RAPID
RESPONSE

COVID-19 AND CO-PRODUCTION IN HEALTH AND SOCIAL CARE RESEARCH, POLICY, AND PRACTICE

Volume 1: The Challenges and Necessity of Co-production

EDITED BY
PETER BERESFORD
MICHELLE FARR
GARY HICKEY
MEERAT KAUR
JOSEPHINE OCLOO
DOREEN TEMBO
OLI WILLIAMS

RAPID RESPONSE

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

Volume 1: The Challenges and Necessity of Co-production

Edited by

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

First published in Great Britain in 2021 by

Policy Press, an imprint of
Bristol University Press
University of Bristol
1–9 Old Park Hill
Bristol
BS2 8BB
UK
t: +44 (0)117 954 5940
e: bup-info@bristol.ac.uk

Details of international sales and distribution partners are available at policy.bristoluniversitypress.co.uk

Editorial matter and selection © the editors. Individual chapters © their respective authors, 2021

British Library Cataloguing in Publication Data
A catalogue record for this book is available from the British Library

ISBN 978-1-4473-6177-0 OA ePub
ISBN 978-1-4473-6176-3 OA Pdf

The digital PDF and ePub versions of this title are available Open Access and distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International license (https://creativecommons.org/licenses/by-nc-nd/4.0/) which permits reproduction and distribution for non-commercial use without further permission provided the original work is attributed. The derivative works do not need to be licensed on the same terms.

The rights of Peter Beresford, Michelle Farr, Gary Hickey, Meerat Kaur, Josephine Ocloo, Doreen Tembo, Oli Williams to be identified as editors of this work have been asserted by them in accordance with the Copyright, Designs and Patents Act 1988.

All rights reserved: no part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical, photocopying, recording, or otherwise without the prior permission of Bristol University Press.

Every reasonable effort has been made to obtain permission to reproduce copyrighted material. If, however, anyone knows of an oversight, please contact the publisher.

The statements and opinions contained within this publication are solely those of the editors and the contributors and not of the University of Bristol or Bristol University Press. The University of Bristol and Bristol University Press disclaim responsibility for any injury to persons or property resulting from any material published in this publication.

Bristol University Press and Policy Press work to counter discrimination on grounds of gender, race, disability, age and sexuality.

Contents

Introduction

Part I: The impact of existing structures

Part II: Infection and (increasing) marginalisation

Afterword

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 practised 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.

Funding statements

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

Michelle Farr's time is supported by the National Institute for Health Research Applied Research Collaboration West (NIHR ARC West).

Gary Hickey's time is supported by the Wessex Institute, University of Southampton, and NIHR Research Design Service South East.

Meerat Kaur's time is supported by the National Institute for Health Research (NIHR) Centre for Engagement and Dissemination (CED).

Josephine Ocloo is funded by the National Institute for Health Research (NIHR) Applied Research Collaboration (ARC) South London.

Doreen Tembo's time is supported by the National Institute for Health Research Evaluation, Trials and Studies Coordinating Centre.

Oli Williams is supported by The Health Foundation's grant to the University of Cambridge for the Healthcare Improvement Studies Institute.

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.

Open Access

Open Access publication has been made possible by the Health Foundation, an independent charity committed to bringing about better health and health care for people in the UK, www.health.org.uk.

List of contributors

Alison Allam is an advisory member of the Chronic Illness Inclusion Project. Her research interests include the lived experiences of energy impairment with the aim of improving current policy and practice. She has lived with chronic illness since her teenage years.

Lucy Allwright is an experienced researcher, project manager, and trainer with specialisms in multiple disadvantage, trauma-informed practice, and expert-by-experience participation. She is committed to creating space and platforms for women to have a voice in creating change. She holds a PhD from the University of Warwick and is one of the co-founders of activist group Sisters Uncut.

Ruth Atkinson is a researcher specialising in gender-based violence and multiple disadvantage. Ruth is passionate about co-production and has been involved in key co-production activities at AVA (Against Violence and Abuse). Ruth is currently Co-chair of Imkaan.

Peter Beresford, OBE is Visiting Professor at the University of East Anglia, Co-Chair of Shaping our Lives, and Emeritus Professor at Brunel University London and Essex University. He has a longstanding interest in user and public participation as activist, service user, researcher, educator, and through involvement in policy development.

Amal Beyrouty is a project manager and advice/advocacy coordinator at Women Connect First. Projects include The Golden Years project, Let's Age Well, Together We Can, a mental health project in response to COVID-19, and World

Community Café on Wheels (delivering free meals for vulnerable people impacted by COVID-19).

Usha Boolaky is Assistant Director of Research at the Health Foundation. She leads the Foundation's externally commissioned research programmes and is responsible for building more inclusive research practice into its commissioning approaches. She is also a board member of the Health Service Research UK Network.

Sonia Braham is a professional peer researcher and support worker with a specialism in homelessness, substance misuse, and domestic abuse. Sonia was previously a director/office manager at Lewisham Service Users Consultancy and is currently studying for a degree in business management and leadership.

Sally Brearley is Patient and Public Involvement Fellow in the Faculty of Health, Social Care and Education at Kingston University, and Visiting Senior Research Fellow, Division of Care for Long Term Conditions, King's College London.

Iain Cameron is Manager of Harm Reduction services in Belfast with Extern. He has been a leading advocate and has been instrumental in helping develop Low Threshold services in Northern Ireland.

Anne Campbell is Co-Director of the Drug and Alcohol Network at Queen's University Belfast and a senior lecturer in social work. She is also a member of the UK Advisory Council on the Misuse of Drugs and co-chair of the Advisory Council on the Misuse of Drug Recovery Committee.

Ellen Clifford is a disabled activist and author of *The War on Disabled People: Capitalism, Welfare and the Making of a Human Catastrophe.*

Natalie Creary is Director of Black Thrive Lambeth and Public Health lecturer at Middlesex University. Black Thrive focuses on addressing inequalities across the social determinants of health and co-creating better futures with Black communities. Her research explores how privilege and systems of oppression shape health and wellbeing outcomes.

Amit Desai is Research Fellow at the Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care, King's College London. He is a social anthropologist interested in the use of patient experience and public voice in health care planning and provision.

Mashmooma Din is a project worker for South Riverside Community Development Centre. She was the learning lead locally for the Welsh Government's Communities First programme and has worked on various community educational projects over the last two decades. She also contributed to the design of the English for Speakers of Other Languages policy in Wales.

Harvinder Kaur Dulku is a registered nurse and works as a Living Kidney Donor Transplant Coordinator in the National Health Service. She has been an active part of Central Gurdwara Khalsa Jatha, the oldest established Sikh place of worship in Europe, since 1991.

Mark Dunk is a disabled trade union activist and has written for the peer reviewed *International Socialism Journal.*

Jacqui Dyer, MBE is founder and Chair of Black Thrive Lambeth and Director of Black Thrive Global. She is Mental Health Equalities Advisor to NHS England, President of the Mental Health Foundation and councillor. She is passionate about addressing inequalities and advocating for Black communities to be at the forefront of change.

Eva Elliott is Honorary Research Fellow at the Wales Institute of Social and Economic Research and Data (WISERD) at Cardiff University, School of Social Sciences. She is also a co-director of Straeon (which means 'stories' in Welsh) a research company in south Wales.

Michelle Farr has expertise in participatory and co-produced research and is a research fellow who works at the NIHR ARC West at University Hospitals Bristol and Weston NHS Foundation Trust, and within Population Health Sciences, Bristol Medical School, University of Bristol.

Kathy Faulkner is a specialised social worker in Extern's Low Threshold Service, Northern Ireland. Kathy focuses on harm reduction with street injectors who are often homeless or at risk of homelessness in Belfast.

Savitri Hensman has long worked in involvement and is also a writer. Born in Sri Lanka and active in anti-racist, LGBT+, and disabled people's movements, she is Patient and Public Involvement Coordinator at ARC South London, and a member of Service User Research Enterprise (SURE), King's College London.

Allan Herbert is a community development 'lifer' and restless soul. Formerly at South Riverside Community Development Centre, he is currently involved with Disability Can Do in Caerphilly and River Music & Arts in Cardiff.

Gary Hickey is Senior Research Fellow in the Research Design Service South East at the University of Brighton and Senior Public Involvement Manager at the Wessex Institute at the University of Southampton. He led on the development of the National Institute for Health Research's 'Guidance on co-producing a research project'.

Yasmin Ibison is the Employment Project Support Officer at Black Thrive Lambeth. The project aims to improve employment outcomes for Black people with long-term health conditions through systems change. She is also the Director of the social enterprise Critics' Club, which supports young people to access cultural spaces and the arts.

Naima Iqbal is a professional lived experience researcher who has worked for a number of organisations including AVA, Mcpin, AGENDA, and Manchester Metropolitan

University. Her research specialisms include multiple disadvantage, trauma, and peer support. She is also a qualified gardener and experienced crafter, using these skills to support her community.

Meerat Kaur is part of the Centre for Engagement and Dissemination at the NIHR, and an advisor on collaborative approaches to tackle inequalities for diverse statutory, and community and voluntary organisations. She specialises in collaborative approaches to evaluation that centre on marginalised and racialised communities.

Sarabjit Kaur works in the transport services in London. She has been part of Central Gurdwara Khalsa Jatha since 2014 and has actively volunteered in her local community for over 15 years.

Lela Kogbara was a senior leader in the public sector for 25 years. She is currently Director of Black Thrive Global, which exists to change the odds stacked against Black people by embedding race equity into systemic change so that thriving is not the exception but the norm.

Graham Martin is Director of Research at The Healthcare Improvement Studies Institute (THIS Institute), University of Cambridge. THIS Institute is supported by the Health Foundation, an independent charity committed to bringing about better health and healthcare for people in the UK.

Tess Mc Manus is a parent and carer with 25 years' experience working in user led disabled peoples' organisations supporting local, regional, and national bodies to understand and implement a social model of disability response to the removal of the barriers that disabled people face accessing services and tackling inequalities.

Sophie Metolli is an artist in her late 20s; her work can be viewed on Instagram @sophiefois. She first developed anorexia almost a decade ago while studying at university. During the pandemic, Sophie has been receiving private treatment for her eating disorder and is supported by her support network in her ongoing recovery.

Cristian R. Montenegro is Assistant Professor at the School of Nursing, Pontificia Universidad Católica de Chile, Researcher at the Millennium Institute for Research on Depression and Personality (MIDAP) and advisor to the Chilean Ministry of Health. He co-founded the Platform for Social Research on Mental Health in Latin America (PLASMA).

Lauren O'Connell is a sociologist working in the civil service who has previously lived with eating disorders. She was awarded a PhD from the University of Essex in 2020 for her doctoral research, which drew on her own and others' experiences of being diagnosed with anorexia nervosa.

Josephine Ocloo is a Senior Researcher based at the Centre for Implementation Science, King's College London, and Equality, Diversity, Inclusion lead for the NIHR Applied Research Collaboration, South London. She is a social scientist, qualitative researcher, and activist-scholar, interested in patient safety and participatory methods in collaborating with diverse communities.

Celestin Okoroji is a postdoctoral fellow at the London School of Economics exploring how stigmatisation impedes relations between individuals and groups, particularly in unemployment. Celestin manages an action-research employment project at Black Thrive.

Harry Pitham is a 17-year-old student studying media production. He loves rugby, cycling, and playing the drums. In 2020, he spent five months receiving treatment for anorexia as an inpatient at an NHS eating disorder service.

Fiona Quigley is a PhD student, based at Ulster University, Northern Ireland. Fiona has a background in technology-based training for healthcare professionals and she has lived experienced of an eating disorder and higher weight. Her doctoral research focuses on weight-related communication using virtual reality to help healthcare professionals better understand weight stigma and weight science.

Chris Rintoul is the Drugs and Alcohol Consultant at Extern, a third sector organisation in Ireland. He specialises in harm reduction, and in particular overdose prevention, among people who inject drugs.

Glenn Robert is Professor of Health Care Quality & Innovation at King's College London. His research draws on the fields of organisational studies and organisational sociology, and incorporates the study of innovations in the organisation and delivery of health care services as well as quality improvement interventions.

Cordelia Ruck is Policy and Projects Officer at AVA (Against Violence and Abuse). Cordy holds an MA in migration and diaspora studies and BA in social anthropology. She has experience working and researching in humanitarian and homelessness settings and is particularly interested in embedding survivor-led approaches in support and research endeavours.

The Secret Welfare Rights Worker has worked supporting people with their welfare benefits issues for many years, first as a qualified and registered professional social worker and now as a welfare rights worker. They remain anonymous to protect the people they work with.

Sophie Staniszewska leads the Patient and Public Involvement (PPI) and Patient Experiences Programme at Warwick Research in Nursing, Warwick Medical School, University of Warwick. Sophie is Co-Editor in Chief of the Springer Nature journal *Research Involvement and Engagement.*

Felipe Szabzon is Researcher at the Brazilian Centre for Analysis and Planning (CEBRAP) and at the Centre for Psychiatric Epidemiology at the University of São Paulo Medical School (IPq – FMUSP). He co-founded the Platform for Social Research on Mental Health in Latin America (PLASMA).

Doreen Tembo is Senior Research Manager at the UK NIHR Evaluation Trials and Studies Coordinating Centre at the Wessex Institute at the University of Southampton. Her research focuses on patient and public involvement, co-production, research management, health policy, and health systems research.

Bob Singh Virdee is an optometrist, husband, father, and wanderluster. He has been involved in Sikh activism since the mid-1990s and has been an active supporter and volunteer for Khalsa Aid, an international non-governmental organisation, since 2010.

Helen West is a registered dietitian specialising in eating disorders and weight inclusive approaches to health. She currently works at the Brighton and Hove Clinic, a specialist inpatient centre for young people with anorexia.

Oli Williams is a postdoctoral research fellow based at King's College London and funded by the Health Foundation's grant to the University of Cambridge for THIS Institute. His research focuses on 'obesity', weight stigma, co-production, health inequalities, and the promotion of health equity.

Giulia Zoccatelli is a research fellow at the Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care, King's College London. A social and medical anthropologist by background, her research focuses on medical activism and patient involvement in China and the UK.

Introduction

1

The challenges and necessity of co-production

Introduction to Volume 1

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

The COVID-19 pandemic has drastically altered people's lives. While pandemics have of course occurred before, for modern times COVID-19 has been unusually destructive and inhibitory in scale. However, what this pandemic shares with previous ones is having a disproportionately detrimental impact on people who were already disadvantaged by structural inequalities before the pandemic began (Bambra et al, 2020; Marmot et al, 2020). The virus has been particularly pervasive and destructive in its impact on Black, Asian, and minoritised ethnic groups; people of lower socioeconomic status; people in undervalued employment; people living in deprived areas, poor housing, and/or overcrowded accommodation; older people; disabled people; people with learning difficulties; people with psycho-social disabilities; and people with long term conditions – especially those who rely on social care. This has caused us to reflect on the relative strengths and weaknesses of approaches typically taken in modern politics and public policy in general, and health and social care specifically, as well as to consider alternatives that could better serve us in the future. For us, key among these alternative approaches is co-production.

Predictably, those most severely affected by COVID-19 are the people and groups who are now largely being ignored in developing responses to the pandemic and consequently are further detrimentally impacted by it – in many cases fatally. Co-production offers an alternative. It is consistent with efforts to challenge the exclusionary nature of much ideology underpinning health and social care policy and practice and to move to more inclusive and participatory approaches (Beresford, 2021). Therefore, our aim has been to begin to redress current failings by ensuring that marginalised voices and viewpoints can be better heard and by demonstrating how co-production can enable this to happen. This aim has led to the creation of a two-volume edited collection for Policy Press' Rapid Responses pandemic series (https://bristoluniversitypress.co.uk/rapid-responses). Collectively, the contributions to these volumes set out *why* co-production is valuable and *how* it can be done. They explore the urgency with which co-production and participatory approaches need to be incorporated into responses to the pandemic and offer examples which have relevance beyond the current health crisis. It is a practical collection and as such demonstrates how researchers, policymakers, practitioners, patients, service users, carers, activists, communities, and public contributors can co-produce better health and social care research, policy, and practice both now and in the future.

In this introduction, we provide some context for the book, outlining how we define co-production and the challenges and necessity of co-production. We then locate co-production in the contexts of the wider participation movement and the COVID-19 pandemic. The introduction ends with some reflections on the challenges we faced while collaborating to create an edited collection on co-production during this pandemic.

Defining co-production

Co-production is one of those concepts, like 'community', 'empowerment', and 'resilience', that has tended to be undermined by being reduced to a buzzword (Williams et al, 2020a); jargon regurgitated without clear definition. We appreciate that co-production is a contested term and as such the need to clarify how we are conceptualising it

(Carr, 2018). We did not want to exclude good practice by being too prescriptive in our definition, but central to our understanding of co-production in this book are processes through which inequalities in power are acknowledged and addressed to facilitate collaboration. In this edited collection, co-production 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. We are committed to an approach that supports and encourages diverse, equitable, and inclusive participation in collaborative partnerships and decision-making processes. This approach enables and supports people who occupy less powerful roles as citizens, activists, patients, carers, and/or service users to form collaborative, cooperative, and meaningful partnerships with others, rather than being ignored or given responsibility to find solutions to problems they face without the power to cause the change necessary for improvement or resolution. Prevailing structures of inequality and discrimination inhibit participation in co-production and encourage tokenistic practice, though we do not believe they rule out possibilities for change or co-production altogether (see Williams et al, 2020b). However, it is important to understand how existing structures and organisational norms create many different inequities, which make it more challenging for everyone's voices to be heard and be influential within co-production processes. For instance, meaningful co-production is about sharing power and many people will need support to participate equitably. This requires investment in resources dedicated to organisational and personal development and facilitation of collaboration.

The COVID-19 pandemic has highlighted how far away we are in this respect and how crucial co-production is for improving health and social care research, policy, and practice. The experiences of the most marginalised in our society are not typically having a direct influence on the policy and practice that has ostensibly been created for their protection. How is it that so many people can be excluded at a time when we have all been rallied to contribute to a national, or indeed global, effort? Things need to change.

This edited collection:

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

The grave consequences of following the precedents set during this pandemic – in terms of morbidity, mortality, marginalisation, and wasteful ineffective policy – emphasise the urgency to do things differently. To achieve these aims, this collection 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 are addressed in this volume and Volume 2 (https://policy.bristoluniversitypress.co.uk/covid-19-and-coproduction-in-health-and-social-care-1) is dedicated to addressing Part III.

The challenges and necessity of co-production

In this volume, we position the response to the pandemic within its sociopolitical context and in relation to the history of the participatory movement in health and social care research, policy, and practice. We demonstrate how hard-earned progress made in recent decades to ensure lived and user experience informs research, policy, and practice, has generally not been reflected in responses to the pandemic. Rather we highlight the numerous examples where lived and user experience has been excluded from key decision-making processes and how its absence has led to discriminatory, inequitable, and ineffective health and social care research, policy, and practice.

In the Part I, 'The impact of existing structures', contributors variously involved in health and social care research, policy, and practice examine how (un)prepared our health and social care system was to co-produce responses to COVID-19. The chapters address the various limitations of many funders, institutions, and systems and show how inadequate resourcing and attention given to collaborative and inclusive ways of working before the pandemic, severely limited the potential for co-producing responses to it. These limitations created and perpetuated power imbalances, discrimination, and exclusion of many different groups. Chapters in this volume and Volume 2 also include examples of where infrastructure and resources for – and a culture of – co-production existed (or their absence was overcome) and how this allowed certain people, communities, and institutions to co-produce responses.

In Part II, 'Infection and (increasing) marginalisation', provides a platform for marginalised communities, groups, and people to describe and explain how they have been affected by this pandemic and to illustrate their experiences. This has created an opportunity for some of those who have been disproportionately disadvantaged and discriminated against prior to and during this pandemic, to share their experiences and views in their own words. Of course, these chapters do not represent an exhaustive collection of marginalised accounts nor the outcome of some ranking exercise. There are many accounts that are not here but could and perhaps should have been. For example, patients with pre-existing conditions who were unable to access care for their condition due to the COVID-19 response, those who are precariously employed and low-paid, and people without citizenship status. However, together, the chapters in Parts I and II (which make up Volume 1) should help to highlight to readers *why* co-produced responses are so important and could have improved national responses to the pandemic.

The third part can be found in Volume 2 (https://policy.bristoluniversitypress.co.uk/covid-19-and-coproduction-in-health-and-social-care-1) and principally addresses *methods*, the means of co-producing both now and in the future. The focus is on *how* co-production has happened during the pandemic and *how* others can follow this example elsewhere both during the pandemic and beyond. Approaches to co-production are explored through practical examples from a diverse range of international settings. Each chapter outlines and explains how teams have operated within existing structures (or attempted to create new ones) in order to co-produce responses to the pandemic while working within the restrictions of lockdowns and social distancing. Consideration is also given to the limitations of pre-pandemic practice and the new ways of working that we have been forced, to some extent, to negotiate and/or create. Predictably, digital innovation and utilisation are key themes and illustrate how many teams have co-produced at a distance during the pandemic. There are also calls not to make digital the default choice for the future and the necessity of considering the impact that growing digital divides within society have on participation in predominantly digitally-facilitated co-production endeavours. These international examples help us to reflect on the relative 'inevitability' of the response in any given country and context and the different possibilities that existed/exist but were/are otherwise marginalised or ignored.

To make the book as practical as possible we asked the authors of each chapter to end with their priorities for 'What needs to be done' to address the issues and better serve the groups and communities discussed in their chapters. We hope readers will find these priorities instructive and that they help them to work with and better support people in their own communities and practice.

The pandemic and the movement for participation

At the time of writing, there have been more than 111 million cases of COVID-19, resulting in more than 2.5 million deaths (World Health Organization, 2021). This figure will of course inevitably be quickly out of date. What is likely to persist however, is the huge variation in outcomes. Some of the most advanced economies have had the highest death rates, notably the United Kingdom (UK) and United States of America (USA). There have been significantly different political and policy responses to the pandemic, some catastrophically unsuccessful, others pre-empting longer-term problems. For instance, Brazil and the USA, whose presidents questioned the existence of the virus and conventional public health responses to it, have had disproportionately high death tolls. Meanwhile New Zealand and Taiwan acted more swiftly and effectively and have had far fewer cases (World Health Organization, 2021). Clearly there will be various reasons and explanations for variations between countries, but it has perhaps never been more evident that public health is political (Chiolero, 2020; Horton, 2020).

Politically and materially, this pandemic has exposed how severe the consequences of social marginalisation can be. The pandemic and responses to it have highlighted, exacerbated, and created disparities in mortality and morbidity. So many people with knowledge and experience pertinent to addressing some of the most pressing issues within the pandemic have been ignored and ‘solutions’ derived without their input have gone on to have dire and, in many cases, fatal outcomes. This was not inevitable. Rather, it is contrary to recent policy and political developments.

In public administration, in recent decades traditional authorities, conventional notions of expertise, and top-down models of management have been challenged as recognition has grown that traditional hierarchies exclude people with important knowledge and experience. This challenge has been driven by a 'movement for participation' which has sought to ensure that people who have traditionally been excluded from processes of knowledge creation and decision-making are instead able to actively participate in these tasks through processes of involvement and co-production (Beresford, 2019). This has involved actively addressing and finding ways to rebalance hierarchies and inequalities in power – a key principle and task of co-production. The advances this movement has made have led to some profoundly important innovations in research, policy, and practice. Notable advances have been made in the public sector most obviously affected by the pandemic: health and social care. In health and social care, a whole literature and new ways of working have developed, and requirements for such participation are now enshrined in law (Beresford and Carr, 2018). Yet there is still significant progress to be made. The sense of crisis and emergency during the pandemic has meant that in some societies this progress has often been undermined or ignored entirely. For instance, in the nations that make up the UK, the promise of participatory decision-making processes in health and social care research, policy, and practice and the accompanying 'nothing about us without us' mantra has been 'left hanging in the breeze' (Richards and Scowcroft, 2020).

Though some progress has been made in recent decades, it is important not to overstate this. We acknowledge that when participatory processes and co-production have been adopted or manufactured in public institutions pre-pandemic they have often simply reproduced the status quo and existing hierarchies (Moini, 2011). Such failures have meant that the very groups most disadvantaged by inequalities have still been largely excluded, and yet an illusion of more inclusive and equitable practice has been presented (Beresford, 2013; 2019; Ocloo et al, 2021; Ocloo and Matthews, 2016; Rose and Kalathil, 2019). This is why action led by communities themselves and representing commonly marginalised people and groups is so important (Beresford and Carr, 2018). This is especially crucial during a pandemic (Jones et al, 2020; Marston et al, 2020).

The marginalisation of Black, Asian, and minoritised ethnic people in relation to the British government's pandemic policies offers an example of failure to respond inclusively and effectively. On 25 May 2020 George Floyd, an African American man, was killed in the USA by a white police officer kneeling on his neck for approximately eight minutes as he arrested him. This flagrant abuse of power sparked the expansion of the existing international Black Lives Matter movement and prompted global demonstrations. These events brought significant attention to existing structures of racism and discrimination and, due to their timing, focused a spotlight on disparities in the risk and outcomes of COVID-19. Yet policymakers in the UK did not pay sufficient attention to either the impact of COVID-19 on Black, Asian, and minoritised ethnic communities, nor the need to involve them in their response to it. Black, Asian and people from other minoritised ethnic groups have been and continue to be disproportionately and detrimentally impacted by COVID-19. However, a report by Public Health England on disparities in the risk and outcomes of COVID-19 was widely criticised for its framing of ethnic disparities and lack of recognition of the role of and need to address structural discrimination (PHE, 2020a; PHE, 2020b; Moore, 2020). Of particular significance to discussions 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. This 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 that had supplied evidence to the review, many explicitly stated that racial discrimination contributed to the increased risk from COVID-19 and made recommendations for what is needed to address this (Iacobucci, 2020). These issues are picked up and explored further in this volume in Chapters 2, 3, and 5.

