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The covid-19 pandemic took power from the people

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Who decides when covid-19 restrictions are lifted? A government might lay out plans for reopening society. It might even emphasise the importance of data, not dates. But, as with any exercise in project management, the milestones tend to loom more powerfully in people's minds than the objectives. Some scientists now argue that, with the rise of variant B.1.617.2, WHO's new delta variant, England's plan for reopening fully on 21 June should be put on hold.^{1 2}

It's a debate that will echo around the world. In England, the decision ultimately rests with the prime minister, Boris Johnson, although any remaining confidence in his ability to master the pandemic was dealt a grievous blow by recent testimony from his former aide.³⁻⁶ One conclusion to emerge from the picture of government incompetence painted by Dominic Cummings is that we need an immediate public inquiry or independent review that is fast, forward looking, and empowered to influence policy.⁷ Another is that we must take immediate action based on what we know already, from the damning National Audit Office report and findings of WHO's independent pandemic review panel.^{8 9} In practice, the two approaches might be the same. A reckoning might not be in the interests of politicians, but it is in the interests of patients.

Something needs to be done. Limping from one crisis to the next is negligence, and quitting a failed approach is often better than gritting it out.¹⁰ More evidence continues to emerge on the growing burden of long term sequelae of SARS-CoV-2 infection, and how they overlap and differ from the sequelae of other viral illnesses.^{11 12} This adds to the existing pressures on health services of managing patients at a distance, providing mental health services for pandemic and climate emergencies, and finding solutions to workforce pressures and doctors' training needs.¹³⁻¹⁵

The missing, disempowered voices in all this are those of patients and the public. Progress in patient engagement—"nothing about us without us"—was sacrificed in the name of the pandemic response.¹⁶ Policy makers remain slow to accept responsibility for their decisions, but they are quick to blame the public for vaccine hesitancy or for not following official advice, even when that advice comes as mixed messages.¹⁷ Involving the public in decision making builds trust and is possibly more important in an emergency when civil liberties are placed at risk.¹⁸ Blame loses public trust—and that loss of trust has a detrimental impact on health.

Indeed patients are central to the remarkable success of the UK's Recovery trial, which continues to lead the world in evaluating treatments for covid-19.¹⁹ Scientists and clinicians have shown how open and clear communication with patients and families is possible even in an unprecedented emergency setting.

A research project hatched on a bus ride, with patients at its heart, has had a beneficial global impact second only to vaccination.

Regrettably, though, the pandemic has put power back into the hands of leaders and their ruling cabals. The public voice is lost; trust is lost. This is particularly concerning in the UK where proposed NHS reforms will cement that undesirable power shift and deliver greater control to politicians over the health service.²⁰ Cummings' evidence reminded us of the dangers of unfettered political control of health. Not every group of politicians, from whichever political party, will perform in this damaging way, but the risk is that they might. One way to restore trust is to redistribute power and shift the balance on who decides about us by rediscovering the lost voices of patients and the public.

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