

# Discovering the social movement experience:

## An exploratory study into social movements and innovation

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A thesis submitted to the Institute of Global Health Innovation in fulfilment of  
the requirements for a Doctor of Philosophy

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Faculty of Medicine  
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August 22, 2020

**Imperial College**  
London

Rise, like lions after slumber  
In unvanquishable number!  
Shake your chains to earth, like dew  
Which in sleep had fallen on you:  
Ye are many – they are few!

Excerpt from *The Masque of Anarchy*<sup>1</sup>

By Percy Bysshe Shelley

Manchester 1819

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<sup>1</sup> *The Masque of Anarchy* is a British political poem written in the aftermath of the Peterloo Massacre which took place on August 16<sup>th</sup> 1819 at St. Peter's Field in Manchester, England. At Peterloo, eighteen people died when voluntary cavalry charged into a peaceful gathering of 60,000 people demanding parliamentary representation. In 2019, Manchester commemorated the 200<sup>th</sup> anniversary of Peterloo. Maxine Peake, *Peterloo* film star, read the poem at John Rylands Library.

## Declaration of Originality

I confirm that the work carried out and written in this thesis was my own work, unless otherwise appropriately referenced and declared in this document.

Jacqueline del Castillo  
August 2020

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## Remembering Dr. Kathy Charmaz

“Not only are justice and injustice abstract concepts, they are, moreover, enacted processes, made real through actions performed again and again.”

Dr. Kathy Charmaz  
August 19, 1939 – July 27, 2020



# Dedication

To Dr. Sathya Jeganathan

## Acknowledgements

I owe the completion of this thesis to so many people who offered their love, support and inspiration along the way. To each and every one of you, and in the words of a traditional Seneca greeting, "Thank you for being."

Nicholas Ponsillo, I must start with you. When we met, you said that if this process were like a balloon flying high into the sky, you'd be holding onto the string as tightly as you could. And, hold you did! Your endless patience and rounds of tea sustained me throughout but most importantly, I have learned that your heart knows no bounds. Dr. Behnam Tabrizi, thank you for always believing in me, for our friendship and for the unconditional love you, Nazy and Sheila have shown me over the past 15 years. It has meant more to me than I could ever put into words. Dr. Barbara Barry, you were with me every step of the way, literally. I would not have completed this thesis without you. May you keep flipping eggs from Rochester to Islington, to the moon and back! Banny Banerjee, I miss watching you sketch new frameworks, especially on Starbucks cardboard cup holders. Thank you for inspiring everyone around you to think big – your brilliance inspired me to take a stab at advancing design theory. Athena Mak, for your laughter and mastery of implementation which I channelled throughout this process. Jaya Goswami, for changing my life by finding this PhD programme! Dr. Aneeta Rattan, for being such a kindred soul and an inspiration to the women who hold your company.

To my family, thank you for your boundless love, support and patience; To my sister, Renée del Castillo, you continually reminded me to "write the book you wish to read;" your little plate sat on my desk as I wrote this thesis. To my mother, Rebecca del Castillo, you are the sunshine of my life and the reason why I am. To my father, Angel Martín del Castillo, for being my "oak tree" of strength and perseverance; I am grateful that this process exposed me to more of your incredible story. To Jackson, you were a special soul and we will never forget you.

To my supervisors at Imperial College London, including Yasser Bhatti, Matthew Harris, Hutan Ashrafian and Lord Ara Darzi. Yasser, a special thank you for believing in this research and continually inspiring me to set BHAGs (Big Hairy Audacious Goals). Lord Ara Darzi, without your support, this research would have not been possible; I certainly would have never experienced a critique in a format of a surgical round! I would also like to acknowledge the people who took the time to examine this work, including Marc Ventresca, James Barlow, Dominic King, Mark Sullivan, Elaine Burns, Mary Lavelle and Karen Kerr who offered such thoughtful and constructive critique. Jennifer Simeon and Paige Marques, thank you for the tremendous source support you offered at times that were pivotal to me completing this work. Finally, Douglas McAdam, Marshall Ganz and Donatella Della Porta – thank you for the incredibly inspiring moments I spent with each of you who challenged my outlook on social movement research and on being a social movement scholar. Susan Kay, thank you for sharing a hidden talent by offering to bind this work into a real book!

To Blue Shield of California Foundation colleagues Jen Lewis-Walden, Richard Thomason, Lucia Corral Peña, Fanny Xue, Madina Zemarialai, Debbie Pearl, Ingrid Happoldt, Carolyn Wang Kong, Theresa Ray-Bustillos, Rachel Wick, Rick Bond, Apana Lei, Namgyal Wangdu, Jelissa Parhnam, Emily Cooper and Peter Long – little did we know that the work we did would be even more relevant in years to come.

To Nesta colleagues Halima Khan, John Loder, Lydia Nicholas, Annie Finnis, Christina Cornwell, Damian Hebron, Sally Zlotowitz, Rachel Nye, Katy Rutherford as well as Susan Kay, Sarah Allport and Ethny Childs from the Dunhill Medical Trust – thank you for the chance to learn, experiment and think differently about how to support and resource social movements.

To Naomi Woychick, Marcia Stanton, Andi Fetzner, and Abhishek Ashok – for the gorgeous memories and collegueship. May we continue to “disrupt the cycle” in our own lives. A special thank you to Mayo Clinic colleagues, Prof Jimmy Yiannias, Gerry Greaney, Linda Cooper, Lorna Ross, Gerald (Jerry) Malagrino, Mary Ann Hare and Dr. Barbara Ruddy.

To everyone who brought joy and inspiration along the way, including everyone mentioned thus far and Roger Pan, Zaw Lin Hteik, Arjun Subramaniam, Amaya, Ronald Ho, Zach Salter, Sheila Tabrizi, Nazy Tabrizi, Andy Broder, Jason Bade, Scott Bade, Jenna Nicholas, Theo Gibbs, Anja Nabergoj, Alan Chiu, Song Toh, Hannah Lou, Yukai Sun, Carey Bamber, Steven Goslyn, Jeremy Orlow, Reva Raghavan, Mayank Sekhsaria, Tanvi Sekhsaria, J. Paul Neeley, Alessandra, Isabella Blatter, Jullie Tran Graham, Rajwinder Cheema, Seema Yalamanchili, Hamdi Issa, Sara Vrbinc, Rachel Kerr-Oliveira, Gehan Soosaipillai, Madeleine Maxwell, Ivor Williams, Matt Harrison, Lenny Naar, Gianpaolo Fusari, Maja Kecman, Linda Kral, Jeff Buenrostro, Greg Hochmuth, Sanjee Singla, Nesra Yannier, Ashish Goel, Kelly Schumutte, Andrew Evans, Dilip Goswami, Sayali Goswami, Shankar Iyer, Shikha Tandon, Tom Cohlmi, Taylor Cone, Mayank Bindal, Estee Pinchasen, Bobby Pinchasen, Giovanna D’Agostino, Adam Davies, Jenny Ponsillo, Ralph Ponsillo, Molly and Fred.

I would like to especially thank new friends I made along the way, including Lydia Nicholas for your incredible wit and open arms, Nikitha Yereddi for conversations over pie, Dr. Valentina lemme for our laughter which I adore, Chris Underhill for such joyful banter and kindness, Jullie Tran Graham for our wisdom dates, Seema Yalamanchili for your brilliance and for being a soul sister, and Mei Lei and Jamie Casanas for creating such a peaceful place where I spent many hours editing drafts of this thesis over matcha (if you know, you know).

Finally, and most importantly, to the extraordinary people whose voices are represented in this study. Your persistence knows no bounds.

In solidarity,  
Jacqueline del Castillo

## Abstract

People organised into social movements have won tremendous victories for health. They are one of the most effective forms of pressure on health and care, drivers of health systems change and sources of transformative ideas. Yet, how social movements aid innovation is an unexplored subtheme within social movement and innovation research. This exploratory study utilised constructivist grounded theory to examine how social movements aid health innovation development and diffusion. It involved interviewing a sampling of people working on public health issues across England representing over 40 health social movements. Interview findings were triangulated against social movement meeting observations and supplementary documents to contribute findings relevant to social movement, innovation and health research.

In the process of investigating how social movements aid innovation, the researcher discovered the social movement experience (SMExp). The SMExp potentially offers a new analytical tool for researchers to understand how people build social movements, a sensemaking tool for social movement actors and a strategy tool for policymakers in devising social movement engagement and support strategies. Investigating the SMExp in light of existing theories of experience excavated new insights from the study data and surfaces new research questions.

Through applying an innovation practitioner lens to the empirical data, the study also identifies twelve ways that social movements aid innovation development and diffusion. Reflecting on the application of this lens offers insight on studying innovation in relation to social movements, opportunities for social movement innovation research and practice as well as a future research agenda at the nascent intersection of social movements and innovation.

Finally, the study also contributes to health as an underrepresented issue within social movement research and reveals that social movements can be a solution to social health issues.

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## List of Abbreviations

ACEs	Adverse Childhood Experiences
ASH	Action on Smoking and Health
CAM	Complementary and alternative medicine
CHP	Centre for Health Policy
EHMs	Embodied health movements
EIP	Early Intervention in Psychosis
FOREST	Freedom Organisation for the Right to Enjoy Smoking Tobacco
GMFA	Gay Men Fighting AIDs
HASM	Health as a Social Movement
HSMs	Health social movements
IGHI	Institute of Global Health Innovation
IRIS	Initiative to Reduce the Impact of Schizophrenia
LEX	Lived experience
MHIN	Mental Health Innovation Network
MGMH	Movement for Global Mental Health
MPs	Members of Parliament
NESTA	National Endowment for Science, Technology and the Arts
NEF	New Economics Foundation
NHS	National Health Service
NNA	New Nicotine Alliance
QCA	Qualitative comparative analysis
RAB	Reachable available base
RCP	Royal College of Physicians
RCT	Randomized control trial
RSA	Royal Society of Arts
SDGs	Sustainable Development Goals
SAM	Serviceable available market
SM	Social movement
SMALC	Social Movement Adoption Lifecycle
SMEExp	Social movement experience
SMO	Social movement organisation
STIs	Science, technology and innovation institutions
TAB	Total available base
TAM	Total available market
TTC	Time to Change

SECTION I:

# Motivation & Methods

## Chapter 1: Introducing the research

### Why do social movements matter now?

As the sun sets on this research endeavour, we find ourselves in the eye of the largest global health pandemic in a century – coronavirus (COVID-19). This crisis is illuminating the need for solidarity in redirecting our societies towards greater equity and social justice (UNDP, 2020). It has already spawned over 100 new and distinct forms of activism (Chenoweth et al., 2020) and is also leading to the rapid development of frugal innovations (Harris et al., 2020).

In 2020, we witnessed tremendous acts of solidarity. During the UK COVID-19 lockdown of May 2020, over 10 million people served in a “volunteering army,” ringing people who live alone and picking up prescriptions for the 1.5 million people shielding at home (NHS, 2020). Yet, the COVID-19 pandemic has also brought long-standing realities to the forefront, including rising health inequalities, racism, a crumbling social care system and increasing threats of NHS privatisation.

Health for all, racial equity, an age-friendly world, these are not outcomes to achieve but values to fight for. One way people fight for these values is by starting and participating in social movements. Social movements represent people organised into “informal networks” with “shared beliefs” utilising “collective action” and “unconventional means” to challenge more powerful norms, narratives, institutions and cultures (Della Porta & Diani, 2006). They have momentum beyond specific events such as protests in that they craft an evolving vision, narrative, identity and collective actions to demand change (Zoller, 2005).

This research study explores how people make sense of social movements to centre people in health social movement research. In the process of investigation, it discovers the social movement experience and utilises it to explore how social movements aid innovation development and diffusion.

Social movement research holds tremendous potential to inform how we realise health for all. This chapter outlines the impact of social movements for health, acknowledges health as a rising subfield within social movement research and situates social movements within innovation research. It then shares the motivation for this study and previews its aims, methods and contributions.

## The impact of social movements for health

Some of the most important changes in the way that we all experience health have been brought about by people in social movements. Scholars recognise social movements as one of the most effective forms of pressure on societal systems affecting health and care, sources of transformative ideas, drivers of public health improvement and political forces for health access (Brown & Fee, 2014; Brown & Zavestoski, 2004). Their ability to continually disrupt power imbalances and persist in their pursuits enables them to inject new thinking into political agendas (Fernando, 2012). This section outlines how health social movements address global health inequalities, draw attention to health issues, transform health systems and challenge scientific, medical, political and economic power.

### **Tackling global health inequalities**

Social movements are essential to public health's efforts to achieve greater health equity (Kapilashrami et al., 2016; see also Vergara-Camus, 2016). Bottom-up social movements, in particular, foster solidarity and collective action locally, nationally and globally; by doing so, they mitigate tensions between public health researchers, practitioners, decision-makers and community members; the countervailing power they build assists people in standing up for their own health rights as well as for health equity and social justice broadly (Kapilashrami et al., 2016). According to a systematic review of health inequalities research in India over the



past 30 years, social and political movements have played a critical role in underscoring global health inequalities (Cash-Gibson et al., 2018).

Research published prior to and during the pandemic found UK health inequalities to be greater than previously thought and widening (All Party Parliamentary Group for Longevity, 2020; Hill, 2020; Guardian, 2020; Marmot et al., 2020). In areas of the greatest socio economic need, men and women were contracting their first long-term health conditions seven to eight years earlier, on average, than their wealthier counterparts at 47 and 49 years of age, respectively (All Party Parliamentary Group for Longevity, 2020; Hill, 2020). Poorer people in England face avoidable and higher rates of ill-health, shorter life expectancies and higher chances of living with a disability (Marmot et al., 2020). The coronavirus (COVID-19) pandemic is exacerbating “deeply entrenched” inequalities; the King’s Fund Director of Policy, Sally Warren, remarks that “the scandal is not that the virus has disproportionately affected certain groups, but that it has taken a global pandemic to shine a light on deeply entrenched health inequalities” (The King's Fund, 2020).

People living in deprivation are facing a higher risk of exposure to COVID-19, more severe health outcomes due to the virus often as a result of pre-existing health conditions and poverty as well as a heavier burden from the societal and governmental response (Bibby, 2020). Sir Michael Marmot, a Professor of Epidemiology at University of College London who has conducted ground-breaking research on health inequalities for 35 years, has suggested on numerous occasions that a social movement approach could reduce health inequalities and address the social determinants of health (Marmot, 2017; Marmot et al., 2008, 2010, 2012).

### **Drawing attention to health issues**

The attention that health issues receive does not necessarily align with objective measures of mortality and morbidity or availability of cost-effective interventions but instead, with how

“supporters of an issue come to understand and portray its importance” (Shiffman, 2009). At the turn of the century, HIV/AIDS represented around 5% of the mortality and morbidity burden in low-and middle-income countries yet received over a third of donor health funding (Shiffman, 2009; see also Lopez et al., 2006). Shiffman explored this discrepancy by looking at global health through a social, rather than a material, lens as well as by challenging the assumptions of medical and public health professionals rooted in objective realities. He drew specifically on a social constructivism paradigm where social constructivism is a sociological theory of knowledge where “the world and the things in it are seen to be not only social constructions, but also, ‘crucial participants’ in the meaning making process” (Crotty, 1998).

### **Transforming health systems**

Scholars have referred to the National Health Service (NHS) as a social movement standing for the ideology that “good healthcare should be available to everyone, regardless of wealth” (Muir, 2014). The launch of the NHS represented an “ambitious reframing of the relationship between State and Individual in healthcare provision, stressing values of equity, inclusion, accessibility and equality” (del Castillo et al., 2016).<sup>2</sup> Prior to 1948, health care coverage and quality were variable and incomplete for taxpayers. The Second World War triggered positive health system change and from its ashes emerged the first centralised Emergency Hospital Service as well as a shared sense that “healthcare should be a right not a privilege” (del Castillo et al., 2016).

An inherent sense of the NHS as a social movement endures amongst the British public. “The NHS to the British public is viewed... as a social movement with a pioneering philosophy – one which makes a global contribution, conceptualizing the moral right to access free healthcare” (Moskovitz & Garcia-Lorenzo, 2016).

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<sup>2</sup> Appendix I depicts the NHS public launch announcement (Ministry of Health, and the Central Office Of Information, 1948).

Since the inception of the NHS, people organised into social movements have improved health within and alongside the NHS. In 1967, the UK hospice movement opened the first hospice in London, radically changing the approach to death and dying. Hospital-based patient advocates of the 1970s shepherded in a focus on patient rights, giving birth to the patient rights movement. People with HIV/AIDs demanded access to drugs and a national policy to fight the disease in the 1980s and 1990s.

At the turn of the century, NHS England's Chief Transformation Officer, Helen Bevan, started applying "social movement thinking" to realising large-scale change across the NHS (Bibby et al., 2009). The report *Towards a Million Change Agents – A Review of the Social Movements Literature: Implications for Large Scale Change in the NHS* has been downloaded over three million times worldwide (Bate et al., 2004). The inspiration for this approach came from policy and social science evidence suggesting that social movements could offer a complementary, bottom-up, locally led approach to healthcare improvement efforts which typically rely on top-down approaches (Bate et al., 2004).

In 2014, the NHS published the *NHS Five-Year Forward View* (2014) calling for greater attention to social movements and framing the NHS as a "social movement."<sup>3</sup> This call inspired NHS England's Health as a Social Movement programme which aimed to understand how the NHS can support social movements in health and care in collaboration with six new care model vanguards (NHS England, 2016). The programme raised critical questions about the relationship between a government health service, sites of local health provision, communities and people mobilised into social movements.<sup>4</sup> Three reports captured the learning and posed new questions (Arnold et al., 2018; Burbidge, 2017; del Castillo et al., 2016). In 2016, NHS

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<sup>3</sup> "The NHS as a social movement" is a section in chapter two, "What will the future look like? A new relationship with patients and communities" of the *NHS Five-Year Forward View* (2014).

<sup>4</sup> I was involved in the Health as a Social Movement programme in my Senior Programme Management role at Nesta Health Lab.

Chief Executive Simon Stevens suggested that social movements have “the power to tap into the fabric of the country in a way that the NHS might never be able to do” (Higgins, 2016).

Recently, the NHS has been under increasing threat of privatisation with British people pouring out onto the streets with banners such as “Keep our NHS Public” (Keep Our NHS Public, 2020) and “Our NHS is not for Sale” (Levine, 2019). As exhibited during the coronavirus (COVID-19) pandemic, The King’s Fund refers to volunteering as *the* social movement for health as nearly 3 million people volunteer for “health, welfare and disability organisations” regularly in England (Buck, 2016). Public health professionals have also referred to social prescribing<sup>5</sup> as a “movement of the people” (Polley, 2016).

### **Challenging scientific, medical, political and economic power**

The “scientisation of decision-making” and rise of “medical authority” reinforce science and medicine as dominant powers as well as support dominant political, socioeconomic systems, state and corporate powers (Brown & Zaventoski, 2004). The scientisation of decision-making is contributing to the co-option of “social” questions as “science” questions with scientific knowledge superseding lived experience (Weinberg, 1972). Lived experience offers tremendous value to civil society, experts by experience and social purpose organisations (Sandhu, 2017a). Yet, within the social sector, “people with lived experience are often viewed more as ‘informants’ than... leaders of change,” further eroding their power and participation in policymaking and decisions concerning their own health (Sandhu, 2017b). A Lived Experience Leaders Movement (2020) is advocating for “connecting, supporting and strengthening the capacity of lived experience leaders to help all our communities thrive.”

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<sup>5</sup> Social prescribing “enables GPs, nurses and other primary care professionals to refer people to a range of local, non-clinical services” (Baird, 2018).

The rise of medical authority has contributed to the prioritisation of biomedical research over health issues, which could be addressed through investment in wider social determinants (Kawachi & Berkman, 2020; Krieger et al., 1993). “For the public, these problems highlight the polemical intersection of science, society and institutional culture, which ultimately paves the way for a critique of the dominant political economy and its adverse effect on the public’s health” (Brown & Zavestoski, 2004; Frickel & Moore, 2008).

Embodied health movements (EHMs), discussed in the next section, have been catalysed by the implications of these trends and are effectively challenging issues such as the production of scientific knowledge, especially through digital tools enabling rapid information sharing and collective knowledge production, as well as the ways in which health care system practices and belief systems maintain gender and racial inequalities (Brown & Zavestoski, 2004).

## Health social movements as a rising field

Health social movements (HSMs), or social movements in health, represent a timely area of study. This section provides an overview of this rising field as a backdrop to this research study.

### **What is a health social movement?**

According to Brown & Zavestoski (2004), health social movements (HSMs) are:

Collective challenges to medical policy, public health policy and politics, belief systems, research and practice which include an array of formal and informal organisations, supporters, networks of co-operation and media. HSMs make many challenges to political power, professional authority and personal and collective identity.

The authors elaborate that:

Health social movements represent the transformation of sporadic and relatively unorganised challenges into formal and institutionalised opposition. In challenging

scientific and medical authority structures, HSMs focus on the frequent medicalization of social problems, increasing scientization in which technical solutions are provided instead of social solutions, and a burgeoning corporatisation that takes many decisions out of people's hands, including what would be considered appropriate care.

A preliminary typology identifies three HSMs types, summarised in Table 1.1, including health access movements, embodied health movements (EHMs) and constituency-based health movements (Brown & Zavestoski, 2004). To Brown and Zavestoski, health social movement types are "ideal" and not mutually exclusive. Alternative typologies recognise condition-based groups, population-based groups and formal alliance organisations (Allsop et al., 2004).

**Table 1.1: A typology of health social movements (Brown & Zavestoski, 2004)**

<b>Health social movement</b>	<b>Issues addressed</b>	<b>Examples</b>
<i>Health access movements</i>	Seek equitable access to healthcare and improved provision of services	National healthcare reform
<i>Embodied health movements (EHMs)</i>	Disease, disability or illness experience by challenging science on etiology, diagnosis, treatment and prevention; include "contested illnesses" that are either unexplained by current medical knowledge or have purported environmental explanations that are often disputed; organise to achieve medical recognition, treatment and/or research	Breast cancer, HIV/AIDS, tobacco control
<i>Constituency-based health movements</i>	Health inequality and health inequity based on race, ethnicity, gender, class and/or sexuality differences; disproportionate outcomes and oversight by the scientific community and/or weak science	Women's health, gay and lesbian health, environmental justice

Research on EHMs is growing and features a genre introduction (Brown & Zavestoski, 2004), conceptual framework for EHMs based on a case study of the environmental breast cancer movement (Zavestoski et al., 2004) and attempt to incorporate issues such as racial exclusion and non-Western cultural health ontologies into EHMs, drawing on autism organising in Somalia (Decoteau, 2017). Further research is needed on the impact of HSMs (Brown & Zavestoski, 2004).

## Rising interest in health social movement research

Since 2004, social movement scholars and sociologists have shown a rising interest in social movement research related to issues of health and care (Brown & Zavestoski, 2004). Prior to 2004, social movement scholars rarely focused on health and medical sociologists rarely referenced social movement theory. *Social Movements in Health* (2005) by Brown and Zavestoski marked the first volume to merge social movement theory with the study of health and illness. Brown & Zavestoski also proposed ways to study HSMs in their *Embodied Health Movements: Uncharted Territory in Social Movement Research* (2004).

## Health as underrepresented within social movement research

Health as an issue area represents just over 1% of social movements studied in leading social movement journals as indicated in Table 1.2 (Mac Sheoin, 2016). Health also rarely features in social movement research related to “non-core” regions, including Central and Eastern Europe, the Middle East, Africa, Latin America, South Asia and East Asia (Mac Sheoin, 2016), despite a few stand outs (e.g., Decoteau, 2017).

**Table 1.2: Leading social movement journals and their reference to health (Mac Sheoin, 2016)**

Name of journal	No. ref
<i>Research in Social Movements: Conflict and Change</i>	6
<i>Mobilisation</i>	1
<i>Social Movement Studies</i>	5
<i>Interface</i>	2
<i>Contention</i>	0
<i>Moving the Social: A Journal of Social History and the History of Social Movements</i>	0
<i>P&amp;C</i>	0
<i>Resistance Studies Magazine</i>	0
<b>Total</b>	<b>14</b>

In assessing how well health is represented in social movement research, Mac Sheoin (2016) stresses that we must “critically interrogate movement designations” or how social movements are classified into issue areas. In Mac Sheoin’s study, social movements were placed into single issue areas which is inherently problematic as they can touch upon multiple and intersecting areas. For example, in the women’s movement, health plays a leading role but perhaps is not primary (Mac Sheoin, 2016). Health is intertwined with social issues such as poverty, racism and the environment, extending far beyond science and medicine into politics, the economy, culture and institutions (Brown & Zavestoski, 2004).

It is also unclear how prominent HSMs have been in social movement theorising efforts. Health offers a ripe context for further social movement theorising. Additional theoretical work on health social movements could either reinforce existing theories or surface inconsistencies for further investigation.