The failure to involve or even consult those disproportionately disadvantaged by the pandemic was also evident with other and intersecting marginalised groups. Disabled people with vast experience of social isolation could have made valuable contributions to 'shielding' policies and social care provision and yet typically were not invited to contribute to decision-making processes. Not enough effort was put into engaging with mental health service users/survivors and their organisations, who have developed their own strategies to deal with the consequences of social isolation. Chapter 10 demonstrates how protected characteristics offered little protection to disabled people during the pandemic. Consulting domestic abuse organisations was an after-thought despite lockdown having clear ramifications for victims and potential victims of domestic abuse. Chapter 12 explores some of the issues of gender-based violence and the need for co-production with women with experience of it. All these marginalised groups and many more could have contributed their knowledge and ideas if policymakers had sought them. Though even then, adopting co-production processes does not mean that these groups always are heard, nor their agendas acted upon, and we recognise there are many daily battles to ensure these inequities are addressed.

Pandemics present significant challenges for decision-makers and are liable to have fatal consequences irrespective of how decisions are made. Although co-produced responses are certainly no panacea, there have been many examples of problems created by the failure to respond to this pandemic in inclusive and participatory ways. We know that innovative participatory and co-produced approaches to health and social care research, policy, and practice can ensure that invaluable experiential knowledge makes an important and unique contribution – our ambition for this collection is to demonstrate *how* and *why*.

Reflections on the challenges of publishing on participation during a pandemic

We have sought to adhere to the principles of participatory practice through the development of this book: accommodating different types of contributions; supporting people with writing and encouraging collaborative contributions; and developing equitable methods of recognising editorship and authorship. However, we acknowledge that both external and internal factors meant we faced significant challenges in attempting to achieve these aims and we were not always successful. The history of the book's development is as follows. One of us (Peter) was approached by Policy Press, a not-for-profit publisher, to write an e-book that was to be published quickly in order to offer contemporary, rather than retrospective, accounts of co-production in relation to COVID-19. The benefit of this is that it gives the book the potential to inform and improve current practice. In order to make this a more participatory venture, other service users and researchers (including those who see themselves as both of these) were approached to see if they had the interest and capacity to form an editorial team and take this idea forward. At this point, Oli, Doreen, Gary, Meerat, Michelle, and Josephine formed an editorial team with Peter. The enthusiasm with which this idea was greeted demonstrates both the value and the interest there now is in co-production. The team of editors assembled was highly diverse, motivated, and committed to contributing equitably to the project. One member (Oli) was granted permission by his funder to incorporate this project into his current research agenda, which made the task achievable.

All the editors were well versed and networked in participatory practice and co-production so we were able to embark on this project much more speedily than might otherwise have been the case. Our strong links with people actively working in these areas made it possible to engage a wide range of contributors including participants from both the Global South as well as the Global North. We began to realise that the breadth of material we could draw on was more than could be included in a single volume rapid response so instead we expanded the publication to become two closely related volumes addressing the hows and whys of co-production in relation to the COVID-19 pandemic. Key to our goal was to make the texts accessible, inclusive, and widely available. We were able to secure funding to make the books 'open access', so that they are freely available. We are grateful to The Health Foundation for making funding available for this.

We realise of course that these books will have many limitations and we want to be honest about these. The books had to be produced quickly and that imposed constraints on who could take part and how inclusive this project could be. However, 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 also wanted to take the opportunity to demonstrate the importance of co-production in addressing global issues and disasters like COVID-19. We have tried to be honest about the limitations as well as the achievements of this project. We share these challenges and 'failures' with you because we believe it is important to give honest accounts of participatory practice, as doing so helps to highlight the need to critically reflect on the theory and practice of co-production.

Co-production during the pandemic and beyond

The need for this work is practical, political, and academic – and of relevance to both the initiated and uninitiated in co-production. Practically, those who are already familiar with the concept of co-production and convinced of the value of working in this way are facing significant challenges. Due to its collaborative and inclusive aims, co-production more usually relies on bringing people together. Now we are faced with the challenge of co-producing at a distance – a notion that is somewhat contradictory for some practitioners but perceived as an opportunity by others. By highlighting in this edited collection the barriers that people have faced before and during this pandemic we hope we have helped prepare and better equipped people for the next health crisis and for making the 'new normal' better than the old one.

The intended impact of this book is to support and promote the creation of structures and practices that facilitate co-production in health and social care both during the pandemic but, importantly, after the impact of COVID-19 has been minimised. The movement for participation has made some strides in recent decades, but the context in research and health and social care policy and practice, and the way the pandemic has played out, has demonstrated that this progress is neither complete nor irreversible. By presenting the hows and whys of co-production in this publication our aim is to offer insight and guidance that will support policymakers, health and social care practitioners, patients, service users, carers, activists, communities, and public contributors to create and promote more diverse, collaborative, equitable, and effective decision-making processes in health and social care research, policy, and practice both now and in the future.

References

Bambra, C., Riordan, R., Ford, J., and Matthews, F. (2020) 'The COVID-19 pandemic and health inequalities', *Journal of Epidemiology Community Health*, 74(11): 964–968.

Beresford, P. (2013) *Beyond the usual suspects: Towards inclusive user involvement—Findings*, London: Shaping Our Lives.

Beresford, P. (2019) 'Public participation in health and social care: exploring the co-production of knowledge', *Frontiers in Sociology*, 3: 41.

Beresford, P. (2021) *Participatory Ideology: From exclusion to involvement*, Bristol: Policy Press.

Beresford, P. and Carr, S. (eds) (2018) *Social policy first hand: An international introduction to participatory social welfare*, Bristol: Policy Press.

Carr, S. (2018) 'Who owns co-production?', in P. Beresford and S. Carr (eds), *Social policy first hand: An international introduction to participatory welfare*, Bristol: Policy Press. pp 74–83.

Chiolero, A. (2020) 'Is science ever enough? Dare to play politics', *The Lancet*, 397(10268): 23.

Horton, R. (2020) 'Offline: science and politics in the era of COVID-19', *The Lancet*, 396(10259): 1319.

Iacobucci, G. (2020) 'Covid-19: PHE review has failed ethnic minorities, leaders tell BMJ', *BMJ*2020,369: m2264.

Jones, N., Byrne, L., and Carr, S. (2020) 'If not now, when? COVID-19, lived experience, and a moment for real change', *The Lancet Psychiatry*, 7(12): 1008–1009.

Marmot, M., Allen, J. Goldblatt, P. Herd, E., and Morrison, J. (2020) *Build back fairer: the COVID-19 Marmot review. The pandemic, socioeconomic and health inequalities in England, London*: Institute of Health Equity.

Marston, C., Renedo, A., and Miles, S. (2020) 'Community participation is crucial in a pandemic', *The Lancet*, 395(10238): 1676–1678.

Moini, G. (2011) 'How participation has become a hegemonic discursive resource: towards an interpretivist research agenda', *Critical Policy Studies*, 5(2): 149–68.

Moore, A. (2020) 'Exclusive: Government censored BAME COVID-risk review', *Health Service Journal*, https://www.hsj.co.uk/

coronavirus/exclusive-government-censored-bame-covid-risk-review/7027761.article

Ocloo, J. and Matthews, R. (2016) 'From tokenism to empowerment: progressing patient and public involvement in healthcare improvement', *BMJ Quality & Safety*, 25(8): 626–632.

Ocloo, J., Garfield, S., Dean Franklin, B., and Dawson, S. (2021) 'Exploring the theory, barriers and enablers for patient and public involvement across health, social care and patient safety: a systematic review of reviews', *Health Research Policy and Systems*, 19(1): 1–21.

Public Health England (2020a) *Disparities in the risk and outcomes of COVID-19*, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892085/disparities_review.pdf

Public Health England (2020b) *Beyond the data: understanding the impact of COVID-19 on BAME groups*, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892376/COVID_stakeholder_engagement_synthesis_beyond_the_data.pdf

Richards, T. and Scowcroft, H. (2020) 'Patient and public involvement in COVID-19 policy making', *BMJ* 2020, 370: m2575.

Rose, D. and Kalathil, J. (2019) 'Power, privilege and knowledge: The untenable promise of co-production in mental "health"', *Frontiers in Sociology*, 4: 57.

Williams, O., Robert, G., Martin, G.P., Hanna, E., and O'Hara, J. (2020a) 'Is co-production just really good PPI? Making sense of patient and public involvement and co-production networks', in M. Bevir and J. Waring (eds), *Decentring health and care networks: Reshaping the organization and delivery of healthcare*, Cham: Palgrave Macmillan. pp 213–237.

Williams, O., Sarre, S., Papoulias, S.C., Knowles, S., Robert, G., Beresford, P., Rose, D., Carr, S., Kaur, M., and Palmer, V.J. (2020b) 'Lost in the shadows: reflections on the dark side of co-production', *Health research policy and systems*, 18: 1–10.

World Health Organization (2021) WHO Coronavirus Disease (COVID-19) Dashboard, Accessed 25th Feb 2021, https://covid19.who.int/?gclid=CjwKCAiAt9z-BRBCEiwA_bWv-C8YUUU1rAjj_iewqn1snjHZGGgS-HUIJc86ysoUM-kRs8UdKNTlDhoCpOMQAvD_BwE

PART I

The impact of existing structures

2

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

Savitri Hensman

Introduction

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

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

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

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

Conflicting trends and the rise of co-production

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

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

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

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

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

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

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

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

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

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

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

Abusing state power and the tangle of consequences

In the decade leading up to the pandemic, though the term 'co-production' was sometimes loosely used, there were many genuine instances of this approach. Awareness grew in the NHS and health research field of its potential

(NIHR, 2015). Yet harsh spending restrictions and mistrust were overshadowing public services, and inequalities were deepening, damaging physical and mental health treatment and care (Gray, 2017), especially for those facing multiple forms of disadvantage and discrimination (Hall et al, 2017).

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

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

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

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

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

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

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

Looking ahead

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

What needs to be done

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

Acknowledgements

The views expressed are those of the author and not necessarily those of the NIHR or the Department of Health and Social Care.

I would like to thank Angela Sweeney, Director of the Service User Research Enterprise, Health Service and Population Research department, King's College London, for commenting on drafts; also the editors and the many people whose views and experiences over the years have informed the ideas in this chapter.

References

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

Gray, E. (2017) 'Health and social care spending cuts linked to 120,000 excess deaths in England', *BMJ Open*, 15.

Bovaird, T. and Downe, J. (2008) 'Innovation in public engagement and co-production of services', *Policy paper for Department of Communities and Local Government*, 39, https://www.researchgate.net/publication/271517523_Innovation_In_Public_Engagement_And_Co-Production_Of_Services_Policy_Paper_for_Department_for_Communities_and_Local_Government?channel=doi&linkId=54ca8eed0cf22f98631b8cd0&showFulltext=true

Butler-Warke, A. and Hood, C. (2020) *Disposable humans?*, https://www.cost-ofliving.net/disposable-humans/

Carers UK (2020) *Caring behind closed doors: Six months on*, https://www.carersuk.org/for-professionals/policy/policy-library?task=download&file=policy_file&id=7279

Cochrane, A. (2004) 'Modernisation, managerialism and the culture wars: the reshaping of the local welfare state in England', *Local Government Studies*, 30(4): 481–496.

Drabble, L. A. and Eliason, M.J. (2021) 'Introduction to Special Issue: Impacts of the COVID-19 pandemic on LGBTQ+ health and well-being', *Journal of Homosexuality*, 68(4): 1–15.

GI-ESCR (Global Initiative for Economic, Social and Cultural Rights) (2020) *'Enough is enough': UN Experts' open editorial sparks worldwide media interest*, https://www.gi-escr.org/latest-news/enough-is-enough-un-experts-open-editorial-sparks-worldwide-media-interest

Hall, S.M., McIntosh, K. et al (2017) *Intersecting inequalities: The impact of austerity on Black and Minority Ethnic women in the UK*, http://wbg.org.uk/wp-content/uploads/2018/08/Intersecting-Inequalities-October-2017-Full-Report.pdf

McIntosh, K. (ed) (2020) *From expendable to key workers and back again*, Runnymede, https://www.runnymedetrust.org/projects-and-publications/equality-and-integration/immigration-and-the-lottery-of-belonging.html

Needham, C. and Carr, S. (2009) SCIE Research Briefing 31: *Co-production: An emerging evidence base for adult social care* *transformation*, https://www.scie.org.uk/publications/briefings/briefing31/

NIHR (2015) *Going the extra mile: improving the nation's health and wellbeing through public involvement in research*, https://www.nihr.ac.uk/documents/about-us/our-contribution-to-research/how-we-involve-patients-carers-and-the-public/Going-the-Extra-Mile.pdf

O'Neill, G.C. (2020) *I'm a Romany Gypsy – why is racism against us still acceptable?*, https://www.theguardian.com/commentisfree/2020/jun/15/romany-gypsy-racism-britain-prejudice-roma-travellers

Romanou, E. and Belton, E. (2020) *Isolated and struggling: social isolation and the risk of child maltreatment, in lockdown and beyond*, NSPCC, https://learning.nspcc.org.uk/research-resources/2020/social-isolation-risk-child-abuse-during-and-after-coronavirus-pandemic

Trussell Trust (2020) *Lockdown, lifelines and the long haul ahead*, https://www.trusselltrust.org/wp-content/uploads/sites/2/2020/09/the-impact-of-covid-19-on-food-banks-report.pdf

UN (2019) *Visit to the UK: Report of the Special Rapporteur on extreme poverty and human rights*, http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=dtYoAzPhJ4NMy4Lu1TOebAzm3S%2bNFShY%2b1IJSrJyNRNI9%2bNcX4M5H1YuOc7S2e8O2KWm0VfyF1xIdm7gfDYZnShBY70j3zH9An44jvrYMNQUXnOValiFnL50H0SjP36O

UN (2021) *View country visits of special procedures of the Human Rights Council since 1998: UK*, https://spinternet.ohchr.org/ViewCountryVisits.aspx?visitType=all&country=GBR&Lang=en

UN CRPD (2017) *Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland*, https://digitallibrary.un.org/record/3850216/files/CRPD_C_GBR_CO_1_Add-1-EN.pdf

Women's Aid (2020) *Women's Aid responds to the latest ONS stats on domestic abuse*, https://www.womensaid.org.uk/womens-aid-responds-to-the-latest-ons-stats-on-domestic-abuse/

Wren-Lewis, S. (2018) 'How the media forgot about the financial crisis and embraced austerity', *Open Democracy*, https://neweconomics.opendemocracy.net/media-forgot-financial-crisis-embraced-austerity/

3

Silenced voices, unequal impact

Addressing health inequities and discrimination in co-producing health and care during the pandemic and beyond

Josephine Ocloo

The COVID-19 pandemic has shone a disturbing light on the stark inequities and discrimination that exists in the United Kingdom. Social, environmental, and economic inequalities in society have been exposed as disproportionately damaging to the health and wellbeing of a number of groups. Inequalities in COVID-19 mortality rates illustrate a similar social gradient to that seen for all causes of death and in the accessibility of healthcare (Marmot et al, 2020). The COVID-19 Marmot Review (Marmot et al, 2020) has illustrated that this inequity in society lies at the heart of why some groups have higher mortality rates and have been more severely affected by the pandemic than others. For example, Office for National Statistics, have shown the unequal mortality impact of the virus on Black and Asian groups (ONS 16 Oct, 2020a), those with disabilities (ONS 11 Feb, 2021), and those living in the most deprived areas (ONS 28 Aug, 2020b). Overall, the Marmot Review on the pandemic and health inequalities, has shown that the likelihood of mortality from COVID-19 is lower among people who are wealthy, working from home, living in good quality housing, White, and have no underlying health conditions (Marmot et al, 2020). This situation is why tackling discrimination and ensuring equity and social justice for excluded groups, including in the way we conduct research with these groups, is so essential in co-producing health and social care.

The policy context for public involvement in research

In the UK, as in other developed countries, public involvement is now established as a central aspect of health research policy (Boote et al, 2015) and practice (NHS Constitution, 2012). The National Institute for Health Research (NIHR) was established in the UK in 2006 to improve the health and wealth of the nation through research. A strategic objective was the need to ensure patients and the public were involved in all stages of the research process. This was considered to lead to better research, that was more relevant and likely to be implemented (Dept. of Health, 2006:34). As far back as 2005, the National UK Research Governance Framework called for research and for those pursuing it, to respect human diversity and the multicultural nature of society, whenever relevant, to take account of age, disability, gender, sexual orientation, race, culture, and religion in its design, undertaking, and reporting (Dept. of Health, 2005).

Unequal involvement

Despite this context, achieving the goals of involvement and partnership with the public has not been straightforward, particularly when it comes to involving the voices of diverse individuals, groups, and communities. In 2012, the organisation INVOLVE, a national advisory group that supported greater public involvement in the NHS, public health and care research, raised concerns about the model of public involvement and who was being included and excluded. Evidence suggested those being involved were the ‘easiest’ to include, who tended to come from a relatively narrow section of the population (INVOLVE, 2012:3). This evidence, about the lack of equality and diversity in public involvement in research has been reinforced consistently since then (Beresford, 2013; NIHR, 2015; Ocloo and Matthews, 2016). These conclusions also reflect patterns of patient and public involvement (PPI) in other areas of public participation (Ocloo and Fulop, 2011; Ocloo and Matthews, 2016; Ocloo, 2018). This shows that those most likely to be involved are from older age groups and from white ethnic and higher socio-economic backgrounds (Ocloo, 2018). This stands in contrast with those people who are most likely to use health and social care services, or who are often the target of public health initiatives, and indeed the people who are disproportionately disadvantaged by societal inequities and consequently most affected by the COVID-19 pandemic (Ocloo, 2020).

Strengthening public involvement in research during and post-pandemic

The NIHR Centre for Engagement and Dissemination (CED), is a new organisation that builds on the work of INVOLVE. The CED has made clear its commitment to ensuring patients, carers, and the public have a say in, and help shape health and care research during the COVID-19 pandemic. This is in line with its long-standing commitment to PPI, engagement, and participation in health and care research. This strategic commitment provides a clear and important opportunity to properly address prior failings in involvement strategies and instead ensures that equity, diversity, and working with marginalised groups and communities, is central to, and supports the successful implementation of, research and co-production. This is critical to being able to challenge the current imbalances of power and inequities in health and social care services that affect different sections of the population.

Power, equity, and diversity

PPI has long been criticised for its top down approach where organisations ‘handpick’ who can be involved and how (Ocloo and Matthews, 2016). New models of co-production must address the fact that current involvement structures largely reflect the same stratification processes and inequities of race, gender, class, disability, and sexuality as in the wider society. This is apparent not only in who is able to participate as public members in research and practice, but in who leads with academic research projects and initiatives associated with involvement, participation, and co-production processes. The top down approach creates the risk of reinforcing the differences in the health of individuals or groups in society (health inequalities), and even worse, of the perpetuation of health inequities, which occur as a result of unjust differences or a lack of fairness in social structures, including those in health and social care. Linking involvement activities to actively challenging health inequities, as part of co-producing health and social care, is therefore fundamental.

When thinking about co-production, addressing issues of power, equity, diversity, and inclusion, need to be central to this process, as well as addressing the considerable organisational enablers and constraints that exist in practice (Ocloo et al, 2021). An intersectional approach is key, one that recognises that patients, service users, carers, and the public are not homogenous groups. Doing so would be ‘denying the reality that individuals’ economic, political, cultural, subjective and experiential lives intersect in intricate and multifarious ways’ (Sandhu et al, 2013:2). Therefore, key approaches to take into account in co-production include: (a) working with those covered by the nine equality strands or legally ‘protected characteristics’: age, disability, gender reassignment, race, religion or belief, sex, sexual orientation, marriage and civil partnership, and pregnancy and maternity (Equality Act, 2010); (b) involving specific groups whose voices are seldom heard in health and social care research such as those who have been in prison, have experiences of seeking asylum or being homeless, and many other groups that should be considered depending on what research is being conducted (Beresford, 2010); (c) identifying people with different perspectives, experiences, skills, and knowledge required for any given task, as the best starting point (INVOLVE, 2012).

Given that research is still being ‘done to’ so many groups who continue to be excluded, rather than in partnership with people and communities, one way to embed more equity into the process is to draw upon more community based methods that combine research and practice, such as participatory action research (PAR). Hall (2001:174) has argued that participatory research is not something that was invented by researchers, educators, or even community activists. This type of practice has always been in existence wherever oppressed and marginalised groups have struggled collectively to understand and to take action, to tackle inequalities of power in their social worlds. In the context of research as participation, PAR can be defined loosely as: ‘systematic inquiry, with the collaboration of those affected by the issues, for the purposes of education or affecting social change’ (George et al, 1998–1999 cited in Minkler et al, 2002:14).

Health and social care research and services can therefore take inspiration from the creative and collectively constructed practices within communities and social movements. This way of working can help facilitate or create ‘new processes for collective knowledge generation, learning and action’ (Hall, 2001:175).

What needs to be done

What can be done in your organisation? Co-producing health and social care with diverse communities requires an organisational and multi-faceted approach using a range of methods. Some key things to start with include:

- Looking at who is in the room and asking how does this reflect the local or target groups or populations you are seeking to work with and decision-making in your organisation. Review who is involved in key strategic decision-making (including boards and executive committees), and how this reflects local diverse communities, particularly those who are often excluded such as people from Black African, Asian, Caribbean, and other minority ethnic backgrounds, and disabled people, who have been disproportionately affected by the pandemic. This will require the use of equality monitoring to evaluate where involvement is taking place with a range of different groups, and particularly those across the nine protected characteristics covered by the Equality Act 2010. This process should also

include looking at representation and leadership in decision-making, with paid research and health and care staff.
- Identifying what are the specific involvement opportunities available in your organisation for diverse groups and then ensuring these can be clearly articulated, advertised, and disseminated with role descriptions in an equitable manner, with proper support and reimbursement provided. When involving community organisations, there is a need to build in their costs in ways that properly reflect their participation and overheads, as is done with research institutions.
- Making sure that diverse groups can be included in research and practice right at the beginning of the process and at all stages of the research, including in the proliferation of COVID-19 projects, research grants, and publications.
- Ensuring academic authorship is equitable and properly includes and reflects the contribution of diverse groups. For example, making sure researchers from Black, Asian, and other minoritised groups, and wider community organisations, are not just approached in order to feed their knowledge to research studies and all white teams about accessing and recruiting diverse participants, but are also properly included in research teams where this community knowledge and expertise can be recognised and credited.

This edited collection, and in particular Volume 2 (which can be read here: https://policy.bristoluniversitypress.co.uk/covid-19-and-coproduction-in-health-and-social-care-1), provides many examples of how community participation can happen with a diversity of groups. Some of the methods described include use of participatory film activity through digital diaries in three countries in the Global South (Chambers et al); co-producing and evaluating public health guidance in the pandemic with Brazilian communities (Mota et al); gathering stories, blogs, visual, and oral accounts from ‘street’ journalists (for example people who have endured the consequences of poverty, inequality, and exclusion), (Beyrouty et al); building an online participatory research methodology developed by and for disabled people with energy limiting chronic illness (Hale and Allam); using peer-led sessions and a 'Champions of Change programme' facilitated by community volunteers with women and girls with disabilities in low and middle-income countries (Ekiikina); building an online co-production collective based on a digital inclusion approach aimed at minimising hierarchies with use of multiple methods and minimal technical barriers (Allam et al); generating a community-informed evidence base shaped through an intersectional lens aimed at creating community-led research with Punjabi communities (Singh); conducting a survey to investigate how Deaf and Disabled people in the United Kingdom are adjusting to remote technologies (Goodall and Meakin); adapting a participation programme during the pandemic to meet the needs of autistic young people, using peer support sessions, and co-producing 'Understanding autism and mental health' webinars with autistic young people (Niner and Portman); purposefully designing a community voices collective that became a social movement of people and organisations acting as a conduit between local communities and health, care and other statutory organisations in North West London, to support, challenge, and co-lead change conversations (Kaur et al).

These approaches all demonstrate that wider methods for participatory practice are possible and provide the basis for working more equitably in co-producing health and social care research, policy, and practice with diverse communities and groups. These approaches need to become the centrepiece and gold standard in working with diverse communities so that equity and appropriate community ownership and leadership can exist, moving forward through the pandemic and beyond.

Acknowledgements

Dr Josephine Ocloo is funded by the NIHR ARC South London. The views expressed are those of the author and not

necessarily those of the NIHR or the Department of Health and Social Care.

References

Beresford P. (2013) *Beyond the usual suspects*, London: Shaping Our Lives.

Boote, J., Wong, R., and Booth, A. (2015) 'Talking the talk or walking the walk?' A bibliometric review of the literature on public involvement in health research published between 1995 and 2009', *Health Expectations*, 18(1):44–57.

Department of Health (2005) *Research governance framework, 2nd edition*, London: Department of Health.

Department of Health (2006) *Best research for best health*, London: Department of Health.

Department of Health (2012) *NHS constitution for England*, London: Department of Health.

