

A CO-PRODUCED REVIEW

OF

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

**Volume 1:
The Challenges
and Necessity of
Co-production**

Welcome

Hello! I'm Lizzie from [Co-Production Collective](#) and editor of this co-produced book review. I've helped the organising team (Clare, Dawn, Niccola and Sudhir – you can meet them in the Introduction) bring their vision to life, and the 30 reviews in these two volumes together.

The reviews accompany the *COVID-19 and Co-production in Health and Social Care Research, Policy and Practice* [Volume 1](#) and [Volume 2](#), which explore the urgent need to put co-production and participatory approaches at the heart of responses to the pandemic and demonstrates how policymakers, health and social care practitioners, patients, service users, carers and public contributors can make this happen.

Given that this is a book about co-production, we wanted do things a bit differently and [co-produce a book review](#) by bringing together people from all of these groups to share their thoughts and reflections on each chapter. The only criteria to be a reviewer was an interest in co-production; those chosen were randomly selected, allocated a chapter of their preference and some guidance questions, as well as offered payment for their contribution.

We'd like to say a big thank you to all our reviewers and everyone who put themselves forward. We hope you agree that the diversity of reviewers and reviews, the range of knowledge and experience they bring, and the richness of reading them alongside the book, speaks volumes about the value of co-production.

How to read this review

However you like! This collection of reviews corresponds to [Volume 1 of COVID-19 and Co-production in Health and Social Care Research, Policy and Practice](#) and each review has the same chapter number as the chapter it reviews in the book.

Each review in this volume is accessible via a clickable link on the contents page, so you can dip in and out or read them all in one go.

It also doesn't matter whether you've read the whole book or even the chapter itself. If you haven't, maybe the review will encourage you to give it a go, and if you have, then you get to experience again through someone else's eyes – maybe you'll see things differently.

You can also [access Volume 2 of the review here](#).

We hope you find it an interesting read. Please let us know your thoughts [on Twitter @UCL_CoPro](#) or via email: coproduction@ucl.ac.uk



Enjoy!
Lizzie

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Introduction

Clare, Dawn, Niccola and Sudhir – the Book Review Organising Team

We're Clare, Dawn, Niccola and Sudhir and we've been working with Oli Williams (one of the editors of *COVID-19 and Co-production in Health and Social Care Research, Policy and Practice: Volumes 1 and 2*) on his Dissecting Health Research Group, so when he had the idea for co-producing a book review, we were on straight on board!

We've co-produced the process behind the review, from the guidance sent to reviewers to the format and promotion. You can read more about the process in [this blog on the Co-Production Collective website](#).

Here, we wanted to share our overall thoughts on *COVID-19 and Co-production in Health and Social Care Research, Policy and Practice* [Volume 1](#) and [Volume 2](#). We decided to do so by reflecting on it in the light of [our core values](#) as Co-Production Collective – human, inclusive, transparent and challenging.

So, what did we find?



Being human

The fact that the book gave a chance for a wide variety of voices to be heard really chimes with us, as it helps make the book more engaging and accessible to more people.

Clare noted with interest the book's drive to get beyond labels and see the people behind them. For example, in the Afterword to Volume 1 (referencing Chapter 10), the editors state that they're seeking to challenge traditional narratives around 'vulnerability'. This is very much in line with our approach, aiming to put lived experience on the same level as any other types of experience – we're all human.

Dawn talked about the how the book identified and outlined the issues of inequalities and discrimination, candidly illustrating how the problems faced by some marginalised communities have been exacerbated by the pandemic. We especially liked that the writers' emotional stance was nonapologetic and sometimes expressed exasperation, taking ownership of their empathy and humanity.

Being transparent

We found the honesty of the editors' introduction very refreshing, and this transparency was displayed again when outlining the limitations of their work and reflecting on what they wished they'd done differently. This openness is not something you often find in academic publishing.

The inequalities of power in healthcare systems are a central theme in the book. In the introduction to Volume 2, it describes how local and national responses during the pandemic were often premised on structural inequalities and that co-production offers an alternative to this approach. As a group who are engaged in

co-production, we deem a need for transparency around any decisions made to be fundamental principles from which we work.

Being inclusive

Each of the chapters in Volume 2 is written from the perspective of people on the ground, trying co-production and collaboration in a diverse range of contexts. The experiences range from Latin America to Sikh communities in London, from an urban community in Wales to street homeless in Northern Ireland. We applaud the book for offering a platform to such a diverse range of contributors. As Co-Production Collective we know the value – and the challenge – of ensuring that everyone can play a part in co-production and being open to identifying barriers that may be preventing this. In a year where people have been defined by statistics and we measured how well the country was doing in numbers of deaths, it was easy to lose sight of personal stories and lived experience; this book gives some of those stories space.

We felt that the book didn't always speak to the general public, although as the book itself outlines, this wasn't meant to be the case. While it is important not to try to be all things to all people, we do think some of the language used could have been less academic, a jargon buster included, or an easy-read version developed. Niccola suggested that some terminology could have been explained more clearly or even more straightforward words used in the first place, while Sudhir noted that a summary in the introductory chapters would have been a useful way into the lengthy texts and to make it more accessible to a wider audience.

While it's great that the book is 'open access' (it can be read by anyone for free online), this is itself an academic term and so doesn't alone make the book accessible. It needs to go hand-in-hand with reaching out to non-academic audiences and working with others to offer support to potential readers to

engage. We're not saying that the book should try to be for everyone, but rather that anyone should be able to pick up and read it if they want to and have an interest. Improving accessibility would help to break down some of the many barriers to being involved in research, service and policy development.