### **Towards theories by, with and for social movement actors**

Now, more than ever, social movement research can play a critical role in devising strategies to reduce inequality and address its macro-structural roots such as systemic racism and power hierarchies (Irons & Tseng, 2019). Scholars have generated theories about how social movements emerge, spread and impact on people, institutions and society. Yet, despite ripe exceptions, social movement research is “not typically addressed to, nor does it generally inform, those who build and support movement organizing” (Irons & Tseng, 2019). Activists are often “suspicious” of scholars who use theory-building as a route to power, as a type of “academic parasitism” (Rootes, 2010).

Rootes (1990) helpfully distinguishes between theory *of* and theory *for* social movements where theory *for* social movements represents “theory fashioned by the people committed to social movements and designed to be useful to movement activists rather than to further the careers



of theorists.” Social movement actors and theorists can be powerful allies as there is “no inherent conflict between an interest in understanding the world and a determination to change it” (Rootes, 2010).

## Situating social movements within innovation research

We now situate this study within innovation research to establish an exploratory study at the nascent intersection of social movements and innovation.

### **Social movements as a critical sub-theme within innovation research**

Innovation management scholars recently identified social movement theory as an important sub-theme for future research, alongside power and institutional actors; an extensive review of the social innovation literature revealed only two papers proposing a “concept or construct” at this intersection (Agostini et al., 2017). Current innovation theories are top-down despite attempts to develop alternate bottom-up innovation theories such as frugal innovation (Bhatti et al., 2018), grassroots innovation (Seyfang & Haxeltine, 2012; Seyfang & Smith, 2007; Smith et al., 2014), informal innovation as an expression of collective action (Cozzens & Sutz, 2014) and grassroots innovation movements (Fressoli et al., 2014; Smith et al., 2012, 2016; Smith & Raven, 2012).

Studying social movements aligns with major trends in innovation studies, including moving from tangible to intangible innovations, from firms to multi-sector collaboratives and towards innovation in informal settings (Cozzens & Sutz 2014) as well as towards a range of innovation types, such as those emerging from the third sector and public institutions (Edwards-Schachter, 2018; Roth, 2009). A rise in social innovation studies is also occurring alongside a rise in research in complementary fields such as design and technology management; therefore, there

is opportunity for shared learning and practice across these three fields (Mulgan et al., 2007) and social movements.

### **Social movements as sites of innovative activity**

History is full of examples of social movements aiding the development and diffusion of healthcare innovations. In the early 20th century, the UK diabetes movement developed “diabetic kitchens” to support healthy cooking and promote the use of insulin, which was an innovation at the time (Diabetes UK, 2020). Since 2006, a consumer-led public health movement has aided the rapid adoption of the e-cigarette (Stimson et al., 2014). Further recognising and understanding how social movements aid the development and diffusion of innovations is an area ripe for research. Health innovations have also given rise to social movements. The contraceptive pill gave rise to the women’s liberation movement (Leadbeater, 2018). Recognising and understanding how innovation aids the emergence, spread and impact of social movements is another area ripe for research.

### **Adopting a process view of innovation**

This study adopts an understanding of innovation as a dynamic and social process:

A theory of innovation is fundamentally a theory of change in a social system. While innovation is defined as the introduction of a new idea, the process of innovation refers to the temporal sequence of events that occur as people interact with others to develop and implement their innovative ideas within an institutional context. (Van de Ven et al., 2000)

This framing of innovation enables the identification of actions related to innovation across the porous boundaries of a social movement. It also enables looking at social movements and innovation as dynamic and social processes. This is important because the social movement literature could benefit from further exploration of the process of building social movements.

Furthermore, a focus on institutional contexts places importance on how the “macro structure” of social movements aid or hinder innovation (Van de Ven et al., 2000). According to Van de Ven, emergent processes, such as social movements, typically exhibit low institutional organisation. Examining innovation processes related to social movements, especially in their early stages, requires looking at informal environments with low institutional organisation. Innovation processes in all contexts can “regularise” and “define” institutional environments as well as “redefine” its rules and organisation (Van de Ven et al., 2000). How innovation processes regularise, define and redefine social movements is another ripe area for study.

## Motivating the research

A number of serendipitous events motivated this research topic and influenced my decision to undertake this PhD.

### **Story of Self**

A brief encounter with Marshall Ganz, community organiser and scholar at Harvard University, introduced me to the concept of a *Story of Self* in his Self-Now-Us framework for launching a social movement (Ganz, 2001). The *Story of Self* describes “the events, challenges and choices” that lead a person to act; the “Story of Us... captures the values, experiences and capacities of an organization or movement” and the “Story of Now... outlines a current challenge, a vision for change and a potential outcome; it summons the listener to join the effort” (Hochman, 2016). For instance, in 2013, while in hospital as a terminally ill cancer patient, Dr. Kate Granter observed many medical staff not introducing themselves or making eye contact while delivering healthcare; she decided to utilise her *Story of Self* to start the #hellomynameis campaign which asks healthcare professionals to introduce themselves to patients and is transforming healthcare conversations worldwide (Hello My Name Is, 2020). In 2017, Marshall asked me, “What’s your story?” I shared that my grandfather was a hospital administrator and Cuban revolutionary in the 1960s. “It makes sense you are working on social

movements for health!" he said. Marshall inspired me to investigate a revolutionary past that I was previously unacquainted with. My father grew up a 31-minute walk from the mausoleum of José Martí, a Cuban revolutionary philosopher and political theorist who happens to be in my family tree. Throughout his life, José promoted liberty, the intellectual independence of Spanish Americans and Cuba's independence from Spain in the 19<sup>th</sup> century. My father frequently shares his story of leaving Cuba at the age of fifteen, working as a newspaper boy to support his family and as a waiter at the King's Arms Tavern in Williamsburg, Virginia to get through college. Growing up the daughter of an immigrant in the small town of Grand Blanc, Michigan made me acutely aware of issues of power and privilege as well as the meaning of perseverance, hard work, respect and resourcefulness. It no surprise that social movements have captivated my passion and intellectual interest.

In 2015, while working as a designer at the Mayo Clinic Center for Innovation,<sup>6</sup> my colleague and I were asked to identify disruptive opportunities for innovation in primary care (Christensen, 2000). We serendipitously came across the Adverse Childhood Experiences (ACE) Study, a 17,000 person public health study identifying a strong dose-response relationship between ten adverse childhood events and the leading causes of death in adulthood as well as negative health behaviours, such as smoking and alcoholism (Felitti et al., 1998). ACEs are "chronic" and "insidious," with their impact passing down from generation to generation via epigenetic inheritance (Dayton, 2018). According to Dr. Robert Anda, ACE study co-investigator, the medical community has been slow to respond to the ACE study, ignoring it for over a decade (Stevens, 2012) and not using it enough in clinical practice (Grinnell, 2016).

For over 10 years, Washington State has been training teachers and students about ACEs which had led to a 66% decrease in youth arrests for violent crime and saved more than \$1.4 billion (National Center for Injury Prevention and Control, 2017). In 2016, more and more

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<sup>6</sup> In 2002, the Mayo Clinic consulted global design consultancy IDEO to set up a "skunkworks outpatient lab," which later became the Center for Innovation serving the Mayo Clinic enterprise (Smith et al., 2010).

people were talking about ACEs and developing innovations to help people heal from ACEs, such as treatment protocols for children with high ACE scores (Chandler, 2016). Some of these people were starting to refer to ACEs as a social movement. I wondered: *What is a social movement? How can they support the development and diffusion of innovations, especially innovations addressing social and relational issues?*

These questions inspired me to pursue a PhD at the Institute of Global Health Innovation (IGHI) at Imperial College London. IGHl houses the Centre for Health Policy (CHP) and the HELIX Centre for Design which respectively focus on the “development, uptake and distribution of innovative, evidence-based health policies around the world” (Darzi & Parston, 2013; Darzi et al., 2015; 2016; Harris et al., 2016; 2018) and on translating research into products improving health outcomes at St. Mary’s hospital in London and beyond. These focus areas offered fertile ground for an exploratory study investigating how social movements aid the development and diffusion of healthcare innovations.

## **Researcher lens**

I formerly started my innovation career at the Stanford Hasso Plattner Institute of Design (“d.school”) after coming across a sign that read, “Redesign the ramen noodle experience” and finding it delightfully peculiar. Since 2006, I participated in design thinking becoming a worldwide phenomenon with the d.school assuming its current identity as “a hub for innovation, collaboration and creativity” in the heart of Silicon Valley (Stanford d.school, 2020). Over 15 years, I have practiced, taught, facilitated and led the design process within universities and organisations globally, for diverse purposes and across sectors with a particular focus on human and planetary health. Appendix II depicts a range of innovation methodologies, including design thinking and human-centered design, that I have utilised throughout my professional career.

My innovation career involved the three layers of design practice – project, process and field (Bourdieu, 1999). My early career focused on projects such as designing the Quick Tabs user interface at Microsoft with the Internet Explorer team as well as an affordable, high-performance medical device for treating babies with jaundice in low-resource hospitals in India. In 2015, I started working on service design projects, including designing the patient and physician experiences of applying Google Glass to humanising healthcare and reducing clerical burden. My work with Banny Banerjee exposed me to the possibility of innovating the design field. Through my engagement with him from 2012-2014, I supported the growth of Stanford ChangeLabs, a systems innovation lab focused on developing systems innovation methodologies for scaled, complex and urgent sustainability challenges.<sup>7</sup> I co-taught these methodologies in a graduate course, *Collaborating with the Future: Launching Large-Scale, Sustainable Transformations*, and co-delivered multi-stakeholder workshops to pilot them.

Researchers unfamiliar with the empirical realities they plan to study can choose to gain experience prior to jumping into formal investigation (Della Porta, 2014). Instead of delaying research activities to gain experience, I was fortunate enough to get involved with social movements as a participant, supporter and researcher. In 2017, I served on the Scientific Committee of the 5<sup>th</sup> Global Mental Health Summit, *Leaving no one Behind*, in Johannesburg, South Africa in 2018. I participated in NHS protest marches and commemorative events such as the 100<sup>th</sup> anniversary of women’s suffrage and the 200<sup>th</sup> anniversary of the Peterloo Massacre (Halliday, 2019). Exploring my inner activist grounded this research in the practical realities of movement-building and offered background context for interpreting the formal data sources as well as for identifying study implications for practice, policy and education.

I also became involved in supporting social movements. From 2016-2018, I led social movement work at Nesta Health Lab, a centre of expertise on people-powered health that

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<sup>7</sup> The methodologies draw on social psychology, resilience theory, ecology, entrepreneurship, data science, economics, organisational behavior, technology strategy and business strategy (Stanford ChangeLabs, 2020).

tests and scales new ideas across the UK healthcare ecosystem. Our research into social movements resulted in two reports – *Health as a Social Movement: The Power of People in Movements for Health* (del Castillo et al., 2016) and *We Change the World: What can we Learn From Global Social Movements* (del Castillo et al., 2017). The first report surfaced the need for new models of engagement between social movements and health institutions. The second interrogates “What can we learn from other social movements?” and presents the challenges and victories of 40 people representing four international movements – HIV/AIDs, global mental health, rare disease and disability rights. It also represented one of the first attempts to look across movements to understand how they spread alongside other attempts such as *How Change Happens: Why Some Social Movements Succeed While Others Don’t* (Crutchfield, 2018). In 2018, together with my colleagues, we proposed a social movement incubation program designed *by, with and for* people that could aid the growth and survival of social movements for health (Nesta, 2018). The inspiration for this programme came from listening to people starting social movements across the UK and research on innovation niches. In 2019, I served as a Senior Movement-Building Fellow at the Blue Shield of California Foundation that aims to end domestic violence across California. The Fellowship involved investigating how funders support social movements and devising movement-building investment strategies for gender and health equity movements.

## Study preview

This study initially aimed to understand how social movements aid the development and diffusion of innovation. It later pivoted to respond to my observation that understanding innovation in relation to social movements requires understanding how people organised into social movements make sense of social movements and innovation. The study embraces constructivist grounded theory, utilising qualitative and inductive methods to generate empirical insights, including semi-structured interviews with people identify with or influence social movements related to public health issues (Public Health England, 2020), observations of social movement meetings and analysis of supplementary documents related to social

movement activity. Purposive sampling enabled the identification of people with experience of social movements where the phenomenon of interest was like to exist or insight could be gained; if the phenomenon does not exist in a small sample, it is unlikely to exist elsewhere, assuming samples are chosen wisely (Ames et al., 2019; Robinson, 2014; Teddlie & Yu, 2007). Variation was sought from people across social movements and public health issues as well as across diverse sectors in health systems and local communities. Reflexivity, a process important to social movement and grounded theory research (Charmaz, 2014), enabled reflecting on power, privilege and politics issues (Olesen, 2007) as well as applying my innovation practitioner lens to analysing social movement data.

This study makes contributions to the social movement, innovation and health literatures in five principal ways. First, it reveals how people make sense of social movements as a concept and that their familiarity with social movements could be assessed according to their awareness, understanding and experience. Second, it discovers the social movement experience (SMExp) as a new analytical tool for social movement and innovation research. Third, it identifies twelve social movement actions aiding innovation development and diffusion as well as new conceptual directions to explore their interrelationships such as social movement and innovation opportunity structures. Fourth, it offers insights about how to study innovation in relation to social movements and suggests that innovation could also be studied as experience. Fifth, it contributes to health as underrepresented in social movement research (Mac Sheoin, 2016) and suggests that social movements can be the solution to social health issues.

The study leads to rich implications for practice, policy and education. For policymakers, an experiential view of social movements could support them in devising support strategies and ways for institutions to work alongside social movements, an original aim of NHS England's Health as a Social Movement programme (NHS England, 2016). For social movement actors, it offers practical insights on how to build social movements and relate to the social movement



experience. For social movement actors and innovators, the study points to opportunities for shared practice, social movement sensemaking and applying innovation approaches to building social movements. For health professionals, it reveals that social movements can be a solution to social health issues such as loneliness and mental health as well as that the nature of social health issues impacts on social movement mobilisation. For educators, social movement experience lends itself to powerful experiential learning.

## Thesis structure

This thesis journey spans nine chapters. The first three chapters offer context and motivation for the study and present the study design. Chapter 1 provided an overview of health social movement research, situated social movements within innovation research, motivated the research through my personal narrative and previewed the study aims, methods and contributions. It also outlined my experience in social movement and social innovation practice, policy and education. Chapter 2 reviews theories about how social movements emerge, grow and impact on people, institutions and society. It also identifies theoretical, methodological and practical research gaps and trends which inform the study design. Chapter 3 presents the study design and choice of methods.

Chapters 4, 5 and 6 present the empirical findings. Chapter 4 investigates how people make sense of social movement as a concept to centre the views of social movement actors. Their views are not only vital to social movement research but to informing movement-building practice, policy and education. Chapter 5 discovers the social movement experience and presents its initial conceptual categories, including Acting, Facing, Sensing and Planning. These categories emerged through an iterative process of grouping, abstracting and framing over 2,000 line-by-line codes, representing a bottom-up analysis of study participant actions. In Chapter 6, we look at participant perceptions of innovation and identify twelve social movement actions aiding innovation development and diffusion.

The exciting task of interpreting the research findings takes place in Chapter 7. At this point in the research journey, extant literature helps excavate new insights about how study participants make sense of social movements as a concept, experience and as innovation. Chapter 8 discusses the study impact and limitations as well as implications for research, practice, policy and education. Chapter 9 sets the sun on the research and charts an exciting path forward through a future research agenda.

### Releasing us on a journey

This research took unexpected turns and pivoted towards promising alternate pathways to arrive at what it has become. The journey felt like experiencing Frank Lloyd Wright's architectural principle of "compression and release," where a person enters a narrow space followed by a subsequent release into a spacious opening (Wright, 2017). I hope this dissertation takes you on a journey and most importantly, that the voices of people in social movements invite you into a world that is either deeply familiar or delightfully novel.

## Chapter 2: Theories of social movement emergence, spread and impact

### Introduction

Scholars have long been fascinated by what social movements are as well as how they emerge and spread to impact on people, institutions and societies. This chapter offers an overview of social movement theories as a backdrop to research on how social movements aid innovation development and diffusion. It traverses three centuries of social movement research and identifies research gaps at the intersection of social movements, innovation and health.

### What is a social movement?

What kind of a thing is a 'social movement?' Is it a coherent and distinctive theoretical object with its own causal properties, such that it makes sense to talk of 'social movement theory?' Or is so-called social movement theory best understood simply as an applied domain within the theory of, say, collective action, culture, or politics? (Martin, 2012)

The quest to define a social movement has a long and contested history spanning three centuries. This section offers a historical journey through social movement definitions and explores opportunities for defining the term.

### **A historical journey through social movement definitions**

Scholars refer to a social movement as a political innovation invented by British antislavery advocates in the 1760s (d'Anjou, 1996). According to d'Anjou, activists developed the social movement to outperform short-lived and locally focused reform efforts; through social movements, activists could deploy sustained claims towards the state and instigate change across national boundaries as well as develop new campaign methods such as the boycott.

German sociologist Lorenz von Stein first used the term “social movement” within intellectual discussions about political thriving in 1848 to describe the working-class fight for social equality (Tilly, 1994). Intending to make a theoretical contribution to the socialism project, he proposed a new academic discipline “the science of society” which would address questions such as:

What is this social movement, the existence of which is being indicated by the socialist and communist impulse? What is a social revolution? What does it want, and where does it lead? How is it different from the political one? In short, what is society and how does it relate to the state? (von Stein, 1848)

During the same year in London, German philosophers Karl Marx and Friedrich Engels released their *Manifesto of the Communist Party*,<sup>8</sup> which reframed the working class fight as a social movement of the majority, stating "All previous historical movements were movements of minorities, or in the interest of minorities. The proletarian movement is the self-conscious, independent movement of the immense majority" (Marx & Engels, 1948).

Scholars, primarily from sociology and political science, have proposed numerous social movement definitions, shedding light on what a social movement is and how it functions. Table 2.1 presents a historical timeline of social movement definitions and authors between 1977 and 2014. The authors primarily represent the Western world, including US, UK, Italy and Australia.

Glancing across the social movement definitions reveals that social movements take on many forms: sets of opinions and beliefs, collectivities, groups, collective challenges, strategies, informal networks, a series of contentious performances, organizational structures and strategies as well as political associations. It also reveals that social movements take on diverse functions: promoting, resisting or effecting change, empowering oppressed populations, mounting effective challenges or collective claims, and resisting more powerful elites.

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<sup>8</sup> In 1872, Marx and Engels changed the title of their work to *The Communist Manifesto*.

**Table 2.1: A historical timeline of social movement definitions and authors (1977-2014)**

Definition	Authors	Discipline	Country
"A set of opinions and beliefs in a population which represents preferences for changing some elements of the social structure and/or reward distribution of a society."	McCarthy & Zald (1977)	Sociology, social work, business	United States
"A collectivity acting with some continuity to promote or resist a change in the society or organisation of which it is part. As a collectivity a movement is a group with indefinite and shifting membership and with leadership whose position is determined more by informal response of adherents than by formal procedures for legitimising authority."	Turner & Killian (1957)	Sociology	United States
"A specific class of collective phenomena which contains three dimensions... [it] is a form of collective action which involves solidarity... [it] is engaged in conflict, and thus in opposition to an adversary who lays claims on the same goods or... [it] breaks the limits of compatibility of the system that it can tolerate without altering its structure."	Melucci (1989)	Sociology, psychology	Italy
"Collective challenges [to elites, authorities, other groups or cultural codes] by people with common purposes and solidarity in sustained interactions with elites, opponents and authorities."	Tarrow (1994)	Political science	United States
"Informal networks based on shared beliefs and solidarity which mobilize around conflictual issues and deploy frequent and varying forms of protest."	Della Porta & Diani (1999)	Sociology, political science	Italy
"A series of contentious performances, displays and campaigns by which ordinary people make collective claims on others." For Tilly, social movements represent a major vehicle for ordinary people's participation in public politics. He argues that there are three major elements to a social movement - campaigns, repertoires of contention, WUNC displays.	Tilly (2004)	Sociology, political science, history	United States
"Organizational structures and strategies that may empower oppressed populations to mount effective challenges and resist the more powerful and advantaged elites."	Glasberg & Shannon (2011)	Political sociology	United States
"A form of political association between persons who have at least a minimal sense of themselves as connected to others in common purpose and who come together across an extended period of time to effect social change in the name of that purpose."	James & Seeters (2014)	Politics, globalisation	Australia

### The social movement as an evolving concept

There is no single definition of a social movement (Tilly, 2004b; see also Karl-Dieter, 2009).

According to Diani (1992), "an implicit, 'empirical' agreement about the use of the term [social movement] is largely missing." At times, scholars contribute to "terminological ambiguity" by using social movements and analogous concepts such as "revolution" and "collective action" interchangeably (McAdam, 1988) as well as by skipping over defining social movements in research work (Diani, 1992). Yet, understanding the social movement concept is critical to any theorising process (Sartori, 1984).

In 1992, Diani conducted a comparative analysis of social movement definitions, identifying three global characteristics of social movements, that social movements are: 1) networks of informal interaction between a plurality of actors, 2) engaged in conflict, on the basis of a 3) shared collective identity.<sup>9</sup> Diani intended for these global characteristics to support social movement theorising and assist researchers in distinguishing social movements from related concepts such as interest groups, coalitions, protest events and political parties. Yet, their lack of widespread adoption has had practical and methodological implications for social movement research. For instance, social movement scholars lack a shared method of identifying social movements and often resort to other identification methods, such as by asking people to self-identify with social movements of interest for study inclusion.

In 2004, Snow broadened the social movement concept to incorporate lifestyles. Snow examined both the lifestyle “wings” of long-standing social movements, such as the environmental movement’s green living wing, and social movements mounting collective challenges for lifestyle choices such as the home birth movement. The concept of a lifestyle movement, which consciously and actively promotes a way of life as a means to foster social change, was born (Miller, 2005). Diffusing a lifestyle without wider social change goals is not classified as a lifestyle movement such as the healthy living movement which focuses on improving personal and physical well-being (Dworkin, 2000).

### **Opportunities for defining social movements**

Reviewing social movement definitions illuminated opportunities for defining the term, including surfacing processes for developing social movement definitions and developing a social movement definition by, with and for social movement actors.

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<sup>9</sup> Diani’s (1992) analysis also showed that “anti-institutional styles of political participation or anti-systemic attitudes may constitute a distinctive trait of the concept of social movements.”

### *Surfacing processes for developing social movement definitions*

Understanding how scholars developed existing social movement definitions, including how and whether they sought input from social movement actors, would be extremely valuable to early-stage researchers and practitioners. Understanding these processes could assist practitioners in selecting and adopting definitions suitable to their context.

### *Developing a social movement definition by, with and for social movement actors*

Putting social movement actors at the centre of defining and understanding social movements would offer a much-needed perspective to social movement actors and policymakers and offer a critical lens to scholarly views.

## Theories of social movement emergence

Scholars have proposed a number of theories about why and how social movements emerge, including Marxism, collective behaviour, relative deprivation, resource mobilisation, political process, and new social movements. Social movements scholars often distinguish between American and European social movement research traditions<sup>10</sup> as depicted in Table 2.2.<sup>11</sup>

**Table 2.2: Four traditions of social movement analysis (Crossley, 2002)**

	<b>America</b>	<b>Europe</b>
<b>Pre-1970s</b>	Collective behaviour	Marxism
<b>1970s onwards</b>	Resource mobilisation Political process	New social movements

<sup>10</sup> As a US citizen studying UK social movement activity, I was aware that I was navigating these distinct cultural traditions.

<sup>11</sup> This table could be adapted to include "relative deprivation theory."

## **Marxism**

The Marxist perspective dominated European social movement research until the 1970s (Barker et al., 2013). Marxism has a contested history but often refers to class-based and anti-capitalist movement struggles that voice alternatives to capitalist societies (Císař, 2010). Class struggles occur as a result of contradictory interests between the underprivileged proletariat, the wage labourer classes employed to produce goods and services, and the privileged capitalists, the ruling class owning the means of production and extracting wealth from good and services.

## **Collective behaviour**

By the mid-nineteenth century, collective behaviour had become the dominant social movement research paradigm amongst American scholars (Crossley, 2002). These scholars saw social movements as part of a collective behaviour repertoire alongside crowds, fads, disasters, panics, fashions, and crazes (Jenkins, 1983; McAdam, 1982; McAdam et al., 1988; Oberschall, 1973; Tilly, 1978). According to the collective behaviour tradition, people start or join social movements in response to hardships such as grievances, structural strains, anomie, or deprivations (Crossley, 2002). Scholars often viewed these people as irrational, emotional, isolated and unintegrated members of society (Blumer, 1969; Crossley, 2002; Le Bon, 1895).

