COVID co-design does not *HAVE* to be digital!: Why 'which platform should we use?' should not be your first question

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RAPID
RESPONSE

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

EDITED BY
OLI WILLIAMS
DOREEN TEMBO
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GARY HICKEY
MICHELLE FARR
PETER BERESFORD

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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

Edited by

Oli Williams, Doreen Tembo, Josephine Ocloo,
Meerat Kaur, Gary Hickey, Michelle Farr,
and Peter Beresford (editors listed in reverse
alphabetical order)

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Editorial statement

The order in which editors or authors' names appear on publications comes with specific assumptions and conventions in academic settings. Specifically, the convention is that the order reflects who had the most influence on the work or who made the greatest contribution, or indeed, who has the highest status in academia. There was tension between these academic and publishing norms and the participatory and collaborative approaches promoted and practiced by the editors of this collection. These norms can perpetuate the exclusion of those who are already marginalised and largely ignore how structural inequalities render simplistic notions of meritocracy unfit for resolving inequities in academic publishing. Given this context and due to the varied but significant contributions made by all of the editors in this book, and in the spirit of collaborative and equitable ways of working, a pragmatic compromise was made to write the names of the editors alphabetically by surname; A–Z for Volume 1 and Z–A for Volume 2.

Contributions

Peter Beresford was approached by Policy Press to write a book for their Rapid Response series exploring co-production in relation to COVID-19. He approached other service users and researchers (including those who see themselves as both of these), to see if they would be interested jointly in taking this idea forward as co-editors on a co-production basis. He has sought from a service user researcher perspective, to support this project by working as an equal member of the editors group, writing one chapter, commissioning another, and editing/reviewing several others as well as the introductions (providing an initial draft for Volume 1 Introduction) and conclusions.

Michelle Farr has co-written one of the chapters in the second volume, edited five chapters, and commented, contributed to, and edited the introductory and concluding chapters.

Gary Hickey has co-written one of the chapters in the first volume, edited six chapters and commented on and contributed to introductory and concluding chapters.

Meerat Kaur wrote two chapters, one as a co-author of an initiative she was part of and another for an initiative she was aware of but which the people involved wanted writing support to share their experiences. She edited five chapters and contributed to the introductory and concluding chapters.

Josephine Ocloo has written her own chapter in Volume 1, which included summarising key methods and examples of co-production discussed in both volumes. Her thinking on equity, diversity, and inclusion has made a substantial contribution to the intellectual thinking in the book, and to the ideas about the need for equitable ways of recognising contributions in editorial processes. She has also edited four chapters, read all chapters, and commented on introductory and concluding chapters.

Doreen Tembo was responsible for sourcing and managing relationships with the majority of the authors who have contributed chapters covering international perspectives. She has co-written one of the chapters in the first volume, edited one chapter, and commented on and contributed to introductory and concluding chapters.

Oli Williams in agreement with the team, has managed this project – drafting the proposal, editing it in line with reviewer comments, responding to reviewers, establishing timelines, creating materials for contributors, repurposing funding from his fellowship, establishing and managing a payment system for contributors, organising and chairing team meetings, coordinating team and tasks, and compiling the manuscripts. He reviewed 11 chapters, co-authored a chapter in Volume 1, drafted and subsequently revised the Introduction and Afterword for Volume 2, as well as contributed to the writing and editing of the Introduction and Afterword for Volume 1.

Disclaimer

The views expressed in this book are those of the authors and not necessarily those of the National Health Service, National Institute for Health Research, Department of Health and Social Care, the Health Foundation, The Healthcare Improvement Studies Institute, or any other funder associated with the editors.

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Peter Beresford's time is supported by the National Institute for Health Research Applied Research Collaboration East of England (NIHR ARC East of England).

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Oli Williams is affiliated to the Samskapa research programme on co-production led by Jönköping University. This is funded by Forte, the Swedish Research Council for Health, Working Life and Welfare under grant agreement no. 2018–01431.

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The Health Foundation

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Introduction

1

Co-production methods and working together at a distance

Introduction to Volume 2

Oli Williams, Doreen Tembo, Josephine Ocloo, Meerat Kaur, Gary Hickey, Michelle Farr, and Peter Beresford (authors listed in reverse alphabetical order)

This contribution to Policy Press's Rapid Responses series on the pandemic (https://bristoluniversitypress.co.uk/rapid-responses) is a practical book about the value and means of co-production. In this edited collection, we address how and why more collaborative, diverse, and inclusive responses could lessen the toll of this pandemic and future health emergencies, as well as challenge and improve 'business as usual' beyond the pandemic. It illustrates how and why this way of working can help to address the social wrongs we need to right: inequalities, discrimination, and marginalisation. The grave consequences of following the precedents set during this pandemic – in terms of morbidity, mortality, marginalisation, and wasteful ineffective policy – emphasise the urgency with which we must act to do things differently, to demonstrate *why* co-produced responses are required, and *how* policymakers, practitioners, service users, activists, communities, and citizens can make this happen both now and in the future.

To achieve these aims this book has been divided into three parts over two volumes: (1) The impact of existing structures; (2) Infection and (increasing) marginalisation; (3) Working together at a distance: guidance and examples. Parts I and II have been addressed in Volume 1, which you can read here: https://policy.bristoluniversitypress.co.uk/covid-19-and-coproduction-in-health-and-social-care. Volume 2 is dedicated to addressing Part III. It does this by providing a series of international examples of *how* groups have co-produced during the COVID-19 pandemic in order to address issues relating to health and social care. Throughout this volume, contributors reflect on their pandemic co-production endeavours in relation to both pre- and post-pandemic times. As a whole, Volumes 1 and 2 address the hows and whys of co-production. In this volume, the focus is on the former. That is, *how* co-production has happened during the COVID-19 pandemic and *how* others can follow this example both while this pandemic persists and after it is over.

The COVID-19 pandemic, inequalities, and exclusion

As with previous pandemics, the COVID-19 pandemic has highlighted the social determinants of health that largely explain the consistency and severity of health inequalities we see throughout societies (Bambra et al, 2020; Marmot et al, 2020). Entrenched social and economic inequalities have meant that the vulnerability to and consequences of COVID-19 have not been evenly distributed. This led Bambra et al (2020) to draw on Merrill Singer's work on the HIV/AIDS epidemics of the 1980s and 90s to argue that rather than this merely being a pandemic, what we are currently experiencing is a 'syndemic' – that is, a synergistic epidemic. Singer et al (2017: 941) explained that syndemics involve the adverse interaction between diseases and health conditions of all types and that they are 'most likely to emerge under conditions of health inequality caused by poverty, stigmatisation, stress, or structural violence because of the role of these factors in disease clustering and exposure and in increased physical and behavioural vulnerability'. In the case of COVID-19 this is due to factors such as existing social gradients in non-communicable diseases; social circumstances and working conditions that make isolating relatively easy for some and impossible for others; structural racism, ableism, and other forms of discrimination leading to inequitable access to and provision of healthcare; and relative reliance on social care provision. It is increasingly clear that COVID-19 is no 'great leveller' as some have claimed, but rather it is merely the latest example of how social and economic inequalities produce and reproduce health inequalities that unevenly distribute the experience of disadvantage, ill-health, and suffering. The current situation led Kamran Abbasi (2021) to use his platform as an executive editor of the *British Medical Journal* to evoke the work of Friedrich Engels to argue that government responses to COVID-19 constitute 'social murder' insomuch as we are witnessing a 'lack of political attention to social determinants and inequities that exacerbate the pandemic'.

During the COVID-19 pandemic, the experiences of the most vulnerable and marginalised in societies have had little direct influence on the policies and practice that should have been created for their benefit and protection. There has also been a consistent trend of health and social care research, policy, and practice being created *about* these people and groups but not *with* them. This is despite community participation being crucial for effective and efficient pandemic responses. Insights and input from communities, and especially marginalised groups, can identify and address important issues that are otherwise exacerbated through a lack of attention and/or resources being dedicated to them (Anoko et al, 2020; Gilmore et al, 2020; Marston et al, 2020). How is it that so many people can be ignored at a time when we have all been rallied to contribute to a national, or indeed global, effort? Well, this outcome was entirely predictable for those already engaging with participatory approaches, patient and public involvement, and user-led initiatives. Rhetoric about public and service user involvement has tended to be in advance of the reality (Beresford, 2019). Organisational barriers have long been documented in patient and public involvement and service user literature (Beresford, 2013a; 2013b; Ocloo and Matthews, 2016; Ocloo et al, 2021). Despite decades of activism, such involvement and participatory practice in health and social care research, policy, and practice is still predominantly considered 'nice to have' but non-essential

(Richards and Scowcroft, 2020). The pandemic has seen statutory policy commitments to patient and public involvement and shared decision-making in health systems largely abandoned with the 'nothing about us without us' mantra 'left hanging in the breeze' (Richards and Scowcroft, 2020). Consequently, with the obvious challenges posed by a pandemic, co-production was always at risk of being considered as an 'added extra' rather than as fundamental to a successful and sustainable response that addresses the needs of communities (Marston et al, 2020). During the pandemic, the gap between rhetoric and reality has caused some to argue that there has been enough talk, empty promises, and superficial gestures, that the time for bold language about being committed to participatory approaches has passed and now more than ever is a time for bold action (Jones et al, 2020). It is clear that things need to change. But even if a genuine will for and commitment to change can be summoned, people need to know *how* to make it happen.

During this pandemic, some have swum against the tide of exclusion, demonstrating that such exclusion was/is not inevitable. Driven by necessity, moral responsibility, pragmatism, a combination of these motivations, and/or many others, some have found ways to ensure marginalised groups and people who would have otherwise been excluded were instead included. Their inclusion enables them to raise awareness of issues and needs that require attention and to actively contribute to decision-making processes that were and are of consequence to them. In many instances, these groups were working together at a distance, often aided by digital technologies. But responses have not been uniform. In this volume we bring together a diversity of efforts and approaches from around the world that have facilitated people to push back against top-down decision-making as a default pandemic response and instead demonstrate innovation though a commitment to more inclusive and participatory practice.

We should not romanticise what was happening pre-pandemic; co-production in practice has long been inhibited, undermined, and questioned for failing to adequately address issues of equality, diversity, and inclusion (eg Fotaki, 2015; Carr, 2018; Steen et al, 2018; Rose and Kalathil, 2019). However, the pandemic has posed significant additional challenges to organising and working in more inclusive and participatory ways. The necessity of overcoming these challenges to co-produce knowledge and action has been emphasised by existing inequalities causing COVID-19, and government responses to it, to disproportionately disadvantage, infect, and kill people who were already marginalised and discriminated against. We have seen many powerful decision-makers and commentators frame these disproportionate impacts as deficiencies in the biology or behaviour of certain groups or individuals. Indeed, Horton (2020) highlighted that an 'attractive deceit is being advanced that individual responsibility is the way out of our predicament'. This has seen the blame game we have become accustomed to in contemporary discussions of public health playing out during the COVID-19 pandemic, that is, shifting responsibility and culpability onto individuals for health statuses that are to a large extent socially determined (Elliott et al, 2015; Williams and Fullagar, 2019). This undermines the need for action on social factors and by extension offers governments convenient excuses for their failings. The unequal impact of the pandemic on different racialised and ethnic groups is an important example of this.

In England, the disproportionate toll the pandemic has had on people with different backgrounds, but often collectively and problematically grouped together as Black, Asian, and minority ethnic groups, and/or communities, has been well documented in scientific evidence. In acknowledgement of the problematic use of the 'BAME' acronym, we do not adopt it here. Many people who are part of these communities and/or work for/with organisations that represent them have felt ignored for years – with issues perpetuating inequalities consistently not being properly acknowledged or addressed by government policy or popular media (Eddo-Lodge, 2018; Bowleg, 2020; Fields et al, 2021). A Public Health England report detailing disparities in the risk and outcomes of COVID-19 was widely criticised for its framing of ethnic disparities and not recognising the role of and need to address structural discrimination (Moore, 2020; Patel et al, 2020). Of particular significance to advocates of co-production, much of the criticism centred on the absence of a section of the report that was included in an earlier draft shared within government. The absent section summarised responses from more than 1,000 organisations and individuals who are part of and/or working with Black, Asian, and minoritised ethnic groups, and had supplied evidence and advice to the review. Many of these contributions explicitly stated that racial discrimination contributed to the increased risk from COVID-19 and made recommendations about how to address this, and the implication is that this is why they were not included in the report (Iacobucci, 2020).

Not only has the significance of the disadvantage and marginalisation of Black, Asian, and other minoritised ethnic groups been undermined during this pandemic, it has also been directly exacerbated. In the United States, research demonstrated that the pandemic response has promoted racism. The study found that public health messages which framed COVID-19 as the 'Chinese virus', as the President of the United States did (when he was not referring to it as 'kung flu'), not only increased anti-Asian American prejudice but promoted racialised prejudice and xenophobia by reinforcing beliefs that *all* immigrants pose a threat to Americans. The same study found that if public health messaging instead emphasised the potential physical threat of the virus, it did not incite negative attitudes toward Asian Americans and immigrants (Dhanani and Franz, 2021).

What these examples highlight is that various national and local responses to the pandemic were not inevitable. Rather, they were based on decision-making that typically excluded the most vulnerable and marginalised in societies and as a result reflected and perpetuated existing structural inequalities. Co-production offers an alternative way of generating knowledge and action that has the potential to address issues of equality, diversity, and inclusion, and therefore improve health and social care research, policy, and practice.

What we mean by co-production

In this volume, we learn from people who have found ways to make co-production part of the pandemic response. There is so much that can be learnt from them. The COVID-19 pandemic has of course led to a highly changeable time as we have gradually learnt more about this new infectious disease and found ourselves adapting at short notice to different contexts designed to limit its impact. As such, it is important to state that all contributors to this collection wrote their chapters between November 2020 and February 2021. That is, the authors are not writing with full hindsight but rather their contributions were shaped by what was experienced and known before and during that particular phase of the pandemic.

Each chapter outlines and explains how teams have operated within existing structures (or attempted to create new ones) in order to co-produce more inclusive and equitable responses to the pandemic while working within the restrictions of lockdowns and social distancing. Consideration is also given to how existing structures influenced pre-pandemic practice as well as the new ways of working that we have, to some extent, been forced to negotiate and/or create. Predictably, digital innovation and utilisation are key themes throughout many of the chapters and illustrate how teams have co-produced at a distance during the pandemic. While some of the benefits of working digitally are well demonstrated, there are also calls not to make digital the default choice and to recognise the necessity of considering the impact that pre-existing and growing digital divides within society have on participation in predominantly digitally facilitated co-production endeavours. Examples from Africa, Asia, Australia, Europe, and a number of diasporas within them, describe a multitude of methods used by groups and communities in order to form new collaborations or continue existing ones. These methods facilitated participatory practice during the pandemic, presenting new opportunities and challenges to negotiate. In every chapter, contributors offer useful reflections about what opportunities were available to them and how they negotiated challenges they faced – both new challenges resulting from new restrictions and methods and the familiar challenges of participatory practice that persisted into these new situations. These international examples can help us to reflect on the relative 'inevitability' of pandemic responses in any given country and the different possibilities for more participatory practice that existed/exist but have been marginalised, ignored, and/or left largely unexplored.

We appreciate that co-production is a contested term that is used by different people in different contexts in different ways (Carr, 2018). This is of particular significance to this volume due to the focus on *how* co-production is done. Although there is some overlap, the various definitions and conceptualisations of 'co-production' can lead to vastly different, and in some cases contradictory, practice. In recent years, as the term has been more commonly used, 'co-production' has been in danger of becoming little more than a buzzword (Hickey et al, 2018; Williams et al, 2020a). And more concerning, co-production can be and has been used as a rhetorical device to hide and/or exploit, rather than to address, power and social inequities (Flinders et al, 2016; Carr, 2018; Thomas-Hughes, 2018). This, of course, highlights the need to critique co-production and for the onus on anyone and everyone who uses the term to explicitly clarify what it is being used to describe and what rationales inform this practice. This would allow any 'co-production' to be evaluated against the conceptualisation from which it developed and help to sharpen critique. For example, it would help to prevent the term co-production illegitimately affording some practice a halo effect that suggests it is more inclusive, participatory, and equitable than it is. However, this does not imply that there is value in advocating for some notion of 'true co-production' or suggesting that there is only one legitimate definition. Different fields have used the term co-production to conceptualise different phenomenon and consequently judging practice informed by one conceptualisation by the expectations of another is neither a logical nor productive activity. Literature published about co-production and the pandemic has highlighted three common conceptualisations that should not be confused, but rather recognised as distinct and critically engaged with.

Firstly, Steen and Brandsen (2020) extended the scholarly origins of co-production into the pandemic. This conceptualisation stems from the work of Elinor Ostrom and other economists in the 1970s and beyond, coming from a public administration/management perspective and investigating how the relationship between citizens and government departments influences the effectiveness of public services (eg Ostrom et al, 1978; Ostrom, 1996). For them, co-production is 'flourishing under COVID-19' because they define co-production as voluntary contributions from citizens improving the effectiveness and efficiency of public services. For instance, they give examples of co-production as the public adhering to social distancing policies, providing informal care, and parents home schooling children while schools have been closed. From this perspective, this co-production illustrates that 'governments have proved utterly dependent on citizens, not only because of compliance with top-down directives but also because of the many spontaneous, bottom-up initiatives that have sprung up in parallel, which have kept society functional, or at least bearable' (Steen and Brandsen, 2020:851).

Secondly, this sense that the pandemic has, to some extent, promoted and proliferated co-production is also apparent in what might be defined as the knowledge mobilisation field – that is, academics and applied health researchers who focus on the generation and dissemination of knowledge to inform policy and practice. During the pandemic this conceptualisation has been represented by a special issue in the *British Medical Journal* (BMJ) on the 'Co-production of knowledge' in which it is claimed the COVID-19 response is 'often being co-produced by default' (Marten et al, 2021:3). This approach is chiefly informed by technocratic rationales, and is consequently concerned with filling the 'know-do' gap in order to improve interventions and policies, and subsequently accelerate their implementation (see also Oliver et al, 2019). This conceptualisation of co-production has previously been critiqued for using the term 'stakeholders' in a very broad sense, and therefore not sufficiently distinguishing between service users, public contributors, and professionals, for example, healthcare practitioners, commissioners, policymakers, and industry partners (Williams et al, 2020b). Such distinctions implicate very different types of collaborative work based on differences in expertise, experience, and power, and may only afford service users, patients, and citizens marginal roles, and leaves open the possibility of not including them at all. These same criticisms hold for the recent special issue. For instance, the working definition of co-production in this BMJ special issue was 'when researchers work together with knowledge users (comprising patients and caregivers, the public, clinicians, policy makers, health system leaders, and others) to identify a problem and produce knowledge, sharing power and responsibility from the start to the end of the research' (Marten et al, 2021:1). As such, researchers are central to this form of co-production and positioned separately from 'knowledge users' presumably as knowledge generators. This stands in rather stark contrast to the third and last common conceptualisation of co-production evident in co-production pandemic literature.

As previously described, those actively engaged specifically in participatory approaches, patient and public involvement, and user-led initiatives in health and social care research, policy, and practice have been left to write about a lack of co-production and a loss of pre-pandemic progress (Jones et al, 2020; Marston et al, 2020; Richards and Scowcroft, 2020). For those engaged in this work, co-production is defined in contrast to more usual decision-making processes in health and social care, which typically exclude or marginalise patients, service users, communities, and public contributors. Instead, co-production represents radical power sharing with patients, service users, communities, and public contributors, and is informed by an egalitarian rationale – this means practice is centrally concerned with addressing issues of equality, diversity, and inclusion with ultimate aims including promoting health equity and improving standards of care (Carr, 2018). In this conceptualisation of co-production, patients, service users, communities, and public contributors are not merely knowledge users but creators of knowledge who are engaged in more equitable collaborations with relevant stakeholders, for example, healthcare professionals, researchers, and policymakers. This approach ascribes legitimacy to ‘lay’ knowledge and ‘lived experience’ and fundamentally addresses issues of power within institutions and associated decision-making processes (Farr, 2018). It is this conceptualisation of co-production that most closely aligns with the one we use in this book.

Due to the expansive and varied conceptualisation of co-production, we did not want to exclude good practice by being too prescriptive in our definition. However, central to our understanding of co-production in this book are processes through which inequalities in power are acknowledged and addressed to facilitate collaboration. So, co-production in this edited collection is about bringing together citizens, communities, patients, and/or service users with those working in health and social care research, policy, and practice, and attempting to form equitable partnerships. This extends to citizens, communities, patients, and/or service users making meaningful contributions to agenda setting and the formation of aims and objectives, not merely being ‘involved’ once these important decisions have been made by those who traditionally hold power. This draws otherwise excluded perspectives and understandings into strategic and procedural decision-making processes and makes the most of everyone’s different skills, knowledge, experience, and abilities. While other forms of participatory practice have their place, in this book we are focusing on theory and practice that is more centrally about addressing inequalities in power. Best practice in co-produced research remains contested, with a significant theory-practice gap (Lambert and Carr, 2018). So, to make this book as practical as possible we asked the authors of each chapter to conclude with their priorities for ‘What needs to be done’ to address the issues they raise and better serve the groups and communities discussed in their chapters. We hope readers will find these international examples of co-production, and the priorities they outline, to be instructive and that they help you to work with and better support people in your own communities and practice.

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PART III

Working together at a distance: guidance and examples

2

Conversations for change during COVID-19

Community Voices North West London

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Introduction

Community Voices North West London is a collective of individuals and organisations created to test alternative models and grassroots approaches to tackle inequalities. The approach centres on collaborative effort and conversations for change led by communities and driven by their needs, rather than the agendas of health and care, or other statutory organisations. This collective rapidly progressed during the COVID-19 pandemic to ensure that communities remained at the heart of policies and investment in engagement and solutions to shape everyday lives. These efforts were framed by a collective desire to craft a more participatory approach and explore how this could influence/change existing systems.

What emerged from Community Voices North West London was a purposefully designed collective that became a social movement. This collective has evolved into a conduit between local communities and health, care, and other statutory organisations in north-west London. Here our aim is to provide learning for people who want to establish voluntary movements composed of people similarly motivated to achieve system-wide change from an equality and community perspective. This is our story, in our own words, from a world and community, which takes people's stories seriously, and as starting points for change.

Part 1: the personal impact of inequalities and COVID-19 in our communities

The Community Voices collective is comprised of people who live and/or work in north-west London. We belong to communities that face higher risks of COVID-19. We are not simply capturing community voices or advancing priorities set by wider structures and organisations, but 'build[ing] a collective, context-specific knowledge, not separat[ing] ourselves from society' (Andrews, 2011:153). Ceesu, a Community Champion whose story was collected through this collective aptly stated, 'We are people who have knowledge, who know the language of the local community, [and] are able to tune into the local community's needs and aspirations.' This way of knowing pre-empted the impact of COVID-19 on specific communities and nudged towards a different narrative, challenging popular, taken-for-granted assumptions. While the various communities across north-west London faced some of the toughest challenges, they also brought a multitude of talent, skills, and experiences.

North-west London is home to people from a host of backgrounds, languages, cultures, and experiences who are among the richest and the poorest in the country. The community groups and individuals who are part of Community Voices highlight increasing inequalities and worsening outcomes for specific people. Some of our members argue this comes from a disregard of racialised individuals and communities, and the resulting chronic disinvestment in the organisations that work with and build trusted relationships with these communities. While the communities felt they had been articulating this for many years, such findings were only validated when published data corroborated this (Marmot, 2020). Community Voices members frequently argue that it is not local people and communities that are hard to engage, but that local health, care, and related statutory organisations do little/nothing to engage with them.

These pre-existing challenges for certain communities in north-west London intensified with the collective impact of the COVID-19 pandemic, the subsequent lockdowns, and the killing of George Floyd in America. Daily life worsened for people who were already in precarious positions.

