

The Rt Hon. the Baroness Hallett DBE
By email: contact@covid19.public-inquiry.uk
April 07, 2022

Dear Baroness Hallett,

National Voices' response to the draft Terms of Reference

National Voices is committed to supporting the UK Covid-19 Inquiry and outlines our response to the draft Terms of Reference below.

Who we are and our work during Covid-19

[National Voices](#) is the leading coalition of health and social care charities in England. We have over **190 members** covering a diverse range of health conditions and communities, connecting us with the experiences of millions of people. We work together to strengthen the voice of patients, service users, carers, their families, and the voluntary organisations that work for them.

Our mission is to make what matters to people matter in health and care.

During the pandemic, we worked closely with the NHS and government to make sure the voice of health and care charities and the people they represent was heard and considered in the response. We hosted webinars with senior decision makers, shared ongoing feedback on policy from our members, produced statements, joint letters, and sat on advisory groups. Some of our most significant outputs include:

- Most recently we produced [a shared statement](#) marking the second anniversary of the first UK Covid lockdown that identifies four key priority areas that need to be addressed going forward.
- We developed [Nothing about us without us: Five principles for the next phase of the COVID-19 response](#), which proposed a framework for policy-making that ensured vulnerable and shielding people's needs were taken into account. This was co-signed by over 90 partner organisations.
- We collected striking first hand evidence and powerful insight to inform policy making during the pandemic including our reports: [What We Know Now: What people with health and care needs experienced during the first wave of COVID-19](#), a rapid review of over 66,000 responses to National Voices members' surveys; and [What We Need Now: What matters to people for health and care, during COVID-19 and beyond](#), that summarised findings from 'Our Covid Voices', a website where people living with mental or physical ill-health or disability could share their experiences of life under lockdown.

Our response to the draft Terms of Reference

In response to the draft Terms of Reference we have heard from our members some key areas that should be embedded, added or altered. We ask you to:

Ensure that the voices of people most impacted by the pandemic are at the heart of the Inquiry

First and foremost, we welcome that you plan to listen to the experiences of bereaved families and others who have suffered hardship or loss because of the pandemic. Too often, during the pandemic, those most affected by the Government's decision making have been the last and least likely to have had their voices heard.

It is vitally important that across all elements of the Inquiry's work, the voices of people who have had a direct, personal impact of Government decision making are heard and that we learn from their experiences. In any area the Inquiry chooses to focus – whether 'do not resuscitate' decisions, provision for people with Long Covid,

access to vaccines or any other topic – people with lived experience of the issue should be at the heart of the Inquiry’s engagement.

The inquiry has an important role in hearing, understanding and documenting the experiences of ‘ordinary’ people, particularly from those communities who bore the heaviest burden in terms of morbidity, mortality and economic and social impacts of the pandemic. It must also design a process where people from these communities can be heard.

Make sure that the Inquiry fully explores the unequal impact of the pandemic

Throughout the pandemic, we have all been in the same storm, but we are not in the same boat. The pandemic has exposed significant yet longstanding inequalities in our society that require us to learn more and fundamentally change how decisions are made that affect health and care.

We have heard of countless examples of the unequal impact of the pandemic and the Government’s response – from the disproportionate use of ‘do not resuscitate’ orders against people with learning disabilities, to the difficulties in accessing water and sanitation for nomadic communities and much more. We know that the impact of the pandemic on black and minority ethnic communities has been particularly severe. For example, [data from the Office for National Statistics](#) showed that the mortality rate for deaths involving Covid was highest among males of Black ethnic background. We have also heard from our members and their networks that often the Government’s guidance on self-isolating, shielding and more were inaccessible to large groups of the population because they were delivered in inaccessible formats.

We welcome the Inquiry’s focus on considering any disparities in the impact of the pandemic and the state’s response, including those relating to the Equality Act 2010 and the Northern Ireland Act 1998. We ask you to ensure that considerations of equality and inclusion are fully explored in every element of the Inquiry’s work. We also ask that in addition to the work you have planned on considering the impact of the pandemic on people from specific protected characteristic groups that you consider the impact on people with low incomes, carers and other groups who experience inequality.

Ensure that the Inquiry has a focus on the indispensable role of the Voluntary, Community and Social Enterprise (VCSE) sector in the pandemic response

The VCSE sector saw a huge increase in demand for its services during the pandemic and rapidly responded to meet these needs. It played an indispensable role in coordinating the pandemic response, particularly for the most vulnerable in our society. It is vital that the role of the VCSE sector during the pandemic is captured in the Inquiry’s factual narrative account and that learning is gathered about how the government can work more closely with the VCSE sector to understand and respond to the needs of diverse groups of people ongoing.

Expand the focus of the Inquiry on ‘shielding and the protection of the clinically vulnerable’ to include a focus on people who are immunocompromised

We are pleased to see that people who are clinically vulnerable are included as a focus in the draft Terms of Reference, but this should also specifically acknowledge people who are immunocompromised who are uniquely impacted by the Covid response which has increasingly relied on use of the vaccine. We also think that the health outcomes for these groups should be specifically mentioned. Our suggested wording, put forward by Blood Cancer UK, is *‘shielding, protection **and health outcomes of the clinically vulnerable and people who are immunocompromised**’*

It is important that we understand how decisions were made and continue to be made at different stages of the pandemic for people who are clinically vulnerable and specifically for people who are immunosuppressed. For example, the needs of the latter only became more pronounced in 2021 after the vaccine was rolled out.

