A co-produced review OF

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

Volume 2: Co-production Methods and Working Together at a Distance

# Welcome

Hello! I’m Lizzie from [Co-Production Collective](https://www.coproductioncollective.co.uk/) 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*](https://policy.bristoluniversitypress.co.uk/covid-19-and-coproduction-in-health-and-social-care) *and* [*Volume 2*](https://policy.bristoluniversitypress.co.uk/covid-19-and-coproduction-in-health-and-social-care-1), 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](https://www.coproductioncollective.co.uk/news/join-us-to-co-produce-a-co-production-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 2 of *COVID-19 and Co-production in Health and Social Care Research, Policy and Practice*](https://policy.bristoluniversitypress.co.uk/covid-19-and-coproduction-in-health-and-social-care-1) 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 1 of the review here](http://www.coproductioncollective.co.uk/news/our-co-produced-book-review-is-here).

We hope you find it an interesting read. Please let us know your thoughts [on Twitter @UCL\_CoPro](https://twitter.com/UCL_CoPro) or via email: coproduction@ucl.ac.uk

Enjoy!
Lizzie

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# 2. Conversations for Change during COVID-19: Community Voices North West London

Meerat Kaur, Sarah Stayt, Janet Wildman, Sharon Tomlin, Chakshu Sharma, Adeola Adeleke, Fatima Elguenuni, Bethany Golding, Phayza Fudlalla, Nafsika Thalassis, Kay Ollivierre, Samira Ben Omar

## **Reviewer:** Katherine Barrett

I am a service user co-producer who gets involved in Co-Production Collective work.

**What was this chapter about?**

Community Voices facilitates healing and support for both the community and those who work in health and care organisations, positioning communities as designers, and deliverers of solutions to tackle inequalities. It was great to see Community Voices working differently in the community and it is a model that can engage specific communities.

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

I learnt a lot about the work of Community Voices and it was important for me to hear how Community Voices test alternative models to tackle inequalities. My personal response is one of happiness reading about their work. They are transparent about sharing power, make decisions openly and collectively, and challenge by continually questioning both the status quo and themselves. For example, they mention ‘*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.’*

Community Voices rapidly progressed during the pandemic to ensure that communities remained at the heart of policies. They shared stories about life and work during COVID-19 where there was professional learning and development. Anna’s story was very powerful. She says that Community Voices is ‘*supportive of its members but pushing against systems and structures'*. It has encouraged me to listen more, without an agenda.

**What did you think about how this chapter was written?**

The chapter was easy to read and understand in easy language. Community Voices understands the language of the local community and it’s needs and aspirations. The layout is clear and the text under the heading is on topic. It is easy to understand because it is broken into Parts 1, 2 and 3.

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

Community Voices value people as people, but I am not sure how they support everyone to be included. It would be a good idea to add how they encourage people to participate outside of the core members. They mention that the collective continues to grow but don’t give information on how members of the community are involved.

As part of the Co-production Collective, I understand their idea of building collective knowledge and how difficult change is for some people. They mention that they are collaborating to realise social change rather than co-production. Community Voices are negative about co-production because of past experiences but I encourage them to consider co-production again as it has been so helpful in my life.

There might be a lack of commitment which reminds them that this approach will be resisted or rejected by some, as Community Voices rocks the boat, which reminds us that change isn’t easy. They are very clear about what needs to be done - let’s hope people listen.

# 3. My Rhodes has no nose: COVID-19 and the two cities of Cape Town

Ed Young and Anastasia Koch

##

## **Reviewer:** Yesmin Begum

I am an active member of the Co-Production Collective and enjoys being part of a team to co-produce research.

**What was this chapter about?**

The authors express empathy towards the harsh and unfair situations from the past to the present. They provide an insight to the reality of Cape Town and the effects of the apartheid, considering how the neglect of action towards those living in Cape Town were affected. Generally, a very hard read, with the need to repeat sentences to fully understand.

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

The effects that Cape Town had on the arrival of media and the effects of media coverage towards those who worked in law enforcement.

Co-production was not mentioned in the chapter as far as I can recall, however, the team efforts of the videographers in Khayelitsha displayed such work.

**What did you think about how this chapter was written?**

The language slightly complex for the average reader, especially the general public who are new to co-production. I had to read it several times to be able to comprehend it. It was rather hard to sum up with all the location names and complex words I didn’t understand. I did learn about the topic; however, it was hard to understand as it was rather wordy, unnecessarily.

Despite the complexity of the sentences, it was still interesting, though I will not be reading it again.