> The impact has been huge … particularly [for] the marginalised ones, they feel under-served … because quite frankly most of our people (and that is the BAME community) are the frontline workers … their savings have been absorbed, … everything is hand to mouth economically, so suddenly they are finding themselves short of food … (Marie, community worker)

The impact on local people and communities led to heightened workloads and stress for people working in community organisations. They had invested time and resources to build relationships with communities, and were capable of communicating with them in appropriate ways during these challenging times. Yet these people, including the volunteers who were crucial to the effective functioning of community organisations, were themselves going through challenges because of the pandemic and lockdown. This included a lack of childcare, and staff being furloughed at a time when increasingly complex situations in their local communities needed to be addressed.

Part 2: our process: evolving collaborative approaches to tackle inequalities

The unique, uncertain, and rapidly changing COVID-19 situation impacted the approach we developed and evolved for the Community Voices initiative. The approach combined supportive spaces (more on these in Part 3 of this chapter) to bring together communities and organisations with a rigorous but rapid methodology. Our journeys to the point of establishing the Community Voices collective are crucial to the development of this melting pot of a model. These journeys focused on finding ways to enable, establish, and evolve community-led solutions to tackle inequalities. As the first lockdown became increasingly imminent, our collective started to take shape rapidly, and a core group of seven individuals came together. This core group was built on long-standing relationships and shared motivation to ensure we amplified the needs, talents, and skills in our communities.

The collective continues to grow into a movement of people and organisations, many of whom have much experience of trying to tackle inequalities but feel their impact has been limited. These members are attracted to Community Voices in part because they see this group as an example of alternative approaches that could actually make a difference and improve people's lives. The aim of the approach then is one of building a movement, and of collaborating to realise social change rather than necessarily 'co-producing'.

Our experiences of co-production in practice has led us to be cautious of the concept. Those of us working in community organisations are familiar with people from statutory or health and care organisations saying to us that they will, or want to, co-produce with us. However, in practice, this rarely happens and the outcomes sought or realised can be divorced from any form of co-productive process. Perhaps controversially, we feel this approach has become an end in itself. People aim to realise 'co-production' and remove it from a wider purpose of improving people's lives. Community Voices instead gives space and voice to challenge inaction and bring a more nuanced understanding of how individuals can work together to champion a collective cause – never detached from the goal of bringing about change that benefits local communities.

Rapid and rigorous approaches to data collection and analysis were adopted to build and strengthen collaboration among the Community Voices members. Data collection aimed to take place through a series of conversations where people in north-west London could share what really mattered to them about COVID-19 and life during lockdown. A brief and broad set of questions were provided if needed, to help people articulate how they were coping, what they needed, and where they were getting information from about the pandemic. The data was rapidly analysed and fed back to wider members at regular reflection sessions that enabled them to corroborate or challenge the findings. Crucially, these sessions gave members an opportunity to highlight the issues they were facing, the work they were doing, and connect challenges with solutions. This purposefully created approach changes in response to ongoing findings and needs, and enables communities to remain at the heart of efforts to manage the pandemic.

Part 3: the impact of Community Voices North West London

Community Voices delivered some relatively rapid impact, which motivated people and organisations to commit to what was essentially an experimental model. The model facilitates individual learning and provides a space for healing, and a process that strengthens ongoing collective action

Facilitating individual learning and support

The process of sharing stories about life and work during COVID-19 facilitated personal and professional learning and development. This was particularly evident among members from health, care, and related organisations, as exemplified by Anna's reflections. Anna works in a healthcare commissioning organisation and also lives in the region. There were times when Anna was the only white woman in the virtual reflection sessions. As evidence emerged of the impact of COVID-19 on racialised groups from the community groups across north-west London, Anna found the Community Voices initiative aided her personal and professional development.

> I usually find it easier to stick to the language I read in reports and presentations, the structure of internal meetings and the accepted measures of success, rather than questioning them. However, the Community Voices approach – supportive of its members, but pushing against systems and structures – has encouraged me to listen more, without an agenda if I can, resist the urge to research my

> way out of an uncomfortable situation, and try to have the difficult conversations. For example, asking where the money is that will support a focus group – rather than just assuming that attendees will continue to volunteer their time – and having conversations with people about what the terms Black and BAME mean to them. These are small steps, but I think the initiative can help people working within the system to look outwards and recognise that the knowledge and solutions already exist within our communities.

Community Voices facilitated healing and support for both community members and those who work in health and care organisations. For members working in health, care, and other statutory organisations, the approach enabled them to speak openly. Deepa, who works in a healthcare consultancy, stated: ‘I’ve been working in this job for 40 years and this is the first time I can take off this cloak and be who I am.’ For all members, but especially those from community organisations, COVID-19 and the subsequent lockdowns led to a sense of increased responsibility for people whose lives were becoming harder. This affected community members who came from an already under-resourced, over-stretched sector. Krishna, for example, spoke of living through ‘maybe the most challenging situation’ and how being ‘the person who is there for everyone’ impacted her own wellbeing.

Facilitating collective action that garnered national attention

Community Voices has received national recognition from organisations and individuals who are interested in taking a more participatory approach. It is seen as a model that can engage specific communities, including those who health, care, and related organisations have struggled to work with, or have inadvertently or actively marginalised. The process and outcomes of the initiative have been shared nationally through think tanks and other research programmes, blogs, and participation in the national policy on poverty. The Community Voices model continues to shape how the NHS works, positioning communities as designers and deliverers of solutions to tackle inequalities. This combination of influence is critical for policy change. The increasing profile of this initiative has enabled some members to demonstrate the importance of the approach to their colleagues. For those who come from health, care, and other statutory organisations in particular, this has provided evidence that can encourage their employers to continue to support their involvement in the initiative.

Conclusion

In a year of irrefutable evidence of the work that we still need to do to tackle inequalities, Community Voices has shown the potential of one solution. The fact that the approach has garnered interest from communities across north-west London, and organisations locally and nationally, demonstrates specific approaches can be designed that appease various agendas. One of the fundamental flaws that hinders progression of such community collaborations is the lack of commitment to truly find, and therefore resource, alternative solutions. This leads to piecemeal approaches that test and evolve single models rather than explorations of more radical potential solutions, at scale, and in differing contexts. This lack of commitment reminds us that this approach will be resisted/rejected by some. Some people are programmed to think and respond in organisational-specific and policy-directed ways, and the Community Voices approach rocks the boat. 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. Yet commitment for such approaches is crucial if we truly want to tackle inequalities and create a world where everyone thrives.

What needs to be done

- Health, care, and statutory organisations must focus on regaining the trust of the local communities they serve by (re)building meaningful relationships – especially with marginalised and racialised communities. Concerted efforts to establish meaningful conversations with local communities, positioning them as part of the solution to tackle inequalities, are required.

- Work with local communities to design and deliver culturally-appropriate solutions that improve people's lives and work for them.
- Invest in local communities. COVID-19 has left much-needed community infrastructure struggling to survive. Health, care, and other statutory organisations should invest in the communities they serve through procurement of independent, community-led services, hiring local centres, paying for local services, and commissioning and working with local people.

Disclaimer

The views expressed in this publication are those of the authors and not necessarily those of their organisations, the NHS, the National Institute for Health Research, or the Department of Health.

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3

My Rhodes has no nose

COVID-19 and the two cities of Cape Town

Ed Young and Anastasia Koch

> How do you tell someone a story that they already know?
> (Coates, 2020)

The 2020 hard lockdown proved difficult for some enduring pre-existing hardships that were as a result of historical disenfranchisement and current day social fatigue. Conditions were exacerbated by the misappropriation of state funds designated for personal protective equipment (PPE), sanitation, housing, and education. Apartheid South Africa's untouched segregational planning ensured that the poor would become poorer and the hungry would become a mortality risk. While South Africa's middle-class battled everyday inconveniences such as resentments toward the government on mask wearing regulations and the ban on cigarettes and alcohol, an invisible 'homelessness pandemic' was fermenting on the far side of the City of Cape Town's cartographical divide. James Baldwin mentioned that, 'The question is really a kind of apathy and ignorance, which is the price we pay for segregation. That's what segregation means. You don't know what's happening on the other side of the wall, because you don't want to know.' (Baldwin and Peck, 2017).

The pandemic became effective not only in intensifying the imbalances among economically diverse populations but also in underlining the ease with which such disparities are generally disregarded. As COVID-19 hit our shores in March 2020, our organisation (https://ehwoza.com/about) pressed pause on one of our oldest, core programmes specifically created to address such sentiments. 'Learner Doccies' is a project that exposes high school learners from

Khayelitsha (a peri-urban township 30 minutes from central Cape Town and the setting for most of Eh!woza's work) to current infectious disease-related biomedical research, concluding in the production of short student-made documentaries with its primary focus around TB, HIV, and associated social determinants of health. Khayelitsha was designed during apartheid as a segregated area in which to house labour – today the area has among the highest TB and HIV rates in the world, which converge with elevated rates of poverty, violence, and currently COVID-19. The project consists of an intensive curriculum that runs annually for the better part of the year and focusses on high school students between the ages of 15 and 17. Our organisation may only be able to resume the high school programme in the latter part of 2021, pending the distribution and availability of vaccines, the real-life effects of vaccine hesitancy and denialism, and the general logistics concerning high school attendance.

During the course of 2019, we initiated an experimental training programme with the aim of expanding capacity and developing our existing programmes. In order to achieve this, we required an increased number of facilitators versed in camera and drone operating skills with interviewing and video editing abilities to implement mentorship via a vernacular peer-to-peer training approach. A group of core trainees were identified and mentored over a period of approximately 18 months. Currently, all participants are based in Khayelitsha and most are from the same area where the high school learners are recruited.

As we closed shop during the initial lockdown, the team was equipped with high-end but discreet film and sound equipment – DJI Osmo Pocket cameras and Zoom H1N field sound recorders – as well as a portable editing suite and the necessary permits and paperwork to responsibly move around the townships during lockdown. The group put out some feelers in Khayelitsha and produced a set of films around what people in Khayelitsha with access to limited health information available in isiXhosa (one of South Africa's 11 official languages, most dominantly spoken in the Cape Town region and the Eastern Cape province) felt about the unknown virus. MAKHAZA 2020 (https://ehwoza.com/

makhaza-2020) was the first short project produced around residents' initial perceptions of the virus and the economic and social struggles of a hard lockdown in informal settlements. As one resident expressed in an interview: "How would we lock 10 people in a squatter camp in a one roomed house? Everyone in that room is breathing against each other. […] Even the house ends up sweating."

The project was further developed while mentoring filmmakers in Khayelitsha via WhatsApp, while confined to our respective homes at often unreasonable hours of the morning, as COVID knows no time. COVID FEARS (https://ehwoza.com/covid-fears) expanded on issues raised in the pilot film and focussed specifically on people's personal fears and feelings around the disease. An elderly couple had locked themselves in their yard and refused to let anyone near them, while a young woman explained that, "At least with AIDS you know how you get it."

Our online visibility remained limited and our own social media platforms were still developing. In an attempt to extend our dissemination, we partnered with Cape Town TV (https://ctv.hcmmedia.co.za/), a local community driven television channel with a wide local viewing audience, and Bhekisisa Centre for Health Journalism (https://bhekisisa.org/what-is-bhekisisa/), and in turn News24 (https://www.news24.com/), as dissemination partners, both of which are prominent national news platforms.

During that time, the team was pursuing a film about the South African Social Security Agency – SASSA vs. COVID (https://www.youtube.com/watch?app=desktop&v=GBvTEzeg_Lo) – a difficult film that identified a complex infrastructure failure during the monthly payouts of social grants and COVID-19 relief funds to grant holders. People, many elderly, were forced to sleep in queues outside the SASSA offices in Khayelitsha in order to try to apply for social grants during midwinter and the heart of the pandemic, often falling victim to muggings, getting sick from exposure to harsh weather conditions, and going without food for several days at a time.

As the films progressed, there was an expansion of newly formed informal settlements throughout Khayelitsha by means of unlawful land occupations, primarily due to COVID’s devastating effect on job security and people’s ability to continue to pay rent. A vast number of affected people were backyard dwellers before the virus exacerbated an already deteriorated labour economy. At the time of producing this article, South Africa was staring down a 30.8% unemployment rate in the third quarter of 2020 (Stats SA, 2020).

It came to light that the City of Cape Town was deploying large numbers of law enforcement officers to demolish informal structures daily, while confiscating residents’ building materials, leaving people stranded and homeless during the pandemic midwinter. This became public after cell phone footage went viral of resident Bulelani Qolani being dragged out of his shack while taking a bath. The clip shows Qolani being manhandled by police while naked, his shack being torn down within seconds.

COVID EVICTIONS (https://www.youtube.com/watch?v=Iwzd8DjZupw) depicts the story of Qolani and the residents of eThembeni, an informal settlement in Khayelitsha. While residents rebuilt previously destroyed shacks, the City would continue to demolish properties and stories would emerge of people’s belongings and money being confiscated by police, police shooting residents and children with rubber bullets and teargas, and in some instances, police urinating on residents’ food. Qolani’s case was successful in a court case brought against the City by the South African Human Rights Commission and the civic group Housing Assembly. The judges ultimately ordered that no evictions were to be carried out without a court order during the COVID-mandated South African State of Disaster and instructed the immediate return of materials and possessions confiscated by the Anti-Land Invasion Unit. However, the City was unrelenting.

THE ANTI-BLACKNESS OF COVID EVICTIONS (https://www.youtube.com/watch?v=rzBHh3qYdOQ), exposed additional examples of police brutality during the shack demolitions, including examples such as law enforcement assaulting a pregnant woman who was fighting for her belongings, as she needed her ID document for when she gave birth, while simultaneously ‘gratuitously’ (Wilderson,

2020) hunting down children with rubber bullets during demolitions. A 15-year-old resident recalls that:

> While we were running, they shot me here behind the ear with a rubber bullet. I got into another shack with another man. I sat down and then I heard one of my friends Sikho crying, 'I'm just a child … I'm just a child.' 'Please, please no!' They didn't let him go. I came out of the shack. When I got out, they were dragging him by his T-shirt. Others (law enforcement) were beating him.

As the films became more accessible and more visible, resentment started to emerge online against Khayelitsha CAN (https://www.canoncollins.org/) and Social Justice Coalition (https://sjc.org.za/about) (two local activist and advocacy organisations) labelling law enforcement as anti-black, as the overwhelming sentiment on social media was that the officers responsible were of colour and therefore could not be anti-black. This shed a murky light on the misgivings and public naivety that these actions were not being carried out at the will of the officers tasked to do so, but by the historic systemic practice of law enforcement itself – in South Africa, a brutal policing system that is in dire need of an overhaul, and refurbishment to become a system that should first and foremost protect, rather than vilify the vulnerable, who subsequently became more exposed as a direct result of the pandemic and its economic impact on the country.

Some weeks later, a sewer pipe burst at eThembeni, an informal settlement, and the residents were forced to live knee-deep in human waste for three months during winter and during the COVID lockdown. While the City insisted that it was 'clean water', and while children were swimming in it and getting sick, the Social Justice Coalition accused the City of constructive eviction, the act in which a landowner deliberately makes a property uninhabitable. Unwanted residents were forced off the property and into homelessness during COVID-19 lockdown restrictions and curfews, and economic insecurity. These views were documented in the film ETHEMBENI (https://www.youtube.com/watch?v=rJXOS9BJwhA).

The worldwide COVID-19 lockdown intensified efforts against systemically unjust practices. The majority of the global population were stuck at home, taking note more than usual, as police brutality was on display on social and mainstream media, and resulted in marches in major capital cities across the globe. Instances of brutality in the US forced people to expose and confront occurrences in their own back yards, inspiring an informal conceptual global alliance for the restructuring of archaic policing. South Africa saw the killing of Collins Khosa, who was murdered by law enforcement for drinking a beer in his yard, allegedly violating COVID-19 lockdown regulations and alcohol restrictions (Bawa, 2020). Soon after, Nathaniel Julies, a 16-year-old teenager with Down syndrome, was gunned down by three police officers at close range with a shotgun, in a case that the South African state acknowledged as premeditated murder (Simelane, 2020).

Some of these protests manifested themselves in sustained assaults and physical criticism of confederate statues in the US, and some infamous slavers in the UK took unfortunate nosedives into the country's canals. These acts of a Duchampian 'rectifying', of statues as social unease, is regarded by some as a regeneration of the 2015 Rhodes Must Fall movement (RMF) (Motsaathebe and Petersen, 2020), a campaign met with significant resistance in which students at the University of Cape Town commanded the removal of the difficult symbol and statue of colonialist Cecil John Rhodes from the university's main campus. Protests extended to Oxford University in the UK, requesting the removal of a Rhodes statue from Oriel College.

But the City of Cape Town kept another statue of Rhodes just down the road. At Rhodes Memorial (it is still called that) there is a sneaky little bust of Cecil that the City decided to keep next to its upmarket tearoom, aptly also known as Rhodes Memorial. The bust, however, did lose its nose during the 2015 RMF movement, presumably cut off by a protestor, but was repaired and remained otherwise intact since the incident in 2015. As international statues started to topple throughout the 2020 pandemic, so did Cape Town's beloved Rhodes, finally losing its head to an anonymous 22 cm angle grinding disc (Gamedze, 2020).

If the pandemic played a significant role in bringing systemically unjust structures to light, so may the rollout of COVID-19 vaccines over the coming months again remind us, as our fallen symbols once did, that some are considered more deserving of life than others.

'My Rhodes has no nose.' 'How does he smell?' 'Awful.'

What needs to be done

- Current and historical socio-economic imbalances must be at the forefront of mitigation of the impact of the COVID-19 pandemic.
- Lived experience of people most affected by the pandemic must be genuinely observed.
- Systemic concerns in services such a policing and health services (including mental health) should be rebuilt from the ground up to serve beneficiaries rather than stigmatise or victimise those most reliant on services.

To view films please visit: www.ehwoza.com

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4

Insider-outsider positions during co-production

Reflections from the Candomblé *terreiros* in Brazil

Clarice Mota, Leny Trad, and Lisa Dikomitis

We are three female anthropologists collaborating in global health research. Across languages, cultures, and ethnicities, we are connected through our social engagement with, and our commitment to, the Brazilian communities where we conduct research. In this chapter, we share our reflections on a 'COVID-19 Control Committee' composed of Candomblé *terreiros* in the Brazilian city of Salvador (from here onwards referred to as the Committee). A *terreiro* is a religious space that serves as a space of inclusion for marginalised community members. We conceptualise this Committee as a site of co-production between researchers, public health specialists, and Candomblé members. Through the experiences of one of us (Clarice Mota), who is both a Candomblé member and has a public health specialist role, we reflect on our social commitments and on the hierarchal relationships between researchers and community members. How can collaboration between community members and researchers work at times of a public health crisis, which is also a political and social crisis?

We describe one type of co-production in which the researcher is both an outsider and an insider. This particular experience in the COVID-19 pandemic allowed us to reflect on the place of science, of researchers, and about the challenges of *co-producing* public health guidance *with*, instead of *producing for*, community members.

COVID-19 impact on Candomblé *terreiros*

Candomblé is an African diasporic religion that originated in Bahia in the 19th century. The Candomblé *terreiros*, Afro-Brazilian temples, can be found throughout Brazil, but especially mark the religious cartography of the state of Bahia, where we work. *Terreiros* vary in size: they can be a single house or a cluster of several houses on a larger domain composing a village. Sometimes whole families live in these houses; some individuals stay for a period of time whenever necessary and many will come for festivities and religious rituals. The *orixás* (deities connected to nature) are worshipped in these religious places, which mark territories of inclusion. Candomblé has its own logic and rationality, founded in a particular cosmology and myths, in which there is no boundary between the mundane world of humans, nature, and the sacred world of *orixás*. It is also important to note that Candomblé is more than a religion; it also acts as a focus of resistance and maintenance of African traditions.

The initial intention of the Committee was to formulate a health surveillance plan for the COVID-19 pandemic. The main objective was to create a Candomblé support network offering online help, providing information about COVID-19 symptoms and treatment, and signposting to available services. Another objective was to produce information on COVID-19 public health measures to prevent infection, and to compile technical notes on the evolution of the pandemic.

When the COVID-19 pandemic hit Brazil, local governments were determined to close all places of worship, including the Candomblé *terreiros*. Gatherings, festivities, and ritual performances were prohibited. This had a great impact on the lives of many Candomblé members because the *terreiros* are commonly located in peripheral deprived neighbourhoods and are spaces for inclusion, counselling, and welcoming, especially for vulnerable groups. The *terreiro* is also a place where the hungry can eat, connect socially, and where one can receive emotional support. In the daily life of the *terreiros*, some take care of each other and everyone takes care of themselves, of the *ori* (the head), the body, their *orixá*, and the *terreiro* itself. A care network is formed that sustains Candomblé members throughout their lives.

The *orixás* are deities who act as intermediaries between humans and the supreme beings, and are central in the Candomblé religion. In the beginning of the pandemic, the *orixá* of one of Salvador's more traditional *terreiros* informed its members that, after consulting the *Ifá* (the shell oracle), the pandemic period was actually a moment of protection. A time to stay at home and to close all the *terreiros*. Religious communications from Candomblé priests (*mãe de santo* or *pai de santo*) were circulated via WhatsApp. A calm and tranquil message encouraged everyone to settle in and wait for the COVID-19 pandemic to end. In August 2020, the month of *Omolu*, an *orixá* related to the cure of diseases, instructed the Candomblé members to pray for the cure of COVID-19 through performing rituals at home every Monday evening. *Omolu* is represented as an *orixá* who moves slowly but strongly and sweeps pests and diseases from the world. However, August ended, and the pandemic was still at large in Brazil.

The COVID-19 Control Committee worked via its WhatsApp group and met monthly in an online meeting. The Committee was composed of Candomblé members who had some healthcare or health-related training: nurses, doctors, physiotherapists, nutritionists, health technicians, academics, and so forth. Although Clarice is not initiated in Candomblé, she sees herself as a Candomblé member. When she was invited to be part of the group, she asked her *pai de santo* if she could represent her *terreiro*. He confirmed that was okay. Clarice realised she was seen as an insider, as a Candomblé member.

One striking characteristic of the groups is that all messages, no matter how scientific they are, were always preceded by a religious blessing. It is a respectful, but also a sacred manner, in which to address someone. In doing so, you recognise that a person always carries an *orixá* within them. The phrase 'Can you give me your blessing (*Sua bênção*)?' would always come first, before any other issue was discussed. The response would identify the *orixá* the person carries within themselves. For instance, '*Lemanjá* (the *orixá* of the sea) blesses you'.

This mode of interaction in the Committee was a permanent reminder that, despite any scientific task or public health role to be carried out during the COVID-19 pandemic, one was never to forget the sacred and spiritual bonds.

The co-production of actions and outputs – the different steps

In July 2020, the City Hall of Salvador issued a public notice allowing religious temples to reopen but to implement public health measures. This included the mandatory use of masks, a maximum of 50 people allowed in temples at any one time, and keeping a 1.5-metre physical distance from each other. At that time, the Committee was furious, as they did not feel represented in this public notice, since it ignored the specifics of the Candomblé *terreiros*. This public document expressed total misinformation regarding Candomblé rituals, its culture, and sociability. The Committee interpreted this to be a result of historical racism and how powerful city representatives have rendered Candomblé invisible.

Since the Committee recognised Clarice as both a public health specialist and as an established researcher at the local Research Institute of Collective Health, she was asked to write the first draft of a document, a technical note that could guide Candomblé members. The Committee members worried about the rapid increase of COVID-19 infections and the mortality rate, especially in deprived neighbourhoods, such as the ones where *terreiros* are located. Another concern of the Committee was about the *terreiros'* senior members, as they were at greater risk of dying. In the Candomblé religion, the elders are considered guardians of wisdoms and sacred secrets of rituals.

The first draft of the document was based on World Health Organization (WHO) guidance and contained basic information on COVID-19 morbidity and mortality rates, and social isolation measures. It was naïve to think that such information alone could produce immediate behaviour change. This raised the issue of raising awareness of the complexity of trying to adjust universal recommendations to a very specific cultural context. For instance, although

Candomblé members can nurture their relationship with their *orixá* at home, following social isolation guidance, it is only in their *terreiro* that they can receive in their body the entity that governs their head, and to dance, sing, and worship their *orixás*. Therefore, opening a *terreiro* meant dealing with the unpredictable actions of a sacred world in which there is no pandemic and no need to take COVID-19 precautions.

