

People's Perspective COVID-19: Preparing for the future

Work with us, work for all of us

July 2021

People's Perspective: COVID-19: Preparing for the future

Last year, a group of people came together with the Academy of Medical Sciences as the Patient and Carer Reference Group for a project on forecasting the priorities for a challenging winter 2020-21. This summer, many of us have returned, and been joined by others who bring a wider range of voices with different experiences of the pandemic. This People's perspective has been written by the Patient and Carer Reference Group and does not necessarily represent the position of the Academy of Medical Sciences.

We have, again, worked alongside the Expert Advisory Group to inform their discussions, and been informed by their discussions. We are not representative of the public and are acutely aware that we don't include people whose voices are seldom heard and have been the most impacted by the pandemic, for example those who are homeless, people who don't speak English as a first language and those living with profound physical and mental disability.

In our People's Perspective last year, we wrote a single, strong plea to policymakers:

*"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."*

Sadly, that request fell on deaf ears. We have seen no evidence of involvement in service redesign in the NHS. Some funders still undervalue the role of involvement in improving research on COVID or any other topic. As HRA reported, only 20% of COVID research proposals seen by research ethics committees at the beginning of the pandemic involved patients and public. Normally, this would be 80%¹. Government and UKRI must show leadership in this – sadly that has been lacking to date.

Involve us now

While we have additional messages this year, our message from last year remains, **involve us now** while there is time, before winter arrives, and before the burden of enduring health problems created in the last 16 months becomes a torrent that will wash away the NHS.

Work with us, work for all of us

"People who have suffered health, financial and psychological consequences from the last 15 months are dealing with lasting damage to their lives. Without genuine collaboration between government and citizens to mitigate this damage, the future of our society will be badly scarred."

Mandy Rudczenko, Member, PCR²

¹ <https://www.hra.nhs.uk/about-us/news-updates/involving-public-covid-19-research-guest-blog-bec-hanley-and-maryrose-tarpey/>

² Patient and Carer Reference Group (for this project)

The need for involvement is greater now than ever before. Involvement has been cast aside when the need is greatest. Decisions with far-reaching consequences are being made without involvement of those they affect. The right to be involved in decisions affecting people is as ancient as the beginnings of democracy in the United Kingdom. King Edward I, summoning the Model Parliament in 1295, said "what touches all, should be approved by all, and it is also clear that common dangers should be met by measures agreed upon in common"³

There is no more 'common danger' than a pandemic. While the measures to control it have been approved by Parliament, those most affected are not *in* Parliament, though their needs should be represented by MPs. To make sure local, national, NHS and other public bodies' policies, services, communications and systems work for everyone, they must be developed with involvement from those who will have most difficulty with access and whose need is greatest. They must be implemented, evaluated and refined in the same way.

Services, measures to mitigate infection risk, communications, decisions about our futures should be agreed upon in common with those most affected.

The role of people alongside scientists on SAGE

Those most affected by COVID must be as much a part of national decisions as anyone else. We have thought hard about how to achieve this.

We feel the best option is to have public members involved in SAGE and devolved equivalent group discussions, to ensure the scientific evidence is complemented by the reality of people's experiences. This must not be tokenistic. Public members must make up a substantial portion of the members of SAGE and its subgroups, we suggest an indicative minimum of 25% at any given time.

Public members of SAGE and devolved equivalents should be offered opportunities as part of their role to talk to local communities across the country to find out about the everyday issues each emergency creates. We feel this option is most in line with the principles of co-development, as outlined in Box 1, whereas other options we considered were not (e.g. a separate group to advise SAGE).

Members of the public who can bring voices from communities most affected by emergencies should be included in SAGE, devolved equivalents and their subgroups, at an indicative minimum 25% of membership at any given time, using an approach that fulfils the spirit of co-development, as set out in box 1.

³ <https://www.britannica.com/topic/Model-Parliament> (the original is in Latin, so translations vary)

Redress the balance

“The lockdown did save lives, but it cost lives and destroyed them as well.”

Kimberlee Cole, Member, PCRG

People in the poorest areas of the UK^{4,5} live shorter, sicker lives than those in the richest, are twice as likely to live with high-impact chronic pain,^{6,7} and more likely to have more than one long-term health condition for more of their life⁸. These problems were there before the pandemic. They had been there for decades, generations. Then COVID struck.