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

Although the chapter is full of facts, it was hard to fully engage due to the wording and the leaping between past and present, from one location to another.

Overall, a rather complex and confusing record of the work carried out by collective groups. I needed to carry out further research about Cecil Rhodes to fully understand the whole chapter and the issues it addressed.

# 4. Insider-outsider positions during co-production: reflections from the Candomblé terreiros in Brazil

Clarice Mota, Leny Trad, and Lisa Dikomitis

## **Reviewer:** Anonymous

I am a retired Special Needs Art Teacher with lived experience of mental health, neurodiversity and autoimmune disease.

**What was this chapter about?**

This chapter is about the difficulty of disseminating important medical recommendations (about the COVID-19 pandemic) in a culturally sensitive way within the religious communities of the Candomble, in Salvador, Brazil. It discusses ways in which a co-production method was used to discuss with and decide with the community, rather than just dictate recommendations by the World Health Organisation.

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

The chapter did discuss the co-production type-work of the community’s COVID-19 Control Committee, how they met online to discuss strategy and the power of the WhatsApp group. It was really interesting to learn about the Candomble region, its history and traditions, especially those that were more easily adapted to incorporate health advice on minimising the spread of COVID-19.

**What did you think about how this chapter was written?**

I think the chapter was relatively easy to sum up. It was an enjoyable to read as it was a good mix of historical and cultural context, which balanced with the science/medical/health angle. The language was accessible and quite easy to read.

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

The intensions of the committee are mentioned but the outcomes or results of their decisions are not completely clear. Knowing how awful Brazil’s death by Covid statistics are across the whole country, I would have like to see some comparison between districts or even communities. Did this co-production methodology save any lives? Did it get taken seriously, not just by the members of the committee, but by members of the community they served? What can we learn from this research without data to back it up? I appreciate that a more comprehensive study or inquiry might occur once Covid is under control and that this is just a small insight during extraordinary times.

It is very respectful of the Candomble traditions and it gives us a lot of information of how these highly sociable communities exist and how they may survive these dark times. I imagine that the Terreiros will be a place of comfort to many grieving families in Brazil and that their charitable activities will be much in demand too. I hope that the co-production methods they have used will be transferable into other aspects of their local governances and social/health provision, ultimately supporting the most vulnerable in their communities.

# 5. Ambitious about co-production: adapting a participation programme during the pandemic to meet the needs of autistic young peopleEmily Niner and Kerrie Portman

## **Reviewer:** Tanja Conway-Grim

I am a neurodivergent trainer and researcher, who is passionate about co-production.

**What was this chapter about?**

This chapter describes how the organisation Ambitious about Autism adapted their participation programme with and for young autistic young people during the pandemic. The young people were all part of the Ambitious Youth Network. This chapter explains the key principles Ambitious about Autism believes must be followed in co-produced work.

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

Ambitious about Autism took a proactive approach to reaching out to their young people, was responsive to their needs and took the opportunity to co-produce and co-deliver training for health professionals, enabling and empowering their young people to develop skills and experience in this important area. It seems this made a big impact on both the young people and the health professionals.

**What did you think about how this chapter was written?**

This chapter was an easy and enjoyable read. It built upon previous research and work done by Ambitious about Autism with and for young people. I enjoyed reading about how responsive they were to the needs of young people and how they grasped the opportunity of lockdown to proactively reach out and co-produce, with their young people, a training opportunity for health care professionals.

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

I would have liked to have the quotes from the young people in italics, so that it is more obvious it is a quote. I would have preferred the referencing to have followed a Harvard Style Referencing format. A few more references from other researchers would have been beneficial. I would have liked to have seen a bit more on digital inclusion and how you empower young people without digital access. Were local organisations approached for digital devices? Was there a postal-based option?

# 6. A co-produced response to COVID-19: impact on women and girls with disabilities in low-and middle-income countriesPeter O. Ekiikina

## **Reviewer:** Ayath Ullah

I am a public policy professional who champions public involvement and has interests in the different facets of research.

**What was this chapter about?**

This chapter explores how co-production has had a meaningful and life-enhancing impact upon disabled women and girls within the African continent. Many are still subject to ill-treatment and abuses through no fault of their own and are more likely to be victims of these acts as a result of COVID-19, which this chapter has sought to present effective solutions to.

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

While I almost anticipated the chapter to take a UK/English scope from the title alone, I was pleasantly surprised to gain an insight to an often poorly understood and challenging problem facing a particular population with very different life experiences compared to those living in the UK. It was especially helpful to have the case studies in this chapter, especially the story of Patricia, who has been empowered as a result of co-produced projects. The fact she is now able to lead sessions for her peers, rather than the NGOs who provided the resources to do this, is testament to the strength of authentic co-production that enables people in communities to be agents of change.

