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

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The impact of existing structures
Whose views, and lives, truly count? The meaning of co-production against a background of worsening inequalities

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Introduction

Amidst the suffering caused by the COVID-19 pandemic in the UK and beyond, serious questions have arisen about social systems and persistent, sometimes worsening, inequalities. While there have also been many instances of cooperation and mutual care, those already facing disadvantage and discrimination have been among the worst-hit and deep divisions within society have surfaced. These differences in power, experience, and whose lives are truly valued, should not be ignored.

This context is relevant to co-production in health and social care practice, policy, and research, which involves working together for common goals and equal sharing of power. Often the focus of what is written about this subject is on bridging the gap between, on the one hand, public sector staff or researchers and, on the other hand, service users, carers, or other members of the public. Sometimes, if the latter are from often-marginalised groups, this imbalance in power and status is seen as being even greater. While these gaps are indeed important, a broader perspective can deepen understanding of what helps or hinders co-production.

Various developments in the years leading up to the pandemic shaped the realities surrounding frontline health and care workers, those they served, carers, communities, and research teams, with effects on their relationships and capacity
for cooperation. This chapter looks most closely at what happened in England, since national governments elsewhere in the UK, have sometimes adopted different policies, though some of the issues touched on here have far wider relevance.

What I write here, amidst a ‘second wave’, is neither complete nor impartial. I offer only a fragment of the picture, seen through a sometimes-foggy lens, in the hope that this will encourage further thinking on the issues raised. I end with some practical suggestions.

Conflicting trends and the rise of co-production

The coronavirus pandemic has caused suffering and death across the world and will continue to wreak damage for years to come. Studies, reports, and UK Office for National Statistics updates can never fully reflect the experiences and human cost but may shed light on patterns and causes.

The UK’s level of excess deaths, and those where COVID-19 is specified, is high by international standards (Barr et al, 2021), affecting all sections of the population. However, some groups have had mortality rates far higher than average, even here. In England and Wales, the toll has been heavy among people who are Black and minority ethnic (only partly explained by socioeconomic status and underlying health), disabled people, and/or those from deprived areas. Death rates have also been high in some occupations, for instance care workers, nurses, security guards, and factory workers.

There is evidence of a sharp rise in domestic abuse of women (Women’s Aid, 2020), child protection issues (Romanou and Belton, 2020) and disproportionately negative effects on mental health among lesbian, gay, bisexual, and transgender (LGBT+) people (Drabble and Eliason, 2021). Job insecurity has soared, hunger grown (Trussell Trust, 2020), and more unpaid carers left exhausted (Carers UK, 2020). Without huge and sometimes sacrificial efforts by staff, volunteers, and activists, the damage would be even greater.

The scale of loss, and drastic health inequalities, may seem surprising in a wealthy country with highly developed public
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services, equalities laws, and research institutions, often involving service users and the public. Understanding how this situation has come to pass, offers useful insights into the social context and relationships surrounding co-production.

Recent decades have been marked by competing social trends: on the one hand, towards participatory democracy and greater equality and, on the other hand, towards putting ‘free market’ principles above protection of human wellbeing and the planet. The cuts to, and privatisation of, public services (from hospital buildings to prisons), which have resulted, along with reduced protection for workers and consumers, have had far-reaching consequences.

To complicate matters further, the state embarked on a modernisation drive that both encouraged involvement and imposed heavy-handed performance management based on top-down measures of quality and efficiency. Professionals and managers were asked to listen more attentively. But how they could act on what they heard was more limited; there was pressure to focus on what could be quite easily quantified and frequent reorganisation and ‘outsourcing’ could disrupt relationships.

In addition, those such as frail older people whose input to society, crudely measured, could be judged not to match the resources spent on them, and could find themselves further marginalised (Butler-Warke and Hood, 2020). Hours of employment are easier to count than mutual love or wisdom. In addition, while the notion that senior doctors and academics knew best was more widely questioned, control sometimes shifted towards senior business people or managers (Cochrane, 2004), rather than service users, carers, and the public in partnership with frontline workers.

Alongside these developments, various social movements pushed for public bodies making decisions about healthcare, social care, and determinants of health (eg, housing), to give a greater say to the people most affected. The statutory sector sometimes funded projects led by service users, carers, and communities, in an attempt to reduce inequalities or draw on existing resources to achieve their own goals. Involvement and partnership mechanisms were also being created, and, by
the early 21st century, the value of co-production was more widely recognised.

This included greater adoption of this approach in local government (Bovaird and Downe, 2008) and specifically social care (Needham and Carr, 2009). However, risks were identified, particularly of further burdening or exploiting disadvantaged people, neutralising challenges to the status quo, diluting public accountability and sidelining Black and minority ethnic and other people facing discrimination. Equality laws were strengthened, though longstanding inequalities persisted and state treatment of minorities and impoverished people was still often experienced as oppressive.

A global economic crash in 2008 drew attention to the hazards of trusting financial corporations to regulate themselves and revering the private sector, especially when top firms turned to the public to bail them out. In the UK, unlike many other countries, the narrative quickly shifted, as much of the media blamed the state for overspending, diverting attention from the dangers of reckless profit-seeking. A leading economist later commented, ‘the view of most macroeconomists was almost completely absent … austerity was increasingly seen as common sense in the media’ (Wren-Lewis, 2018). Slashing public spending and handing even more control to private companies was promoted as a way forward. In countries that followed this route, the effects on public health was deeply damaging (GI-ESCR, 2020).

The government did a poor job of explaining its actions aimed at making the economy stable again, instead encouraging scapegoating of unemployed and disabled people. The idea that some sections of society were not doing their fair share took hold, while Black and minority ethnic workers were sometimes seen as rivals for scarce jobs and resources.