When Clarice presented the first version of the document, she received several criticisms, especially for not considering the particularities of the religion. Candomblé members told her: 'This document looks like it [was written] by somebody from the WHO, it cannot be like that (*esse documento ta parecendo da organizaçao mundial de saúde não dá pra ser assim não*).' Clarice apologised and recognised its limitations. She explained that she was acting as a public health specialist trying to save lives. The document also highlighted different perspectives within the Committee. Some argued that the *terreiros* should not remain closed, mainly because they are welcoming spaces and provide social support for the population, while others pointed out that the closing of the *terreiros* was necessary to protect the lives of the older Candomblé members. In these discussions, Clarice felt like an outsider, observing the different positions and arguments.

Formulating context bespoke public health guidance

From that meeting a smaller sub-group was formed. They were tasked with rewriting the document and co-producing COVID-19 guidance. The document was divided into two parts. The first section provided general information about the pandemic and common public health measures such as hand washing, using masks, and cleaning surfaces. After many discussions, they agreed that it would be naïve to think that the *terreiros* would remain closed for a long period of time, so the objective became to reduce the infection risk. Many discussions followed. For example, how can Candomblé members engage in religious performances playing drums, dancing, and singing while wearing masks? The second part of the document included specific recommendations for daily life in the *terreiros.* Advice included keeping windows open whenever possible, removing shoes upon arrival, and taking extra care when preparing food. One complex challenge was how to eat together. The cultural habit is always to eat together as a big family. After discussion, the recommendation was to avoid gathering during meals, even though it was recognised that this would alter the sociability of members and that this advice would probably not be implemented.

It became clear that some practices within the Candomblé religion could be adjusted to enable people to live during the COVID-19 pandemic, while other rituals were much more complex and not easily adaptable. Limiting the number of people attending festivals was difficult since the ethos of a *terreiro* is to be a welcoming place to anyone who wants to visit, eat, and watch. Some other situations were even more complex to adjust to COVID-19 recommendations. During religious performances, how can the person incorporating the *orixá* keep their mask on? Besides that, in a non-pandemic world, the presence of *orixá* is always celebrated with hugs and other expressions of honour and affection. The *equedes*, people responsible for taking care of the *orixá,* use a handkerchief to wipe the face of the one who dances in a trance. How can you fit such a ritual into a set of public health recommendations? Would the handkerchief be exchanged for a disposable paper? Would the *orixás* accept that?

In the group discussions, some cultural habits prior to the pandemic were valued, as these were already part of the routine of these spaces. For example, when one enters a *terreiro*, which is considered a sacred space, before engaging in any ritual, one takes a special bath, including using certain leaves, in order to purify the body from the outside world. After this bath, one puts on clean clothes, usually ritual clothes. This habit, which has always been part of Candomblé, was now identified as something very positive and hygienic and valued as a preventive measure. In a similar vein, certain common health practices were maintained. For instance, the traditional use of plants and herbs for healing purposes was valued. In the final version of the Committee's document, some of these plants and herbs were listed, including their prescription and ways of being used, and this became part of the materials produced by the Committee.

Conclusion

The experience of working as an 'insider-outsider' researcher in religious communities and collaborating during a public health crisis was a great opportunity to reflect on the challenges of co-production. Co-production required, from the part of the researcher-cum-public health specialist, an openness to listen, to observe, and to learn. This demanded a certain attitude of trust in order to develop a relationship of partnership and co-production. The experience made abundantly clear that so called 'universal public health guidance', like the WHO COVID-19 recommendations, do not encompass an understanding of daily life, cultural habits, and ritual practices in many communities throughout the world. The challenge was to co-produce context bespoke and culturally acceptable public health measures and to reach beyond such universal public health strategies during this pandemic.

What needs to be done

- Understand the cultural and social context of the community before suggesting action/producing interventions.
- Acknowledge that public health recommendations of local governments can exclude certain communities and render religious practices invisible.
- Co-produce guidance *with* community members, rather than present standard public health guidance.
- Ensure a horizontal dialogue and trustful relationship, in order to co-produce *with* the community instead of *for* the community.
- Embed an evaluation of the action/interventions with the community and make adjustments before implementing the action/interventions.

5

Ambitious about co-production

Adapting a participation programme during the pandemic to meet the needs of autistic young people

Emily Niner and Kerrie Portman

Before the pandemic, as a community, four out of five autistic young people had a mental health condition (Crane, 2017), and as many as 79% of autistic people and 70% of their families felt socially isolated (National Autistic Society, 2016). 82% of young autistic people believed they spent less time socialising than their non-autistic peers (Crane, 2017) and formal exclusions of autistic pupils have risen by 60% in the last five years (Ambitious about Autism, 2018).

These statistics were already unacceptable. However, the pandemic has exacerbated these inequalities, and autistic young people are suffering. Routines and coping strategies have had to be abandoned, appointments rescheduled, or indefinitely postponed, and the unknown reigns supreme.

Based on the survey we, Ambitious about Autism (https://www.ambitiousaboutautism.org.uk/about-us), conducted during the pandemic, nearly two thirds (63%) of autistic children and young people report that their mental health is worse than before the outbreak of COVID-19. Three quarters of respondents (75%) said they felt more anxious since the pandemic began and over half described feeling stressed (56%) and overwhelmed (54%).

At a time when there are already long waiting lists for support services, three quarters of respondents think that they will need ongoing support for anxiety or mental health issues following the pandemic. Unfortunately, we also know that 76% of autistic people feel their doctor does not make changes to meet their needs (Westminster Commission on Autism, 2016) and one of the leading causes of death in the autistic community is suicide.

Therefore, action must be taken. The participation team at Ambitious about Autism have been working for many years with autistic young people across England to amplify their voices and support them to influence change on topics that matter to them. This youth-led approach has resulted in multiple campaigns such as: Include Autism (https://www.ambitiousaboutautism.org.uk/what-we-do/youth-participation/youth-led-toolkits/include-autism) – improving the inclusivity of extra-curricular opportunities; Know Your Normal (https://www.ambitiousaboutautism.org.uk/what-we-do/youth-participation/youth-led-toolkits/know-your-normal) – understanding autistic young people's experience of mental health; and We Need an Education (https://www.ambitiousaboutautism.org.uk/what-we-do/policy-and-campaigns/campaigns/we-need-an-education) – challenging the rising exclusions of autistic young people in education. The programme also provides opportunities for young autistic people to co-produce research, training webinars, and, since moving online, peer support sessions.

This chapter covers how we adapted the participation programme during the pandemic with and for the autistic young people who are part of the Ambitious Youth Network, and the key principles we believe must be followed in co-produced work.

Responding to young people's diverse needs

At the start of the pandemic, the young people across the Ambitious Youth Network asked for more support from the participation team. They were feeling isolated, anxious, and upset that our ordinary face-to-face panels and projects were indefinitely postponed. Together, we decided on online peer support sessions run on Zoom. The sessions were for any young autistic person who would benefit, and the topics and activities were to be decided by the group. The participation team were there to facilitate the sessions and ensure it was a safe space for all. Rules of engagement were co-produced, and making the sessions accessible for people with differing communication needs and preferences was prioritised.

Bella, a young person involved in the sessions, describes how they have supported her:

> With everything that's going on my coping mechanisms have just been taken away. I've just kind of been left not knowing how to manage or cope in all this chaos. I rely so much on structure and routine and I've lost all of that. I can't describe how awful that feels when it's the centre of your life. I just didn't know how I would get through life without it. After finding out about the online chats and being able to speak to other young autistic people that know how I'm feeling, I don't feel alone in all this anymore. Seeing their familiar faces and hearing their voices is more powerful than you would ever know right now. It's little things like knowing that they care about me, and hearing them say that they are struggling too but also what they are doing to cope. We can share our feelings and advice in a safe space full of honesty, kindness and support. Thanks to the participation team I'm making it through this when I didn't think I could.

Controlling the narrative and educating others

Creating peer support sessions was just one part of the work that the Ambitious Youth Network led during the pandemic. Thanks to additional funding, we were able to facilitate planning meetings about how we could develop our former campaign about young autistic people's experience of mental health.

A group of 30 young autistic people participated in the interactive online planning sessions, giving their thoughts on how we could develop a webinar to educate professionals about autism and mental health. They knew that people were working from home and this could be the perfect opportunity to improve the understanding and knowledge that professionals had around autism, especially when so many young people had struggled with services that did not understand their needs. By co-delivering the sessions, the young people were controlling the narrative about autism and educating others with their lived experience and expertise. We ensured they were paid for their time and expertise.

The ‘Understanding autism and mental health’ webinars became our biggest co-production project to date. Being online meant we could include a much wider range of young people and were not limited by geography or budgets. Where young people were not comfortable being online, we sent out worksheets to gather their feedback and had calls with those who wanted to feed in. As a member of the Ambitious Youth Network references below, we had run-throughs with each young person before their webinar, deciding what slides they wanted to deliver and how they wanted to communicate during the session.

> As it was my first time, I was very nervous, but I also knew that I was extremely well supported because we had had preparation meetings and a chance for me to prepare my answers. During the webinar I knew that if I was struggling I could stop at any time but once I was in the moment, I loved every second as I got to share my story and advocate for autism.

These webinars had a significant impact on the almost 1,000 professionals who attended; afterwards 90% felt more confident and knowledgeable in working with autistic young people. One attendee wrote in their evaluation:

> A wonderful introduction to autism and mental health that centres the voice of autistic young people … with many ideas around reasonable adjustments that could really make a positive difference to patients and squash some inequalities in their care and treatment.

For the Ambitious Youth Network, the impact of being listened to and empowered is powerfully articulated by one of the members, Saffron:

> Being part of the Know Your Normal project has truly been an amazing experience for me. Actually feeling part of something tangible that could make a real change in the world was so incredibly empowering; getting to share my story, and, even better, receiving actual feedback from people and knowing that what I was saying had impact, had worth … it has made me so determined to fight for more change and improve things for autistic people struggling with their mental health. I want to use my negative experiences and this project showed me I can be heard, which is something I haven't understood before.

Nothing about us, without us: centring lived experience in research

Another area of work that had to be adapted to online engagement was our Young Researchers participatory research project. The 'Finished at School' project investigated the impact of the Children and Families Act of 2014 on educational entitlements and was a collaborative project with the Centre for Research in Autism Education.

According to Autistica, the autism research charity, nine in ten autistic people want to take part in research. Yet very few autistic people ever get the chance. Here Kerrie, one of the Young Researchers, shares her thoughts about why autistic people should have an equal role in research and how the pandemic has highlighted this further.

People who don't have autism can't fully know what it's like, so research always benefits from 'own voices' input. As someone with autism, I think it feels really different reading research when autistic people are involved and when they're not. I think the standard is improving recently, but a few years ago right after I was diagnosed, the research I found was by professionals and I didn't relate to any of it. It's a really powerful thing in so many areas for children with autism or those who are newly diagnosed to see people with autism doing things and having a voice because there's so much stigma implying we can't achieve anything. That's not true but it's often spread as truth and sometimes can be a self-fulfilling prophecy; if you tell someone they're never going to achieve, they won't have the confidence to do so. I think it helps give autistic people control and empowerment over the research about our diagnosis, especially as that often informs treatment. While there are people with autism who want to participate in research, there's no reason not to use that resource.

The main thing for successful co-production is communication; ask the person what they need, listen to what they're saying, and take it into account. Since I was 16, my biggest message to everybody I've worked with is to communicate and treat people like people. And every successful professional relationship did that and the ones that didn't were deeply scarring. Don't assume you know the answer, genuinely listen and compromise with everyone involved.

Also, think about how you're trying to find autistic people to get involved in your research. If it is only shared by a university and uses academic language, which would most likely attract autistic people who do well academically, but not those who are more vocational or younger. If research projects were open to making adaptations, I can't see that there are any major challenges that would stop autistic people being involved.

During testing and trying times, it is important to remember the most vulnerable and to be kind. I think the pandemic has highlighted the disparities in society and an often-overlooked aspect of accessibility to online learning, engagement, support services, or co-production opportunities, is the privilege of those who have family support networks to help them.

What needs to be done

- Co-produce rules of engagement with your group and refer to these at the start of each session or meeting. This creates a group understanding and supports strong peer relationships.
- Develop strong safeguarding protocols. Have risk assessments for sessions and know how and when to

escalate disclosures. We have made use of breakout rooms online for 1:1 conversations with young people when they need support.

- Make sure your team can provide differentiated and individualised support. This means knowing everyone's support needs and being able to respond accordingly. We always have a ratio of three staff to ten young people to facilitate this.
- Prioritise breaks. Online sessions can be incredibly draining so have breaks where everyone turns off their video and audio. These can be scheduled in advance or upon consensus in the group.
- Do not insist on people sharing their videos. This can be very uncomfortable for some people who find the sensory input too much. In our sessions, you can communicate in whichever way works for you – speaking, typing, or simply listening.
- Utilise accessible features and provide information in advance. Create agendas and worksheets that support the session and invest in a live transcription service so people can read along as well as listen.
- Make sessions as interactive as possible using polls, Q&As, and other online services such as Mentimeter or Google Jamboards. These allow young people to take part without talking or identifying themselves and their views.
- Understand that even being as inclusive and accessible as possible, online sessions may not work for some young people. Be adaptable – send agendas and worksheets via email and seek their input that way. Or communicate via text or phone call. All methods are equal if it means a young person is having their voice heard.
- Constantly evaluate the support or services you offer and listen to the needs of your group. Things that worked at the beginning might not always work; this does not mean you have failed. Be humble, learn from what people are telling you and adjust as you go.

Notes

Ambitious about Autism ran an online survey between August and September 2020. 383 autistic young people completed it themselves and 1,782 people filled in the survey about an autistic child or young person. Results available here (https://www.ambitiousaboutautism.org.uk/sites/default/files/reports/files/Coronavirus-and-lockdown-report-2021.pdf).

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6

A co-produced response to COVID-19

Impact on women and girls with disabilities in low- and middle-income countries

Peter O. Ekiikina

Background

Co-production is an approach in which researchers, practitioners, and public or community put a concerted effort to work together as a team to achieve a sustainable desired goal centred on power sharing and responsibility. I would like to assert that co-production seems to be like rights-based approaches to development, implying that it involves the community or public 'voice' to participate in matters that affect them. This promotes the spirit of ownership, which is at the core of public involvement and community engagement. This approach is important for local transformation of public and communities, not only in low- and middle-income countries but also world over because the public is at the centre of inclusive working.

Co-production can be more efficient, effective, and responsive to public or community needs because it is holistic in nature and it positions the community(ies)/public to be active agents in grassroots decision-making.

Impact of COVID-19 on women and girls with disabilities

A growing body of reporting and analysis confirms that COVID-19 disproportionately impacts on women and girls in Africa, living with disabilities.

Approximately one billion persons of the world's most significant and most frequently overlooked minority groups are estimated to be living with disabilities, out of which 80% are in low- and middle-income countries. Women and girls with disabilities are said to be even more overlooked, face increased discrimination, and are likely to be more vulnerable (UN Department of Economic and Social Affairs, 2020). They are increasingly vulnerable because they have limited or no access to sexual and reproductive health and rights education, community support services, communication and information, health care, opportunities for education and employment, and accessing justice in view of their status. Violence against women and girls with disability during COVID-19 has increased globally perhaps because social distancing, economic hardships, and stress make it more difficult for them to access treatment, health services, and other social amenities (UN Women, 2020).

In our (https://foundationforopendevelopment.org/about-5/) experience, women and girls with disabilities experience violence in different forms, including during COVID-19, and many suffer in silence. They experience domestic violence where women and girls with disabilities have to stay at home, without the right to go out. There is sexual abuse of disabled women and girls by family members or by people within their communities. There are also cases of exploitation of disabled women and girls by their families and examples where these women, who may experience economic hardship, are forced to cohabit with men. These women and girls increasingly face stigma and discrimination in communities and yet most of these cases remain undisclosed. For instance, when disabled young girls who stay with their relatives are raped and they become pregnant, the perpetrators deny it with greatest terms possible.

In Uganda, "Women and girls suffer the most in crises and are very vulnerable to gender-based violence. The socio-cultural realities and the resulting power dynamics place women and girls in a position of subservience" (Gabazira interviewed by Habib, 2020). Some harmful myths, cultural, and religious beliefs make women and girls with disabilities easy targets of violence. We have heard that some communities in Uganda believe they will become wealthy or rich by having sex with a virgin girl, and they often perceive those with disabilities as virgins. Therefore, the pandemic has increased the vulnerability of women and girls with disabilities not only to sexual violence but also to intimate partner violence perpetuated by harmful traditional practices.

Inclusion of young people with disabilities to positively impact their communities during COVID-19: snapshot of what has been done

Testimony of Patricia

I am Patricia, and I am 17 years old. I have a physical disability and come from Awaya village. I led and conducted peer-led sessions with other young people with disabilities under a coach called Awori Grace.

One aspect of this work is to learn about the importance of savings and put aside regular (financial) savings by being part of a savings group. This has empowered me economically, as a disabled young woman, and I encourage other girls like me to join saving groups to develop a saving culture. When we meet at savings group meetings, we also discuss other related concerns of young people. Additionally, working with the Foundation for Open Development has enabled me to gain productive knowledge about sexual and reproductive health and rights and gender-based violence prevention, and I can advise other fearful girls to access and utilise safe spaces and existing services that I know about. This work has helped me improve my communication skills, and I can confidently stand firmly and assertively among girls and engage the boys on important topics such as sexual and reproductive health and rights, and gender-based violence prevention. As a young advocate, I thank Foundation for Open Development (FOD) and Plan International Uganda for the platform it has given me as young person with a disability, and I look forward to bigger platforms so I can inspire other young people with disabilities within my region and beyond.

During the COVID-19 lockdown, these sessions changed in how they were carried out. We worked with smaller, manageable groups of ten to 15 people to highlight, teach, and discuss gender-based violence prevention during COVID-19, and to discuss sexual and reproductive health and rights. These smaller group sessions were challenging as some attendees of sessions conducted before COVID-19 felt excluded. They did not understand the different ways of working during the pandemic and expected large numbers of attendees, and so thought they had been left behind since the new normal.

Faith's story of life

Faith was born in October 2004 and is 16 years old. When she was four years old, she fell very sick for two and a half years, which resulted in her becoming physically disabled. Her body cracked in every part and her legs became stuck on her neck for several months, but with prayers and medication she became better. During Faith's illness, her parents divorced and her father became her carer. Faith's father tries as much as he can to ensure Faith leads a full and active life.

Faith later fell from a tree and broke her hands so her father rushed her to the hospital for an X-ray. It was found that she had a kidney problem. All of this had financial implications for a family who were already financially struggling. Faith also needed a wheelchair and other things to help her. Faith became shy, fearful, hopeless, lonely, traumatised, and lost her self-confidence.

Faith was asked to attend the Champions of Change programme by its facilitators Sylvia Adikini and Rosemary Aketch. These were small group sessions comprising health workers and women and girls with disabilities, facilitated by community volunteers. These volunteer facilitators are trained to build a youth-led vibrant society among their peers especially with focus on girls with disabilities.

During the COVID-19 lockdown, the Champions of Change facilitators carried out sessions while observing requirements for working with people and communities that were created by the pandemic. For example, under normal circumstances, there used to be a minimum of 60 participants per session but under the COVID-19 era, this had to change, reducing the number to 20 participants per session. The participants are known as ‘Champions of Change’ and are between 10 and 24 years old. This youth-led movement aimed to create vibrant inclusive spaces for young people, especially girls, to empower them to become proactive citizens who know their rights. The young people with disabilities are empowered with skills and knowledge on sexual and reproductive health rights and practical skills such as making reusable sanitary towels for girls in communities and schools. The participants learn about the existing referral pathways to prevent gender-based violence. During the pandemic, there was also focus on raising awareness of COVID-19 among young people with disabilities.

These specifically designed sessions with the peer-led youth facilitators helped Faith become more assertive. The facilitators conducted specific activities that enabled Faith to identify and explore different types of behaviour. As Faith’s engagement with the sessions continued, her assertiveness grew, and she built positive self-esteem and confidence in herself. Faith continues to socialise with other peers and speaks her mind. Faith now wishes to go back to school after recovering from the illness and wishes to be a teacher. She hopes that one day the FOD will support her to go back to school and get better health services.

What needs to be done

- Governments, development partners, and communities should ensure that access to treatment and lifesaving services for women and girls with disabilities is given priority, focusing on provision of health and psychosocial support services. This is because access to health and psychosocial support services for women and girls with disabilities is important for saving lives.
- We should all use our powers to dispense equitable services to all humankind without discrimination, and special attention should be given to women and girls

living with disabilities in our localities, deploying co-production approaches to problem solving.
- There is need for civil society organisations globally to come up with strategies on how to enable girls and women with disabilities access and share skills and knowledge on sexual reproductive health and rights and prevention of gender-based violence in the communities they live in. This can be attained by encouraging partnerships and committing funds for the cause.
- There is need to establish localised, grassroots processes to handle the gender-specific needs of women and girls with disabilities. Such processes should amplify the voices of women and girls with disabilities, assist them to seek immediate support, and assess their needs. These processes should combine referral, assessment, and provision of information functions.
- Governments should enable girls and women with disabilities to socially and economically support themselves in and beyond crises such as COVID-19. This can be done by bringing together all stakeholders, especially cultural and religious leaders, with the girls and women with disabilities to challenge and eliminate harmful practices that perpetuate the discrimination they face.

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7

#WirVsVirus

Communities co-producing new solutions to meet COVID-19 challenges through a hackathon in Germany

Elke Loeffler and Claudia Masiga

Introduction

This chapter provides a conceptual framework for digital co-production, including co-commissioning, co-design, co-delivery, and co-assessment of public services and outcomes. It illustrates this conceptual framework through a German case study involving citizens participating in a large-scale hackathon to meet COVID-19 challenges. In particular, we will analyse how the #WirVsVirus hackathon (https://wirvsvirus.org/hackaton/) put co-production into practice from the perspective of a hackathon participant (Claudia Masiga), who has been working on the OpenFoodBank initiative.

A conceptual framework for digital co-production

Digital co-production is not new. Indeed, early applications of e-government in the late 1990s can be considered as a form of co-delivery, through which e-government solutions enabled governments to increase the contributions of service users (Loeffler, 2021:135). However, as recent surveys of municipalities and businesses in Germany show (Bertschek and Erdsiek, 2020; KfW, 2020), there is a widely held view that the COVID-19 crisis has brought about a push towards digitalisation in both the public and private sectors. It has also reinforced the use of existing forms of digital co-production, such as hackathons. Hackathons involve a competition between innovative ideas. They typically start with an open call by a government for solutions to a particular problem, followed by citizens working in teams through a government-platform to identify innovative solutions under time pressure (Gegenhuber et al, 2020). The #WirVsVirus hackathon, which took place in Germany between 20 and 22 March 2020, is considered to be 'the biggest hackathon globally' to date (Berg et al, 2020).

In order to assess the impact of digital technologies on co-production, it is useful to distinguish between different types of co-production – in particular, we distinguish citizen voice from citizen action. For example, the #WirVsVirus hackathon encouraged people in Germany to voice their ideas on how to tackle the COVID-19 crisis through new solutions. A participant commented on how citizen voice now had a greater perceived impact, welcoming the opportunity 'to be taken seriously as a small hacker by a big government' (https://wirvsvirus.org/hackaton/). At the same time, digital co-production may also involve citizen action, recruiting volunteers for new co-production initiatives such as the OpenFoodBank, which was selected by the German Federal Chancellery as one of the ten projects emerging from the hackathon that most urgently deserved implementation.