What is important to recognise is that while COVID-19 has limited the numbers to participate, governments need to be proactive in expanding programmes to educate women in these groups to better tackle the existing problems after the pandemic.

**What did you think about how this chapter was written?**

The chapter flows in an accessible and straightforward format in the manner it is presented. A real strength in this case was the case study, which came across as authentic and distinctive from Patricia’s voice who wrote about her experience, as well as Faith’s journey in activism. I would have happily read another case study or example in which individuals affected by such abuse have been able to overcome these barriers and thrive in the paths that they follow. I had no difficulty with the language as such and found this could be easily shared with an uninformed audience on this subject matter.

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

Nothing to disagree with.

# 7. #WirVsVirus: communities co-producing new solutions to meet COVID-19 challenges through a hackathon in GermanyElke Loeffler and Claudia Masiga

## **Reviewer:** Barod CIC

Bryan Collis, Claudia Magwood, Simon Rice, Simon Richards are the Barod Research Team. Barod CIC is a cooperative of people with and without learning disabilities based in Wales. We work co-productively all the time and are all paid the same. The Research Team have been working together for a year.

We did the review by producing an ‘easier to read’ version that the team could read by themselves. We then had a video meeting to discuss what we thought and agreed what we wanted to say. One of us wrote the review and sent it in.

**What was this chapter about?**

The chapter was about using technology (an online hackathon) to help people co-produce a way of helping foodbanks get donations. It used four stages of co-production to look at how well the co-production worked.

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

We were encouraged that co-production can still happen in a pandemic! One of us learnt about hackathons and foodbanks in Germany. We learnt some words or labels for what we do every day – co-commission, co-design, co-deliver and co-assess.

**What did you think about how this chapter was written?**

We did this review as a group of people with and without learning disabilities. One of us produced an ‘easier to read’ version for three of us to read by ourselves. This helped a bit with the language, but we all had to read the chapter two or three times to get our heads around it. The way the chapter is put together made sense, but we found it hard to work out the main message. When we do an easy read, we often move the words around so the main message is first. One of us had to google ‘hackathon’ because they were not sure what it meant from the chapter.

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

We agreed with the chapter, but we are agreeable people. One of us who has done lots of reading said the way co-production is described is only one way of thinking about co-production. The chapter switches between organisations and individuals and this could have been explored more. The chapter talks about the large number of ‘citizens’ that took part, but then about organisations that start things or are brought into support or help. So, the hackathon increased engagement but doesn’t seem to share power. We didn’t like the way ‘citizens’ were not paid to take part. One of us thought it would be a stronger chapter if it had compared another hackathon or another way of developing ideas into projects or services.

# 8. Locked In or Locked Out: redistributing Power to d/Deaf and Disabled People when using Remote TechnologiesAdam Goodall and Becki Meakinread

## **Reviewer:** Alison Allam

I am involved with several organisations including the Co-Production Collective. I am interested in embedding the patient and carer voice throughout the research process.

**What was this chapter about?**

This chapter explores the experiences of D/deaf and disabled people using remote technologies to access a wide range of activities during the Covid pandemic lockdown. Drawing on the findings of a recent survey conducted by Shaping our Lives, the chapter primarily focuses on disabled people’s experiences of remote technology in accessing health and social care services.

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

I think this chapter provides a useful insight into many of the challenges D/deaf and disabled people have faced using remote technologies during the Covid pandemic lockdown. The presentation of the findings – and specifically the use of direct quotes from disabled people about their experiences is interesting and relatable. Perhaps the chapter could have been strengthened further by discussing how co-production was embedded in the research process.

Overall, this chapter was balanced in sense it acknowledged both the potential advantages of remote technology, for example, saving time and energy by removing need to travel, as well as, potential disadvantages, for example, poor Internet connection and potential loss of the relational aspects of face-to-face contact.

**What did you think about how this chapter was written?**

I think this chapter was written in an accessible manner both in terms of content and style of language.

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

Overall, I agree with the key message of the chapter that moving forward a blended approach (i.e., having the option/choice of accessing activities either face-to-face or remotely) should be offered and that digital exclusion should be tackled. I thought the ‘what needs to be done’ section of the chapter was particularly useful in terms beginning to think about how a blended approach could be facilitated for and by disabled people beyond the pandemic/lockdown and when remote access is not the only option.