Equality Act (2010). *Equality Act 2010*, https://www.legislation.gov.uk/ukpga/2010/15/contents

Hall, B.L. (2001) 'I wish this were a poem of practices of participatory research', in P. Reason and H. Bradbury (eds), *Handbook of Action Research*, London: SAGE Publications, pp 171–178.

INVOLVE (2012) *Diversity and inclusion: What's it about and why is it important for public involvement in research?* London: INVOLVE.

Marmot, M., Allen, J. Goldblatt, P. Herd, E., and Morrison, J. (2020) *Build back fairer: the COVID-19 Marmot review. The pandemic, socioeconomic and health inequalities in England*, London: Institute of Health Equity.

Minkler, M., Fadem, P., Perry, M., Blum, K., Moore, L., and Rogers, J. (2002) 'Ethical dilemmas in participatory action research: a case study from the disability community', *Health Education & Behaviour*, 29 (1): 14–29.

National Institute of Health Research (NIHR) (2015) *Going the extra mile*, London: National Institute of Health Research.

Ocloo, J. (2018) 'Involving a greater diversity of people in healthcare processes', *Health Service Journal*, https://www.hsj.co.uk/comment/end-discrimination-in-solving-the-health-services-problems/7021729.article

Ocloo, J. (2020) 'Being heard, not, "seldom heard": democratising research with diverse communities during the covid-19 pandemic', *BMJ*, https://blogs.bmj.com/bmj/2020/06/02/being-heard-not-seldom-heard-democratising-research-with-diverse-communities-during-the-covid-19-pandemic/

Ocloo, J., and Fulop, N. (2011) 'Developing a 'critical' approach to patient and public involvement in patient safety in the NHS: Learning lessons from other parts of the public sector?', *Health Expectations*, 15(4): 424–432.

Ocloo, J. and Matthews, R. (2016) 'From tokenism to empowerment: progressing patient and public involvement in healthcare improvement', *BMJ Quality & Safety*, 25(8): 626–632.

Ocloo, J., Garfield, S., Dean Franklin, B., and Dawson, S. (2021) 'Exploring the theory, barriers and enablers for patient and public involvement across health, social care and patient safety: a systematic review of reviews', *Health Research Policy and Systems*, 19(1): 1–21.

Office for National Statistics (2020a). *Updating ethnic contrasts in deaths involving the coronavirus (COVID-19), England and Wales: deaths occurring 2 March to 28 July 2020*, London: Office for National Statistics.

Office for National Statistics (2020b). *Deaths involving COVID-19 by local area and socioeconomic deprivation: deaths occurring between 1 March and 31 July 2020*, London: Office for National Statistics.

Office for National Statistics (2021) *Updated estimates of coronavirus (COVID-19) related deaths by disability status, England: 24 January to 20 November 2020*, London: Office for National Statistics.

Sandhu, S., Bjerre, N.V., Dauvrin, M., Dias, S., Gaddini, A., Greacen, T., Ioannidis, E., Kluge, U., Jensen, N.K., Lamkaddem, M., i Riera, R.P. et al (2013) 'Experiences with treating immigrants: A qualitative study in mental health services across 16 European countries', *Social psychiatry and psychiatric epidemiology*, 48(1): 105–116.

4

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

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

Introduction

The past decade or so has seen a greater push for more inclusive practice in the way research is developed and co-produced with patients and the public. The drivers have been a complex mixture of democratic right, increasing accountability, ensuring that research is meeting the needs of the people and communities it is trying to support, and the perceived positive impact on the quality of the research. Indeed there was an assertion that patient and public involvement and co-production (Hickey et al, 2018) were increasingly well established in the research process, from commissioning, through to designing, undertaking, and delivering research (INVOLVE, 2012) – although we should acknowledge that the practical implementation of co-production was limited even before COVID-19 (Green et al, 2019). And then came COVID-19.

The impact of COVID-19 on co-production, it is asserted here, can be characterised as an initial sidelining of patient and public involvement in research and the highlighting of existing health inequalities. This was followed by a reassertion of the importance of patient and public involvement. Included in this narrative are themes of the resilience of patient and public involvement and co-production and the embracing of digital responses to patient and public involvement and co-production. Indeed, we note here that, although digital exclusion is a genuine challenge, digital techniques also have the potential to increase reach and accessibility and assert that the 'new normal' will involve more digital working than hitherto, creating a new hybrid approach to public involvement in research.

The initial impact of COVID-19

Patient and public involvement sidelined

In responding to COVID-19, governments and major funders of health and social care research swung into action, pausing and postponing some research and policy activity, and changing well-established processes and procedures as they prioritised responding to COVID-19 as quickly as possible. The speed with which funders mobilised, in terms of the commissioning and approving of research, was impressive. Indeed, so much so that in the future it will be difficult to justify any inertia in the face of future requests for funders to change processes, procedures, and culture to enable, for example, co-production. Funders have realised the important role they play in influencing and enhancing research culture, including co-production.

Unprecedented levels of funding were disbursed across clinical, biomedical, and social science research. Commissioning and award processes were accelerated; funders pooled funds and expertise wherever possible to address these gaps. Co-funding meant that even funders that might have had good patient and public involvement (for example in reviewing proposals and board membership) may have had to drop that in favour of moving the process along quickly rather than convincing other funders, with less of a track record in patient and public involvement, to embrace the voice of patients and public. In short, it soon became apparent the systems and structures, and therefore the decisions on what to fund and how, were being inherently skewed towards the needs of the research community and did not address the complexity of differential experience of many patients, publics, and communities during the first wave. In an emergency, the focus was on the science rather than patient and public involvement.

The potential for patient and public involvement and co-production in research was diminished or did not happen at all. For those developing research applications, there was simply no time to put in place the things we know make patient and public involvement work well if they didn't already exist , that is the right infrastructure (for example, access to technology) and strategic support within a university, and existing high-quality relationships between researchers and patients and the public. The pressures resulted in a large drop in patient and public involvement identified by the Health Research Authority, who reviewed patient and public involvement in the development of ethical applications. They found a decrease in studies containing public involvement from 78% in 2019, to 20% in the first 40 trial submissions received during the COVID-19 pandemic (Academy of Medical Sciences, 2020). The patient and public involvement community started detecting a worrying trend: patient and public involvement was not seen as a vital part of research, embedded in systems and structures. In many cases, it was missed in the rush to design studies that could address key pandemic challenges. Our assumptions that patient and public involvement had become embedded in research as a key expectation had been shaken. When pressure was applied, the truth emerged. Patient and public involvement was still seen as an optional add on. Indeed, it did feel that patient and public involvement had perhaps fallen off (or at least slipped down) the research agenda.

The exclusion of people with lived experience no doubt had deleterious consequences. Not least, their inclusion may have ensured that research addressed patient and public needs, and prevented, for example, some of the morbidity and mortality experienced among elderly people, those with long term conditions, and those in lower socioeconomic groups (Redding, 2020). Greater inclusion of the public may also have helped address the expected resistance to the vaccination from the 'anti-vax' movement (Megget, 2020), helping ensure trust in research and scientists.

COVID-19 highlighted existing inequalities

As the pandemic progressed, it shone a spotlight on inequalities across the UK, with communities and individuals being disproportionately impacted by both the disease itself and the policies put in place to contain its spread. It highlighted the gaps in our understanding of the factors underpinning these inequalities, the mechanism and spread of disease and how to treat it in different communities, and how little we knew about how to address these challenges. Indeed, a report by Public Health England concluded that:

> There is clear evidence that COVID-19 does not affect all population groups equally. Many analyses have shown that older age, ethnicity, male sex and geographical area, for example, are associated with the risk of getting the infection, experiencing more severe symptoms and higher rates of death.
>
> (Public Health England, 2020)

As a research community, we need to think carefully about how we redress that balance and bring in more diverse perspectives into how we set our research agendas, shape our funding programmes, and ensure the research we commission and deliver addresses the experiences of a broad range of people across the UK.

The reassertion of patient and public involvement

Moving to digital working

Both the funding and co-production of research have ‘gone digital’. For example, funding committees now meet online, and research priorities can be identified via crowd sourcing (Lichten et al, 2018). Research, by necessity, has to be undertaken online in terms of both project management and data collection.

The pace of research has increased, with public contributors asked to provide feedback almost immediately on rapidly evolving studies. Face-to-face interactions changed to virtual almost overnight. If the right infrastructure (eg access to technology) and strategic support existed within a university, high-quality relationships had already been developed among existing groups, and people were able to respond rapidly, studies could more easily embed public involvement and co-production at their very heart.

Online working also offers opportunities for wider inclusion – for example, for disabled people who may find attending a face-to-face event tricky due to, for example, inaccessible transport and venues as well as their own (ill) health. For some disabled people it can feel less 'othering' so that people can attend a meeting without having to negotiate asking for 'reasonable adjustments'. In short, there is the potential to involve the public more quickly and flexibly (The Academy of Medical Sciences, 2020), save time in meetings (McAlister and Rennard, 2020), be more cost effective, and widen access and increase diversity (Gray et al, 2020). However, it is 'potential' – 'going digital' is not a panacea and there are some people who are digitally excluded and who may also face other health inequalities. We need to make sure that we develop online platforms to ensure that professionals and patient groups can meet and develop solutions, learning from existing models (such as the Centre of Excellence on Partnerships with Patients and the Public). Funders also have a responsibility. For example, the Health Foundation have been developing an online inclusion panel which brings together people with professional and/or lived experience to advise the Foundation on the inclusivity of its in-house analytical work and its external research programmes in response to COVID-19. As part of the development process, the Foundation spoke to all panel members to identify any barriers that would prevent them from participating fully in the meetings. Digital exclusion was flagged as a significant barrier and to overcome this, IT equipment was supplied where needed and data allowances paid for. Furthermore, the Foundation has ensured that all written materials are produced in plain English and easy read documents, and where appropriate, presentations are filmed and sent in advance to panel members. An external agency supports the panel on behalf of the Health Foundation, and they work with the members of the panel to make sure they can access panel meetings, including support to use the technology.

The patient and public involvement community is flexible, responsive, and creative. Our biggest adjustment was the move from face-to-face interaction to virtual forms of communication. While universities have access to different platforms and IT support, many patient and public contributors had to learn fast, sometimes with support, but often without. Alongside a new set of skills, using these platforms has brought a range of benefits. Firstly, having online meetings and workshops has, for some, increased efficiency and accessibility; many people welcome the time, effort, and money saved in not having to travel to attend meetings. If someone has the necessary technology then they can get involved from the comfort of their own home. Secondly, many platforms, with their breakout rooms, whiteboards, voting, polls and other tools and facilities offer an opportunity to break free from the rigidities and restrictions that can characterise traditional research meetings, and enable more creative ways of engaging with each other. Traditional meetings often take place on the terms of researchers and professionals, with formal agendas, minutes, and an emphasis on individuals being able to express and argue their views using the power of language in these forums. Such scenarios can exacerbate existing power differentials and discriminate against the inclusion of some people. That said, we do of course recognise, that there is still an emphasis on 'how' people use digital – it is as easy to speak over someone online as it is in a face-to-face meeting!

Looking to the future

Seismic events, such as a global pandemic, lead to seismic changes in how we work. There is unlikely to be a return to the 'old normal'. Rather, the new normal will likely be a hybrid of face-to-face and online working. We assert here that the online working experience should not seek to replicate face-to-face meetings or events and should not be regarded as 'the next best thing' to face-to-face meetings – it is different.

Sometimes it can be a better option than face-to-face, improving reach and providing a more accessible, efficient, and effective way of involving people. However, we recognise that alongside benefits there have been many frustrations and shortcomings of involvement online. For example, the absence of in person meetings regarded as essential to the development of relationships and the loss of voice for digitally excluded people. Online tools have the potential to enable us to provide creative spaces in which to work co-productively. Our experience has often been that in this creative space via, for example, the use of jam boards, writing comments in the chat room rather than having to speak, online voting, and with a shift away from the more standard and formal approach to meetings, we can achieve a greater equity in the room and unlock the potential of people less comfortable in expressing themselves in the traditional meeting format. Clearly, this isn't always the case. However, we can work together to ensure that technological approaches build in the aspects of involvement we value.

We also need to work on 'what does good look like'. We need more work to determine what combination of various online tools and face-to-face work best – for example, see Chapter 10 in Volume 2 (https://policy.bristoluniversitypress.co.uk/covid-19-and-coproduction-in-health-and-social-care-1). As we move toward a hybrid model of working, we need to address these issues. We also need to ensure that university strategy and infrastructure can support and enable involvement and ensure it is in place for the next time pressure is applied to patient and public involvement. This can't just be linked to specific projects but rather needs to reflect a wider recognition in the university sector of the vital importance of public involvement.

What needs to be done?

- Clearly, we need to do more to address health inequalities. Solutions could include ongoing sustainable equalities mentoring for decision makers and future leaders, and equality impact assessments in partnership with self-determining groups so that we can start to design discrimination out of research practice.

- We need to firmly establish patient and public involvement and co-production in the processes, procedures, and cultures of all research funders and develop systems for emergency scenarios. The latter could include establishing rapid patient and public involvement response panels that can respond quickly.
- The 'new normal' is likely to be a blend of face-to-face working and working digitally. We need to build on existing good practice to identify 'what good looks like'.
- Our research community, including the various organisations and their processes, procedures, and culture, is capable of acting swiftly and changing rapidly in response to crises. The co-production community would do well to remember and use this knowledge when faced with barriers and inertia in the future.

References

The Academy of Medical Sciences (2020) *Public involvement and engagement in research during the COVID-19 pandemic: Summary of a FORUM workshop held on 19 May 2020*, London: Academy of Medical Sciences.

Gray, L.M., Wong-Wylie, G., Rempel, G.R., and Cook, K. (2020) 'Expanding qualitative research interviewing strategies: Zoom video communications', *The Qualitative Report* 25(5): 1292–1301.

Green, G., Boaz, A., and Stuttaford, M. (2019) 'Editorial: Public participation in healthcare: Exploring the co-production of knowledge', *Frontiers in Sociology* 4(73): 5–7.

Hickey, G., Brearley, S., Coldham, T., Denegri, S., Green, G., Staniszweska, S., Tembo, D., Torok, K., and Turner, K. (2018) *Guidance on co-producing a research project*, Southampton: INVOLVE.

INVOLVE (2012) *Briefing notes for researchers: Public involvement in NHS, public health and social care research*, Southampton: INVOLVE.

Lichten, C., Ioppolo, R., D'Angelo, C., Simmons, R.K., and Jones, M.M. (2018) *Citizen science: Crowdsourcing for research*, Cambridge: The Healthcare Improvement Studies Institute.

McAlister, B. and Rennard, U. (2020) *UK standards for public involvement – One 'very different' year on*, https://www.nihr.ac.uk/blog/uk-standards-for-public-involvement-one-very-different-year-on/26600

Megget, K. (2020) *Even COVID-19 can't kill the anti-vaccination movement*, https://www.bmj.com/content/369/bmj.m2184

Public Health England (2020) *Beyond the data: Understanding the impact of COVID-19 on BAME groups*, London: PHE Publications.

Redding, D. (2020) *Service 'reset' must be informed by patients' experience of the COVID-19 pandemic*, https://blogs.bmj.com/bmj/2020/05/21/don-redding-service-reset-must-be-informed-by-patients-experience-of-the-COVID-19-pandemic/

5

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

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

Introduction

The COVID-19 pandemic and the Black Lives Matter Movement have mobilised a global community to engage with Black people's experiences of exclusion, detention, violence, and neglect at the hands of the state and within wider society. This awakening has been a welcomed catalyst for change; placing pressure on organisations to demonstrate their commitment to antiracist practice. For some, the drivers for change may be economic, rather than moral. Whatever their personal or organisational position, many are embarking on new territory and seeking a quick fix to address entrenched racist structures and systems. On the surface, co-production presents the opportunity to invite lesser-known voices to take a seat at the table to design solutions for the greater good. This optimism leads many to believe it will narrow the inequalities gap.

Black Thrive Lambeth, a system's change initiative was established in 2014. This cross-sector partnership addresses systemic racism that creates and sustains inequalities for Black African and African-Caribbean communities. Guided by FSG's Collective Impact Model (Kania & Kramer, 2011), the partnership is supported by a Black-led backbone team who provide strategic oversight, mobilise resources, and undertake a convening role to centre the voices of Black communities in decision-making. Co-production is one of several methodologies used to influence policy, commissioning, the design of services and practice. This chapter draws on our reflections as the backbone team. We illustrate the tensions that arise when applying this methodology, critically explore the extent to which co-production offers the potential for societal transformation, and highlight how a well-intentioned approach may inadvertently marginalise communities.

Co-production in the context of Black Thrive

As a Black-led team, we are consulted on the perspectives of 'The' Black community. Our racialised identities add value and enable us to speak with authenticity. However, the concept of community is arbitrary, intersectional, ever evolving, and challenges the notion of a singular Black voice. We grapple with the idea of 'speaking for' and are acutely aware of 'the dangers of … misrepresentation, expanding one's own authority and privilege. [However,] … speaking with and to can lessen these dangers' (Alcoff, 1992). Through our work, we seek to create platforms and spaces where Black communities can speak for themselves.

During the COVID-19 pandemic, systems were detached from the realities for Black communities (Public Health England, 2020). Their voices and experiences were undermined by narratives that the pandemic was 'the great leveller' (Hartog, 2020). While statutory organisations waited on data to confirm what Black communities already knew, we engaged stakeholders to undertake research. Black people rooted in the community were trained as researchers and participated in the entire research process. We also commissioned an organisation to explore the experiences of people who had no recourse to public funds.

Our research surfaced how our social identities create shared and distinct experiences of the pandemic. This modestly resourced project provided insights into local need, the interventions required for the recovery process and informed decision-making locally and nationally. Interest in this work was partly due to the statutory system and academic institutions not having the reach into communities. The social capital that comes with our shared identities enabled us to mobilise swiftly and created the foundation for developing connections and building trust. That is not to say that people did not approach our work with caution, but we had access to sections of the community who are ordinarily out of the view of white-led organisations (Addae & Danquah, 2019).

Our employment project supports system change to create environments where Black people living with long-term conditions thrive in work. Research led by the community identified structural barriers to accessing and sustaining ‘good work’ (Amasowomwan et al, 2021). This has informed efforts to transform Human Resources processes within partner organisations. It also surfaced the aspirations within communities to deliver solutions for themselves (Aseru et al, 2020). However, the chronic underinvestment in Black-led organisations presented a barrier. These insights informed the design of a grant-giving programme co-produced with experts by experience. The first round of funding has demonstrated the benefits of devolving decision-making and removed some of the structural barriers that prevent Black-led organisations from accessing resources (Crawford et al, 2020). We hope to provide a template that funders may wish to build upon to distribute resources more equitably.

When Black people are vulnerable or in distress, the statutory system is either slow to act or adopts punitive responses. The disproportionate use of the Mental Health Act (1983) is one example of the restrictive practices imposed on Black bodies. We engaged communities during the review of the Act and shaped legislative reforms, which included the provision of culturally appropriate peer support and advocacy (GOV.UK, 2018). This intervention aims to support people to navigate and challenge racism within mental health systems and improve care quality. We have worked with service users, carers, and other stakeholders to co-produce a service that centres the racialised experience of Black communities. Health and social care systems who wish to design services that narrow the inequalities gap must embody antiracist practice, recognising that it goes beyond an intellectual process but engages the physical, emotional, and spiritual aspects of our being.

Co-production is often hailed as the gold standard of involvement, many feeling the pressure to engage in elaborate co-production activities. However, co-production need not have a distinct beginning nor end. We have worked with communities over many years; the intensity of their involvement fluctuates depending upon capacity, resources, and the levers available for systems change. It can take time for a solution to come to fruition, but it is crucial to act on what we know and avoid revisiting discussions that have been exhausted. We bring people together to sense-check our collective efforts, surface new knowledge, and refine our approach to distributing power equitably.

Co-production: the (un)intended art of exclusion, extraction, and exploitation

> [C]o-production risks functioning as a means for academics [facilitators and organisations] to reproduce themselves through a parasitic […] relationship with the collective labour of communities.
>
> (Bell and Pahl, 2018)

Co-production has become a lucrative industry and within the racial justice space, it comes with many contradictions. A history of systematic marginalisation creates a context where Black people are less likely to occupy positions of power within public services. Co-production's ideologies and practice continue to uphold the status quo. It seems to accept the assumption that today's service user could not be the CEO of tomorrow, and often uncritically accepts that white people produce, and Black people must be brought into the space to share power. It is complicit in maintaining power differentials by 'engaging' Black communities in a ritualistic dance where decisions only *appear* to be shared. In this way, co-production perpetuates the marginalisation of Black communities. A more radical position would be to ensure that groups who currently do not hold institutional power are equitably and proportionately represented in the organisations responsible for decision-making.

White-led organisations commissioned to co-produce with minoritised communities often have an overwhelmingly white workforce. Consequently, challenges and solutions are framed and understood through the white gaze. Implicitly, this sets the parameters and rules that govern what is achievable, who is ‘suitable’, or who can bring value to the process. By default, it excludes individuals perceived as ‘disruptive’ or ‘overly negative’, through the fear that they will derail the process. Failed attempts to sift out ‘undesirable contributors’ lead to behaviour management approaches that enforce prescribed norms. It may appear reasonable to engage individuals who enable the process to run smoothly. However, voices may be silenced when facilitators fail to recognise that behaviour perceived as disruptive may be an expression of unprocessed and deep-rooted trauma.

Community co-producers rarely have the privilege of privacy and are invited to share their traumas in public spaces. There is an unspoken expectation for them to share their innermost thoughts and feelings in good faith, without assurances that it will lead to improvements for them, their loved ones, or community. The emotional labour required and the risk that people may be re-traumatised is often underestimated. To collaborate with compassion it is essential to resource support systems, such as therapy, coaching, and/or activities that bring community members joy.

Other ways in which co-production pays lip service to addressing inequities in power, occurs when the causes of inequalities are located within individuals and communities rather than framing challenges within the context of systemic racism and other forms of oppression. Facilitators and system co-producers often fail to interrogate whiteness or create space to explore their prejudices. Neither is it common practice to encourage all participants to delve into their experiences of racism, homophobia, sexism, ableism, and so forth. Racialised communities may feel unable to express their experiences of oppression and empowerment for fear of making people who do not share their lived experience feel uncomfortable.

Although efforts are made to create safe spaces, they may still be subjected to overt and indirect expressions of racism during the co-production process.

The white gaze may also confine or restrict Black communities' imaginations, where they are discouraged from exploring radical solutions with the potential to disrupt the status quo. These ideas are perceived as too ambitious, unrealistic, too expensive, too political, and so on. There is often little appetite to rock the boat, let alone to capsize it. Rarely is there an opportunity to dismantle something and start again; instead, the focus is on working with what is already there, which raises the question about the extent to which you can create sustainable change if you are building on structurally flawed foundations.

When solutions are generated, community co-producers seldom benefit financially, neither does it improve their status. New knowledge and ideas cannot be achieved without lived experience. It brings 'world-making power' to the process and should not only be acknowledged but remunerated (Bell and Pahl, 2018). There are stark inequities in the value placed on Black and brown labour where racialised communities are rarely recognised financially for their contribution.

The process assumes that Black communities should be satisfied with improvements in policy or service provision. The intellectual property, status, and financial gains from the process remain in the firm grasp of the facilitator(s), organisation, or funder. For too long, dominant systems have misappropriated the ideas and cultures of marginalised communities for profit. Steps should be taken to ensure that the labour of Black communities is remunerated, that they are credited for their work, remain the experts on their experience, and material benefits that arise during or after the co-production process are distributed equitably for the benefit of Black communities.

As a Black-led team, we hold many parallels between our co-production experiences with organisations and those of individuals in the community. We are invited into predominantly white-led spaces to share our expertise, to support them to address racism within their systems. We resist expectations to co-produce palatable recommendations, but we too are faced with power imbalances in these spaces. Despite the expertise that resides within the team, there is a reluctance to reimburse us for the time we commit. We have also been confronted with situations where people and organisations with an insatiable thirst to be at the forefront of antiracism and mental health, race to document our thinking without crediting the source of their inspiration. Through our personal experience, we are acutely aware of the power differentials and strive to address this in our work.

Conclusion

It is important to maintain a healthy level of cynicism. To consider that co-production's ability to create equitable and just systems may at times be ineffectual. Radical forms of organising that seek to shift power dynamics often cease to be transformative once they have been co-opted into 'standard practice' (Cooke and Kothari, 2001).

Co-production can be a useful tool to support systems change. When done well, it embraces complexity, welcomes uncertainty, creates space to build relationships founded on mutual trust and disrupts power hierarchies. In our work, co-producing with Black communities has led to new insights, ideas, and innovations that deliver benefits for communities and wider society.

This work is hard; at times, it can feel like you are swimming against the tide. The status quo is maintained through existing legal and policy frameworks, and the people who uphold these structures create obstacles that bring transformative work to a standstill. We occupy the space between our community and the system. Our loyalties and allegiance are questioned on both sides. We continue to hold this tension between the need to amplify communities' voices in white-dominated spaces, while being conscious that co-production is an imperfect process and cannot serve as a quick fix to address deeply entrenched systemic issues.

What needs to be done

Co-production requires appropriate care, resources, infrastructure, time, and deep reflection to get it right. It is essential to:

- Value the expertise within Black communities and resource them to lead the process.
- Create space for reflexive practice, purposefully engaging stakeholders in self-critique, whereby they interrogate whiteness and white privilege as it manifests itself in people's lives, organisations, systems, and the co-production process; take action to address the issues that arise from this work.
- Ensure that the products (eg intellectual property) and benefits (eg financial gains) that emerge from the process are both owned and distributed equitably with communities.
- Situate 'the problem' within broader structures in society and systems of oppression rather than within individuals and communities.
- Involving Black communities in decision-making should not be reserved for the co-production process. Organisations must commit to attracting, developing, and retaining Black people in senior positions within their workforce.