Between March 2020 and April 2021, the mortality rate from COVID was 175.3 per 100,000 higher in the 10% most deprived places in England than in the least. Similarly, provisional data from Public Health England⁹ show life expectancy fell by similar amounts for both sexes from 2015 to 2018 across all communities. But as the table below shows, there were shocking differences in the drop in life expectancy between 2019 and 2020 for the least and most deprived places.

Life expectancy	10% most deprived		10% least deprived		Change	
	2019	2020	2019	2020	Most dep	Least dep
Females	78.9	77.3	86.8	85.8	1.6	1
Males	74.3	72.4	83.6	82.6	1.9	1

While these are provisional data which must be treated with caution, the contrast is stark. They illustrate an outrage we cannot tolerate. Accepting a level of mortality from COVID as the price of removing restrictions means accepting that COVID will probably kill more people living in deprivation than people who don't. The same may well be true of other inequalities. To us, that is not levelling up.

Those living in deprivation do not have the financial and other means – the social capital – to adapt to our constantly changing COVID circumstances. These past months have been harder, the impacts greater, and the material and psychological effects more profound, than for those living with the means to adapt and navigate systems successfully.

“We have heard in our discussions about the different ways communities have responded to the pandemic. It was clear that deep, ingrained inequalities, not knowing where to turn or who to trust, poor communications and unwillingness to trust establishment bodies caused problems.”

Isaac Samuels, Member, PCRG

National initiatives to address problems such as contact tracing faltered without the on-the-ground knowledge of people, cultures and communities to make things work. For the coming winter, control needs to pass to local areas. Addressing inequalities isn't done by

⁴ <https://data.oecd.org/inequality/income-inequality.htm>

⁵ <https://data.oecd.org/inequality/poverty-gap.htm#indicator-chart>

⁶ <https://jech.bmj.com/content/53/10/603.short>

⁷ <https://www.versusarthritis.org/media/23782/chronic-pain-report-june2021-print-friendly.pdf>

⁸ https://richmondgroupofcharities.org.uk/sites/default/files/multimorbidity_-_understanding_the_challenge.pdf

⁹ <https://analytics.phe.gov.uk/apps/covid-19-indirect-effects/#>

giving everyone the same, national offering, it's done best by those who know who needs most help and what they need.

"When we start to address inequalities and disparities, which can take a significant investment of time, we need to start where the need is greatest, especially in those communities where there is deprivation and lack of opportunities - not just in cities."

Winston Allamby, Member, PCRG

The role of national governments must, from now on, be to provide the budget, support, resources and coordination to enable communities to assist those within their community that need help, starting with those who need it most. Investment now will pay off for decades, by equipping communities to help themselves.

The UK Government and devolved administrations must equip and fund local communities to work together, through local authorities and community groups, to tackle inequalities in their areas.

"What we need now is a handbrake turn in policy, to ensure we are ready for winter and start the process of addressing inequalities for real. We must hand control and management of this pandemic back to communities to manage it in their area, with all the resources national and UK governments can provide behind them."

Colin Wilkinson, Co-Chair, PCRG

The unequal long-term health effects of COVID

Long COVID Support¹⁰ is monitoring service quality for people with long COVID. The patient stories in that research¹¹ are truly shocking. Recent Government and NHS announcements^{12,13} addressing this are welcome, as are guidelines for assessment^{14,15} and management¹⁶ of long COVID. However, the route to successful assessment and management – to being listened to and receiving care – is too long and does not exist everywhere, or GPs are unaware of how to refer into it.

For whatever reason, people with long COVID are not getting the care they need. This must change, and quickly.

People with long COVID need coordinated, personalised care. According to the Office for National Statistics¹⁷, long COVID was most common in a range of groups, including those

¹⁰ <https://www.longcovid.org/>

¹¹ <https://www.longcovid.org/impact/long-covid-clinic-survey-may-analysis>

¹² <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2021/06/C1312-long-covid-plan-june-2021.pdf>

¹³ <https://www.england.nhs.uk/2020/12/long-covid-patients-to-get-help-at-more-than-60-clinics/>

¹⁴ <https://www.nice.org.uk/guidance/ng188/chapter/2-Assessing-people-with-new-or-ongoing-symptoms-after-acute-COVID-19>

¹⁵ <https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/11/C1248-national-guidance-post-covid-syndrome-assessment-clinics-v2.pdf>

¹⁶ <https://www.nice.org.uk/guidance/ng188>

¹⁷

<https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/bulletins/prevalenceofongoingsymptomsfollowingcoronaviruscovid19infectionintheuk/1july2021>

living in the most deprived areas and those with existing health problems or disabilities. They also showed that long COVID was more common among health and social care workers than those working in other sectors.