# 9. Bridging Gaps: how we’ve managed digital exclusion during COVID-19 to improve access to healthcare for women who have experienced trauma

The Bridging Gaps group, supported by Michelle Farr, Lesley Wye, Maria Carvalho, Lucy Potter

## **Reviewer:** Julie Wright

Julie Wright loves being out in nature, and encouraging the people, animals and plants around her to enjoy and express their natural selves; one way she’s done this is by co-founding [www.growingwellbeing.org.uk](http://www.growingwellbeing.org.uk).

**What was this chapter about?**

I really enjoyed reading about this brilliant sounding Bristol-based project, Bridging Gaps. It’s run by and for women with trauma related complex needs, to enable better access to primary healthcare. It was a fascinating story of how technology enabled them to continue their crucial work during the pandemic – designing and delivering awareness training for health service providers, which supports them to identify those in need and co-create innovative services that really make a difference.

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

It was really interesting to follow a first-hand account of a positive response to the sudden changes needed to co-produce during a pandemic. And how to ensure people involved have the technology and other facilities or support to enable this. There were many inspiring insights, including what enormous benefits it can have for the people involved, and an example of what good co-production can lead to – in the form of a really positive and innovative new service.

**What did you think about how this chapter was written?**

The chapter was accessible and engaging. And I loved the quotes towards the end from the women involved - they were so open, honest and heart-warming. It was beautiful to hear how life-affirming and transformative co-production can be, I was almost moved to tears – in a good way! Anyone considering co-producing something like this should read it. The personal impact that this project had on the individuals involved, combined with the fact that it is leading to such fruitful solutions, was really inspiring.

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

The chapter provides a valuable real-life description of how to switch over to remote working - when some people don’t have, and aren’t used to using, the technology required. Overall, it provided an excellent narrative of the process the group went through, and how to make remote working effective and enjoyable. I’ve made myself a list of useful pointers as a result of reading this and I’m sure it will be helpful.

I’d have been interested to know more about how the group co-produced the decisions about which technology to use, and if everyone was happy with this. Were other methods suggested? Did some people like the telephone conferencing option, or not want to use a tablet or have online meetings at all? I’d have been curious to hear a bit more about challenges or resistance to co-producing remotely and learn about how they were overcome.

10. COVID co-design does not \*HAVE\* to be digital! Why "which platform should we use?" should not be your first question
Joe Langley, Niki Wallace, Aaron Davis, Ian Gwilt, Sarah Knowles, Rebecca Partridge, Gemma Wheeler, Ursula Ankeny

##

## **Reviewer:** Laura Sibarella

I am a social worker with a passion for reproductive justice and social research. I am currently pursuing a PhD at Ulster University, exploring the role of civil society organisations in translating the Sustainable Development Goals to address reproductive health issues in Uganda.

**What was this chapter about?**

The chapter presented and discussed ways to overcome challenges of co-design during the Covid-19 pandemic. More specifically, the focus was on the importance to understand people’s need and designing the tools accordingly, instead of simply shifting from face-to-face workshops to online platforms.

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

I have found most interesting the possibility to assemble or combine different co-design tools, and to take the opportunity, arisen by the Covid-19 related challenges, to explore blended approaches to co-design and to investigate new opportunities to engage people.

I have learned some basic characteristics of co-design but the core of the chapter and most of the information were about tools. I have learned to classify tools in four categories, based on two variables (space and time) and I have learned advantages and disadvantages of some tools that can be used in different spaces.

I have found very useful the recommendations at the end of chapter, opening the space for further discussion and development for a post pandemic world.

**What did you think about how this chapter was written?**

The chapter was easy to read and understand, and the use of tables and figures helped in clarifying some concepts. The language was accessible even for non-native English speakers and sentences were clear.

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

I agree with the key message of the chapter. Many researchers, both in more conventional qualitative research and in co-production and co-design projects, had to adapt and modify their projects and data collection tools during the pandemic. I believe most of them tried to understand how to replicate face-to-face tools online and which was the best platform for doing that and I think that the shift suggested in this chapter is really valuable; it is important to take this occasion to invest in new opportunities for co-design and people’s engagement.

I think the chapter is clear and comprehensive, no fundamental information is missing. I appreciate the synthesis and clarity of the information learned and the query presented in the title “Why ‘which platform should we use?’ should not be your first question” has been fully addressed.