References

Addae. P. and Danquah, S. (2019) *Research weariness and community scepticism*. Unpublished.

Alcoff, L. (1991) 'The problem of speaking for others', *Cultural Critique*, 20: 5–32.

Amasowomwan, F., Beckford, D., Crawford, A., Hazzard, R., and Robotham, D. (2021) *Good work: Employment support for black people with long-term health c*onditions. London: McPin Foundation.

Aseru, F., Beckford, D., Crawford,A., Danquah, S., Morris, D., Morris, M., Richards, D., Simms, K., Solomon, D., Talantsi, Y., Tayebwa, M., Theophane, K., and Walcott, S. (2020) *An equitable* *recovery: Insights from Lambeth community research.* London: The Social Innovation Partnership.

Bell, D.M. and Pahl, K. (2018) 'Co-production: towards a utopian approach', *International Journal of Social Research Methodology*, 21(1): 105–117, DOI: 10.1080/13645579.2017.1348581

Cooke, B. and Kothari, U. (eds) (2001) *Participation: The new tyranny?* New York: Zed Books.

Crawford, A, Beckford, D., Amasowomwan, Hazzard, R., and Mackay, T. (2020) *The Black Thrive employment project developmental evaluation report (cycle one)*, London: McPin Foundation.

GOV.UK (2018) *Modernising the Mental Health Act: Increasing choice, reducing compulsion. Final report of the independent review of the Mental Health Act 1983*, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/763547/Modernising_the_Mental_Health_Act___increasing_choice__reducing_compulsion___summary_version.pdf

Hartog, K. (2020) 'Black Death historian: A coronavirus depression could be the great leveller', *The Guardian*, 30 April, https://amp.theguardian.com/world/commentisfree/2020/apr/30/walter-scheidel-a-shock-to-the-established-order-can-deliver-change?__twitter_impression=true

Kania, J. and Kramer, M. (2011) 'Collective impact', Stanford Social Innovation Review, 9: 36–41.

Mental Health Act (1983) https://www.legislation.gov.uk/ukpga/1983/20/contents

Public Health England (2020) *Beyond the data: Understanding the impact of COVID-19 on BAME groups*, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/892376/COVID_stakeholder_engagement_synthesis_beyond_the_data.pdf

6

Finding the voice of the people in the pandemic

An ethnographic account of the work of local Healthwatch in the first weeks of England's COVID-19 crisis

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

On 23 March 2020, the UK government issued a broad range of advice and regulations intended to curb the spread of COVID-19 and prevent the National Health Service (NHS) from being overwhelmed by people needing care. At that time, our research team was in the midst of a 30-month study aimed at exploring the work of Healthwatch, England's statutory organisation with responsibility for championing the views of citizens in the commissioning and provision of health and social care services in each of the country's 152 local authorities (see Box 6.1).

The core of our study was a year-long ethnography (started in August 2019) of five Healthwatch groups, focusing on their daily activities and relationships with key stakeholders locally. Alongside our work in the five study sites, our study relied on a panel of 15 Healthwatch representatives, both staff and volunteers, to increase the breadth and generalisability of our ethnographic findings.

After the pandemic hit, we moved our research online. We kept in regular contact with Healthwatch staff, board members, volunteers, and local stakeholders, and observed them in the virtual meetings they attended. We also carried out one-to-one virtual interviews with 13 of our panel members and held a virtual meeting attended by 14 of them

Box 6.1 The six statutory functions of local Healthwatch (adapted from Healthwatch website)

Local Healthwatch are funded by and accountable to local authorities to:

- Obtain the views of people about their needs and experience of local health and social care services. They make these views known to those involved in the commissioning and scrutiny of care services.
- Make reports and make recommendations about how those services could or should be improved.
- Promote and support the involvement of people in the monitoring, commissioning, and provision of local health and social care services.
- Provide information and advice to the public about accessing health and social care services and the options available to them.
- Make the views and experiences of people known to Healthwatch England, supporting its role as national champion.
- Make recommendations to Healthwatch England to advise the Care Quality Commission (CQC) to carry out special reviews or investigations into areas of concern.
- Make recommendations to Healthwatch England to advise the Care Quality Commission (CQC) to carry out special reviews or investigations into areas of concern.

to discuss how their organisations were adjusting their work during the pandemic. Here we draw on data collected in the first six weeks of the national lockdown to describe how the COVID-19 crisis impacted the work of local Healthwatch.

The United Kingdom government, the pandemic, and Healthwatch

For Healthwatch organisations in England, the new 'stay-at-home' regulations had immediate effects. Healthwatch staff began doing just that, all face-to-face intelligence-gathering activities with the public were suspended and 'Enter and View' visits to hospitals, care homes, and GP surgeries were cancelled. Local governance fora attended by Healthwatch were also largely suspended in the initial phases of the pandemic.

In adjusting the ways in which they worked, Healthwatch staff chose which of their statutory functions to prioritise. In the first few weeks of the COVID-19 crisis, the priority of the health and care system was for people to adhere to the new regulations in order to protect its ability to cope under the strain of an already high number of hospital admissions. Most local Healthwatch were immediately enlisted by their local health and care systems to disseminate official information through different channels, including their websites, bulletins, and newsletters. Some also reported compiling lists of NHS and government websites, creating directories of voluntary sector organisations, and signposting members of the public to appropriate support agencies.

However, the lockdown posed practical challenges in Healthwatch's ability to fulfil some of its functions. Healthwatch were no longer able to access public and patient views as they used to, nor could they contribute to health and social care scrutiny and decision-making at a formal level because boards and committees either were no longer meeting, or were meeting in new configurations (eg virtual meetings arranged at short notice), which excluded Healthwatch.

In this context, many Healthwatch groups described a shift in the relative emphasis placed upon their statutory functions. Whereas before the pandemic most Healthwatch regarded the provision of information and signposting of local services as a marginal part of their role, these functions moved centre-stage. In the initial phases of the crisis, 'acting as a messenger', as one Healthwatch CEO put it, led Healthwatch to primarily become a voice of the system *to* the people. But what spaces were then left for conveying the voice *of* the people to the system at this time?

This question provoked dilemmas for Healthwatch staff. Talking about her frustration about the lack of interest shown by overwhelmed local organisations to engage with feedback, a Healthwatch CEO in the Northeast of England, told us:

> ‘I think at the moment […] the explanation to come back, […] is “look, we just can’t do anything at the moment, we have to deal with this”. But, for us, it would be “well let’s just see how long that [explanation] goes on for because life still goes on, there’s people still needing operations, there’s still people getting diagnosed with cancer and other different illnesses and things, they still need that help”’.

To discuss how local Healthwatch tried to tackle such dilemmas, we draw on our ethnographic data to provide three examples of innovative strategies deployed by Healthwatch to ensure that the voice of local people was still heard by local systems in the early days of the pandemic.

Finding the voice of the people

Healthwatch A: Socially distanced public engagement

Soon after the beginning of the pandemic, Healthwatch A moved its engagement activities online and set up two types of weekly ‘engagement and support’ Zoom meetings open to residents to attend. The first type of meeting was aimed at gathering feedback from specific local communities, for example unpaid carers, people with learning disabilities, Black and minority ethnic communities, and young people. For this work, Healthwatch A linked up with community organisations, working closely with them to collate the experiences of ‘different demographics and different communities’.

The second type of ‘engagement and support’ Zoom meeting was open to all residents to join. Participants were encouraged to share experiences and challenges in accessing services during the pandemic and to ask questions about COVID-19 and local health and social care planning and provision. In organising this work, Healthwatch A's manager, described focusing most of his efforts on liaising with local stakeholders, including patient experience teams at local hospitals, commissioners, council staff, and quality accreditation officials. Once the fora were set up, he invited these officials to propose relevant topics for discussion. For example, Healthwatch A's manager told us that his local contacts in the CQC proposed dedicating a forum to discussing the drop in the number of people contacting GPs and community healthcare providers. According to the CQC, there was a risk that some health conditions, like diabetes or cancer, could go undetected if the trend continued. The discussion at Healthwatch A's Zoom meetings highlighted how people were indeed more reluctant to contact healthcare providers in the first few weeks of the pandemic. Most forum attendees said that this was because they did not want to put extra pressure on local NHS services. As a consequence, the CQC was considering whether 'the messaging needed to be changed slightly' to help address this attitude.

Healthwatch B: Virtual intelligence gathering

Healthwatch B initially stopped gathering data about local residents' experience of the health and care system and feeding them back to the NHS or local authorities: 'they do not want to hear anything right now', Healthwatch B's CEO told us. However, shortly after, she said that her position was changing. Talking with senior managers at the local hospital, she learned that they were actually keen to hear how people were coping with the pandemic and gaps in care or services.

Healthwatch B found two ways of gathering people's experiences while complying with physical distancing. First, the team designed and circulated an ongoing online survey to residents. Second, they asked to join the WhatsApp groups of the numerous mutual aid societies established by local residents to identify and support people who were self-isolating. After joining the WhatsApp groups, Healthwatch staff encouraged their members to feed back their views to them. They also monitored members' exchanges in the groups to identify trends or themes of concern.

By the end of April 2020, Healthwatch B had already produced two reports presenting the analysis of this data and made recommendations as to how the local authority and NHS might address emerging issues. The topics covered a broad range relating to residents' health and wellbeing during the pandemic. These included physical, mental, and economic wellbeing, understanding of government advice, and experiences of accessing health and social care services.

The reports received considerable attention from elected officials in local government, and from healthcare providers. Healthwatch B's CEO was asked to present the findings regularly to the local authority's pandemic committee, a central coordination body bringing together local health and social care leaders, and the only health-related local authority committee meeting running at the time. The reports seemed to have real influence on the local provision of some services. For instance, Healthwatch B found that pregnant women, classed as a vulnerable group, were reporting high levels of anxiety and would welcome a tailored programme of information provided through midwives and health visitors, as well as online consultations instead of phone consultations. The local maternity service providers responded by committing to redesign their work to take account of these wishes.

Healthwatch C: Coordinating local administrators to address inconsistencies in system responses

At the beginning of the pandemic, Healthwatch C received numerous telephone calls from members of the public who reported being unsure about the government's advice on COVID-19. In particular, these people reported inconsistencies in who was categorised as 'vulnerable', and which regimes of isolation applied to different categories of vulnerability.

Through their contacts in the local system, Healthwatch C's staff began investigating the information local administrators were using to identify people especially vulnerable to COVID-19. Healthwatch C found out that the local authority, which is responsible for social care and public health, was using different sources of information from the one used by the local NHS, which is responsible for healthcare services and for officially categorising people according to clinical risk. As the CEO of Healthwatch C described, by taking up the role of the 'go-between between the local authority and the [service commissioners] who were doing completely their own thing', Healthwatch C helped ensure better communication between key stakeholders in an area with a history of weak cooperation. This eventually helped the public in having clearer instructions about what to do and what support was available to them.

Healthwatch C's CEO also realised the need to similarly facilitate coordination between local officials and the voluntary sector. This was particularly important regarding small community groups, including condition-specific support groups (eg diabetes), faith-based associations, and street-based neighbourhood groups, of which the council had been hitherto unaware. Healthwatch C collated a database of voluntary sector activity during the pandemic, which included these smaller community groups and made it available to the council and to the local organisation responsible for coordinating local voluntary sector activity. By facilitating communication between grassroots groups, the voluntary sector, the council, and the NHS, Healthwatch C addressed the need of local people to access support and information tailored to their needs.

Discussion

Health and social care in England, as elsewhere, have been radically reorganised to deal with the pandemic. In normal times, such sweeping changes (eg cancelling all elective surgery, moving primary care consultations online, relaxing hospitals' discharge obligations to patients) would likely have required formal consultation with the public, and would certainly have attracted a great deal of public scrutiny.

As shown through the three examples earlier, even in the first weeks of the pandemic when traditional avenues to feed the voice of the people into local decision-making processes had become unavailable, local Healthwatch embraced new innovative strategies to continue providing this essential function. By either directly engaging local people through technology (eg video calls and WhatsApp) or helping with coordinating institutional responses to the pandemic, Healthwatch mobilised quickly to ensure local peoples' experiences could still be heard. This allowed Healthwatch to address gaps in services and highlight how already-vulnerable and seldom-heard groups of people (for example people with learning disability, ethnic minorities, and pregnant women) were being adversely affected by a pandemic response that produced inequitable outcomes. Despite their different approaches, most local Healthwatch involved in our study remained committed to resisting and ultimately overcoming the potential for the pandemic to transform their organisation into one that primarily conveyed the voice of the system *to* the people, rather than fulfilling their mandate to deliver the voice *of* the people to the system.

Crucial to Healthwatch's ability to act in this way was its formally mandated position in England's health and social care system. For instance, as in Healthwatch B's example, involvement in mutual aid groups' WhatsApp chats allowed access to the views and experiences of people (such as those who were self-isolating), which might otherwise be difficult to access. But it was Healthwatch's status as a formal statutory organisation (as well as the expertise, reputation, and relationships built up over time as a result of that status) that provided it with a direct channel through which to communicate these views back to people with decision-making power in the health and social care system.

Healthwatch C's expanded coordinating role similarly demonstrates the uniqueness of Healthwatch in the English health and social care governance landscape. Combined with its broad and deep knowledge of the local voluntary sector, Healthwatch C was able to gather feedback from residents, seek answers from and coordinate information between health and council agencies. A statutory organisation like Healthwatch is well positioned to mobilise relationships with different stakeholders because of the status provided by Healthwatch's legal mandate. The changes experienced by Healthwatch during the pandemic and their implications for its longer-term role in championing public voice require further investigation and analysis – and this will be crucial post-pandemic for understanding how public health actions and planning can ensure equitable outcomes for all.

What needs to be done

- Better awareness should be raised about the function of Healthwatch in local health and care systems. This will ensure that local people's voices are taken into account in the planning and provision of services beyond the COVID-19 crisis.
- Post-pandemic, health and care systems at both local and regional level should enhance Healthwatch's role as the main channel to seek and hear a diversity of local people's voices. This will ensure that local decision-making processes are transparent and service planning for local people is effective.
- Healthwatch should be formally encouraged to cultivate the coordinating role between key stakeholders (both statutory and from the voluntary sector) in local health and care systems. This will support democratic, equitable, and fully representative decision-making in the aftermath of the pandemic.

The wider study on which this chapter is based is funded by the National Institute for Health Research (NIHR) Health Services & Delivery Research (project reference 17/05/110). The views expressed are those of the authors and not necessarily those of the NIHR or the Department of Health and Social Care.

7

Co-production? We do community participation

Experiences and perspectives in the context of the COVID-19 crisis from Latin America

Cristian R. Montenegro and Felipe Szabzon

Background

In this chapter, we draw on examples from São Paulo (Brazil) and Santiago (Chile) to explore how, in the context of the current pandemic of COVID-19, grassroots community mobilisation interacted with public health authorities and the State more broadly. For this, we consider the experiences of social movements trying to meet vulnerable communities' needs in both countries. In the discussion, we argue that, even in contexts of widespread mistrust and abandonment by authorities, the institutionalised forms of interaction between communities and public health services was critical for shaping the nature of grassroots social action and its collaboration with the State. We also discuss how the interaction between the pandemic and co-occurring sociopolitical processes in both countries is reshaping – again – the meanings of community participation.

The arrival of the pandemic

On 26 February, the first case of COVID-19 was confirmed in São Paulo, Brazil. In the following months, the virus spread throughout the main cities of the country and elsewhere in the Latin American region. Brazil has one of the largest universal health systems globally, operating in a decentralised way, with primary care at ground level, particularly in large and medium-sized cities (Mendonça et al, 2018). The large contingent of workers and the substantial network of basic health units seemed well equipped for track and tracing actions, redirecting cases to specialised treatment, and guiding the general population in adopting protective measures and behaviours (Coelho et al, 2020a).

Unfortunately, this is not what happened. At the time of the pandemic's arrival, the country's president denied the virus's existence and dismantled structures for national monitoring of the evolution of the number of cases, encouraging agglomerations and the use of medicines without proven efficacy, and relativising the need for protective equipment. Throughout 2020, two ministers of health were dismissed. A military minister with no healthcare experience was appointed in the interim for over four months, leaving the country with no leadership in the sector for that whole period (Cancián and Fernandes, 2020). More recently, the federal government has been facing difficulties in negotiating the buy-out of vaccines and managing the acquisition of needles and syringes for a national vaccination programme (Boadle, 2020).

This forced federal states and municipalities to coordinate their sanitary measures, supervise the enforcement of quarantines, redeploy the health workforce, and even finance vaccine research. Poor and Black communities were especially affected by the mismanagement, presenting significantly higher death rates, particularly in larger cities' peripheries (Oliveira et al, 2020).

Similarly, Chile faced the start of the pandemic in the middle of an unresolved social and political crisis that began in October 2019, with massive unrest and mobilisations, demanding social justice and equity in numerous areas including health (Barrios and Méndez, 2020). This 'social outburst' paralysed the country, generating a legitimacy crisis that included the police, the political system and state authorities.

The first case of the disease was registered on 3 March and the first death on 21 March. By mid-March, borders were closed, and classes suspended, with the president declaring a 'state of catastrophe'. Nighttime curfews and mandatory quarantines were established in the most affected parts of the country. In the beginning, the virus moved out from high-income neighbourhoods in Santiago to the most disadvantaged parts, where residents could not avoid crowds or stay at home (Beaubien, 2020).

Over the last decades both countries have developed a decentralised, primary care network that includes participatory mechanisms aiming to foster social accountability and allow scaling and implementing policies at ground level (Labra, 2001). Notwithstanding, despite these significant investments and developments, the primary care network was not mobilised, nor were community-based, participatory structures consulted or constituted for the development of more effective policies, or to define clear messages that could respond to the population's real needs. Quite the opposite, guidelines and essential protective equipment for frontline professionals were lacking, and communities were rarely consulted in elaborating an action plan (Lotta et al, 2020).

At the time of writing this piece, Brazil had reached a total number of cases per million people of 38,009 and a rate of deaths per million inhabitants of 952. Although contrasting with numbers from Brazil, the situation in Chile is also alarming. The total number of cases per million people is of 33,635, and the death rate reached 894 (worldometers, 2021).

Social mobilisation and community participation in South America

Despite the notorious mismanagement at the upper levels of public administration, several local initiatives took place in both countries to support those in need, and to ameliorate the living standards of the population. While some of these initiatives operated in complete autonomy, many have interacted with local healthcare agents to promote more synergistic action.

In Brazil, one such initiative is the 'Brigade for Life of Sapopemba' (Loewenson et al, 2020; Coelho et al, 2020b).

Sapopemba is a district located in São Paulo, where about 20% of its population lives below the poverty line and where there is often no piped water supply and sewerage. Today, Sapopemba appears at the sad position at the top on the number of deaths by COVID-19 in São Paulo's municipality (Travassos et al, 2020).

One of the Brigade's first initiatives, supported by city commissioners and congressional members, was to hold meetings with different municipal government departments to identify preventive actions. These meetings called for more transparency and details on data on pandemic cases and deaths in each sub-area of the region. When provided with this data, the Brigade discussed with personnel in the 16 Basic Health Units to identify and jointly coordinate actions and priority groups. One task force handed out protective masks donated by companies on the streets and talked with passers-by and merchants. Black cloths were placed on gates as a sign of mourning for the deaths in the community, and a union provided a car with a loudspeaker to honour the victims.

The Brigade carried out similarly coordinated actions around education, organising debates with school communities regarding returning to classes. Brigade members also called attention to situations where infection risk is high, such as street markets, which remained open during the quarantine. Furthermore, to gain an in-depth understanding of risk factors, the Brigade surveyed the impacts of the pandemic on residents' lives and the difficulties they were experiencing. Brigade members aim to use such information to identify priorities for action and to give it weight in negotiating with the government.

The Brigade's initiatives were only possible by building on relationships that already existed between community members and technical personnel from the regular council meetings used by the national health system (SUS) for social participation. In addition, to increase success, the Brigade mobilised people who hold credibility in the region and used appropriate language to publicise the risks and number of deaths in different areas.

In Chile, the social outburst of late 2019 produced an explosion in grassroots initiatives, notably creating countless 'cabildos ciudadanos', territorial and self-convened assemblies (Albert and Köhler, 2020). These assemblies grew in parallel with a deep distrust towards the political system and institutional democratic representation, and a resurgence of various forms of mutual aid. Many expected that during 2020 these and other forms of grassroots activity would play a central role in pushing for a constitutional referendum. The referendum, originally scheduled for 26 April, had to be postponed to 25 October due to the COVID-19 crisis. With a historical voter turnout, the option to draft a new constitution won with 78% of the votes.

The sanitary crisis halted most of the street manifestations and the local assemblies, refocusing most people's attention towards the new, unexpected threat. The country moved from a frenetic, future-oriented 're-vival' to a passive, day-to-day 'survival' (Richard, 2020).

In May and June of 2020, a consortium of public universities launched an online survey to explore the community-based response to Chile's pandemic. Early results revealed that behind this fear-based passivity, many local initiatives were developed precisely as a survival mechanism, a way for marginalised communities to self-sustain in the context of a perceived abandonment by health authorities and the State. Unsurprisingly, the main form of action developed at the grassroots level where the 'ollas comunes', cooperative cooking of meals for people who, due to the pandemic, couldn't afford food – provided a strategy of resistance and solidarity that had only been seen with this intensity in the 1980s, amid dictatorship and a deep economic crisis (Espinoza, 2020).

While food insecurity was the main target of local action, other autonomously coordinated activities included recreational and self-care activities, sanitation of public spaces, and manufacture and distribution of masks.

The survey also revealed that the people who participated in this type of action became aware of the existence of local participation spaces in 2019, in the context of the social crisis. The structure of self-organised local action created by the political agitation of 2019, such as the 'cabildos ciudadanos', generated the conditions for the community response to the

COVID-19 crisis throughout 2020. Interestingly, according to the same survey, a third of those participating in community-based action indicated that they were collaborating with local health teams or authorities. Despite the mistrust that characterised the political explosion of 2019 – a trend continued and deepened after the failed institutional response to COVID-19 – local instances of community participation remained (or became) a channel of collaboration with the State for many activists.

Structures for community participation and their role in shaping community engagement in health

Given the critical sanitary and sociopolitical landscape, either in São Paulo's peripheries or in Santiago's marginalised communities, several local initiatives were created, especially in poor neighbourhoods – the most affected by the crisis.

While the broader political scenario frequently indicates a lack of leadership and difficulty implementing solutions to the real problems faced by the poor in times of pandemic, a closer look to the ground level reveals a fertile environment of social mobilisations. Communities took action to fight the spread of the virus and overcome its economic downturns, frequently hand in hand with the public health system.

Where there was already a paved path for social participation, nourished over the previous decades of institutionalised councils for public engagement, channels for a closer dialogue with the State were already settled. Even when recently acknowledged (as in Chile), participatory structures are perceived as potential spaces for change and have inspired a style of social action that seeks to contribute and to co-produce 'with the State' and not 'despite the State'.

Conclusions: where are we and what needs to be done?

Notwithstanding, the advancements in recent decades in public health, national health systems in the region have suffered significant blows. Not only have the models of welfare policy changed, but also health programmes have been incrementally dismantled. Systems are also becoming more complex, involving evermore technologies, processes and actors in the provision of health services, frequently in partnerships with the private sector. This is further compounded by co-occurring social and political scenarios marked by the systematic abandonment of the poor, the increasingly violent attack on social mobilisation and protests, and a growing mistrust towards the State and the political elite. This, in turn creates conditions for polarisation which has an immediate impact and will continue to impact the broader politics of participation in health.

What needs to be done

- Traditional structures of community participation – institutionalised through the formal healthcare administration and operating almost exclusively at the primary care level – need to be renovated, in order to account, on the one hand, for the many forms that grassroots activism is taking, and on the other, to the new forms of public health's governance, especially in the face of the COVID-19 pandemic.
- Nonetheless, attention needs to be given to the emergent roles that those structures have played – and are still playing – in the face of the current crisis. Only by carefully examining this process will it be possible to integrate culturally and structurally the principles of co-production into the region's healthcare infrastructures.
- More ethnographically oriented research is needed to shed light onto the concrete expression of health-related participatory activity, in order to untangle the interplay of trust, survival, and institutional activity on at the grassroots level.

References

Albert, C. and Köhler, T. (2020, 14 February) 'Yo me organizo en la plaza: Las cientos de asambleas que surgieron tras el estallido social', *CIPER Chile*, https://ciperchile.cl/2020/02/14/yo-me-organizo-en-la-plaza-las-cientos-de-asambleas-que-surgieron-tras-el-estallido-social/

Barrios, O.A. and Méndez, C.A. (2020) 'Crisis social y política en Chile: La demanda por acceso y cobertura universal de salud', *Revista Panamericana de Salud Pública*, 44: 1.