## **Relative deprivation theory**

By the late 1960s and early 1970s, scholars were embracing relative deprivation theory (Gurr, 1970; Merton, 1938). According to this theory, people start or join social movements because they feel deprived of power, wealth, status, or opportunities in relation to others (Rose, 1982). Feelings of deprivation may amplify if there is "temporal relative deprivation" or a long period of rising economic and social development followed by a short period of "sharp reversal" (Davies, 1962). Runciman (1966) suggested four preconditions for relative deprivation: person



A does not have object X, person A knows of other people who have X, person A wants to have X and person A believes obtaining X is realistic. A critical review of relative deprivation theory concluded that while this theory is an advancement over previous theories of social movement emergence, it has too many theoretical, conceptual and empirical weaknesses (Gurney & Tierney, 1982). According to these scholars, relative deprivation falls short of explaining why only some deprived people choose to start or join social movements and others do not; it is not a sufficient condition, only a necessary factor or partial explanation. Kendall (2005) identifies underlying reasons why deprived people might not feel compelled to start or join social movements, including conflict-avoidance or imminent life difficulties.

### **Resource mobilisation theory**

In 1977, McCarthy and Zald proposed a partial theory of resource mobilization. Their partial theory represented a major shift towards thinking of social movements as “conscious actors making rational decisions” (Della Porta & Diani, 2006) and proposed that social movements emerge when deprived people mobilise sufficient resources to take action to alleviate grievances (Kendall, 2006). Resources include money, knowledge, labour, skills, experience, media and elite support, legitimacy and social status (Dobson, 2001; Foweraker, 1995; McAdam et al., 1988; Phongpaichit, 1999). Their theory was considered “partial” because it was situated in an American context and relied on empirical material from the political left.

Resource mobilization theory rapidly gained significant merit (Buechler, 1995; McCarthy & Zald, 1977; Tilly, 1978), representing a major shift from the social psychology of collective behaviour to economic, political and sociological theories (Downs, 1972; Gamson, 1975; Lipsky, 1968; McCarthy & Zald, 1973; Oberschall, 1973; Tilly, 1973; 1975; Wilson, 1973). Givan et al., (2010) note that resource mobilization theory enabled studying social movement diffusion in new ways:

With the development of the resource mobilization tradition in the 1970s, and its focus on social movement organizations and the rationality of movement actors, it became possible to consider diffusion as something other than a simple process of contagion. Scholars thus began to study diffusion as a function of connections between different organizations and other mechanisms of strategic innovation. We might usefully classify these mechanisms into three very broad categories: relational, non-relational and mediated mechanisms of diffusion.

Critics say it overemphasises material resources (e.g., the civil rights movement relied on voluntary efforts) and fails to account for identity, culture and macro-sociological factors such as how political landscapes affect social movement emergence and diffusion (Kendall, 2006).

### **Political process theory**

In the 1980s, social movement scholars proposed “political process theory,” a political version of resource mobilization theory. In political process theory, the emergence of a social movement depends on: 1) Insurgent consciousness, 2) Organisational strength, and 3) Political opportunities (Meyer, 2004). In this theory, an opportunity or vulnerability in the political system creates an opening for a social movement to emerge and make an impact through collective action. It can give people a reason to mobilise, enable recruitment or justify mobilisation of resources. Vulnerabilities might include less effective repression of social movement activity, political or elite fragmentation, growing political pluralism or a State-level crisis which slackens the resistance that social movement leaders face.

### **New social movement theories**

The mid-1960s triggered a wave of Western social movements focused on quality of life (Buechler, 1995; Bürklin, 1984; Inglehart, 1990; Parkin, 1968; Touraine, 1971), including women and gay rights, anti-war efforts and the ecology movement (Laclau & Mouffe, 2001). New scholarly debates emerged as to whether these rising movements challenged the relevance, robustness and explanatory power of existing social movement theories, specifically resource

mobilization and Marxism (Eyerman, 1984; Olofsson, 1988; Pichardo, 1997). The movements seemed qualitatively different from those concerning industrialism or the working class (Melucci, 1981; Olofsson, 1988) as they addressed issues such as human rights, gender equality, autonomy, political participation, and environmental protection (Císař, 2015). For classical Marxists, economics and class are factors excluded from many contemporary social movements (Canel, 1992).

New social movement (NSMs) theories drew on Western left-wing contemporary social movements within European social theory and political philosophy (Cohen, 1985; Klandermans, 1991; Klandermans & Tarrow, 1988; Larana et al., 1994) and introduced the role of culture, identity and the civic sphere in social movement emergence (Bagguley, 1992; Pichardo, 1997). They focused on why, rather than how, social movements emerge (Buechler, 1999; Klandermans & Tarrow, 1988; Melucci, 1985). Buechler (1995) stressed the importance of talking about new social movement *theories*, identifying political and cultural versions (Table 2.3). The two versions are not mutually exclusive and inevitably risk oversimplification but can serve as sensitising concepts, sorting devices or heuristic tools.

**Table 2.3: Political and cultural versions of new social movement theories (Buechler, 1995)**

Issue	Political version	Cultural version
<i>General orientation</i>	Pro-Marxist	Post-Marxist
<i>Representative theorist</i>	Manuel Castells	Alberto Melucci
<i>Societal totality</i>	Advanced capitalism	Information security
<i>Image of power</i>	Systemic, centralized	Diffuse, decentralized
<i>Level of analysis</i>	Macro-, meso-level, state-oriented	Meso-, microlevel, civil society, everyday life
<i>Movement activity</i>	Retains roles for instrumental action toward strategic goals	Eschews strategic concerns in favour of symbolic expressions
<i>First debate: view of new movements</i>	Recognizes their role without rejecting role of working-class movements	Regards new movements as having displaced working-class movements
<i>Second debate: movement orientations</i>	Potential for progressive orientations if allied with working-class movements	Sees new movements as defensive or rejects category of "progressive"
<i>Third debate: evaluation of movements</i>	Sees political movements as most radical, cultural movements as apolitical	Sees cultural movements as most radical, political movements as co-optable
<i>Fourth debate: social base of movements</i>	Analysed in class terms via contradictory locations, new class, or middle class	Analysed in terms of non-class constituencies or issues and ideologies

Critics debate whether NSM theories are defensible as they describes only a “portion of the social movement universe,” omitting right-wing movements from their analysis; each NSM variation carries weaknesses, including “inconclusive empirical support, questionable operationalization of variables, ambiguous abstract concepts, and feasible alternative explanations” (Pichardo, 1997). It is also unclear whether, and on what basis, NSMs demand new theory; NSMs illuminate new analysis factors (Pichardo, 1997). However, the field has incorporated new analysis factors into social movement repertoires before (Tilly, 1979; Pichardo, 1997). Pichardo (1997) suggests that a more thorough analysis of the history and nature of conflict within the civic sphere in a post-industrial world would offer deeper insight.

## Theories of social movement diffusion

According to Givan et al. (2010), “one cannot understand social movements – how they evolve, how they expand, how they engage the political arena – without understanding the dynamics of diffusion.” These same scholars also identify social movements as a contemporary area of research on diffusion (Givan et al., 2010; Soule, 2004; Strang & Soule, 1998). This section presents social movement theories related to their growth, spread and diffusion.<sup>12</sup> It discusses the five stages of a social movement, the dynamic interplay between social movements and host societies, the application of diffusion theory to social movements and the development of an overarching framework for social movement diffusion.

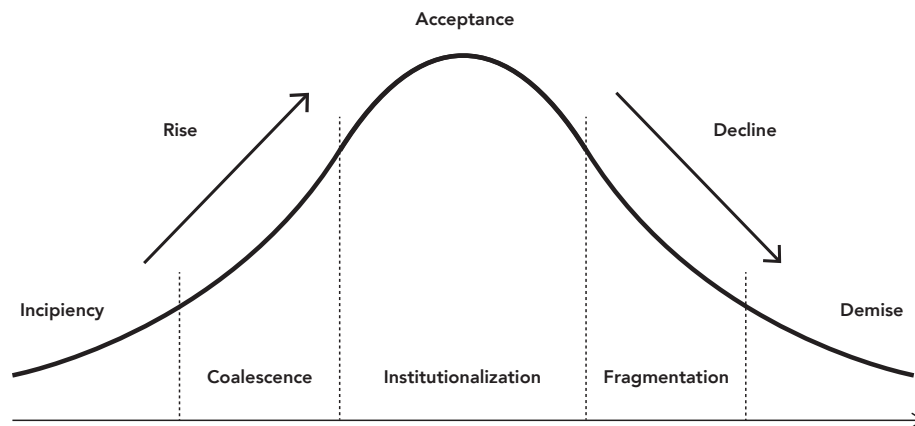
### **The five stages of a social movement**

According to Mauss (1975), the characteristics of social movements – subjective definitions of reality, formation of interest groups, mobilisation of public opinion – can mirror those of social problems. Analysing the histories of social problems led Mauss to the “natural history” of a

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<sup>12</sup> Scholars often use these three terms – growth, spread, diffusion – interchangeably in the social movement literature.

social movement (Figure 2.1) which consists of five stages – incipency, coalescence, institutionalisation, fragmentation, demise. The stages follow a rising, accepting and declining.



**Figure 2.1: The normal pattern for the natural history of a social movement (Mauss, 1975)**

In the incipency stage, social movement activity is informal and uncoordinated with people mobilising around shared grievances (Blumer, 1951; Mauss, 1975). A movement rises when it starts to coalesce around shared grievances and escalate those grievances through formal and informal alliances at increasing levels of scale to promote “convictions effectively and insure more sustained activity” (Turner & Killian, 1957). At this stage, there is typically a growing base of new members and resources, system-wide organising and rising movement power, credibility or legitimacy. There might be mass media attention, political support or legislation. If the movement is highly subversive, the “host society” might attempt to repress it. After a period of heightened activity around institutionalisation of the change programme, the movement usually starts to decline and fragment when a subset of supporters believe their grievances have been sufficiently addressed. These supporters might join other causes or leave the movement entirely, even joining the “host society” in labelling members as “fanatics.” Remaining movement members might infight for power by modifying their goals or strategies. Movements demise when the change programme has been sufficiently “appropriated” or when they experience a “temporary setback” such as losing leaders or critical resources.

Social movements follow three patterns towards demise – abortive, revival and overlapping (Mauss, 1975). A social movement aborts (Figure 2.2) when the host society represses it and forces its decline. Abortion can happen at any stage but usually happens before a movement can institutionalise its demands. In revival (Figure 2.3), social movements go dormant, reviving at a later time. In overlapping (Figure 2.4), a social movement with new objectives rises before its predecessor declines, often competing for the same members and resources.

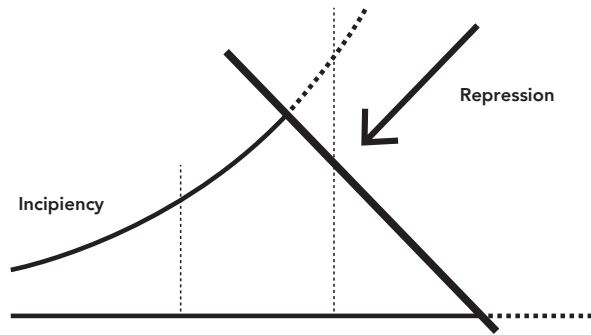


Figure 2.2: The abortive pattern of social movement demise (Mauss, 1975)

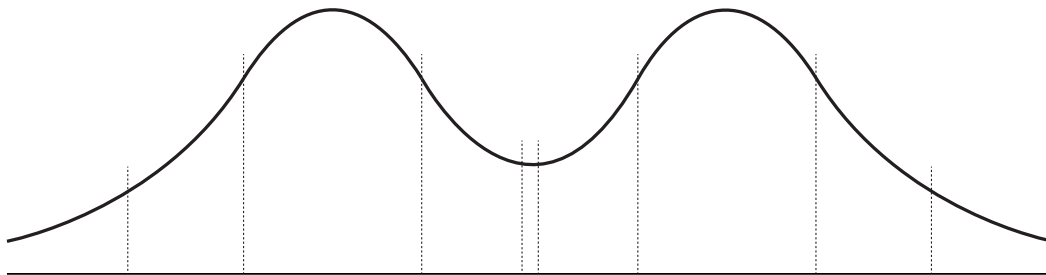


Figure 2.3: The revival pattern of social movement demise (Mauss, 1975)

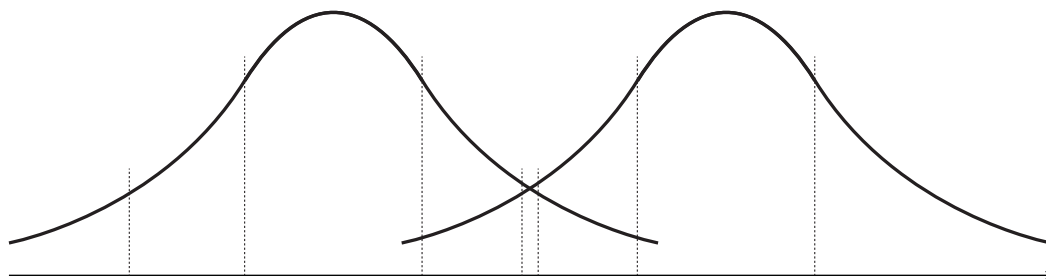


Figure 2.4: The overlapping pattern of social movement demise (Mauss, 1975)

Any model describing the dynamic trajectory of a social movement risks “over-simplification” and “distortion” (Mauss, 1975). The “natural history” offers an empirical tool for social movement analysis, not an accurate representation of all movements. Still, controversy exists over the demarcations and designations of stages. The term “social problem” faces definitional challenges but remains a suitable lens through which to analyse social movements for social problems involving “a rise, a thriving and a decline” (Leroux & Petrunik, 1990; Tanaka, 2011).

### **The dynamic interplay between social movements and host societies**

According to Mauss (1975), the dynamic interaction between a social movement and its host society propels it through its lifecycle (Figure 2.1); social movement members act to promote their agendas while the host society re-acts with co-optation and repression strategies, often deploying a “mix” of both. Both parties continue to act and re-act based on their subjective views of reality which are constantly in flux (Killian, 1964).

The cycle begins and ends with individuals and groups on all sides of an issue acting out their own perceived interests in respect to each other. When the interaction we have described brings the movement to an end, then the social problem disappears, whatever may be the case with the social conditions which had once been defined as problematic. (Mauss, 1975)

A social movement can run its course without any changes in objective reality (Killian, 1964). In fact, it almost always ends on an unsatisfactory note (Tilly, 2004a). According to Mauss (1975), “social problems are rarely solved in anything near the sense originally expected and demanded by the interest groups that identify them.” After all, “institutionalisation does not bring us to a fixed point; it is, rather, a continuing and continually challenged process” (Rootes, 1999). Eventually, a subset of members will trigger the next wave of contention (Tilly, 2004a).

The boundary between the social movement and the host society can blur as the movement progresses through its lifecycle. For example, activists can gain institutional access and

institutional actors can become activists. Goldner (2004) asks, “How does gaining institutional access blur the boundary between movements and mainstream organisations, and how does this ultimately impact upon the movements?” Brown & Zavestoski (2004) similarly points out that HSMs can move “fluidly between lay and expert identifies” and “blur the distinction between insiders and outsiders.” Social movements and host societies co-determine each other. As Wolpe (1999) shares “even as biomedicine has fought alternatives, it has nurtured them, drawn from them, used them as testing grounds. Even as alternatives have fought against the orthodoxy, they have envied it, drawn from it, longed for legitimacy from it.”

Goldner (2004) expands the “mix” of host society responses by utilising empirical data on the complementary and alternative medicine (CAM) movement and an existing typology on strategic institutional responses (Oliver, 1991).<sup>13</sup> Goldner examines how activists perceive strategic responses from Western physicians and hospitals. Strategic responses range from passive acquiescence to proactive manipulation – acquiesce, compromise, avoid, defy or manipulate – and can be empirically observed through their associated tactics (Table 2.4). CAM activists exhibited conflicting ideologies and aspirations as well as varied meanings of complementary, alternative and integrative medicine. CAM purists desired an alternative medical model; mainstreamers, integration with Western medicine. These conflicting ideologies led to diverse counter reactions amongst activists.

Opportunities to extend Goldner’s work include: 1) applying and adapting the typology to additional host society actors, such as political leaders, reflecting that “professionalization takes place in a complex environment with multiple influences” (Abbott, 1988, 1998; Goldner, 2004), 2) testing the value of the typology as a sensemaking tool for social movement actors to observe and plan strategic responses to host society activity, 3) exploring positive host society

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<sup>13</sup> Goldner conceptualises CAM as a social movement due to “the number of people identifying as activists and the collective impact they [were] achieving” (Goldner, 1999; Goldner, 2004).



responses to social movement actions, and, 4) overlaying the typology onto the social movement lifecycle to decipher whether mix types correlate with lifecycle stages.

**Table 2.4: Strategic organisational responses to activism (Goldner, 2004)**

Strategies	Tactics	Examples
Acquiesce	Habit	Following invisible, taken-for-granted norms
	Imitate	Mimicking institutional models
	Comply	Obeying rules and accepting norms
Compromise	Balance	Balancing the expectations of multiple constituents
	Pacify	Placating and accommodating institutional elements
	Bargain	Negotiating with institutional stakeholders
Avoid	Conceal	Disguising nonconformity
	Buffer	Loosening institutional attachments
	Escape	Changing goals, activities, or domains
Defy	Dismiss	Ignoring explicit norms and values
	Challenge	Contesting rules and requirements
	Attack	Assaulting the sources of institutional pressure
Manipulate	Co-opt	Importing influential constituents
	Influence	Shaping values and criteria
	Control	Dominating institutional constituents and processes

### Applying diffusion theory to social movement research

In *Diffusion of Innovations* (1962), Rogers defined diffusion as the spread of an innovation through direct or indirect channels across members of a social system. Rogers' research synthesised over 500 diffusion studies across diverse fields such as sociology, education, medical sociology and anthropology. It revealed that diffusion is influenced by: 1) the transmitter, 2) the adopter, 3) the diffusing item and 4) the diffusion channel linking transmitter with adopter. Transmitters and adopters can be people, groups or organisations.

Research applying diffusion theory to social movements was limited up until the 1990s. At that time, social movement research was dominated by studies of single movements rather than comparative research on how social movements interact and interrelate (McAdam & Rucht, 1993) as well as on social movement outcomes rather than on processes (Rosenau, 1990). Pinard (1971) and McAdam (1982) had applied traditional diffusion theory to social movement

research yet without distinguishing between intra- and inter-movement diffusion (McAdam & Rucht, 1993). Researchers had also looked at the role of contagion in the spread of collective behaviour (Turner & Killian, 1957) and at diffusion mechanisms such as circular reasoning, suggestibility, identification, and limitation (Tarde, 1903). Implicitly, work on protest cycles and action repertoires also looked at diffusion dynamics (Rosenau, 1990).

In 1993, McAdam and Rucht called for a more systematic application of diffusion theory to social movements, suggesting that diffusion theory could be an effective starting point for theorising about the conditions and means through which diffusion happens within and across movements. They broadened the definition of diffusion beyond innovation to “the acceptance of some specific item, over time, by adopting units – individuals, groups, communities – that are linked both to external channels of communication and to each other by means of both a structure of social relations and a system of values, or culture.” Diffusion theory can be applied to how movement diffusion “items” spread, including cognitive frames, tactical repertoires, behavioural routines and organisational forms. Cognitive frames are statements communicating the vision, grievances or ideologies of a social movement resulting from members debating shared interests; tactical repertoires, the collection of tactics a social movement utilises such as to make claims or put pressure on institutions (Wang & Soule, 2016). According to Taylor (2016), tactics can support political persuasion (e.g., lobbying, petitioning), confrontation (e.g., marches, strikes) and cultural expressions of solidarity (e.g., rituals, street art).

Since 1993, research applying diffusion theory to social movements has grown considerably (Ayres, 1999; Giugni, 1998; Soule, 1999; Tarrow, 1994). In 1998, Strang and Soule published their seminal work on diffusion in social movements and organisations, examining the structural and cultural bases of diffusion with structural arguments drawing disproportionately from organisational literature and cultural arguments from social movement literature. They also shifted away from relational and towards “macro” diffusion analysis. According to them, “contemporary work on organisations and social movements typically examines the spread of

behavioural strategies and structures rather than technical innovations, emphasizes adoptions by social collectivities more than individuals... works with a much larger historical and spatial canvas, and incorporates diffusion as one sort of explanation rather than as the overarching framework." For social movements, Strang and Soule propose more comparative research designs that examine rates, patterns, and causal diffusion mechanisms as well as replacing theories of "connections" with "connecting" by investigating what spreads, such as through interpretive work between actors as well as through investigating the cultural status of the item diffusing and the diffusion industry of discourse.

Chabot and Duybendak (2002) contend that applying diffusion theory to social movements has led to the social movement field accepting the biases of classic diffusion theory,<sup>14</sup> stemming from modernisation theory and "essentialist diffusionism." Strang and Soule (1998) advise proceeding with caution, that "diffusion research on social movements can learn from the classics but should not blindly copy them."

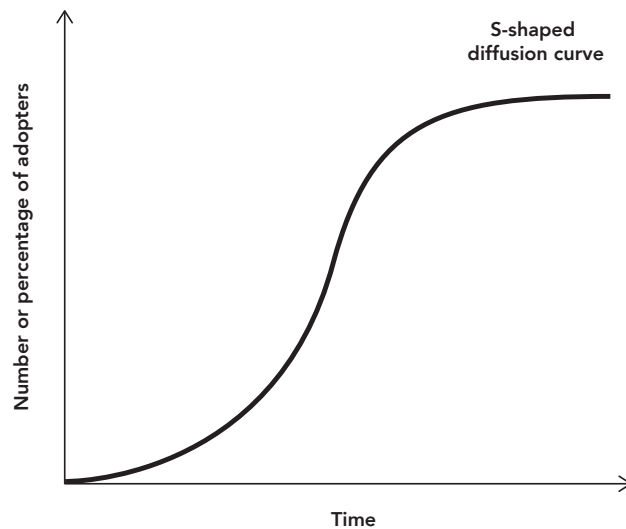
Scholars continue to investigate how social movement "items" diffuse, including work on meso-level networks (Hedström et al., 2000), transnational diffusion (Chabot & Duyvendak, 2002) and social networks (Krinsky & Crossley, 2014). Benford and Snow (2000) investigate how collective action frames diffuse across movements and cultures as well as how framing processes affect the diffusion of beliefs, objects and practices within social movements. They also look at how objects of diffusion need to be framed to increase their resonance with the adopter. They identify two situations where the adopter or transmitter takes an active role in diffusion: 1) strategic selection or adaptation and 2) strategic fitting or accommodation.

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<sup>14</sup> According to Blaut (1993), essentialist diffusionism embraces seven propositions: "1) Innovation and progress stem from Western democracies in the core of the world system, 2) Non-Western countries in the world system's periphery are usually stagnant and traditional, 3) Western progress derives from superior rationality, spirit, and values, 4) The cultural reason for non-Western backwardness is inferiority in above areas, 5) Non-Western countries can only advance through rapid diffusion of progressive ideas and practices from the West, 6) In exchange, Western democracies receive material wealth and manpower from non-Western areas, and 7) Ideas and practices that diffuse from the non-West to the West are ancient, savage, and destructive" (Chabot & Duybendak, 2002).

## Developing an overarching analytical framework for social movement diffusion

Tarrow first recognised the need for a comprehensive view of social movement diffusion, noticing that protests in one place or time period can influence those in others. Nudged by Tarrow, Givan et al. (2010) compiled social movement diffusion research into an overarching analytical framework, identifying opportunities for future research and promoting integrated investigations. The framework focuses on what diffuses, how diffusion occurs and the impact of diffusion on other social processes. Figure 2.5 displays the S-shaped Diffusion Curve (Rogers, 1995) which Givan et al. (2010) apply to social movements.



**Figure 2.5: S-shaped diffusion curve (Rogers, 1995)**

Within their framework, Givan et al. (2010) recognise three social movement diffusion mechanisms – relational, non-relational, and mediated. Relational diffusion involves spreading directly through trusted social relationships; non-relational, through indirect communication between groups otherwise having little contact; mediated diffusion, through an intermediary broker such as a transnational activist networks which links disparate actors. Social movement diffusion can also happen through political learning and cognitive liberation involving

movement members learning from other movements, making sense of their experiences, and shaping or reshaping what is desirable or possible. Social movement diffusion can impact on other social processes, such as the emergence and growth of organisations, as well as instigate scale shifts such as turning a local protest into a national movement.

Developing a comprehensive framework for social movement diffusion is challenging (Givan et al., 2010). It is complex and multi-faceted, involving a range of actors, networks and mechanisms. At a single point in time, multiple elements (e.g., cognitive frames, tactical repertoires, behavioural routines, organisational forms) are diffusing simultaneously across diverse channels and at differing rates. These elements can diffuse both horizontally, from one site to another, and vertically, from local to increasing levels of scale. Scholars have yet to fully understand the distinction between horizontal and vertical diffusion or their complex inter-relationships.

