

December 2020

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# National Voices Statement on COVID-19 vaccination

# National Voices statement on COVID-19 vaccination: 'Nothing about us without us' must be the guiding principle

Much has been said about how the COVID-19 pandemic has enhanced and encouraged community spirit and taught us all about the importance of communal action for the benefit of all.




⑧ *I am not forgotten*

At National Voices, we have heard many examples of communities and their organisations stepping up and caring for people who need support. But we are also aware that some of the people we have engaged with, often those who are most vulnerable to the virus, are [anxious that their interests and needs might be marginalised or forgotten](#).

People living with ill health, impairment or disability have the most to gain from the protection a vaccine can provide. We have clearly [evidenced](#) that their freedoms have been severely impacted, and their services and support disrupted, as a result of which their physical and mental health has deteriorated.

It is not clear whether all the people whose return to normality most depends on us collectively controlling the virus can have the vaccine themselves. They may depend on the rest of us to provide the shared immunity that derives from, and depends on, a high vaccination uptake.

Our lives and health are connected to those of the people around us – people who are vulnerable to the virus live with family members who are not, and all of us depend on services and businesses reopening, and employment returning to normal. We are truly all in this together.



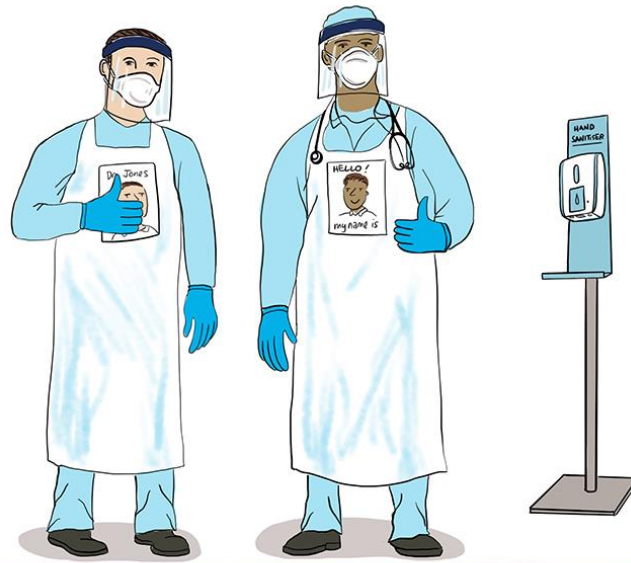
This also needs to be recognised in the priority that is given to formal and informal carers: most of people's lives, including the lives of those of us who are clinically extremely vulnerable to the virus, exist outside of formal service settings. This is where contact occurs, this is where health is created, so vaccination needs to address this reality. We need to explain to those who have been categorised as extremely clinically vulnerable how they have been prioritised and why, and also whether those who are socially vulnerable to the virus - because they are homeless or at high risk of exposure because of the work they do, for example - are being prioritised as they should be.

But people living with ill health or disability have also got questions about whether the vaccine can be given to people who are immune suppressed, for example, or whether it creates a strong protective effect even in people whose immune system is compromised. This and many other questions need to be answered without accusing people of scare mongering or quackery. We must not scare or subdue people into taking the vaccine. We need to listen to questions, concerns and worries, and respond with empathy and evidence.

This is particularly true for groups of people whose trust in services might be lower to begin with, many of whom have suffered disproportionately as a result of COVID-19. Previous experiences of not being listened to, or of racism or stigma, have eroded trust and will understandably make some reluctant to engage in these conversations.

As always, it is important that we meet people on their ground, speak their language, and adapt our service models to maximise access and reach, for example by offering mobile vaccination in their communities, flexible opening hours, low or no threshold services, and clear alternatives to online booking. One size truly doesn't fit all. Never has, never will. Charities and civil society organisations have a massive contribution to make in sharing information and convening respectful conversations to ensure this inequity is properly addressed as the vaccine is rolled out.

We have also heard clearly from our [engagement with people who have health and care needs](#) that they want to understand [what service providers are doing to keep them safe](#) from COVID-19 during their treatments or appointments. This will also be the case for people who are planning to take up the vaccine too. We need an explanation, in accessible and credible formats, about what is being done to minimise the risk of picking up the virus as we attend vaccination centres.



⑥ I know what to expect and that I am safe when I have treatment and care

We have so much to gain by getting this vaccination programme right: grandparents seeing their grandchildren, people in care homes hugging their loved ones, women in labour being with their partners, people who are dying being held by their families. We must not jeopardize these longed-for gains by messing up the communication and service models that are needed to reach all of us, but particularly those who bear the biggest burdens – often of both ill health and disadvantage. [Nothing about us without us.](#)

Dr Rebecca Steinfeld  
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## National Voices

National Voices is the leading coalition of health and social care charities in England. We work together to strengthen the voice of patients, service users, carers, their families and the voluntary organisations that work for them. We have more than 160 members covering a diverse range of health conditions and communities, connecting us with the experiences of millions of people.

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