Beaubien, J. (2020, 2 July) 'How Chile ended up with one of the highest COVID-19 rates', *KRWG Public Media*, https://www.krwg.org/post/COVID-19-exploits-cracks-chilean-society

Boadle, A. (2020) 'Brazil fails to secure syringes for COVID-19 vaccine jabs', *Reuters*, https://www.reuters.com/article/us-health-coronavirus-brazil-syringes-idUSKBN29500N

Cancián, N. and Fernandes, T. (2020, 22 May) 'Brazil's interim health minister improves relationship with states, but COVID data crisis ensues', São Paulo: Folha de São Paulo, https://www1.folha.uol.com.br/internacional/en/brazil/2020/06/brazils-interim-health-minister-improves-relationship-with-states-but-COVID-data-crisis-ensues.shtml

Coelho, V.S.R.P, Szabzon, F., Sanchez, I., and Bhrun, L. (2020a) 'Pandemia, mobilização social e Atenção Primária à Saúde na cidade de São Paulo', *Blog Revista Novos Estudos – Especial Pandemia*, http://novosestudos.com.br/pandemia-mobilizacao-social-e-atencao-primaria-a-saude-na-cidade-de-sao-paulo/

Coelho, V.S.R.P, Lotta, G., Shankland, A., Szabzon, F., and Sanchez, I. (2020b) 'Vale apostar na Atenção Primária àSaúde contra a COVID-19?' *Blog Revista Novos Estudos – Especial Pandemia*, http://novosestudos.com.br/vale-apostar-na-atencao-primaria-a-saude-contra-a-COVID-19/

Espinoza, D. (2020, 23 June) 'Ollas comunes: lección de resistencia y solidaridad en tiempos de crisis', *Palabra pública – Universidad de Chile*, *18*, https://palabrapublica.uchile.cl/2020/07/23/ollas-comunes-resistencia-solidaridad-crisis-2/

Labra, M.E. (2001) 'Política e saúde no Chile e no Brasil: contribuições para uma comparação'. *Ciência & Saúde Coletiva*, 6(2): 361–376.

Loewenson, R., Colvin, C.J., Szabson, F., Das, S., Khanna, R., Coelho, V.S.R.P., Gansane, Z., Yao, S., Asibu, W.D., Rome, N., and Nolan, E. (2020) 'Beyond command and control: a rapid review of meaningful community engaged responses to COVID-19', *Global Public Health*, 0(0): 1–15, https://doi.org/10.1080/17441692.2021.1900316

Lotta, G., Wenham, C., Nunes, J., and Pimenta, D.N. (2020) Community health workers reveal COVID-19 disaster in Brazil, *The Lancet*, 396(10248): 365–366, https://doi.org/10.1016/S0140-6736(20)31521-X

Mendonça, M.H.M. de, Matta, G.C., Gondim, R., and Giovanella, L. (2018) *Atenção primária àsaúde no Brasil: conceitos, práticas e pesquisa*, Rio de Janeiro: Editora FIOCRUZ.

Oliveira, R.G. de, Cunha, A.P. da, Gadelha, A.G. dos S., Carpio, C.G., Oliveira, R.B. de, and Corrêa, R.M. (2020) 'Desigualdades raciais e a morte como horizonte: considerações sobre a COVID-19 e o racismo estrutural', *Cadernos de Saúde Pública*, 36(9): 1–14.

Richard, N. (2020) 'Del descontrol de la revuelta al control de la pandemia', *Anales de la Universidad de Chile*, 17: 421–436.

Travassos, L.R.F.C., Moreira, R.M.P., and Cortez, R.S. (2020) 'The virus, the disease and the inequality', *Ambiente e Sociedade*, 23: 1–12.

Worldometers (2021) *Current world population*, https://www.worldometers.info/coronavirus

8

Sovereigns and servers

Enablers and challenges to Sikh community-led activism during COVID-19

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

Introduction

Early on during the COVID-19 pandemic and subsequent lockdown in the United Kingdom, community intelligence highlighted a growing need among people who had already been struggling. Some of these people, who come from all ethnicities, races, and religions, were familiar faces in Gurdwara langar halls (the communal dining areas in every Sikh place of worship). As soon as Gurdwara attendees noticed these community needs, phone calls and text messages started to spread, and plans were made to find solutions to help.

The events that this chapter covers, the systematic processes that spur people into action during situations of need, is not new. The acts of providing hot food, things that people need, and standing alongside people who are oppressed, is a normal practice in Sikh communities. It describes 'Sikh activism around social justice and humanitarian relief [that centres on] Sikh concepts of *sewa* (selfless service) and *langar* (community kitchen) in a contemporary context' (Singh, 2018).

This chapter therefore describes individual and collective actions by minoritised and often racialised Sikh communities to address needs and provide services that were necessary during the pandemic and related lockdowns. These services have included health and care services, like support for mental wellbeing, and provisions to nurture physical and emotional wellbeing. The co-production described in this chapter, therefore, relates less to research and more to the actual design and delivery of services by Sikh individuals and organisations. This chapter brings together the experiences of individuals and organisations, and describes the impact of existing structures on activism in racialised communities.

Community-led activism: an intrinsic aspect of Sikh identity

This section presents the experiences and contributions of three individuals who were part of the initiatives to provide support during COVID-19 and the related lockdowns in London during 2020–21. These efforts were mirrored in all parts of the United Kingdom and in many other countries across the world. These examples have been chosen to highlight why some individuals from Sikh backgrounds partake in this action.

Project Hot Meals

Central Gurdwara (Khalsa Jatha) in West London has an active community who frequently rally around to provide necessary services and support to individuals globally and locally. The Gurdwara worked to provide over 14,000 meals a month for individuals across London during the lockdowns. Some of the work described in these scenarios was conducted in collaboration with other Sikh organisations, and it was funded through donations.

Sarabjit Kaur

> Early on in Lockdown, Ramneek Kaur, the Assistant General Secretary of the Gurdwara, asked who wanted to do sewa on the Gurdwara text message group. She set up a rota so that we would still be socially distancing, working in line with COVID-19 requirements. I took four weeks holiday to help. Tejinder Singh, my brother-in-law, also

helped and he would collect me from home and we'd head to the Gurdwara.

Amarjit Bhenji, who is from India, is the main langar (communal kitchen) manager in the Gurdwara. She guided us and told us what to do. She has amazing talents and can make 3–4 dishes a day that feed hundreds in a couple of hours. Her son had time off work during COVID-19 so he would help her prepare the vegetables so they were ready for when the rest of us helpers arrived. Amarjit Bhenji and her son would start doing this at 5am. The rest of us would help when we arrived, and by 9am, we started cooking; at 10am we started packing, and by lunchtime the food would be in the hospitals. It was a well-organised process because we have done this before and we could make up to 1,000 boxes a day.

We would drop the food boxes off at Hammersmith Hospital, Charing Cross, at food banks, and women's shelters. We also took the food to Southall where I live. We gave some to a church, to some of the older ladies who lived in that area from non-Sikh backgrounds, and a community organisation there set up for homeless people. We used to drop 250 boxes for each food bank daily and there would be such long queues, which was really sad to see, and there were so many women in the refuges at the time.

This was just a very small contribution. I have been raised experiencing our grandparents in Malaysia making langar as the first thing they thought of in all situations, so it has become second-nature. But this also helped me too. I wanted to get out of the house and to connect with others, so this helped with my mental health. It energised us and it helped me relax and stay calm.

Harvinder Kaur Dulku

Sewa means "Selfless Service", which involves helping someone without expecting anything back in return. I have been involved in many different kinds of sewa since a young child. This includes at the Gurdwara where I grew up in Penang, Malaysia and community sewa with the Red Crescent Society in school. I read about Bhai Khanaiya (who served under the leadership of Guru Gobind Singh, the tenth Guru of the Sikhs) when I was young and was inspired about what he did on the battleground in the 1700s. He gave water to everyone who was wounded, regardless of who they were fighting for. This demonstrated equality and the importance of all human lives.

Through sewa, my desire to be a nurse grew stronger and I did not hesitate to train as one, and am extremely proud that I have survived the nursing journey for 30 years. I am addicted to doing sewa and feel a huge void if I don't partake in it whether it's at work or in the community. Through sewa, I have met many wonderful people and they are now part of my life's journey and it gives me a lot of strength to keep up with and deal with all life's problems.

Our ten Gurus and elders have sacrificed a lot for our dharam (spiritual path) so it's high time we return the favour and instil their teachings by doing sewa for the betterment of our community. This teaches us humility, to be humble and to appreciate human lives. It teaches us self-discipline and moulds our souls into oneness with God.

I have been participating in the Langar Hot Meals project since it started during the COVID pandemic on Good Friday in 2020. I feel blessed to be able to assist with this wonderful sewa. I have devoted my weekends to this work.

As a mother I'm setting an example for my daughter to follow, as the saying goes 'practice what we preach'. Being a role model to her and others is a challenge in trying to practise and empower them with good deeds which will result in blessings.

Distributing hot food to frontline workers with Khalsa Aid

Bob Singh Virdee met Ravi Singh, the founder of a charity called Khalsa Aid, in 2012 during increased political action about an impending death sentence being carried out on a Sikh in India. Bob felt he related to Ravi Singh, leading to a longer-term friendship. Bob has helped Khalsa Aid over the years, including after the Grenfell Tower fire, which happened a few streets away from his opticians shop, and which impacted some of his patients. COVID-19 provided another opportunity for Bob to continue this work, and he describes his experience as follows.

> I saw that Ravi Singh was going to Casualty and going to hospitals by himself with a few volunteers to give hot food as a way of keeping up staff morale. Ravi is inspirational and living the way we have been instructed to live by our Gurus. He has great charisma, which inspires people to live as a Sikh. This was just one example of a way to do that.
>
> March 2020 was initially cold and quite dreary. So I said I would go with Ravi to the hospitals. A few restaurants in Southall had made food so we collected it and then went to the first hospital to drop it off. Going through that first A&E department with physical red flags everywhere, and warning signs, was a shock. We walked through all that to take this food to the staff rooms and the workers clapped because they were so appreciative that people were doing something for them too. I won't lie though, it was quite scary, because you were so physically close to COVID-19.
>
> If you are so close to tragedy and you can do something to help, you do. We keep our kesh (uncut hair) to stand out and stand up, and to be people who others can come to when they need something. Being a Sikh is not only a word; your actions have to portray your true nature. Whatever I can do, I hope to live by the teachings and practice of Guru Nanak Dev Ji [the first Sikh Guru] and to do as much as you can little. These are the principles I hope to live by. The Gurus lived their life by example and we have to live our lives by example, to teach our kids, and show and act the way the Gurus taught us to …

Community-led activism: a threat to the system?

Sikh individuals and organisations over the years have reported a number of challenges to their efforts to initiate community-led activism. These challenges have been anonymised so that they do not impact the continuation of this work, and are presented in the following.

Sikhs, through their regular community-focused actions during the pandemic, were seen as demonstrating 'model minority' traits evidenced in social media commentary, which others (specifically racialised minorities) should emulate. This attempts to separate the political and the spiritual and pacify a community, which has, through the practical examples of ten Gurus, been told to stand with the oppressed. Guru Hargobind, the sixth Guru of the Sikhs, stated in the 1600s that political sovereignty and spiritual power were necessary bedfellows, formalising almost two centuries of examples set by preceding Gurus. The individuals and organisations whose experiences have formed this piece, all speak out against Islamophobia or in support of justice for Black communities. Yet snide comments underneath any social media posts about such 'Sikh activism … [centring on] … *sewa* and *langar*' (Singh, 2018), allude to this community action being an example of acceptable and expected behaviour by well-behaved racialised communities. In an apparent hierarchy of behaviours created for racialised communities, we Sikhs are blessed that racists position us and our 'good behaviour' at the pinnacle.

Such Sikh forms of activism are lauded when they are seen to benefit our communities and society, but this activism is also structured to ensure it stays within acceptable parameters. For example, the Charity Commission is frequently felt to regulate and restrict campaigning and political activities within Sikh communities. The Charity's Chair, Baroness Stowell has stated, 'If you want to improve lives and strengthen communities through charity, you need to leave party politics and the culture wars out of it' (Stowell, 2020). This simplifies the intrinsically political nature of community-led action for many people of colour, negating the fact that much of this action has arisen because of oppressive and historical political contexts. For

Sikh charities, the Charity Commission, and comments such as those by Baroness Stowell, a Tory peer, may appear to be attempts to pacify the actions of marginalised communities. Could Sikh charities be challenged when speaking out about the involvement of a Tory government and the British secret service in the storming of Sikh Gurdwaras in Punjab in 1984 (Miller, 2014)? The Charity Commission's unhelpful direction in this space is viewed as increased policing of the behaviour of racialised communities, requiring Sikh charities to be ever aware of what they say and do.

Sikh organisations and individuals have generally faced many challenges from individuals and institutions within the geographical spaces in which they are working. These experiences of microaggressions have caused additional (emotional) labour:

> As we were cooking the food at the Gurdwara, the lady who lives opposite called the police to say we were having a gathering. She has done this type of thing before and obviously this was during lockdown when gatherings were not allowed. Then the President of the Gurdwara had to tell the police we were, in fact, preparing langar. (Sarabjit Kaur)

There is a pervading view within some Sikh communities that institutions such as local councils and the police hinder this community-led action. Anonymous contributors to this chapter told us some of the richest councils in London did not contribute financially to the efforts by the Sikh community, and one council has established strict rotas stating when organisations can distribute food for homeless communities. The actions of such councils have limited rather than optimised the potential of such humanitarian relief.

Conclusion

Sikh community-led activism provides one example of a potential model of community-led co-production, through which communities can help those who are struggling to thrive. We suggest three priorities to strengthen the impact of this activism.

What needs to be done

- Statutory organisations and institutions should facilitate the contribution of such communities.

Organisations and institutions should value and actively enable examples of community-led activism by building relationships with these communities. Such relationships can make explicit the barriers and enablers to embedding and scaling up action as a solution to tackling inequalities.

- Anti-racism training for the Charity Commission and statutory organisations.

There is a need to review structures such as the Charity Commission and assess the extent to which they facilitate or pacify charitable work. Anti-racism training at such institutions would be a useful way to initiate such assessment.

- Accept the political component of community-led social activism.

As stated in this article, it is not uncommon for social activism for racialised communities to have and be intertwined with political origins. These political underpinnings and facilitators should be acknowledged rather than policed.

Disclaimer

The views expressed in this publication are those of the authors and not necessarily those of the organisations whose work is described.

References

Singh, J. (2018) *Is Sikh extremism really active in Canada?* https://nationalpost.com/pmn/news-pmn/is-sikh-extremism-really-active-in-canada

Stowell, Baroness (2020) *If you want to improve lives through charity, leave political fights out of it*, https://www.dailymail.co.uk/debate/article-8996635/Charity-Commission-chair-BARONESS-STOWELL-Leave-political-fights-charity.html

Miller, P. (2014) *British Special Forces advised 1984 Amritsar raid*, https://www.opendemocracy.net/en/shine-a-light/british-special-forces-advised-1984-amritsar-raid/

9

What are we clapping for? Sending people to die in social care: why the NHS did this and what needs to happen next?

Peter Beresford

The United Kingdom (UK) National Health Service (NHS) was sold as our saviour during the COVID-19 pandemic, and its staff presented as heroes. Yet the NHS was responsible for the deaths of many thousands of vulnerable people who it discharged without due care for their wellbeing or that of others, who then became infected by the virus. Why did this happen and how did we get to that position? Do we need to look more carefully at the relationship between the people who make up the NHS and its nature as a social institution and politicised system? What does it tell us about the intersection of ideology, health and care, and how we might avoid a repeat situation in the future through a stronger commitment to user involvement and co-production?

Protecting people or policy?

The NHS became the focus for public support and concern as the seriousness of COVID-19 began to emerge. In fact, the highest profile response to the virus outbreak was the public relations rather than policy one. Thus during the first outbreak, there were the front-page diversions of centenarian Captain Tom's NHS charity fundraising and knighthood. Then the public clapping for the NHS each Thursday at 8pm, where even those who may have been more concerned about the inadequacy of the political response to the pandemic were wary of breaking ranks and not joining in for fear of coming under personal attack. There were posters everywhere calling on us to 'Protect Your NHS', as if protecting the public wasn't the actual issue and endless children's drawings of rainbows in front windows with no sign of any policy crock of gold. Instead, concerns rose about the lack of personal protective equipment (PPE), the continuing failure of test and trace arrangements, and the costly opening and rapid closure of 'Nightingale' hospitals that lacked the staff to function.

It was quickly clear who was most likely to be at risk from COVID-19. From an early stage, it emerged that this was a pandemic that affected different groups very differently. If infected, children might be symptomless, and younger people without any underlying conditions barely affected. It was older people, disabled people, people with long-term and underlying conditions and compromised health and immunity who would be hit hardest. It later became apparent that disadvantaged and discriminated-against groups, like members of Black and minority ethnic communities, people on low income and living in impoverished areas, who generally face health inequalities, were also particularly badly hit by the pandemic (NHS, 2021). These are exactly the people that the UK's crisis-ridden social care system is meant to support and protect, and also groups particularly likely to turn to it for employment.

The victimisation of social care, its staff, and service users

But through all this brouhaha, the same NHS was discharging many thousands of patients back to social care and into the community, spiking the number of infections and deaths. We were encouraged to clap for the NHS, but the issue was always social care. In addition, we now know that people were discharged from hospital in large numbers to social care – its homes and domiciliary services – to spread the infection. Long devalued temporary care workers working across different homes spread it further, their workforce suffering much higher losses than those in the NHS and these were heavily racialised (Hodgson et al, 2020). During the first outbreak, at least 22,000 people were estimated to have died in care homes – homes where they were meant to be safe. There were earlier warnings, which went unheeded (Booth, 2020).

The hollowing out of the NHS

So why did this happen? During the COVID-19 crisis, it seemed that when the public thought of the NHS and wanted to express their appreciation, they conceived of it in terms of its frontline doctors, nurses, and many other health workers – some of whom were dying. However, there was actually an increasing gap between them and those controlling the NHS and making key decisions. It was the senior managers, massively expanded in importance and numbers since pressures to market politicisation and privatisation began with Margaret Thatcher, who made arbitrary and sweeping decisions to clear out thousands of older, long-term patients to clear the decks for COVID-19, which then caused the infection to spread on a massive scale. Nothing accelerated and widened the impact of COVID-19 in Britain more than this ill-considered bureaucratic action (Carter, 2020). The truth is that the NHS, from the start a patriarchal and inherently racist organisation, has become increasingly ambiguous and contradictory. Under neoliberal reform, the often-herculean efforts of its frontline practitioners have been additionally subjected to a culture of bullying, managerialism, and contracting out that has undermined efficiency, sapped enthusiasm, and deflected it from its original humanitarian purpose (Beresford, 2016; Duffy, 2019).

By mid-April 2020, it was admitted there had been COVID-19 outbreaks at more than 2,000 care homes. The CEO of Age UK accused the government of 'airbrushing older people out' of the pandemic 'as if they don't matter' (BBC News, 2020). The Labour Party called on the government to publish daily figures of deaths in care homes to highlight the 'true scale' of the spread of COVID-19. And *months not weeks* after the outbreak became evident; there was still no testing, and an acute shortage of protective gear and ventilators. Sky News headlined this as 'a scandal our grandchildren will ask about' (Crawford, 2020) and the right wing *Daily Mail* a 'care homes catastrophe'. Thus as-yet unknown tens of thousands have died unnecessarily. Ruthlessly neglected social care became the site for the loss of disproportionate numbers of the most vulnerable of citizens, who we knew from the start were the most liable to be killed by the virus. We can guess the suffering; we still don't even know reliably how many are dying and how many staff may ultimately share the same unnecessary fate.

Social care: the policy politicians forget

The NHS's action was made doubly dangerous and discriminatory by the appalling state of social care in England. It has been identified as in chronic failure both cross-party and by key interests and the experts involved. It has been a case study of the short-termism of modern UK politics. For years, regardless of party, successive governments relied on the mantra of *integrating* health and social care, without making any fundamental change. Symbolically the ministry was renamed the Department for Health and *Social Care*. In reality, the two policies couldn't be more different and accordingly more impossible to integrate successfully. On one side, we have the NHS, survivor of welfare state principles, still largely free at the point of delivery and paid for out of general taxation, despite all the privatising efforts to undermine it from within. On the other side, there is social care, a relic of poor law principles, with means and needs testing still central to its operation. The better funded more politically powerful NHS's use of social care as a dustbin for COVID-19 casualties was no more than a culmination of the divisions and inequalities between the two.

Given that the worst consequences of the COVID-19 virus mainly affect older and vulnerable people, we could guess from the start that good social care support would be at a premium. Even though we already knew this, there was no mention of improving social care in the 2020 spring budget. When emergency legislation to address COVID-19 was introduced 'late in the day', it actually further restricted access to social care rather than improving it.

This pandemic was always going to be difficult, confusing, and disturbing for those most at risk; for people with Alzheimer's it is frightening, and it's difficult for many mental health service users, with the possibility of damaging isolation for some disabled people and people with learning difficulties. Nevertheless, the inadequacy of social care and the lack of government leadership and its incompetence resulted in something incalculably worse. It will be a long time before we are likely to know the scale of this and the indirect as well as direct casualties.

Ignoring experiential knowledge

One of the many disasters of the UK government response to the COVID-19 pandemic has been the way in which the British government, with shocking even-handedness, has ignored both old and new science. Thus, little notice has been taken, in shaping policy, of old-style experimental research, while as yet even less attention has been paid to the new user-led and co-produced approaches, which represents perhaps the biggest innovation in modern knowledge production. While disabled people and other long-term service users and their organisations tried to report the problems they were experiencing and what was actually going on, they were ignored. It was only after pressure from disabled people's organisations that data on the death rate for disabled people from COVID-19 was collected. The adjusted results indicate that disabled men were nearly twice as likely to die as non-disabled men were, and disabled women were two and a half times more likely to die than non-disabled women were. The Office for National Statistics report suggests that these figures, if anything, are likely to be an understatement and yet it still delayed on producing a further set of figures (Pring, 2020).

This reflects a broader political and policy failure to involve and to listen. There has been minimal systematic involvement of frontline staff, yet who else can offer crucial 'practitioner wisdom'? Little if any effort was made to involve those groups most at risk in the pandemic to contribute to developing policy, practice, or research priorities. This was despite their requests to do so and although the experience of many, from living a life routinely 'locked-down', could have offered very helpful insights into developing evidence-based policy and practice to combat resulting mental distress and other damaging effects.

The Westminster political response to COVID-19 raised concerns among service users, carers, and our organisations that the large-scale emergency conditions engendered by the pandemic may be creating an unhelpful watershed in user and carer involvement and co-production. It was as if the thinking was that this crisis is too urgent, there just isn't time to listen to people in the firing line, however much we recognise the value of that in normal times. However, if any proof were needed that this was a fundamental error, then the wastefulness and inefficiency of Westminster's response to COVID-19, highlighted it.

From exclusion to co-production

COVID-19 has laid bare the inadequacy of UK social care policies. If the rights and needs of disabled people and other long-term health and care service users are to be met, then fundamental and far-reaching change will be needed. This will, of course, require wider reform of public health, employment, income maintenance, education, and other public policies. But such change will need to start with radical social care reform – reform in both the process and direction of policymaking.

We already have the blueprint for such change and how to achieve it. This is provided by the United Nations Convention on the Rights of People with Disabilities (UNCRPD), informed by the pioneering thinking of the disabled people's movement. These move us from the present broken model of social care based on poor law principles of impoverishment and a residual service, to the NHS's founding principles of a universal service, free at the point of delivery and paid through a progressive system of taxation, based on a process of co-production. We already know this from service users and user-led organisations (ULOs); what's needed now is to act upon it.

The UNCRPD is based on the notion of 'independent living' developed by disabled people; that is, ensuring them the support to live their lives on as equal terms as possible with non-disabled people. And finally, with its concept of 'progressive realisation', the UNCRPD acknowledging political and economic realities recognises that such reform will need to be introduced gradually. This can be done on a rolling programme basis, gaining an accurate idea of the cost of recording unmet need for the first time, in order to get a realistic idea of the funding gap. Adopting such a vision and strategy rather than seeking yet another quick fix workaround could be the positive enduring inheritance of the present COVID-19 health and policy tragedy (Slasberg and Beresford, 2020).

Key points for the future

If social care reform is to achieve real synergy between health and care then it needs to be based on moving to the same principles of care, free at the point of delivery and paid for out of a progressive system of general taxation, as was the original NHS.

What needs to be done

- Specific funding should be allocated for co-production research, policy, and professional development in relation to COVID-19 and other health emergencies in health, social care, and public health.
- A programme of research and development based on user-led and co-production principles should urgently be established to access, evaluate, and share the experiential knowledge of groups that routinely face barriers and exclusions similar to those experienced more generally in situations of pandemic and lock-down.

- The perspectives of marginalised groups, especially those most affected by COVID-19 and other health emergencies should be routinely and systemically involved in policy and practice development.

References

BBC News (2020) 'Coronavirus: older people being "airbrushed" out of virus figures', https://www.bbc.co.uk/news/uk-52275823

Beresford, P. (2016) *All our welfare: towards participatory social policy*, Bristol: Policy Press.