Being challenging

Being challenging is a necessary part of co-production. Without it, we risk falling into a comfort zone which may exclude the voices of those who are less engaged or allow traditional views to prevail because it's harder to speak out against the establishment.

This book challenges those norms in some exciting ways and the reviewers have also brought their own challenges. As Sudhir notes, Safina challenges the use of BAME in her review of Chapter 15, Volume 2, arguing against grouping diverse individuals with varying needs together, ignoring their differences and risking stereotyping.

We applaud that this isn't an academic book just written by theorists. Whilst it is written for a readership that has some knowledge of co-production, it still offers accessible and diverse perspectives. It also challenges the very notion of what co-production is without entering into a lengthy debate, defining it with principles and values rather than a rigid structure. This very much aligns with our approach to co-production as a way of being and of working together, rather than a tick box exercise.

In her review, Katherine's reflections on co-production caught our eye:

"This approach can be challenging for people who need to unlearn practices and find new ways of asking, responding and working outside of the norm in a collective, trusting others to support, challenge and co-lead change conversations."

Conclusion

Considering this book has been produced by many authors in a very short time, it is well-written, feels cohesive and showcases many powerful examples of the impact of the pandemic on real lives.

At the beginning of Volume 1, the editors state:

“We know that innovative participatory and co-produced approaches to health and social care research, policy, and practice can ensure that invaluable experiential knowledge makes an important and unique contribution – our ambition for this collection is to demonstrate how and why.”

We think that this has been achieved. The relevance, merit and credibility of co-production is established across of a range of settings in a way that is believable and pragmatic.

More importantly, we wholeheartedly agreed that:

“The grave consequences of following the precedents set during this pandemic – in terms of morbidity, mortality, marginalisation, and wasteful ineffective policy – emphasise the urgency to do things differently.”

We hope that you feel this too.

Now we hand over to our reviewers to share their reflections on each chapter of COVID-19 and Co-production in Health and Social Care Research, Policy and Practice, Volume 1 and Volume 2.

We'll see you again in the Afterword, at the end of the Volume 2 review, with our closing thoughts on 'where next?' for co-production.

Clare, Dawn, Niccola and Sudhir

2. Whose views, and lives, truly count?

The meaning of co-production against a background of worsening inequalities

Savitri Hensman

Reviewer: Patrick Wood

I have been active in the mental health survivor movement since the late 1980s and a member of the SCIE Co-production Steering Group since 2015.



What was this chapter about?

This chapter provides an overview of the ways in which government policies and health and care systems impact on people from marginalised communities, often resulting in their situation becoming worse than it was already. It also highlights the difficulties associated with contrasting policy drivers, which make any gains from involvement or co-produced activities uncertain and insecure.

What did you find most interesting or important about this chapter?

The chapter is particularly strong on identifying the ways in which Black and minority ethnic people, disabled people and people from deprived areas have suffered disproportionately as a result of the pandemic, and in demonstrating how these inequalities are linked to social trends that value free market principles over wellbeing, which are associated with 'heavy handed performance management based on top-down measures of quality and efficiency' and a trend towards the privatisation of public services. Although there was a parallel movement towards greater social democracy at the same time as these

measures were introduced, any gains in this area took place in the context of worsening power imbalances and deadly inequalities, which are unfriendly to the principles of joint decision making and equality that lie at the heart of successful co-production.

What did you think about how this chapter was written?

The chapter was engaging, and the author's arguments were clearly expressed and easy to follow, without being reductive or simplistic. Although it includes a focus on technical matters relating to policy development, health and social care markets and research, it remains accessible throughout.

Did you disagree with anything in this chapter, or think there was anything missing?

The author makes repeated references to successful involvement and co-production throughout the chapter, without providing any clear examples or defining the core principles and necessary conditions that enable these activities to take place. The author concludes by identifying three things that need to be done to support the development of co-production, which I fully support, but which either lack detail about how they might be achieved or seem to lack ambition.

Overall, this chapter succeeds in clearly identifying issues around inequality that need to be addressed to enable co-production to flourish, and to build a fairer society. It represents a valuable resource for people who are committed to upholding the principles of co-production in the work that they undertake in the fields of health and social care, research and community-based activism.

3. Silenced Voices, Unequal Impact: addressing health inequities and discrimination in co-producing health and care during the pandemic and beyond

Josephine Ocloo

Reviewer: Jason Paul Grant

I am a lived experience consultant who uses their experience to improve outcomes for people in mental health. I'm currently working for Sussex Partnership NHS Foundation Trust, The Royal College of Psychiatrists, and The University of Manchester, on a study looking into the ethnic inequalities in severe mental illness.



What was this chapter about?

The chapter describes the unrepresentativeness of health and care research and goes on to discuss how to rectify the situation. The author grounds the chapter in the current and recent policy landscape which ensures that the recommendations are appropriate. There is a focus on acknowledging 'who is not in the room' and without ignoring the elephant in the room, owning up to the disparity, so that researchers can start making more concerted efforts to bring 'others' into the room.

What did you find most interesting or important about this chapter?

The most interesting part of the chapter was the nod towards participatory action research. I am slightly biased as I have been working on a study at the University of Manchester which uses the PAR methodology. So, to see the author

talk about the benefits of that approach in including often unheard voices was refreshing to see. Another important focus was in describing those voices who are often unheard, including people who have been to prison, people in the asylum/immigration system, and homeless people. The author shares a number of ideas on how to meaningfully include people who have been forgotten about in the research process. I learnt a lot about co-production from reading this chapter, but more importantly, how to go further than current mainstream attempts.

