 23 March 2021 SAGE Report

Key Statement from Patient and Public Voice:

Following a year since the introduction of the first lockdown, whilst significant advances have been made, we must not lose momentum especially given the number of unanswered research questions that remain, particularly around:

- Vaccines – effectiveness in different populations, effect on transmission rates and factors that influence vaccine uptake.
- COVID-19 has shown to affect referral, diagnosis and treatment, particularly in cardiovascular disease and cancer – to what extent does this affect other health conditions too and are particular groups and populations are affected more than others?
- After being in a range of restrictions for a year, whilst we start to move out of it on a long-term basis, this change could cause mental health problems and further research is needed to understand the true extent to better prepare services for the coming months.



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

- Immunity and Vaccines
 - It is encouraging and positive to see the ongoing research into the effectiveness of the vaccines available to the UK population. However, there are a number of unanswered questions that remain where research is vital, such as:
 - Understanding factors that would influence vaccine uptake and policy on prioritisation for vaccines
 - Targeted interventions to improve vaccines hesitancy appear to have slowed down – does the data and research show an improvement in vaccine uptake?
 - Does the data and research show that the interventions have been successful?
 - What learnings can we take to better prepare for the future?
 - Recent research that explored the [effects of COVID-19 on people with learning disabilities and the increased risk for those with Down Syndrome and Cerebral Palsy](#) demonstrates how important it is to better understand the effects and risk of COVID-19 on different populations as opposed to grouping under 'clinically extremely vulnerable'.
 - A priority needs to be to drill down further and ensure there is greater understanding in different ethnicities, ages and conditions.
 - As the vaccine programme continues to build and we see groups such as healthcare professionals receive two doses, this raises the possibility for a greater understanding of priority unanswered questions that include:
 - How long immunity lasts following vaccinations
 - We see that a handful of common medications are being used as treatment for COVID-19, this leads to questions of if medications have an effect on level of immunity too.
 - Does it have the same level of effectiveness in different populations e.g., the virus affects different ethnicities in different ways – will the vaccine be the same? Evidence is needed to better prepare against health inequalities.
 - Is there an impact on hospital admissions following uptake of the first dose and beginning of uptake of second dose.
 - The effects of the vaccines on transmission rates is becoming more and more important.
 - We are moving out of a national lockdown with a reliance on the protection of the vaccines, so it is imperative that the data and research in this area is carried out as a matter of urgency.
 - [Initial studies with healthcare professionals appear to show it reduces transmission](#) – this needs to be investigated on a larger scale so as to truly protect those classed as 'clinically extremely vulnerable'.
 - Additionally, research is needed to understand if the vaccines could affect the type of symptoms presented as this could influence transmission rates.

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



5 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.

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

- Surveillance and Epidemiology
 - It is extremely concerning to see the results [of recent research using data from the UK Zoe COVID Symptom Study and the UK UMD Facebook COVID 19 Symptom Survey that showed 25% of individuals](#) with symptoms do not get tested.
 - If we are to reduce transmission, this needs to be explored further as a matter of urgency.
 - Public health messaging may have a role to play but what is imperative is the need to better understand why people do not get tested (is it only lack of information?) and implement interventions accordingly.
 - Following a year since the introduction of the first lockdown, there is a need for research to truly understand the behavioural monitoring of lockdown.
 - If there are any changes to restrictions, interventions or guidelines, research should explore and evaluate its effectiveness immediately with results shared at speed.
- Longitudinal Health and Wellbeing
 - Further research has added to the evidence base that there has been a [reduction in routine procedures \(in this case endoscopic procedures\)](#) that could enable diagnosis and therefore treatment of various conditions.
 - What is most concerning is that models suggest that even with mitigation measures in place it could take more than a year to clear this backlog.
 - We've already seen the existing and alarmingly growing evidence that has identified the likelihood of excess deaths from cardiovascular disease and cancer due to the reductions in referral, diagnosis and treatment – urgent research is needed to determine the extent to which this is the other case for other health conditions too and if particular groups and populations are affected more than others.
 - As we move to a stage where restrictions are lifted, this is considered to be a positive move in the fight against COVID-19. However, after being in a range of restrictions for a year, this change could cause mental health problems and further research is needed to understand the true extent to better prepare services for the coming months.
- Clinical Trials
 - Whilst the vaccination roll-out will have an impact on prevention of COVID-19 infection, there will undoubtedly still be a need to identify and thoroughly test possible treatment options and ensure clinical practice is updated. This appears to be a reduced level of research into this compared to others and would urge this to become a priority – complete reliance on vaccination would be detrimental.
 - There is also a need to ensure clinical trials (where it meets requirements) are quickly set up with set plans for speedy recruitment – it is imperative this research is carried out but will be harder to recruit as the population becomes vaccinated.
- Transmission and Environment
 - As the public begin to see the easing of lockdown and a slow return to 'normalcy', the recurring question remains around international travel. With research showing travel restrictions are effective in reducing onwards transmission of COVID 19, this does cause concern as borders start to open.
 - Research is urgently needed to better understand how variations of restrictions to travel could have an impact on transmission and evaluate various interventions.

HDRUK
Health Data Research UK

 Office for
National Statistics

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