

Why are patient and public voices absent in COVID-19 policy-making?

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Patient and public voices were "regrettably" absent in the early stages of the COVID-19 pandemic, but must now move centre stage, argue experts in *The BMJ* today.

Patient Partnership Editor Tessa Richards, Patient Editor Henry Sowcroft, and the members of The BMJs International Patient and Public Advisory Panel, acknowledge that decisions had to be made fast, but say "[policy makers](#)' choice of expert advisers excluded those with expertise rooted in lived experience—patients, families, and frontline [health](#) and [social care professionals](#)."

This was regrettable, they say. "Their input would have helped to mitigate the predictable adverse effects of massive service reconfiguration and lockdown, and emphasised the need for clarity on which services would be suspended and which would remain accessible."

But while patient and civil society advocacy groups may have lacked seats on expert committees, they have taken the lead in providing information, advice, and support for their communities, note the authors.

For instance, they have lobbied for a voice in policy making, for a focus on inequalities, and for policies to take account of the reality of people's lives. They have also accumulated a wealth of information from the patient community on the physical, mental, social and [economic effects](#) of the pandemic, effects that highlight the urgency of restoring essential medical services and the need for a comprehensive public health response.

So why were the voices of patients and the public tuned out, they ask?

Despite decades of activism, they argue that public and patient involvement is still largely seen as "nice to have" but non-essential. "The resources, skills, views, priorities, and preferences of patients, carers, and the communities which support them are not well recognised, valued, or systematically used to improve care."

They urge health leaders to listen to and engage with patient advocates,

organisations and civil society networks who are "primed to inform joint learning from the pandemic and help shape post-COVID services."

And they say more collaborative platforms to unite patient communities with professional groups should be established to ensure that public and patient involvement "becomes irreversibly embedded in decision making."

Providing people with full online access to personal health records and test results "will improve the quality and safety of care, and raise health literacy on both sides of the professional fence," they add.

Finally, they say mutual understanding and respect is essential in any partnership, and patient leadership must be taken seriously by both health professionals and patients.

They conclude: "COVID-19 has precipitated a global health crisis, plunged the world into economic recession, put the spotlight on structural inequalities, including racism, and galvanised the call for action on climate change. The knowledge to confront these challenges needs to be co-produced. Patient involvement must be taken seriously, embedded robustly, and never sidelined again."

In 2014, *The BMJ* launched its patient and [public partnership strategy](#) to encourage doctors and patients and those who care for them to work together as partners to improve healthcare. Since then, input from patients has been an integral part of how the journal works and thinks.

The BMJ's collection of patient and public perspectives on the pandemic can be found here:

<https://blogs.bmj.com/bmj/category/patient-perspectives/>

More information: Editorial: Patient and public involvement in

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