COVID-19 and Co-production in Health and Social Care Research, Policy, and Practice

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Co-producing and funding research in the context of a global health pandemic

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Introduction

The past decade or so has seen a greater push for more inclusive practice in the way research is developed and co-produced with patients and the public. The drivers have been a complex mixture of democratic right, increasing accountability, ensuring that research is meeting the needs of the people and communities it is trying to support, and the perceived positive impact on the quality of the research. Indeed there was an assertion that patient and public involvement and co-production (Hickey et al, 2018) were increasingly well established in the research process, from commissioning, through to designing, undertaking, and delivering research (INVOLVE, 2012) – although we should acknowledge that the practical implementation of co-production was limited even before COVID-19 (Green et al, 2019). And then came COVID-19.

The impact of COVID-19 on co-production, it is asserted here, can be characterised as an initial sidelining of patient and public involvement in research and the highlighting of existing health inequalities. This was followed by a reassertion of the importance of patient and public involvement. Included in this narrative are themes of the resilience of patient and public involvement and co-production and the embracing of digital responses to patient and public involvement and
co-production. Indeed, we note here that, although digital exclusion is a genuine challenge, digital techniques also have the potential to increase reach and accessibility and assert that the ‘new normal’ will involve more digital working than hitherto, creating a new hybrid approach to public involvement in research.

The initial impact of COVID-19

Patient and public involvement sidelined

In responding to COVID-19, governments and major funders of health and social care research swung into action, pausing and postponing some research and policy activity, and changing well-established processes and procedures as they prioritised responding to COVID-19 as quickly as possible. The speed with which funders mobilised, in terms of the commissioning and approving of research, was impressive. Indeed, so much so that in the future it will be difficult to justify any inertia in the face of future requests for funders to change processes, procedures, and culture to enable, for example, co-production. Funders have realised the important role they play in influencing and enhancing research culture, including co-production.

Unprecedented levels of funding were disbursed across clinical, biomedical, and social science research. Commissioning and award processes were accelerated; funders pooled funds and expertise wherever possible to address these gaps. Co-funding meant that even funders that might have had good patient and public involvement (for example in reviewing proposals and board membership) may have had to drop that in favour of moving the process along quickly rather than convincing other funders, with less of a track record in patient and public involvement, to embrace the voice of patients and public. In short, it soon became apparent the systems and structures, and therefore the decisions on what to fund and how, were being inherently skewed towards the needs of the research community and did not address the complexity of differential experience of many
patients, publics, and communities during the first wave. In an emergency, the focus was on the science rather than patient and public involvement.

The potential for patient and public involvement and co-production in research was diminished or did not happen at all. For those developing research applications, there was simply no time to put in place the things we know make patient and public involvement work well if they didn’t already exist, that is the right infrastructure (for example, access to technology) and strategic support within a university, and existing high-quality relationships between researchers and patients and the public. The pressures resulted in a large drop in patient and public involvement identified by the Health Research Authority, who reviewed patient and public involvement in the development of ethical applications. They found a decrease in studies containing public involvement from 78% in 2019, to 20% in the first 40 trial submissions received during the COVID-19 pandemic (Academy of Medical Sciences, 2020). The patient and public involvement community started detecting a worrying trend: patient and public involvement was not seen as a vital part of research, embedded in systems and structures. In many cases, it was missed in the rush to design studies that could address key pandemic challenges. Our assumptions that patient and public involvement had become embedded in research as a key expectation had been shaken. When pressure was applied, the truth emerged. Patient and public involvement was still seen as an optional add on. Indeed, it did feel that patient and public involvement had perhaps fallen off (or at least slipped down) the research agenda.

The exclusion of people with lived experience no doubt had deleterious consequences. Not least, their inclusion may have ensured that research addressed patient and public needs, and prevented, for example, some of the morbidity and mortality experienced among elderly people, those with long term conditions, and those in lower socioeconomic groups (Redding, 2020). Greater inclusion of the public may also have helped address the expected resistance to the vaccination from the ‘anti-vax’ movement (Megget, 2020), helping ensure trust in research and scientists.
COVID-19 highlighted existing inequalities

As the pandemic progressed, it shone a spotlight on inequalities across the UK, with communities and individuals being disproportionately impacted by both the disease itself and the policies put in place to contain its spread. It highlighted the gaps in our understanding of the factors underpinning these inequalities, the mechanism and spread of disease and how to treat it in different communities, and how little we knew about how to address these challenges. Indeed, a report by Public Health England concluded that:

There is clear evidence that COVID-19 does not affect all population groups equally. Many analyses have shown that older age, ethnicity, male sex and geographical area, for example, are associated with the risk of getting the infection, experiencing more severe symptoms and higher rates of death.

(Public Health England, 2020)

As a research community, we need to think carefully about how we redress that balance and bring in more diverse perspectives into how we set our research agendas, shape our funding programmes, and ensure the research we commission and deliver addresses the experiences of a broad range of people across the UK.

The reassertion of patient and public involvement

Moving to digital working

Both the funding and co-production of research have ‘gone digital’. For example, funding committees now meet online, and research priorities can be identified via crowd sourcing (Lichten et al, 2018). Research, by necessity, has to be undertaken online in terms of both project management and data collection.

The pace of research has increased, with public contributors asked to provide feedback almost immediately on rapidly
evolving studies. Face-to-face interactions changed to virtual almost overnight. If the right infrastructure (eg access to technology) and strategic support existed within a university, high-quality relationships had already been developed among existing groups, and people were able to respond rapidly, studies could more easily embed public involvement and co-production at their very heart.