# 11. Co-producing virtual co-production: adapting to changeAlison Allam, Scott Ballard-Ridley, Katherine Barrett, Lizzie Cain, Cristina Serrao, Niccola Hutchinson-Pascal [authors listed alphabetically]

##

## **Reviewer:** Daniel Stephen Turner

I am a Singer-Songwriter, and Mental Health Advocate.

**What was this chapter about?**

This chapter discusses the challenges of virtual co-production but also makes it clear that there are a number of benefits that come along with it. For example, the necessity of doing the official launch of the Co-Production Collective back in Oct 2020 online, meant that many more people were able to get involved, allowing for something special that wouldn't have happened in person.

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

While I understood what co-production was, the chapter helped to get a better understanding on the concept.

The most interesting thing for me was how much the chapter solidified the ideas I already had in my head. One thing the lockdown has given us is an appreciation for online video chat like Zoom, and how much of an impact this will have on our lives going forward. There are experiences I have had online that I would not have been part of if they happened in person and it truly is a wonderful thing.

 **What did you think about how this chapter was written?**

I did feel that the chapter may have been more exciting if the perspectives of the different individuals involved was more apparent. While a number of people wrote the chapter, it could have just as easily been written by one person who had spoken to other individuals. It did however get the point across which is of course more important.

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

I agree with the points made in this chapter. It is incredibly important to move forward with online meetings even when it is possible to go back to in person meet-ups. I also agree that getting the correct technology in the hands of the marginalised is incredibly important to get a true inclusion.

12. Co-production and COVID-19: digital diaries as a platform for participating in Covid-19 research
**Mary Chambers, Dinesh Deokota, Ragil Dien, Nguyen Hoang Yen**

## **Reviewer:** Victoria Hamer

I grew up in Ireland, under the spell of Wexford Festival Opera, and worked at Glyndebourne Opera and at the Royal Academy of Arts. I am a Patient and Public Involvement Public Contributor.

**What was this chapter about?**

This chapter is about community members in Vietnam, Nepal and Indonesia telling their stories of their lived experiences of Covid-19 using photographs and videos as ‘digital diaries’.

This was a participatory community engagement and social science research study. The project allowed the participants to express themselves in less formal ways than by formal interviews or focus groups. This fostered relationships and gave voice to some in poor areas, marginalised, and often excluded from discussions about medical research. In Nepal, five digital diaries were screened at a film festival in Kathmandu, which provided a platform for the participants to speak about their experiences of making the diaries and to engage with experts and a wider public.

In some rural areas, training was needed to build confidence in camera use and to assist the participants to tell stories of their lives. Some were reticent to speak by themselves, so a collective film was made with a group of youth.

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

The deeply personal stories told from 12 sites (from highly urban to remote rural), and the vivid picture of the challenging logistics, made me want to keep reading.

Reports of ambulance drivers travelling to remote clinics to take equipment for the project (cameras, hard drives, instruction sheets) painted the background. We read stories about a man unable to be driven to the hospital for dialysis treatment; the rural health worker walking for five hours to take HIV drugs to a patient, the film capturing truck drivers refusing to give her a lift because she ‘may be contagious’; and the health worker who faced stigma from neighbours and colleagues when she tested positive. We learnt about a cultural concern of families holding Marapu beliefs in Indonesia regarding the Covid-19 regulations restricting burial practices and the moving of bodies of relatives who had died elsewhere back to a shared grave.

**What did you think about how this chapter was written?**

This chapter was both gripping and moving. Occasionally it was written in a slightly academic way, such as when using references, but overall, it was very engaging.

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

The ‘diaries’ provided insights on incidents or periods of time and portrayed people’s “deep courage and resilience”. However, it was only when accessing the project website that I discovered these were available to view online. More generalised role titles for some of the participants’ stories were referred to in the chapter than in the titles given in some of the videos.

You can see the digital diaries here: <http://www.oucru.org/digital-diary/>

13. Going remote: using technology to co-produce homeless health research
**PJ Annand, Spike Hudson, Maame Esi D. Yankah, Martin Burrows, Stan Burridge, Michelle Cornes, Sujit D. Rathod, Paniz Hosseini, Lucy Platt, Andy Guise**

## **Reviewer:** Mandy Rudczenko

I have been helping my son to manage his long-term condition (Cystic Fibrosis) for 20 years. I have become passionately involved in co-producing various health projects and has a strong interest in co-producing health research.

**What was this chapter about?**

This chapter was a reflective, honest evaluation of the challenges to involving people experiencing homelessness in digital research. The chapter details the challenging backdrop to co-producing research during a pandemic, whilst highlighting that this makes it even more important to address ‘*the gulf between those affected by policy and those developing it*…’.