Booth, R. (2020) 'Agency staff were spreading COVID-19 between care homes, PHE found in April', *The Guardian*, https://www.theguardian.com/world/2020/may/18/agency-staff-were-spreading-covid-19-between-care-homes-phe-found-in-april

Carter, C. (2020) 'Covid-19 drive to clear hospital beds left some of those discharged with unmet needs and no support', *Community Care*, https://www.communitycare.co.uk/2020/11/04/covid-19-drive-clear-hospital-beds-left-discharged-unmet-needs-support/

Crawford, A. (2020) 'Coronavirus: what's happening in UK care homes right now is a scandal our grandchildren will ask about', *Sky News*, https://news.sky.com/story/coronavirus-why-care-homes-are-the-scandal-among-scandals-during-this-pandemic-11971795

Duffy, P. (2019) *Whistle in the wind: life, death, detriment and dismissal in the NHS. A whistleblower's story*, independently published, https://books.google.co.uk/books/about/Whistle_in_the_Wind.html?id=VG8yyAEACAAJ&source=kp_book_description&redir_esc=y

Hodgson, K., Grimm, F., Vestesson, E., Brine, R., and Deeny, S. (2020) *Briefing: adult social care and COVID-19 – a Assessing the impact on social care users and staff in England so far*, London: The Health Foundation, https://www.health.org.uk/sites/default/files/upload/publications/2020/20200730-Adult-social-care-and-COVID-19-impact-so-far.pdf

NHS (2021) 'People at higher risk from coronavirus', https://www.nhs.uk/conditions/coronavirus-covid-19/people-at-higher-risk/

Pring, J. (2020) '"Devastating" COVID deaths figures "show government breached disabled people's right to life"', *Disability News Service*, https://www.disabilitynewsservice.com/devastating-covid-deaths-figures-show-government-breached-disabled-peoples-right-to-life/

Slasberg, C. and Beresford, P. (2020) 'Towards a new and sustainable future for adult social care', *Research Policy and Planning*, 33(3–4): 169–184.

Part II

Infection and (increasing) marginalisation

10

Disabled people's deaths don't count

How a protected characteristic offered disabled people little protection during this pandemic

Ellen Clifford and Mark Dunk

Most at risk, but we don't count

'Less of a terrible loss' – this was how a journalist described the COVID-related deaths of disabled people and those from more disadvantaged communities during the first wave of the pandemic. Others around the world echoed the sentiment (Neilson, 2020). We find ourselves in a situation where disabled people are most at risk of COVID-19 yet their needs have been disregarded within official responses to it globally.

Lindsey Lee, a former World Health Organization technical officer, has identified three distinct but related dimensions of disabled people's increased risk from COVID-19: (1) increased risk of contracting the disease related to reliance on daily contact in order for support needs to be met and, to residential placements in environments that make physical distancing difficult; (2) increased risk of developing a severe case due to a combination of increased barriers to healthcare; and (3) increased risk of negative secondary consequences from the COVID-19 response due to, for example, cancelled or delayed health treatment for other conditions (Lee, 2020).

In developing their responses to the pandemic, governments have widely failed to consult disabled people or to consider the impacts of their strategies on the most disadvantaged in society. This is in spite of legal duties, such as the duty on public bodies in England, Wales, and Scotland to pay due regard to policy impacts on people with protected characteristics, and human rights legislation. A global report on disability rights during the pandemic drew 'the worrying conclusion that states have overwhelmingly failed to take sufficient measures to protect the rights of persons with disabilities in their response to the pandemic. … Perhaps most troubling of all, it highlights that some states have actively pursued policies which result in wide scale violations of the rights to life and health of persons with disabilities, as well as impacting on a wide range of other rights' (Brennan, 2020:7).

One significant finding of the COVID-19 Disability Rights Monitor study was that disabled people 'report being left behind in countries regardless of their level of development, across both wealthy and developing states' (Brennan, 2020:7). Disabled people of all ages have been disproportionately represented among those who have died. Across Europe and North America, disabled and older people living in care homes have accounted for such a shocking proportion of deaths that the OECD has called on states to address 'the pre-existing structural problems in the long-term care (LTC) sector' that the crisis has both highlighted and exacerbated (OECD, 2020). This chapter examines the COVID-19 response and its impacts on disabled people in one such wealthy state: England.

Devolution of power in the United Kingdom has often meant that since 2010 disabled people have been disadvantaged more greatly in England compared to the devolved administrations of Scotland, Wales, and Northern Ireland (Reed and Portes, 2018). In relation to the pandemic, there is significant differentiation between the approaches taken. However, there are certain facts and statistics relevant to this chapter which concern the UK more widely than England and where this is the case, this is stated.

Context

Britain was once considered a world leader in support provision in rights protections for disabled people. Significant independent living advances enabling disabled people to live in the community regardless of impairment, and ground-breaking disability anti-discrimination legislation were granted in response to sustained campaigning by disabled people themselves. Progress has since been reversed through a deliberate programme of austerity and welfare reform measures implemented by the UK government and that has been found to have inflicted 'grave and serious violations of disabled people's rights' (Disability Committee, 2016).

In 2019, health spending as a share of UK Gross Domestic Product remained at its lowest level in a decade (Health Foundation, 2019). That same year, the Association of Directors of Adult Social Services accused the government of putting tens of thousands of older and disabled people at risk of being denied basic support, such as help with washing and dressing by their 'failure to get to grips with the escalating financial crisis in social care'. £7.7 billion had been cut from adult social care budgets in England (Butler, 2019), with a further £700 million of cuts made by the end of 2020 – although two thirds of directors were not wholly confident they could be delivered.

It is now widely understood that austerity and welfare reform were not a necessary response to the financial crisis but rather a political choice made by successive governments. This strategy prioritised economic interests over the health and wellbeing of the populace and is also evident in the UK government's approach to the pandemic. In June, a former member of the UK government's scientific advisory group argued that Britain's death toll from COVID-19 could have been halved if lockdown was introduced a week earlier (Reuters, 2020).

Disproportionate deaths

The scale of the disproportionate impact of COVID-19 on disabled people has not been reflected in the response to the crisis. Disabled people made up almost six in ten of all COVID-related deaths in England and Wales between 2 March and 14 July 2020. In all, there were more than 27,500 deaths of disabled people, compared with about 18,800 of non-disabled people. Disabled girls and women between ages

9 and 64 were especially at risk compared with their non-disabled counterparts, with a rate of death 10.8 times higher (ONS, 2020).

More recent analysis from Public Health England (PHE, 2020) showed that between 21 March and 5 June people with learning difficulties had a death rate 4.1 times higher than the general population and acknowledged this was likely an under-estimation. It could be as much as 6.3 times higher than the general population because the databases used for the research do not register all deaths of people with learning difficulties. Alarmingly, for people with learning difficulties aged 18–34, the death rate was 30 times higher than for non-disabled people in the same age group. Reasons posited by the PHE for the disproportionate number of deaths among this group included prevalence of comorbidities such as obesity and diabetes as well as potential problems understanding information about how to keep safe during the pandemic. In effect, people with learning difficulties were blamed for their own deaths.

PHE failed to mention any of the numerous social factors that undoubtedly placed people with learning difficulties at greater risk and which could have been avoided had the early stage of the pandemic been handled differently by government. These include lack of PPE in group homes where it is difficult to socially distance, test and trace failures, and lack of thought given to accessible dissemination of safety messages.

PHE also omitted any reference to the ongoing Care Quality Commission investigation into unlawful use of Do Not Resuscitate/Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) notices on disabled people's medical notes and coercion of disabled people to agree to it (CQC, 2020). Even after the NHS publicly spoke out against this practice in response to public concerns, group homes for autistic people and people with learning difficulties continued to receive communications from their local clinical commissioning groups pressing them to complete DNACPR forms for all residents.

Resistance and the limitations of legal protections

Disabled campaigners have been alert to discriminatory policymaking and practice involved in the COVID-19 response. Networks that originally formed to oppose the disproportionate impact of austerity and welfare reform measures on disabled people have monitored the situation since the early days of the pandemic. Campaigners have been kept busy taking action over numerous aspects of the pandemic response, including priority access to online deliveries for disabled people unable to leave the house, lack of COVID-19 guidance for disabled people employing personal assistants; the discharge of untested patients from hospitals straight into care homes; and initial rules banning all hospital visitors. These rules left disabled people who require additional support to understand or to be understood to die confused, misunderstood/ignored, and/or frightened.

The existing legal framework has been one of the tools that campaigners have to mitigate these avoidable harms. At the same time, the pandemic has further underlined the limitations of legislative protections already exposed by austerity and welfare reform. The Coronavirus Act has removed statutory duties on local authorities to assess the support needs of disabled people by introducing 'easements' to the Care Act 2014. Another easement to Section 42 duties of the Children and Families Act negatively affects disabled children with an Education, Health and Care Plan (ECHP).

Disability News Service reported in July that the UK government breached the rights of disabled people in at least 17 different ways during the coronavirus pandemic (Pring, 2020). Such findings have been described as an affront to dignity, inclusion, and equality (Tidball et al, 2020). However, the UK government continues to ignore the recommendation – issued by Parliament's Joint Committee on Human Rights (JCHR) in September – to carry out a 'swift lessons-learned review and a public inquiry' (JCHR, 2020).

Secret orders

One of the issues picked up by the JCHR was how 'decision-making relating to admission to hospital, in particular critical care, for adults with COVID-19 has discriminated against older and disabled people'. This is a particular case in point regarding the limitations of legislative protections.

In March, campaigners secured a revision of the 'rapid COVID-19 critical care guideline' produced by the National Institute for Clinical Excellence (NICE). The guideline originally stated that all adults on admission to hospital, irrespective of COVID-19 status, should be assessed for frailty using the Clinical Frailty Scale (CFS), and that comorbidities and underlying health conditions should be considered. In response to a public outcry and threat of legal action, NICE updated its guidelines on 25 March to emphasise the need to consider additional patient factors when interpreting the CFS score (NICE, 2020).

This was far short of the reassurance that campaigners were seeking and left disabled people completing homemade 'hospital passports'. These documents emphasised the valuable roles they play in the community and their contributions to society and were to be taken with them should they be admitted to hospital during the pandemic. They were a grassroots attempt to resist denial of critical care.

Unprecedented steps were taken to keep large numbers of elderly and 'frail' patients at home and out of intensive care wards in order to avoid these services becoming overwhelmed. It also now appears that an unpublished age-based frailty score system commissioned by the UK government's Chief Medical Advisor, Professor Chris Whitty, was behind the widespread denial of intensive care to people over 80 years old. It also excluded many disabled people over the age of 60 from life-saving treatment. Testimony by doctors has confirmed that the system was used by medics to prevent elderly patients 'blocking' intensive care beds. A second version increased the score for specific illnesses but lowered it for age – in other words, made it more targeted at denial of treatment on the basis of impairment as opposed to age. NHS doctors were forced to make tough decisions about which patients to treat and who to leave to die.

Evidence that intensive care treatment is of 'crucial importance' for survival is reflected in the statistic that only one in nine people who died of COVID-19 were given it. A study comparing the number of COVID-19 deaths on normal wards against the number of intensive care beds said to be available in UK drew the conclusion that intensive care was being overzealously withheld (Shovlin and Vizcaychip, 2020). This finding has been linked to a 'COVID-19 decision support tool' in circulation in March.

Moving forwards

A number of bodies including the OECD, the World Health Organization, and the Swedish Corona Commission have called on governments to use the tragedy of care home deaths to incentivise the introduction of serious measures to address pre-existing structural issues with the social care sector. History suggests that it is unlikely that governments scrambling to 'boost' their respective economies in the wake of the virus will follow these recommendations. The relationship of impairment to the processes of production that makes disabled people a less ready source of profits will further compound this tendency to disregard impacts on disabled people.

The question is then, what actions can we as disabled people, service users, and health and social care practitioners take to raise awareness of how oppression and injustice, exacerbated by crises such as COVID-19, are built into the fabric of the current system? In building awareness there is a need to promote widespread, united support for alternatives that can better serve those who are otherwise discriminated and (in many cases fatally) harmed by the system.

What needs to be done

- Explore and unravel the overlaps between old age, impairment, and illness in order to better challenge mainstream narratives concerning 'vulnerability' that effectively devalue those who are labelled as vulnerable.
- Build support for a National Independent Living Support Service (ROFA, 2019) paid for from general taxation and free at the point of delivery, capable of supporting disabled people's equal participation in the community and providing the social care workforce with appropriate conditions, pay, training, and profile.
- Concerted campaigning needs to happen to prevent further privatisation of the NHS and the damage this has done to disabled people through inadequate and at times abusive social care.
- Disabled people's organisations and practitioners in the UK need to build stronger alliances with disabled people both nationally and internationally in order to share experiences and solidarity.

References

Brennan, C.S. (2020) *Disability rights during the pandemic: a global report on findings of the COVID-19 Disability Rights Monitor*, https://www.internationaldisabilityalliance.org/sites/default/files/disability_rights_during_the_pandemic_report_web_pdf_1.pdf

Butler, P. (2019) *Social care chiefs: funding crisis puts tens of thousands at risk*, https://www.theguardian.com/society/2019/jun/26/social-care-funding-crisis-putting-tens-of-thousands-at-risk

Care Quality Commission (CQC) (2020) *Reviewing the use of Do Not Resuscitate Decisions during COVID-19*, https://www.cqc.org.uk/news/stories/reviewing-use-do-not-resuscitate-decisions-during-covid-19

Disability Committee (2016) *Inquiry concerning the United Kingdom of Great Britain and Northern Ireland, carried out by the Committee under article 6 of the Optional Protocol to the Convention. Office of the High Commissioner for Human Rights*, https://www.inclusionlondon.org.uk/wp-content/uploads/2018/10/UNCRPD-Report-Oct-2016.doc

Health Foundation (2019) *Health spending as a share of GDP remains at lowest level in a decade*, https://www.health.

org.uk/news-and-comment/charts-and-infographics/health-spending-as-a-share-of-gdp-remains-at-lowest-level-in

Joint Committee on Human Rights (JCHR) (2020) *The government must urgently consider the human rights implications of COVID-19 measures, says Joint Committee on Human Rights*, https://committees.parliament.uk/work/218/the-governments-response-to-covid19-human-rights-implications/news/119291/the-government-must-urgently-consider-the-human-rights-implications-of-covid19-measures-says-joint-committee-on-human-rights

Lee, L. (2020) 'Disabled people's access to healthcare services', *An affront to dignity, inclusion and equality: Coronavirus and the impact of law, policy and practice on people with disabilities in the United Kingdom*, Oxford: Oxford University Faculty of Law, pp 10–11, https://www.law.ox.ac.uk/news/2020-07-02-affront-dignity-inclusion-and-equality-coronavirus-and-impact-law-policy-practice

National Institute for Health and Care Excellence [NICE] (2020) *NICE updates rapid COVID-19 guideline on critical care*, https://www.nice.org.uk/news/article/nice-updates-rapid-covid-19-guideline-on-critical-care

Neilson, S. (2020) *Eugenics, COVID-19 and international solidarity*, https://www.youtube.com/watch?v=ZSvQ6RQ2ieM

Office for National Statistics [ONS] (2020) *Coronavirus (COVID-19) related deaths by disability status, England and Wales: 2 March to 14 July 2020*, https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/articles/coronaviruscovid19relateddeathsbydisabilitystatusenglandandwales/2marchto14july2020

Organisation for Economic Co-operation and Development (OECD) (2020) *Workforce and safety in long-term care during the COVID-19 pandemic*, http://www.oecd.org/coronavirus/policy-responses/workforce-and-safety-in-long-term-care-during-the-covid-19-pandemic-43fc5d50/

Pring, J. (2020) *Coronavirus: how the government breached disabled people's rights 17 times during the pandemic*, https://www.disabilitynewsservice.com/coronavirus-how-the-government-breached-disabled-peoples-rights-17-times-during-the-pandemic/

Public Health England (PHE) (2020) *People with learning disabilities had higher death rate from COVID-19*, https://www.gov.uk/government/news/people-with-learning-disabilities-had-higher-death-rate-from-covid-19

Reclaiming Our Futures Alliance (ROFA) (2019) *Independent living for the future our vision for a national independent living support system*, https://www.inclusionlondon.org.uk/wp-content/uploads/2019/06/NILSS_final.pdf

Reed, H. and Portes, J. (2018) *The cumulative impact on living standards of public spending changes*, Equality and Human Rights Commission Research Report 120, https://www.equalityhumanrights.com/sites/default/files/cumulative-impact-on-living-standards-of-public-spending-changes.pdf

Reuters (2020) *UK lockdown a week earlier could have halved COVID-19 death toll, scientist says*, https://www.independent.co.uk/news/

uk/politics/uk-lockdown-coronavirus-death-toll-neil-ferguson-a9559051.html

Shovlin, C. and Vizcaychip, M. (2020) *Implications for COVID-19 triage from the ICNARC report of 2204 COVID-19 cases managed in UK adult intensive care units*, http://orcid.org/0000-0001-7894-873XMarcela P Vizcaychipi3,4

Tidball, M., Lawson, A., Lee, L., Herring, J., Sloan, B., Mallick, K., Holloway, D., and Ryan, S. (2020) *An affront to dignity, inclusion and equality: Coronavirus and the impact of law, policy and practice on people with disabilities in the United Kingdom*, Oxford: Oxford University Press.

11

Realities of welfare reform under COVID-19 lockdown

What disabled and older people actually experience

The Secret Welfare Rights Worker

Since the first lockdown I have spent my days as a welfare rights worker on the phone supporting people to claim the benefits they are entitled to, or if their claim has been rejected, helping them to appeal against this.

The increased importance of welfare benefits in a pandemic

Although understandably the COVID-19 pandemic has resulted in a focus on health and public health policy, income maintenance policy is no less important. In the UK for example, numerous policies have been introduced since lockdown to deal with the two big interrelated problems any such pandemic poses – making people ill and damaging the economy. Fear of spreading infection has resulted in more and more people being temporarily unable to work, furloughed, losing their jobs, or being made redundant as well, as self-employed people losing their income and often their businesses. In such cases in the UK, people may claim universal credit. If they become sick, they may claim employer or statutory sick pay, although as we shall see, the small print gets more complicated.

This means that there has predictably been a massive increase in the numbers of people reliant on UK state benefits. Historically when that happens, for example, during the last World War, with the blitz injuring and making people homeless, or in times of depression and massive unemployment, it often leads to improvements in benefits policies as many more people discover for themselves that living on welfare is far from the easy option that the right-wing media often portray it as.

COVID-19 has happened following just such a moral panic with the harshest of 'welfare reform' policies in operation now in the UK for more than a decade. Under successive governments, welfare benefits reform has been pursued with increasing severity, particularly in relation to those of working age, to force more and more people into employment, regardless of whether it's available or appropriate for them (Shefer et al, 2016). However, the direction of travel during COVID-19 has been in exactly the opposite direction, with many jobs furloughed and lost through the contraction of the economy and sickness from the pandemic.

The reality of benefit reform for those most at risk

So, what is life actually like for those who are reliant on welfare benefits and, particularly important, what is it like for those overlapping groups who are most at risk from COVID-19 – older and disabled people, family carers, and people with compromised health?

In this chapter, I hope to cast some light on this under-exposed topic from my daily experience as a welfare rights worker working directly with these groups, and – in the spirit of co-production – to offer people's own direct comments and experience who were faced with just such a situation first hand, while safeguarding their anonymity. Perhaps one such comment from a woman I have been working with sums up the nature and scale of the issues involved.

> Everything's so difficult now. I'm stuck at home with the virus. My children can't come over at present. I've no one to turn to. I don't know what to do. Have I got to claim Universal Credit? Someone told me I'll have to claim it. I know it's a terrible thing.

And the answer is yes, unless qualifying for the furlough scheme, you *will* have to claim Universal Credit in your situation to receive your income and ensure housing costs are met. First, though, for readers who haven't been claimants or advocates, perhaps something should be said about how this system actually operates.

COVID-19 has fundamentally changed the way I work and the situation of many of the people I work with. Before I met face-to-face with people needing help, I got to know them a bit and worked out together how best to make their claim. The UK welfare benefits system run by the Department for Work and Pensions (DWP) does not seem to have changed at all since the pandemic. Dealing with them is a difficult, stressful, and often harsh and painful exercise, as it has been ever since governments and politicians in the UK, and increasingly in other countries, started to talk up their unevidenced belief that many disabled and other claimants are actually 'scroungers' and work-shy, and would be better off getting a job rather than living on welfare benefits (Garthwaite, 2011). They called this 'welfare reform' as if it were trying to make the system better, when all the evidence shows that they just wanted to get disabled people off benefits regardless of whether they needed or were entitled to them – or not. This is why the rates of successful appeal against DWP decisions to deny or cut off people's benefits are inordinately high and most people represented by a trained advocate like me, tend to win their case.

Negotiating a hostile system

People are expected to fill in forms that may be 15 to 30 or more pages long – not so much forms as booklets. With more and more of these, claimants are expected to fill them in online. Universal Credit, which is one of the most important, *must* be done online. You can get help from the Citizens Advice Bureau to start your claim, but to do it over the phone, you have to prove exceptional circumstances to the DWP. Yet we know that the demographics of people seeking such welfare support have restricted access to computers and the internet. Since lockdown, I have had to communicate with people – family members and claimants – almost entirely by phone.

Obviously, this creates problems for people with hearing and visual impairments. But the problems go much further. Many people are still using landlines without loudspeakers. While a few use modern technology like Zoom or MS Teams, in my experience, most don't. You can't pick up on the same cues as you can face-to-face. They say things like: 'I was hoping for a home visit. I thought you were coming to see me at home. Can't I come in to see you, can't I come to the office?'

I try and support people to fill in the forms together over the phone. But this is easier said than done. People understandably want to tell their story; they don't think like a form. They don't know how to put things in order, and they certainly don't know what order the DWP wants or what it will regard as relevant. So they may want to give you a detailed account, perhaps of something relevant to them that happened 20 years ago – telling their story, which helps you get an idea of what has happened. Thus, 'So you said you had a serious heart attack five years ago, now if you could tell me what happened next and how the heart attack affected you.' But it is difficult for people to remember the sequence of events, what happened next, how it affected them. As one older man, now with memory problems, put it: 'So much has happened, there have been so many changes. I'd have had to keep a diary to remember all the ins and outs. So many things happening, bang, bang, how can they expect you to remember.'

And something else the DWP chooses not to recognise is that filling in their forms is actually beyond many people. I regularly encounter people whose reading and writing skills are not enough for them to be able to complete the forms. It is not a rare or isolated problem for people. When I could visit them, I could write things down for people, as they told me, if this were the case. It's not so easy to do this remotely. But for some people, even working out with them what the accurate answer to a question is, is too difficult for them to sort out on the phone. Even when you run through it with them, they don't have the experience, confidence, or skill to 'take dictation'. If you are frail, you may not be able to write quickly or well.

When applying for health-related benefits people don't necessarily know what is wrong with them or understand all the medication that they have been prescribed. Even if they have received written information from their GP or consultant, they may not know where they put it, or may not even have kept it.

We do not live in a society where everyone is equally medically literate. I have encountered at least two people after they have had a stroke, who have stopped taking their statins because they have read in the *Daily Express* that they are harmful!

Perhaps most damaging is that our social security system seems to be based on the assumption that the people who need its help want to cheat and defraud it (Garthwaite, 2011). Despite the fact that, historically, levels of welfare benefit abuse are very low and it results in far less lost state income than tax avoidance and evasion, it has become the focus of official discourse. This is particularly important in a system based on proving what's wrong with you and what you *can't* do to secure support, rather than resting on the philosophy of independent living developed by the disabled people's movement, where the purpose of support is to *maximise* what people can do and prevent things getting worse.

A system based on perverse incentives

In my experience, most older and disabled people making benefit claims want to emphasise what they *can do*, what's possible for them on a 'good day', rather than report the struggles they have and how bad things can be for them. This honesty of course plays into the DWP welfare reform strategy of restricting access to benefits and raising the bar as high as possible (Barr et al, 2016). As one disabled woman put it:

> It's like they want you to play up what's wrong with you. I think it is important to be very honest. I am an honest person. I really try to do things. I try to walk to the corner shop. I tried to have a shower on my own. No, I don't feel safe in the shower.

So it's especially important to help people work out what is really possible for them, what they can do without a serious struggle, and not to feel that their need for help casts them as dependent and 'scroungers' – as people in their position are increasingly stereotyped. As an advocate, it is therefore essential to try and work with people in a co-produced way that doesn't disadvantage them because they fall into the traps laid by the system, while not making them cast themselves as pathetic and dependent. The only way to do this is to try and work alongside the person in an equal inclusive way something that is more difficult to do with remote working.

Many people are terrified of Universal Credit, the benefit for people still of working age and under state pension age. It's also the benefit you have to claim for help with your rent if you are under pension age. They have heard how hard it is to get it, how you don't get paid quickly. 'It's a horrible benefit. I know you have to do it online. The whole thing frightens me.' A common expression I encounter is. 'I've worked all my life,' as if other people claiming benefits may not have done. People are disempowered by the sense of shame generated by the current welfare benefits policy and the generation of hostile public attitudes. 'I've never had to claim anything before. I've worked all my life and never had to claim benefits before I was made redundant.'

The need for radical reform

The people I work with are some of those most badly affected by COVID-19 and at highest risk from it. They are also among those most significantly impacted upon by the restrictions that have been put in place to try to control COVID-19. Most are resigned to the consequences, but this doesn't make it any less hard to deal with. For example:

> It's been terrible looking after (partner) with dementia. Day centres are closed. He can't stay with anyone else. He was going to stay with his son every other weekend for the whole weekend. You aren't allowed to do that now.

> My husband was going every Saturday afternoon to his daughter, then I could see my own son and grandchildren, now I can't because he's not allowed to go and I can't leave him. He sits all day watching the same DVD and I have to keep putting it on for him again. But that's the only thing that keeps him calm.

One older disabled man, crying, said:

> I can't see my daughter. I'm sticking to the rules. I cried with the GP the other day, he offered me counselling but I can't talk very well with what I've got so I don't want it. And when I talk about things it makes me very sad. I can't go out much so people come to me, so it's important they can't. It's awful.