A comprehensive framework for social movement diffusion would ideally account for: 1) a diverse range of social movement types and their unique diffusion elements, mechanisms and effects, 2) diffusion dynamics within social movement families and societies, 3) the broader social and institutional context, such as the impact of political agency, power dynamics, culture and institutional fields, 4) the impact of digital networks and 5) predictive tools for social movement diffusion (Givan et al., 2010). Analytical tools are also needed to weave together the spread of protest repertoires (Soule, 1997) the role of communication forms (Singer, 1970) and institutional conditions for coordination and collective action (Gould, 1991).

## Transnational social movement diffusion

Scholars of contentious politics mostly examine inter-movement diffusion in the West (Chabot & Duyvendak, 2002). Exceptions include work on cyber diffusion (Ayres, 1999), the influence of the Japanese Buddhist movement on the U.S. (Snow & Benford, 1999), and transnational public spheres (Guidry et al., 2000). Chabot and Duyvendak (2002) propose an alternative framework for transnational diffusion research aimed at eliminating essentialist diffusionism and the “centrifugal assumptions at the root of contemporary social science, globalization theory and contentious politics research.”<sup>15</sup> They apply their framework to how U.S. civil rights leaders creatively adapted and applied satyagraha, Gandhi’s contentious repertoire.<sup>16</sup>

## Theories of social movement impact

Research that systematically looks at the outcomes and consequences of social movement action has been sparse (Giugni, 1998). A few scholars have attempted to conceptualise social movement outcomes (Burstein et al., 1995; Giugni, 1994; Giugni et al., 1999; Rucht, 1992) and empirically understand them (Gamson, 1975; Giugni, 1995; Gurr, 1980; Huberts, 1989; Kitschelt, 1986; Midttun & Rucht, 1994; Piven & Cloward, 1977; Rudig, 1990). A comparative look at social movement outcomes and consequences is needed, one that looks across social movements, political contexts and time periods (Giugni, 1998).

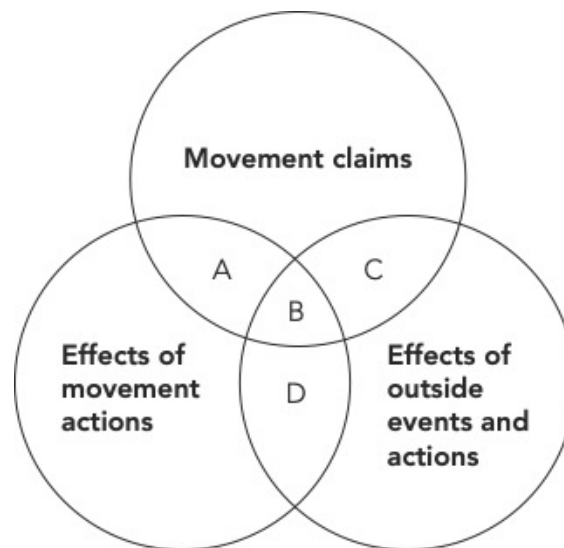
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<sup>15</sup> A transnational diffusion framework incorporated: 1) Diffusion items that are dynamic, ambiguous, malleable, works-in-progress, 2) Receiving groups that interpret and employ foreign innovations, including critical communities and networks of excluded citizens who identify new social problems, formulate new modes of thinking and feeling as well as develop new political and cultural solutions, 3) Non-linear diffusion which can skip phases or proceed forward and backward and 4) Transnational diffusion that can occur between heterogeneous and relational fields of diffusion (e.g., Western & non-Western, periphery & core, “non-democratic outskirts” \* “democratic heartland”) instead of within hierarchical and orderly social systems (Chabot & Duyvendak, 2002).

<sup>16</sup> To Gandhi, satyagraha is the “force which is born of Truth and Love or non-violence” (Gandhi, 1968). In the 1920s, W.E.B. Du Bois and John Holmes introduced satyagraha to African American intellectuals and religious pacifist groups, respectively; in the 1930s and 40s, civil rights activists wrote books and experimented with satyagraha; in the 1950s, Bayard Rustin and Glenn Smiley ensured the bus boycott of 1955-56 followed satyagraha principles (Chabot and Duyvendak, 2002).

### Analysing social movement outcomes and consequences

A number of methodological challenges arise when studying social movement outcomes and consequences (Beverley & Zimmerman, 1990). According to Beverley and Zimmerman (1990), outcomes can manifest over long time horizons and there is an issue of causality between social movement actions and observed changes (e.g., is an observed change the result of movement action or a political reform in response to a movement action?). Figure 2.6 depicts overlaps between movement claims, the effects of movement actions and the effects of outside events and actions.



- A** = Effects of movement actions that bear directly on movement claims
- B** = Effects of movement actions and outside influences that bear directly on movement claims
- C** = Effects of outside influences (but not of movement actions) that bear directly on movement claims
- D** = Effects of movement actions and outside influences that do not bear on movement claims

**Figure 2.6: A framework for analysing social movement outcomes (Giugni et al., 1999)**

### **Social movement spillover**

Social movement spillover refers to the effects that social movements have on one other (Meyer & Whittier, 1994). Through a case study of the impact of the women's movement on the US peace movement, Meyer and Whittier propose a theory of movement-movement influence focusing on types of spillover effects and mechanisms. Spillover can change protest intensity, offer new opportunities for protest, spur social movement actors to develop new tactics and provoke counter-movements (Tarrow & McAdam, 2005).

### **Social movement residues**

Social movements create many residues such as changes in popular culture (e.g., argot, jokes, leisure time, activities, styles, fads), norms and laws (Mauss, 1975). The mental hygiene movement left behind a new understanding of "mental illness" in popular culture and within the medical community (Crossley, 2002). The breast cancer movement, in conjunction with the women's movement, eventually catalysed changes in normative boundaries, recasting breast cancer as a public health issue rather than a private problem (Klawiter, 2004). In the 1990s, people living with AIDS in Costa Rica brought legal cases against the medical system. They did not win their cases but in 1998, the new constitutional court ruled to offer free, anti-retroviral drugs to all people living with AIDS (Wilson & Rodríguez Cordero, 2006).

### **Social movement opportunity structures**

Gamson (1990) described the relationship between institutional and discursive opportunity structures and social movement outcomes (Figure 2.7). According to Gamson, a social movement group must have both institutional and discursive opportunity structures to elicit a full response from targets. Lack of either structure will lead to pre-emption or co-optation; lack of both, collapse or marginalisation.



**Figure 2.7: Relationship between opportunities and movement outcomes (Gamson, 1990)**

		Discursive Opportunity Structure	
		<i>Open</i>	<i>Closed</i>
Institutional Opportunity Structure	<i>Open</i>	Full response	Co-optation
	<i>Closed</i>	Pre-emption	Collapse or marginalization

### Reflections on the social movement literature

This theoretical literature review surfaced reflections: embracing middle-range theories within social movement studies, approaching theoretical integration, growing theoretical work in the Global South, enumerating theorist identities, ensuring the usefulness of social movement theories and discovering at the crossroads of social movement theories and cognate fields.

### Embracing middle-range theories within social movements studies

Middle-range theories aim to understand social phenomena within a specific context and set of conditions (Merton, 1968). Middle-range theory also represents an approach to sociological theory construction, recognised since the 1960s (Bailey, 1991).

Our major task today is to develop special theories applicable to limited conceptual ranges – theories, for example, of deviant behaviour, the unanticipated consequences of purposive action, social perception, reference groups, social control, the interdependence of social institutions – rather than to seek the total conceptual structure that is adequate to derive these and other theories of the middle range. (Merton, 1968)

A middle-range approach allows scholars to examine aspects of social movements without the need for an “all-encompassing theory of social and political change;” middle-range theories

can have connections with grand sociological theories and other middle-range theories (Rootes, 1990). It also generates theories that are less abstract and therefore, more easily understood; it avoids “the elevation or importation of a virtual priesthood of intellectuals to act as translators and guides” (Rootes, 2010). Social movement studies first embraced the middle-range approach in 1978 with the collective event as the unit of observation (Kriesberg, 1984). Since then, a number of scholars have referred to many social movement theories as middle-range theories (Altaweel et al., 2012; Rootes, 1990).

### **Approaching theoretical integration**

Social movement theoretical integration is a long-standing debate within the social movement field. Each social movement theory “illuminates some issues while leaving others in the dark” and speaks to different levels of analysis; new social movement theories, to the macro, resource mobilisation theory, to the meso and social constructivism, to the micro-level, for example (Buechler, 1995). Some options for theoretical integration include formulating an alternate social movement theory or selecting a dominant theoretical approach – collective behaviour, resource mobilization theory or even, Marxism (Barker et al., 2013; Císař, 2015). Other scholars suggest “identifying points of convergence and divergence” amongst social movement theories or identifying new questions across paradigms (Buechler, 1995). Pichardo (1997) proposes incorporating theoretical insights from “the entire social movement universe” – the left, right and historically – and critically analysing all concepts and evidence, desiring a theory that is empirically grounded and cogent. Buechler (1995) values a theory which can explain a wide range of movements because from the 1970s onwards, scholars crafted theories representing social movements from their respective time periods. Contemporary social movement theory is largely based on the new left “movement family” – the Vietnam anti-war struggle as well as anti-nuclear, gay and lesbian, women’s and environmental movements – and potentially irrelevant to movements outside these times and places (Tarrow & McAdam, 2005).

### **Growing theoretical work in the Global South**

Social movement research has taken a disproportionate focus on Western society with attribution to parochialism or isomorphism (Poulson et al., 2014). There has been a rise in studying social movements in the Global South. Some scholars are examining the relevance and applicability of social movement theories, based on social movements in the Global North, to social movements in the Global South. For instance, Engels & Müller (2019) apply four social movement approaches – resource mobilisation, political opportunity structures, framing and collective identity – to social movements in sub-Saharan Africa. The approaches reveal similar limitations in these movements as those in other parts of the world.

### **Exploring social movement theorist identities**

Scholars refer to people who develop social movement theories as social theorists (Rootes, 1990), practical theorists (McCarthy & Zald, 1977), activist theories (Rootes, 1990) or purely, theorists. Some of these identities carry historical baggage, especially within heated debates about the relationship between theory and practice (Rootes, 2010). It would be useful to understand how social movement theorists identify themselves and explore the origins and implications of all social movement theoretical identities on research and practice.

### **Usefulness of social movement theories to social movement activists**

Some scholars feel that theories serving a social movement activist audience are lacking (Irons & Tseng, 2019). Others feel that theories developed about social movements should continue to be *of* social movements, leaving it up to the activists to determine their practical relevance (Rootes, 2010). Engaging social movement actors in determining the usefulness of existing social movement theories, including how theories have been useful and under what conditions,

feels like a critical next step, alongside engaging actors in setting new research priorities and designing participatory research. A robust practice of participatory social movement action research could involve developing new social movement theories, interrogating existing theories, translating theory into practice and co-developing practical tools.

### **Discovering social movement concepts of potential value to innovation studies**

Two concepts in the social movement literature – tactical repertoires and political opportunity structure – stood out as potentially relevant to innovation practice and research, respectively.

#### ***Tactical repertoires***

A “tactical repertoire” refers to “the actions and strategies used by collective actors to persuade or coerce authorities to support their claims” (Taylor, 2016). Tilly (2004a) introduced the concept to explain variations in tactics across social movement groups. An “innovation repertoire” could explain variations in innovation approaches across innovation groups. For instance, to health innovation labs that hire people with diverse backgrounds and approaches to inject disparate ideas into innovation processes (LaRusso et al., 2014). Innovation team members could more effectively collaborate given ways to illuminate their respective approaches.

#### ***Political opportunity structure***

Political opportunity structure describes how political opportunities affect social movement emergence and spread (McAdam et al., 1996). An “innovation opportunity structure” could describe how innovations create opportunities for social movements to emerge and spread. Conversely, a “social movement opportunity structure” could describe how social movements create opportunities for innovations to develop and diffuse.

## Summary of research gaps

Leading social movement scholars propose that opportunities for further theoretical development await at the intersection of social movement theories and cognate fields (Della Porta, 2014). Chapters 1 and 2 highlighted relevant theoretical, methodological and practical gaps in the social movement and innovation fields within health. Table 2.5 summarises these gaps which inform the research questions and study design outlined in the next chapter.

**Table 2.5: Relevant research gaps in the social movement, innovation and health literatures**

Gap type	Description
<b>Theoretical</b>	<ul style="list-style-type: none"> <li>• Opportunities for further social movement theory development await at the crossroads of social movements and cognate fields (Della Porta, 2014) such as innovation</li> <li>• Social movements are an important and relatively unexplored sub-theme within social innovation research with very few “concepts or constructs” at this intersection (Agostini et al., 2017)</li> <li>• Social movements could offer theoretical and empirical insights on informal, bottom-up, inclusive innovation approaches</li> <li>• Social movements have not been well-recognised or understood for their ability to develop and diffuse all innovation types or as “sites” of innovative activity</li> <li>• Examining how people build social movements from a people’s perspective could yield new insights about social movements as processes</li> <li>• Greater representation in social movement theorising in terms of gender, race and geography</li> <li>• Health is an underrepresented issue area within social movement research (Mac Sheoin, 2016)</li> </ul>
<b>Methodological</b>	<ul style="list-style-type: none"> <li>• A grounded theory approach combining qualitative methods is an underutilised method within social movement research, only applied in “scattered and implicit” ways (Mattoni, 2014) and needing greater accuracy in its application (Peters, 2014)</li> <li>• Integrating the social movement actor voice into definitional processes</li> </ul>
<b>Practical</b>	<ul style="list-style-type: none"> <li>• Social movement research lacking usefulness to people building and supporting movement organising (Irons &amp; Tseng, 2019)</li> <li>• Health professionals desiring to understand how to build social movements (del Castillo et al., 2016)</li> <li>• Articulating opportunities for shared practice across social movement and innovation processes</li> <li>• Investigating social movements as a form of collective innovation and “humanity-centered design” (Girling &amp; Palaveeva, 2017)</li> </ul>
<b>Trends</b>	<ul style="list-style-type: none"> <li>• Growth in the study of health social movements (Brown &amp; Zavestoski, 2004)</li> <li>• Social movement diffusion as a relatively new research area into diffusion theory (Givan et al., 2010)</li> <li>• Replacing static theories of “connections” with dynamic theories of “connecting” in social movement diffusion processes (Strang &amp; Soule, 1998)</li> <li>• Rising interest in studying social innovation amongst social movement scholars (Mulgan et al., 2007)</li> <li>• Major trends within innovation studies include moving from tangible to intangible innovations and firms to multi-sector collaboratives as central actors (Edwards-Schachter, 2018)</li> <li>• There is a recognised need for further bottom-up and inclusive innovation approaches as existing innovation theories are top-down rather than bottom-up (Lindberg, 2011) or lateral</li> <li>• Informal innovation as the “next broadening of innovation studies concepts” (Cozzens &amp; Sutz, 2014)</li> <li>• Methodological innovations have emerged at the intersection of social movement studies and cognate fields (Della Porta, 2014)</li> </ul>

## Chapter 3: Utilising grounded theory research method

### Introduction

Selecting a methodology is an exciting step in the research journey. An exploratory study at the intersection of two fields – social movements and innovation – required a methodology that would enable crossing disciplines, working flexibly, examining complex social processes (Whiteside et al., 2012) and reflecting on power, privilege and politics issues (Olesen, 2007). These considerations made constructivist grounded theory a fitting choice for this research. This chapter presents the initial research question and set of objectives which set the stage for an inductive qualitative research journey. It then outlines the contested history of grounded theory method, presents a rationale for selecting the constructivist tradition and describes the application of the method within this research.

### Research question, objectives and context

The following question served as an initial point of departure for this research (Charmaz, 2014):

“How do social movements aid innovation development and diffusion?”<sup>17</sup>

As the study progressed, initial findings led me to revise this primary research question to:

“How do people make sense of social movements and innovation?”

This pivot responded to my observation that understanding innovation in relation to social movements requires understanding how people organised into social movements make sense of the innovation and social movement concepts. For the purpose of presenting my empirical findings in an accessible and digestible format, I structured this research around three secondary research questions:

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<sup>17</sup> An equally exciting point of departure would have been, “How does innovation aid social movement development and diffusion” Endogeneity can be an inherent tension within social movement research (Mattoni, 2014).

1. How do people make sense of social movements as a concept?
2. How do people make sense of social movements as experience?
3. How do people make sense of social movements as innovation?

Responding to the primary and secondary research questions sets up this study to:

1. Produce empirical and theoretical insights about how people make sense of social movements as a concept, as experience and as innovation
2. Surface research opportunities at the nascent intersection of social movements and innovation
3. Inform effective social movement and innovation research, practice, policy and education

This research takes place in the United Kingdom, examining UK social movement activity in a health and care context and contextualising extant literature through UK health examples. The UK is home to a long lineage of people organised into social movements for health. This study situates itself within this lineage and simultaneously, the wider societal, political and institutional landscape of social movement activity impacting on health and care. As described in the introduction, this research began two years after the publication of the *NHS Five-Year Forward View* (2014) and its section on “The NHS as a social movement.” Fast forward four years and we find ourselves in the midst of novel, impending and long-standing social issues such as coronavirus, climate change, racism and health inequity.

## Selecting constructivist grounded theory

The exploratory nature of this research and its focus on a “how” question makes it ripe for inductive, qualitative research (Heist, 2012; Merriam, 2009). Qualitative work supports an “open and relatively unstructured research design, avoiding concepts and theories at an early stage” as well as the “generation of new hypotheses” (Silverman, 1993).

Qualitative research has had a significant impact on a wide variety of fields over the past few decades, introducing new theories and shaping “core theoretical constructs” (Bartunek et al., 2006; Gehman et al., 2018). Qualitative research scholars have employed diverse theory-building approaches (Gehman et al., 2018), which draw on diverse definitions of theory

(Gehman et al., 2018; Morse et al., 2009; Sandberg & Alvesson, 2011). This research adopts a grounded theory approach to theory-building rooted in the constructivist tradition.

This section explores the history of grounded theory method, its associated traditions and its application within health research. It then describes the rationale for selecting grounded theory and the constructivist tradition.

### **What is grounded theory?**

Grounded theory is “a qualitative research method that uses a systematic set of procedures to develop an inductively derived theory about a phenomenon” (Strauss & Corbin, 1998).

Grounded refers to both the method and the output, theory grounded in data (Charmaz, 2008). The resulting theory is expressed as “an explanatory scheme comprising a set of concepts related to each other through logical patterns of connectivity” (Birks & Mills, 2011; Heist, 2012) or a “descriptive narrative” about the phenomenon (Strauss & Corbin, 1990).

Intense debates about what constitutes theory in grounded theory research abound, stemming in-part from the contested notion of theory in social science research (Charmaz, 2014). To some scholars, grounded theory produces middle-range theories (Charmaz, 2008; Glaser & Strauss, 1967) where theory reflects the research context (Charmaz, 2014). A middle-range theory starts with an empirical phenomenon and develops abstract statements about it, verifiable through data (Merton, 1968). Other scholars refer to grounded theory as “substantive” or applicable to a specific situation or area, exhibiting “usefulness” and “resonance” (Berterö, 2012; Heist, 2012). Still, others feel that it does not produce “actual theory” (Charmaz, 2014).

A strong grounded theory has an “enduring nature” and “continues to fit, work and remain relevant” with continued cycles of data collection and analysis (Holton, 2007). The seminal grounded theory study *Awareness of Dying* (Glaser & Strauss, 1965), for instance, continues to remain relevant as well as inform dying discourse and service design (Andrews, 2015).



Furthermore, Covan's (1998) work on "care sharing" in retirement communities shows that a grounded theory can evolve to achieve enduring relevance (Holton, 2007).<sup>18</sup>

### **Grounded theory: objectivist, constructivist and critical traditions**

Grounded theory emerged amidst intense debates about the legitimacy of qualitative research and has been central to those debates ever since (Charmaz, 2014). In 1967, sociologists Glaser and Strauss introduced grounded theory in their seminal work *The Discovery of Grounded Theory: Strategies for Qualitative Research*.<sup>19</sup> They developed grounded theory as a method of discovery and used it in a six-year study to examine how awareness of death and dying influenced patient care in hospitals (Glaser & Strauss, 1965, 1968, 1970). Their study (1965) revealed four types of dying awareness – closed, suspected, mutual pretence, open – and examined the impact of them on patients, relatives, nurses and physicians. It became the first published grounded theory with the goal of contributing to more compassionate end-of-life care (Andrews, 2015). After 50 years, the findings continue to shape the dying experience, addressing disclosure issues (Field & Copp, 1999) and placing people at the centre of care (Andrews, 2015; Field, 1996). Over time, grounded theory came to be known as a "breakthrough" in qualitative research, enabling "methodological consensus" amongst qualitative researchers (Berterö, 2012) and representing a "revolutionary message" (Charmaz, 2014) that "testable, relevant and valid theory" could emerge from empirical reality through systematic qualitative analysis (Glaser & Strauss, 1967).

Since 1967, three traditions of grounded theory have emerged – objectivist, constructivist and critical – each with distinct epistemological and methodological considerations.<sup>20</sup> Objectivist or positivist grounded theory treats emerging concepts as variables and researcher as "neutral

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<sup>18</sup> Covan's paper on "care sharing" (1998) modified the (1988) grounded theory using data collected a decade prior (Holton, 2007).

<sup>19</sup> Glaser wanted to codify qualitative research after training with quantitative researchers (Lazarsfeld & Rosenberg, 1955).

<sup>20</sup> It can be challenging to determine whether a particular scholarly perspective on grounded theory relates to a specific tradition (e.g., objectivist, constructivist) or to the method generally. I have done my best to depict all perspectives accurately.

observer and value-free expert." Positivists value "generality" and "objectivity" seeking "explanation" and "prediction" that can be "abstracted" from a research context (Charmaz, 2008). A positivist grounded theory "establishes a relationship between two or more variables" (Abend, 2008) and is well-suited to "why" questions (Atkinson et al., 2003).

In 1990, Strauss and Corbin published *Basics of Qualitative Research*, promoting grounded theory as a "method of verification" rather than a "method of discovery." They advocated applying more rigid rules and procedures to data collection and analysis, stressing "technical procedures" over comparative methods (Berterö, 2012). Glaser fervently rejected their method, arguing that it contradicted the original format in fundamental ways, such as by forcing data into categories and casting off the importance of emergence and comparative methods. Still, Strauss and Corbin's strand spawned a renewed wave of interest in grounded theory and resulted in many new adopters (Charmaz, 2014).

The 1990s saw a growing belief amongst sociologists that theory construction does not occur in isolation of researcher effects on their own processes, including how researchers represent participants, produce data and position their analyses. Researchers such as Charmaz (2014) felt that sociologists were "erasing" these subjective factors, believing that research occurs under "specific conditions – of which we may not be aware, and which may not be of our choosing."

In 1993, Charmaz steered grounded theory away from its positivist origins, proposing constructivist grounded theory and bringing reflexivity and subjectivity into epistemological debates (Charmaz, 2014). In Charmaz's constructivist tradition, research is a "social construction" between researcher and participant set in a particular context. Researchers adopt a reflexive practice, exploring how their perspectives, positions, privileges, practices, values and preconceptions affect their research process and interpretations.<sup>21</sup> Constructivists tends to

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<sup>21</sup> According to Charmaz, initial reactions to constructivist grounded theory split across gender lines (Charmaz, 2000b).

look at “what” and “how” questions,<sup>22</sup> encouraging flexible guidelines rather than “mechanical applications.” Novel constructivist grounded theories include “comparative failure”<sup>23</sup> (Glaser, 1964) and “temporal emotions”<sup>24</sup> (Lois, 2010).

Critical grounded theory adapts the grounded theory applications to a critical realist ontology and epistemology (Belfrage, 2017) and has been utilised to develop theories about leadership (Kempster & Parry, 2011) and mental health (Hense & McFerran, 2016). More generally, scholars have proposed melding grounded theory with numerous approaches such as community-based participatory research (Duckles et al., 2019), participatory action research (Teram, Schachter, & Stalker, 2005), feminism and post-structuralism (Clarke, 2005) and dimensional analysis (Scahtzman, 1991). Recently, grounded theory has been referred to as a “movement” because intense negotiations amongst grounded theory proponents and the research establishment ultimately led to its development and adoption by both quantitative and qualitative researchers (Berterö, 2012; Charmaz, 2014).<sup>25</sup>

Within health research, grounded theory has been referred to as “perhaps one of the most abused phrases in the qualitative health literature” with researchers increasingly utilising grounded theory to conduct “superficial thematic content analysis” (Green & Thorogood, 2009). Yet, proceeding with rigour and attention to the method has yielded grounded theory studies with value beyond, and even contrary to, analogous quantitative studies. For instance, a study of older women with breast cancer led to “new understandings” of the cancer experience, addressing issues such as ageism, “positive collusion” with health professionals and burdens associated with researching older women (Crooks, 2001).