What did you think about how this chapter was written?

The chapter was very easy to read, extremely clear and accessible. I enjoyed reading the chapter as it spoke to me on both a professional and personal level. The main points and arguments were made in a direct way which is good.

Did you disagree with anything in this chapter, or think there was anything missing?

I really enjoyed the chapter and tended to agree with most of the arguments being made. The only area that I would have liked more clarity on was the practical steps to take to conduct meaningful participation in research, especially with people who have not gone to university. I was fortunate that I went to university at the age of 25, as a widening participation student, so I'm very comfortable around academic circles. However, a lot of my friends who I grew up with, who have not gone to university, are not comfortable with research and academic process. Maybe the rest of the book will touch on some practical examples and I was keen to hear about the work happening in the global south.

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

Gary Hickey, Alison Allam, Usha Boolaky, Tess Mc Manus, Sophie Staniszewska, Doreen Tembo

Reviewer: Sarah O'Brien

I am someone with lived experience of chronic health conditions and disabilities who blends my personal experience with my professional work.



What was this chapter about?

Health and social care research funding quickly refocused and reprioritised during COVID-19; funders reflect on what this pace exposed about the funding process. Digital involvement happened quickly in some cases, in others excluded some co-producers. Although involvement was a clear priority for some funders before COVID-19, involvement became a distant aspiration in much of the early COVID-19 response as research applications were written and funded without public contributor input. The funders summarise that we need to learn from this unintended exclusion and bring forward the best parts of inclusive involvement that work for the many

What did you find most interesting or important about this chapter?

The writers' reflections, as those in positions of power to allocate funding, of the exclusion of public voice in much of COVID-19 funding were interesting and validating as someone who was one of many public contributors raising concerns about this exclusion in the pandemic response. I learnt about how

funders are already working to compensate for these 'errors' by exploring ways of embedding public voice in their processes, even at speed – for example, the Health Foundation's Inclusion Panel* mentioned in the chapter which was developed in hindsight of how public involvement disappeared in the early pandemic response. This chapter primarily re-highlighted existing tensions in how funders approach co-production but could have gone further in describing what role funders play in perpetuating these inequalities and the exclusive/exclusionary practice around public involvement.

** I have been a member of Health Foundation's Inclusion Panel since October 2020 as an autistic person with lived experience of chronic pain conditions.*

What did you think about how this chapter was written?

This chapter is almost written in plain English but relies on some insider knowledge of research funding to understand. Some terms or ideas are explained using brackets so the reader can understand the context of the word being used but this isn't done consistently to support 'outsiders' to understand all of the language used. Despite this, I found it enjoyable to read. Although it is an insider perspective, this perspective has not been a part of the discussion pushed forward by public contributors during 2020.

Did you disagree with anything in this chapter, or think there was anything missing?

I think the authors missed out on discussing who is no longer in the room with the move to digital conversations. It is touched upon but not to the depth that might be needed to do justice to how harmful this transition has been to some individuals.

This point on page 41 was slightly overlooked in the chapter:

"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."

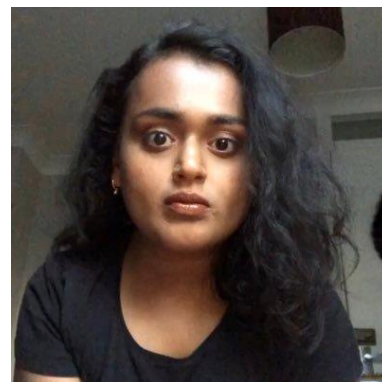
I think the expectation exists in public contributors and researchers that engage in co-production/ involvement, but it is naive to think that involvement is embedded broadly in research. So much of the tension comes from a lack of pre-application funds for co-producing applications (funders), difficult to navigate payment systems (universities), uncooperative or tokenistic organisational cultures and aspects of involvement. Even before COVID-19, involvement was seen as an optional add-on and there was no rigorous way for making sure that communities and researchers came together for mutual, power-sharing benefit. I think the authors overestimated how much involvement was and is embedded in research and underestimated the barriers held up by institutions and systems.

5. Are we there yet? Co-production and Black Thrive's journey towards race equity in mental health

Natalie Creary, Celestin Okoroji, Yasmin Ibison, Lela Kogbara, Jacqui Dyer

Reviewer: Humma Andleeb

I am a Mental Health Science PhD student at University College London. I previously worked as a mental health researcher and have lived experience of mental health problems. My interests are particularly in the area of the mental health of minoritised communities.



What was this chapter about?

The Black Thrive team explore what co-production looks like when working with racialised communities, and their experience of co-production when working with white organisations – especially during COVID-19 and when organisations are facing the stark realities of the racism they perpetuate.

The chapter highlights the challenges of attempting to adopt co-production within institutions that are historically hierarchical and oppressive of Black and other racialised identities, jumping on the bandwagon of working with marginalised groups. The chapter offers an alternative perspective to what we are used to seeing.

The authors highlight the timely and informed outcomes of their Black-led mental health research in local Black communities that traditionally white researchers have tried and unsatisfactorily engaged with. The chapter dissects how co-production can be co-opted as a mask to extract and re-produce the labour of minoritised communities through the lens of white-dominated fields,

which risks diluting and downplaying the lived realities of Black people. In doing so, they present a case of examining what this means for Black people sharing traumatic experiences and how those involved are remunerated for their work. The chapter offers a frank insight into the reality of oppressive and racist systems which are being perpetuated in co-production and how we can move towards systems change where co-production is not another one of the master's tool.