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

The chapter succeeds in informing the reader about the strong need to address the inequalities exacerbated by the pandemic, by showing a strong commitment to exploring accessible methods of involvement. It also demonstrates that the potential for meaningful co-production is always possible, despite the barriers. The chapter raised my awareness of the need to allow plenty of time for flexibility, creativity and reflexivity in projects. I was particularly inspired by the following ideas:

* peer supported citizen journalism;
* remote sessions broken down into smaller sections over longer periods of time.

**What did you think about how this chapter was written?**

The chapter is well organised, making the flow of information easy to follow. Some of the language used was quite convoluted and formal, and could have been simplified. The introductory paragraph could be more welcoming with an easy read revision. The chapter would have benefited from contributions from people experiencing homelessness who were involved in the projects.

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

Opportunities were missed to include contributions from people experiencing homelessness; e.g. the reference to Groundswell’s (2020c) research which highlighted insights.

One method of research which I wasn’t totally comfortable with was the co-interviewing. This seemed to work well for research staff but there wasn’t any mention of how this worked for people experiencing homelessness. Would people feel intimidated by being interviewed by more than one person?

14. “A place where we could listen to each other and be heard”: enabling remote participation spaces for research and co-production among disabled people with energy impairment beyond COVID-19
**Alison Allam and Catherine Hale**

## **Reviewer:** Sue Wood

I am part of the Applied Research Collaboration (ARC) in Greater Manchester with a lead role in managing the public involvement and engagement activity making sure the diverse communities of Greater Manchester have a voice.

**What was this chapter about?**

This chapter describes a new approach of an online focus group for people who are housebound due to energy limiting chronic illness. The focus group was run over a longer time frame than traditional focus groups (8 weeks) and participants could take part at flexible times to accommodate fluctuations in energy levels and ability to concentrate. Participants were able to select an anonymised identity allowing them the freedom to express their views without fear of knowing other participants in the group, which may be an issue for other online forums.

The chapter also describes the issues people have with energy limiting chronic illness and why they have previously been excluded from more traditional face-to-face groups that require prolonged periods of concentration in inaccessible venues.

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

The sign of a good article is one that makes you stop and think, and this chapter certainly did. With the rush to make many things digital in the past year, there has been a lot of concern about the inequalities people may face due to lack of access to technology ‘digital exclusion’. However, this is an example of where ‘digital inclusion’ has been enabled for a group who were previously excluded and often told that it wasn’t possible to enable remote access as a reasonable adjustment. The needs some individuals have to be able to take part in their own way at their own pace over an extended period can apply to many other groups of individuals, but is particularly important for those who are housebound due to energy limiting illness where taking part in face-to-face activities presents challenges that cannot be mitigated.

The chapter talks about the importance of maintaining remote forms of inclusion and participation for those who need it once face-to-face life resumes for the majority. What it importantly does though, is state that remote participation should not be forced on those who prefer to and can be supported to contribute face-to-face because it may seem to be the easier option.

This chapter describes one approach that could work for those who are excluded from traditional face-to-face approaches providing ‘*a space where we could listen and be heard*,’ enabling co-production in sharing knowledge, deliberation of the issues and decision making as a community.

**What did you think about how this chapter was written?**

The chapter was easy to read and created a balanced discussion of the issues that needed to be addressed, a clear description of the approach taken, how this helped the participants who took part and what they gained as a research team from the discussion. There is reference and a link to the software that was used. The ‘what needs to be done’ section at the end summarises some key points that focuses on practical things the readers can do to acknowledge the issues raised. Where they use more technical vocabulary or acronyms these are explained.

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

There is very little to disagree with in this chapter as it describes an approach to enabling the voices of people who are at high risk of being excluded. It does not try to claim that this is the only approach, or that it can replace face to face interaction where this is preferred and can be supported, but gives the opportunity to explore an approach that may help more voices to be heard in a meaningful way through different ways of doing things.

# 15. Reflections on Punjabi Communities, COVID-19, and Mental HealthShuranjeet Singh

## **Reviewer:** Safina Niazi

I am a dental science student with a keen interest in evidence-based research informing healthcare practices.

**What was this chapter about?**

A reflective piece on the impact on COVID-19 from a community informed evidence base, with the premise that our health, inclusive of mental health, is socially determinant feature of the community we ascribe to.