It is important to be clear what we mean by co-production. This chapter uses the definition from the recent Palgrave Macmillan monograph *Co-Production of Public Services and Outcomes*, which states: 'User and community co-production of public services and outcomes means public service organisations and citizens making better use of each other's assets, resources and contributions to achieve better outcomes or improved efficiency' (Loeffler, 2021:27). Clearly, 'public service organisations' in this definition include not only public sector organisations but also other service providers, whether from the public, private, or non-profit sectors, which make a significant contribution to public services.

More specifically, as outlined in Loeffler (2021: chapter 3), we propose to distinguish four ways of co-producing, including:

- *co-commissioning* of priority outcomes;
- *co-design* of improved pathways to outcomes;
- *co-delivery* of pathways to outcomes;
- *co-assessment* of public services, public governance, and quality of life outcomes.

In the following sections, we analyse to what extent the Four Co's were evident in the German hackathon #WirVsVirus. Our analysis focuses on the experience of one project that emerged from the hackathon, OpenFoodBank (https://openfoodbank.net/regions/). This project developed an online platform for the collection and distribution of corporate food donations at regional and international levels. Its main goal is to make large-scale donations available especially to smaller non-governmental organisations (NGOs), according to their specific needs. Currently, the project team includes six citizens who act as volunteers.

The German hackathon #WirVsVirus as a case study of digital co-production from the perspective of the OpenFoodBank project

The Federal Chancellery in Germany joined up with seven third sector organisations specialising in digital services to organise a national hackathon in response to the COVID-19 pandemic – the result was #WirVsVirus. As this initiative came from the 'civictech community' – partly as a response to similar hackathons taking place in Estonia and other countries – this is a (rare) example of co-production, which followed the 'outside-in' pathway to co-production, through which the public sector adds value to initiatives started in civil society, rather than the more traditional 'inside-out' pathway to co-production, where public sector organisations invite citizens to co-produce better public services and outcomes (Loeffler, 2021:53).

What made this hackathon special was its size, scale, and speed: more than 28,000 people participated as unpaid volunteers and generated about 1,500 project ideas within 48 hours. From the very start, there was a strong focus on supporting the implementation of social innovation, whereas conventional hackathons are often limited to the rapid generation of ideas, rather than seeing them through to implementation. Here, using the Four Co's framework, we analyse the co-production process facilitated by the #WirVsVirus hackathon from the perspective of the project team involved in the OpenFoodBank initiative.

Co-commissioning

The hackathon was open, in the sense that the organising team invited everybody 'who has time, interest and internet access' (https://wirvsvirus.org/hackaton/) to identify COVID-19 related challenges. Within a week, about 1,900 proposed challenges were submitted by citizens, which the organisers aggregated into 48 challenges (Berg et al, 2020:30). This meant that 80 million residents in Germany were given the opportunity to voice what mattered to them in the context of COVID-19 and therefore to participate in the commissioning process. All citizens who participated were able to choose which of the 48 themes they were most interested in and which they were most likely to be able to contribute constructively.

However, not all citizens were successful in having their voice heard about which challenges mattered most to them. In fact, the current OpenFoodBank team tried to submit their project idea during the hackathon application process, but the system suffered overload due to the large number of participants and simultaneous submissions, so they were unsuccessful. Despite this, another suggestion was approved that turned out to be very similar to the original OpenFoodBank idea and consequently the OpenFoodBank team helped to develop this approach instead.

Co-design

The next challenge was to develop team building so that participants could work together in small teams of about

10–15 to co-design new solutions. This process was facilitated by about 3,000 volunteers who helped to form 'micro-communities' based on their competences and their interest in a specific topic.

In the case of the OpenFoodBank, during the hackathon, a group of 10 to 12 participants, including members of the NGO fairdirect.org, developed a concept for an online marketplace that provides an infrastructure for a digital and contactless facilitation of food donations. During this co-design process fairdirect.org decided to turn their existing online marketplace software into an open-source platform, so it could be adapted to the needs of a donation-based network.

Co-delivery

The 1,500 'solutions' resulting from the hackathon included ideas to improve health system challenges, such as the management of hospital resources and the digital assessment of new infections. Moreover, it also included wider community challenges such as food distribution. However, as outlined above, this was not the end of the hackathon. The weekend devoted to ideas generation was followed by a call for participation in the implementation phase, which was also open to new external project proposals. About 400 proposals for initiatives were received. A jury of 26 representatives from civil society, tech companies, and the federal government, selected 130 initiatives for the implementation phase based on the potential of the solution, its feasibility as a project, and the willingness of the team to collaborate. The OpenFoodBank initiative applied and got the go-ahead a few days later.

The selected project teams were provided with three support programmes (Gegenhuber et al, 2020), which involved further competitive selection processes:

- **The Solution Enabler Programme provided the project teams with new skills such as project management and marketing, networking opportunities, and specific advice.**

In the case of OpenFoodBank, the contact with and input from other initiatives, citizens, and involved experts proved to be of some use in gaining new insights and perspectives. Many presentations and workshops concerning issues like marketing strategies and gender equality were interesting for the team members. However, given the tight time frame and the complex set-up phase of the project, the OpenFoodBank initiative judged that the support it received was not really effective enough.

- **The Solution Builder Programme was based on a business accelerator model, which is usually aimed at start-ups, providing access to investors and other support to help them to grow. In the #WirVsVirus hackathon, a small cohort of ten teams, selected out of the Solution Enabler programme, was provided with venture partners.**

  The OpenFoodBank initiative was paired with Ragnarson, a Polish software developer. This organisation supported the OpenFoodBank project by programming an add-on to the platform for donating logistic services, such as empty cargo space and transporting goods. In this case, the extremely short time frame of eight weeks in the Solution Enabler programme proved to be an obstacle, since the work on this add-on was still in progress several months after the programme was finished.
- **Crowdfunding matching funds had the objective of providing additional financial resources to projects and giving them wider visibility.**

  Due to the tight schedule for the Solution Builder Programme and the extra workload involved, the OpenFoodBank team decided not to participate in this option at that point of time.

The implementation phase involved peer support between the participating citizens and support of the citizens involved by mentors from the federal government and large corporations. For example, the OpenFoodBank project team members were put in touch with the German Foodbank Network, as well as with Ragnarson. The implementation phase ended on 1 October 2020 with a public online event at which a range of projects were presented.

Co-assessment

The hackathon was characterised by a regular (in most cases weekly) co-assessment during the implementation phase of the progress made by the project team and mentors.

For the OpenFoodBank team these weekly meetings consisted mainly of status updates concerning the progress of software development and following up on leads concerning possible cooperation partners. A more detailed and deeper progress assessment was often not possible due to a lack of time, since all participants were doing this work during their free time.

The combination of a very ambitious time frame of eight weeks with the rather rigid and very bureaucratic German government system proved to be a difficult set-up for promoting fast moving and flexible start-up ideas. Also, at times, the focus seemed to be placed more on the public presentation of the projects rather than on progressing them effectively. Nevertheless, the OpenFoodBank team consider the contacts and marketing material resulting from participation in the hackathon useful in identifying and accessing seed funding in order to roll out this innovative project in Germany and internationally.

Outlook

The #WirVsVirus hackathon has shown the potential but also the limitations of digital co-production. In particular, the fact that this hackathon was initiated from the civictech community rather than the government was innovative. It should be noted that the citizens involved tended to have quite advanced technical capabilities (although those who did not were able to receive support). It has enabled the large-scale generation by citizens of innovative ways for addressing pressing societal issues at speed and at low cost to the taxpayer. The question is to what extent the government, participating business organisations, and citizens acting as volunteers considered it a worthwhile investment of time and resources? As the experience of the OpenFoodBank team shows, this first large-scale co-production initiative at federal level has also revealed some key obstacles to co-production, such as the inflexibility of the federal government and its commissioning processes. Consequently, it is hoped that this hackathon will be followed up by further academic research to throw light on how the weaknesses of this approach might be rectified.

What needs to be done

- Increase support and lengthen time frames. While the #WirVsVirus hackathon differed from conventional hackathons by including an implementation phase, giving considerable support for the project teams with the most promising and urgently needed solutions, the support provided was insufficient and the time frame was too short for scaling the innovations.
- Volunteers involved in the project teams require some funding during their participation in the hackathon. Furthermore, the finalists who make it to the last implementation phase require easier access to seed funding with less work involved than the crowdfunding scheme set up by the hackathon organisers.
- The implementation phase requires more time for experimentation and taking stock than was the case in the #WirVsVirus hackathon.
- Further research is needed on the extent to which the ‘outside-in’ pathway to co-production is more effective for initiating and scaling social innovation.

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8

Locked in or locked out

Redistributing power to d/Deaf and Disabled people when using remote technologies

Adam Goodall and Becki Meakin

Introduction

The early months of the COVID-19 pandemic saw the world locked down. Unable to leave their homes for work, school, or doctor's appointments, people flocked to remote technologies to keep in touch and keep on top of the meetings they were meant to have in person.

Zoom had 200 million daily users worldwide in March 2020, up from 10 million in December 2019 (Evans, 2020), including more than 100,000 schools across the globe (*The Guardian*, 2020). Google Meet's user base grew by more than 30 times in the same period (Barrett, 2020). Primary care services in the UK, which prior to the pandemic fielded 1.2 million face-to-face consultations a day, swiftly moved to online and telephone appointments: by April 12, NHS GPs were seeing only seven in every 100 patients face-to-face (Lynch and Wainwright, 2020).

During this time, members of Shaping Our Lives (https://www.shapingourlives.org.uk/), our national organisation and network of user-led groups, service users, and Disabled people, began telling us that they were concerned about the sudden adoption of these remote technologies for a wide range of activities. These included social and leisure activities, peer groups, and support activities, community services, education, work activities, and, of particular relevance to this publication, the provision of health and social care services. Our members were particularly concerned about people they worked with who could not use these technologies, or did not know how to do so.

In June, Shaping Our Lives was awarded a grant by the National Lottery Community Fund to carry out research into the impacts of COVID-19 on d/Deaf and Disabled people. With this support, we put together a survey investigating how d/Deaf and Disabled people in the United Kingdom were adjusting to the new ubiquity of these remote technologies, and what could be done to ensure they were supported and involved in decision-making when it came to this new way of working.

We surveyed people about three different types of remote technology: telephone calls, video calls, and video meeting solutions such as Zoom and Microsoft Teams. We received 90 responses. Those responses formed the backbone of our resulting report, *Locked In or Locked Out: d/Deaf and Disabled people's experiences of using remote technologies during COVID-19.*

We found a lot of variety in the experiences with remote technologies that d/Deaf and Disabled people were reporting, for a variety of reasons. These reasons included the nature of each person's impairments and long-term health conditions; their geographic location, and how that impacted the quality of their internet and telephone reception; their employment status, and their social and economic status; and the opportunities available to them to practise and receive training in these technologies.

Around one in ten survey participants (approximately 12 people in total) were more than comfortable with all three types of remote technology. A further one in ten participants felt that all three types were completely inaccessible to them. The remaining participants, around four fifths of those who responded, reported that they found some positives and some challenges in this new way of communicating and accessing services.

Using the telephone

Of the survey participants who had used telephone calls for social activities, meetings, or appointments, two fifths (36 people) were doing so for the first time during the first lockdown. Just under two thirds of participants (57 people) used the telephone to talk with a health or social care professional.

Participants indicated that there were a number of benefits to using the telephone for meetings and appointments, especially appointments with health or social care professionals:

> It saves me the effort of having to travel to meetings, etc. As a wheelchair user, getting in and out of my car and dealing with access issues is time-consuming and physically tiring.
>
> As an autistic person, not having the pressure of face-to-face meetings (including the issues of travel to get there, etc.) was a benefit in general.
>
> [It] reduced the need to travel for routine 'check in' appointments.

However, one in ten participants (11 people) told us that telephones were not accessible for them and that they needed assistance when using them:

> I like to keep in touch with people but need an assistant to help make the call.
>
> Not able to understand fully the conversation. Had to end a call and requested a call back at another time when help is in the house.

Others felt the telephone was inappropriate for meetings with health and social care professionals for other reasons, such as the lack of a visual connection or the risk of a poor connection:

> It was better than having no contact with my mental health team but it was impossible to go into in-depth issues the way we might face-to-face.
>
> It felt rushed, so I didn't open up and tell the professional everything that I usually would have. I felt less connected to them, like the trust wasn't there.

Using video call technology

Of the participants who used video call applications like WhatsApp and FaceTime, one third (28 people) used them for the first time during lockdown. A large number of those participants said they had positive experiences using them for their appointments and meetings. Several participants commented on the access benefits:

> For friends and family video call is better than the phone as I can use lip reading to help … For work-related meetings the same applies re lip reading and it's easier to see who is talking than on a group conference telephone call.
>
> Professionally, it's been a good experience and allowed me to stay home and reduce anxiety of infection. It's also given more structure to meetings (enforced turn-taking, raising hands to speak, etc.), which is an autism-friendly way of conducting a meeting.

Fewer people used video calls for appointments with health and social care professionals than used the telephone. Those who did were, on balance, more likely to have a bad experience than those who used video calls to talk with other groups, such as community volunteers, or employers. That said, only a small number who used a video call to talk with a health or social care professional had a bad experience – four out of 21 people total.

Those people who had negative experiences often commented on the physical and technological barriers to access:

> I find FaceTime and WhatsApp calls exhausting and anxiety-inducing and would always prefer just to talk on the phone.
>
> It was really bad. I was sent the link ten minutes before meeting started. Then call started, picture froze, the internet dropped, it took 30 minutes the appointment was only due to last 60 minutes. By the time all the technical issues was sorted out. I was so upset as during my appointment different people were on my video call talking to the doctor.
>
> For meetings with NHS workers I would much prefer video to phone but the technology never worked at their end.

Using video meeting technology

Of the participants who used video meeting solutions such as Zoom, Google Meet, and Microsoft Teams, just over half (42 people) told us that they used those solutions for the first time during the first lockdown. Many found this technology to be a great way to communicate remotely:

> Ability to see faces, interact on a more personal level, and include more than one other person. If an in-person appointment is not feasible, I find this the next best option for meetings and consultations.
>
> With a speech impairment it is much easier than phone calls.

Using video meeting technology to talk with health and social care professionals, participants reported more positive experiences than negative. However, more participants still used the telephone for those appointments.

A small number of participants (12 people) said that video meetings were not accessible for them. The physical and technological barriers they experienced were quite similar to the barriers that participants reported with video calls:

> Subtitles slow and often incorrect.
>
> I find video calls extremely difficult – exhausting, anxiety-inducing, confusing, and not very useful as I am rarely able to say what I need to say and I rarely fully grasp what is going on during the meeting or remember afterwards what has been said.
>
> It was great providing the connection was stable – I pay extra for fibre optic – but even then there were issues with the screen freezing or the connection dropping – it meant that conversations had to be repeated and that was tiring.

We asked participants about the additional functions available in video meeting solutions, including text chat, breakout rooms, and on-screen document sharing. Of those who answered, one in three (17 people) said they had experienced difficulties or had only found these functions accessible once they had learned how to use them:

> It was difficult to read shared presentations at a focus group I attended on Zoom. They were small and apparently screen readers don't read them either as they see them as images.
>
> I found these facilities accessible but I was aware that they were not accessible to everyone participating in the online workshop I facilitated and I know that other people I have worked alongside regularly have been unable to participate in meetings because support around accessibility has not been available to them.

Redistributing power

Our research found that for d/Deaf and Disabled people there were a number of positives in the sudden popularity of remote technologies. They saved time and energy, helped people avoid the stress of travel, and enabled them to meet others and safely attend appointments. For many, these technologies provided greater access to activities and opportunities and helped them keep in touch with friends and family during a difficult period of social isolation.

However, these technologies do not provide a like-for-like replacement for face-to-face contact, and more needs to be done to reduce the barriers to access. There are a number of steps that health and social care professionals in particular can take to redistribute power to d/Deaf and Disabled people when using these remote technologies.

Health and social care professionals should establish the preferred method of communication in advance, and be prepared to offer service users a choice of different communication options. Some Disabled people may have equipment for a video meeting but not for a phone call; others may not have access to a reliable internet connection, making video calls or meetings inappropriate.

Health and social care professionals should check with the service user about their access requirements well in advance of their appointment. Once those requirements have been ascertained, make the adjustments required to meet them. For example, provide subtitles for video meetings, include a free or standard-cost dial-in number if the service user doesn't have a reliable internet connection, and allow for breaks if a meeting is going to run long.

If contact can only be made through a specific technology, health and social care professionals should make sure the service user has the equipment they need for access: up-to-date headsets, iPad stands, reliable internet connections, and so forth. If they don't, the professional should research what support is available to the service user through community and voluntary sector services.

If the service user needs training to use the technology, they should be provided with accessible information and offered separate practice sessions. If the service user needs a support worker to help them, the appointment should be scheduled for when the support worker is available.

Health and social care professionals should maintain guidelines on accessible use and inclusive practice, and these should include the use of remote technologies. Professionals should also maintain standards for use of those technologies that can be applied to all appointments and interactions. These guidelines should include information about consulting with participants in advance and redistributing power to the service user.

Remote technologies cannot wholly replace face-to-face interactions. They can be good for some kinds of meeting and wholly inadequate for others. With that in mind, it is vital that health and social care professionals use these technologies in a mindful and accessible way, prioritising the full and equal participation of all parties. If you plan on replacing a face-to-face activity or service with one that uses remote technology, first consult with the Disabled people who are affected, and redistribute the decision-making power to them.

What needs to be done

- Treat remote meetings in the same way you would face-to-face meetings: establish clear guidelines and standards for the accessible use of remote technologies.
- Patient/user choice must be prioritised: establish the preferred mode of communication in advance, and make adjustments based on the service user's accessibility needs.
- Plan appointments well in advance and provide service users with training in the relevant technology.
- Ensure that the patient has the equipment they need in order to use the remote technology in question.

For more information, please see Meakin, B. (December 2020) *Locked In or Locked Out: d/Deaf and Disabled people's experiences of using remote technologies during COVID-19.* Shaping Our Lives, https://www.shapingourlives.org.uk/

resources/our-resources/research-reports/locked-in-or-locked-out-report-from-our-covid-19-remote-technology-research-project

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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, and Lucy Potter

Introduction

In this chapter, we share our experiences about a project that aims to improve access to primary care services within GP (general practitioner) practices for women who have experienced trauma and have complex needs – the Bridging Gaps project. This chapter is written by some of the women in the group in their own words. It is a combination of our different experiences and thoughts about the project. As some of the Bridging Gaps group would rather not share names, this has been written anonymously.

About the Bridging Gaps project

Bridging Gaps was started by a group of Bristol women with personal experience of trauma, including addiction, homelessness, mental health problems, sexual exploitation, domestic and sexual violence, and poverty. Women who have faced extensive trauma often have low engagement with mainstream health services. They can experience extreme health and social inequalities, and have complex needs that are not always understood, or met, within primary care services.

Bridging Gaps offers health professionals who work with women with complex needs a greater understanding and awareness of complex needs and trauma via a one-hour training programme led by a group of women with lived experience of these issues. The women involved in our group range in age, ethnicity, and expertise including doctors, health professionals, support workers, researchers, and most importantly, women with lived experiences who are experts in their own traumas. These experiences include genuine, honest, and extremely raw hardship that they deal with, or used to deal with, on a day-to-day or week-to-week basis. Collectively, we aim to work collaboratively with health services so that they can identify, engage and work in a meaningful way with women who face many barriers to seeking and engaging with treatment. We are raising awareness and making vital steps to enable easier access to healthcare for women with complex needs.

We are developing and delivering an online staff training programme for anyone who works in primary care on how services can be more accessible and appropriate for women who have experienced extensive trauma. Before the COVID-19 pandemic, we developed a video to give an insight and a real, genuine understanding of not only the story but the raw emotions, pain, and hardship that comes along with some of our experiences.

> This has been probably the most challenging part of the training for me but on the other hand the most rewarding!! As a group we decided to include some of our own traumatic experiences. I'd never opened up and allowed myself to be vulnerable, but I felt I could be completely transparent and after talking about it a weight was lifted from me. I've noticed in some of my appointments (eg a shared care worker appointment) instead of leaving as soon as possible I'd stay the full slot and enjoy expressing myself.

With having to deal with one struggle after another throughout our whole lives, we know that if we can co-produce a training package for up-and-coming doctors and healthcare professionals, both health professionals who support women, and women who use services, will have a better understanding of how to help or how to receive help. Giving women a voice and knowing that their voice could make big changes in services is so empowering. It gives those women who have been let down in services a real chance to see change and help others coming through services see real positive change. Due to COVID-19 and the move toward online appointments, we believe Bridging Gaps could be instrumental in helping professionals to identify and support women that may otherwise fall through the cracks!

Managing digital exclusion during COVID-19

When the pandemic began, we had to reorganise our meetings from face-to-face to remote working. Not everyone had computer equipment to be able to access online conferencing like Zoom, so we had to use a free phone call conference system. This was quite challenging as people tended to talk over one another.

We were lucky enough to receive mobile computer tablets to carry on our work remotely through the pandemic. This took quite a long time for researchers at the university to organise through their systems, and an agreement had to be signed so that we then had ownership of the equipment and were responsible for it. Since then, it has been fantastic to see each other and keep our brilliant work going. There have been some challenges with the sound at times, but this has since been resolved. It is great to be able to carry on our vital work.

> I cherish my mobile tablet. Once you get past the initial teething problems it's very easy to use. My tablet has made a positive improvement to my life. I use it daily.

> Having the mobile tablets has been a total game changer, even though I'm still camera shy.

Not everybody has access to Wi-Fi either, or a safe and secure place to access online meetings. So sometimes, we need to organise a separate, socially distanced, and safe space so that people could access Wi-Fi for our meetings. This was also helpful to work through any IT problems that people had as they were learning to use the mobile tablets. Sometimes extra support might be needed, for example with IT skills, but the objective should always be to aim for empowerment and transition of knowledge, so that the women in the group can have final decision about when they are ready to do something on their own. Thankfully, any technical problems were soon overcome.

When government restrictions were more relaxed in the summer of 2020, we managed to have some socially distanced face-to-face meetings, which people really appreciated. Some new members joined at this time as well. We all had to wear masks and were socially distanced.

> As a new member, I only got to see half of everyone's face but was made welcome.

Others of us have been shielding throughout the pandemic.

> As someone who is shielding, I haven't done any face-to-face since January. This has been really hard for me not to see the rest of the group in person, but it's still nice to do it online and feel part of the meetings. It's been really challenging being at home all of the time through this awful pandemic. I have felt very isolated and have become very introvert.

To ensure the inclusion of everyone when we had socially distanced face-to-face meetings, we also had an online connection available for those people who couldn't join us in the room. By having online meetings, it really helps to keep you in the loop, and it makes you want to get up in the morning and do something productive.

Communicating with each other through the pandemic has sometimes been a challenge. Sometimes not everyone wants to talk and they don't get their thoughts out there, so we need to remember to ask the women individually if they want to respond to anything. That way everyone is included in decision-making. Language varies among our diverse group.

Some medical jargon can be confusing; sometimes people might zone out. We always need to remember to make space and listen to each other.

In the months before the first March 2020 lockdown, we did two training sessions with GP practices, and one of them started a new 'Open Doors' clinic for people with complex needs – with extended 30 minute appointments, drop-in availability, and improved collaboration with other professionals. The GPs reported that they started to see patients who hadn't been to a GP for years and are keen to continue the clinic. We hope that once access is easier, the next step is how to make it not just a one-off access but to help women with complex needs feel more accepted and comfortable enough to want to build relationships with healthcare professionals. This might mean not trying to achieve every goal/health problem in one session/appointment, or not addressing anything else apart from whatever is number one on the list, as there isn't enough time to discuss any others.

> As a woman who has a number of complex needs I feel like if I had the right support at the beginning I would have achieved more of what health care I needed.

Since the pandemic started, we can't do any face-to-face training but we have done two online GP training sessions. Mobile tablets were essential to be able to deliver these professionally.

> As someone who is newer to the project, I thought the online training was brilliant and I can imagine the impact in person must be very powerful.