What did you find most interesting or important about this chapter?

The chapter enabled me to think about the facilitation of co-production and how those who hold funding also hold power, restricting the extent to which Black communities can contribute and share. These restrictions bar people from being radical in their thinking and participation. This essentially goes against the principles of co-production and actually replicates exactly what co-production is supposed to move away from. It made me question the authenticity of attempting to slot co-production into institutions that are at the root hierarchical and succeed through minoritising people to maintain a power imbalance. It made me recognise that work like this demotes co-production as a means of extracting triggering experiences and the emotional and physical labour of minoritised people in order to advance an alternate agenda.

The topic is something that has been on many of our minds over the past year. However, it's beneficial to this space to hear this through the lens of an organisation that have placed themselves as a bridge between the Black community and white-dominated institutions who have observed and experienced the dynamics of co-production in racialised contexts. Co-production cannot thrive if it is only benefitting the very systems and practises that it is seeking to dismantle, especially if it is done through the exploitation of traumatised Black people. I learnt that co-production requires more than involving minoritised people, but examination through a racial lens that I hadn't

previously thought of. It needs careful thought and preparation, through creating safe spaces, effective and accurate financial remuneration, and allowing individuals the freedom to imagine and be radical in their actions to achieve the desired outcomes. What I found most interesting was Black Thrive's experiences of co-production across a breadth of social topics, not restricted to just the co-production process, but through training and employment for Black individuals in the workforce. This pitches co-production as more than a linear process.

What did you think about how this chapter was written?

The chapter was written succinctly and easy to navigate and follow throughout. The sub-headings split up the text and follow on from each other, and the points made were backed up with examples. This was beneficial for me as a visual person reading because it allowed me to critically analyse the chapter coherently and sum it up through the ordered way it was written. Although, where the chapter explores Black Thrive's research, it would have been helpful if there was a smoother transition perhaps linking them together or introducing them more extensively. However, the summary and conclusions provoke thought on Black Thrive's learning and experience for the reader. I found the language was accessible and where more complex language was used, a conscious effort was made to simplify or explain. I felt like the formatting of the chapter could have benefitted from splitting up the writing a bit more to allow the reader to really take in and hit home the richness of the crucial points.

Did you disagree with anything in this chapter, or think there was anything missing?

I don't think this is a chapter that you can agree or disagree with. I think it provides the real-life context of an organisation set out to help Black

communities get involved in mental health research through partnerships and being authentic and radical throughout the process. Through their lived experiences they offer an insight into how their identities shape the work that they do and the barriers they face within this. They acknowledge their positionality as individuals and not on behalf of a community, although they work with Black communities.

As a South-Asian woman who works in mental health research and has lived experience of mental health problems, it provoked a deep reflection of how we perpetuate these systems that exploit, extract and exclude Black and other racialised communities from research, and how even I am complicit in this. I also feel like the chapter could've expanded on reflexivity (examining one's own beliefs, judgement, etc.) and encouraged the reflexivity of senior researchers, HR and CEOs when working with organisations like Black Thrive and other racialised communities in challenging their own views and decision-making – instead of reflexivity being limited to junior researchers.

The only thing I feel is missing is perhaps some quotes or case studies of individuals who have experienced involvement in Black Thrive's research and research that white-dominated organisations conduct. However, I am mindful that this is also labour, and the sharing of such experiences can be sensitive and (re)-traumatising. I would also argue that involving Black communities and other minoritised groups in the process of applying for funding, creating partnerships and developing projects where there is explorative need, will be beneficial to mental health research. It would mean that co-production can be adopted even earlier and thus disrupt traditional research processes where those with status and power tend to approach partners to secure funding and set the precedent for holding the executive decision power and overseeing the research. Of course, this is difficult due to payment for those involved. However, institutions should be prepared to cover this financial cost if they are truly invested in the ethos of co-production and to bettering mental health for Black and racialised communities.

6. Finding the voice of the people in the pandemic: an ethnographic account of the work of local Healthwatch in the first weeks of England's COVID-19 crisis

Giulia Zoccatelli, Amit Desai, Graham Martin, Sally Brearley, Glenn Robert

Reviewer: Clifford Johnson

I am a current PhD. student with lived experience of heroin addiction and homelessness, employed by Teesside University. I'm currently managing a co-production project on alcohol use during COVID. My main interest area in terms of research is drug use and offending, especially where heroin is a factor.



What was this chapter about?

As original study began pre-COVID, the chapter showed how this evolved following the onset of the crisis, and how the research process, organisations and its participants adapted to this enforced change. Resisting change was of primary importance, ensuring that Healthwatch fulfilled their mandate of being the voice of the people, rather than a voice of the system to the people. Adopting such an approach highlighted how the more vulnerable populations were adversely affected by the governments 'response to the pandemic', and how this produced 'inequitable outcomes'.

What did you find most interesting or important about this chapter?

Although COVID-19 crisis imposed severe limitations on the research, the quick response of Healthwatch ensured that the voices of local citizens were still heard. This allowed for gaps in service provision to be highlighted, especially those

affecting our more marginalised and vulnerable communities. This approach to sharing power between professionals and citizens encapsulates the ‘true meaning’ of co-production, ensuring a vital contribution is made that enhances the quality of life for individuals, and the communities they reside in.