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

The author believes that it would be far more meaningful to consider the impacts of the current pandemic from a less reductive viewpoint, rather than evading the stark underlying reality of ethnic inequalities which were exacerbated and brought to fore with the ‘Black Lives Matter’ movement earlier this year. He explains how we can use the events of the past few months as a learning opportunity to discuss facilitating and investing in substantive change towards incorporating a holistic model of health and social care. This is one where the individual, their intrinsic facets of identity and varying complexities are appreciated and integrated into their care.

Using his teams’ experience of the challenge they faced in sourcing funding for their research, he was able to empathise with the Punjabi community - and other minority groups by extension – in the collective frustration and sense of injustice that bureaucratic and administrative barriers pose.

**What did you think about how this chapter was written?**

The topic of the chapter was clearly reflected upon from the beginning through to the conclusion.

It was an easy chapter to sum up – once I had processed my emotional response to it! The research concept, tools and scientific language was familiar to me as I am involved in a similar field of research, so it was both an easy and familiar read. The author made succinct and simple conclusions based on his research findings. His sentence structure had an easy flow where the preceding topic was nicely linked to the subsequent point of discussion.

I found it an engaging read. At various points I found myself nodding furiously in agreement with the author, as well as taking a pause to re-read and then contemplate on other recommendations – but mostly I was left feeling ‘short-changed’ by his generic and laborious conclusion of ‘more research needs to be done, etc.’

I felt the language was appropriate for both the topic, content and the type of writing the author was using to explain the findings of his research.

The author did not make any reference to co-production in his writing.

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

I firmly agree with the author’s opinion on directing healthcare, advocacy and research organisations in moving away from acronyms in reference to minority groups. Speaking as a female of brown skin, I have always recoiled at the term BAME, not out of shame or insecurity, but pride. I think it’s lazy to blanket label a human being into a social category based on factors external to their control. I find it demeaning and reductive to my experience as it enforces on me a burden of responsibility and accountability for the actions and behaviours of every other individual within my so-called ‘tribe’.

I also appreciated the discussion of spiritual and religious belief systems inherent within communities and validating them as a potential support mechanism. However, I believe the author failed to understand the subtle yet significant distinction between ‘religion’ and ‘spirituality’ in his definition as “contemplation and meditation”. As a member of the Punjabi community and as someone with several seventh day Baptist and orthodox Christian friends, the role that religion plays is so much more than a set of prayers, it is a way of life, a guide for personal, interpersonal, and moral conduct. And this nuance plays a massive part in mental health which I believe he could have elaborated on.

# 16. International perspectives on the impact of COVID-19 on community engagement of young people for involvement in mental health researchRosemary Musesengwa, Vanessa Bennett, Kiran Manku, Biggy Dziro, Sapfo Lignou, Kudzai Kanyere, Peter Lewis

## **Reviewer:** Alison Finch

I am a doctoral researcher and nurse based at University College London and University College Hospitals NHS Foundation Trust (UCLH). Joined by members of the young people's cancer community, I am currently exploring people's experiences of ambulatory cancer care.

**What was this chapter about?**

This chapter presents two case studies of co-produced mental health research from a UK and African perspective, foregrounding digital engagement and the experiences of two young people’s advisory group members. It is underpinned by a contextual description of the principles of young people’s participatory research and describes the practical application of shifting to an online co-produced research approach in response to the pandemic.

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

Co-produced research can take many forms and what this chapter helps illustrate is the importance of working flexibly as researchers, co-researchers and advisory group members in a way that is tailored to individual’s interests, the situation and cultural context. Importantly, this chapter offers practical insight into how the agency generated from knowledge by experience can influence and integrate with more traditional knowledge sources. Personally, I was helped to reflect on the opportunities and challenges of digital engagement within the context of my own work.

**What did you think about how this chapter was written?**

The chapter is written in an accessible style integrating the voices and perspectives of different members of the research community. I found it a useful basis to think about how the values underpinning collaborative research relationships play out in my own practice.

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

One of the chapter authors positively describes the opportunity to build a digital online footprint in association with their participation in research. Thinking more widely, I am curious whether participation in research that amplifies someone’s lived experience and integrates an online presence could, in the future, make it difficult to distance from should it become their preference.

# 17. From Utopia Now to Dystopia Now: co-producing knowledge about young people’s hopes and fears for the futureHannah Cowan, Charlotte Kühlbrandt, Hana Riazuddin, Oli Polidore-Perrins, Destiny Boka Batesa, Bella Swinburne

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## **Reviewer:** Nikki Genner

I am a creative producer, fundraiser and creative practitioner based in the West Midlands, working at the intersections of arts, culture, health and community. My practice focuses on community-led co-creation that enables cross-sector partnerships to instigate positive social change.