It is difficult to know what the long-term consequences of COVID-19 may be. We know that some people are suffering long-term COVID-19 symptoms but we can guess that the UK benefits system with its present repressive preoccupations is unlikely to be sympathetic and is more likely to question them. So far, there's been no suggestion that essentially flawed benefits like Universal Credit and Personal Independence Payment (PIP) will be radically reviewed. We can only hope that like the poor law before, with many more people exposed to the benefits system's operation through the pandemic health emergency and its failings, dragged forcibly into the light, the pressure for real welfare reform will grow and become unstoppable.

What needs to be done

- The UK welfare benefits system needs to be subjected to radical reform in line with the philosophy of independent living developed by the disabled people's movement.
- There are currently no provisions for co-production in the UK welfare benefits system. Such a programme

should be urgently funded with the active involvement of people with experience of living on such benefits.
- Requirements for effective participation and user involvement developed in health and social care need to be extended to the welfare benefits system.

References

Barr, B., Taylor-Robinson, D., Stuckler, D., Loopstra, R., Reeves, A., and Whitehead, M. (2016) "'First, do no harm': are disability assessments associated with adverse trends in mental health? A longitudinal ecological study', *Journal of Epidemiology and Community Health*, 70(4): 339–345.

Garthwaite, K. (2011) 'The language of shirkers and scroungers?' Talking about illness, disability and coalition welfare reform', *Disability & Society*, 26(3): 369–372.

Shefer, G., Henderson, C., Frost-Gaskin, M., and Pacitti, R. (2016) 'Only making things worse: a qualitative study of the impact of wrongly removing disability benefits from people with mental illness', *Community Mental Health Journal*, 52(7): 834–841.

12

Against violence and abuse

Gender-based violence and the need for co-production with women with experience

Sonia Braham, Naima Iqbal,
Lucy Allwright, Ruth Atkinson, and
Cordelia Ruck

Introduction

AVA (Against Violence and Abuse) is a feminist charity committed to ending gender-based violence (GBV) and abuse. By GBV we mean harm or abuse directed at someone because of their gender (UNHCR, 2020).

AVA aims to place experts-by-experience (EBEs) at the centre of our work: working towards an approach based on participatory involvement. Recent work with EBEs includes recruiting and paying EBEs to develop projects, deliver training, undertake research, co-write policy reports, facilitate groups, and influence change through media and public speaking activities. Core to how we work is the understanding of GBV as a form of trauma that survivors carry with them long after abuse is over.

This chapter discusses AVA's co-production activities and learning during the COVID-19 pandemic, specifically focusing on our Women's Voices Peer Support project: a project working with EBEs to run peer support groups in one London borough.

The chapter is centred on the voices of two EBEs: Naima Iqbal and Sonia Braham. Through their experiences, we explore the challenges faced by survivors during the pandemic, as well as the lessons of co-production during this time.

COVID-19 and experiences of abuse

Globally, people have faced wide-ranging challenges because of COVID-19, including negative psychological impacts, physical ill-health, and financial insecurity (Brooks et al, 2020; United Nations Department of Economic and Social Affairs, 2020). For survivors of GBV, challenges and risks increased, and routes to safety narrowed (Women's Aid, 2020).

GBV is a form of trauma with long-lasting impacts (Ferrari et al, 2016). Reports of abuse have increased during the pandemic, and demand for GBV services has risen (ONS, 2020; Refuge, 2020). Numerous ways in which COVID-19 has played out – confinement, social isolation, lack of control, financial challenges – mirror perpetrators' tactics of abuse. For survivors, COVID-19 has compounded trauma.

Despite demand, many services were forced to operate at reduced capacity and/or through remote delivery. Many survivors were left without support – both from services, and from social networks.

Experiences of co-production during COVID-19 pandemic

The Women's Voices project

The Women's Voices project began in March 2020 with the aim to improve responses to homeless survivors of GBV in one London borough through peer support groups, alongside delivering training to professionals and working towards the development of gender- and trauma-informed service provision. Groups would be delivered by EBEs, providing space for women to come together, support one another, and feed into local service provision. With 'lockdown', the ability to run face-to-face community groups ended. Our concern remained the health and safety of the women we would be working with. Plans for peer support were paused; we changed the project and decided to build a peer-led evidence base of women's experiences of GBV and homelessness during lockdown.

This research was led by Naima and Sonia – peer researchers who have worked with AVA for several years. To ensure safety during the research process we recruited interviewees via key workers. Interviews took place by phone or online, and data was shared digitally.

Alongside research activities, recruitment for peer-group facilitators commenced with the aim of establishing peer support groups online. By November 2020, nine peer facilitators were recruited and trained.

The impact of COVID-19

Naima and Sonia co-wrote the following section, sharing their experiences of living and working through the pandemic. The messages from Naima and Sonia are clear – organisations working with women must understand women's specific experiences, and work in partnership *with*, not *for*, them.

What follows are key themes they identified regarding their own experiences, alongside those of women they interviewed.

Experiences of lockdown mirrored abuse

Naima and Sonia felt patterns of coercion and abuse were mirrored by the restrictions of lockdown. Naima describes GBV as intensely isolating: women are 'cut off from family' or 'shunned by others due to shame'. Rebuilding after abuse causes many women to face destitution; lockdown exacerbated this, leaving women afraid, alone, and financially insecure. Indeed, all those who Naima interviewed 'spoke about going through severe financial difficulties'.

Sonia's story mirrors that of many women during the pandemic – she faced the return of her abuser. 'When lockdown happened I felt isolated, trapped and far away from people and places, … the fact that I didn't know how long this lockdown would go on made me more reliant on the perpetrator's company.' The pandemic created an opening for her abuser to return: 'During this fearful pandemic he made me feel like I was not alone and gave me some form of comfort.'

Sonia reflected that the ability to escape coercion is limited when trapped at home and isolated from support networks or organisations.

Experiences of lockdown triggered trauma

Both women described the triggering nature of lockdown. Naima's PTSD symptoms were exacerbated: 'The isolation impacts your mental health even further as now there is no one you can talk to when you are having a bad day.' Sonia's intense isolation and exhaustion meant she began using alcohol to escape her abuser's presence: 'I started drinking so that I could be around him, tolerate his ways and block the whole situation out of my head.'

For some interviewees the stress of recently leaving an abusive situation was compounded by stresses of the pandemic: 'I'm living with the fear of the illness and I know that it's increasing again. Just as I felt ready to take a breath and be able to live with my children in peace, this has happened.'

Experiences of lockdown left people without support

The lockdown restricted access to support and coping mechanisms: 'All my coping mechanisms to combat isolation – all gone' (Naima). Interviewees reiterated this, referencing being unable to access substance-use support groups, and limited options for practising self-care. 'I started doing yoga before corona, so that got stopped … even though I'm a person that's ok to be at home, it's been difficult as I never had the option of doing things or going places.'

For others, COVID-19 prolonged waiting times for support – notably delaying access to housing and mental health support, as well as asylum application processes. Women experienced setbacks in their recovery; several struggled with addiction and relapse where support was unavailable.

Experiences of co-production during the pandemic

Naima and Sonia described the value of co-production during the pandemic as a means to counter the impacts captured earlier. In what follows they share their experiences of being a part of the Women's Voices project in the context of COVID-19.

Sonia was juggling reconnecting with services, police involvement, and managing alcohol use; co-production offered her hope:

> It was a very scary time … and I needed to carry on with my goals … being able to have something to do was vital … it gave hope … you lot didn't give up and carried on. … It gave me something else to pick me up … what else could I do … when everyone else is moving you're moving … it's an encouragement … I could easily give up in my mind … I could easily fool myself that I should go back to the drugs … to go back to him … to die … but I didn't because I had something.

Participating and feeling valued were vital to keeping Sonia going: 'You give them [survivors] opportunities that no one else will give.'

Sonia articulated how co-production, compared to 'service use', is a different kind of relationship. Participation provided opportunities to build skills and confidence. This was a broader reflection on experiences of co-production, however, Sonia felt it was crucial that opportunities for involvement continued during the pandemic: 'I didn't know I could do half the things I could do … I am learning that I can do things.'

Both women indicated that trust – the heart of co-production – is vital to rebuilding self-worth, and this was particularly important during the isolation and uncertainty of lockdown: 'We were left to our own devices and grow in confidence as we used our lived experience to help us shape the interview structure' (Naima).

Naima, who lives with PTSD, described the importance of being accommodated to participate where she was at: 'We were given a very gentle paced workload and not very strict deadlines to help make it easier and less stressful.'

Sonia noted how, despite some challenges in her relationship with AVA, time and space were given to work through mistakes on both sides, and involvement wasn't stopped: 'You've allowed me to look at myself and work through things … when a person is damaged [by an abuser] … you don't always know what is going on … working through things is really good … never write someone off.' This was also a vital lesson for AVA: the path of co-production isn't always smooth and it is important to reflect with EBEs, learn from each other, and grow.

Both women acknowledged that paying people for their work is vital for helping them feel valued: 'I want to feel a part of it all, I am working, I am responsible. I just want the chance to work.' Naima also described the importance of feeling on an equal footing with other staff members.

Sonia shared that, because of a specialist local women's service, she got help and protection to escape from her abuser. Alongside this, she highlighted the importance of being enabled to have hope, ambition, and dreams through the opportunity to participate in the Women's Voices project, and more broadly to continue working alongside AVA.

Learning from co-production during COVID-19

The following captures AVA's learning from delivering participation activities during COVID-19 and beyond, building on Naima and Sonia's insights. Underpinning lessons shared is the importance of co-producing with survivors. Organisations must be brave in knowing women's safety is centred on agency, and co-production provides crucial opportunities for building self-efficacy and worth.

Learning opportunities

AVA works with a pre-established group of EBEs, meaning we could mobilise quickly to enable peer-research activities during the pandemic. Naima and Sonia's peer-research skills and personal experience helped AVA understand women's experiences during COVID-19.

Their involvement also allowed us to understand women's experiences and priorities around co-production.

> When you do things together and get out there … as women together … doing something together … it's a good thing to do for support … I really think women go back [to abuse] because they don't have that support network … you should let the women know they are not alone. (Sonia)

The invaluable knowledge gained will support our peer-group development going forward.

Trauma-informed approaches

Working in a way that acknowledges trauma is vital in co-production with women: 'Organisations that work with women need to gain an understanding of how broken and vulnerable a person feels after experiencing trauma and abuse. Having experts-by-experience working with women makes the organisation more accessible to vulnerable women' (Naima).

GBV removes choice and agency. The stories and experiences of women under COVID-19 are not new; the pandemic has exposed deep-rooted processes of exclusion. Acknowledging trauma and women's right to control, empowerment, and safety is vital to helping survivors heal (Herman, 1992; Harris and Fallot, 2001).

Naima and Sonia's experiences and research helped evidence how we should be working with women. As the Women's Voices project's peer support model develops, our focus is holding trauma safely and creating accessible groups where women can participate at their own pace. Providing participatory, survivor-led models can be a lifeline: 'If you give people opportunities … It makes them feel like they belong and they are worth it' (Sonia).

Peer involvement offers opportunities to build trust and connection with and between women. Naima stated that participating in peer research is a chance to 'cope emotionally' and reduce isolation – particularly vital during the pandemic. This was reiterated by interviewees as well as newly trained peer facilitators.

Both women felt that managing difficulty and uncertainty in a safe environment is vital in co-production with survivors; 'being able to work through things' allows EBEs to realise their worth. This counters perpetrators' use of punishment and humiliation.

Trauma-informed co-production allows individuals to safely make mistakes, together.

What needs to be done

Good co-production creates opportunities to 'do with', not 'do to'. Projects and programmes should be designed with and by survivors, taking a gender and trauma-informed approach centred on participants' strengths. What follows is a list of tips for implementing trauma-informed co-production:

- **Provide fair payment:** GBV is based around transactional relationships, exploitation, and devaluing women. Adequate valuation and payment counters this. This is particularly pertinent considering financial challenges exacerbated by the pandemic.
- **Provide flexibility and choice:** Women need flexibility, options and control over how they participate. In the context of COVID-19, think about digital accessibility. For example, providing participants with tech equipment and support can help overcome challenges of remote participation.
- **Build trusting relationships through collaboration:** Working collaboratively provides an opportunity to balance power and challenge past unequal relationships. Creating trusting relationships builds confidence and places the right to equality and having a voice at the core of practice. This can also help combat isolation during COVID-19.

- **Prioritise physical and emotional safety of participants at all stages:** Involvement work can be triggering and difficult. Collectively creating clear boundaries and embedding check-ins, reflective practice and self-care are of vital importance – especially important when face-to-face support is less readily available.
- **Create opportunities for empowerment and healing:** Co-production must focus on empowerment, providing women with opportunities for growth. Embed opportunities for learning, skills, and training and give women control over inputs and outputs.

While abuse takes away power, co-production collectively builds power, giving voice to those who are too often silenced. This is pertinent in the context of COVID-19, where survivors' experiences of the pandemic mirrored experiences of GBV, and coping mechanisms were removed.

Creating space for those with lived experience during this time is vital – 'fighting together to survive is a good thing' (Sonia).

References

Brooks, S.K., Webster, R.K., Smith, L.E., Woodland, L., Wessely, S., Greenberg, N., and Rubin, G.J. (2020) The psychological impact of quarantine and how to reduce it: rapid review of the evidence, *The Lancet*, 395(10227): 912–920.

Ferrari, G., Agnew-Davies, R., Bailey, J., Howard, L., Howarth, E., Peters, T.J., Sardinha, L., and Feder, G.S. (2016) 'Domestic violence and mental health: a cross-sectional survey of women seeking help from domestic violence support services'. *Global Health Action*, 9(1).

Harris, M. and Fallot, R. (eds) (2001) *Using trauma theory to design service systems. new directions for mental health services*, San Francisco: Jossey-Bass.

Herman, J. (1992) *Trauma and Recovery: the aftermath of violence from domestic abuse to political terror*, New York: Basic Books.

ONS (2020) *Domestic abuse during the coronavirus (COVID-19) pandemic, England and Wales*, London: ONS.

Refuge (2020) 25% *increase in calls to National Domestic Abuse Helpline since lockdown measures began*, https://www.refuge.org.uk/25-increase-in-calls-to-national-domestic-abuse-helpline-since-lockdown-measures-began/

UNHCR (2020) *Gender based violence*, https://www.unhcr.org/gender-based-violence.html

United Nations Department of Economic and Social Affairs (2020) *Monthly briefing: COVID-19 disrupting lives, economies and societies*, https://www.un.org/development/desa/dpad/publication/world-economic-situation-and-prospects-april-2020-briefing-no-136/

Women's Aid (2020) *A perfect storm: the impact of the Covid-19 pandemic on domestic abuse survivors and the services supporting them,* Bristol: Women's Aid.

13

COVID-19 and multi-generational households

Reflections on the experience of a diverse urban community in Wales

Amal Beyrouty, Mashmooma Din,
Eva Elliott, and Allan Herbert
(authors listed alphabetically)

Over the last year, statistics on COVID-19 have highlighted the higher number of infections and deaths in some Black, Asian, and other minority ethnic (BAME) groups. Data suggest that differences remain after accounting for underlying conditions (Fox and Monahan, 2020). The reasons are likely due to structural inequalities that shape people's lives and disproportionately disadvantage particular groups of people. One risk factor that the Office of National Statistics (ONS) has identified is older people living in multi-generational households. Someone over 70 is much more likely to be living in a house with a mix of generations if their ethnicity is identified as Bangladeshi (56%) or Pakistani (35%) (Fox and Monahan, 2020). For Indian households it is still relatively high at 13%, whereas for those who identify themselves as 'white' this goes down to around 2%. People over 70 are more likely to become severely ill or die from COVID-19 and living with people from three generations or more increases their risk of exposure to the virus (Ogbonna, 2020). However, there is scant literature on the experiences of older people living in multi-generational households during the pandemic.

In the UK, Pakistani, Bangladeshi, and Indian domestic settings are home to people with very different life experiences. For many older people in these households, they grew up in environments, often rural, where change was slow. They now find themselves in Britain in a time of accelerated change.

This is a challenging process for the generation of older people now living in the UK. Their children have grown up Indian, Pakistani, or Bangladeshi, often subsequently British citizens, and progressed into adulthood in a maelstrom of trans-continental physical and cultural change, which subsequent generations have been born into, and they know no differently. These are the generations that live in the same household, many in economically challenged circumstances. Here we try to understand how this pandemic has disrupted, and in some instances surprisingly improved, the already disadvantaged lives of these households and the responses of grassroots organisations that work alongside them.

The place, the authors, and the process

The authors of this chapter are involved in an international project, The Other Front Line (https://www.otherfrontline.org), currently coordinated by Professor Jennie Popay and a team of academic activists. Participants are gathering stories, blogs, and visual and oral accounts from 'street' journalists across the globe. The 'journalists' (people who have endured the consequences of poverty, inequality, and exclusion), speak of the troubles that they and the people around them face, as well as of the resourceful ways in which they individually and collectively manage to support themselves and each other. The project will use the stories to advocate for social justice and policies that will address the conditions that lead to health inequalities.

This chapter is based on a conversation between the four authors concerning people living in multi-generational households in a diverse urban area in south Wales called South Riverside (an area of extreme deprivation adjacent to the city centre of the Welsh capital, Cardiff). Eva was initially approached and she contacted Allan with whom she has collaborated on a number of research and engagement projects over the last two decades. Allan lives in South Riverside, and until recently, managed community projects for the South Riverside Community Development Centre (SRCDC; https://www.srcdc.org.uk/). He was aware of the anxieties that multi-generational families were expressing during the pandemic and so approached Mashmooma Din from SRCDC and Amal Beyrouty from Women Connect First (WCF; https://womenconnectfirst.org.uk/). Through these organisations, they have built strong relationships with older people and families, and specifically women. Both organisations are rooted in the local community and have operated for over 40 and 20 years respectively. SRCDC is a place-based community anchor organisation that is open and responsive to all people and groups living in the area. WCF is located nearby and focuses on the empowerment of Black and minority ethic women. While being separate organisations, they also connect and bring together their knowledge and skills when it is needed.

Multi-generational households

To Allan, Amal, and Mashmooma, Bangladeshi, Pakistani, and Indian multi-generational households are familiar. Of course, every household is different, and they do not all contain three or more generations. However, such arrangements are common and make economic sense to the families living both in the UK and in the countries of origin.

Men are more likely to be responsible for bringing money into these households. Typically, women are the homemakers and carers but with grandparents caring for their grandchildren in situations where the sons and daughters of the next generation are in employment. There is, however, often a tension regarding expectations of the presumed roles relating to family care. Younger generations can have ‘tangled thoughts’, often expressed differently by boys and girls, yet both are caught between two cultures: their family cultures and norms on one side and the culture of the society they live in on the other side.

Care homes are rarely seen as an obvious choice in these communities. There is a generational and cultural pressure to look after elders at home, exasperated by UK care homes rarely being geared to the diverse needs and expectations of different cultural groups – usually accommodating and occupied by indigenous white people.

In more recent years, women in these communities have experienced small but significant shifts in household dynamics. Ironically, this may partly be due to more stringent welfare reforms. Previously many young women in these communities were restricted from studying or working by either their husband or in-laws because they were perceived to have other obligations at home. Changes in the benefits system has resulted in alterations in the decision-making within domestic settings, resulting in young women seeking new opportunities.

And then COVID-19 came along: the local response

While the ramifications of COVID-19, and measures taken to control its spread, have been overwhelming in the lives of people living in multi-generational households, SRCDC and WCF have the trust of the local community, the knowledge of the particular individuals and families that they support, and the ability to galvanise resources that have helped to mitigate the worst effects. In addition, they ease the anxieties that have penetrated the intimate settings of home life. The organisations themselves are diverse, able to communicate in different community languages, and have an understanding of the interrelationships between cultural, social, and economic needs.

This has allowed the responses of SRCDC and WCF to be developed in partnership with communities and families and to have easy points of entry. All of these responses are rooted in an understanding of the interplay of poverty and cultural and faith practices in the particular context in which they are experienced. Responses have included a community pantry scheme, a culturally sensitive meals delivery scheme, online cooking sessions, sourcing, and collection of clothes for children and young people, and the sourcing and provision of tablets, sim cards, mobile data plus support with training where needed. The organisations also offer advice and advocacy and since the pandemic started, these services for older people have often been extended to whole families. Therefore, an older woman may be the initial point of contact but then the organisations are helping the husband, the children, and the grandchildren. Staff at these organisations feel they cannot say no because they know that during the pandemic local people are restricted in terms of what services and support are available to them and that their organisations are trusted in these communities. They can help them and so they do – everything is confidential.

Challenges: coordinating households with many different needs

The virus has shaken the community in South Riverside. There is anxiety about managing household dynamics with children (at times) going to school, and family members going to work in jobs where homeworking is not possible. These working arrangements place older people in multi-generational households at a high risk of catching the virus and, because of their age, at a higher risk of becoming seriously ill, hospitalised, or dying. Employment is also often precarious. In England and Wales, Bangladeshi men are four times more, and Pakistani men three times more likely than white British men to have jobs in what have been described as 'shut-down industries' (including restaurant work and taxi driving) (Ogbonna, 2020). Families are trying to manage the intense demands of economic survival, family wellbeing, and infection control.

Anxiety has also created other risks to health. Amal is aware of a number of people who need carers but have refused to let them enter the house because of anxieties relating to family exposure. Many are isolating on their own even though they need care. SRCDC and WCF have both witnessed the effects in terms of malnutrition. Amal reported that one woman was hallucinating due to malnutrition because she was refusing to have visits from carers out of fear of the virus.

Amal, Mashmooma, and Allan had all noticed that some older people were voluntarily self-isolating, in their own room within multi-generational households. One elderly man in his 70s with underlying health conditions would not even come into the front garden. He said that he was not doing it out of concern for himself but to avoid putting extra strain on the family. He told Allan it was 'the easiest thing for me to do – and I can do this. I am at peace with myself … I can do this, and then everyone is protected.' There is an element of sacrifice. However, this has amplified the sense of loneliness and isolation that many older people face.

Some informal carers, usually women, are also at risk. These are generally members of the family who are trapped, through circumstance or poverty, in a situation where they have little option other than to undertake a caring role. In some cases, they may be in receipt of a carer's allowance, which Amal feels is inadequate. She has heard comments from a few people saying, 'Is that the wages we are paid? We have to wash; we have to clean them up.' She feels that these carers are under significant pressure, and feel both isolated and overwhelmed. Poor financial remuneration and the fact that it is within the household can also lead to abuse of older people because there is no inspection. Carers, and the cared for, in these situations risk isolation and neglect.

Positives: offering support through digital means

Both organisations have been consciously involved in the progression of digital literacy for women from BAME communities over many years, and consequently they have been able to have some positive impact on women who have found virtual ways of meeting during the pandemic. Amal's Golden Years project at WCF has allowed her to connect with older women in their own homes. After initial reluctance, and as a result of encouragement, free tablets, data, and technical support, the project, and the women, have flourished.

The key has been keeping it informal and fun. To an older person, the formality of sessions can be daunting – some of them have never been to school. By keeping it informal, the attendance has always been very high. Over 200 women regularly participate in activities remotely – this did not happen before the pandemic. They do activities that they enjoy: mask making for Halloween and a Halloween party, and cooking for fun. WCF give them the resources and they do cooking sessions together from their own kitchens. For Ramadan, 130 women come together digitally for a party – each at home but dancing together. In the beginning, they said, ‘No, we can’t, we can’t,’ and now they find it is fun.

The use of e-consult and the use of visual messages online has changed the way in which local people engage with primary health care services and public health messages on behalf of their whole family. Individuals are often reluctant to consult with doctors themselves or there are other barriers that make this difficult. SRCDC did whole sessions on e-consult. When doctors are not meeting face-to-face, people have to put a request in online and then the doctor phones them back and they do an e-consultation. It is also the case that many people cannot read the language they have been brought up speaking, so visual messages have been more useful than written translations and these have been provided online. When restrictions relaxed for a while, some people have preferred participating on Zoom, even when there was a chance to meet at the local community centre, because it is a lot easier for them. They can do it in the comfort of their home.

Not only are more women participating, but also those who have previously been quiet in face-to-face events are speaking for the first time. Some women who come to the community centres can be very quiet, sometimes not even speaking in meetings and activities. Now on Zoom they are active. They engage; they talk. Amal said to one woman, ‘I have seen you for over two years and now this is the first time I hear your voice.’ And she replied, ‘Well because on Zoom I’m alone in my room, and it doesn’t matter who is looking at me on the screen, I can talk. If I am with everyone else I’m shy.’

What needs to be done

This is a snapshot of the lives in a rapidly changing area, focusing on multi-generational households, primarily from Bangladeshi, Pakistani, and Indian communities. Older people are particularly vulnerable to the virus, and in these households, there are wider pressures on the whole family, which may help to explain why BAME communities have disproportionately struggled and suffered during this pandemic. Community grassroots organisations such as the SRCDC and WCF have the trust of the local community, knowledge of the matters that concern them, and they have network capital that enables them to access resources and services that could make a real difference during a time of crisis – like this pandemic. For us, such organisations need to be involved in the co-production of future research, policy, and practice as they apply to BAME families in diverse settings. The following recommendations are specific but not definitive.

- Address digital exclusion by providing opportunities and resources for people of all generations to engage with the wider community, education, and economy.
- Review the support needed by women who feel trapped in coercive family relationships, which may be intensified in multi-generational households.
- Review the impact of carers allowance on informal carers and the people they care for in multi-generational households, with a focus on families living in poverty.
- Review the impact of loneliness and isolation on the care for older people in BAME communities where multi-generational arrangements are changing.