Online working also offers opportunities for wider inclusion – for example, for disabled people who may find attending a face-to-face event tricky due to, for example, inaccessible transport and venues as well as their own (ill) health. For some disabled people it can feel less ‘othering’ so that people can attend a meeting without having to negotiate asking for ‘reasonable adjustments’. In short, there is the potential to involve the public more quickly and flexibly (The Academy of Medical Sciences, 2020), save time in meetings (McAlister and Rennard, 2020), be more cost effective, and widen access and increase diversity (Gray et al, 2020). However, it is ‘potential’ – ‘going digital’ is not a panacea and there are some people who are digitally excluded and who may also face other health inequalities. We need to make sure that we develop online platforms to ensure that professionals and patient groups can meet and develop solutions, learning from existing models (such as the Centre of Excellence on Partnerships with Patients and the Public). Funders also have a responsibility. For example, the Health Foundation have been developing an online inclusion panel which brings together people with professional and/or lived experience to advise the Foundation on the inclusivity of its in-house analytical work and its external research programmes in response to COVID-19. As part of the development process, the Foundation spoke to all panel members to identify any barriers that would prevent them from participating fully in the meetings. Digital exclusion was flagged as a significant barrier and to overcome this, IT equipment was supplied where needed and data allowances paid for. Furthermore, the Foundation has ensured that all written materials are produced in plain English and easy read documents, and where appropriate, presentations are filmed and sent in advance to panel members. An external agency supports the panel on behalf of the Health Foundation,
and they work with the members of the panel to make sure they can access panel meetings, including support to use the technology.

The patient and public involvement community is flexible, responsive, and creative. Our biggest adjustment was the move from face-to-face interaction to virtual forms of communication. While universities have access to different platforms and IT support, many patient and public contributors had to learn fast, sometimes with support, but often without. Alongside a new set of skills, using these platforms has brought a range of benefits. Firstly, having online meetings and workshops has, for some, increased efficiency and accessibility; many people welcome the time, effort, and money saved in not having to travel to attend meetings. If someone has the necessary technology then they can get involved from the comfort of their own home. Secondly, many platforms, with their breakout rooms, whiteboards, voting, polls and other tools and facilities offer an opportunity to break free from the rigidities and restrictions that can characterise traditional research meetings, and enable more creative ways of engaging with each other. Traditional meetings often take place on the terms of researchers and professionals, with formal agendas, minutes, and an emphasis on individuals being able to express and argue their views using the power of language in these forums. Such scenarios can exacerbate existing power differentials and discriminate against the inclusion of some people. That said, we do of course recognise, that there is still an emphasis on ‘how’ people use digital – it is as easy to speak over someone online as it is in a face-to-face meeting!

Looking to the future

Seismic events, such as a global pandemic, lead to seismic changes in how we work. There is unlikely to be a return to the ‘old normal’. Rather, the new normal will likely be a hybrid of face-to-face and online working. We assert here that the online working experience should not seek to replicate face-to-face meetings or events and should not be regarded as ‘the next best thing’ to face-to-face meetings – it is different.
Sometimes it can be a better option than face-to-face, improving reach and providing a more accessible, efficient, and effective way of involving people. However, we recognise that alongside benefits there have been many frustrations and shortcomings of involvement online. For example, the absence of in person meetings regarded as essential to the development of relationships and the loss of voice for digitally excluded people. Online tools have the potential to enable us to provide creative spaces in which to work co-productively. Our experience has often been that in this creative space via, for example, the use of jam boards, writing comments in the chat room rather than having to speak, online voting, and with a shift away from the more standard and formal approach to meetings, we can achieve a greater equity in the room and unlock the potential of people less comfortable in expressing themselves in the traditional meeting format. Clearly, this isn’t always the case. However, we can work together to ensure that technological approaches build in the aspects of involvement we value.

We also need to work on ‘what does good look like’. We need more work to determine what combination of various online tools and face-to-face work best – for example, see Chapter 10 in Volume 2 (https://policy.bristoluniversitypress.co.uk/covid-19-and-coproduction-in-health-and-social-care-1). As we move toward a hybrid model of working, we need to address these issues. We also need to ensure that university strategy and infrastructure can support and enable involvement and ensure it is in place for the next time pressure is applied to patient and public involvement. This can’t just be linked to specific projects but rather needs to reflect a wider recognition in the university sector of the vital importance of public involvement.

What needs to be done?

- Clearly, we need to do more to address health inequalities. Solutions could include ongoing sustainable equalities mentoring for decision makers and future leaders, and equality impact assessments in partnership with
self-determining groups so that we can start to design discrimination out of research practice.

- We need to firmly establish patient and public involvement and co-production in the processes, procedures, and cultures of all research funders and develop systems for emergency scenarios. The latter could include establishing rapid patient and public involvement response panels that can respond quickly.
- The ‘new normal’ is likely to be a blend of face-to-face working and working digitally. We need to build on existing good practice to identify ‘what good looks like’.
- Our research community, including the various organisations and their processes, procedures, and culture, is capable of acting swiftly and changing rapidly in response to crises. The co-production community would do well to remember and use this knowledge when faced with barriers and inertia in the future.

References


Megget, K. (2020) *Even COVID-19 can’t kill the anti-vaccination movement*, https://www.bmj.com/content/369/bmj.m2184