Health and social care workers have been at much higher risk of catching COVID, as have many other key workers. For us, the most important reason to make sure that health and social care workers with long COVID get the care they need quickly is that their service to the rest of us – and indeed to our country – demands it. When they are in difficulty, we must help them properly, not with a postcode lottery of uncertain care. Aside from the fact it is the right thing to do, getting health and social care workers fit for work again will help ease staff shortages, a key priority outlined in the expert report.

“All I want to do is to get back to work and help my colleagues deal with this crisis and care for our patients.”

Sophie Evans, nurse living with long COVID and Member, PCRG

Everyone living with long COVID deserves better. We need to make sure those in greatest need come first. Local implementation of plans for long COVID care must go hand in hand with planning how to fully and safely restart care for those with long-term conditions needing secondary care support.

“Lack of access to help, support and care has had a profound effect on those living with long-term conditions.”

Lynn Laidlaw, Co-chair, PCRG

Some people with pre-existing long-term conditions have had no or little access to vital secondary care support for many months, often worsening their condition. We must ensure this care deficit is addressed alongside providing care for people with long COVID.

Care for people with the long-term effects of COVID must be balanced with addressing the backlog of ongoing care needs for people with pre-existing long-term conditions.

At local level, it appears patients have not been involved in designing changes to services for long-term conditions or initiating services for people with long COVID. There are unacceptable delays for both groups, and those needing surgery or other treatment.

“Before and during the winter, the NHS must make sure people can get seen, and get the treatment they need, much sooner. We can't continue with people waiting so long for care.”

Sudhir Shah, Member, PCRG

Long COVID clinics and services, changes to care for people with pre-existing long-term conditions and for those awaiting surgery must be co-developed with those who will use them, demonstrating the approach outlined below.

Box 1: Co-Production Collective¹⁸ approach to Co-production¹⁹

<p>Being human</p> <ul style="list-style-type: none"> • Valuing diversity of knowledge, experience and perspective • Building mutually beneficial relationships based on honesty and trust 	<p>Being inclusive</p> <ul style="list-style-type: none"> • Removing barriers to participation • Recognising people's strengths and supporting their development
<p>Being transparent</p> <ul style="list-style-type: none"> • Addressing power imbalances and hierarchies • Sharing roles and responsibilities 	<p>Being challenging</p> <ul style="list-style-type: none"> • Continuous reflection, learning and improvement • Embracing new ideas and ways of working

The unequal impacts of the COVID crisis on mental health

The COVID pandemic has had a dramatic effect on the nation's mental health, as the Expert Advisory Group's report highlights. In our view, uncertainty and the rate at which facts, policies, regulations and guidelines have changed were key factors in this. We know the effects have been unequal, with those who have pre-existing mental health problems, health and social care workers and those living with difficult circumstances including deprivation, isolation and bereavement during the pandemic most affected.

Urgent action to dramatically increase the availability of co-developed, tailored mental health support is essential to help us through the coming winter. Triage options must be put in place to ensure people get to the right care quickly. Options must be co-developed with those affected by mental health problems, especially those for whom COVID has overlaid new problems on existing mental health problems.

These options must include significantly higher-profile and better information about how people can care for their own mental health.

Ensuring that IAPT²⁰ (open access talking therapies) services have the resources (money, support and training) to meet the dramatic surge in need is essential. It is unacceptable for people to have to wait six months or more to access talking therapies. Community and secondary mental health services will also need additional capacity to respond and meet the needs of those who need them.

Everyone should get the care they need for their mental health quickly, but triage must ensure those in greatest need get the right care first. Open access triage and talking therapies (IAPT) must be expanded to meet the need, as must the community and secondary mental health services that will back them up.

¹⁸ <https://www.coproductioncollective.co.uk/>

¹⁹ Reproduced with kind permission of the Co-production Collective: <https://www.coproductioncollective.co.uk/what-is-co-production/our-approach>

²⁰ Improving Access to Psychological Therapies - <https://www.nhs.uk/mental-health/talking-therapies-medicine-treatments/talking-therapies-and-counselling/nhs-talking-therapies/>

The unequal uptake of vaccinations

“Even with vaccination, we are not free of this virus. We must all be cautious and careful as we move forward and lift more restrictions.”

