16. Co-production in emergency responses and the ‘new normal'

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Afterword
Co-production in emergency responses and the ‘new normal’

An afterword for Volume 1

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What we aimed to achieve through this collection

In the introduction to this volume, we outlined how the COVID-19 pandemic has highlighted the need to better understand and utilise co-produced responses to improve public policy, political responses, and health and social care research and practice. However, there are extensive constraining social structures that inhibit working in this way. The experiences of the most exposed, marginalised, and discriminated – in short, those who are systematically excluded in our societies – rarely directly influence the policies and practice that are ostensibly created for their protection. Crucially, given the disparities in the risk and outcomes of COVID-19, why are these people and communities not considered best placed to create and implement sought-after solutions for effective management, improvement, and research of pandemic responses?

Through this book, we wanted to:

• explore how so many people are ignored, disempowered, and discriminated against in health and social care research, policy, and practice;
address how and why more collaborative, diverse, and inclusive responses could lessen the toll of this pandemic and future health emergencies, as well as more generally improve health and social care research, policy, and practice;
illustrate how and why collaborative ways of working can help to address the social wrongs and power imbalances that we need to right.

In particular, this volume set out to explore: (1) the impact of existing structures on ambitions and efforts to work in more participatory and collaborative ways in health and social care research, policy, and practice, and (2) how the pandemic has highlighted and exacerbated existing inequities and marginalisation both in practice and research. The collection has demonstrated through a diverse range of examples the impact of the pandemic on people’s lives and ways of working. In Part I, ‘The impact of existing structures’, authors examined how existing health inequities were widespread in the population, leaving many groups at serious risk from the pandemic. These groups were also most likely to be excluded from current systems of involvement and participation in health and social care research, policy, and practice, meaning that health and social care systems were largely unprepared and/or unable to co-produce responses to COVID-19. The second section, ‘Infection and (increasing) marginalisation’, provided a platform for marginalised communities, groups, and people to describe and explain how they have been affected by this pandemic and to illustrate their experiences. This created an opportunity for some of those who have been disproportionately disadvantaged and discriminated against during this pandemic to share their experiences and views in their own words. We feel the sum of these sections provides a convincing account of why co-production is valuable and should be used and considerably resourced, as a means to improve health and social care research, policy, and practice. In particular, authors’ contributions and recommendations provide a number of learning points and actions to address ongoing challenges – these are summarised here.
Structural inequalities

Preceding chapters have highlighted long-standing inequities that have been created by the various limitations and constraints of funders, research institutions, and health and social care systems. Co-production takes place within contexts of multiple power imbalances that are informed by and exacerbate inequalities that have been highlighted during the pandemic. We need to be clear about the limits of co-production and how institutional power constantly affects these processes. Various chapters (Chapter 2, Hensman; Chapter 3, Ocloo; Chapter 5, Creary et al) have highlighted the importance and relevance of recognising broader inequalities and human rights in the co-production of health and social care research, policy, and practice. Situating ‘the problem’ within broader structures in society and systems of oppression rather than within individuals and communities is essential. Research and healthcare institutions are typically not including in their involvement processes the very groups who experience the most discrimination and/or who are most disproportionately disadvantaged by structural inequities. This exclusion mirrors patterns of disparity and disadvantage in wider society (Chapter 3, Ocloo). Therefore, it is predictable that health and social care and welfare systems that were created to improve the lives of those in need can further perpetuate these inequalities (Chapter 11, The Secret Welfare Rights Worker).

Anti-discriminatory policy and practice

Active anti-discriminatory policies and practices are needed to enable people who are disproportionately disadvantaged by structural inequities and systematic exclusion to shape strategic and procedural decision-making. Processes and mechanisms that facilitate anti-discrimination such as equalities mentoring, monitoring, and impact assessments can actively engage and support people to be in the room who may otherwise have been excluded (Chapter 3, Ocloo; Chapter 4, Hickey et al). This includes organisations committed to attracting, developing,
and retaining Black people, who belong to communities who are often excluded, in senior positions within research and health and social care organisations (Chapter 5, Creary et al). It also means overhauling statutory organisations or those like the Charity Commission by embedding anti-racism training as a way to review and assess the extent to which these structures facilitate or pacify charitable work (Chapter 8, Kaur et al).

