

People's Perspective: Preparing
for a challenging winter 2020/21

Nothing about us, without us.

July 2020

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"Only when patients can influence do they have power. When patients hold influence, services are designed for their experience..."¹

Dr Jessica Drinkwater, General Practitioner

This is our perspective

Our words accompany an Academy of Medical Sciences report '[Preparing for a challenging winter 2020/21](#)'. The report describes the scientific perspective on factors that could make winter 20/21 difficult for everyone in the UK, and see the NHS stretched beyond its capacity. We² all live with, or care for someone who lives with, one or more long-term conditions³. These conditions make us uniquely vulnerable to the coming UK winter and the challenges it brings. Between us, we have lifetimes of experience of living with long-term conditions. It has never been more important to involve us in the decisions made about our lives. We have rarely experienced more meaningful and genuine involvement than we have with this project. This is our perspective.

"I was wary before COVID-19. Every cold, tummy bug, every child with chickenpox was a threat. Now, any contact with anyone might be fatal. I don't play Russian roulette."

Colin Wilkinson

We are all used to being vigilant about infections. For one reason or another, we are all at greater risk from every kind of infection. We've all learned to live with that. When this pandemic struck, it took away our control of our lives, our care and our futures. Our support networks vanished overnight. At best, the partnerships we had built with the NHS workers who care for us were put on hold. At worst, we were forgotten, some missed off shielding lists when we knew we should be on them, unable to access supermarket online shopping slots or council food boxes, feeling we didn't matter. Now, like many, we're exhausted. We recognised the feelings of those interviewed by Ipsos MORI,⁴ but we all felt the stakes were higher for us.

"for those in vulnerable groups the prospect of going outside, near people who may not abide by social distancing rules, was a major source of concern. Some wondered whether they might ever take public transport or visit town centres again."

Ipsos MORI workshop participant

Many vital processes came to a sudden halt – not just our care. This was understandable, given the life or death struggle in which the whole of the UK was engaged at the time. As that struggle subsides, we feel that the most crucial, pervasive and fundamental need is

¹ <https://blogs.bmj.com/bmj/2020/06/04/jessica-drinkwater-back-to-the-future-patient-participation-in-general-practice-during-covid-19/>

² A full list of the members of the Academy of Medical Sciences Winter challenges Patient and Carer Reference Group is available at <https://acmedsci.ac.uk/policy/policy-projects/coronavirus-preparing-for-challenges-this-winter> (tab 3). This group provided information and advice on the issues most important to those who would be most affected by a bad winter. The two co-Chairs of this group sat on the Academy's Expert Advisory Group to feed patient and carer perspectives into their discussions.

³ https://richmondgroupofcharities.org.uk/sites/default/files/multimorbidity_-_understanding_the_challenge.pdf

⁴ Ipsos MORI COVID-19 winter preparedness workshops www.acmedsci.ac.uk/coronavirus-winter-challenges-public-dialogue

to involve people in determining which health services are needed most, and how they should be delivered. Where such involvement did not exist before the pandemic, it must be put in place now. **Building back better doesn't just apply to our economy or our environment. It has to apply to our care.** Disparities between people and places have to be addressed.^{6,7,8,9,10,11}

"The pandemic has not landed evenly across the population: it has taken a greater toll on older people, on men, on poorer communities, and on black and minority ethnic groups."⁵

We can find the best way forward together

Involving people in service design must not be a continuing casualty of COVID-19. If the people's stake in the redesign of services to cope with the challenges of winter continues to be ignored, poorer physical and mental health and a greater strain on the NHS will be the result.

"the only way to get quality, meaningful healthcare is to involve the disenfranchised patients. Theirs is the biggest need."
Carol Liddle

Facing the challenges of winter, we must have the option to make shared decisions about what matters to us, and what will enable us to cope with the challenges ahead. Designing options to access the support we want will empower us to manage our own health, working towards the life we choose for ourselves, not the treatment outcomes clinicians think we need. The only way that can happen is if we are involved in deciding which services are offered and how.¹² Working with clinicians, we can find the best way forward – together.

"When decisions are made without the people affected – they are usually the wrong decisions."
Mandy Rudczenko

Of course, our lives and our care are also shaped by guidance our Government produces, and we need a greater role in this as well. The evolving guidance from Government has become much more complex as lockdown starts to be lifted. While the risk of contracting the virus may be lower, the consequences of doing so remain unchanged for us. Those consequences vary widely, even among people who are classified as extremely clinically vulnerable. For those of us who received them, the shielding letters were complicated, long and difficult to understand. We understand that involving people in developing guidance can seem difficult. Living with guidance developed without us is much more so.

"Decisions must reflect realities. The only way to achieve this is through true collaboration."

⁵ <https://www.kingsfund.org.uk/publications/letter-to-health-and-social-care-select-committee-covid-19>

⁶ <https://www.kingsfund.org.uk/publications/what-are-health-inequalities>

⁷ <https://www.health.org.uk/topics/inequalities>

⁸ <https://www.gov.uk/government/publications/health-inequalities-place-based-approaches-to-reduce-inequalities>

⁹ <https://www.gov.uk/government/publications/covid-19-review-of-disparities-in-risks-and-outcomes>

¹⁰ <https://www.gov.uk/government/publications/covid-19-understanding-the-impact-on-bame-communities>

¹¹ <https://bmcmmedicine.biomedcentral.com/articles/10.1186/s12916-020-01640-8#Abs1>

¹² <https://www.kingsfund.org.uk/publications/delivering-better-services-people-long-term-conditions>

Carol Liddle

There is now a window of opportunity in which Government, the NHS and social care providers can work with the people they support to design a set of services, guidelines and communications that will work for the whole person – not individual conditions – and will give people options.

Involve us now

We support National Voices' five principles¹³ for the next phase of the COVID-19 response. However, we recognise that coproduction processes^{14,15,16,17} will be difficult to undertake remotely. Healthcare organisations must do everything they can to use involvement processes which embody the values¹⁵ of coproduction.

"You can't have equality without power being shared. We are a long way from that."

Lynn Laidlaw

Any involvement and shared decision-making process has to be real, not a tokenistic effort. From experience, we feel this will not happen without Government leading by example and compelling health and other local bodies to share decision making. There is one test we would apply to any involvement process. If the decisions are not made by all the groups involved, at the same time, in the same virtual or real room, it is not real involvement. **Nothing about us should be decided without us.**

"Don't assume you know what I need unless you ask me"

Kimberlee Cole

We make one simple, heartfelt request. **Involve us now** in preparing for the challenges this winter will present - or create a burden of health problems which may last for decades. The members of this reference group, and we are sure, many like us, stand ready to assist.

"Government must listen to the voices of communities now, especially vulnerable people, and work with us to tackle the prospect of a challenging winter."

Sudhir Shah

¹³ https://www.nationalvoices.org.uk/sites/default/files/public/publications/5_principles_statement_250620.pdf

¹⁴ <https://www.scie.org.uk/publications/guides/guide51/>

¹⁵ <http://coalitionforcollaborativecare.org.uk/features/a-co-production-model-five-values-and-seven-steps-to-make-this-happen-in-reality/>

¹⁶ <https://www.kingsfund.org.uk/publications/patients-partners>

¹⁷ <https://journalofethics.ama-assn.org/article/using-principles-co-production-improve-patient-care-and-enhance-value/2017-11>



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