Include a specific focus on experiences of carers in the Inquiry

Dementia UK told us that Covid led to limited or no access to respite and other support services for carers especially during the first wave in 2020, when many primary carers were caring 24/7 with no break or access to

wider family support. Many carers reported that they had no choice but to give up work or reduce their hours to provide more care. This led to a sharp reduction in income while still having to pay the rising costs for care such as higher utility bills, paying for additional care and adaptive equipment. This remains an ongoing issue – particularly with the rising cost of living.

It is important that we build an understanding of how carers experienced the pandemic as this will inform learning on how carers can be supported going forward.

Include a specific focus on people who have died at home during the pandemic in the Inquiry

We welcome the Inquiry's proposed focus on the approach to palliative care during the pandemic, however, we fully support our member charity Hospice UK in their [call for the Inquiry to have a focus on the significant increase in deaths in private homes](#) during the pandemic.

There have been more than 100,000 excess deaths in private homes across the UK during the pandemic so far. Hospice UK estimate that at least 67,000 people are likely to have missed out on the specialist palliative care they needed, such as adequate pain relief, with support needs often falling on the shoulders of friends and family.

It is important that we develop our understanding of how people experienced deaths in private homes and identify how their loved ones can be better supported.

Include a specific focus on mental health in the Inquiry

The draft Terms of Reference do not include a focus on mental health which we know was massively impacted by the response to the pandemic. We fully support our member charity Mind in [their call](#) to include mental health in the Inquiry. Mind have set out a series of questions which the Inquiry should seek to uncover the answers to in relation to mental health:

1. Were we prepared? Were the mental health impacts of a pandemic part of the civil emergency planning process and to what extent were these ever implemented?
2. What planning or provision was made once we knew there would be those traumatised by the pandemic: frontline staff, those with Covid or Long Covid themselves, those devastated because they couldn't comfort a dying loved one or mourn with their family?
3. What are the consequences of failing to intervene to help people back to good health? Why is it that despite the huge increase in mental health problems across society during the pandemic, that not one penny of the money announced to meet the NHS backlog is going to mental health?

The Inquiry should examine the mental health impacts of the pandemic, the mental health provision for those traumatised by the pandemic particularly frontline staff, the disproportionate impact of restrictions on those with pre-existing mental health conditions, and inadequate provision for mental health services to be able to meet a huge increase in demand.

Ensure the Inquiry has a focus on understanding the management of the pandemic within primary care

We welcome that the draft Terms of Reference for the Inquiry includes a focus on the consequences of the pandemic on provision for non-Covid related conditions and needs; and provision for those experiencing long-Covid, as well as a specific mention of hospitals. The Inquiry must also examine the management of the pandemic within primary care (including general practice, community pharmacy, dentistry and optometry). It is important that this includes a focus on the response to patients with Covid, meeting urgent care needs and the on-going provision of routine primary care services.

Use the testimonies and learning gathered through the Inquiry to inform the ongoing impact of Covid-19

We call for the inquiry to make recommendations addressing the ongoing impact of Covid that can be enacted now, rather than the next time we're facing a pandemic.

The draft Terms of Reference proposes that the Inquiry examines *past* preparations and the response to the pandemic and lessons learnt for *future* pandemics, but we must also acknowledge that the pandemic is not over. There is an urgent need to look at current concerns. The Inquiry could, for example, undertake a rapid review to provide recommendations about changes that need to take place now to ensure improved protection and treatment for people who are immunocompromised, cancer patients and people in care homes.

Ensure that the Inquiry has a focus on ensuring health and care services have the resilience to be able to cope with future pandemics

As a result of underfunding, workforce planning and other issues, in the run up to the Covid-19 pandemic, the NHS and social care were already struggling. It is important that the Inquiry has a specific focus on how the government together with health and care system leaders can ensure that NHS and social care services have enough resilience (through adequate investment and capacity) to be able to cope with future pandemics.

An offer of support

We have extensive experience in what matters to people relating to health and care, how to involve people, and how to work with the VCSE sector. We are keen to offer our support in ensuring the Inquiry is designed and run in a way that engages with people in a meaningful and constructive way, avoiding tokenism, from the early stages.

Sharing our learning

As described earlier, we have a wealth of insight collected over the course of the pandemic response and can share this with the inquiry as needed.

Working with VCSE sector

We can connect the inquiry with our thriving and committed network of over 190 member health and social care organisations and the people they represent. We are willing and able to consult with our members and provide evidence to the Inquiry at the relevant stages.

Working with people who have lived experience

As detailed above, the inquiry has an important role in hearing, understanding and documenting the experiences of 'ordinary' people, particularly from those communities who bore the heaviest burden in terms of morbidity, mortality and economic and social impacts. At National Voices we are therefore interested in finding ways to support you to centre the inquiry process on the lived experience of people, particularly those living with ill health or disability and inequality.

Through our members, we can connect the inquiry with diverse people and communities who can offer expertise through their lived experience during the pandemic to inform lessons learned. We can also offer advice on designing a process of engagement that is accessible, inclusive and non-tokenistic informed by our experience with co-production methodologies.

Yours Sincerely,



Sarah Sweeney
Head of Policy
National Voices