What did you think about how this chapter was written?

This was a well-written and informative chapter, providing an insight on a topic of great significance within the current climate. The content of the chapter was not overly academic, and therefore could be easily understood by the general public and those affected by its topical content. It would be interesting to now read the original study that was funded by NIHR.

Did you disagree with anything in this chapter, or think there was anything missing?

Although word count and time schedules may have imposed limitations on the study, it would have been interesting if more information were given as to how ethnography (a form of research which focuses on people and cultures) has morphed to accommodate this change. Will this be something that remains post-COVID, enabling access to populations that would otherwise not be possible due to limited resources? It will be interesting to see if future ethnographic studies employ wide-ranging strategies, where the use of virtual methods of data collection are embraced, ensuring access to vulnerable and isolated populations, particularly when resources are limited. I personally feel that this could improve the scope for future studies.

7. Co-production? We do community participation: experiences and perspectives in the context of the COVID-19 crisis from Latin America

Cristian R. Montenegro and Felipe Szabzon

Reviewer: Niamh McGarry

I am an experienced researcher with a background in psychology, neuroscience and social research. I am part of ClearView Research, a social and market research agency, and Founder of the independent research consultancy Insightful Health Research. I am passionate about co-production, and as well as co-producing my own research wherever possible, I also actively promote this approach at speaking engagements.



What was this chapter about?

The chapter examines the response to the Covid-19 pandemic in Sao Paulo (Brazil) and Santiago (Chile). Both countries have over the last decades developed a decentralised (managed at a local rather than national level) primary health care network that includes involving patients in decision making. However, in both cities, for different reasons, the response of this formalised health system to the crisis was poor. This forced a more locally led response that required social mobilisation. While not all local initiatives operated in collaboration with state bodies or council members, some did.

What did you find most interesting or important about this chapter?

It was really interesting to learn about how health systems are run in Brazil and Chile, and how the local response overcame the challenges posed by lack of action. It is a really interesting study on social mobilisation.

I feel that the chapter could have interrogated deeper into co-production in this setting. It touched on the idea of how the systems that were in place in these countries were or were not used and where these channels or systems need to be reviewed or changed to work more effectively. However, I feel a deeper exploration of how the social mobilisation led to a person centred and co-produced response would have really added to the discussion.

What did you think about how this chapter was written?

The chapter was easy to digest and summarise. It was an enjoyable read, though I think the main point, 'reshaping the meaning of community participation, was a little lost in the detail. The language was mostly accessible though the reader would need previous knowledge of healthcare systems to follow it completely.

Did you disagree with anything in this chapter, or think there was anything missing?

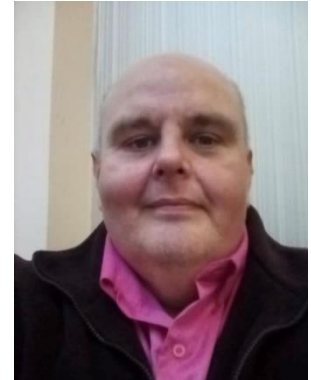
In the section titled 'Structures for community participation and their role in shaping community engagement in health', I felt that the sentiment or tone of this section suggested that communities need to be encouraged to collaborate/co-create with state. However, I would suggest that state need to learn to let go of some control in order to effectively listen to and co-produce with communities.

8. Sovereigns and servers: enablers and challenges to Sikh community-led activism during COVID-19

Meerat Kaur, Harvinder Kaur Dulku, Bob Singh Virdee, Sarabjit Kaur

Reviewer: Mark Dale

I'm passionate about co-production and its effects on people who are working in health, social care or the community in general, providing a more equal society for all.



What was this chapter about?

The Sikh community and its endeavours providing meals to those within the community and other sectors during Covid-19. It gives examples from all the contributors of their experiences of not only feeding people out in the areas people live but helping people in statutory sectors like hospitals as well. The chapter also goes into issues with the charity commission and its chair, but even with this there is a simple and useful description of how to overcome these issues mentioning at the end what needs to be done.

The chapter underlines that at the very heart of Sikh Identity is a standard of productive co-production.

What did you find most interesting or important about this chapter?

Not coming from this community I have learned a lot about Sikh History and its foundations to help and be selfless without wanting anything in return.

The chapter emphasises that any community and every community can be affected by the pandemic and has been. The chapter highlights and showcases

where communities like the Sikh Community adapted but also enhanced their support, emotional strength and wellbeing for the community.

The fundamental aspect of what I see in this chapter is the long history of the Sikh community's unbridled sense of compassion and help for their fellow humans – not only those within the Sikh community but to all.

It speaks of living by example and teaching to children as what the Gurus taught them, a self-fulfilling hope for all you would say.

What did you think about how this chapter was written?

The chapter was easy to read however I needed to be more mindful of the differing words and language as not coming from the Sikh Community.

Some of the language and knowledge has been an eye-opening discovery for myself the Sikh concepts of Sewa (Selfless Service) also Langar (Community Kitchen) and of course Gurdwara which are community dining areas in each place of worship.

Did you disagree with anything in this chapter, or think there was anything missing?

The purpose of the chapter I agree with 100%. I also agree with what needs to be done next. For a person from a non-Sikh background I found the chapter uplifting and exhilarating too, because it absolutely and positively embeds and upholds the values I have in relation to co-production and what it means.