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<sup>22</sup> Through examples, such as Star (1989), Charmaz (2008a) shows how a social constructivist approach employed through grounded theory can also have “theoretical implications” for why questions.

<sup>23</sup> Scientists perceive their own achievements as “comparative failures” when compared to other scientists (Glaser, 1964).

<sup>24</sup> Emotions such as hope, regret and nostalgia arise when moving between past, present and future (Lois, 2010).

<sup>25</sup> It would be interesting to apply social movement theories to the emergence, development and diffusion of grounded theory as a methodological innovation.

## **Rationale for utilising grounded theory and the constructivist tradition**

This study chose grounded theory for its ability to work flexibly and systematically. Grounded theory enables: 1) Inductively exploring a ripe research area, 2) Examining the complexities of social life and social issues, 3) Applying an innovation practitioner lens to social movement studies, and 4) Aiming for transferability of findings to other social movement contexts.

Adopting the constructivist tradition enables the adoption of a reflexive practice to address issues such as power, privilege and politics which are particularly critical aspects to social movement research involving disadvantaged communities (Olesen, 2007).

### *Inductively exploring a ripe research area*

Grounded theory is an inductive research process enabling the exploration of nascent research areas such as the intersection of social movements and innovation. Utilising induction ensures that study findings “emerge out of the data rather than being imposed on them prior to data collection and analysis” (Patton, 1980). Qualitative research methods support a flexible, rigorous process, enabling the relationship between theory and data to be emerging and data collection tools to adapt over time based on study participant voices (Della Porta, 2014).

### *Examining the complexities of social life and social issues*

Social movements and innovation are both complex, social phenomena and thus require an approach that can acknowledge the relational and “situated nature of knowledge” (Pilny, 2015). Constructivist grounded theory is particularly well-suited to studying experiences and social aspects (Charmaz, 2018). Examples include work on “verbal teaching interactions” in the operating room (Roberts et al., 2012) and chronic illness (Charmaz, 2000a).

### *Applying an innovation practitioner lens to social movement studies*

Grounded theory has “subversive potential” enabling researchers to “push pass disciplinary boundaries by broadening the “relevant” literatures” (Martin, 2006). Researchers are advised to “avoid preconceptions” by reading relevant literatures too early on in the research process. Apart from reviewing the grassroots innovation literature, I actively avoided reading innovation theories early on in the research process to avoid biasing what I was seeing in the data.<sup>26</sup>

Meanwhile, social movement studies have trended towards methodological pluralism enabling “a dialogue between different epistemological approaches” with methodological innovations emerging at the intersection of social movement studies and cognate fields (Della Porta, 2014) such as innovation. Utilising grounded theory to investigate this nascent intersection – social movements and innovation – enables transcending the disciplinary boundaries of both fields and increasing the probability of discovering new insights and epistemological approaches.

### *Aiming for transferability of findings to other social movement contexts*

Grounded theory aims for substantive theory that is transferable to other contexts (Heist, 2012). Transferability refers to the applicability of theoretical elements to contexts sharing similar characteristics; generalisability, to applicability in all situations. In this study, we might expect to identify theoretical elements transferable to other UK social movements impacting health, where health concerns are not primary or other geographies. If transferability cannot be validated, finding usefulness and resonance with findings in other contexts should be possible.

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<sup>26</sup> I took an early interest in grassroots innovation and therefore, brought familiarity of that literature to this study.

### *Grounded theory as an underutilised research method within social movement studies*

There is a long tradition of scholars utilising qualitative research methods to study social movements (Eyerman, 1992; Klandermans & Staggenborg, 2002).<sup>27</sup> Grounded theory approaches that combine qualitative methods are a recent field addition, applied only in “scattered and implicit” ways (Mattoni, 2014). This study attempts to join other scholars in ensuring “accuracy in the application and documentation of research methods” (Peters, 2014).

### Embarking on the research journey

Constructivist grounded theorists embrace three tenets: 1) Engage in early analytic work to expedite progress, 2) Pursue hunches, accepting that “a flash of insight or instantaneous realization of analytic connections can happen any time,” and 3) Study empirical events, situations and experiences (Charmaz, 2014). Figure 3.1 depicts the activities of a constructivist grounded theorist which produces the evidence of, not a full-fledged, grounded theory, according to Charmaz. We will reflect on if, when and how the study progresses through them.

**Figure 3.1: Activities of a grounded theorist (Charmaz, 2014)**

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**Grounded theorists engage in the following activities:**

1. Construct data collection and analysis simultaneously as an iterative process. Data might include observations, interactions, or materials about a particular topic or setting.
  2. Analyse actions and processes rather than themes and structure.
  3. Use comparative methods.
  4. Draw on data (e.g., narratives & descriptions) in service of developing new conceptual categories.
  5. Develop inductive abstract analytic categories through systematic data analysis.
  6. Emphasize theory construction rather than description or application of current theories.
  7. Engage in theoretical sampling.
  8. Search for variation in the study categories or process.
  9. Pursue developing a category rather than covering a specific empirical topic.
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<sup>27</sup> This study referenced three social movement methodological overviews while designing this qualitative research study, including *Methodological Practices in Social Movement Research* Della Porta (2014), *Methods of Social Movement Research* (Klandermans & Staggenborg, 2002) and *Studying Social Movements* (Diani & Eyerman, 1992).

Next, we discuss how constructivist grounded theory was applied within this study, including the data collection and analysis methods, relating emerging theory to the literature and writing up the study. Data analysis proceeded in lockstep with data collection to enable the early and rapid identification of emerging themes and analytical understanding (Charmaz, 2014).

### **Data collection methods**

In terms of data collection methods, this study adopted semi-structured interviews with social movement actors, observations of social movement meetings, analysis of supplementary documents related to the social movements of study as well as adopting a reflexive practice. This section justifies the choice of semi-structured interviews, outlines the initial sampling strategies, empirical instruments and sensitising concepts as well as presents the formal and informal data sources. It also acknowledges my previous empirical, practical and theoretical knowledge as well as articulates the value of immersing myself in social movement activity throughout the study duration.

### ***Semi-structured interviews***

Semi-structured interviews placed human accounts at the centre of the analysis, amplifying the voices of people represented by study participants (Blee, 2013; Blee & Taylor, 2002). This method supported understanding the meaning people place on their actions and behaviours, including capturing their “process of interpretation” (Bogdan, 1975), and gathering data about social movements which often face limited coordinating bodies and out-dated member databases (Blee, 2013). I approached semi-structured interviewing as an “interactive product” between me and the participant, embracing the “freedom to talk” and inquire (Noaks & Wincup, 2004). I was not a passive recipient but rather a direct actor in helping participants developing concepts of relevance to their lives (Gubrium & Holstein, 1997). Despite my active role, I was careful not to “hijack” or “monopolise” the interview to assert ideas, interrupt the flow of the narrative, anticipate answers, interrogate views or convert interviewees to specific

opinions (Miller, 2000). There were instances where this proved difficult, such as when participants expressed views about social movements that are contrary to the literature or when they desired for me to confirm their views about social movements. As interviews progressed, I sought ways to address the latter issue more productively such as by stressing the subjective nature of social movements as well as by circling back at the end of an interview to share knowledge that might prove helpful to their understanding or practical activities.

### *Initial sampling strategies*

This research involved a sample of people who identify with or influence social movements related to UK public health issues. Initial study participants were selected based on non-probability, purposive sampling, relying on the researcher's subjective judgement. Thirty people were identified according to the following criteria:<sup>28</sup>

- Located in the United Kingdom
- Aged 18 years or above
- Willing and able to give informed consent for study participation
- Identify with or influence a social movement group related to a UK public health issue as determined by Public Health England (Public Health England, 2020).

Non-probability sampling is particularly well-suited to exploratory research where the goal is to surface empirical opportunities. Purposive sampling enabled the identification of a small sample of people with experience of social movements ("key informants") where the phenomenon of interest was likely to exist or insight could be gained (Ames et al., 2019; Robinson, 2014; Teddlie & Yu, 2007).<sup>29</sup> Variation was sought from people across social movements and public health issues as well as across diverse sectors in health systems and local communities. The sample was not intended to be representative of the entire population of people associating with UK social movements related to UK public health issues. The study

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<sup>28</sup> Researchers can develop initial sampling criteria for people, cases, or immersion in a setting or situation (Charmaz, 2014).

<sup>29</sup> If the phenomenon does not exist in a small sample, it is unlikely to exist elsewhere, assuming samples are chosen wisely (Ames et al., 2019; Robinson, 2014; Teddlie & Yu, 2007).



also employed snowball sampling, asking participants to recommend people they felt could offer insight into the research questions.<sup>30</sup> Snowball sampling is a particularly popular method within social movement research because social movements can lack membership directories and involve people who are difficult to reach or do not wish to be publicly identified. Actors can often identify peers who are able speak to particular topics.

### *Empirical instruments*

An initial set of interview questions served as a “guide” for conducting semi-structured interviews. Questions focused on understanding how study participants identify with social movements, the story of their involvement in social movements and how they define social movements and innovation as well as identifying innovations associated with social movements and determining whether they see social movements as playing a role in innovation. The questions included:

1. What social movements do you identify with?<sup>31</sup>
2. Tell me the story of your involvement in those social movements.
3. How would you define a social movement?
4. How would you define innovation?
5. Tell me about 1-2 innovations that people within your movement are developing?
6. Do you feel the movement is supporting the development of these innovations? If so, how?
7. If you were me, what question(s) would you ask the interviewee? Anything else to share?

These guiding questions were tested with research supervisor, Dr. Yasser Bhatti, as well as two people who identify with the dementia care and smoking cessation movements. I was advised to shorten the interview guide as well as re-word a few questions to speak the language of participants. I also informally drew insights on the structure and wording of the guide from 41 interviews I previously conducted at Nesta with social movement actors related to HIV/AIDs, rare disease, global mental health and disability rights. This experience offered background

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<sup>30</sup> Snowball sampling enabled me to reach an additional four people of whom I interviewed two.

<sup>31</sup> In a study of the CAM movement, Goldner (1999) asked each interviewee whether they define their participation as activism, a practice I took inspiration from in this study by asking people what social movements they identify with.

context for interpreting the formal data sources as well as an understanding of how to conduct interviews with activists. As interviewing progressed, new topics and nuances emerged, leading me to update and refine the protocol guide.

### *Sensitising concepts*

This study utilised “sensitising concepts” to guide initial data collection (Blumer, 1954). Sensitising concepts suggest “directions along which to look” not “prescriptions of what to see” (Blumer, 1954; Bowen, 2006). This latter point is particularly important because some qualitative research traditions encourage the application of pre-existing knowledge or theories to data collection and analysis. Initial sensitising concepts were focused on how people identify with, perceive and approach building social movements as well as on identifying innovations emerging through social movement activity. As data collection and analysis proceeded, new sensitising concepts emerged which coincided with emerging conceptual categories, including the social movement experience, social lineage and a contested relationship with innovation.

### *Formal and informal data sources*

Formal data sources for this study included 21 semi-structured interviews with “social movement actors” lasting a total of 1,405 minutes (23.41 hours), observation notes from four social movement meetings to which the researcher was invited by study participants as well as over 100 supporting documents.<sup>32</sup> Tables 3.1 and 3.2 provide an overview of study participant interviews and meeting observations, respectively. Supporting documents included 10 recommended by study participants, 10 discovered in the interview transcripts and over 80 discovered via online searches related to formal data sources. Documents covered a range of

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<sup>32</sup> I chose to refer to participants as “social movement actors” to acknowledge the diverse ways in which they describe acting in and on social movements.

materials, including meeting agendas, conference materials, organisational brochures, presentation slides, video recordings, grant proposals, academic articles, reports and websites.

**Table 3.1: Overview of study participants**

	Date	Location	Social movement	Duration	Nickname	Sector	UK Region
1	10-Oct-17	Skype	Vaping movement	71 min	Magnus	Public health	Greater London
2	17-Oct-17	London	Smoking cessation	47 min	Agnes	Public health	Greater London
3	17-Oct-17	London	Vaping movement	74 min	Tannhaus	Public health	Greater London
4	17-Oct-17	London	Global mental health	88 min	Egon	Academia	Greater London
5	30-Oct-17	London	Global mental health	84 min	Ulrich	Entrepreneur	South East
6	01-Nov-17	Skype	FundaMentalSDG	27 min	Noah	Academia	Greater London
7	01-Nov-17	Skype	MGMH	93 min	Adam	Health and care	South East
8	09-Nov-17	Skype	Global mental health	81 min	Martha	Service user	South East
9	13-Nov-17	Skype	MGMH	68 min	Katarina	Service user	South West
10	15-Nov-17	London	FundaMentalSDG	24 min	Torben	Academia	Greater London
11	23-Nov-17	London	Early Intervention	101 min	Jonas	Academia	West Midlands
12	06-Dec-18	Manchester	Ears Against Loneliness	62 min	Peter	Academia	North West
13	06-Dec-18	Manchester	Early Intervention	128 min	Doris	Public health	North West
14	07-Dec-18	Skype	Smoking cessation	72 min	Regina	Health and care	East Midlands
15	10-Dec-18	Manchester	Ears Against Loneliness	17 min	Claudia	Consulting	North West
16	10-Dec-18	Manchester	Social Care Future	105 min	Mikkel	Health and care	North West
17	14-Dec-18	Manchester	HASM	44 min	Silja	Consulting	North West
18	14-Dec-18	Manchester	HASM	44 min	Bartosz	Consulting	North West
19	14-Dec-18	Manchester	TIDE	101 min	Greta	Health and care	North West
20	15-Jan-19	Leeds	Strength-based practice	10 min	Winden	Health and care	Yorkshire & Humber
21	26-Jul-19	London	The women's movement	64 min	Hannah	Activism	Greater London

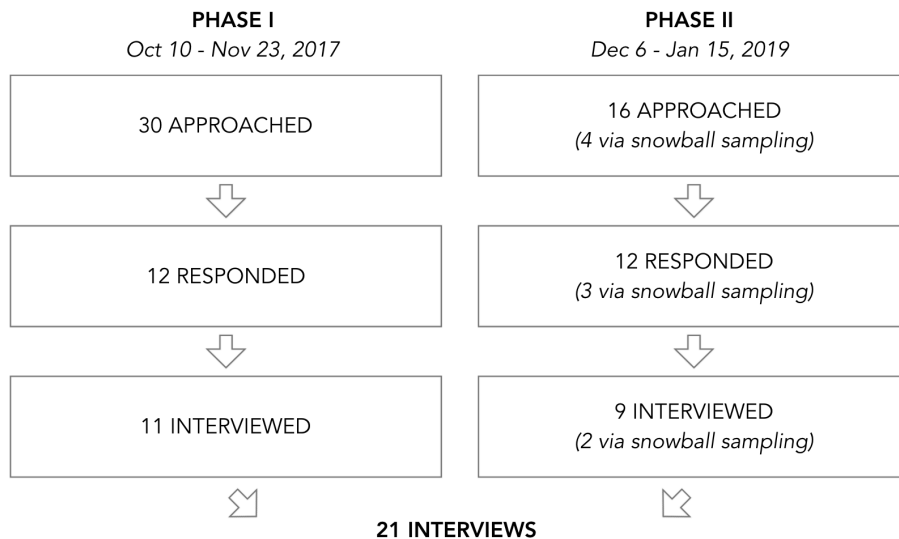
**Table 3.2: Social movement meeting observations**

	Date	Location	Data type	Description	Duration
1	21-Mar-17	People's History Museum Manchester, UK	Observation	Health as a Social Movement	420 min
2	31-Oct-17	The Guildhall, London, UK	Observation	Understanding Vaping: Engaging Disadvantaged Groups, hosted by London Drug and Alcohol Policy Forum, Global Forum on Nicotine	180 min
3	17-Nov-17	The Royal Society of Medicine, London, UK	Observation	The E-Cigarette Summit: Science, Regulation & Public Health	420 min
4	15-Jan-19	The Carriageworks, Leeds, UK	Observation	Strengths to Strengths	240 min

Interviews were conducted in two phases: from Oct 10 – Nov 23, 2017 (Phase I) and from Dec 6 – Jan 15, 2019 (Phase II) as depicted in Figure 3.2. In Phase I, 30 potential study participants were contacted; of the 12 respondents, 11 were interviewed with the remaining person responding outside of the ethical period for Phase I. The 11 participants represented 16 social

movement groups. At this point, I paused the data collection effort to ensure sufficient time to analyse all data prior to commencing Phase II. In Phase II, 16 people were contacted; of the 12 respondents, 10 were interviewed with the remaining three responding outside of the ethical period for Phase II. The 10 interviews represented 6 additional social movement groups. Recruitment for Phase II was based on access and theoretical sampling which will be discussed later in this chapter.

The 21 interviews afforded a copious amount of data which was then analysed and triangulated against supplementary documents as well as observation notes. Of the 22 social movement groups, 9 groups had at least two voices represented. Non-respondents would have offered greater volume rather than diversity of participants representing each social movement group, as well as greater representation from all English regions and four home countries.



**Figure 3.2: Interview data collection process**

### *Immersing in social movements*

As discussed in Chapter 1, researchers desiring to understand the empirical realities they plan to study can choose to gain experience prior to commencing formal investigation (Della Porta, 2014). Instead of delaying research activities to gain experience, I got involved with social

movements during this study as a participant and supporter.<sup>33</sup> Opportunities to engage with social movements arose through my personal involvement and professional roles at Imperial and Nesta. Immersive work in social movements led a deeper practical understanding of how people approach starting and growing social movements as well as how organisations approach supporting them. It also meant that study participants saw me as one of their own. We could relate to each other’s experiences and in some cases, we developed a relationship which meant I felt comfortable asking clarifying follow-up questions on a few occasions. Finally, it helped me better understand how social movement research could be useful to social movement actors as well as identify the implications for practice, policy and education in Chapter 8. Tables 3.3 and 3.4 present the social movement meetings and workshops that I participated in and facilitated, respectively, in a capacity outside of the scope of this study. As informal data sources, they had bearing on how I understood and interpreted the formal data.

**Table 3.3: Social movement meeting participation**

Date	Location	Description	Duration
Mar 2017	Manchester	<i>How social movements spread</i> hosted by the RSA	90 min
Apr 2017	Newcastle	<i>How social movements spread</i> hosted by the RSA	180 min
May 2017	London	<i>How social movements spread</i> hosted by the RSA	60 min
Nov 16, 2017	Blackburn	Adverse Child Experiences (ACEs) Strategic Coordinating Group as part of Together a Healthier Future Transformation Programme: The Accountable Health and Care Partnership for Pennine Lancashire	60 min
Feb 2018	Johannesburg	The Movement for Global Mental Health: Leaving No One Behind	90 min
Feb 8, 2018	London	All Children Thrive (ACT) UK meeting	60 min
Jul 5, 2018	London	All Children Thrive (ACT) UK meeting	60 min
Nov 20, 2018	London	All Children Thrive (ACT) UK meeting	60 min
Dec 14, 2018	London	All Children Thrive (ACT) UK meeting	60 min
Nov 14, 2018	Manchester	Social Care Future (#socialcarefuture)	60 min
Aug 16, 2020; Aug 18, 2020	Manchester	Peterloo <i>From the Crowd &amp; March for Democracy</i>	60 min

<sup>33</sup> My desire to gain direct experience with social movements stems from my design thinking training where the first step in the design thinking process is to empathise with the people you are intending to design for.

**Table 3.4: Social movement workshops**

Date	Location	Description	Duration
May 2, 2018	The Brewery, London, UK	The Future of People-Powered Health Conference	90 min
Sept 27-29, 2017	Rochester, Minnesota	Mayo Clinic Transform, "Closing the Gap between People and Health" conference session on, "Forces which cannot be ignore"	90 min
Sept 21, 2018	Oxford Saïd Business School	Oxford Hong Kong Jockey Club Innovation Workshop	180 min
Jan 2017, 2019	Imperial College School of Medicine	Imperial College Master's in Public Health, Global Health Innovation Module	60 min
Sept 14, 2017	Royal Northern College of Music, Manchester, UK	NHS R&D North West <i>Let's Talk Research 4 Conference – Building Community</i>	60 min
Sept 20, 2018	Royal Holloway, Egham, UK	CoCreate Leadership 20/20 conference	90 min

### *The social movements*

All potential study participants were approached due to their perceived identification or involvement with a particular social movement group. Participants often chose to talk about multiple groups in the interview, resulting in them referring to 40 "social movement groups" in total.<sup>34</sup> Table 3.5 depicts all groups alongside the number of study participants referring to, and associating with, each group. The 22 italicised groups are those that participants discussed beyond a single mention and make up the raw study data as well as feature in the data analysis and empirical findings of Chapters 4, 5 and 6. In Chapter 5 ("Identifying"), we examine how participants describe their association with these groups. Appendix III lists an additional 44 social movement groups compiled throughout the study for a total of 84 groups across the UK.

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<sup>34</sup> We cannot assume that study participants talked about all of the social movements they are involved with.

**Table 3.5: Groups that study participants refer to as “social movements” in the interviews**

	<b>Group name</b>	<b># of people referring</b>	<b># of people associating</b>
1	<i>Global mental health</i>	4	4
2	<i>The Movement for Global Mental Health (MGMH)</i>	4	4
3	<i>Smoking cessation</i>	4	4
4	<i>Health as a Social Movement</i>	4	4
5	<i>Ears Against Loneliness</i>	3	3
6	<i>Call to Action: Movement of Movements in Greater Manchester</i>	3	3
7	<i>Vaping Movement</i>	3	3
8	<i>Social Care Future (#socialcarefuture)</i>	3	3
9	<i>FundaMentalSDG</i>	2	2
10	<i>Early Intervention in Psychosis (EIP)</i>	2	2
11	<i>Time to Change (TTC)</i>	2	2
12	<i>HIV/AIDS Movement</i>	1	1
13	<i>Together in dementia everyday (tide)</i>	1	1
14	<i>Zero Suicide</i>	1	1
15	<i>Action on Smoking and Health (ASH)</i>	1	1
16	<i>Lesbian and Gay Social Movements</i>	1	1
17	<i>Sexual politics, anti-sexual violence, child sexual abuse movements</i>	1	1
18	<i>CBM (originally, Christian Blind Mission)<sup>35</sup></i>	1	1
19	<i>First 1001 Days Movement</i>	1	1
20	<i>Disability Rights Movement</i>	1	1
21	<i>Gay Liberation Movement</i>	1	1
22	<i>Relational practice movement</i>	1	1
23	<i>Rare Disease</i>	1	1
24	<i>Climate Change</i>	1	1
25	<i>NHS Change Day</i>	1	1
26	<i>Suicide prevention</i>	1	1
27	<i>The feminist movement</i>	1	1
28	<i>Living Well Dying Well</i>	1	1
29	<i>Campaign to End Loneliness</i>	1	1
30	<i>Adverse Childhood Experiences (ACEs) movement</i>	1	0
31	<i>Greenpeace</i>	1	0
32	<i>Friends of the Earth</i>	1	0
33	<i>Environmental movement</i>	1	0
34	<i>Freedom Organisation for the Right to Enjoy Smoking Tobacco</i>	1	0
35	<i>Autism rights movement</i>	1	0
36	<i>Anti-service movement</i>	1	0
37	<i>Anti-medicalisation</i>	1	0
38	<i>Anti-tobacco movement</i>	1	0
39	<i>National Movement in Zimbabwe</i>	1	0
40	<i>Treatment Action Campaign</i>	1	0

<sup>35</sup> In 2007, Christian Blind Mission changed its name to CBM to broaden the remit of the organisation (CBM, 2020).

All 22 social movement groups address a disease, health condition, health system issue, social determinant of health or health equity issue. They can be plotted along two continuums at their point of emergence, depicted in Figure 3.3, exhibiting diversity across four quadrants. The first continuum represents group leadership, with “community-led” at one end and “profession-led” at the other. For instance, the Early Intervention in Psychosis (EIP) movement is primarily led by scientific and medical professionals whereas the vaping movement is led by people. Along the continuum are groups such as #socialcarefuture composed of professionals and people with lived experience. The other continuum represents group origin, with “in-system” at one end and “out-of-system” at the other. For instance, HASM emerged from NHS England whereas the vaping movement emerged outside public health systems. These groups were plotted at their point of emergence and therefore, that their leadership, as well as their presence outside and inside of health systems, could change over time.