References

Fox, H. and Monahan, E. (2020) *Coronavirus (COVID-19) review: data and analysis, March to October 2020*, Office for National Statistics, https://static.ons.gov.uk/files/covid-19-review--hh-and-community-impact.pdf

Ogbonna, E. (2020) *First Minister's report of the BAME Covid-19 socio-economic subgroup*, Welsh Government, https://gov.wales/sites/default/files/publications/2020-06/first-ministers-bame-covid-19-advisory-group-report-of-the-socioeconomic-subgroup.pdf

14

Drug use and street homelessness during a pandemic

Synergetic working with a vulnerable population

Anne Campbell, Kathy Faulkner, Chris Rintoul, and Iain Cameron

Introduction

In 2017, a sudden rise in the number of people injecting in public areas in Belfast city centre required a new response that met the needs of this population. There was also an associated rise in discarded injecting equipment and both fatal and non-fatal overdoses. Local authorities knew little about this new group of people who used public spaces such as public toilets, alleys, and scrub areas as their injecting environment. A large Northern Ireland (NI) organisation, Extern was already working with a range of vulnerable populations including those who are homeless and who use drugs in Belfast and other areas throughout NI. Two senior Extern workers began a mapping exercise in summer 2017, logging and removing discarded injecting equipment and recording engagement with people who use drugs. It was soon clear that the scale of the issue had been underestimated. Extern offered assistance with practical support for individuals with a range of interventions including needle exchange, responding to potential overdoses, signposting to appropriate services such as housing, wound care, substitution, blood borne virus (BBV) vaccination, testing, and treatment.

Subsequently, eight staff within Extern were trained in assertive outreach and a small pot of funding was secured. The organisation piloted an assertive outreach service to continue to remove discarded equipment and engage with people who inject drugs in the city centre. The project established relationships with injectors who were unknown to other support services and worked in partnership to effect positive change for the service users. The majority of service users' injecting knowledge and practice was poor, so soft tissue infections were very common, and overdoses were an almost daily occurrence among the wider population. Additionally, a number of service users were young females who were highly vulnerable to predation. Since then, deaths involving heroin, morphine, and cocaine were recorded as being the highest on record in 2018–19 in NI. One hundred and eighty-nine people died because of drugs in 2019–20 with just over half (95) being men aged 25–44 (NISRA, 2020). During the first COVID lockdown, anecdotal reports from frontline drug outreach workers and service users in Belfast indicated that drug overdose deaths initially decreased, but rates were beginning to increase again since the first national lockdown was lifted.

Local information from staff and service users within the Street Injectors Support Service (SISS) showed that at the beginning of the first lockdown in March–May 2020, levels of heroin use fell due to decreased supply, and less funds were available because of the lack of street begging opportunities (Extern, 2020). Service users and Extern staff worked together to highlight that there had also been an increasing reliance on opioids mixed with street manufactured benzodiazepines, which are highly potent and increase the chance of overdose deaths when ingested with opioids. Anecdotally, there have been reported changes in trends in drugs and alcohol use, specifically a move away from heroin to the use of more synthetic cannabinoids with concomitant use of street benzos and other 'unknown' substances. Extern staff are reliant on partnership working with service users to inform practice and note the trends in drug use behaviours, which have changed on a weekly basis, and the service has responded accordingly.

After the start of the lockdown on 16 March 2020, the SISS project moved to a seven-day week, working 12-hour shifts until June 2020. These shifts were conducted by worker dyads (primarily comprised of counsellor, social work trained individuals, and non-professional workers, all with years of experience within the sector). During the pandemic, SISS workers spend their time giving harm reduction advice, checking hostel eligibility, retrieving needles from known needle drop areas and administering naloxone packs. They also administer naloxone in overdose situations on the streets prior to the arrival of the emergency services and have saved countless lives over the last two years.

Prior to and during the pandemic, the SISS workers assess the needs of each individual they encounter on street outreach. Where further support is required, the worker makes a further assessment in full partnership with the service users and ascertains the most relevant referral pathway. The workers also signpost service users daily to relevant agencies in order to provide them with an excellent service and ensure they receive the wrap-around support needed. The outreach approach enables engagement with the same individuals on numerous occasions over months, and in some cases over a number of years. These interactions are important as they provide the team with the time to engage with the individual and build a trusting professional relationship. It also enables the workers to develop an understanding of the individual's circumstances and provide sufficient support, ensuring that it is inclusive, co-produced, person-centred, and needs-led (Galvanni, 2012; ACMD, 2019).

M's experiences of COVID-19

M was born in Lithuania prior to the dissolution of the USSR. He is an active opioid user and tried several times to stop using heroin and other drugs. He has been street homeless on regular occasions and cannot access the majority of hostel accommodation as he has a dog, which is his constant companion. He calls the dog (B) his 'border patrol' dog as the border collie affords him love and protection. One hostel permits him to bring his dog into the building, but that organisation has had reduced occupation during the pandemic. M has linked with the Extern service over the last six years and has availed of support services over that time. He has worked closely with the organisation and his experiences have informed practice and interaction with other drug users who have arrived in NI under a range of circumstances.

M discussed his use of drugs and how he had bought subutex (opioid maintenance medication), as he found it very difficult to get a prescription for methadone or subutex.

> I buy the subutex on the street … I couldn't get it for long time otherwise [ie could not get a prescription]. I also get methadone on the street and was then trying to go down, down, down off it … I don't want the same addiction [with methadone] and then you just swap your drug … I don't like that…

He described how the pandemic had made it difficult to make money as he would usually. 'I had [previously] survived through begging … yes it's very hard … today I don't know where to go … yesterday there were one or two people passing … don't know how I can get money now.'

M likened his current situation to the levels within an online gaming session as he tried to battle through the various levels.

> And now it's like it is another harder level … like you know when you play the games and you stuck on a level … I came off the drugs and then end up on the street again but now it's harder, much harder because of the COVID so now I need to get to the next level.

M was disheartened that local people who use drugs, who had supported each other prior to the pandemic, were now more likely to participate in negative interpersonal relations with their peers because they were finding it difficult to survive. 'They do not have enough money to support their drug habit, they are stealing from each other, they are robbing each other. Its survival … it's a jungle.'

There are multiple oppressions and stigma experienced by people who are homeless and who have substance use problems (ACMD, 2019). These problems can be exacerbated when people have migrated or been trafficked from another country.

People who have lived through upheaval, migration, trauma, and modern slavery are also disadvantaged by the lack of adequate structural government response to their situations. People are often stuck in a system, which is slow, unwieldy, and hard to navigate, and has become increasingly complex for the immigrant population, asylum seekers, and trafficked individuals. This problem has been further exacerbated by the pandemic.

Ongoing and emerging issues during the pandemic

At the beginning of the pandemic, the SISS team noticed an increase in the number of needles that were discarded. Data highlights that in April 2020 there were 601 needle finds. However, the team identified a decline in needle finds in May 2020, as 441 needles were recorded by the outreach team. The team indicated that this was because they had adapted service delivery and focused primarily on providing support to the cohort of clients that were experiencing psychological difficulties. Unfortunately, due to the pandemic other relevant services were unable to support clients face-to-face. Therefore, SISS witnessed an increase in the number of people that they were supporting, and incidents that they were responding to on a regular basis. Consequently, SISS could not rely on the network of information that had been available prior to lockdown, and therefore it was important that the relationship between the team and service users became more reciprocally engaging at each level of communication and interaction.

During the pandemic, SISS workers continued to identify young injectors who had very little experience of injecting drug use. Their limited experience led to particular issues, including infections, abscesses, and inadvertently hitting nerves while injecting. A number of service users highlighted the importance of the SISS guidance and commented on how important harm reduction advice is to people who inject drugs on the street. In addition, service users provide information on rapidly changing drug using behaviours, thus informing the harm reduction advice offered by SISS.

M highlighted how some people still take dangerous risks even with the support Extern offers.

> People think of nothing but their hit … after a hit there is nothing … If Extern service wasn't here people would use dirty needles … I know many guys who get out of police station before all this and got a little stuff hidden. He is running around [anonymised area] and is looking for the needle … he is finding the needle, he don't even wash it properly and then he doing his thing … Such a face palm! … It's scary.

Harm reduction advice the reduces the risk of people re-using previously used equipment, which reduces risk of blood borne viruses, skin infections, deep vein thrombosis, and other physical health conditions (Pericàs et al, 2019; PHE, 2019). To reduce injecting related issues, the Extern team also continues to promote smoking opiates as opposed to injecting.

As the city centre began to reopen after the first lockdown, communities across the UK were experiencing a sense of expectancy and uncertainty in the post first wave juncture. The team continued to work with service users who were extremely vulnerable and were struggling with the ongoing pandemic in addition to already complex comorbidities. It was clear that the extra pressure associated with the pandemic was continuing to have an impact on the most vulnerable service users who had limited or no support. The team continued to engage with people who were struggling to access money to buy substances and who were experiencing or were at risk of overdoses due to the lack of availability of some substances and/or support services.

SISS continued to work from an assertive outreach approach to support people via the provision of injecting equipment, naloxone, and basic harm reduction advice. The project also continues to support the police service of Northern Ireland (PSNI), the Northern Ireland Ambulance Service, and local business within a collaborative partnership.

What needs to be done

- In future, local, regional, or national crisis situations, supporting individuals who are opioid dependent and homeless to access substitute prescribing in a timely fashion should be prioritised.
- Ensure that people who use or have used drugs have access to medication, which will prevent them from experiencing sickness or withdrawals, while also reducing the risks of engagement in street activity to access substances.
- Naloxone provision, harm reduction advice, guidance and face-to-face support need to be made available to people who use drugs on the streets and who are often lacking in support.
- We must ensure that service users are heard through synergetic and reciprocal working relationships with service providers as the usefulness and effectiveness of these services relies on their experiences, expert knowledge, and practical suggestions for change.

Acknowledgements

B the dog is a companion to M and was the perfect aid during the conversation that informed this chapter.

References

ACMD (2019) *Drug-related harms in homeless populations and how they can be reduced*, London: ACMD, https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/810284/Drug-related_harms_in_homeless_populations.pdf

Extern (2020) *Quarterly report to the PHA, April to June 2020*, Belfast: Extern.

Galvanni, S. (2012) *Supporting people with drug and alcohol problems: making a difference*, Bristol: Policy Press.

NISRA (2020) *Statistics – drug related and drug misuse deaths registered in Northern Ireland (2008–2018)*, Belfast: NISRA.

Pericàs J.M., Bromberg D.J., Ocampo D., Scatz E., Wawer I., Wysocki P., Safreed-Harmon K., and Lazarus J.V. (2019) 'Hepatitis C services at harm reduction centres in the European Union: a 28-country survey', *Harm Reduction Journal*, 16(1): 20.

Public Health England (2019) *Shooting up: infections among people who inject drugs in the UK*, Gov.uk, 2018, https://www.gov.uk/government/publications/shooting-up-infections-among-people-who-inject-drugs-in-the-uk

15

‘It’s all right for you thinnies’

‘Obesity’, eating disorders, and COVID-19

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

Our title quotes what British Prime Minister Boris Johnson reportedly said when comparing his COVID-19 experience (which required intensive care) with cabinet members who had mild symptoms. It is suggested that Johnson’s brush with mortality profoundly impacted him – it was followed by public declarations to lose weight and policy shifts he previously would have likely dismissed as nanny statism. While it is politically convenient for Johnson to link the severity of his illness (and by inference the impact of the virus more generally) with factors popularly promoted as within individual control (for example, bodyweight), he is not alone in exploiting this pandemic to promote simplistic and stigmatising ideas about bodyweight and health.

Although not popularly known or accepted, in recent decades research, advocacy, and activism has made significant progress in demonstrating the complexity of relationships between bodyweight and health, the multifaceted and interrelated biological, psychological, and social causes of ‘obesity’, and how common (mis)conceptions and prejudice ultimately promote discrimination of people who variously identify as (among others) Fat, higher weight, and living with obesity. Responses to the COVID-19 and Body Mass Index (BMI) link have largely ignored this. The urgency of a pandemic, and opportunism of those with vested interests in over-emphasising personal control and responsibility, create a perfect storm for harming people across the weight spectrum

– particularly those above and below what is considered ‘healthy’. We consider evidence that has been ignored and ways this pandemic is disproportionately harming those who transgress medically and/or popularly ‘acceptable’ bodyweight and eating norms – drawing on personal experiences of transgressing these norms, providing healthcare to those with eating disorders, and academic expertise (including that imbued with related ‘lived experience’).

Sobering conclusions and scapegoats

Early evidence indicates that people with higher BMIs are at greater risk of severe COVID-19 outcomes (Popkin et al, 2020). However, the inaccuracy and harm that comes from assuming causality and homogeneity on the basis of BMI alone must not be forgotten. Retrospective analysis of studies from the 2009–10 influenza pandemic indicated that the initial association between ‘obesity’ and poor prognosis was no longer apparent after adjusting for early antiviral treatment (Sun et al, 2016). The initial finding was therefore more likely attributable to the well-documented relationship between weight stigma and poor/avoided medical interactions than physiology (Tomiyama et al, 2018). This is not to claim the same thing is happening now, nor deny that on average people in higher BMI categories are at greater risk from COVID-19, but is a reminder that the full complexity of an issue can rarely be grasped from early findings or without due consideration of the social processes through which medical outcomes materialise.

The pandemic death toll is sobering – as is consensus that it would be significantly lower had the government acted more swiftly and effectively. This, together with the COVID-19 and BMI link and the dominant narrative that ‘obesity’ is a self-inflicted and costly condition of the slothful, stupid, and/or irresponsible, has made people who are Fat/higher weight/living with obesity convenient scapegoats. Pre-COVID-19, public bodies and popular media regularly disparagingly reported that the majority of the UK are ‘overweight’ or ‘obese’. If the priority now is to protect those at greatest risk, these statistics should be used to protect (rather than blame) the majority of the country. To date, the advice is that people with a BMI of >40 should be particularly stringent in social distancing and potentially prioritised for vaccination only after everyone 65 or older is vaccinated. How are those who are Fat/higher weight/living with obesity supposed to interpret this? That we/they are unimportant or, more gravely, expendable? Patient advocates identifying as living with obesity reported increased fear, confusion, and stigma during the pandemic – particularly fearing not receiving necessary and appropriate medical support if admitted to hospital (Le Brocq et al, 2020). These are not baseless fears and it is therefore predictable and warranted that internationally those identifying as fat activists are rejecting fatness/‘obesity’ being used to distract from government responsibility for pandemic preparedness, response, and management (Pausé et al, 2021).

Are those driving the ‘war on obesity’ – including policymakers and even well-meaning healthcare professionals – unaware or unconcerned about collateral damage? Many hide behind the ‘unintended consequences’ explanation or claim a hoped-for future end justifies the harmful present means. Much of this harm is avoidable and greater consideration of the relationships between ‘obesity’ and ‘eating disorders’ helps demonstrate this.

‘Eat less, move more’ rebranded

The ‘obesity’ policy paper published during the pandemic *Tackling obesity: empowering adults and children to live healthier lives* (DHSC, 2020) is apt for the era, with ‘empowerment’ yet again doing heavy lifting for what largely represents responsibilisation through individual behaviour change interventions. It presents ‘excess weight’ as ‘one of the few modifiable factors for COVID-19’ and states the nation ‘owe it to the NHS’ to lose weight to reduce risk (DHSC, 2020). The resulting ‘Better Health’ campaign presents COVID-19 as a ‘wake up call’ for a complacent overweight nation, and proposes to ‘kick start’ the population’s health, though it is essentially ‘eat less, move more’ rebranded – focusing on weight-loss achieved through apps and commercial weight-loss services. Commercial partners include WW (Weight Watchers post-rebrand), Slimming World, and GetSlim.

The policy assumes mass scale weight-loss is achievable and will improve health. This overlooks evidence indicating that – by their own standards – 'obesity' policy and weight-loss interventions are largely ineffective (Hall and Kahan, 2018; Theis and White, 2021), weight/weight-loss focused anti-obesity campaigns risk exacerbating disordered eating (Bristow et al, 2020), and commercial interests and methods are not always conducive to promoting health. 'Better Health' draws on fears about COVID-19 to 'motivate' weight-loss. If scaremongering were effective then previous campaigns emphasising links between BMI and diabetes, heart disease, and cancer would have already achieved this. The focus on weight-loss undermines health promotion and does little to actually address COVID-19 risk.

My (Fiona) eating disorder initially developed from anti-obesity rhetoric. When 'the obesity crisis' came to prominence in the public health domain in the 1980s, the 'pinch more than an inch' weight-loss campaign, led by a commercial cereal company, was popular. I was relentlessly teased – on the end of jokes like 'if you can pinch more than a foot'. Fast forward to 2021 and little has changed; 'obesity' campaigns continue their fear- and shame-inducing approach to health. The pandemic has brought about new challenges for me. The same circumstances that triggered my susceptibility to eating disorders – early weight-based teasing and repeated restrictive diets – have returned. Constant messages about weight-loss, individual responsibility, and taking pressure off the NHS brought me back to my childhood. Instead of feeling empowered and motivated, I felt shame, blame, and helplessness. Old habits returned – avoiding medical care, isolating myself, and feeling unworthy of care unless I lost weight.

Policies both shape and are shaped by contemporary culture, and popular media play significant roles. Early in the pandemic, the BBC broadcast *The Restaurant That Burns off Calories* – a programme investigating laboratory findings indicating that people generally eat less when calories are equated to physical activity. People were invited to eat a free meal while, unbeknownst to them, people in an on-site gym burned their calories. Post-meal the sweaty squad were revealed to diners like a surprisingly costly bill. In response, Beat (UK's eating disorder charity) publicly discouraged people from watching and extended their support services' opening hours. Soon after, one of the programme's presenters helped organise an online conference: 'Covid-19: A lifestyle disease and the vital role GPs have in beating it'. Over 500 healthcare professionals attended the Royal College of General Practitioners (RCGP) and Sport England funded event. After protest, the RCGP clarified it did not consider COVID-19 a lifestyle disease (a term chiefly and problematically used to describe non-communicable diseases), and formally apologised for the offence this implication caused (Rimmer, 2020).

Sport England also funded research exploring pandemic physical activity (Sport England, 2020). The majority surveyed felt being active during the pandemic was more important compared to other times. It showed big increases in online activities with 26% naming Joe Wicks the most useful instructor/influencer. Wicks, a fitness coach, declared himself 'The Nation's PE Teacher' as he streamed free fitness classes on YouTube marketed as PE lesson replacements during school closures. We should consider what is lost when PE is reduced to fitness classes and the potential harms of training children using logic from the commercial fitness industry. For instance, when Wicks's wife stepped in as 'supply teacher', they celebrated her having 'earned breakfast'. From such logic, problematic relationships with bodies, diet, and exercise can spring.

Two of us (Harry and Sophie) had treatment for anorexia during the pandemic. My (Harry) parents had been worried for years about how focused I was on healthy eating and exercising, but my doctor deemed me too well to need eating disorder services. When lockdown hit, things got more serious. I went from having a busy life, going to school, clubs, and hanging out with friends, to spending lots of time by myself at home. This gave me more time to think about what I *should* be doing and to look online for answers. I watched loads of videos by celebrities like Joe Wicks. I started exercising more.

I felt that to be healthy I had to exercise outside once a day like the government said. The restrictions made me think I really needed to make the most of that time. I was running 3 miles and doing Joe Wicks's workouts before breakfast. I ate less and less and then started skipping meals altogether. I bought into the idea of earning food and that developed into anorexia. Eating nothing became a good thing. Pretty quickly, I became unwell and was admitted to an inpatient eating disorder unit.

My (Sophie) issues with food began nine years ago. Past therapy had little effect, but I started seeing a dietitian and psychologist privately in January 2020 after my family suggested it. In March, I hit rock bottom. I finally realised my eating disorder was an issue, became really sick with COVID-19, and lost more weight. I was really down, but I had support. I was seeing my dietitian and psychologist regularly and being supported by my husband. Going into lockdown was a real turning point. My routine changed – I went from being at home alone all day to having my husband working from home and supporting me. This forced change meant I was able to address the more difficult behaviours that supported my anorexia. I often wonder what would have happened without that support. During lockdown, I knew there was lots of talk about health and weight and especially exercise, and that those messages were unhelpful for me. The people around me helped me to avoid being sucked in by them. I still have work to do, but I am grateful I was able to come through the lockdowns moving towards recovery.

Our (Fiona, Sophie, Harry) experiences chime with others. Research highlighted that people with experience of eating disorders commonly expressed that spending more time online during the pandemic had worsened their 'symptoms'. Increases in diet- and exercise-related messages were highlighted as particularly problematic. Disruptions to routine and reduced access to support and services have been common, with some people reporting positive experiences of people being at home to support them (Branley-Bell and Talbot, 2020).

Support not stigma

The government response to the link between higher BMIs and poor COVID-19 prognosis highlights that 'following the science' is political rhetoric. This link could have been responded to in various ways. The notion that people who are Fat/higher weight/living with obesity are the problem and weight-loss is the solution was predictable because the pandemic merely offers the latest example of the prejudice and discrimination we/they face. The personal experiences and evidence we have shared demonstrate the ineffectiveness and harmfulness of anti-obesity campaigns and highlights the significance of support. Weight-loss focused anti-obesity campaigns create a need for support – both to cope with the hostility they create towards people who are Fat/higher weight/living with obesity and to mitigate the risks of developing/worsening eating disorders. This support is needed primarily because of pre-pandemic political failings to address the social determinants of health (*modifiable* factors related to the structural inequalities that significantly increase COVID-19 risk) and government policy and popular media proliferating weight stigma. Moving away from weight-focused approaches promoting individual behaviour change would reduce this need. Though this pandemic illustrates just how far away we are.

What needs to be done

- Create research, policy, and practice in the areas of 'obesity' and eating disorders *with* people with a diversity of relevant lived experience.
- Research on the unintended consequences of anti-obesity messages, with attention given to all forms of eating distress.
- Increase availability and person-centredness of healthcare services for people who are Fat/higher weight/living with obesity and/or have experience of eating disorders.

- Move away from weight-focused, and to weight inclusive approaches to public health.
- Replace 'anti-obesity' public health policies and messages with policies that promote health equity by focusing on what governments can do to address the social determinants of health.

References

Branley-Bell, D. and Talbot, C. (2020) 'Exploring the impact of the COVID-19 pandemic and UK lockdown on individuals with experience of eating disorders', *Journal of Eating Disorders*, 8: 44.

Bristow, C., Meurer, C., Simmonds, J., and Snell, T. (2020) 'Anti-obesity public health messages and risk factors for disordered eating: a systematic review', *Health Promotion International*, 35(6): 1551–1569.

Department of Health & Social Care (2020) *Tackling obesity: empowering adults and children to live healthier lives*, https://www.gov.uk/government/publications/tackling-obesity-government-strategy/tackling-obesity-empowering-adults-and-children-to-live-healthier-lives

Hall, K.D., Kahan, S. (2018) 'Maintenance of lost weight and long-term management of obesity', *Medical Clinics*, 102(1): 183–197.

Le Brocq, S., Clare, K., Bryant, M., Roberts, K., and Tahrani, A.A. (2020) 'Obesity and COVID-19: a call for action from people living with obesity', *The Lancet Diabetes & Endocrinology*, 8(8): 652–654.

Pausé, C., Parker, G., and Gray, L. (2021) 'Resisting the problematisation of fatness in COVID-19: in pursuit of health justice', *International Journal of Disaster Risk Reduction*, p 102021.

Popkin, B.M., Du, S., Green, W.D., Beck, M.A., et al. (2020) 'Individuals with obesity and COVID-19: a global perspective on the epidemiology and biological relationships', *Obesity Reviews*, 21(11): e13128.

Rimmer, A. (2020) 'Covid-19: RCGP apologises for covid-19 "lifestyle" event title', *BMJ*, 369: m2623.

Sport England (2020) *COVID-19 briefing: exploring attitudes and behaviours in England during the COVID-19 pandemic*, https://indd.adobe.com/view/793b48d5-bbcd-4de3-a50f-11d241a506b3

Sun, Y., Wang, Q., Yang, G., Lin, C., et al. (2016) 'Weight and prognosis for influenza A (H1N1) pdm09 infection during the pandemic period between 2009 and 2011: a systematic review of observational studies with meta-analysis', *Infectious Diseases*, 48(11–12): 813–822.

Theis, D., White, M. (2021) 'Is obesity policy in England fit for purpose? Analysis of government strategies and policies, 1992–2020', *The Milbank Quarterly*, https://doi.org/10.1111/1468-0009.12498

Tomiyama, A.J., Carr, D., Granberg, E.M., Major, B. et al (2018) ‘How and why weight stigma drives the obesity ‘epidemic’ and harms health’, *BMC Medicine*, 16(1): 123.

Afterword

16

Co-production in emergency responses and the 'new normal'

An afterword for Volume 1

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

What we aimed to achieve through this collection

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

Through this book, we wanted to:

- explore how so many people are ignored, disempowered, and discriminated against in health and social care research, policy, and practice;

- address how and why more collaborative, diverse, and inclusive responses could lessen the toll of this pandemic and future health emergencies, as well as more generally improve health and social care research, policy, and practice;
- illustrate how and why collaborative ways of working can help to address the social wrongs and power imbalances that we need to right.

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

Structural inequalities

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

Anti-discriminatory policy and practice

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

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

Institutional changes and funding

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

Setting agendas and policy

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

Methods and processes of involvement

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

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

Alliances, collective action, and community activism

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

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

Limitations

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

Volume 2

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