The chapter itself has like any good chapter in a book a Good Beginning, and Stable Middle, and with this not an end, but examples and good connections on how we all can go further and make a change.

9. What Are We Clapping For? Sending people to die in social care. Why the NHS did this and what needs to happen next?

Peter Beresford

Reviewer: Nira Malde

I am a retired social worker who wanted to continue to make a difference to people's lives, so I joined the Co-Production Collective group. I am also a member of the Research Advisory Panel at University College London and involved in a few other projects as a Patient Public Involvement member with a few other universities. I am also a carer to a close family member.



What was this chapter about?

The chapter highlights how thousands of elderly and vulnerable people through failure on the part of the NHS were discharged back into the community resulting in the spread of Covid 19 virus and the death toll. For the NHS and social care to work in collaboration, social care policies need to be reformed through co-production by involving the public, who are experts by experience, to develop policy, practice and research.

What did you find most interesting or important about this chapter?

I found it interesting to learn why the NHS and Social Care have not integrated successfully because of their differing policies. The chapter highlights the importance of co-production by empowering marginalised people, who have personal experience, to impact change.

What did you think about how this chapter was written?

The chapter is informative, pleasant and written in plain English.

Did you disagree with anything in this chapter, or think there was anything missing?

The author summarises the chaos and the confusion brought by the pandemic. He highlights the errors made by the NHS in discharging elderly vulnerable people back into the community which spread the Covid 19 virus followed by the death of the vulnerable, disable people, people from Black and ethnic minority communities, those with underlying health issues and those living in impoverished areas. He outlines the difference in policies between the NHS and Social Care and highlights that for the two to work collaboratively, a reform of the social care policy is required. He emphasises that for this to work meaningfully, co-production is necessary.

10. Disabled People's Deaths Don't Count: how a protected characteristic offered Disabled people little protection during this pandemic

Ellen Clifford and Mark Dunk

Reviewer: Jack Welch

I am an Autistic Advocate and Expert by Experience.



What was this chapter about?

This chapter documented the systemic manner in which disabled people have been failed and disregarded in the course of the COVID-19 pandemic, with a specific focus upon England. It outlines how government economic policy over the years created the conditions for the eventual outcome that left the disabled population more vulnerable to the pandemic's severity.

What did you find most interesting or important about this chapter?

I had a broad awareness of the general context that this chapter was addressing and how within the UK, the rights of disabled people and those around them were overlooked with profound consequences in light of the pandemic's growth across the country. What I found to be especially enlightening was just how official measurements, such as the age-based frailty score, added to the acceptance of the shocking attitude for the right to life and haste for people to subscribe to DNRs (Do Not Resuscitate order). What is perhaps most important is the wider context of how policies in the last decade have eroded the quality of life for disabled people - cuts in social care, welfare reform and reversing the rights that campaigners fought for sealed the fate of thousands when COVID-19 arrived. There are key recommendations at the conclusion of this chapter that Disabled People's Organisations and those in the disability sector need to make

a more conscious effort of working alongside disabled people 'to build stronger alliances'. However, as this chapter sadly observes, there have been very few efforts to consult or develop policies in a co-produced setting.

What did you think about how this chapter was written?

The chapter, on the whole, is very engaging and written with a sense of calm anger and frustration in which the authors detail the disparity of how disabled people have been unfair victims during this pandemic. The opening statement of this chapter, which quotes an unnamed journalist, sets the tone for the verdict which is depicted by the issues broken down throughout. It is a topic that is of personal interest to me already and which I began reading without feeling overly surprised or confronted by the facts on the page. However, it does not cancel out the shocking or alarming information and the scale of the challenge to enhance the lives of disabled people again. The language, while generally understandable to me, would perhaps be a learning curve for those who are not as familiar with the issues or concepts which are presented. It is not written in a strictly academic format, though there are certain terms that would benefit from an explanation for those who require this. The chapter personally did maintain my interest and there were no points in which it felt intentionally exclusionary for its readers.

Did you disagree with anything in this chapter, or think there was anything missing?

I largely agree with the sentiment and commentary of this chapter. However, I do take issue with the description of 'learning difficulties' when I believe this was meant to imply people with learning disabilities at risk of being infected with COVID-19. There is a distinction with how the two differ, with conditions such as dyslexia as a known learning difficulty which does not have as much significant physical impact upon people and health complications in that instance. There is perhaps a child/young person perspective that is not discussed, apart from the mention of the emergency laws and Education Health and Care Plan barriers.

11. Realities of Welfare Reform Under Covid-19 Lockdown: what disabled and older people actually experience

The Secret Welfare Rights Worker

Reviewer: John Spriggs Taylor

I live with schizophrenia. I'm a carer for my mother and I'm a member of a charity's housing board.



What was this chapter about?

This chapter is written by The Secret Welfare Rights Worker, to whom we all owe a large debt of gratitude. It is about making a claim for benefits from the Department for Work and Pensions (DWP) during Covid -19 and focuses on the experiences of disabled and elderly clients trying to navigate the system. I urge everyone to read and reread this chapter to understand how difficult it is.

What did you find most interesting or important about this chapter?