Abusing state power and the tangle of consequences

In the decade leading up to the pandemic, though the term ‘co-production’ was sometimes loosely used, there were many genuine instances of this approach. Awareness grew in the NHS and health research field of its potential
(NIHR, 2015). Yet harsh spending restrictions and mistrust were overshadowing public services, and inequalities were deepening, damaging physical and mental health treatment and care (Gray, 2017), especially for those facing multiple forms of disadvantage and discrimination (Hall et al, 2017).

An international human rights framework has developed since the mid-20th century, setting out the states’ duties to those over whom they exercise power, with a moral obligation to treat others with respect. This requires those in charge not only to avoid riding roughshod over the vulnerable but also not to leave them dependent on good luck in the face of nature, or goodwill by employers, landlords, and others for basic necessities. If arguing with one’s boss about dangerous working conditions may lead to one’s family starving, one is not truly free. The UK government had signed up to various agreements. But it became a serial offender on human rights, as Parliamentary and other official reports and investigations by the United Nations (UN) showed (UN, 2021).

In 2013, the UN special rapporteur on the right to adequate housing pointed to a crisis, which included overcrowding (to become such an important issue during the pandemic) and insecurity. The rapporteur on the rights to freedom of peaceful assembly and of association warned in 2016 about measures such as making it harder for trade unions to call strikes, with even higher thresholds of votes required for industrial action in some public services. A UN inquiry found in 2017 that the UK government had gravely violated the rights of disabled people, including through cuts in social care (UN CRDP, 2017). In 2018, the rapporteur on extreme poverty echoed some concerns about disabled people’s treatment and pointed to harsh and arbitrary punishments of people requiring social security, and the devastating effects of austerity, leading in some cases to cuts in life expectancy (UN, 2019).

Policies aimed at creating a hostile environment for immigrants have also led to the ‘Windrush scandal’, when people from the Caribbean, who had been long legally settled in Britain, found their citizenship questioned, their right to work, and medical treatment blocked. Some were forcibly detained and even deported. In 2018, the rapporteur on racism criticised such mistreatment, ongoing racial inequalities, and
a sharp rise in hate-crime as the UK moved closer to Brexit. As usual, the UK government indignantly rejected the report. Further immigration proposals were announced, which would leave many UK residents originally from European Union countries or of African or Asian descent even less secure (McIntosh, 2020). Yet more drastic, were plans which would result in destroying the homes and cultural artefacts of many Gypsy, Roma, and Traveller people (O’Neill, 2020).

Social care, NHS, and other staff often tried to keep vital services going, at some cost to themselves. Yet increasingly, on behalf of the state, they were required to refuse or to withdraw services, or to exercise coercive, rather than supportive, functions. For instance, in mental health crisis responses. In the years leading up to the pandemic, this has inevitably affected the chances of building trusting, equal relationships between staff and those unable to obtain adequate and appropriate services.

During this context, however, there were also extra opportunities for what might be described as co-production via contestation: when the authorities met resistance (for instance when planning cuts or failing to meet diverse needs), then both parties jointly developed a way forward. Yet, while some projects were co-produced in more conventional ways, the scope for major change was often limited amid worsening inequalities, inadequate resources, unresponsive systems, and human rights violations. People facing prejudice or poverty had often been bypassed by involvement mechanisms: by 2020, many were focusing on personal or collective survival, with less time and energy for other (often unpaid) activities.

In research, tensions over cuts or state hostility were perhaps less likely. Yet researchers, often on short-term contracts, were under pressure to focus on work of the kind most likely to be published in ‘high impact’ journals or secure funding. This limited opportunities to work together on service users’ and communities’ most pressing concerns, especially if these involved delving more deeply into structural issues not easily explored through randomised controlled trials.

Genuinely co-produced work was still important, both for those involved and others benefiting from what was developed or discovered. It also helped to encourage values of empathy
and cooperation, amid deepening divisions. Yet there were risks in co-production and other kinds of involvement if this glossed over major developments affecting the wellbeing of the most marginalised or negatively targeted. Involving people might then appear to distract attention from their main concerns or even implicate them in changes harmful to them.

Looking ahead

So far, I am a less personally affected member of various communities badly affected by the pandemic – minority ethnic, disabled, LGBT+ – but I have been confronted by the stark realities of worsening power imbalances and deadly inequalities. This is the context in which co-production takes place; yet, if the challenges can be openly addressed, there may be important opportunities to learn and act together. A few suggestions follow.

What needs to be done

- Recognise broader inequalities and human rights concerns which might affect service users, carers, communities, and staff seeking to work together.
- Be clear about co-production’s limits and the influence of institutional power and the shift towards market principles.
- Value modest improvements which are co-produced – but try also to create space for public members and professionals to share big/burning issues and consider possibilities for exploring these jointly.

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References

Barr, C., Davis, N., and Duncan, P. (2021) UK coronavirus deaths pass 100,000 after 1,564 reported in one day, https://www.theguardian.com/world/2021/jan/13/uk-coronavirus-deaths-pass-100000


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transformation, https://www.scie.org.uk/publications/briefings/briefing31/
UN (2019) Visit to the UK: Report of the Special Rapporteur on extreme poverty and human rights, http://docstore.ohchr.org/Services/FilesHandler.ashx?enc=dtYoAzPhJ4NMy4Lu1TOe-bAzm3S%2bNFShY%2b1IJ5rJyNRN19%2bNcX4M5H1YuOc-7S2e8O2K_WM0VfyF1xIdm7gfDYZnShBY70j3zH9An44jvrYMNQUxnOVaIFnL50H0SjP36O