We're still all trying to work together through the challenges of the pandemic. Below we share some of our personal experiences about working on the project:

> Since the very first day the Bridging Gaps group began, I've noticed so much growth and change in myself. At the beginning, I'd be anxious to talk and had low confidence. The women I've grown so close to, I see so much change

> and growth. I truly believe we have built a bond over the time we've spent together … getting to know the car so to speak but more importantly what's underneath the hood. I appreciate every single one of you, am super proud of what we have achieved and the changes we have made so far … My growth is astronomical. I would recommend all walks of women having a positive group like Bridging Gaps in their lives …
>
> I have a purpose. My voice is being heard and more importantly I'm being heard. I look forward to our meetings. It feels I'm part of something important, life changing. I continue building myself as a woman with a voice I'm not scared of people hearing. Bridging Gaps has made me think of my future. It helps give me strength when I thought I was weak. I think this fabulous project is going to go far, to reach the people who are forgotten and need it most. I am excited to be part of Bridging Gaps. It has a diverse and wide range of ladies who are welcoming and treat everyone with respect.
>
> I really enjoy working with Bridging Gaps, we are a group of diverse women. I have learnt some fantastic skills and learning to work in a group has really helped my self-esteem and helps with my mental health. Working with Bridging Gaps has given me a real sense of pride and fulfilment, to actually see changes happening because of such amazing and strong women is fantastic. Working with GPs to be more trauma informed in services is such a vital part of supporting women who have been through so much in their lives.

What needs to be done

To conclude, here are some of the things we think need to be done to support co-production in a pandemic.

- Have patience. Go with the flow. Some people find using IT equipment easier than others, so bear that in mind. Involvement is important – listening to each other.

- If possible try to include everyone in meetings by providing mobile tablets/IT equipment if face-to-face meetings are not an option. If not possible then have phone calls just to keep the project moving and also to keep people involved and interested. Sometimes not everyone wants to talk and they don't get their thoughts out there, so ask people individually if they want to respond to anything. That way everyone is included in decision-making.
- The more peer-led work there is for survivors the better. It is the way forward because it gives us a voice. It makes you feel part of something and see change.

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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, and Ursula Ankeny

Context

Physical distancing in response to the global pandemic has posed the challenge of if and how co-design work could continue without face-to-face interactions. One of the authors (SK) set up an open-access online document for researchers to share suggestions about how this challenge could be overcome (Knowles et al, 2020). This was widely shared and commented on, demonstrating that researchers were anxious to ensure co-design activities were not abandoned in an effort to control the spread of COVID-19.

Reflecting on the suggestions and questions added to the document, one anxiety in particular stood out: 'Which platform should I use?'. The document's main focus became an expanding list of different digital meeting packages, and the pros and cons of each (considering cost, security, recording options, popularity, and more). Despite SK frequently condensing this section, as of January 2021 it runs to seven pages (almost half the document). By contrast, a suggestion (instigated by JL) to explore (non-digital) cultural probes did not provoke further discussion.

The document is evidence of how committed researchers were to ensuring co-design continues. But the focus was largely on how to replicate common co-design events, such as face-to-face workshops, via online meeting platforms. This may have been pragmatically driven; researchers had access to computers and meeting software. But it also suggests a missed opportunity to expand our repertoire of co-design tools and think more creatively about how (remote) co-design could happen out in the world, as part of people's lives, distinct from how co-design typically looks in research. Rather than consider how co-design might look beyond a university meeting room, digital platforms put meetings inside people's homes and the realities of digital exclusion were largely unaccounted for.

Introduction

The driving imperative of co-design is egalitarian; ensuring the people who rely on or are affected by a product or service are involved in and influence the design of it. Therefore, the modes of engaging and collaborating under this imperative should be inclusive and accessible, even tailored to the needs and/or preferences of these people.

We (the authors) have many years' experience in co-design. Pre-pandemic, our predominant form of interaction was face-to-face workshops designed to be cognitively, emotionally, and physically accessible for all parties. However, COVID-19 forced us to rethink this model and to begin experimenting with alternative modes of engagement. Early explorations on how to expand the spatiotemporal framework for co-design practice led to the establishment of four quadrants, reproduced in Figure 10.1.

Social distancing has forced a critical examination and experimental adjustment of our approaches to co-design. Like others, we embraced digital platforms (as outlined below) but also extended our exploration to analogue and blended digital-analogue approaches. The latter approaches (such as door-to-door, letterbox-to-letterbox, radio and more) explore and extend formats of collaboration. Testing new or updated modes of collaboration encourages critique of who we are engaging, and how. For us, this critique and

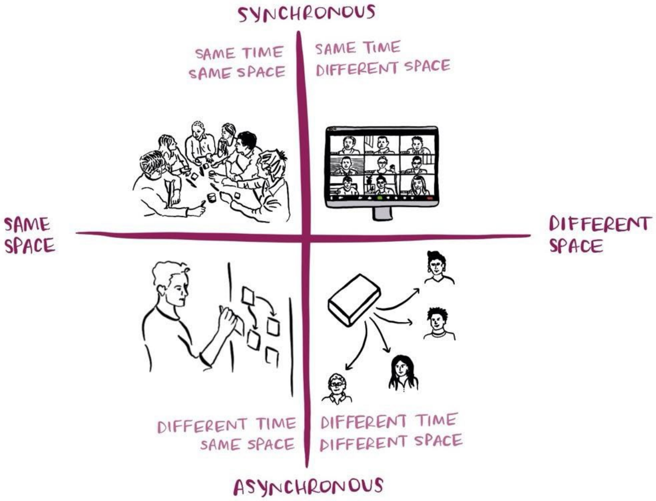

Figure 10.1: Spatiotemporal framework for co-design (reproduced from Davis et al, 2021)

new approaches should remain part of the co-design toolkit beyond the current pandemic.

This chapter reports on four approaches to engagement that we have trialled with co-design participants, starting where we did in early lockdown with a purely digital solution, before gradually expanding and blending our approaches. It draws together our early, evolving learnings, and shares our reflections on these ongoing experiments in co-design. More details about these particular cases and a number of others can be found online at: https://lab4living.org.uk/projects/co-design-during-covid/ (Langley et al, 2021). These are not hypothetical or 'in theory' examples; they are things we have actually tried or are trying.

Typologies

Here we expand on the thinking behind the ‘low contact’ design models shown in Figure 10.1, focusing on the second (Same time and different space) and third (Different time and different space) quadrants. A selection of projects are summarised in Table 10.1 to illustrate a variety of approaches taken.

Same time and different space

Online workshops using videoconferencing and digital collaboration software

Projects: Microsolidarity, NOVELL Redesign

Tools: Zoom, Jitsy, Toasty, Miro, Mural, Google Slides, Mentimeter

The use of digital collaboration tools has extended boundaries for participation. Videoconferencing enabled a geographic dis-location of participants but also allowed us to engage with broader demographic groups. We found it important to consider the design of the experience and that the interaction must extend beyond developing a workshop schedule and content. Creating preparation materials, training packs, and drop-in sessions helped engage those with limited computer skills, or using technology such as a smartphone rather than a laptop computer, which limits the usability of collaboration tools. Allowing access to the platforms beyond the time-boundary of the workshop session can also help engage participants who would like ‘just a little more time’ to contribute their thoughts after the official end of the workshop session.

Unstable internet connections, personal resistance, fear of ‘getting it wrong’, a lack of confidence, or inexperience with technology were all seen to inhibit participation in a digital space and require careful intervention.

Table 10.1 Selection of test-bed projects

Project title	**Synopsis**
Active Wythenshawe	Supporting the residents of Wythenshawe to be more active, whatever their physical ability, using existing/natural resources in the neighbourhood. Tools: Postal drop of zines, social media, radio, email.
(Re)building Stories of Harm in the NHS	Exploring how patients and families can be meaningfully involved (beyond their role as a 'witness' or source of evidence) in Serious Incident Investigations and developing resources to support their involvement in future investigations. Tools: Narrative reconstruction kits, activity books, virtual/physical workshops, Miro.
Downsizing	Exploring the experience of people aged 65+ moving from a suburban home to an inner-city apartment. Tools: Postal workbooks.
Food Futures	Using a gamified co-research process to help community members to discover their local food system, build their adaptive capacity, and explore what the future of food in their region could be. Tools: Workshop in a box, Virtual games, Miro, Google Docs.
Microsolidarity-in-Action	Using the community building and communicative practices of Microsolidarity to host empathy and capacity building games. Tools: Workshops, Google slides, liberating structures, Jitsy, Toasty, Mural.
NOVELL Redesign	Engaging nationally with stroke survivors, neuroscience researchers, rehabilitation professionals, designers, and health administrators to rethink the design of in-patient rehabilitation environments. Tools: Miro, Zoom, Mentimeter.
Whole Mouth Health	Investigating the perceptions of 'whole of mouth health' with international stakeholders and participant groups from Australia, Chile, Nigeria, Switzerland, and the United Kingdom. Tools: Workbooks, workshops.

Online workshops using videoconferencing and physical materials

Projects: FDI, (Re)building Stories of Harm in the NHS, Food Futures

Tools: Activity booklets, zines, story kits, Zoom, Miro

Digital communication does not necessarily mean digital interaction, and it is possible to blend the distribution of physical materials with a virtual event. We have employed zines, activity booklets, and story kits as physical materials used in partnership with real-time digital communication. The advantage of this approach is that as a facilitator, the designer can be present and responsive. This experience largely tries to replicate a face-to-face workshop rather than investing in new opportunities to engage with people in a distributed way. As participants cannot physically share or pass around materials, the tacit experience of collectively contributing can be diminished. Engagement can extend beyond the temporal constraints of the session, but the live nature can limit the potential for exploring these objects in-situ.

Different time and different space

Distributed workshops using 'workshop in a box' with a pass-the-parcel approach for collaboration

Projects: Food Futures

Tools: Card games, co-research game boards, systems discovery canvases

Initial provocations are prepared, participants respond to them, and then pass on via post, with later recipients interacting with, and adding to, others' responses. Provocations are mock-ups, props, visuals, or sketch ideas, sometimes deliberately 'extreme' or even contentious, intended to stimulate thinking, reflection, feedback, and discussion. This increases the flexibility of participation and takes gamified workshop processes into participants' homes/workplaces, increasing engagement for time-poor participants. The pressure of the unfamiliar is reduced by working in private, but the self-facilitated process can limit the ability to ask for help. Participation through pre-existing networks results in swifter parcel movement but raises questions around a potential echo-chamber effect. Although slower, a longer, mediated chain can facilitate greater diversity of participant voices, and in doing so, expand social learning opportunities between participants.

Distributed workbooks or activities sent via post, with digital interface made available independently

Projects: Downsizing, FDI, NOVELL Redesign, Active Wythenshawe, (Re)building Stories of Harm

Tools: Workbooks, Zoom (on request), 3D story building kits

In this fully distributed, hybrid model we have found a significant increase in the depth of engagement, particularly on tasks that engage people with their surroundings. This model capitalises on the strengths and capacities of digital and material formats but not necessarily at the same time. However, facilitation usually happens independently with limited opportunities for real-time group interaction.

This model provides an opportunity to contribute at a time *and* location that suits individual participants. The process of synthesis and engaging with the ideas of others occurs through a multi-stage approach built on the British Design Council's Double Diamond Design Process (Design Council, 2015). Data contributed in previous workbooks and activities are represented back in subsequent activities that enable participants to reflect on how their contributions fit with others.

While this approach is successful in allowing people to remain connected and contributing over a long timescale, some participants requested opportunities to engage in real-time. We responded by distributing activities that facilitated a conversation, such as completing an activity, or gathering perspectives from their family, friends, or colleagues.

The key challenge for facilitators is that they cannot respond to queries or redirect participants in real-time. Guidance has been built into these processes, but a negative experience appears to be amplified by the distributed approach. With no opportunity for intervention, frustration can build.

Assemblages

The examples above discuss specific tools and techniques deployed across various co-design projects, many of which incorporate multiple models of collaboration. This blended approach provides significant opportunities to plan collaborative processes that can be agile and tailored to many different stakeholders' needs. The spatiotemporal framework developed provides a strong foundation for considering the options for engagement in low contact co-design and suggests forms that may be suitable to different communities. We use Critical Pragmatism (Forester, 2013) to guide our planning process, mapping and investigating various stakeholder's needs and preferences to assemble a suite of collaborative approaches (we refer to this as an assemblage). Rather than limit ourselves to replicating face-to-face meetings digitally, we consider stakeholder needs first, then explore tools and techniques to address these. It is future oriented, deliberate, and reflective. We offer Table 10.2 to help overcome barriers to participation with explorations of blended assemblages.

Ongoing explorations: barriers

Ongoing engagement with our test-bed projects continues to raise questions and prompt deliberative, reflective conversations around who participates and how. This discussion also relates to the role of power and its distribution throughout co-design processes. Flattening hierarchies poses questions around consensus and plurality, a topic we continue to engage with through investigations in group decision-making and consensus building.

Table 10.2: Indicative mapping of barriers to participation among various participation models (Y indicates 'yes a significant barrier', M indicates 'maybe a barrier')

	Q1: same time same space	Q2: same time different space	Q3: different time same space	Q4: different time different space
Participants' time	Y	Y		
Mobility	Y		Y	
Accessibility		Y	Y	
Digital Skills		Y		
Literacy		Y	Y	M
Compromised immunity	Y		M	
Social fears or phobias	Y	Y		
Dexterity challenges		M	M	Y
Cognitive/Neural challenges		M	M	M
Process duration			M	Y

Throughout, continued mapping and consideration of the spatiotemporal framework reveals some of the barriers to participation that can (but do not always) occur in each quadrant (see Table 10.2).

While no single method is barrier-free, working with blended assemblages, adopting a critically pragmatic approach, and foregrounding participants' needs, creates a support structure by compensating the weaknesses of one method through the strengths of another. The assemblages that best scaffolds participation is contextual, particularly where facilitators (and/or other participants) are absent.

Conclusion

Blended assemblages of co-design processes can help to overcome barriers and challenges in particular methods to minimise exclusion and maximise inclusion and collective decision-making in participation. They provide a flexible framework for processes that are highly contextual. Resources, budget, and timeframe all play a role in how a blended assemblage is devised. Context also informs the consideration of inclusivity, empowerment, and creativity to determine the blend that maximises participation for all.

The examples we have outlined above are still being evaluated for their efficacy; they are offered here as inspiration and to challenge the digital default as well as complement digital approaches. We have found the practical tools offered here useful for both planning and evaluating approaches and encourage others to reflect and discuss their experiences. In a post-pandemic world, there is no benefit in returning solely to previous co-design practices. These expanded spatiotemporal models will continue to be relevant to the co-design community and should be utilised.

What needs to be done

- Explore blended approaches to promote inclusivity for varying literacy levels, and accessibility for differing neural, cognitive, physical, technological abilities.
- Enable partners to contribute to an ongoing process rather than at time-locked windows of opportunity (events) organised and controlled by you.
- Explore collaboration in blended approaches with the aim of achieving collective participation, not just individual engagement in parallel.
- Learn about the balance between prescriptive tasks and emergent thinking through 'doing' activities and participatory sessions.
- Critically appraise the emerging role of designers/researchers within each blended approach.
- Prioritise (co-)creating blended approaches that empower participants with the space and authority to participate in ways of their own choosing.

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11

Co-producing virtual co-production

Adapting to change

Alison Allam, Scott Ballard-Ridley, Katherine Barrett, Lizzie Cain, Cristina Serrao, and Niccola Hutchinson-Pascal (authors listed alphabetically)

Introduction

Along with everyone else in 2020, Co-Production Collective (https://www.coproductioncollective.co.uk/) had to adapt to the changes, challenges, and uncertainty that arose, and continue to develop due to the COVID-19 pandemic. We needed to respond to these 'unprecedented times', keep on track with the plans leading to our launch in October 2020, and, most importantly, stay true to our approach to co-production.

This chapter has been co-produced by six members of the Co-Production Collective and draws on our perspectives and experiences of co-producing virtually. Through personal reflections and conversations with our wider community, we identified what we'd learnt from adapting to the unplanned move from face-to-face to virtual co-production, mapping this learning onto our four core values: human, inclusive, transparent, and challenging (Co-Production Collective, 2021). Living these values in practice, learning, and improving together, gave us the foundation for the successful launch of Co-Production Collective.

We are human

Co-production Collective is a community where everyone is welcome. Together, we learn, connect, and champion co-production (in health and social care research and more widely) to create lasting change. Fundamentally, our approach to co-production is about being human, building mutually beneficial relationships based on honesty and trust. However, it often feels easier to develop, nurture, and sustain such relationships face-to-face. This is especially the case for those first joining a group, where they may not know anyone else, or what to expect.

Given this, we were delighted that lots of newcomers joined this year; in some sessions, over half of the attendees had never attended before. Reflecting on why people felt able to do this, we think that it's because we prioritise being human in our communications, language, and approach. For example, we contact newcomers in advance and offer an informal chat. We don't leave people in a Zoom waiting room but bring them in to join some general conversation before we start, greeting everyone by name. Breakout sessions also ensure that everyone has the chance to contribute to smaller groups. In other words, we try to make people feel welcomed and part of our community immediately.

From conversations in those first few months, we also recognised that people were really missing the opportunity to meet and talk informally, so we came up with the idea of Co-Pro Cuppas. Essentially, these are open sessions with no aim other than to get together with others and have a natter! Some great ideas for other projects emerged from these chats over a cuppa. For example, Cristina found that the Co-Production Collective network offered organic opportunities to connect others into the co-produced national musculoskeletal strategy work she is doing with NHS England and Improvement (https://www.gov.uk/government/organisations/nhs-improvement) and in partnership with the Arthritis and Musculoskeletal Alliance (ARMA, 2020), and vice versa; people heard about our work elsewhere and were curious to find out more.

The value of co-producing together as one team has stood out as particularly important. We aren't categorised by our job titles or labelled with our experience. Instead, we are all people, equally important to the process and valued as a friend and teammate. Cristina reflects that lived experience roles can be lonely when you are the only person pushing for change. Joining the Co-Production Collective sessions felt different, with everyone working together regardless of who they were or where they'd come from. For us, this is the heart of co-production. Although it might be slightly trickier, it is possible to create meaningful opportunities for this to happen in a virtual world.

We are inclusive

Removing barriers to participation is vital to enable genuine co-production. We have found many benefits to this way of working, including the possibility for wider geographic inclusion. For example, Alison lives in York and, although we cover co-producer travel expenses, the time and energy needed to travel would previously have prevented her from participating. Virtual co-production offers the real possibility for our work to involve and include co-producers from across the UK and internationally.

As well as being more geographically inclusive, virtual co-production improves accessibility for those living with ill health and/or disabilities. Alison lives with a chronic illness and travelling is often not possible, and even when it is possible, the 'pay-back symptoms' afterwards are high. She felt well enough to participate in some of the sessions virtually, but would not have been well enough to attend in person. Similarly, co-producers can join sessions from their own homes, which may feel more manageable. Co-Production Collective's community has grown substantially during the last year, in large part due to our virtual sessions being more inclusive to a broader range of people.

We have followed an approach of digital inclusion rather than exclusion, working differently to try to ensure as many people as possible can join. This means using platforms with minimum technical barriers, identifying accessibility concerns (such as not being able to participate in an interactive feature if using a mobile phone), and planning sessions which take these into account. As Niccola reflects, co-production doesn't need to be complicated; we ask people what they need to participate, and then do our best to provide it.

We have also prioritised offering a blended approach to co-producing with us – virtual co-production doesn't only have to be video calls (UCL Public Engagement Blog, 2020a). There are many other ways to work collaboratively, including phone calls, working on documents over email or via post, or online collaboration tools (although often these are not often fully accessible). By using a variety of approaches, more people can get involved in a way that works for them, rather than squashing everyone into 'one size fits all'.

This is especially important given the digital fatigue that impacts many people. As Katherine highlights, the concentration needed for virtual meetings can be significant, especially if you're living with health conditions. We have kept our sessions to a maximum of two hours, changing the time of day they run, timetabling regular breaks, and ensuring people don't feel pressured to have their videos on. We've also done our best to avoid actively sending people to sleep with dry slide decks, keeping things fun and interactive! Over the last few months, we have successfully co-created a new strategy, brand, and identity, and the beginnings of a new website.

However, digital exclusion remains an important and pressing issue. While we offer to pay for data or phone credit to join our sessions, we recognise that many individuals don't have access to digital devices in the first place. Our sessions are open to anyone, but largely promoted online, so those who do not have access to the internet may not even be aware of them, and/or be unable to join. Additionally, digital exclusion disproportionately affects those who are already excluded or marginalised– their voices are still unheard. We remain committed to identifying and overcoming the barriers to digital inclusion for all.

We are transparent

For us, a key aspect of transparency in co-production is addressing power imbalances and hierarchies. So when we became aware that the ethnic diversity in our sessions had declined, we spoke about this publicly and committed to working to change it (UCL Public Engagement Blog, 2020b). We offered our blog and other platforms to organisations and individuals of colour working in this space, and proactively reached out to build relationships with underrepresented groups (UCL Public Engagement Blog, 2020c). We know that it needs to be an ongoing effort on our part.

To try to dismantle hierarchies, we act transparently through sharing roles and responsibilities. For example, as a blind co-producer with expertise in online accessibility, Scott put himself forward to be an interview panellist to choose the design partner to co-produce our website and brand. We were very clear that the successful organisation had to share our values and be able to facilitate an accessible co-productive process.

This transparent way of working extends to designing and delivering our sessions themselves. Katherine has been part of the teams co-producing a network session and our launch event, working on everything from planning the content to facilitating breakout groups. As a co-producer, this process of development has been so important for Katherine; her confidence, health and wellbeing has benefited, and she's learnt new skills. Niccola agrees that taking the time to co-produce sessions together with co-producers leads to much more enjoyable and rewarding results.

We are challenging

Our approach to being challenging in co-production includes embracing new ideas and ways of working, along with continuous reflection, learning, and improvement. At the very beginning of lockdown, we reached out to others working in this space, to collaborate on a Co-Production Network session and build on their existing experience of virtual co-production (UCL Public Engagement Blog, 2020d). We used this opportunity to hear from our community about their experiences, concerns, and ideas. We then shared our joint learning more widely through our blog and newsletter, incorporated it into our own activity and collaboratively developed our new way of working (UCL Public Engagement Blog, 2020e).

A key lesson we took from this was the importance of skilled facilitation. Perhaps even more so than in face-to-face co-production, it can be hard to create space for everyone's voices to be heard in a virtual room. Conversely, Lizzie highlights that tools such as the chat function also mean people can contribute to sessions even if they feel unable do so verbally. Some facilitators we worked with initially found this challenging, as they were used to being able to ask people to be quiet if there were multiple conversations going on at once. However, it soon became clear that the chat box was providing a platform for quieter voices, as well as a space for relationships to form between co-producers.

Officially launching Co-Production Collective was our biggest challenge to date, virtual or otherwise, and our chance to put everything we'd learnt into practice (UCL Public Engagement Blog, 2020f). Although we were originally disappointed that we wouldn't be able to mark this milestone with each other in person, it quickly became clear that launching virtually was an amazing opportunity to create the kind of impact we could never have had otherwise. Not only were we able to bring over 300 people together, but they also joined us from their living rooms, offices, and bedrooms from all over the world. While we may have been physically distant, we were still able to feel like one community for those two hours. The event itself was entirely co-produced with music after the official launch from GagaRadio (gagaradio.org); it wasn't your standard launch! As Cristina says, we're not interested in just looking outside the box; we want to blow it up!

What needs to be done

Below, we present the key points we think policymakers, practitioners, and anyone involved in co-production should be putting in practice. However, the learning we've shared isn't just applicable to co-production; we think it can be applied to many new forms of virtual practice across healthcare and beyond.

- **Human** – put people first, focusing on building relationships based on trust, in equal partnership for equal benefit. Keep in mind the importance of maintaining informal spaces in the virtual world and recognise that this is as important as the formal work.
- **Inclusive** – commit to promoting digital inclusion for all. This is in terms of both digital access and accessibility of the activities themselves.
- **Transparent** – share power, roles, and responsibilities with your community, and be honest about whose voices are missing. What can you do, together, to change this?
- **Challenging** – offer a blended approach to co-production, which supports virtual, face-to-face, phone, and other offline methods. Resist the idea that there is a 'gold standard' or 'one size fits all'.