I found the quotes from claimants to be really heart-breaking and certainly the most informative and interesting. People are terrified of the Department for Work and Pensions for very good reasons. Exhausting all other possibilities, going into debt, hoping for the best when having to choose between eating and heating. These are the everyday problems for the poor and vulnerable in this, the fifth richest country in the world. We have a benefit system that is unforgiving, cruel and denies any duty of care to clients. Why don't we give people money when they need it most? Some people were able to receive what amounted to a universal basic income, on furlough during lockdown, whilst many benefit claimants were being rejected. Why do we make the lives of poor and vulnerable

people even more difficult? Food parcels can be lifesaving but not always helpful if your gas or electricity has been cut off or you are homeless. Co-production with the Department for Work and Pensions is vitally necessary. I did a focus group in Birmingham for them in 2019. This is not co-production and they know it. The only thing that changed after that was ending Vivaldi's music on the phone waits, without addressing the real issue of the twenty minutes on hold, to speak to someone when you are already extremely anxious.

What did you think about how this chapter was written?

This is an easy read, with mostly short paragraphs, and guides us through the role of advisor to disabled and older clients. 'People don't think like forms' and you are left thinking just how hard they are for people already in a distressed state. We need many more welfare rights advisors and a kinder response from the Department for Work and Pensions. I wouldn't call this chapter enjoyable reading, but it is accurate and alarming. There needs to be major reform of the Department for Work and Pensions, not more welfare reforms designed only to save money by cutting benefits to vulnerable people.

Did you disagree with anything in this chapter, or think there was anything missing?

A longer chapter would I'm sure have covered the waits, on the phone, written responses and payment. A great feature of it is the lack of jargon, especially as the Department for Work and Pensions, like the NHS, tends to think in three letter acronyms. We do need to work alongside the Department for Work and Pensions. Having personally experienced the loss of DLA (Disability Living Allowance) and a rejection for PIP (Personal Independence Payment), we need to be open to all approaches from them. Perhaps we could even help with the waits!

12. Against Violence and Abuse: gender-based violence and the need for co-production with women with experience

Sonia Braham, Naima Iqbal, Lucy Allwright, Ruth Atkinson, Cordelia Rucke

Reviewer: Giulia Piazza

I am in my first year of a PhD in Mental Health Science at University College London.



What was this chapter about?

This chapter focused on the impact of the Covid-19 pandemic on women who have experienced Gender-based Violence, and specifically on the challenges posed to co-producing research, developing projects and training that involve experts-by-experience. The chapter tells the story of these challenges from the point of view of the feminist charity Against Violence and Abuse and their experts Sonia and Naima.

What did you find most interesting or important about this chapter?

I was particularly impressed by the parallels drawn between the Covid-19 pandemic (and subsequent need to socially distance) and the consequences of Gender-based Violence. Women who experience Gender-based Violence are often isolated from family and friends and feel a lack of support. Gender-based Violence deprives women of agency. Similarly, the arrival of measures to curb Covid-19 meant isolation was exacerbated, and it was much harder to sustain good coping mechanisms. It was fascinating to read about the interplay and intersection of Gender-based Violence and trauma, financial difficulties and

other mental health challenges related to trauma (such as substance abuse and PTSD) from the point of view of the experts by experience.

I very much liked reading about co-production in this context, especially because the authors underline how co-production does not always go smoothly. Sonia and Naima highlighted how being able to work and be paid to contribute as experts has allowed both them and Against Violence and Abuse to learn from their mistakes, given them space to grow together, and built a solid set of skills. This experience is in stark contrast with that of abuse. It is fundamental that experts by experience are paid adequately for their time and allowed to grow in confidence.

What did you think about how this chapter was written?

The chapter is very well written and enjoyable to read, as it does not include unnecessary technical jargon.

Did you disagree with anything in this chapter, or think there was anything missing?

I don't disagree with anything in this chapter.

13. COVID-19 and multi-generational households: reflections on the experience of a diverse urban community in Wales

Amal Beyrouthy, Mashmooma Din, Eva Elliott, Allan Herbert
[authors listed alphabetically]

Reviewer: Karen Smith

I am a researcher in a charity, mainly involved in information sharing/gathering and consultation, I aim to open up to more participative and co-production ways of engaging and working.



What was this chapter about?

This chapter describes the challenges experienced during the pandemic of multi-generational households from Bangladeshi, Pakistani and Indian communities living in South Riverside, Cardiff, an area of extreme deprivation. It shares why older relatives are more prone to Covid-19 due to family circumstances and to anxiety and isolation. The chapter documents how researchers and two trusted, well-established community organisations have worked together and learnt about these challenges, as well as some surprising improvements as a result of the pandemic.

What did you find most interesting or important about this chapter?

I had never thought about differences between care for and the role of the elderly in BAME (Black and Minority Ethnic) and White indigenous communities in the UK. Care homes are predominantly filled with White (affluent) older people

whereas in the BAME communities discussed elderly family members care for children or are cared for at home.

I was struck by the difficulties faced by elderly BAME people – literacy; the whirlwind speed of change; differing social and cultural expectations to younger generations; the dangers of voluntary self-isolation either to protect themselves or their families.

I really enjoyed finding out how digital inclusion during the pandemic had benefitted women in particular, enabling them to join virtual leisure activities. A knock-on effect has been the increased confidence of some women to speak in a Zoom meeting, when they would remain silent in a public setting. Virtual meetings and health e-consultations were successful at overcoming barriers to involvement.

It was refreshing to learn that the researchers who had co-authored the chapter with staff from two community organisations were ‘academic activists’, part of The Other Front Line. Researchers gather stories/accounts from ‘street journalists’ – people in situations of poverty, inequality and exclusion – of the challenges they face and how they support each other. I appreciated this empowering, appreciative approach, and the aim to use street journalists’ stories to advocate for changes to overcome health inequalities.