Anti-discriminatory policy and practice can strengthen co-production, but in practice co-production does not always equate to being anti-discriminatory (Chapter 3, Ocloo; Chapter 5, Creary et al). It is essential to create space for reflective practice, purposefully engaging stakeholders in self-critique, whereby they interrogate whiteness and white privilege as it manifests itself in people’s lives, organisations, systems, and the co-production process; and take action to address the issues that arise from this work (Chapter 5, Creary et al). Likewise, the pandemic has demonstrated the urgency with which ableism in health and social care must be challenged and rectified through structural and systematic change (Chapter 9, Beresford; Chapter 10, Clifford and Dunk; Chapter 11, The Secret Welfare Rights Worker). Furthermore, we need to explore and unravel the overlaps between old age, impairment, and illness in order to better challenge mainstream narratives concerning ‘vulnerability’ that effectively devalue those who are labelled vulnerable (Chapter 10, Clifford and Dunk).

**Institutional changes and funding**

The pandemic has demonstrated that organisations can act and change swiftly, and has shown the importance of building trusting relationships between organisations and people (Chapter 4, Hickey et al; Chapter 14, Campbell et al). For example, the welfare system needs radical reform, ensuring both funding and regulations for the effective and active involvement of people with experience of living on such benefits. These reforms should align with the philosophy of independent living developed by the disabled people’s
movement and embedded in the United Nations Convention on the rights of People with Disabilities. The reforms need to be shaped with the active involvement of people with experience of living on such benefits (Chapter 11, The Secret Welfare Rights Worker). This could include services paid for from general taxation and free at the point of delivery, capable of supporting disabled people’s equal participation in the community and providing the social care workforce with appropriate conditions, pay, and training (Chapter 10, Clifford and Dunk). Specific funding should be allocated for co-production research, policy, and professional development in relation to COVID-19 and other health emergencies in health, social care, and public health (Chapter 9, Beresford). Research based on user-led and co-production principles should urgently be established to access, evaluate, and share the experiential knowledge of groups that routinely face barriers and exclusions similar to those experienced more generally in situations of pandemics and lockdowns (Chapter 9, Beresford).

**Setting agendas and policy**

Diverse groups need to be involved right at the beginning to set agendas and frames of reference (Chapter 3, Ocloo; Chapter 12, Braham et al; Chapter 15, O’Connell et al). People need to be included at the heart of policymaking and not as an afterthought. The perspectives of marginalised groups, especially those most affected by COVID-19 and other health emergencies, should be routinely and systemically involved in policy and practice development (Chapter 9, Beresford). This includes refocusing current public health policies and messages to ensure they focus on health equity and include what governments can do to address the social determinants of health (Chapter 15, O’Connell et al).
Methods and processes of involvement

Co-production needs to be firmly established in the processes, procedures, and cultures of institutions (Chapter 4, Hickey et al), and a range of methods are needed to co-produce health and care with diverse communities (Chapter 3, Ocloo; Chapter 14, Campbell et al). Involvement opportunities need to be articulated and advertised in an equitable manner, with proper support and reimbursement. Costs should be built in that reflect the participation and overheads faced by individuals and organisations who are part of the process (Chapter 3, Ocloo). Against Violence and Abuse (AVA) highlight how gender-based violence is based around transactional relationships, exploitation, and devaluing women. Fair and adequate valuation and payment challenges this and makes participation possible for people who would otherwise be excluded. This is particularly pertinent considering financial challenges exacerbated by the pandemic (Chapter 12, Braham et al). We also need to ensure that the products (for example intellectual property) and benefits (for example financial gains) that emerge from the process are both owned and distributed equitably with communities (Chapter 5, Creary et al; Chapter 12, Braham et al). Different approaches to involvement are useful but can also exclude people, therefore regular reflection and learning about how people work together can facilitate meaningful and successful collaboration. More digital working is likely to be a part of the ‘new normal’. We can embrace the positives – potentially greater reach, accessibility, and efficiency – while also recognising and attempting to overcome digital exclusion and the challenges of inclusive practice when collaborating via digital means (Chapter 4, Hickey et al; Chapter 13, Beyrouty et al).