Reflecting on adapting to change and co-producing virtually, it's clear that there is no turning back. The pandemic forced us to diversify our methods and has been a huge learning curve, but we've seen so many real benefits. We'll definitely still be co-producing in person when able again, but we will also use a mixed methods approach, supporting people to join us their way.

Virtual co-production is not something that can be done half-heartedly. Effective virtual co-production still takes time, resources, facilitation, and planning – possibly more so, in some ways, than face-to-face. It is not, and nor should it be, a cheap and quick alternative. As with any co-production work, it's important not to wait to try and get it perfect, but to get stuck in together and be open to learning as you go.

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12

Co-production and COVID-19

Digital diaries as a platform for participating in COVID-19 research

Mary Chambers, Dinesh Deokota, Ragil Dien, and Yen Hoang Nguyen

Introduction

This chapter describes a participatory film activity, conducted in three global south countries, to support a wider social sciences research study on the impact of COVID-19 on vulnerable individuals and communities. We describe the challenges in conducting the project and the contribution that this method can offer to more formal qualitative research methodologies.

Community engagement and social sciences in pandemic settings and COVID-19

The recognition that public health emergencies require a broader range of expertise outside traditional biomedical and epidemiological disciplines has increased with each passing epidemic from the HIV/AIDS pandemic in the 1990s, to Ebola in 2014–16, and now COVID-19. These outbreaks have highlighted the fact that human behaviour drives epidemic emergence, transmission, and amplification. There is an increasing recognition from the public health field that each outbreak is unique, and community understanding of diseases is complex, context dependent, and culturally mediated (Bavel et al, 2020). The recognition of the critical role of communities in a disease response has been reflected in multiple calls for more social science and community engagement involvement in public health emergencies and the development of guidelines for increased participation and person-centred approaches in epidemic/pandemic research settings (Janes et al, 2012; WHO, 2012; Hankins, 2016; WHO, 2018).

Community or person-centred methods are key to detecting behaviours and practices that increase the risk of death, disease, or societal and economic loss. Furthermore, these methods can help to uncover the relationships and pathways needed to foster enabling and reinforcing conditions for behaviour change to reduce the impact of the diseases (Bardosh et al, 2020). It is not enough for the emergency response effort, or epidemic research agendas, to respond only to the disease at the heart of the outbreak: this may not be the only, or even main, concern of affected populations. Community engagement and social sciences can create platforms for the people affected to speak of their needs and priorities (WHO, 2012; Wright et al, 2020).

The term 'participatory visual methods' (PVMs) encompasses a wide range of techniques that involve people taking part in the production of creative outputs that are used to convey their knowledge, experience, opinions, and ideas. PVMs are utilised in engagement settings, and as a person-centred research methodology and can catalyse an important transition from one-way, top-down health communication (Gubrium, 2009). Examples of PVM products include dramatisations, drawings, paintings, maps, photographs, digital stories, and films. As creative forms of expression, these products can enable participants and wider audiences to see and understand other people's situations in new ways. Many of the biggest global health challenges occur in the poorest and most marginalised areas of the world. Working with visual methods can enable those who are marginalised and often excluded from discussion and debate about medical research – such as women, youth, less-able, or elderly – to take part more meaningfully (Black et al, 2018). Participatory approaches may encourage medical research participants to express themselves in ways that are not made possible by formal interviews or focus group discussions, and therefore can be a valuable addition to qualitative and quantitative research methods (Wang, 1996; Gubrium et al, 2014; Black et al, 2018). We have selected to use digital diaries as a method that empowers community members to give their interpretation of events and experiences and that harnesses the power of stories as an empathetic communication tool. Details of the method are given elsewhere (Black et al, 2019). Here we discuss the benefits and challenges to using digital diaries in a pandemic setting.

The COVID-19 'SPEAR' study

Apart from the devastating effect of COVID-19 on health, the pandemic is affecting individuals, communities, and nations in myriad and often untold ways. The economic impact of the public health measures may be visible whereas the toll on people's mental health may be less obvious. The ways that societies and individuals are able to respond to the challenges of the pandemic are not equal, and existing structural inequalities may heighten vulnerabilities and deepen the impact of COVID-19. The Oxford University Clinical Research Unit (OUCRU) Social Science and Public Engagement Action Research (SPEAR) study was set up in June 2020 to draw on anthropological and participatory engagement methods to explore the wider socio-cultural context of COVID-19 and its impact on health-related workers and vulnerable communities in Vietnam, Nepal, and Indonesia (Van Nuil et al, 2020). One component of this study is PVMs that enable community members to tell their personal stories of lived experiences in the COVID-19 context.

Digital diaries in the SPEAR study

The SPEAR studies community settings across three countries (Vietnam, Nepal, and Indonesia) and 12 sites, which vary from highly urban (e. Kathmandu, Nepal, and Bandung, Indonesia) to remote rural areas (eg Dak Lak province, Vietnam, and Southwest Sumba, Indonesia). The experiences of the COVID-19 pandemic have also varied greatly, with Vietnam having low levels of restrictions compared to months of enforced lockdown in Nepal and Indonesia. This meant that our implementation of the digital diaries project has been pragmatic rather than adhering to a strict protocol. Our aim was to enable community members to use simple digital cameras to record photographs or videos of aspects of their lives that have been impacted by the pandemic. In most settings, people have mobile phones with cameras. In rural Nepal, we had to lend them digital cameras, as some did not have camera phones.

Reflections on using digital diaries

Training for community members has been challenging in unique ways for each setting. Firstly, in Nepal and urban Indonesia, where COVID-19 transmission has been high, face-to-face meetings and training sessions were not possible, instructions were relayed to participants by phone, and Zoom calls. In rural Nepal, filmmaker Dinesh Deokota was unable to travel and so took a training of trainer approach – giving instructions to his contacts, health workers living in remote areas, to relay to the digital diaries participants. Dinesh asked ambulance drivers travelling to these remote clinics to take equipment (cameras, hard drives, instruction sheets) to the participants. In the large city of Bandung, West Java, the COVID-19 lockdown restrictions limited face-to-face trainings. To overcome this, Ragil Dien asked participants to post photographs and a caption on an Instagram site. This is a social media platform they are familiar with and the project needed much less facilitation. For these reasons, this method has worked well with the technology savvy urban participants, although the photographs may not be as informative as video stories.

In rural Vietnam, we faced a different challenge and so the film training focused on building confidence in participants. Participatory filmmaker Yen Hoang Nguyen was able to travel to the rural villages in central Vietnam but found that the most vulnerable community members – those we wanted to hear from, lacked confidence to use a camera, or experience of speaking about their lives. Training and empowering them to do so has been time consuming, and the stories they tell, although authentic, are more facilitated. In rural Sumba, Ragil found that community members were reticent to speak by themselves and so she has worked with a group of youth to make a collective film.

The participants and their stories are varied, but all are deeply personal and moving. Many highlighted how existing vulnerabilities are deepened by the pandemic. In Nepal, these include a construction worker who became unemployed when building work was stopped in the lockdown. He was unable to feed his children or pay rent. Another Nepali man shared how his brother was stuck outside of Kathmandu and now he has no one to help him to drive to the hospital to access dialysis treatment. Another participant is a rural health worker who had to walk five or more hours to take HIV drugs to one of her patients. Her film shows truck drivers refusing to give her a lift because she 'may be contagious'.

The stories also portray people's deep courage and resilience. On the island of Sumba, there has been little community transmission but the impact of the pandemic has been felt acutely on people's livelihoods. Women involved in weaving and the tourist industry tell their stories of coping with loss of income. A health cadre in Jakarta was unable to do her day-to-day work so she has started distributing food parcels to isolated people in her community. A Nepali health worker faced stigma from neighbours and colleagues when she tested positive but tells of how she and her family found the inner strength to cope with this.

Finally, these participant-led diaries have revealed details of the impact of the pandemic that are culturally and community specific. In Southwest Sumba, the government restrictions on burial practices have concerned the communities who follow the Marapu beliefs. Each family has a shared grave and will move relatives who have died elsewhere back to these graves. They worry about the current government COVID-19 regulations that restrict families from having ceremonies and moving bodies.

Conclusions and recommendations

At the time of writing this chapter, the SPEAR study and digital diaries project is ongoing and analysis of the data is not completed. However, it is already clear that the participant-led stories of experiences of the COVID-19 pandemic add a depth and colour to the research data that is hugely valuable. The community engagement work was able to start before the research study and the digital diaries stories helped us identify some key issues to explore through surveys and interviews.

We also recognise that if used as a data collection method, digital diaries may be more extractive in nature than participatory. Where possible we will continue conversations and relationships with participants. In Nepal, five of the digital diaries were screened at the Kathmandu Mountain Film Festival (December 2020) which provided a platform for the participants to speak about their experiences making the diaries and engage with experts and a wider public.

What needs to be done

- Biomedical and social science research methods to examine pathways and impacts of the COVID-19 pandemic can be greatly augmented by including collaborative, participant-led stories of people's lived experiences.
- A pragmatic approach to involving community members is helpful because pandemic-related restrictions may mean that traditional methods of participation aren't possible.
- Researchers should be aware that participatory approaches may still be extractive in nature unless processes for ongoing engagement in the research or projects are included. These activities could include a screening for participants and researchers/policy makers or follow-up community meetings using the films to prompt a wider discussion about experiences and needs. These activities should be part of the project plan rather than an 'add-on'.

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13

Going remote

Using technology to co-produce homeless health research

PJ Annand, Michael 'Spike' Hudson, Maame Esi D. Yankah, Martin Burrows, Stan Burridge, Michelle Cornes, Sujit D. Rathod, Paniz Hosseini, Lucy Platt, and Andy Guise

Introduction

For a group co-producing participatory homeless health research, the COVID-19 pandemic presented challenging circumstances, notably physically distanced working. With limited technology among the research team and participants alike, remote research – especially participatory research – was not easy. However, participatory approaches are important because they enable teams to bring together a wide range of collective expertise and experience that is vital for addressing need, especially during health crises. Another benefit is their focus on reflexivity: that is, taking stock of one's own positions, beliefs, and experiences; understanding their impact; and using this to inform working practices. This varied expertise and a process of ongoing reflexivity helped us devise creative and practical solutions to some of the obstacles to co-producing research posed by the pandemic.

COVID-19 and the need for co-produced research

Along with health threats from COVID-19, the pandemic policy response changed much of our health, social, political, and legal landscape. These shifts had wide-ranging implications for people experiencing homelessness. Many day centres, which support people experiencing homelessness to access vital resources, closed during ‘lockdown’ (Groundswell, 2020a). Hostels also implemented physical distancing measures, and rules preventing people from visiting the premises. Such measures increased social isolation, especially given limited access to communication technology, which had a significant impact on mental health (Groundswell, 2020a). Already poor health and social outcomes for many experiencing homelessness were exacerbated by reduced access to healthcare and healthcare appointments moving online or being by telephone (Groundswell, 2020b).

There were also positive policy developments, like the ‘Everybody In’ initiative: the repurposing of hotel rooms and other facilities as temporary accommodation. Recognition of the urgency to address homelessness, including domestic abuse and other unsafe living conditions, also grew (Ministry of Housing, Communities and Local Government, 2020).

These circumstances, positive and negative, represented both a focus for our homeless health research, and an unprecedented context in which to co-produce it. Physical distancing meant our team had to rethink many routine activities, including the collaborative delivery of interviews and surveys. Simultaneously, participatory research elevating the voices of those particularly vulnerable to COVID-19 – and to existing social, political, and economic inequalities alike – had arguably never been more vital. Indeed, Groundswell’s (2020c) research into COVID-19 highlights several crucial insights from those with lived experience of homelessness. For example, regarding the accessibility of health information, and the digital divide preventing many from accessing healthcare and other statutory services.

The gulf between those affected by policy and those developing it must be addressed to achieve meaningful solutions, regarding both the factors contributing to homelessness, as well as the impacts. While co-produced research is not enough in and of itself, it represents an important step to (a) make sure people experiencing homelessness are heard within policy, academia, and public spheres, and (b) deliver on the 'nothing about us without us' principle of self-determination.

Remote delivery of co-produced research: our studies

Across our group, we were all involved, in differing and linked ways, in implementing three studies:

1. **Monitoring COVID-19** (https://groundswell.org.uk/monitoring-covid-19/): A Groundswell-led project using 'citizen journalism', whereby people experiencing homelessness worked as mobile reporters making regular audio and text reports on their experiences of the pandemic, and the experiences of those around them.
2. **Homeless Health Peer Advocacy evaluation** (https://www.lshtm.ac.uk/research/centres-projects-groups/hhpa): A mixed-method (qualitative and quantitative) evaluation of Groundswell's Homeless Health Peer Advocacy service in London.
3. **After the Lockdown**: A qualitative study building on the above projects to explore in-depth experiences of COVID-19 among people experiencing homelessness.

In the context of physical distancing rules, limited access to data and devices among researchers and participants made the research process more difficult. We had to consider how to collaborate effectively when working remotely, and how to use technology to deliver inclusive research representing a diverse range of voices. An added difficulty was posed by the well-established and ongoing 'digital divide' that particularly excludes those experiencing homelessness. Each project provided opportunities for learning and exploring new approaches, which we will now reflect on.

1. **Citizen journalism**: The Groundswell study used a 'citizen journalism' approach, which saw community members playing an active role in collecting, reporting, analysing, and disseminating news and information. 'Mobile reporters' were engaged remotely, and trained

digitally, to report back using text, email, video, and audio. They provided raw insight into how the pandemic was impacting them and other people around them who were experiencing homelessness. A significant concern with remote research, especially in homeless health research, is the risk of excluding those most isolated – for example, those who do not have their own telephones and are not in contact with services where phones are available. With citizen journalism, members of the community who do have access to mobile technology can engage people with shared experience who might otherwise be excluded.

- ***Disadvantages:*** It took significant resource to deliver citizen journalism safely and support mobile reporters effectively, particularly during a pandemic when there was likely to be greater instability in their lives. Secondly, while helping combat exclusion among participants, this method still required the use of mobile technology among reporters.
- ***Advantages:*** This approach provided live insight direct from a community that might otherwise go unheard, and ensured that stories were generated from lived experience.
- ***Tips:*** It is important to ensure co-production from the start when designing the approach. It is also essential that people have access to the resources they need to do the job: whether that is technology, phone credit, training, or moral and psychological support.

2. **Online steering groups**: Steering groups that include experts with experience of homelessness help ensure that those with lived experience shape research development and delivery. We found it was possible to deliver steering groups online. Where internet access is a problem, telephone alternatives are usually available, and inexpensive handsets and SIM cards can often be covered by research budgets when needed.
   - ***Disadvantages:*** Connection issues meant people sometimes dropped out of the call for short periods. We also found important meetings like these tended

  to be longer, making it harder to maintain energy and concentration.
  - ***Advantages:*** Groups were often able to come together quickly and relatively easily online to discuss the research, despite being located in different parts of the country. Consequently, we found attendance was higher than for pre-pandemic face-to-face events. It was also possible to record online meetings to share with people unable to attend. The chat function was also helpful for people who are shy to input.
  - ***Tips:*** To improve accessibility, we recommend consulting with all members of the steering group beforehand to understand (a) whether a remote meeting would be possible for them or what extra resource may be needed to facilitate it; (b) what the best means of communication and input might be – digital platform, telephone conference call, or something else (eg inputting separately).

3. **Remote research skills-sharing**: Skills-sharing sessions can, in many instances, be delivered remotely if team members have internet, or even telephone, access. For us, ensuring everyone on our research team had access to communications devices was key to their success.
   - ***Disadvantages:*** When delivered in person, this type of event might take the form of a 'training day'. However, we felt running a whole-day session online was unfeasible. To avoid 'conference-call fatigue', we broke activities up into smaller sections spread over a six-week period – though, of course, this slowed the process down.
   - ***Advantages:*** Delivering shorter sessions over a longer period prompted unexpected benefits – for example, compelling us to dedicate more time to whole-team engagement with, and reflection on, the research process. This sort of reflexive practice, while important, is something that is often neglected in time-constrained research projects. Meeting more regularly over a longer time frame also helped mitigate the limitations on team-bonding posed by online working. For some, online training and skills-sharing

  was thought to be less intimidating than in-person events and thus improved ease-of-participation.
  - ***Tips:*** Flexibility is key to delivering remote skills-sharing – that is, understanding and responding to different ways of working and communication preferences, and adapting these along the way. Secondly, as with all digital endeavours, it is advisable to do a test run beforehand, prepare a back-up plan in case of technical hitches, and factor in ten minutes at the beginning of each session to resolve connection issues. Even with these safeguards, this process is likely to prove time-consuming, which should be acknowledged and accounted for.

4. **Telephone interviewing**: Online video conferencing may feel ideal for interviewing. However, this is less viable for homeless health research as it requires internet communications technologies that people experiencing homelessness may struggle to access, especially during a pandemic when community facilities have often been closed. For some researchers and participants, telephone interviewing may be an option here.
   - ***Disadvantages:*** Firstly, research teams sometimes had to rely on hostel staff, key workers, and other frontline staff to facilitate connections. As an already very busy workforce, however, engaging the assistance of staff was not always feasible, resulting in delays to recruitment and data collection. Secondly, we found scheduled telephone interviews to be less suitable for research with people with stressful lives, who may not be available when or for as long as required. Thirdly, the audio quality of recorded conversations was lower when interviewing by phone due to handset and signal limitations, with implications for transcription and analysis. Additionally, without the visual and non-verbal cues of in-person communication, telephone interviewing posed additional challenges for rapport building with participants, and transmission delays sometimes resulted in stilted conversations. Lastly, we had to consider potential privacy issues when interviewing by phone – it could be challenging for

those in shared accommodation to find a place out of earshot for the telephone conversation to take place.

- ***Advantages:*** In some cases, telephone interviewing proved more efficient and convenient, with less time lost due to travelling around and locating interview sites, and researchers being able to schedule other tasks around the interviews. It was also possible to break up a telephone interview into smaller pieces and deliver it over several days when required. While people experiencing homelessness, hostel staff and key workers can be very busy, the opportunity to contribute to research in a convenient telephone interview was often welcomed.
- ***Tips:*** When working remotely, project information and consent sheets can usually be sent to participants by post, email, or via keyworkers. In addition, however, we recommend verbally reviewing this information over the phone prior to interview to make sure everything is clear and to provide an opportunity for questions. It may be useful to draft an abbreviated but comprehensive version of the information sheet for this purpose: while long forms may be feasible when completing by hand, reading a list of more than six or eight consent points prior to interview can become straining, disrupt the 'flow' of the conversation, and set an overly formal tone. Moreover, we would suggest working with hostels, day centres, and other services to coordinate access to quiet spaces for interviews to take place, and checking in with participants at the beginning of the interview to make sure they are comfortable and do not feel they will be overheard. It is also important to allow for a high rate of scheduled interviews not being completed. A flexible approach is ideal, with back-up options put in place for when a specific recruit or participant is not available.

5. **Co-interviewing**: It is common for researchers from a range of organisations, universities, and freelance contractors to collaborate on co-produced research. Here, delivering work remotely can pose challenges for

securely recording, storing, and transferring data given the Data Protection Act 2018 and strict institutional policies about use of encrypted technologies and easy access to internal secure repositories. There are several solutions to these challenges, including the purchase of encrypted devices for all team members. When budgets are limited, we found a useful alternative to be co-interviewing, which helped bring together technology access and different expertise: for example, a freelance researcher can lead the interview, while a university-based researcher hosts the conference call, records, and uploads to a secure server, thus eliminating the need for transfer of data between team members.

- ***Disadvantages:*** Call merging and conference-calling facilities, while widely available on standard mobile phone handsets, can be barred by some networks for pay-as-you-go account holders. Yearlong contracts, however, may not be compatible with research budgets. For one of our studies that meant additional time spent researching and coordinating with different networks and handset providers.
- ***Advantages:*** Co-interviewing meant more frequent interaction between different team members, outside of formal meetings. This was helpful for facilitating team bonding, given the more solitary nature of remote working. For qualitative research, combining the knowledge and skills of two researchers in the interview setting was also useful for bringing rich, in-depth data, and building further reflexivity into the research process.
- ***Tips:*** It is important to choose your network provider carefully if considering a system of conference-call co-interviewing. Trial runs are strongly recommended to develop mastery of the technology.

Conclusion

While the barriers to co-producing remote research are not insurmountable, they are substantial. Overcoming such challenges requires a combination of creativity, planning, and flexibility. Nonetheless, working collaboratively to adapt research in the face of new challenges is vital and can present a number of opportunities – including the chance to reassert the importance of reflexivity and to ensure people experiencing homelessness are heard within policy, academia, and public spheres.

What needs to be done

- To ensure co-produced homeless health research is inclusive, research teams need to be aware of potential limitations in access to technology at an early stage in the research design process and work collaboratively to devise creative methodological solutions.
- Having to adapt to the COVID-19 context, for us, prompted an even more concerted effort towards reflexive practice. We believe continuing to uphold this principle throughout the research process should be an ongoing priority in all studies.
- With the possibility of remote work increasingly becoming the 'new normal', routes for people with experience of homelessness to feed into policy may become even more limited without significant efforts to address the digital divide. While this issue can, of course, only be meaningfully and comprehensively resolved via broader efforts to reduce inequalities at large, ensuring research finds ways to help bridge this gap in the short-term is an important step. Strategies in future may include budgeting to: (a) cover the purchase of encrypted, smart technologies for team members; (b) provide free access to digital devices within homelessness services; (c) set up/partner with digital accessibility initiatives, such as 'tech banks' that make new and used communications devices available; (d) support the development of digital skills among those who feel less confident using technology to participate in research or decision-making.

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'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

Catherine Hale and Alison Allam

Introduction

The COVID-19 pandemic triggered a remote access revolution. It enabled entire populations, newly confined to their homes, to stay connected to each other online through digital platforms such as Zoom and Teams. While disabled people have been adversely affected by starkly disproportionate deaths and other inequalities during the pandemic (Women and Equalities Committee, 2020), including through digital exclusion (Majeed et al, 2020), this remote access revolution had the positive effect of levelling the playing field for some disabled people. It afforded us equal participation in many areas of life that we had previously only dreamed of.

Some disabled people are, and will remain, housebound, long after COVID-19 restrictions have ended. This is true regardless of the progress in disabled people's right to participate in society achieved under the social model of disability. Many people with energy limiting chronic illness (ELCI) are in this category. Those of us (including ourselves) in this situation have historically been excluded from activities of co-production, among other forms of participation, that have tended to rely on meeting in physical spaces. But the pandemic has shown that our exclusion is not inevitable.

We must seize the opportunity provided by this unexpected remote access revolution to prevent a return to pre-pandemic inequality and exclusion.

In this chapter, we describe an online participatory research methodology developed by and for disabled people with ELCI. Our purpose-built online research forum was developed in 2018, by Jenny Lyus and Catherine Hale, under the Chronic Illness Inclusion Project (CIIP). It was part of the Disability Research into Independent Living and Learning (DRILL) programme of disabled-led research, which aimed to give a voice to this seldom-heard community. It is not the only digital tool for inclusion; indeed, videoconferencing is the more obvious solution (Hale and Allam, 2020). But in many ways, our online research forum is the most accessible remote participation solution for people with ELCI and we hope this methodology will become part of a toolkit for including disabled people who are housebound in co-production in the future.

Unfortunately, another adverse effect of COVID-19 appears to be the creation of a new cohort of disabled people through the debilitating condition of long COVID. The most prevalent feature of long COVID is bone-crushing exhaustion (Nabavi, 2020). However, ELCI and energy impairment are not new. One in three disabled people in the United Kingdom (UK) experience impairment of stamina and breathing, or fatigue (Department for Work and Pensions, 2019). As an impairment group, people with ELCI are largely invisible within health and social care policymaking. Due to difficulties accessing face-to-face meetings, we are also not well represented in patient and public involvement (PPI) and engagement activities. Many of us have previously asked for remote access as a ‘reasonable adjustment’ to enable us to join a meeting or event, but all too often this has been denied, or poorly implemented (Hale, 2020). Drawing the attention of policymakers to the needs of disabled people with ELCI, including remote forms of participation, is long overdue.

