

January 2021

Communication is Key

National Voices statement on the impact on patients and communities of unprecedented pressures on the NHS

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We are in a deep crisis. It is a distressing time, as COVID-19 rips through people's lives, leaving loss and grief in its wake. Our deepest gratitude goes to those working in health and care, confronting that loss head-on every day, yet continuing to care with compassion.

Given the circumstances, we clearly recognise the need to lockdown to curb the spread of more transmissible strains of coronavirus as vaccines are rolled out. But we at the National Voices coalition, comprising over 170 health and social care member charities, have serious concerns about the ways in which now unavoidable changes to health and care services are being communicated to those desperately needing care.

Our members have told us about urgent cancer treatment being cancelled, a lack of ITU beds for those having heart attacks, and people effectively being turned away from primary care.

These may be necessary changes, but they beg answers to urgent questions: To what extent are NHS services open? Where services are closed, how are people being supported while they wait for treatment?

National Voices members support people with these and many other questions, but they also report that unclear and inconsistent messaging is exacerbating an already dire situation, especially for people with long-term conditions, disabilities and impairments. Our ask is therefore that better communication is addressed as a priority now.

The need to clarify which NHS services are open and where

During the last lockdown in November 2020, the Prime Minister reassured us that the NHS was open for business as usual. Back then, he stated: "Unless your clinicians tell you otherwise, you should continue to use the NHS, get your scans, turn up for your appointments and pick up your treatments."

This time around, there were no such reassurances. In fact, the Prime Minister did not mention the extent to which core NHS services are open in his lockdown statement. Confusing text messages from GP's surgeries have compounded that lack of clarity. Is only emergency treatment now available? Or urgent treatment too? What about essential ongoing care for those living with long-term conditions and disabilities? Our members have reported variable messages and

services across the UK. Some physiotherapy services, for example, are available in some areas, but not in others.

The impact of service closures is not neutral. Our members tell us that a lot of people are being left in pain or with undiagnosed conditions, and point out that delays in treatment will inevitably cause avoidable harm.

One member organisation said that no treatment and rehabilitation is being offered to patients who have suffered a stroke, and that some people are being transferred to care homes instead of rehab, with some end-of-life patients being transferred to care homes who are not always able to care for them well.

Communicate to people how they are being supported while they wait for care

Given this acute crisis, people understand that many core services will be unable to continue delivering care, while the NHS temporarily becomes effectively a 'COVID-19 Health Service' at least in some parts of the country. But our members, and fellow patient charities, believe that there urgently needs to be clarity for those who are waiting for new or ongoing treatment about how long they can expect to wait, what services and resources are available while they wait, and what to do if they deteriorate.

Signposting people to voluntary sector-provided services is one option, but it must be recognised that such requests for support have already skyrocketed at the same time as the community fundraising model upon which many charities depend has taken a severe hit. So charities cannot simply pick up the pieces without further government support.

Provide open and tailored information about vaccines

Our members have told us about the concerns of those they support around the vaccine and accessing it. They have shared that there is a lot of worry around changes to the vaccine schedule, the extent to which a single shot impacts the efficacy of the vaccine, especially in the longer term, and the relative efficacy of the three different vaccine types. We have also picked up on confusion around the primary care led vaccination roll out versus centrally driven invitations to attend vaccination centres. For many people, the GP surgery is much more accessible.

People who are immunocompromised have specific concerns about whether the vaccine works for them, and how it might interact with medications they take. Those categorised as Clinically Extremely Vulnerable are unsure about whether they will need to continue shielding after being vaccinated, or if they can return to work and send their children back to school, when the time comes.

Some told us about their concerns around family carers not being able to access the vaccine. Since carers will not be able to look after their loved ones if they become ill, there is a clear case for prioritisation. Others expressed concern around the lack of demographic data being gathered and published around vaccine administration – in particular, whether Black and Minority Ethnic citizens are

accessing the vaccine, given what we now know about COVID-19's disproportionate impact on those communities. So clearly there is a need for more information – and, crucially, more tailored information – about the vaccines too.

Clarify the guidance to shield

Our members have also emphasised the need to clarify the guidance to those Extremely Clinically Vulnerable people advised to shield. Should they send their children into nurseries and other care settings, or into school if they or their partner is a critical worker? The current ECV guidance does not directly address this – and it should. Beyond that, what rights do ECV people have if they can't work from home? People are worried that they might lose their homes because Statutory Sick Pay does not cover the cost of their rent. Why isn't furlough a right rather than at the employer's discretion? Why, during this third lockdown, nearly a year into this pandemic, are people still being asked to choose between their lives and livelihoods?

Our asks

We know the health and care system and all services are under unprecedented pressure. We are not criticising the NHS or health and care workers for not being able to meet all needs right now. But this makes it even more important that we don't lose sight of the importance of good information and communication. Our asks are that there is improved communication about:

- Which NHS core services are available and how to access them
- How people will be kept safe if they use services
- How people are being supported while they wait for care
- Vaccines, their efficacy for those with long-term conditions, and how to access them
- The guidance to shield, covering practical, financial, clinical and emotional concerns
- Efforts to ensure that vaccine and service uptake is equitable, based on comprehensive data

All communication needs to be made available in all accessible formats – sign language, easy read and community languages.

These are difficult times that generate difficult decisions. But we can't now avoid them. Leaders must provide a narrative that's both realistic and hopeful, to help people get through. More than that though, they must provide clarity and honesty about the decisions being made, and how they are supporting people to get the care they need while core services are effectively suspended.

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 170 members covering a diverse range of health conditions and communities, connecting us with the experiences of millions of people.

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