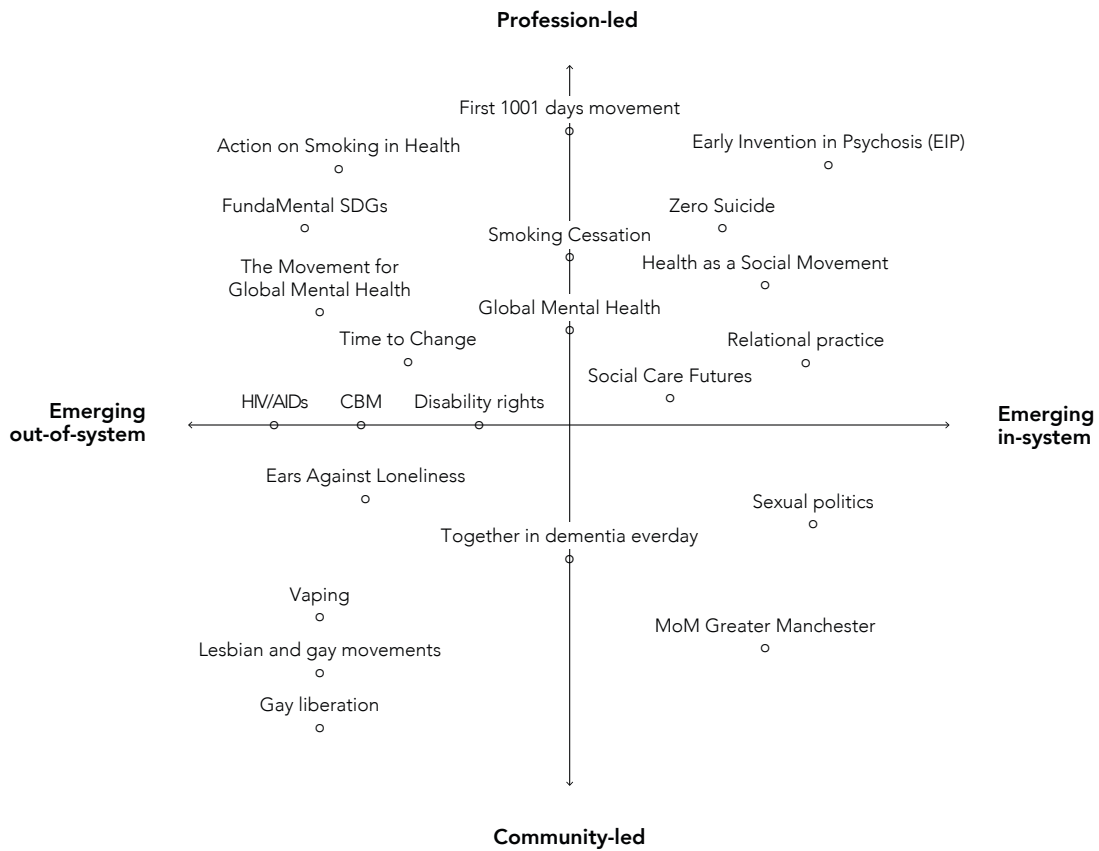


Figure 3.3: Origin and leadership of social movement groups



Appendix IV provides a description of a subset of the 22 social movement groups which study participants chose to talk about in the interviews. The descriptions serve as background context for the findings; they do not represent case studies. Information from the study participants provides the scaffolding for these descriptions; statements lacking citations should be assumed to come from them. Academic articles, formal reports, meeting notes, conference materials, organisational brochures and websites provided factual details and additional nuance and narratives. Great care was taken to maintain study participant views while also highlighting the contested issues, diverse interests and historical baggage at the heart of their groups. There are inherent challenges with writing historical accounts of social movement groups that can represent diverse, and often competing, interests, ideologies and perspectives as well as more and less powerful voices. I ask the reader to keep these truths in mind. A lively debate within social movement research exists around whether researchers can be truly “value free.” In response, I take inspiration from C. Wright Mills: “I have tried to be objective. I do not claim to be detached” (Mills, 1962). Yet, the viewpoints described are not my own.

### *Theoretical sampling*

It is important to distinguish between initial and theoretical sampling in grounded theory research (Charmaz, 2014). Initial sampling offers a “point of departure” whereas theoretical sampling guides further data collection along specific conceptual lines and involves gathering data to advance emerging theoretical ideas (Charmaz, 2014). According to Charmaz (2014), theoretical sampling distinguishes grounded theory from other types of qualitative studies.<sup>36</sup>

The initial sample of social movements actors was kept deliberately wide to enable discovery and variation in the findings. Phase I data collection surfaced people who had participated in long-standing social movements such as HIV/AIDs, gay liberation, smoking cessation, sexual

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<sup>36</sup> Theoretical sampling differs from traditional sampling that happens around research questions, population distributions, negative cases or until no new data emerges (Charmaz, 2014).

politics, disability rights as well as in social movement groups that have achieved some victories such as vaping, Time to Change (TTC) and FundaMentalSDG. Phase II data collection involved pursuing voices that could add depth along specific conceptual line, including:

1. People growing a social movement from infancy, including members of Social Care Future (#socialcarefuture), Ears Against Loneliness, relational practice and HASM.
2. People involved in social movements and innovation activities such as developing a new model for EIP and integrating e-cigarettes into smoking cessation services.

Reaching the first theoretical sample was made possible due to my involvement with Nesta Health Lab. In 2017, I was asked to deliver a learning session with HASM participants in Manchester, Newcastle and London on *How Social Movements Spread*. Through these sessions, I encountered people starting social movements who asked me to attend their social movement meetings.<sup>37</sup> Reaching the second theoretical sample was made possible through recommendations from study participants from Phase I as well as through social movement meetings to which I was invited by participants.

Theoretical sampling starts after an initial sampling and data collection effort when “too much still remains assumed, unknown, or questionable,” with the additional data functioning to refine or surface detail and complexity around existing categories in order to produce concepts that “stand on firm, not shaky, ground” (Charmaz, 2014). Theoretical sampling stops when a researcher has “gained an adequate understanding of the dimensions and properties of the concepts... that have emerged” (Charmaz, 2014). A reoccurring error is for researchers claiming to be employing grounded theory approaches to collect additional data to saturate empirical themes rather than theoretical categories (Charmaz, 2014). As we will discuss in Chapter 8, this study moved through two formal rounds of theoretical saturation. Additional rounds of theoretical saturation are suggested in the future research agenda in Chapter 9.

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<sup>37</sup> It felt impossible to escape an expert identity that comes with studying social movements and working on behalf of national organisations. My conversations were inevitably influenced by how other people reacted to this identity.

## Data analysis methods

Grounded theorists employ a range of data analysis methods to capture empirical insights and raise the analytic strength of emerging concepts. This study employed initial and focused coding,<sup>38</sup> memo-writing, constant comparison, and triangulation, each of which is described in this section. Data collection proceeded in lockstep with data analysis, with initial coding of new interviews happening alongside deeper analysis of previously collected data. Appendix V illustrates the coding process which involved multiple levels of coding, including initial and focused coding.

### *Initial coding*

Initial coding involved reviewing interview transcripts and generating line-by-line codes describing the actions and meanings of study participants. Special attention was paid to utilising in vivo codes to maintain study participant voices and gerunds to maintain a focus on what is happening (Charmaz, 2018). Utilising in vivo codes is particularly important to social movements where issues of power and representation are paramount. I traversed each interview transcript at least three times – first, to conduct line-by-line coding by hand; second, to read the interview holistically and more abstractly, such as to uncover deeper meanings, read between the lines or spot contradictions between what participants say and describe doing (Charmaz, 2018); third, to refine and rephrase codes to ensure accuracy. Initial coding was done by hand on printed interview transcripts. Phase 1 interviews produced over 2,000 line-by-line codes. These codes were then refined on tiny 2.5" x 1.75" post-it notes which were then copied<sup>39</sup> and placed onto a blank notebook in preparation for focused coding.

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<sup>38</sup> Coding involves labelling a piece of data with a short phrase representing its meaning (Charmaz, 2018).

<sup>39</sup> The line-by-line codes were copied so as to maintain a copy of them in the printed interview transcripts. To maintain the association between line-by-line codes and the interviews from which they emerged, numbers were placed at the bottom of each post-it note corresponding to its respective interview.

### *Focused coding*

Focused coding involves raising initial codes to higher and higher levels of abstraction (Charmaz, 2014). Within this study, we use the terms “codes, clusters, categories and concepts” to refer to ever higher levels of data abstraction. One of the first clusters to emerge was “characteristics of social movements” which then, got merged into a category, “people describing social movements” with other clusters on “social movement types” and “what social movements are not.” This cluster was later raised to a concept, “people making sense of social movements” to enumerate the ways in which study participants make sense of social movements as a concept. This new concept incorporated all previous codes focused on how people describe the term while at the same time, expanded it to include codes such as “comparing social movements to other social change forms” and “utilising metaphors.”

To conduct focused coding, I arranged and re-arranged the tiny post-its in the notebook into higher level “clusters.” Once I was happy with the framing of these clusters, I then moved them onto large post-it pads with each pad representing a category. Along the way, I used yellow post-its to document questions I had about my data. Finally, I entered all line-by-line codes, clusters, categories and concepts into the NVivo 12 software programme where all data is now stored and where I continued with the coding process. Once I decided on a final coding structure, I re-read all interview transcript for instances of all supporting categories, clusters and line-by-line codes for each concept.

The latter example illustrates that the ordering, re-ordering, naming and renaming of conceptual concepts is a feature of grounded theory as an iterative process. The process started as a bottom-up process but at times, required taking a top-down approach to organising the clusters and codes underneath each category and concept. As a researcher, I had to make decisions about which conceptual directions to follow, which to leave behind and how to focus my time and energy. NVivo facilitated documenting the conceptual choices. For instance, “social movement lineage” is a concept that emerged to describe how participants

describe experiencing a “social movement upbringing” as well as “inheriting a worldview” about how communities act and change the world. This concept is still salient in the findings but due to limited time within the context of a PhD programme, I chose to pursue other concepts such as the social movement experience and park social movement lineage.

### **Memo-writing**

Memo-writing began in the early stages of data collection and proceeded throughout. It functioned to capture interpretive and reflexive thoughts as well as raise the abstraction of concepts (Charmaz, 2014; Glaser, 1998). Memos were written in NVivo 12 to associate them with codes and track their evolution (Charmaz, 2018). One of the memos is shown in Table 3.6.

**Table 3.6: Example of a memo on “movement multiplicity”**

Study participant narratives often feature multiple social movements. So far, the data reveals two patterns to describe this “movement multiplicity.”

Serial social movement participation refers to a person who gets involved in social movements in succession. It was not uncommon for people to get recruited to work on other social movements given their social movement experience (e.g., a person working on the ground level of a child sexual abuse movement was later recruited to work on an asthma movement). This finding might suggest that a person’s experience with social movements is perceived as valuable and transferrable to other social movement contexts.

Parallel social movement participation refers to a person who works on multiple social movements simultaneously (e.g., a person who gets involved in HIV/AIDs alongside gay liberation). How do study participants prioritise their involvement in multiple social movements and allocate their time and resources across them? The study data suggests the presence of a “pecking order,” one that is perhaps not always explicitly stated.

As illustrated, writing can surface new conceptual ideas such as “movement multiplicity.” It can also lead us to ask new questions such as how do participants prioritize their involvement in multiple social movements? In this way, writing can illuminate and deepen concepts.

### *Constant comparison*

Constant comparison involves comparing sections of the study data. The method functions to uncover latent ideas and can be utilised at every stage of analytic development. It can involve comparing codes with codes, codes with categories, categories with categories, and eventually, categories with scholarly literatures (Charmaz, 2014). Beyond codes and concepts, additional dimensions along which to conduct comparisons revealed themselves, such as:

1. Social issues (e.g., mental health issues)
2. Social movement stage (e.g., early-stage)
3. Social movement actions (e.g., mobilising people)
4. Study participant attributes (e.g., exhibiting serial social movement behaviour)
5. Innovation types (e.g., products)
6. Innovation activities (e.g., brainstorming ideas)

I developed conceptual maps for the first 11 interviews (Phase 1) to aid comparisons across interviews and emerging concepts. Appendix VI depicts two sample conceptual maps, one from a single interview and another about how study participants refer to social movements.

### *Triangulation*

Social movement scholars advocate using triangulation or utilising multiple data sources to investigate concepts arising in the study data (Della Porta & Keating, 2008; Tarrow, 2004).<sup>40</sup> Throughout data collection and analysis, emerging concepts from the interviews were triangulated against other interview transcripts, observation notes from social movement meetings and supplementary documents related to social movement activity. Supplementary documents were most often used to plug gaps in participant narratives and elaborate on discussed topics. For instance, a book chapter about the EIP movement provided a rich narrative of the movement's emergence and spread. In some cases, a supplementary

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<sup>40</sup> Triangulation can reveal new conceptual dimensions, reducing "the distance between method and ontology" and enabling a more holistic picture of a phenomena; it can also validate findings for theory-building (Della Porta & Keating, 2008; Tarrow, 2004).

document brought a new concept to the forefront, prompting me to revisit the study data and explore if it had conceptual weight. For instance, an article talked about the EIP movement developing an “optimistic mindset” (McGorry et al., 2008; McGorry, 2015). Triangulating with interview data resulted in reframing this code to “diffusing an optimistic mindset for reform.” Similarly, investigating the Mental Health Innovations Network (MHIN) revealed that it was not simply a “database of innovations,” as described by a study participant, but also a platform for developing innovations to promote mental health and diffusing innovations globally.

### *Adopting a reflexive practice*

In a constructivist grounded theory approach, the researcher can bring to bear previous empirical and theoretical knowledge related to the subject of interest (Charmaz, 2014). Adopting a reflexive practice as to how and when this knowledge enters the study is at its central heart. This reflexive practice enabled viewing social movement data through an innovation practitioner lens, the results of which are presented in Chapter 6, as well as reflecting on issues of power, privilege and politics. It also enabled reflecting on how my researcher lens shaped, and was shaped by, emerging empirical findings, discussed in Chapter 8. Chapter 1 provided an overview of the researcher innovation lens, captured in Figure 3.4.

**Figure 3.4: Researcher innovation lens**

<b>Identities</b>	Strategist, designer, engineer, activist
<b>Innovation repertoire</b>	Human-centered design, design thinking, systems innovation, social innovation
<b>Beliefs</b>	Designer as social change agent, innovation as social change mechanism
<b>Formal training</b>	Design thinking from Stanford Hasso Plattner Institute of Design (aka “d.school”)
<b>Purpose</b>	Human and planetary health
<b>Practical experience</b>	Designing innovations in low-income and high-income settings; Teaching and facilitating design thinking; Communicating the value of design and the trade-offs of innovation approaches; Conceptualising new innovation projects and funding programmes; Growing innovation labs within university and think-tank settings; Developing innovation methodologies and practical tools; Informing health delivery and policy related to social movements; Devising social movement support programmes and investment strategies.

Immersing in social movements throughout this study also impacted on my researcher lens. It instilled greater confidence in what the data was showing me because some findings resembled scenarios I was seeing in real life. On numerous occasions, immersive work foregrounded issues I might not have immediately spotted in the data such as study participant deliberations about what makes a social movement “real” as we will see in Chapter 4. Finally, immersive work enabled me to contextualise research findings within social movements and the broader UK social and political landscape. I hope the findings in the forthcoming empirical chapters are presented in more useful ways as a result of my immersive work. I am committed to continually learning how to present research findings in ways that are useful to activists, professionals and policymakers.

### **Relating emerging theory to the literature**

Relating an emerging grounded theory to the literature has become a “red herring” for some scholars, especially those utilising grounded theory within their own disciplines (Martin, 2006). Grounded theorists are advised to wait to “tunnel down” into relevant literatures until well into the data analysis when emerging concepts have become clear (Holton, 2006). Early exposure to literatures can “contaminate” the analysis and “divert attention from the methodology’s subversive potential... to push pass disciplinary boundaries” (Martin, 2006). At Imperial, writing a literature review prior to starting data collection was a necessary “marker of progress” (Urquhart, 2017) but risked early exposure to relevant literatures.<sup>41</sup> I decided to produce a “non-committal literature review” (Urquhart & Fernandez, 2006) on theories of social movement emergence, diffusion and impact, allowing the study data to determine their eventual relevance but also, providing a theoretical background to research on how social movements aid innovation. During Phase I of data collection and analysis, the experience

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<sup>41</sup> On occasion, I was asked what theories I would apply to the study data but resisted the temptation to adopt specific theories.



literature emerged as relevant to study findings. Traversing experiences theories commenced only after the initial conceptual categories of the social movement experience were identified. In this way, inductive coding happened without knowledge of those theories.

### **Writing up the grounded theory study**

Doctoral students utilising grounded theory often find it challenging to structure a PhD write-up which often represents a snapshot of a “moving product” (Charmaz, 2018). I decided to gain inspiration from constructivist grounded theory peers who had structured their empirical chapters around three conceptual properties or categories. This write-up is structured around three conceptual categories in the chronological order in which they became important.

1. How do people make sense of social movements as a concept? (Chapter 4)
2. How do people make sense of social movements as experience? (Chapter 5)
3. How do people make sense of social movements as innovation? (Chapter 6)

Landing on a thesis structure felt prolonged, materialising only towards the tail end of data collection and analysis. Feeling the pressure to write intervened with following through on labour-intensive data analysis processes. Every potential thesis structure felt premature as the research journey unfolded. Trusting the process was necessary, but admittedly nerve-wracking, once the decision had been made to tunnel down the constructivist grounded theory route.

### **Quality assurance and ethics**

This section covers the ethical considerations relevant to this study, including informant recruitment and consent, obtaining access to observe conferences, data security and dissemination, vulnerable populations as well as the sensitive issues social movements cover. Appendix VI presents the ethical approval letter from the Imperial College Research Ethics Committee.

### *Informant recruitment and consent*

All potential participants were formally invited to the study by email. Potential participant emails were obtained through an online search of publicly available information or from a recommendation by a study participant in the case of snowball sampling during Phase II. The email described the purpose of the study, the benefits to participation and provided the participant information and consent forms. Participation was voluntary with no monetary benefit associated with participation. Prior to commencing each interview, the researcher sought and obtained informed consent. Interviews were expected to last approximately 60 minutes and were recorded. At the start of each interview, the researcher explained how the findings would be used, that all information would be treated with strict confidence (e.g., informant identity would not be passed to a third party or connected with answers), and that informants had the right to withdraw at any stage. Interviews were transcribed, with all personally identifiable information removed, keeping the informant list separate from the data. All interview data, notes and recordings were stored on password and firewall protected Imperial College computers accessible only by the researcher. Interviews took place at a location of the participant's choosing or over Skype, posing no specific risk to study participants or the researcher beyond day-to-day activities.

### *Obtaining access to observe conferences*

To gain permission to observe conferences, the host organization was required to read the participant information sheet and sign an agreement form. Conference attendees desiring further details about the research were provided with a participant information sheet.

### *Data security and dissemination*

The findings have been analysed and incorporated into this PhD study and could be utilised for future publications for relevant audiences. This intent was clearly explained to all respondents.

### *Vulnerable populations*

The study does not involve vulnerable populations, people in health contexts or people in a patient or service user capacity. If a person had been construed as vulnerable, they would not have been included in the study. As a participant of the ACEs movement, some might perceive me to fall into this vulnerable category. I did not perceive this to be the case with any of the study participants. However, through my participation in multiple movements related to mental health, I have come to more deeply understand the importance in social movement contexts of providing safe spaces for conversations which may lead to people feeling vulnerable and recognising when signposting people to further support may be necessary.

### *The sensitive issues social movements cover*

Social movements often revolve around sensitive issues. In the interviews, study participants were not asked about their direct experiences of health and care. In accordance with the level of clearance I attained from the University ethics board, participants were only asked to talk about their experiences with social movement groups, not their lived experiences of health.

## Summary

This chapter acquainted us with the study design and methods. It presented the contested origin of grounded theory amidst the growing legitimacy of qualitative inquiry. It outlined a rationale for the use of constructivist grounded theory and how the approach is particularly well-suited to studying social movements. The study was set in motion with initial interviews that ultimately led to an emerging and iterative journey of data collection and analysis. The next three chapters are reflective of that journey and present the study findings.

SECTION II:

# Empirical Findings

## Chapter 4: How people make sense of social movements as a concept

### Introduction

“What is a social movement?” I hear this question time and time again in social movement meetings. Yet, as we learned in Chapter 2, there is no single definition of a social movement (Tilly, 2004b; see also Karl-Dieter, 2009) and social movements are socially constructed phenomena (Stammers, 1999). Therefore, understanding what social movements are requires investigating what people think they are within a given context. This chapter responds to the secondary research question, “How do people make sense of social movements as a concept?” Investigating *how* people make sense of social movements through the rich narratives of study participants also helps us understand *what* people think they are.

### Sensemaking by the study participants

Study participants make sense of social movements in diverse ways – by becoming familiar with social movements, utilising metaphors as well as characterising, deliberating on, relating to and valuing social movements. Table 4.1 organises findings into a data structure with three levels of abstraction – clusters, categories and concept. All levels of abstraction retain the words of study participants to maintain their voices in the analysis and presentation of study findings. Clusters, categories and concept are also phrased as gerunds, when possible, to maintain a focus on actions and what is happening (Charmaz, 2018). In the case of “utilising metaphors,” “characterising” and “valuing,” clusters represent line-by-line codes and categories, the first level abstraction. In the case of “becoming familiar with,” “deliberating on” and “relating to,” clusters represent the first level of abstraction.

**Table 4.1: Data structure for how people make sense of social movements as a concept**

Concept	Categories	Clusters
Making sense of social movements as a concept	Becoming familiar with social movements	Social movement awareness
		Social movement understanding
		Social movement experience
	Utilising metaphors	"Kindling a flame"
		"Seed"
		"Sailing craft"
		"Nucleus"
		"Amoeba-like flowing"
		"Constellation of activities"
		"Brand"
		"March of the oppressed"
		"Swelling"
		"A lot of little fiefdoms"
	"Tribes"	
	Characterising social movements	"Driven by values"
		"Emerging"
		"Bottom-up"
		"Dynamic"
		"Antagonistic"
		"Inclusive"
		"A mindset"
		"Peer-to-peer"
		"Go beyond traditional boundaries"
		"Political"
	"Aspirational"	
	Deliberating on social movements	Organisations as social movements
		Profession-led social movements
		Funded programmes as movements
		Indicating a social movement status
		Using the term, "social movement"
		Identifying "real" social movements
	Relating to other social movements	Drawing "inspiration" from other social movements
		Actively "learning" from other social movements
		Benchmarking against other social movements
		Recognising similarities between social movements
	Valuing social movements	Purpose and self-fulfilment
		Identity formation and transformation
"Making life exciting"		
Recruiting resources to an issue		
Putting an issue on the agenda		
Creating spaces for "unscripted conversation"		
Working on "contaminating" issues		
Pressuring persistently		
"Wide-scale norms changing"		
Serving as a status symbol		
Social movement as the solution		

## Becoming familiar with social movements

Through their narratives, participants implicitly revealed three continuums along which to describe their familiarity level with social movements: awareness, understanding and experience.

### *Social movement awareness*

Some participants see social movements as the backdrop to their personal and professional lives. For instance, "Magnus" feels he had a "social movement upbringing:"

I was brought up on... social movements... from a kid doing voluntary work... some of it... self-organised... like me and my brother and my sister... stuff we decided to do... other stuff was linked to more formal community organisations that maybe our parents were associated with... St. Vincent de Paul was a big thing in our community... we were involved in organising the youth wing... so, community involvement... steeped in it from the start... just a big thing that my extended family did and that transferred in my early twenties to sexual politics and then HIV/AIDs.

Social movements were a way of life for Magnus and his family. This way of life continued into his adulthood, influencing his later involvement in movements such as HIV/AIDs. Looking back, "Adam" says that "most of my working life has been about social movements." He says that his experience working for a national campaigning organisation "shaped my thinking about how much the culture and ethos within the movement influences it."

Other participants were not used to thinking in terms of social movements. "Claudia" said, "I probably never thought in terms of social movements... I thought in terms of campaigns... activism... politics... challenge to systems... social justice programs." "Torben" only recently became aware of social movements, despite having worked with two social movement groups. He says, "The descriptor has only sort of dawned in my consciousness relatively recently." "Greta" describes the moment when "social movements" entered her awareness.

As a second-year student, I got a couple of students together... prior to email... we... got... quite a number of the hospitals across England... wrote to them... to really shine a light on why people were staying in hospital for longer than they needed to... to think about how we do things differently... that was my first ever time being asked to go on the radio... people thought I was mad... I remember raising quite a lot of money... about £60/70,000... what is it?... it is about injustice... about righting something... seeing something where there's a need and then thinking, "Okay, what can we do about it... together, as opposed to a single voice?"... if somebody said to me 30 years ago, "You were involved in a social movement," I would not have even identified as that... until I started to read the Nesta stuff... which was long after we developed [our social movement group]... for me... reading the research actually fitted with what we were doing, as opposed to me fitting the research... it was a real revelation, and it was really inspiring because I'm thinking, "I didn't know that's what we called it."