The community organisations described in the chapter operated on the basis of co-production values, being deeply grass rooted, with trusted relationships and strong networks.

What did you think about how this chapter was written?

I really enjoyed reading this chapter. I found the emphasis on the organisations a bit distracting. The flow from the paragraph on multigenerational households (pg. 130) into the next one, which was about organisational activities didn’t work

for me. The 'And then Covid-19 came along' section might have been better placed integrated into pg. 129 when describing the place, the authors and the process.

Did you disagree with anything in this chapter, or think there was anything missing?

I agree that BAME organisations like those described need to be involved in the co-production of future research, policy and practice. I would love to read something longer that includes accounts from different generations in multi-generational households, their Covid-19 difficulties and benefits, their hopes, fears, any changes in personal aspiration or personal/community connections.

14. Drug use and street homelessness during a pandemic: synergetic working with a vulnerable population

Anne Campbell, Kathy Faulkner, Chris Rintoul, Iain Cameron

Reviewer: Naheen Ali

I have lived experience of mental health and homelessness, and have worked with various vulnerable groups over the years. I have an interest in creative writing, drama, and in helping the vulnerable, and also fighting social injustices.

What was this chapter about?

This chapter covers street homelessness and vulnerable people using injecting equipment for their drug use in Northern Ireland from 2017, and during the pandemic in 2020. An organisation called Extern who works with service users, examined discarded injecting equipment and monitored who used drugs, particularly opioid. With this information they tried to improve the service they offered to their service users, such as offering harm reduction advice, a needle exchange service, psychological and housing support.

What did you find most interesting or important about this chapter?

What I found most interesting and important about this chapter was that people engaging with drugs were poor, and so Extern were supporting people to inject more safely. They also signposted to other services such as housing, testing and treatment, to ensure services were holistic and person centred.

In terms of co-production, Extern worked with service users in a partnership and collaborative way to understand how service users were using drugs during the

pandemic, in order to identify how they could change their work practices to help service users.

The case study story of M using drugs was interesting as it provides a raw account of his feelings of using drugs during the pandemic, and of feeling stuck in a vicious cycle.

What did you think about how this chapter was written?

I think the chapter was fairly easy to read as it was divided into sections such as introducing the story about the issue, the start of the pandemic, what was being done, a service user's story, issues arising in the pandemic, and what needs to be done now. I found it interesting to read as it focused on one area of the country I did not know about, i.e. Belfast and Northern Ireland. The language was easy to understand, with no jargon, making it easy for different readers to read.

Did you disagree with anything in this chapter, or think there was anything missing?

I think this chapter summed up the main points with regards to needle use during the pandemic. I would have liked to see more about general drug use such as the use of different drugs, and more about the issues of street homelessness too. The chapter felt like it was more about needle exchanges for opioid specifically and was less about the issue of homelessness. The 'What needs to be done' section was brief and clear. I liked this chapter coming from the organisation providing the service and considering the service users' needs too.

15. 'It's all right for you thinnies': 'obesity', eating disorders, and COVID-19

Lauren O'Connell, Fiona Quigley, Oli Williams, Helen West, Sophie Metolli, Harry Pitham

Reviewer: Freya Rowson

I am a 21-year-old History and Film student at the University of Warwick



What was this chapter about?

The chapter discussed the focus and impact on fat and higher weight people during the Covid-19 pandemic. It looks particularly at both how the government equated fatness with a vulnerability to coronavirus, without implementing protective measures for those in question, and also how the pandemic itself affected those with eating disorders. The authors attribute this impact to emphases on weight-loss and the equation of exercise to simply 'weight-loss,' and how damaging that is as a mindset. They also offer solutions and future steps to combat these attitudes.

What did you find most interesting or important about this chapter?

The most interesting part was hearing the personal experiences of the various authors and how the pandemic affected their eating disorders and relationships with their bodies. It was also fascinating to see the fitness drive in the early months of the pandemic reframed as somewhat toxic and focused on weight-loss rather than movement and health. I learnt more about the government's discussion of weight alongside the coronavirus, and also the statistics which show that in previous epidemics, long term research shows that there is less of a

link between weight and vulnerability, leading to a false stigma towards weight increasing during times like these.

What did you think about how this chapter was written?

The chapter was clearly structured and cohesive, with personal touches from the authors which made it memorable and unique. It was easy to summarise due to its concise structure, use of bullet-points in the section 'What needs to be done,' and the clear line of argument. It was written clearly and personably, while still maintaining a formal academic style which made it engaging and informative.

The chapter was an enjoyable, if somewhat emotionally painful read. While fascinating, reading the personal experiences of the various authors and their own relationships with their bodies hit fairly close to home, and served as a reminder of how the Covid-19 pandemic has impacts beyond the virus itself.

Did you disagree with anything in this chapter, or think there was anything missing?

I'm not sure if I fully agree with the discussion of Joe Wick's 'virtual P.E. lessons' as having a negative impact in terms of equating P.E. directly with weight-loss. While the examples cited by the authors certainly suggested that and I don't disagree with those, it seems that Joe Wick's project was not deliberately promoting weight-loss and diet culture in school-age children, but rather was encouraging movement and daily exercise. Furthermore, without the structure of P.E. lessons which contain a variety of sports and games, Wicks' provision of exercise videos during the pandemic seemed generous and thoughtful and are certainly more welcome than an alternative where school children are getting absolutely no exercise whatsoever. I believe a wholly negative view of that project is redundant, but the rest of the chapter is fairly nuanced.