**What was this chapter about?**

From Utopia Now to Dystopia Now\* charts a creativity-led research project and its change in direction due to the UK COVID-19 lockdown in Spring-Summer 2020. Utopia Now set out to consider and explore ‘meta-co-production’ with people who would be affected by future research (primarily young people). The lockdown ended Utopia Now activities, so the research team generated Dystopia Now which aimed to understand how the pandemic was affecting young people. This chapter proposes that to effectively co-produce research with more equal power dynamics many changes are required, from improved equity of access to resources (specifically tech and internet) to a shift in universities’ systemic priorities.

*\*Utopia is an imagined place or state of things where everything is perfect.
Dystopia is the opposite, where everything in an imagined place is terrible.*

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

This chapter reiterates the shameful reality of digital disparity that many children, young people and families face in the UK and importantly, contributes to literature that increases understanding of how this barrier leads to heightened inequalities. Elsewhere, it explains the benefits of utilising playful and creative participatory methods of collaborative data collection, a practice the writers propose enables effective co-produced knowledge exchange through facilitating spaces that are more equal and imaginative. This approach gives the opportunity to review how researchers describe the people studied, preferring ‘artists or creators’ and not ‘interviewees or study participants’; this serves to highlight the value of their contribution as ‘active makers of data’ rather than passive contributors. For effective co-production it is vital that creators retain ownership of their knowledge and feel empowered to share in a non-hierarchical and non-judgemental environment.

**What did you think about how this chapter was written?**

This chapter was easy to follow and digest; written in a storytelling manner it painted a clear picture of the evolving situation of the research project. The story-like reflections on creative activity and ‘collaborating creators’ gives the reader a good understanding of the people and partners who were involved in the research, as well as an insight of social context that surrounds their lived experience. It felt vital to understand this so the perspective of how inequalities negatively impact knowledge sharing can be better appreciated and empathised with by the reader.

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

There is a quick jump in the final paragraph through the explanation of the link between the project narrative, its findings and how inequalities are barriers to knowledge sharing. This section could benefit from being broken down further to showcase the necessity and reasoning behind the recommendations.

Furthermore, the recommendations are predominantly broad statements. This brings into question how achievable and actionable they can be in both the short and long term to initiate change or influence new thinking. While the writers encourage more diverse voices to be heard (‘pay attention to young people’s knowledge’ and ‘listening to young people’) this does not equate to the direct action taking and change that the writer's view as vital for universities and funders to deliver more agile processes, better distribution of resources and delivering heightened civic responsibility in times of greater need.

# Afterword

## Clare, Dawn, Niccola and Sudhir – 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](http://www.coproductioncollective.co.uk/news/our-co-produced-book-review-is-here).

In Volume 1 of this review, we shared introductory reflections on the book as a whole, including the ways it speaks to Co-Production Collective’s [core values](https://uploads-ssl.webflow.com/5ffee76a01a63b6b7213780c/608ac90dfc3d6b21d71f5176_Core%20values%201%20pg%20branded.pdf). Here, we wanted to share some concluding thoughts.

**Where next for co-production?**

Co-production is certainly not a quick fix, nor does it provide a total solution to every social problem. Nevertheless, from our experience, meaningful co-production significantly adds to the authenticity and relevance of processes and outcomes. It allows overlooked voices to be heard and, as such, leads to research, policies and services that are more likely to meet the needs of our diverse society.

However, the ‘systems’ within which we operate doesn’t always support this way of working. This means that those who do not exist within traditional structures of research, policy or service development (for example, within institutions such as the NHS, academia or government) aren’t often allowed to be meaningfully part of that process and so their voices, perspectives and knowledge do not inform the results.

Instead, we want to see a system where everyone’s experience is valued equally. We feel that this book can help in our vision of a world more like this.

Clare reflects that this book feels like a conversation that should be happening everywhere, in any institution where co-production can help (i.e. any institution!). As a patient interested in the structures and inequities within healthcare, she – and many like her – have been trying to have these conversations for a long time.

Health inequalities have been more evident than ever as a result of the pandemic, and so these volumes are a timely and important contribution to the movement.

The editors summed up our feelings perfectly in Volume 2 when they said:

*“These inequalities and inequities have helped COVID-19 to have such a devastating impact but have been damaging the health and wellbeing of the vast majority of the global population long before COVID-19 arrived. Co-production can play a significant role in addressing this if it can become part of the ‘new normal’.”*

We hope this is realised sooner rather than later. It is something we will continue to fight for.

Clare, Dawn, Niccola and Sudhir