While abuse takes away power, co-production can collectively build power, giving voice and influence to those too often silenced and ignored. This is pertinent in the context of COVID-19 where survivors’ experiences of the pandemic mirrored experiences of gender-based violence, and coping mechanisms were removed (Chapter 12, Braham et al). Facilitating space for those with diverse relevant, lived
experience during this time is vital so that people can create better research, policy, and practice (Chapter 12, Braham et al; Chapter 15, O’Connell et al). For people who may have experienced trauma, prioritising physical and emotional safety of participants at all stages is important, as involvement work can be triggering and difficult. Collectively creating clear boundaries and embedding check-ins, reflective practice, and self-care are of vital importance – especially when face-to-face support is less readily available (Chapter 12, Braham et al).

**Alliances, collective action, and community activism**

During the pandemic, disabled people’s organisations and practitioners in the United Kingdom have sought to build stronger alliances with disabled people both nationally and internationally to share experiences and solidarity (Chapter 10, Clifford and Dunk). Similarly, Fat activists and patient advocates have mobilised within and between nations to combat discrimination (Chapter 15, O’Connell). Black Thrive have done the same with Black communities but remind us of the need to value the expertise within Black communities and resource these people to lead the process (Chapter 5, Creary et al). Structures and processes in traditional health and social care settings need to be able to acknowledge and value the many forms of grassroots activism that are taking place. Statutory organisations and institutions should value and actively enable examples of community-led activism by engaging and building relationships with these communities (Chapter 13, Beyrouty et al). This can help to tackle the barriers, and enables embedding and scaling up action to tackle inequalities (Chapter 8, Kaur et al; Chapter 13, Beyrouty et al). There is a need to acknowledge that community-led social activism in some communities has arisen through intertwined and equally important political and social foundations that influence how this activism continues to manifest (Chapter 8, Kaur et al).

Collective advocacy is needed more than ever, as well as integrating the principles of co-production into regional health and social infrastructures, both culturally and
Challenges and Necessity of Co-production structurally. More ethnographically-oriented research can help to explore interplays of trust, survival, and institutional activity at the grassroots level (Chapter 6, Zoccatelli et al; Chapter 7, Montenegro and Szabzon). An adequately resourced Healthwatch in the United Kingdom can also play a key coordinating role between stakeholders in local health and social care systems, helping support democratic, equitable, and fully representative decision-making in the aftermath of the pandemic (Chapter 6, Zoccatelli et al). This role can ensure that the diversity of local people’s voices are taken into account in the planning and provision of local health and care services.

Limitations

These chapters do not represent an exhaustive collection of accounts from those who have been most impacted by the pandemic and/or worsening inequalities. As will be explored further in Volume 2, we aimed to include contributions from people and communities who are among the most marginalised, and/or most impacted by the pandemic. Additionally, some may question whether the contributions to this volume provide examples of ‘true’ co-production. As explained in the Introduction, the definition of co-production we adopted to frame these volumes aimed to generate and include contributions that described a variety of participatory and collaborative approaches. We accept there are many accounts that are not here but could, and perhaps should, have been. This includes people who stated that they could not be open about their experiences of co-production in research, and health and social care contexts, because of potential personal or professional ramifications. Though we also feel that the contributions that have been made within the limitations that we were operating under have strengthened our understanding of the effects the pandemic is having and the potential of co-production to have improved responses to it. This volume has illustrated some of the challenges and the necessity of co-producing health and social care research, policy, and practice as demonstrated through the wide variety
of contributions compiled from diverse contexts and examples. We now urge others to advance this exploration by critically reflecting on and sharing and developing, other examples of co-production. Such examples will be crucial to evolve a more effective, equitable, and collaborative ‘new normal’ that provides person- and community-focused health and social care research, policy, and practice – including responses for emergency management.

Volume 2

These books address the ongoing need to understand what inhibits the potential for co-production and other collaborative approaches to improve health and social care research, policy, and practice, and who this excludes. Volume 2 complements this by illustrating with international examples how co-production and wider participatory and collaborative approaches have been implemented during the pandemic. These diverse examples demonstrate the different approaches and methods adopted and adapted during this health emergency and illustrate the ongoing relevance of co-production beyond the pandemic.