This awareness helped "Greta" finally understand what she had been doing. "Doris" shares that "stuff that I've been doing over the years probably could be defined as relating to social movement activity."

### *Social movement understanding*

Some participants revealed their uncertainty about what social movements are through their choice of words, doubtful facial expressions or actions such as changing the subject when asked to describe a social movement. "Claudia" feels that an understanding of "social movements probably isn't well developed culturally... it probably is by academics but less so by people." "Winden" feels that what a social movement does is far more important than understanding what it is.

We can call it what we want but it's all about how do we intervene? How do we do things with people to change their lives? I'm involved in a children's social movement... how can we revolutionize the life of the child?... What we call it, I'm not that interested. It's what we do. It's the value. It is all about the value.

Yet, still others feel that it can be practically important to understand what social movements are, which we will look at more deeply in Chapter 7.



### ***Social movement experience***

Many participants use their “social movement experience” (“Claudia”) to make sense of them. “Torben” drew out an understanding of social movements from his experiences, “I wouldn’t claim that I’m a knowledgeable expert about social movements, except that I’m probably a part of some... so, I can give you 1-2 examples and then try and draw out what it means more generally.” Chapter 5 is dedicated to understanding social movement experience.

### **Utilising metaphors**

Participants utilise a variety of metaphors to make sense of social movements such as kindling a flame, seeds, a sailing craft, a nucleus, amoeba-like flowing, constellations of activities, a brand, a march of the oppressed, a lot of little fiefdoms and tribes.

### ***Kindling a flame***

To “Claudia,” starting a social movement is like “kindling a flame... once it gets going, you never know how far and wide it will spread... and you do not have control over it.” It could spread like wildfire. “Jonas” advises “be careful what you wish for... it may take you in directions that you’ve never ever conceived.”

### ***Seeds***

To “Jonas,” social movements are like seeds that spring up when people become emotionally engaged in an issue.

If you appeal through a narrative, you tell a story, which engages people through their heart so that they become emotionally connected... they think about themselves in that circumstance or they think about the issues... the thing is... you can only go so far with that because you do have to combine this twin chariot... of head and heart... initially, you might drive with heart in order to appeal to values, but you do have to back it up

with head... otherwise it'll just fizzle. It's a bit like a seed that springs up... in order for it to be sustained, it's also got to be evidence-based so, you've got to ride both.

In early intervention, we started off with a narrative... we had some research... and... practical evidence. One of the colleagues I worked with... we... reconfigured his service as a demonstrator to show people it was possible to do it in the NHS so when we were talking about a new vision, we were able to say, "Come and look at it, come and see it, talk to families, talk to people, talk to staff." It was not some sort of aspirational thing; we also showed a very practical model of it.

According to "Jonas," nurturing social movements requires appealing both emotionally and logically to people through narratives and evidence, respectively.

### *Sailing craft*

"Jonas," an EIP movement member, shares a guiding principle for social movements: "If you want to build a ship, don't drum up the men and women to gather wood, divide the work, and give orders. Instead, teach them to yearn for the vast and endless sea."<sup>42</sup> This yearning and "commitment to change became not an option but an imperative, and by doing so strengthened commitment to overcome uncertainty and difficulties" (Shiers & Smith, 2014).

Just as a sailboat in the middle of a storm has no option but to weather the choppy waves, people in a social crisis have no option but to weather the intense resistance to solving it. Dr. Roberts refers to three complementary vectors representing "the winds that filled the sails to drive the craft forward" and saw these vectors – policy, research and practice – as critical to the spread and survival of the EIP movement (Shiers & Smith, 2014).

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<sup>42</sup> This quote originates from French writer, poet and aviator, Antoine de Saint-Exupéry (1900-1944).

### *Nucleus*

“Torben” believes that a social movement is like “a nucleus designed to motivate and inspire and accelerate change and engagement... it’s a point of recruitment, a point of um congregation... of people who want to join in, um contribute.” Important cellular functions include motivating, inspiring, congregating, and coordinating existing social movement members as well as engaging people to join and contribute.

### *Amoeba-like flowing*

According to “Torben,” social movements have a “polymorphic” quality.

That’s likely to be another aspect of a social movement... that there are preferably, non-antagonistic elements, amoeba-like flowing in an evolving way, which at particular times and for particular purposes interact and support each other’s work... sometimes there are particular separate tasks... sometimes they come together for bigger aims.

These amoeba-like flowing elements, such as people and organisations, can spontaneously organise or disband when coordination offers little benefit. Acknowledging “preferable” aspects of social movements suggests that there are unpreferable aspects, such as antagonism.

### *Constellation of activities*

“Torben” compares the field of global mental health to a “constellation of activities” sharing that, “The reason I’d refer to this in the same breath as a social movement is that there are now 100s of people around the world who are working together in various sort of constellations of activities essentially pursuing the... idea of better mental health in the world.” There are perhaps recognisable patterns in the relationships between people and organisations, or “stars,” pursuing a common vision. These recognisable patterns will be discussed in Chapter 7.

## **Brand**

Social movements are like “brands” that people subscribe to. People are proud to “associate” with a social movement so long as it does not constrain or compete with their activities.

It’s now 10 years in, we’ve [TTC] shown moderate reduction in stigma and discrimination across England over that period... there are now hundreds of groups all across the country who have contributed variously. They have the shared title... because it’s seen as a brand that they’d like to subscribe to which has been a facilitatory phrasing or framing, not one that’s seen to be overly centrally controlled or divisive. So, it’s got to be flexible enough to allow people to do local activities... while feeling proud of being linked to the main vehicle... without it being one that’s sort of overly constraining or at all competitive or antagonistic to what people want to do locally.

A brand consists of visuals and messages functioning together to achieve specific aims such as spreading a vision, building credibility, communicating values and attracting customers with similar values (Rosner & Bean, 2014).<sup>43</sup> The data reveals social movements also utilising a variety of visuals and messages, including symbols, narratives, a “shared title” and “facilitatory phrasing or framing” as “Torben” refers to.

## **March of the oppressed**

Freedom Organisation for the Right to Enjoy Smoking Tobacco (FOREST) describes itself as the “voice and friend of the smoker” (FOREST, 2020) and has been identified as an “astroturf front group,” or fake grassroots group, created and funded by the tobacco industry (Brotchie, 2005; Cho et al., 2011; Smith & Malone, 2006).<sup>44</sup> “Regina” thinks FOREST wrongly perceives heavy smokers as part of a “march for the oppressed.”

I think organisations like FOREST would like to think that smokers belong to a social movement, a march of the oppressed sort of thing, but I don’t think they do. I think

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<sup>43</sup> Brand assessment tools could assist social movements in assessing brand strength or resonance with members and influencers.

<sup>44</sup> This research looks at the impact of astroturf organisations in a global warming context, finding that they threaten the credibility of grassroots movements, successfully influence public opinion and promote business interests as well as raise ethical concerns.

most of them – certainly the ones I have talked to... wish they had never started... they are a bit embarrassed about their habit... they are expecting to quit within the next few months or years... they don't feel a particular solidarity with all the other mugs that are going outside the bar smoking.

“Regina” contrasts FOREST with vaping as a social movement, suggesting that the “march of the oppressed” metaphor is only representative of a subset of vapers. “There are segments of the vaping community... who feel utterly oppressed,” she explains, “I think it has a lot to do with... Brexit... people that I watch on social media, the vaping lot, definitely want to be out of Europe and voted to leave simply because of the TPD [Tobacco Products Directive].” Other vapers identify with saving lives, smoking cleanly or are happy “doing their own thing.”

### *Swelling*

Participants held differing views about whether smoking cessation is a social movement. For instance, “Regina” did not feel that it has that “kind of swelling,” suggesting that a social issue becomes a social movement when there is growing intensity of activity around it.

### *A lot of little fiefdoms*

“Regina” goes on to share another reason why smoking cessation is not a social movement:

There are a lot of little fiefdoms that do it all their own way. There is no sense of unity. They are supposed to all work to the same principle... when people try and convince somebody else to do it their way... they are not particularly keen on listening... it is people working in silos... bound by what their commissioner thinks they have got to do.

Mental health movements face a similar situation where “There’s a lot going on... in very small bits here and there... lots of people are doing the work. Sometimes, they’re connected. Oftentimes, people who work in the same area from the same country... are not even aligned. Everyone is basically doing, more or less, their own thing” (“Noah”). Members of these groups

struggle to unify around a common goal, partly due to the wide range of mental health conditions they represent.

### *Tribes*

Some social movements appeal to different “tribes” of people simultaneously, as “Mikkel” describes:

I think we’ve got an increasing number [of people] ... who are saying, “I’ve got to be in charge of my own life” and are looking for the best ideas on how to do that... and peers to associate with... there’s a whole bunch of... tribes... that they’ll be attracted to... and think, “Yeah, it’s kind of like that.”

A unifying goal can be deliberately broad to attract a high number of people who are yearning for a different way of doing things. This topic relates to social movements adopting “converging goals” which will be discussed in Chapter 5.

### **Characterising social movements**

Participants also assign characteristics to social movements, including that they are driven by values, emerging, bottom-up, dynamic, antagonistic, inclusive, peer-to-peer, boundary-spanning, political and aspirational.

### *Driven by values*

To “Claudia,” social movements are about “how people work together who have shared values.” She contrasts that way of working with “being a programme manager, you come to work, and you get paid.” With social movement work, “I don’t think it’s the kind of thing where you say right, that funding has now ended, and that project’s now done... I’m moving onto something else now... because it’s the nature of who you are as a person.”

“Jonas” contrasts “driven by values” with “change driven by fear.”

The NHS typically tries to achieve change through top-down, performance-managed deliverables where people are told to do things... and people jump... but the moment that target or whatever is met, the NHS takes its eye off the ball and people stop delivering. Top-down is... someone telling... it's driven by fear... it's guiltful people doing it. A social movement is much more driven by values. (“Jonas”)

People driven by their values are more likely to sustain their commitment to change as well.

### **Emerging**

“A social movement is an emerging thing,” according to “Claudia.” As we saw in Chapter 2, social movements “emerge” in response to diverse factors. Participants similarly describe social movements as “spontaneous,” “unpredictable,” “organic” and “unforced.” The emerging nature of social movements affords them the agility to freely and rapidly explore new opportunities, a competency that formal organisations often lack. “Claudia” elaborates that:

You can't control [a social movement] ... be careful what you wish for... it may take you in directions that you've never ever conceived... I think that's one of the things that often people get edgy about because actually they want to control it... [The NHS is] a very control-driven organisation.

### **Bottom-up**

Social movements arising from the “bottom-up” emerge from the interests of people such as vapers fighting for the use of e-cigarettes in public places and people with HIV/AIDs advocating for reduced stigma and discrimination. Some participants associate bottom-up movements with “mass movements.” According to “Agnes,” “Tobacco control... is... not a mass movement, it's not like... Greenpeace or Friends of the Earth... which was much more bottom-up.” Some participants also reveal a preference for movements that “indigenously” emerge from people as opposed to movements that are started and led by professionals.

Participants contrast social movements with top-down change. For instance, Helen Bevan, NHS England Chief Transformation Officer, advocates utilising social movement thinking as an alternate, bottom-up approach to top-down change in the NHS (Bibby et al., 2009).

### *Dynamic*

Participants also note the “flexible” and “polymorphic” nature of social movements in that they can assume a variety of formats across time. “Claudia” recognises the social movement as “a floaty out there thing that waxes and wanes and grows and dies and comes back in different formats.” This finding is consistent with the “natural history” of a social movement (Chapter 2) which recognised that the “rise” and “decline” of social movements are two characteristics that all social movements share (Mauss, 1975). “Claudia” also refers to “waning” and “dying” like Mauss’ concepts of “dormancy” and “death.”

### *Antagonistic*

Most social movements are “antagonistic to the orthodoxy” (“Jonas”). The “orthodoxy” is represented broadly in the data as an organisation, a health or societal system, an incumbent regime, social norms, culture, discourse, lifestyles or personal behaviour.

Very often social movements arise outside of the orthodoxy... by its very nature you’re challenging the orthodoxy... it’s the level degree that the orthodoxy can tolerate... certainly in my experience in Early Intervention in Psychosis, we had to have two places – to be in the orthodoxy... to have the credibility within the orthodoxy... but also to have places outside of the orthodoxy to challenge the orthodoxy... health... is an area that doesn’t tolerate challenge no matter what is said in terms of um whistleblowing... it very much preserves the status quo... that’s one of the challenges with health... most social movements are... no matter how peaceful... very antagonistic to the orthodoxy because it’s challenging the way things are done... how they’re done... the leadership.



In the data, some participants look to other social movements for tactical innovations,<sup>45</sup> a topic covered in, "Drawing 'inspiration' from other social movements."

### *Inclusive*

According to "Jonas," the EIP movement was very inclusive:

We never said no to anyone. If someone came arbitrarily, we just said, "Come along." We weren't exclusive saying oh... we can only have the regional leads. Sometimes... I'd say we're going onto a... meeting and someone would say, "How do you get to that?" I'd say, "Well, come along and see." It had an informality to it... very inclusive.

Social movements can face challenges with inclusion. "Agnes" feels that tobacco control has failed to include people who benefit from nicotine usage. Instead, it chose to disempower and shame smokers, alienating them from efforts to address smoking as a public health issue. "If we're to... eliminate smoking," she says, "we need to have a broader social movement which will include those who smoke and those who see nicotine as necessary... that's how we'll get the behaviour change, we'll get those people not to feel isolated."

### *A mindset*

"Bartosz" refers to a social movement "as a mindset." This characteristic needs further investigation but some of the mindsets participants note are: embracing humour, comfort with ambiguity, accepting failure, following your intuition, adapting to the context, not letting hurdles stop you as well as being committed, entrepreneurial, opportunistic, resourceful, willing to let go and willing to get your hands dirty.

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<sup>45</sup> Tactical innovation refers to the adoption of a previously unused tactic, resurrection of an old tactic or the novel recombination of existing tactics (Wang & Soule, 2016).

### *Peer-to-peer*

“Social movements are peer-to-peer” (“Jonas”). In the early days of the vaping movement, vapers and vape shops were replacing smoking cessation services with “vapers... running an AIDs model with peer educators and outreach workers” (“Tannhus”). “Claudia” also says that, “[Social movements] depend on the people... these are relationship-based things.”

Successful social movements, it’s all about relationships... well, everything is about relationships, isn’t it ultimately?... but particularly, social movements, because they’re not hierarchical... they’re not top-down... that’s not how they work... they’re a myriad of individuals and groups and organisations... trying to find some way to pull in a similar direction around some topic... and you know... that is relational. (“Claudia”)

Within the context of the #socialcarefuture movement, “There are an increasing number of families, disabled people... who are saying, “I’ve got to be in charge of my own life... and are looking for the best ideas on how to do that... they’re looking for peers to associate with” (“Mikkel”).

### *Go beyond traditional boundaries*

Social movements “go beyond traditional boundaries” (“Torben”), bringing people together around a common mission. By attracting people across boundaries, social movements can assume many faces which enabled the EIP movement group to speak the language of, and influence, a range of important people and groups.

Two of us were psychologists, so we could appeal to psychology... one was a psychiatrist... so she could talk peer-to-peer to medics... one was a family member but also a GP so could talk to families but also to family care... if it was a psychology or CBT conference... we’d front me or [Matt]. If it was about a family member or a user, we’d front [Yasser] or we’d front in pairs... so it meant that we appealed... we had many faces... so even if say users and carers who might say they are professionals they couldn’t say that because we had a number of users and carers involved... who were family members of young people with psychosis... and we had young people with

psychosis working with us... people like [Hutan] who is now... in the orthodoxy working as an employee in Manchester. ("Jonas")

### *Political*

"I think they're [social movements] almost always political," says "Noah," as they simultaneously can unite and divide people. Social movements can represent politically charged issues. When "Agnes" was advocating for smoke-free laws across the country, a government official told her, "Don't bother with the evidence... we all know that second-hand smoke is not good for you but show me the votes." "Tannhaus" also talks about how symbols, slogans and social media help perpetuate the political nature of social movements:

Some [people] are very hostile... to the World Health Organisation because it is still opposed to e-cigarettes... you see vapers who've got their little... gravatar... a WHO with little skull and cross bones on it... superimposed... and they're quite right because WHO has not come off well in this... so [the vapers are] kind of politically aware but not physically organized.

### *Aspirational*

According to "Regina," in social movements, "There are no terms of reference. There is no constitution. It is for people what they want it to be." Social movements are aspirational, representing social containers people fill with their hopes for a better world. Understanding social movements is about making sense of how people perceive them and what people aspire for them to be or do. How people perceive social movements is also linked with their beliefs about what change is needed and how to create it.

### **Deliberating on social movements**

Through their narratives, participants implicitly revealed a number of deliberations about social movements, including whether social movements can be organisations, profession-led, funded programmes or "real." Each deliberation represents a source of conceptual confusion.

### *Organisations and social movements*

Participants reveal diverse perspectives about how organisations relate to social movements. To some, organisations can be social movements and a social movement, can be "... an organisation of people running around a common problem" ("Egon"). According to "Egon," the field of global mental health is made up of smaller movements, some of which are organisations.

What we have in mental health... is a series of small movements... some are organisations, some are national, some are user-led, some are mainly practitioners... and... there's old ones. The World Federation for Mental Health was founded in 1948... a... cross-disciplinary campaigning organisation... it's got a much bigger membership... than the Movement for Global Mental Health... it's also not a really a big mass movement.

Some participants believe that social movements only embrace non-traditional forms of organising. "Egon" feels that the MGMH is not yet a movement because "it's still largely driven by... structures that... ordinary organisations... getting a bit of money to support the secretariat and all of that..."

As we saw in Chapter 1, some scholars believe that the NHS was founded by a social movement. Furthermore, "The NHS is viewed by the British public as a social movement with a pioneering philosophy – one which makes a global contribution, conceptualizing the moral right to access free healthcare" (Moskovitz & Garcia-Lorenzo, 2016). In 2014, NHS England Chief Executive Simon Stevens described the NHS as, "part of what it means to be British" (Muir, 2014), a feature of British identity.

### *Profession-led social movements*

Can professionals lead social movements? "Agnes" feels that smoking cessation is not a social movement because it is not led by smokers but rather scientific and medical professionals. As a professional in global mental health, "Egon" felt that it would be inappropriate for him to

assume a leadership role within a social movement.<sup>46</sup> “Academics cannot lead a movement,” he said. The data reveals two perspectives about this belief. First, that there are “no rules” (“Regina”) in social movements such as about who, and who cannot, start and lead social movements. Second, that the boundary between professionals and people with lived experience is not clear-cut. Many of the medical and scientific professionals who started EIP and TTC movements, for instance, are also people with lived experience.

The Time to Change social movement is supported by a team of 60 people. Many of us have our own personal experience of mental health problems. We're all passionate about challenging the negative attitudes that impact the lives of those experiencing mental health problems. (Time To Change, 2020)

There is a longstanding power dynamic between professionals and people with lived experience in the health field, as discussed in Chapter 1. Framing TTC staff as “supporters,” shifts the power dynamic between TTC staff and non-staff, creating space for more people to join, belong and lead change. If TTC staff were framed as “leaders,” non-staff contributors might feel the need to seek staff permission to act, inadvertently undermining their agency.

### *Funded programmes as movements*

TTC started as a funded programme and evolved into supporters referring to it as a social movement. As “Torben” describes:

Initially we didn't call it or think of it as a social movement... it became clear quite quickly that for this to have a major, national-level impact, it would require many more people to be active than those... paid by the programme. It had to excite the imagination of people who were... ready, willing and able to contribute but that didn't realise that there was a core vehicle that they were being recruited around... where they also felt they could do something, small or large, to help build momentum for the overall impetus of the thing.

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<sup>46</sup> I have observed resource holders discounting professional social movement narratives: “That is interesting, but professionals can't start social movements.”

The reason I would refer to this as a social movement, even though the core is a funded programme of work, is because it's deliberately designed to go much wider and to have momentum much longer than the core funding applies. It's a sort of a nucleus designed to motivate and to inspire and accelerate change and engagement by many more people than those, if you like, that are funded directly.

This passage suggests that funded programmes can be "contenders for social movements" in the sense that they can be designed to become social movements in order to achieve wider influence and longevity as was the case for TTC.

### *Indicating a social movement status*

When does a group become a "social movement?" Participants draw a distinction between the stage and status of a social movement – that a social movement can be evolving and momentarily stopped. "Noah" feels that FundaMentalSDG has "been a social movement" but lost its status once it reached its aim to get mental health indicators adopted into the Sustainable Development Goals (SDGs).

I'm not sure what the time limits for a movement are. It has stopped... FundaMentalSDG would probably have the potential to become a movement but the policy aims... asks that we had were quite specified in the SDGs [Sustainable Development Goals] and hence, limited in continuation. We are at the moment discussing with the steering group: where and how we might focus... the indicators are a relevant issue but are more or less decided now... there's no further movement possible at the moment.

The data indicates other reasons why a movement would lose its social movement status, such as losing leaders or critical resources, as well as why it would regain its status, such as by receiving an influx of resources or facing a political opportunity. "Agnes" seemed to believe that a social issue or group can take on "social movement status" in one country but not another: "Tobacco control... not just in this country, but in most countries, is a... movement." The data suggests that social movements can move in and out of "social movement status" and that social movement status is socially situated and contextually dependent.

### *Using the term, "social movement"*

Participants shared their hesitations around using the term, "social movement." First, as "Mikkel" shares, "Part of my reluctance to use the word 'movement' has been a perceived arrogance... who do you think you are talking about having a movement when there's, like, a couple of dozen people actively involved?" Secondly, "Mikkel" desires creating an initiative that will, "...be resilient to damp squibs and failures... which inevitably will happen..." He explains, "... that's one of the reasons why I didn't want to use the word 'movement,' because... I thought it would provoke attack... it hasn't so far, to any significant extent." He specifically fears an attack from the political left who might say that social movements are, "... just a new fashionable way of presenting something." When HASM started, some health professionals were also afraid that the programme would be criticised for promoting social movements as "... community development wrapped up in new words" (del Castillo et al., 2016). Finally, not using the term can stem from a lack of understanding. "I don't know that we can actually claim that we are a movement... I think that's partly to do with me not knowing enough about it to say that's what it is." Even "using social movement principles," without explicitly using the term, "social movement," can create issues, according to "Jonas," who also says, "I think you tread a line... you really have to think about what you're doing."

People will say lots of things... because it looks nice or because it's trendy or because they think it will be helpful or they realise the limits of top-down... but what they don't realise is that again, social movements are peer-to-peer... it's an emerging thing... so you can't control it... be careful what you wish for... it may take you in directions that you've never ever conceived... that's one of the things that often people get edgy about...

### *Identifying "real" social movements*

In the section on "Indicating a social movement status," "Noah" says, "I'm not sure what the time limits for a movement are." Does a group have to exist for a period of time to earn social movement status? For the MGMH to become a "real" social movement, some participants felt

that the leadership must shift from professionals to service users. According to “Egon,” “[The MGMH] is only partially successful... it’s not got a massive membership... it’s not driven by millions of members yet.”

Perhaps a group can be a social movement in some senses but not others. Speaking about Action on Smoking and Health (ASH), “Agnes” says, “Our work is for doctors... what that means is, our heritage, where we come from, is that medical and scientific background... most of the people on their board are either doctors or researchers... so, we’re a social movement in that sense.” Furthermore, acknowledging “real” social movements suggests that “fake” social movements also exist. FOREST, for example, is an “astroturf front group,” created and funded by the tobacco industry (Brotchie, 2005; Cho et al., 2011; Smith & Malone, 2006).

Participants classify social movements according to whether they are “real” or fake, successful or unsuccessful,<sup>47</sup> formal or informal, person- or profession-led, bottom-up or top-down, early- or late-stage, new or old, and active or inactive. Additional empirical work is needed to surface additional ways people classify social movements and to understand the meaning behind these classifications.

### **Relating to other social movements**

“What can we learn from other movements such as HIV?” is another question I often hear in social movement meetings.<sup>48</sup> In the study data, people were drawing inspiration, and actively learning, from other social movements. They were also benchmarking their social movements against others and referencing their past social movement experiences.

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<sup>47</sup> Characteristics for successful social movements from the data included credible, enduring and mass. Yet, the study data illuminates scenarios where mass membership is not required to achieve success. For instance, the EIP movement targeted professionals with the power to change psychosis care.

<sup>48</sup> I heard someone ask this question at the E-Cigarette Summit in 2017.



### *Drawing “inspiration” from other social movements*

In 2008, MGMH members believed that the HIV/AIDS movement represented what was yet to happen with mental health. It took “inspiration from HIV movements that have successfully mobilised significant global resources for the care of people living with HIV/AIDS in LAMI [low and middle income] countries” (Patel et al., 2011) and actively learned from HIV/AIDS activists. MGMH members invited global HIV campaigners to the Global Mental Health Summit in 2009 as keynote speakers (Patel et al., 2011) and examined the success of initiatives such as Treatment Action Campaign (Patel & Prince, 2010).<sup>49</sup> By 2011, MGMH members were speaking about critical success factors of the HIV/AIDS movement.