Katherine Barrett, Member, PCRG

One of the most alarming aspects of inequality in the pandemic has been the differential rates of vaccination by the socioeconomic status of communities and people’s ethnic origins. Recent data²¹ show 55% of those in the least deprived 10% of communities had received both doses of vaccine, while only 40% of those in the most deprived 10% had. This is a stark and shocking difference. Equally shocking are the differences between groups with different ethnicity, ranging from 95.1% of people of white British ethnicity to 64.8% of people of black or black Caribbean ethnicity aged 50+ having received at least one dose. For those aged 16+, it ranges from 75.6% of white British people to 34.7% of people of Chinese ethnicity. While these inequalities are complex, we do know people respond best to people in their communities – people they trust – giving them messages. Vaccination is the only way for all of us to get out of restrictions.

A rapid, targeted expansion of the COVID-19 Community Champions²² programme must be put in place to address local inequalities in vaccine uptake.

An additional issue is the lack of information or clear options for those who, for medical reasons, are unable to have any of the current vaccines. This must be urgently addressed.

These inequalities are symptoms of the underlying, long-standing differences between areas and people in the UK. If ‘levelling up’ is to be more than words:

Government must help local communities to find their own solutions to inequalities through co-development approaches, with their first priority being to address disparities in the uptake of vaccines, ensuring those in greatest need get help first.

Without urgent action now, we fear the coming winter will make the divides between people and places wider still, making these inequalities even harder to resolve.

²¹ <https://www.england.nhs.uk/statistics/statistical-work-areas/covid-19-vaccinations/>

²² <https://www.gov.uk/government/news/community-champions-to-give-covid-19-vaccine-advice-and-boost-take-up>

Develop better communications and guidance

“Communication is more than just sending a message. It has to be received and understood in the right way too.”

Bo Rutter, Member, PCRG

One of our greatest disappointments of the last year has been the communication with the public from Government and NHS organisations. Communications since the first lockdown have been much too unclear.

Having seen the modelling undertaken in this project, we are convinced there is a high probability further restrictions will be needed. As members of the public with a wide range of different experiences of healthcare, we can see that unlocking permanently this summer creates a hostage to fortune.

While we all need hope, it must be realistic hope. We feel very strongly that the effective communication principles in the main report (Box 3) should be the basis for national communications going forward. Communications to those in the clinically extremely vulnerable group need to be shorter. If shielding letters need an easy-read version, they are too complicated. Communications must not be on the basis of ‘do as I say, not as I do’ – everyone giving these messages must display the highest standards of probity if trust is to be retained.

All agencies must give out consistent messages to ensure the public do not lower their guard against COVID and other winter viruses.

Going forward, communications must be clear, simple, consistent and co-designed with those they address. Clear guidance on what to do and when is essential.

Our key messages

Involve us now

- Services, measures to mitigate infection risk, communications, decisions about our futures should be agreed upon in common with those most affected.
- Members of the public who can bring voices from communities most affected by emergencies should be included in SAGE, devolved equivalents and their subgroups, at an indicative minimum 25% of membership at any given time, using an approach that fulfils the spirit of co-development, as set out in box 1.

Redress the balance

- The UK Government and devolved administrations must equip and fund local communities to work together, through local authorities and community groups, to tackle inequalities in their areas.
- A rapid, targeted expansion of the COVID-19 Community Champions²³ programme must be put in place to address local inequalities in vaccine uptake.

Develop better communications and guidance

- Going forward, communications must be clear, simple, consistent and co-designed with those they address.
- Clear guidance on what to do and when is essential.

“The members of this reference group, and we are sure, many like us, stand ready to assist.”

Winston Allamby
Katherine Barrett (she/her)
Kimberlee Cole (she/her)
Sophie Evans
Lynn Laidlaw (she/her)
Carol Liddle
Nira Malde-Shah (she/her)

Noah Roberts (he/him)
Mandy Rudczenko
Bo Rutter (she/they)
Isaac Samuels (they/them)
Sudhir Shah (he/him)
Colin Wilkinson (he/him)

²³ <https://www.gov.uk/government/news/community-champions-to-give-covid-19-vaccine-advice-and-boost-take-up>



Academy of Medical Sciences
41 Portland Place
London, W1B 1QH
+44(0)20 3141 3200

info@acmedsci.ac.uk
www.acmedsci.ac.uk

 [@acmedsci](https://twitter.com/acmedsci)

Registered Charity No. 1185329
Incorporated by Royal Charter. Registration No. RC000905