About ELCI and being housebound

We, in the chronic illness community, were experts-by-experience in convening in digital spaces long before the pandemic struck. Indeed, our community emerged with the evolution of the world wide web to allow networking through blogging and social media. Disabled people who had lost face-to-face communities through ELCI seized these technologies to create social worlds and communities that they could take part in from home or bed (Ytre-Arne, 2016).

Before outlining the remote participation research methodology that grew out of this community, however, we need to explain the new terminology of ELCI and energy impairment we deploy, as well as our use of the term 'housebound'. The latter appears especially challenging to the social model of disability that unites the Disabled People's Movement in the UK, and yet our need for remote participation tools is premised on these concepts.

The terms ELCI and energy impairment emerged from the CIIP's programme of emancipatory disability research among the online chronic illness community (Hale et al, 2020). They reflect two key findings: (1) that fatigue and limited energy were found to be the most debilitating feature of chronic illness for the total of over 2,000 respondents, and (2) dissatisfaction with the existing lexicon of impairment and disability in the UK and the felt need for a new language of self-identity to strengthen advocacy for equality and inclusion.

People with ELCI identify as housebound when they are unable to leave their home without adverse consequences, even with provision of personal assistance, mobility aids, and accessible transport and environments. Being housebound in this way is different to being trapped at home by socially constructed barriers, failures of independent living support, or inaccessible environments. The latter situation is all too common for many disabled people, increasingly so with cuts to services engendered by austerity. For disabled people with ELCI, being housebound results from severe energy impairment, including the dynamics of 'pay back', fluctuation, cognitive dysfunction, and sensory intolerance that form the experience of ELCI (Hale et al, 2021), and cannot be adequately mitigated by external changes. We may be completely housebound. We can also be partially housebound, meaning we are sometimes able to go out and take part in face-to-face activities but only unreliably, and at a high cost in terms of ‘pay back’.

It is crucially important to differentiate between being trapped at home by socially created barriers and a failure to uphold disabled people’s human rights and being housebound due to impairment-related challenges that cannot be mitigated. The needs of both groups must be accounted for.

Methodology – an extended online research forum

Our research methodology involved the repurposing of readily available market-research software. Our aim was for an ‘ethnographic’ style of research, that is, with researchers immersed in the research environment and ‘data’ emerging through social connection with, and especially between, participants, over an extended period. The online forum was designed to replicate the natural environment of online communities but avoid its ethical risks. It was also designed to adjust for fluctuation and cognitive fatigue, two key features of ELCI.

Our online research forum was built using focus group software from a small company called focusgroupit.com. Focusgroupit.com offered a simple, easy-to-use platform for text-based discussion and interaction. It was inexpensive, intuitive to use, and involved very little learning for either researchers or participants.

Ensuring anonymity and confidentiality

Our participants were already familiar with, and active in, social media platforms such as Facebook. However, even ‘private’ Facebook groups pose a problem for privacy and anonymity. Participants might encounter others whose identity was known to them outside the group. Focusgroupit.com encouraged participants to adopt a pseudonym unrelated to their identity, either ‘in real life’, or across other social media platforms. This allowed for a greater level of anonymity and confidentiality. Focusgroupit.com also offered greater protection against intrusion than free-to-use discussion groups.

Adjusting for fluctuation and cognitive fatigue

Focusgroupit.com proved to be suitable for social research that was (1) extended over a longer time than a traditional focus group and (2) was ‘asynchronous’. These two features gave participants flexibility over participation times and was crucial to accommodating fluctuating impairment and individual cycles of rest and activity. Synchronous discussion groups, such as Zoom meetings, require activity at a set time and tend to require fast processing of information and response. Because of unpredictable fluctuation in energy and cognitive fatigue and dysfunction, synchronous discussion groups are less accessible to people with ELCI than asynchronous discussion.

Unbiased responses

Focusgroupit.com enable ‘unbiased’ answers to questions from participants. Participants had to post their response to a question before they could see or respond to other participants’ responses. This was another advantage of focusgroupit.com over a Facebook group.

The research process

Our extended online focus group took place over an eight-week period. We initially recruited 25 participants. Nineteen of them were active throughout the research period. Researchers had to approve participants’ registration to the site at the start to allow them access to the forum and safeguard it from intruders.

Over the eight weeks, a new ‘topic’ was posted to the focus group every two weeks. Each topic had a short introduction, and between one and three questions to answer. Participants could choose to skip one or more questions and move onto the next. Once they had answered the initial question(s) participants could read other participants’ answers and respond to them as they would in a Facebook group.

Participants were prompted via email when a new topic had been posted, which gave them a link to access the latest topic. They could also select to have an email alert when someone had posted a new comment or had replied to their comment. These features gave them control over their level of involvement in the group beyond answering the initial questions.

Three researchers were active during the focus group period. Two were ‘moderators’, who engaged in, responded to, and prompted further discussion among participants. Another researcher was an ‘observer’, who did not take part in discussion but read and summarised discussions. The observer also looked out for any disagreements between participants that could have escalated to conflict.

The design of our research practice was new and experimental. We did not know how much or how little our participants would communicate in the online focus group, or how long they would remain engaged with it. We were surprised at how intense the discussion was, how much trust and solidarity developed between participants, and how honest and revealing the information they shared was. The focus group generated over 38,000 words of discussion. Some participants formed bonds of peer support and friendship that they chose to carry over into their online networks beyond the life of the focus group.

Conclusions and recommendations

Our online research forum methodology provided ‘a space where we could listen and be heard’, in the words of one participant, where previously they had been marginalised and excluded by virtue of being housebound. Thanks to developments in digital communications, and their accelerated uptake under lockdowns during COVID-19, our exclusion from spaces of knowledge exchange, deliberation, and decision-making as a community of disabled people is no longer inevitable. Remote forms of inclusion and participation for those who need it must be maintained once face-to-face life resumes for the majority.

Our innovative online, extended research forum has the potential to further promote inclusive co-production. This is particularly the case for people with ELCI, who, even with reasonable adjustments (for example, travel and accommodation), are unable to attend meetings due to energy impairment and 'pay back' that follows. Also, while videoconferencing technology has opened many opportunities for remote participation, again this may not be fully accessible to those with ELCI. Through being able to participate at a time and pace that is manageable for the participant, online extended research forum removes some of the barriers they face to co-production. It offers an inclusive and accessible environment for people with ELCI to engage in co-production research and have a voice.

What needs to be done

- Recognise ELCI and energy impairment, including long COVID, as a form of disability or impairment.
- Acknowledge that some disabled people cannot be brought into physical spaces of PPI, including co-production, and may need remote forms of participation as a reasonable adjustment if they are to be included as equals.
- Adopt the use of asynchronous discussion groups, such as our online research forum methodology, as a tool for remote participation where appropriate. Alternatively enable remote participation through video conferencing facilities.
- Do not use remote participation where disabled people could be supported to, and prefer to, attend co-production activities in person.

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Reflections on Punjabi communities, COVID-19, and mental health

Shuranjeet Singh

Context

COVID-19 has elicited multiple crises around the world that stretch far beyond health. The consequences of the global pandemic have revealed the extent to which our health is intrinsically linked to our social and material realities. Media have highlighted how COVID-19 experiences differ within racialised and multiply marginalised communities, a topic which intensified through the Black Lives Matter movement following the death of George Floyd at the hands of a police officer in Michigan.

While heightened discussion is welcome, it does not necessarily lead to substantive change. The latter requires time, energy, and investment in shaping a space for social transformation. In the summer of 2020, I was a part of a team at Taraki that undertook research on Punjabi mental health through COVID-19 and the lockdown. This reflective piece focuses on the development, deployment, and dissemination of this research and its significance in shaping a community-informed evidence base.

What we observed and what we wanted to do differently

Early in the pandemic, the United Kingdom (UK) government came under fire for suggesting that COVID-19 was the 'great leveller' (Milne, 2020). Fortunately, such suggestions were quickly challenged and refuted by public figures and institutions. There was then a distinct turn towards how social and material realities relate to direct and indirect consequences of COVID-19. However, as will be outlined, these considerations also fell victim to the homogenising and reductive tendencies of social categorisation.

The term ‘Black and minority ethnic’ was again thrust into public consciousness through reflections on COVID-19’s unique impacts across social groups. Public Health England (2020) found that death rates from COVID-19 were higher among Black and minority ethnic groups when compared to white ethnic groups, and existing inequalities impacting the former were exposed and exacerbated. Concurrently, the mental health of populations during the pandemic was being recognised as an increasingly pressing concern. Figures from the COVID social study (Fancourt et al, 2020), which assesses the social and psychological impacts of the pandemic, demonstrate how ethnic inequalities are reflected in the presence of mental health challenges across the pandemic in Black and minority ethnic communities.

Concerns directed towards the label Black and minority ethnic are not without reason; the term has often been used to belittle communities and reduce vast complexities of peoples from around the world into a short acronym (Joseph, 2020). Similarly, we at Taraki felt that while these findings provided an important starting point, they failed to communicate the depth and granularity of grassroots realities. Oftentimes, the relative privilege of specific racialised groups was used to mask the challenges faced by others. For instance, the health inequalities experienced by Black communities may be understated when they are compounded with the experiences of other racialised groups. To develop and add nuance to these narratives requires time, energy, and investment. As will be outlined, this often falls on the shoulders of those working in time-restricted capacities with fewer resources.

These findings into Black, Asian, and minority ethnic (BAME) experiences and outcomes of COVID-19 did not help Taraki respond to the dynamic needs of those we serve. Taraki is an organisation working with Punjabi communities who are often overlooked in existing healthcare systems. We had unanswered questions and a looming sense of helplessness in trying to react to COVID-19 related challenges. Despite some analyses which looked beyond the category of Black and minority ethnic (Siddique, 2020) there was still a sense of confusion especially in mental health. Furthermore, we observed a distinct lack of intersectional approaches in discussions around COVID-19, which rarely considered the functioning of multiple marginalisations upon one's experiences. Our work with Punjabi men, Punjabi women and particularly with Punjabi LGBTQIA+ (Lesbian, Gay, Bisexual, Trans, Queer/Questioning, Intersex, Asexual + all of the other sexualities, sexes, and genders that are not included in these few letters) communities showed us that a more in-depth exploration was required to provide some clarity on this topic.

Attempting to address gaps

Upon observing these gaps in existing knowledge, I convened a small group of community mental health organisations, advocates, and members of the Taraki team. As someone with lived and living experiences of mental health challenges who has also been privileged enough to develop a wide-ranging methodological and research toolkit, I was able to access resources to bring people together with established relationships to Punjabi communities. As a group, we held knowledge derived from lived experiences of mental health challenges, academic study, and professional work.

Through ongoing deliberation, we decided to conduct a study with over 460 participants (Taraki, 2020). We derived a number of learnings that highlighted barriers to shaping research and knowledge-making activities in our world. Here, I discuss a few factors which helped and hindered our pursuit of generating a community-informed evidence base shaped through the intersectional lens which helps us best support those we serve every day.

Funding

The UK's National Institute for Health Research (2020) released a funding opportunity focused on COVID-19 and mental health in minoritised ethnic communities which aligned with our intended research. However, we realised that bureaucratic and administrative barriers made the application process both confusing and daunting. Our team had little experience in applying for such research grants, and the process quickly revealed itself as impenetrable without the collaboration, and implied legitimisation, of an academic institution. This, we felt, required a huge time investment that we were unable to offer especially as it would not necessarily lead to guaranteed funding. Furthermore, members of our team who have worked with universities in the past noted the high level of bureaucracy that could further slow the evolution of this research from ideation to implementation. We, therefore, decided not to pursue formal funding, but drew from the core areas of interest presented by the National Institute for Health Research (NIHR) to develop our research questions which revolved around the impact of COVID-19 and lockdown on the mental health of people with and without previously identified mental health challenges and the supports people have used during the pandemic.

Our approach

It was integral that the voices of those we serve remained at the heart of our approach and so we embedded a collaborative approach throughout the research process, from development to data collection and dissemination. Rather than having knowledge created 'about us', our research aimed to be community-led and driven by people with a range of interests, skill sets, and expertise. Within this, we centred the experiences of those who are marginalised in multiple ways through an intersectional approach, understanding that Punjabi communities are themselves diverse and should not be homogenised. We refined our intersectional and community-based approach to ensure we focused on those we aim to serve through research that is relevant and applicable. Throughout these conversations, several topics arose but one in particular stood out. The language of 'faith' during the pandemic was ever-present, whether associated with a religious or faith tradition, with a set of practices, or simply a belief system. Our team relayed the concerns, challenges, and coping mechanisms of themselves and their communities, demonstrating that faith, in its multiple dimensions, was playing an integral role in Punjabi communities and their mental health. Much academic literature overlooks the role of faith and we wanted to ensure that it was given attention in this research because of its significance. Developing our intersectional approach and deploying our community-based research was only possible through the mutual exchange of knowledge within our research team.

Technology

Our work leveraged popular technologies and digital platforms such as video conferencing, social media, and design software to engage and access audiences to undertake this research. We found that using technology and our team's skill set helped us to conduct and coordinate an entire research project without having to hire or pay for external consultations or support. There were, undoubtedly, challenges wherein our focus on social media for participant recruitment excluded those in Punjabi communities without access to social media, internet, or video conferencing platforms. However, technology did allow us to conduct our research entirely online, allowed for robust quantitative and qualitative analysis, and enabled us to write, present, and disseminate our report without cost. Upon dissemination, we were able to use technology to create innovative knowledge products beyond the report itself. Short videos, consultation sessions, infographics, and poster presentations were developed alongside the report, ensuring that the research reached a wider audience beyond academics and researchers. Even though technological advances have accelerated during the COVID-19 pandemic and related lockdowns, those without access to them still risk being left behind.

Findings

Our survey and interviews gathered data from 470 respondents about their experiences of COVID-19 and lockdown. The data highlighted the impact these situations had on the mental health of Punjabi communities with and without previously identified mental health challenges and the supports that people had accessed during this time.

We found that 60% of respondents reported a decrease in their self-rated mental wellbeing from before to during COVID-19 and lockdown; on average, self-rated mental wellbeing fell by 18% across respondents. However, these decreases were not experienced equally. LGBTQIA+ Punjabis, first generation migrant Punjabis, and Punjabis living with comorbidities, all of whom had previously identified mental health challenges, experienced the largest declines in self-rated mental health at minus 30%, minus 29%, and minus 25% respectively.

Across all respondents, the most utilised structures of support were family, friends, and faith, accessed by 63%, 56%, and 41% of respondents respectively. Importantly, state and private healthcare services were comparatively low on the list of most used supports, which can further contribute towards discussions concerning help-seeking behaviours in racialised groups. We defined faith as ‘contemplation or meditation’ to ensure it was accessible to those with narrow and broadly defined faith identities. The presence of faith in the top three presents an important facet that needs further research and exploration.

While we may be tempted to view Punjabi communities as a homogenous group, our data demonstrate vital nuances at the intersections of identities and experiences, which can shape mental health outcomes. By acknowledging and speaking to diversities within diversities, we are able to work against overly simplistic analysis that risks platforming the experiences of a dominant subgroup. Our research approach brought visibility to communities that may have been wholly ignored. Such lessons are important beyond Punjabi communities and can speak to the need for more intersectional and community-led approaches to mental health research across the board.

Conclusion

These findings remind us that we cannot assume that all racialised groups experience mental health challenges in the same way. Working alongside particular pockets of often-ignored racialised communities, we were able to add significant depth to discussion rather than reducing experiences. If we are to move towards a health and social care system that works alongside communities and existing support pathways, it is important that we do not invalidate some mechanisms of support used by already marginalised groups. An integrated, impactful, and sustainable system is one where the individual and the facets of identity are considered more holistically when delivering health and social care.

As elaborated, COVID-19 has revealed and exacerbated underlying inequalities in society. We can, however, use this as a chance to capture a renewed focus on inequalities and healthcare, with a concerted move towards a more just and equitable world. The processes of imagining, undertaking, deploying and disseminating this research project was done with and alongside those individuals and organisations it aims to serve. A team from a range of backgrounds and with diverse skill sets came together to produce knowledge grounded in a critical compassion to make sense of a world in which uncertainty continues to loom over the heads of many.

What needs to be done

- Research organisations need to support community-led organisations to undertake research through sharing financial resources, knowledge resources, and other skills.
- Research and advocacy organisations should take a greater focus on intersectional approaches to understand best how structures of oppression operate alongside one another.
- Research and healthcare organisations need to look further into the role and place of faith as a support mechanism within particular communities to understand

best how certain communities conceptualise and seek help.

- Large healthcare advocacy organisations and research organisations need to be wary of using the term Black and Minority Ethnic (and associated BAME acronym) and should work towards more targeted interventions that speak to the complexities of racialised and other intersecting identities.
- Mental health organisations must be more explicit about the links between social and material conditions and mental health outcomes.

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International perspectives on the impact of COVID-19 on community engagement of young people for involvement in mental health research

Rosemary Musesengwa, Vanessa Bennett, Kiran Manku, Biggy Dziro, Sapfo Lignou, Kudzai Kanyere, and Peter Lewis

Introduction

Recently, the engagement of young people in research has shifted to involvement in the research process as co-producers. Co-production is a collaborative model that includes stakeholders in the process of research (Oliver et al, 2019), and reflects a combination of experiential and scientific expertise. Co-produced research increasingly values experiential and practical knowledge, mutual and continual learning, and an equality of status between stakeholders who contribute different skills and experiences (Lignou et al, 2019). A recent scoping review demonstrated the involvement of young people spanning across all stages of research, including the formulation of research questions, tools development, methodology design, data collection, and interpretation of results (Sellars et al, 2020). Farthing (2012) defines youth participation as 'a process where young people, as active citizens, take part in, express views on, and have decision making power about issues that affect them' . He explains that this participation ranges from passive involvement to youth-led research. Young people's advisory groups (YPAGs) promote agency and facilitate greater involvement of youth in health-based research, as evidenced in mental health research (Pavarini et al, 2019; Sellars et al, 2020).

The pandemic has presented challenges and opportunities for researchers in this regard. Meaningful engagement of young people at this time is particularly important to capitalise on the benefits to agency and wellbeing that may build young people's resilience during and after the pandemic (Pavarini et al, 2020). However, no guidance was available to researchers on how to conduct research during a prolonged pandemic so researchers and young people have had to develop robust ways to conduct mental health research, despite the pandemic (Gilmore et al, 2020). Adhering to ethical boundaries and principles of co-production, most research teams have therefore continued by leveraging existing relationships, shifting to various digital platforms and involving the creativity of young people to discover new approaches to continue their research.

This chapter is a reflection of our journey as research teams, including some of the young people involved in mental health research across Africa and the United Kingdom (UK). We present two case studies of co-produced research with young people and describe how we have been conducting this work during this pandemic. We also share the perspectives of two YPAG members, providing a direct insight into their views of participation and co-production during the pandemic.

NeurOX YPAG: opportunities and challenges in transitioning co-production with young people to a digital approach

The UK-based NeurOX YPAG was set up in 2016, as part of a Wellcome Trust Investigator award that grounded the Neuroscience, Ethics and Society (NEUROSEC) team in the Department of Psychiatry at The University of Oxford. The YPAG has 26 young people (14–19 years old) who are keen to offer their perspectives in the application of digital technologies in mental health. The YPAG are integral in the team's research programmes, informing and implementing methodology through processes of shared decision-making with an emphasis towards co-production.

Prior to the pandemic, half-day YPAG meetings were face-to-face, then after the lockdown we explored using Zoom, Google Docs, Google Sheets, and Padlet to build an accessible, sustainable platform. Since March 2020, the YPAG have held over 20 digital workshops or meetings, which have been 1–3 hours each, with additional off-line working and a virtual work experience week. Through listening to young people and responsively evolving our practice, we have enabled the YPAG to support five co-produced research studies during this period – COVID Peer Support Study, PERL Active Ingredients Mental Health Review, NSPCC/Childline Peer Support Message Board Project, Coping during COVID-19 Study, and Nottingham University Seasonal Antidepressant Prescribing project. Understandably, not all of the NeurOX YPAG members have found virtual conferencing 'socially' manageable and we have lost two members, who would like to resume when 'physical' meetings commence. We have also adapted practices to utilising smaller breakout groups and pairings.

For more information: www.begoodeie.com

YPAG personal reflection: Peter Lewis, NeurOX YPAG member (age 16 years)

The shift to an online YPAG came with advantages and disadvantages, most notably affecting our ability to connect with each other, and the number of opportunities available to us.

Digital meetings increased our ability to connect, allowing us to hold meetings with people from around the world, which was previously impossible. Throughout our Peer Support Project, we had Zoom calls with people and organisations from the US Peer Support Trainer and a Young Leader for the Lancet Commission on Global Mental Health from Barbados for example. In our regular meetings, we have connected with other UK-based youth organisations, with the aim of building a lasting network of connections, a possibility highlighted by the digital focus.

We have also used blog posts, podcasts and Instagram accounts to boost connectivity. Inevitably, there have been downsides, such as technical issues and the difficulty of interacting with another person over a screen.

Perhaps most significantly, we have had an increased number of opportunities. I've digitally met with researchers from Nottingham University, senior Childline representatives, and interestingly a researcher looking to use virtual reality in schools to improve mental health. It seems unlikely that so many opportunities would have been available had we not gone online; probably it was lockdown increasing concern for young people's mental health that played a part.

There are many takeaways from the digital period, which I expect will feature in the future once we have returned to in-person meetings.

EMDIYA: formation of a virtual YPAG across five African countries

The Ethics of Mental Health Digital Innovation in Young People in Africa (EMDIYA) network, funded by UKRI [EP/T029595/1], launched in May 2020 against the backdrop of the COVID-19 pandemic. The EMDIYA network is a young-people-led network that seeks to inform the development of accessible, relevant, and responsible digital mental health innovations to enable improved mental health and wellbeing in young people across Africa. Using a co-production model supported by a capabilities approach, we involved a small group of young people to be the initial seed of young people who became our EMDIYA Network YPAG.

The EMDIYA YPAG spans five African countries: Ghana, Kenya, South Africa, Uganda, and Zimbabwe. The EMDIYA network includes active inclusion of vulnerable young people, including urban young people, rural young people, young people living with HIV/AIDS, young LGBTQIA+ (Lesbian, Gay, Bisexual, Trans, Queer/Questioning, Intersex, Asexual, + all other sexualities, sexes, and genders that are not included in these few letters) community members, young people in tertiary institutions, young survivors of sexual abuse, and young women selling sex. The YPAG has 13 members, 2–3 per country, aged 18–25 years old. Most engagement was virtual, using emails, phone calls, and WhatsApp. Over six months, we held four Zoom calls and two WhatsApp meetings at network level. In each country, a total of 20 meetings took place (12 virtual and eight face-to-face). Overall, we had at least 80% attendance for each virtual meeting. The formation of a digital network amid the pandemic provided the opportunity for young people to connect with each other both within and across five African countries.

For more information: https://neurogene.org/groups/emdiya/

YPAG personal reflection: Kudzanayi Kanyere EMDIYA YPAG member

As a non-binary person from Zimbabwe, an opportunity to connect and discuss the ethics of mental health digital innovation has been more than just something I'm grateful for. Being a part of EMDIYA has directed my mind towards interrogating and researching more on appropriate strategies to ensure that digital mental health innovations are effective and efficient. It has also posed an opportunity to involve the LGBTQ youth who are usually left behind in many processes in southern Africa, if we have physical meetings. It has been very useful during this COVID-19 era to get involved in this project as it builds the foundation for an accessible digital platform that addresses mental health issues.

Being part of the EMDIYA network has given me a platform to build a digital footprint by interacting online, uploading bios, writing blogs, and making presentations in platforms that are not available locally. The biggest challenge is data costs and sometimes the connection is not reliable so I miss out on some information, but whenever that happens I always follow up on the WhatsApp group to ensure that I am up to date. Working with strangers from across the continent has been a fascinating and educating experience for me.

Reflections of online engagement

The two case studies and reflections from young people highlight diverse contextual and cultural scenarios in which co-production with young people has been implemented during the pandemic. Notably, common challenges were related to accessibility, digital exclusion, and a consequent impact on diversity, while opportunities included greater accessibility and involvement for some young people, wider connection, and improved social acceptability of alternative digital approaches to continue co-production through the pandemic. More positively, feedback from the young people indicated preference for flexibility of online approaches to better fit with their academic and social lives. Clear benefits were also identified in the capacity to continue to connect with the other young people and the expanded opportunities this provided to be involved in more diverse projects.

Conclusion

Overall, this move to use digital applications for engagement, participation in research, and mental health support required us to focus on developing a different skill set compared to those required for physical meetings. We focused on digital literacy, delivering a blend of online and off-line engagement, and building online confidence, overcoming language barriers, and building skills such as writing bio-sketches, online presentations, and chairing meetings. Despite the challenges of online engagement, and the need to consider local-tech solutions to reach more diverse youth, the pandemic made us adapt our thinking towards empowering young people to participate in research activities online.

What needs to be done

- Research involving low- and/or middle-income countries should include low-tech solutions using available resources.
- Researchers should ensure that virtual approaches are chosen to support digital inclusion and facilitate wider inclusion at multiple stages of the research process.
- Digital literacy and skills training needs to be incorporated into virtual engagement approaches.

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From Utopia Now to Dystopia Now

Co-producing knowledge about young people's hopes and fears for the future

Hannah Cowan, Charlotte Kühlbrandt, Hana Riazuddin, Oli Polidore-Perrins, Destiny Boka Batesa, and Bella Swinburne

"So we've got Amara who's come to the centre, Kamal is already here on the screen, joining from home, and we're just waiting for Ryan to get hold of a mouse – he might have to come here and pick one up, which might take 20 minutes or so." Oli, Play Leader for the centre, was scrambling about the room frantically, apologetically, visible through his computer's camera. There was lots of noise, shouting, play, coming through his microphone, making it difficult to hear what he was saying. We were about to start the first online session for our research project looking at how the pandemic is affecting young people's wellbeing in south London: a two-hour Minecraft workshop in which we were asking young people to build their dream lockdown neighbourhood. The first half-hour was just about getting everyone hooked up, ready to go; Ryan found a way to work without a mouse, Amara had to try a couple of the laptops that had been donated to the centre to find one good enough for Minecraft to work, and Kamal and his mum eventually managed to download the software. It was only thanks to a local computer refurbishment business and some community action to redistribute tech that this workshop could go ahead, but we got there in the end.

We'd met at the Adventure Playground in real life just before the first United Kingdom-wide lockdown. At that time, a few children were still coming to the centre and they had recently made a batch of homemade hand gel, but Oli was starting to wonder when they would have to shut down. We'd met to talk about our research – *Utopia Now!* – an arts-based project, in which we're working with young people to understand their hopes and fears for the future, with the end goal of influencing research agendas at King's College London.

The project came about in response to a public event held at King's College London where researchers were speaking about technology as a rapid and unstoppable force, through which everyone was moving towards an automated, technological world with greater power over nature. A direction inspired by advances in genomics, robotics, and artificial intelligence, labelled the 'fourth industrial revolution' by the World Economic Forum. Around this time, we were joining young people in marching on the streets of London and around the world carrying placards that read 'We are the future'. They were demanding that we all slow down, take notice of the world we're destroying. 'You're burning our future', they told us with their chants and signs. What kind of world were we leaving them to live in? On that day in the Adventure Playground, we discussed our concerns about how the discourse of technological progress in the university left out the big questions on what kind of world this technology was creating. The people who would ultimately be living in these new worlds had little say in where the world of research is heading.

Rather than attempting to change this predicament through the traditional format of young people's councils or advisory groups, we're doing this creatively, aiming for a kind of meta-co-production. Meta-co-production, we suggest, is about co-formulating not just individual research projects, but whole research agendas together with people who will be affected by future research. We wanted to do this by thinking about the kind of future world we collectively want to live in. We wanted to think big, build new worlds, and stretch our imaginations to expand on what seems possible for the future. We had devised pilot workshops with youth leaders and the Young People's Advisory Group at the Biomedical Research Centre. Our aim is to allow young people to build new worlds that might not be ready formulated in their minds or words, but which could emerge through playful activities such as Minecraft, drama, sci-fi flash fiction, and documentary filmmaking. Many of the young people at this play centre were really into Minecraft, “I’m sure they’d love to do a workshop”, Oli told us.

Little did we expect that the breakneck speed ‘fourth industrial revolution’ that we were concerned about would be stopped in its tracks by a tiny virus. As late as February 2020, during a *Utopia Now!* drama workshop, we had joined young people in seeing COVID-19 as a joke when they acted out an improvised encounter: two people fighting over a facemask. As the young people developed their plays on their utopian and dystopian visions of the future, we saw how one of the groups shared our scepticism for how much humans could really rely on robots, especially with emotional tasks. In another play, the young people were spookily on point, predicting not a distant future, but the months that would follow the workshop: they had come up with a utopian world where everyone could communicate telepathically and teleport to each other’s houses, so no one would be lonely. But then, three friends got stuck in the void…

A month later, we experienced the void which COVID-19 had created in all our lives. The lockdown had put an end to the activities we had planned for building utopian worlds with young people. We connected back up with youth leaders through Zoom, who were, of course, concerned about the impact on the young people they worked with. Some young people were struggling, others actually enjoying the independence from institutionalised education. Some youth centres turned into food distribution centres, others into tech repair shops. While the youth centres were thinking about how they could react, and what they could do to help, we also put our minds to the task. If we couldn’t do the utopian workshops, how could we put our research skills to good use? What needed to be done? We asked. We listened. We planned.

Co-production isn’t always, indeed not often, a formal process. It’s about building long-term relationships and taking what partners have to say seriously. This is how *Utopia Now!* generated *Dystopia Now!*, a research project aiming to understand how the pandemic would affect young people. We redirected our focus but used the same playful, participatory methods to develop meaningful conversations with young people about how the pandemic was affecting their wellbeing directly, or the social determinants of their mental health more broadly. We applied for one of the many rapid COVID-19 funding calls, arguing that creative methods might help young people better explore emotions which can be difficult to put into words. We included funding for Oli to do some ethnographic research, aware that he might have real-life contact with young people who aren't so connected to technology, but no one funded our super co-productive research proposal. We managed to find a smaller funding pot to use our participatory creative methods online. It wasn't enough to pay Oli for ethnographic observations, but still enough to pay the youth centres a bit for the work of getting young people involved. We were told that all funds that could make their way to the youth centre would be really valuable, however small they might be.

Dystopia Now! soon showed us that the very premise of our original project didn't hold true in our immediate surroundings; among the youth centres, we couldn't see rapid technological expansion anywhere. We joined the rest of the world in moving activities online, only to find that we had been right in suspecting that this inherently excluded all those who didn't have access to computers at home. Even when laptops were around, young people would have to negotiate with their family for the time and a quiet space of their own.

It also turned out that rapid research isn't always so very rapid, and sometimes it really isn't rapid enough. We started applying for *Dystopia Now!* in April, but funding wasn't secured until July, and then we only received ethical approval in August. By the time we had coordinated and started putting on workshops with young people it was October. The first lockdown was long past and, as we found out, many young people were tired of speaking about how COVID-19 had affected their lives. While Bella and Destiny, along with their advisory group members, agreed that it was good to keep talking about it, and far better to do so through a fun, creative process, our questions no longer seemed so urgent.

People had made arrangements, got used to them. Even if things were dystopian, habit made them appear normal, okay.

When we linked back up with Bella and Destiny to see how we could increase participation, they told us that access to technology during the pandemic has created a real divide both within and between households. Households are starkly divided by the quantity and quality of technology they have, the number of people sharing devices, and how tech-savvy adults are at home. Most young people have smart phones and can try to join activities that way, but it isn't always easy. Even when they have the right tech, they don't always have a stable internet connection, and it interrupts their schooling, and more importantly, socialising with friends. We heard these stories through our own glitchy Wi-Fi, thinking of the thousands of empty university offices, brimming with unused computers.

Successful co-production in a pandemic requires tech to be situated in private households rather than in public institutions. Tech redistribution schemes have no doubt helped many young people (and research projects!) during the pandemic, and Amara from the Minecraft workshop even got to keep the laptop they found for her. But it is difficult when those without tech get given the oldest and slowest of gadgets. We're now looking to redirect some of our project funding originally put aside for big public events, to purchase some decent internet-connected laptops for our workshops. We're responding to our findings as we go, doing what little we can.

We were also stalled by our inability to employ Oli as a co-researcher. But for us, co-production is not just about having 'lay' co-researchers. It is about ensuring knowledge is produced with more equal power dynamics. This is possible across generations, Bella and Destiny stress, if age is just seen as *difference* – different experiences and knowledge – rather than a signifier for more or less experience or knowledge. We see the young people we work with as artists, as creators – not interviewees or study participants. This ensures they are active makers of the data, not passive givers of their thoughts and opinions. Artists have authority over what they produce. The data is created collaboratively, and will be analysed collaboratively: all the poems, films, and Minecraft designs will together form a COVID-19 time capsule. Our plan is to use this time capsule to have collective conversations with all involved. What we hope to change isn't just policy affecting young people's mental health but also the ways in which the university reproduces a hierarchy of knowledge, for example through the use of exam grades to gatekeep entry, and the assumption that researchers know *more*, rather than *different*.

From *Utopia Now!* to *Dystopia Now!* we have also come to see that co-production requires material distribution. As the young people in the project have made clear, the pandemic has only exacerbated inequalities. These very inequalities prevent people from sharing their knowledge. As Destiny and Bella put it, access to tech and the internet should be like access to clean water. It's not only needed for education and socialising, the right resources are needed in the right places for young people's knowledge to be known by those with power to make change. We've heard rustlings that the university might join efforts to repurpose disused laptops. But of course, it's other actors who can make a real difference here: the tech industry shouldn't be making profit out of basic needs and governments aren't delivering on the tech distribution schemes they promised. The real difference universities could make is in their long-held position as governors of what knowledge should be heard. Listening to young people gives us a better chance of making better places that people actually want to live in.

What needs to be done

- Universities need to rethink their leadership on what counts as valuable knowledge, and pay attention to young people's knowledge and experience.
- Utilise arts-based methods and play to enable more equalised and imaginative spaces to shape futures and facilitate knowledge exchange.
- Research infrastructures need to be better set up for co-production. Universities and funders need to have

the capacity for faster turnaround in terms of research ethics, contractual, and financial arrangements.
- Rethink how universities aspire to ‘serve society’, especially when society is facing acute crises. Research institutions should not merely observe the unequal distribution of material resources, but influence policymakers, and redistribute their own resources in times of urgent need.

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Afterword

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Co-producing during a pandemic and beyond

An afterword for Volume 2

Oli Williams, Doreen Tembo, Josephine Ocloo, Meerat Kaur, Gary Hickey, Michelle Farr, and Peter Beresford (authors listed in reverse alphabetical order)

In this edited collection, our aim was to illustrate the value and means of co-production or, more specifically, *why* it is valuable and *how* it can be done. It is worth noting that our starting point for achieving this aim was reflecting on who has been disproportionately disadvantaged by the pandemic and how discrimination, marginalisation, and exclusion increased their vulnerability to both the COVID-19 virus (in terms of mortality and morbidity) and the implications of responses to its spread (in terms of relative access to resources, support, and involvement in key decision-making processes in research, policy, and practice). Our attention then turned to how we could ensure this book became a platform for these people, groups, and communities to share their experiences, insights, and expertise. As was outlined in the introduction to this volume, co-production has over time been defined and conceptualised in different ways. What our ambition for this book reveals is that central to our conceptualisation and practice of co-production in health and social care research, policy, and practice is an egalitarian imperative. That is, our primary interest in and advocation for co-production is as a means to ensuring that collaborative endeavours that explicitly address inequities in power can support marginalised communities, citizens, patients, and services users to create, shape, and improve health and social care research, policy, and practice.

Collectively, co-production endeavours must actively seek to promote health equity, by addressing inequity, diversity, and exclusion, and recognise the significant role that the social determinants of health have in creating and perpetuating inequalities in health and access to care. We hope others agree that the contents of this edited collection reflects these principles and ambitions, but we also welcome scrutiny and criticism, as this will serve to shed light on blind spots, sharpen perspectives, and improve future work on co-production and endeavours to co-produce.

The diversity of the examples of co-production in this volume demonstrates that there is not one way to co-produce. We want to take this opportunity to highlight this variation. As we outlined in the introduction to this volume, as editors we were not overly prescriptive in our definition and conceptualisation of co-production, so some of this variation may come from contributors adopting differing definitions and/or conceptualisations of co-production. However, it strikes us that this variation is largely due to contributors having a shared appreciation for the need to adapt practice to any given context and the people who participate in any given collaboration. Prescriptive definitions and conceptualisations of co-production could needlessly inhibit this sort of variation. That said, the absence of a hard definition does not mean that we countenance co-production constituting anything and everything. When reviewing these examples of co-production together what also strikes us about them is how they appear to be informed by *shared* principles and practicalities. For instance:

- a focus on the importance of relationships and the need to take time and dedicate energy to build them;
- the need to accommodate difference and preference by finding ways to make everyone feel comfortable when contributing to collaborative endeavours, so that people with different personalities, capacities, and needs can make meaningful contributions;
- a need for resources and supportive working environments to facilitate this way of working (and how,

when these are compromised or absent, this inhibits good practice); and
- a recognition of how central the skills and experiences of patients, service users, public contributors, and communities are to the success of co-production endeavours due to the vital role they play in generating effective and sustainable solutions with the ultimate aim of improving people's lives.

We hope that appreciation of and subsequent reflection on the similarities and differences of these diverse examples of co-production supports co-production endeavours in the future and strengthens the position from which we can assess, critique, and develop co-production theory and practice.

Co-production now: celebrating and critiquing this collection

We feel it is worth both celebrating the diversity, accessibility, and existence of this edited collection and acknowledging its limitations. The diversity of the contributors and contributions is impressive and relatively rare. This was something we were committed to from the start and hope goes some way to elevating the experiences, insights, and expertise of those who are typically un(der)represented, marginalised, and/or excluded in academic publishing and formal decision-making processes. We think it is significant and important that in this collection, contributors put forward *their* practical recommendations for addressing the issues that the pandemic has created and/or exacerbated. In so doing we feel this collection challenges the status quo and presents readers with an opportunity to learn from these experiences, insights, and examples and demonstrates why it is worth pursuing co-production in the future as a means to improve health and social care research, policy, and practice.

We wanted to make this collection more accessible for both contributors and readers than academic texts tend to be and feel that to some extent this has been achieved. We loosened the formalities and conventions associated with academic texts by giving contributors greater freedom to adopt a style they felt was best for communicating their contribution. We recognised that the academic convention of writing for 'free' can inhibit the participation and contributions of those who are not securely employed within academia, and/or undermine the value of their contributions. As such, we used what funding we had available to us to increase the accessibility of contributing to the collection by offering payment to public contributors, service users, and patients. We also recognise accessibility issues that potential readers can face. We catered for a wide readership by encouraging (and, where necessary, supporting) all contributors to write in clear and accessible language and to provide practical recommendations for action. However, such measures mean little unless the text is freely available to read. We take the issue of open access publishing seriously, and making this collection freely available to all was a priority for us from the very beginning. All too often, the experience, insight, and expertise shared in academic publications is only available to the few who are privileged enough to be able to access them behind exclusive paywalls. As such, we are incredibly grateful to the Health Foundation for positively responding to our request for funding to cover the open access fees and to Policy Press for not seeking to maximise profit on this publication.

Additionally, the mere existence of this publication is not to be taken for granted. As a not-for-profit publisher, Policy Press are able to put integrity before profit. They publish work that seeks to understand social problems, promotes social change, and informs policy and practice. Their core aim is to improve the day-to-day lives of those most in need. It is these core values and aims which led them to see the value in co-production and to subsequently seek out someone (in this case, Peter) to put together a book about co-production in the context of COVID-19 and a pandemic that has been defined by inequalities and inequities. They have been incredibly patient with us and supportive of our commitments to diversity and inclusion which, over time, transformed a far more achievable task into a two-volume collection, the scope of which even an optimist might suggest was unrealistic given the time (and many other) constraints. Similarly, we thank the six anonymous reviewers who reviewed our proposal and encouraged us (and advised Policy Press) to expand the collection further to ensure even greater diversity and representation.

Though it is worth recognising these achievements, we feel it is important to acknowledge that this collection has limitations, and to be explicit about these. Policy Press's Rapid Responses series (https://bristoluniversitypress.co.uk/rapid-responses) is designed to offer contemporary, rather than retrospective, accounts of the COVID-19 pandemic. The aim is to publish within a timeframe that creates the possibility for contributions to this series to inform pandemic decision-making. This meant that our contribution on how the pandemic relates to co-production had to be created quickly and within the constraints placed on us by the pandemic. Once the proposal had been approved, we had approximately four months to submit the manuscript – this included the Christmas period when many people take a break from working. Inevitably, this meant that the book would be far from exhaustive – there are many people and groups who experience discrimination, marginalisation, and exclusion, and teams who managed to co-produce during this pandemic, who are not represented here. For instance, though the collection is international, there are clearly more contributions from the United Kingdom than anywhere else. Any absences and overrepresentation are not the outcome of deliberate editorial decisions nor some ranking exercise, but rather an illustration of the limitations within which we, as an editorial team, were working in order to create a contemporary account. Absences also reflect the limited availability and capacity that others had to contribute, as not everyone that we thought to invite to write a chapter was able to do so. Additionally, although we were able to offer supportive editorship, as an editorial team we were limited in how much support we could offer people and groups who did not have the writing experience, capacity, and/or inclination to communicate what they had to share by writing a book chapter. As such, this collection will lack contributions from these people and groups.

We have sought to give a platform to grassroots voices in an effort to raise awareness of their experiences of discrimination, marginalisation, exclusion, and/or activism during the pandemic. We wanted to do this in part to set the ball rolling on highlighting the importance of co-production in addressing health issues and emergencies, such as COVID-19, that have an impact both globally and locally. If we had more time and funding available, this process could have been more accessible and inclusive. For instance, due to having very limited funds available (which we were granted permission to repurpose from a related project on co-production funded by The Healthcare Improvement Studies Institute), we were only able to offer payment of £75 for up to 55 public contributors, service users, and patients to make contributions to this collection. We know this does not represent sufficient recompense and it will have limited who was able to contribute – likely excluding some of those most disproportionately disadvantaged by inequities both before and during the pandemic. Simply put, we did what we could with the limited funds we had, and we hope the limitations of our project act as an example to support the now well-established argument for the necessity of greater investment in participatory practice in health and social care research, policy, and practice. Ethics and effort only get you so far; proper investment is needed to ensure participatory endeavours offer an avenue through which to reduce health inequalities and promote health equity.

This edited collection is *about* co-production. We do not claim it is an example *of* co-production. We suggest there is no irony in this – cookbooks do not have to be cooked. The editing and writing of this collection has, however, been highly collaborative, and what we have done as an editorial team has been informed by the principles of co-production. Chiefly what this meant for us was acknowledging and attempting to explicitly address inequities in power, not expecting equal, but rather equitable contributions, and committing to openly discussing ideas, and attempting to make decisions democratically. This has been challenging and we have tried to be open about these challenges to ensure that they are not 'brushed under the carpet' (Lennette et al, 2019). But openness will not always offer immediate solutions. It became ever more apparent that many of the challenges we faced were the result of the structures and systems we are a part of and therefore not easily changed by us – certainly not in the short term anyway. We were aware that research and academia ‘predominantly provides a context for which co-production is ill-fitted’, and as such, can have a corrupting influence on more participatory and inclusive ways of working (Williams et al, 2020:8). Where openness can potentially support co-production in the longer term is in highlighting and providing opportunity for critical reflection on how structures and systems inhibit this way of working. For example, we compromised to reach an imperfect solution to an imperfect situation with regard to recognising the relative contributions of each editor. We outline this in the Editorial statement included at the beginning of both volumes of this collection. Ultimately, it is difficult to square the principles of co-production with the norms and expectations of academia and the associated metrics of academic success. This is something that needs to be more widely acknowledged and requires further critical attention.

Co-production in the future: this collection and the post-pandemic landscape

In sketching out ‘pandemic sociology’, Pickersgill (2020) drew on the work of fellow sociologist Phil Strong who, when researching AIDS epidemics in the 1990s, coined the phrase ‘epidemic psychology’. Strong (1990:255) noted ‘For anyone who already has a mission to change the world – or some part of it – an epidemic is a new opportunity for change and conversion.’ This would appear to be true of pandemics too and it could be argued that this edited collection is an example of this. Everyone in the editorial team has dedicated significant time to developing, doing, and promoting co-production as a means to challenge norms and improve decision-making processes in health and social care. The driving force of this dedication is addressing issues of equality, diversity, and exclusion by ensuring marginalised communities, citizens, patients, and service users help to create, shape, and improve research, policy, and practice. By demonstrating why co-production is valuable and how it can be done we hope this edited collection plays a role in supporting change and converting people who were either unaware or sceptical of co-production. Pickersgill (2020:349) went on to argue that while it may already be clichéd to talk about how COVID-19 has exposed 'the fragilities of infrastructures, bodies, economies, and communities … we need to continue to talk about the deficiencies of systems, governments, and leaders'. We offer this edited collection as a continuation of this conversation. As has been illustrated throughout, co-production is now so important because it offers a means through which to address the failures in systems, governments, and leadership that have led to, supported, and/or failed to adequately address inequalities, discrimination, and marginalisation. These failures have exacerbated the toll of this pandemic both in how they play out in societies at large and in how they have shaped health and social care research, policy, and practice both before and during this pandemic.

What we have attempted to do in both volumes of this collection is to illustrate the importance of the experiences and insights of those who are discriminated against, marginalised, and/or excluded, as well as demonstrate *how*, through processes of co-production, they could otherwise contribute to efforts to improve health and social care research, policy, and practice. While guidelines on how co-production can be done in health and social care research, policy, and practice can be useful (eg Hickey et al, 2018; Farr et al, 2020), the examples shared in this collection shed light on the all-important stage of translating theory into practice. We suspect those working in health and social care will find them particularly useful because the prevailing structures and systems of these fields often inhibit or prevent the translation of co-production theory into practice. Therefore, the chapters in this volume represent examples of groups finding ways to do things differently. We hope this brings attention to how much more could be achieved if these systems and structures were changed so that more participatory approaches to creating health and social care research, policy, and practice were better understood, actively promoted, and sufficiently resourced.

This edited collection is a contemporary account of co-production that we intend to be used both as a resource to inform the particular challenges of co-producing during a pandemic *and* as a means to aid navigation of the known and unknown co-production challenges of the post-pandemic landscape. For instance, we hope the digital innovations that played a significant role in facilitating co-production during the pandemic continue to be utilised and developed. However, existing inequalities mean that such innovations are limited in their reach and capacity to fulfil co-production's egalitarian imperative. Such innovations should not be used in the future as a cheap means of presenting the illusion of inclusive practice and/or to undermine calls for participatory approaches in health and social care to be better resourced.

Pandemics present significant challenges for decision-makers and health and social care systems, and are liable to have fatal consequences irrespective of how decisions are made. As such, co-production is certainly no panacea. However, we assert that more inclusive and participatory approaches – that explicitly address inequalities and inequities – would improve pandemic responses. This edited collection highlights the value of co-production and how health and social care can better support and do co-production. Although it has been framed by the COVID-19 pandemic, its content is relevant to what was happening before and what will happen after the pandemic. Our hope now is that this collection, and any critical engagement it inspires, will challenge and support health and social care research, policy, and practice to address inequalities and inequities. 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'.

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