Critical to the success of the global HIV campaign were its specific and clear calls to action, its grounding in the evidence of effective treatments and human rights, and its united front of people living with HIV/AIDS, health practitioners, policymakers and researchers sharing a common platform. The Movement seeks to emulate these characteristics, offering a platform where members from diverse backgrounds stand together as partners to promote the shared vision of closing the treatment gap. (Patel et al., 2011)

Similarly, in the early 1980s, “The HIV movement was kind of really powerfully informed by uh the... gay liberation movement” (“Magnus”). In 1987, AIDS Coalition to Unleash Power (ACT UP) activists stormed Wall Street, chaining themselves to fences with the slogan “silence = death” (Solem, 2019). According to Solem, their inspiration for this “tenacious” action stemmed from the Stonewall riots of 1969 which began after a trans woman of colour hurled an object at New York City police during a violent raid of Stonewall Inn.<sup>50</sup> Underground gay liberation groups seized the opportunity to act, unifying people to participate in

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<sup>49</sup> Treatment Action Campaign is an HIV/AIDS campaign originating in developing countries and referred to as one of the “most effective AIDS groups” and “smartest activist groups” worldwide (Masiya, 2015).

<sup>50</sup> Reports vary as to whether the object was a brick, high heel, shot glass or bag (Solem, 2019).

demonstrations resulting in many arrests and hospitalisations.<sup>51</sup> The riots charted a path to LGBTQ rights.

Stonewall's legacy pumps through the veins of the work of ACT UP and other movements that built a path toward acceptance, support and liberation for people living with HIV/AIDS. "Stonewall gave LGBTQ people a sense of the tremendous power they have as a collective and how focused anger can be used as a tool for change," reflected Kim Hunt, executive director of Chicago-based Pride Action Tank, a project of the AIDS Foundation of Chicago. "Stonewall let people know that institutions could be toppled, at least for a moment. The act of physical rebellion, camp, performance as activism, speaking truth to power were all incorporated in the direct-action strategies of ACT UP. (Solem, 2019)

As a predecessor to the HIV/AIDS movement, Stonewall contributed activists or "foot soldiers," an understanding of LGBTQ and "bold radicalism" as a gay rights approach focused on root causes such as poverty, racism and homophobia (Solem, 2019). As Solem wrote: "We had a larger and stronger movement in place to be able to respond to this horror within, and to fight the ignorance and neglect from the outside." Many other movements contributed to HIV/AIDS as well, including the women's health and civil rights movements.

Stonewall contributed... to an American playbook for effectively protesting for human rights, which movements for equity, visibility and inclusion continue to contribute to today. It also created an emotional model for coming out publicly with very personal, very stigmatized news. Author and activist John-Manuel Andriote noted, "The first gay men to go public about having AIDS acted from a place of gay pride and power that came after Stonewall... They likened 'coming out' about having HIV/AIDS to their experience of coming out as gay."

### *Benchmarking against other social movements*

Numerous participants referred to the victories of other social movements. "Egon," a global mental health member, praised the autism rights movement for its ability to secure "hundreds

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<sup>51</sup> The participants represented an "intersectional collective of queer Black and Latinx folks, transgender and gender-nonconforming people" (Solem, 2019).

of millions of research money. We haven't been able to do that at all in other areas of mental health." He also painted a picture of what non-communicable disease professionals were able to achieve by "getting organised."

They used to be like us. They used to sit in university commons doing their lab work on parasites... then, they got organized and identified the 17 top diseases... they excited Bill Gates. They got all of the drug companies together and said, if you produce these drugs, I will pay for them to be distributed across Africa. Let's eradicate polio... let's get rid of leprosy and malaria... people got excited about it and now, it's a massive industry... a tiny fraction of the burden of disease.

"Egon" is both inspired by and benchmarking mental health against the non-communicable disease community, indicating that the clusters in this category are not mutually exclusive.

### *Referencing past social movement experiences*

Finally, participants were referencing their past social movement experiences to make sense of their current movement activities. "Magnus" compared his current experience working with vapers to one in his past when working on HIV/AIDs in the 1980s and 90s.

It seems really pretty familiar... very similar process... the community works in similar ways... there's this core of people with whom the identity is central... whether it's... gay urban male in London or... a vaper identity... both groups are really quite atypical of the wider communities they seek to represent... some would have very little to do with that... it doesn't work for them, it's just not the thing they do, not the thing they are... some are kind of apologetic and somewhat ashamed... for whom it's a secret vice... so those parallels in the way the community is... organized is interesting... the time I spend with NNA [New Nicotine Alliance]... I'm perfectly upfront about it... it's like being back in the GMFA [Gay Men Fighting AIDs] office circa 1989.

Participants also spotted similar actions. "Magnus" reflects, "Not since the 1990s when... lots of gay men used to go to conferences and bring their... research back and share them in various community outlets have I seen the kind of engagement that we're seeing with vapers who are very keen to advise on studies."

## Valuing social movements<sup>52</sup>

Participants value social movements for offering a sense of purpose and fulfilment, forming and transforming identities, making life exciting, recruiting resources to an issue, learning through experience, putting an issue on the map, creating spaces for “unscripted conversation,” working on “contaminating” issues, pressuring persistently, contributing to wide-scale norms change and serving as a “status” symbol. Sometimes, a social movement is even the solution to a social health issue. This section looks at how participants explicitly value social movements.

### *Purpose and fulfilment*

Many participants expressed feeling a sense of purpose and fulfilment while participating in social movements such as this TTC campaigner:

Time to Change has changed me. It gave me a clear focus and added impetus to use my skills and experience, and perhaps more importantly my passion, to encourage real change in society. It has given me hope that finally here is a dedicated national campaign to eradicate the scourge of the stigma and discrimination of mental health. (Time to Change, 2012b)

HIV/AIDs gave people the opportunity to contribute their unused skills, according to “Magnus.” He said, “People had their sort of drive and commitment... it was often stuff they weren’t able to do in their... paid workplace... we had people working for advertising agencies... professional researchers... publishers who were producing our materials for us for free.”

### *Forming and transforming identities*

People switching from smoking to vaping have pre-existing notions of what it means to be a smoker. People are used to feeling “rotten,” according to “Tannhaus,” when they try to stop

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<sup>52</sup> It is important to distinguish this section from the section in Chapter on “Evaluating.” “Valuing” is about how people value social movements while “Evaluating” is about how people assess the impact of social movement activity.

smoking because they've been stigmatised and disempowered; some people "feel bad about themselves for doing it." According to "Tannhaus," changing a behaviour involves transforming how you identify with that behaviour and how you see yourself in relation to it.

Most of the people I've worked with... social activists... I call them... "niconistas" ... people who have a strong liking for nicotine whose identity now revolves around being a vaper... that's important in transformation... getting people who are addicted... to become an ex-alcoholic or member of AA... identity transformation is very important to behaviour change... they're hard-lined vapers and they see themselves as vapers.

The vaping movement is forming a new vaper identity, including transforming public perceptions of the vaper identity so that the public treats vapers differently. There is a real danger that public establishments will treat vapers like smokers.

The vaping in public places campaign will... persuade shops, clubs, transport operators not to ban e-cigarettes... or to do so on the basis of considered evidence and reason rather than lumping it in with smoking... just this last week, people have been taking photographs at Audi's, Greggs the bakers, trains... which say things like, "It's illegal to smoke on these premises," including e-cigarettes which is a lie... that's proactive to try to protect environments so that people choosing to vape aren't kind of chucked out in the world of smokers outside... now, there could be a good reason to not want vapers in a restaurant... vapers are not their best friends because blowing clouds and having highly perfume vapes is not a good way of re-assuring somebody over there that it's all right... it's just like a strong perfume... I mean some of the flavours are quite strong and not very sophisticated... but the idea is for employers not to jump to think the way to solve this is to ban it... we need to facilitate vaping... so the campaign will be to consider a vaper's role. ("Tannhaus")

Finally, social movements can give people something to identify with. "Tannhaus" believes that, "With the decline of party politics, social movements as membership things become even more important... because the traditional party alignment... the left, right... is declining."

### *Making life exciting*

Social movements can create a sense of excitement. A little drama should never be underestimated to get people engaged! "I like a bit of conflict... it makes life quite exciting!" shared "Regina." Chapter 5 presents the range of positive and negative feelings participants reveal in relation to social movements.

### *Recruiting resources to an issue*

The HIV/AIDS movement recruited people from the gay liberation movement who had not been previously involved. These people brought resources, including skills, money and connections, according to "Magnus."

HIV... it drafted in a whole bunch of people... who weren't previously involved... professionals who were keeping their nose clean at work... and going out clubbing at night but weren't really involved in the politics... then of course, when their friends began to get sick, they began to think, "Well actually, I've got to do something here." They were doctors and lawyers and retailers and there was stuff they had to do, and they brought their skills and commitment more than their money... but then again, they also brought quite a lot of rich friends... I remember being in the office of one of the co-founders of GMFA who was talking to Liz who was doing him a big favour... 'Thank you very much, Liz. I can always rely on you. It's terrific... oh, by the way, love that hang bag. Ok, speak to you soon sweetheart.' It was of course, Liz Taylor.

HIV/AIDS movement members were able to tap expertise on an ad hoc basis to achieve specific aims. "Magnus" refers to this dynamic pool of expertise as a "commonwealth of skills and knowledge" and "warehouse exchange place for skills."

### *Putting an issue on the agenda*

"Noah" feels that TTC has been successful at raising awareness for mental health and putting it on the agenda.

What we see in the UK in the last 10 years... movements... that de-stigmatize and raise awareness of mental health... are gaining traction and have helped put mental health on the agenda. Yesterday there was on BBC programme... the biggest of its kind... the media is more and more willing to pick the subject up.

### *Creating spaces for “unscripted conversation”*

“Winden” believes that social movements give people a space for “unscripted conversation,” to talk with one another and develop different ways of doing things.

The idea [social movements] is one of the things I believe in... the notion of unscripted conversation as a way to come to a different view of how we do things. I deliberately didn't want to be... we'll do this and then we'll do this... what's important is people saying... yeah, that's interesting... they can actually talk to each other... what I want is let's just talk to each other in a way that develops work with children... families... communities... whatever.

Informal conversations can enable thinking differently together. Chapter 6 looks at how people in social movements often identify with thinking differently.

### *Working on “contaminating” issues*

Some participants note that social movements tend to address issues that no one person or organisation can solve alone. “Torben” goes further to say that social movements work on issues that “contaminate” everything else.

Fundamentals... which we haven't got right by a long way... methods to destigmatize mental health... particularly in... countries where the least has been done... the low and middle-income countries... 85% of the population lives there... I see that as an over-arching problem because... in a sense, it contaminates everything else in the mental health field... whether it's getting funds for new projects or development initiatives... getting research going... setting up service user groups...the consequence of stigma start... they start at a governmental... national... even international level... it's only recently... the United Nations has paid attention to mental illness and they filter down to every other level you can imagine... one of the... over-arching challenges is not just stigma between individuals... structural stigma...

Framing an issue as “contaminating” stresses its impact on all downstream solutions.

### *Pressuring persistently*

Time and time again, participants recognise social movements as “providing... ongoing pressure for change” (“Egon”). Social movement groups pressure in diverse ways and with varying levels of intensity. “Mikkel,” for instance, has been part of a group trying to change social care. He had been attending an annual social care conference for about 15 years. “Mikkel” shared, “A bunch of us had been saying... to the organisers... ‘It’s a missed opportunity’... giving them ideas about who goes, what gets talked about, how it gets done... we would get some tokenistic response.” After gently pressuring for five years, this small group decided to increase the intensity level by hosting an underground conference just down the road from the main conference.

My view was that some challenge was needed in order to lever it to be different... if we do want to see significant change... different use of public resources... we have to persuade the custodians of those resources to make some changes... we won’t be able to make this change simply from people with lived experience or people angry with... the system... I’ve been one of those people... inside the system... it’s not as simple as a load of bad people wanting to do bad things to people or being useless or whatever... there are many people inside of that system who want it to be different... we wouldn’t be able to detach all of those politicians and managers, but we might be able to start to build a bigger coalition of the willing, and do something with that...

I wrote an initial blog... which was quite offensive... saying that... not only is it a really terrible conference but it reflects where the leadership of social care is... to administrate a system rather than to make change in a really strongly positive different direction... if you gather the leadership of social care in a place for three days and they simply have conversations about... “How do we sustain the existing system?” ... and... “Why doesn’t the government give us more money?” ... we wouldn’t make any change...

... as soon as I put that blog out... I was inundated with responses... scores and scores... not just angry people... saying, “Yeah, stick it to them”... but existing directors of social services... politicians... people who had recently left those roles... saying... “Something like this is really needed... the narrative is stuck... a paradigm change is needed... we’re stuck on keeping the show on the road... we’ve been stuck a



long time... that sounds like a good starting point to shake things up... rattle some trees... see what we can do."

The underground conference created a visible "threat" to the conference organisers with regular attendants having to choose which conference to attend. It also mobilised 300 people who wanted a chance, "... leveraging them to change their own event." "To use a threat rather than... a polite engagement," according to "Mikkel," was a "way of making them think harder... to do something different... something concrete... not just a chat together for three days... to use it as a launching pad."

### *Wide-scale norms changing*

As an expert in drug harm reduction, "Tannhaus" observes that social movements represent new norms and encourage their adoption.

[Social movements are] wide-scale norms changing... for drug addiction, it was norm-changing to share syringes... anti-smoking worked because smokers used to share, "Do you want one?" Of course, with campaigns against smoking, it becomes very uncool. The social etiquette around using cigarettes changed... condoms, safer sex... suddenly, everyone is signed up to the practice.

These new norms supported behaviour change, including declines in syringe borrowing and uptake of syringe sharing.

### *Serving as a status symbol*

A social movement can be a status symbol that the fight for a social issue continues. A member of TTC talks about what would symbolise that the goals of TTC have been realised.

The sign that we had reached this change would be marked when the disclosure of a mental health problem is routine and unremarkable... when it happens during a first date, filling out an application for college, becoming a new member of a congregation, joining a sports team, running for election, or looking for somewhere to live... an emerging social movement bringing us ever closer to the crucial "tipping point" which

will see stigma and discrimination around mental health no longer socially acceptable and the emergence of a new period of respect and social justice around mental health. (Time to Change, 2011)

One of the reasons why a social movement would dissipate is because it is no longer needed!

### *Social movement as solution*

Social movements can be the solution to health issues. Research shows that, "one of the most effective ways to reduce stigma [associated with mental illness] is through direct personal contact with someone who has a mental illness... people can learn the truth that people with mental illness are just like everyone else" (King's College London, 2021). Joining a mental health movement to "have a real impact on what global mental health looks like" with other people is "actually good for your mental health," says "Egon," and engages them in feeling "ownership of their situation." For instance, Time to Change (TTC) is facilitating social contact amongst people with mental health conditions. A TTC media volunteer talked about participating in TTC being, "good medicine against the feelings of isolation that mental health problems sometimes lead to" (Stone, 2016). Since TTC began, an estimated 66,911 people have made a friend outside of the mental health sector, combatting loneliness and enabling people to meet others outside of self-help groups (Time to Change, 2011).

### Summary

This Chapter reveals that there can be different levels of familiarity with social movements in terms of levels of awareness, understanding and experience. It also illuminated the diverse ways that study participants make sense of the social movement concept, including utilising metaphors as well as characterising, deliberating on, relating to other social movements and valuing social movements. It highlighted a number of on-going deliberations about social movements, including whether organisations can be social movements, profession-led, funded programmes or "real" as well as opinions on using the term, "social movement." These

deliberations have implications for how people build social movements and how external actors interact with them, as will be discussed in Chapter 7. Chapter 8 looks at the potential value of developing social movement sensemaking tools with, by and for social movement actors to aid a shared and co-created view of social movements.

This chapter offered an “outsider” view of social movements in the sense that findings represent how study participants look in on the social movement concept. Perhaps exploring social movements as experience could illuminate an “insider” view of what they are. The next chapter takes us on a journey through the social movement experience.

## Chapter 5: How people make sense of social movements as experience

### Introduction

The exhibit title on the wall reads, “You who are getting obliterated by the giant fireflies” by Yayoi Kusama (Phoenix Art Museum, 2020).<sup>53</sup> You enter and proceed through a dark hallway, which suddenly reveals an infinite space of tiny twinkling lights, like a galaxy of suspended stars. You awe at its wonder. The lights seem to envelope you and replicate across the mirrored walls. You reach your arms out to find the boundaries of the room. You panic, “Why do I need to find the boundaries?” As you exit to return to a world of concrete physical dimensions, you reflect on the experience which tested your relationship with ambiguity.

This narrative captures the essence of what this chapter explores: experiencing. Just like the transformative journey Kusama plots for exhibition goers, people in social movements face an uncertain future, full of obstacles, profound victories and everyday happenings. This chapter investigates: “How do people make sense of social movements as experience?” The idea of a social movement as experience emerged during my first interview with “Magnus” who shared what it was like to participate in numerous social movements throughout his life and career, including gay liberation, HIV/AIDs, sexual politics and child sexual abuse. He shared his memories with such raw emotion as if he was reliving them.

The child sexual abuse movement... survivors’ movement... it was great to be... on the ground level... it was an enormous uh... privilege... I remember my 25<sup>th</sup> birthday... I was giving a talk at an annual conference that we organised... on the sexual abuse of males... there were about 200 people in the room... when I was about to get up to give my talk, somebody said that it was my birthday... these 200 guys sang happy birthday to me and I cried...

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<sup>53</sup> “You who are getting obliterated by the giant fireflies” is a permanent exhibition at the Phoenix Art Museum (2020) and was “inspired by a Japanese folk tale about a person in a field with 10,000 fireflies.”

In the interviews, people shared their experiences participating in and interacting with social movements. Each narrative was rich with passion, action and emotion. Yet, their journeys were sometimes vastly different. In an experience as collective as a social movement, I wondered: What binds their journeys? What separates them and why? Does a social movement represent the sum of its participant experiences? Or does it perhaps represent something more? In this chapter, we investigate how study participants refer to the concept of “experience” explicitly, without prompting, and then, start to identify the conceptual categories of the social movement experience.

## How study participants refer to the concept of experience

Our first port of call is to examine how study participants refer to the concept of “experience” in the interviews as a useful starting point for understanding what experience means. Four ways emerged and are analysed in this section: experience as expertise, experience as lived experience, experience as learning and an experience as the impetus for a social movement.

### **Experience as expertise**

Participants describe “having experience” with social movements, implying that a person can accumulate experience and develop expertise through experience (“Claudia”). “Tannhaus,” as a subjective observer, assesses the experience level of organisers advocating for the use of nicotine in public places saying, “These people have no experience of organising... I’m the chair of this bunch... I’m trying to strategise and to think clearly about what we’re doing... not just to jump this way and that.”

## Experience as lived experience

Experience can refer to the lived experience of a health condition or disease. Participants reveal multiple ways that professionals attempt to amplify the voices of people lived experience, including seizing opportunities for them to share their experiences and supporting organizations led by people with lived experience.

I'm going to a meeting in Baltimore... on neglected tropical diseases... and we're taking a guy who's got [a mental condition] ... to talk about his experience because we think... it is well-demonstrated that it has a bigger impact than scientists talking at a platform... we're... really involved in trying to generate... organisations of people with psycho-social disabilities... in many countries. ("Egon")

As discussed in Chapter 1, UK social purpose organisations often undervalue lived experience, placing people with lived experience in "informer" rather than leadership roles (Sandhu, 2017b).

## Experience as learning

A person trying an e-cigarette for the first time experiences multiple aspects: the physical product, the way their body processes the drug, the way they enjoy their reaction to the drug and social norms surrounding the experience. According to "Tannhaus," the experience of switching from smoking to vaping is like "learning a new relationship with a drug... a new way of using." He shares:

Howard Becker... wrote a book called... *Becoming a Marijuana User* (1953)... a sociologist in Chicago... jazz musician... did his PhD on becoming a marijuana smoker... this is in the 50s and 60s when it was enigma... he said, you have to learn the technique... did you ever smoke? It's difficult because you're not sure how to do it... how deep to inhale... how often... once you've learned all that... if you're moving onto something else, you're looking for that... and... when you learn a new drug... you have to learn what it is that you're enjoying... I don't like this... I'm feeling a bit sick... but all my friends are enjoying it... you're picking up cues, both about the technique but also

about how to enjoy this drug because... lots of drugs, are not inherently enjoyable the first time. When you learn to become a drinker, you have some really bad experiences where you drink too much... and you get sick... and you make a fool of yourself. ("Tannhaus")

A person can adjust their vaping experience, such as by altering their usage patterns or brand. They might choose to make their experience more enjoyable or socially acceptable, for example.

### **An experience as the impetus for a social movement**

In 2002, a young girl's experience of receiving care for a psychotic episode was the impetus for a social movement, according to "Jonas."

She went into an adult psychiatric ward at 15... with 40-year old men... she didn't make a good or quick recovery... no one seemed to bother that she wasn't doing any exams... that she wasn't mixing with her peers... that she was mixing with totally inappropriate... no one worried she was in an 8-bed ward with just curtains as a 15-year old in an adult ward... and instead of being reassured that she was being treated, [her parents] worried for her safety... eventually she was rehabilitated to a rehab ward in an old asylum and um... and basically left there really... and she was 17... and no one seemed to be worrying about either her education, employment prospects, social prospects, her interests. They just seemed pleased that they'd moved her from an acute ward to a rehab ward and that she was effectively now being rehabilitated.

The girl's father, also a practicing GP, observed the poor care his daughter received. With anger and dissatisfaction, he shared his story and indirect experience with colleagues; at some point, his story touched their hearts too. They told and retold the story until eventually, it spread beyond the West Midlands and nationally to other people who got involved, setting in motion a social movement that spread across the UK.

## The conceptual categories of the social movement experience

Once the social movement experience concept emerged, I started filtering new data through it to its relevance and pervasiveness in the study data. I documented relevant line-by-line codes. Then, through an inductive coding process, line-by-line codes were iteratively organised, abstracted, framed, reframed and re-organised until higher level codes emerged. This section presents four conceptual categories – Acting, Sensing, Facing and Planning – organised in the data structure in Tables 5.1, and into four levels of data abstraction – codes, clusters, categories and concept. Clusters and categories represent line-by-line codes converging into second and third levels of abstraction, respectively, with the concept, “making sense of social movements as experience” representing the highest level. Table 5.1 omits this overarching concept for readability. Tables associated with each category are presented throughout the chapter for ease of referencing the material while reading the supporting findings. All levels of abstraction retain the words of study participants to maintain their voices in the analysis and presentation of study findings. Codes, clusters, categories and concept are also phrased as gerunds, when possible, to maintain a focus in the data analysis on what is happening (Charmaz, 2018). Now, let us delve into them.

### **Acting**

“A movement is not a movement if it does not move,” said an NHS health and care professional. Participants spoke about taking a wide range of actions, both individually and collectively. Categorising and abstracting these actions resulted in six clusters: learning, influencing, organising, building, contributing and adopting.



Table 5.1: Data structure for how people make sense of social movements as experience

Category	Clusters	Second-level codes	First-level codes
Acting	Learning	How people were learning	"Learning as we go along," talking to other people, sharing lived experiences, mobilising with peers, consulting past work, through moments of realisation
		Why people were learning	Out of necessity, "becoming interested in new areas"
		Where people were learning from	Peers, ancestors, experts, social movements, customers, experience, literature
		What people were learning	Deeper understanding of issues and solutions, new skills, new ways of working, about the evidence, how to work with people with shared values
	Influencing	Through relationships	Building allies, offering mutual support, recognising someone, "disabling" people, getting people out of their comfort zone, connecting people, using narratives, speaking their language, investing in communities, working through people
		Educating	Developing interactive workshops and training sessions, disseminating evidence, sharing practices, explaining the issues, connecting people who can educate each other, raising awareness
		Pressurising	Persistently, utilising a place "outside of the orthodoxy," getting a balance between challenge and collaboration, campaigning, taking legal action, demanding resources to help solutions work, policymakers to change legislation, using different parts of the system against one another, having influence in multiple places
		Persuading	People to act based on the evidence, people to setup organisations, researchers to release evidence early, donate, attracting rich friends, persuading your own organisation, utilising evidence and narratives, explaining the issues to funders, celebrities to get involved, people to invest in communities
		Exercising voice	Sharing your point of view, sharing your narrative, acting as a spokesperson, representing mental illness, speaking with the media, utilising platforms
		Building credibility	Demonstrating success, getting recognised as a stakeholder by institutions
		Organising	Around a common
	Across boundaries		Communities, sectors, professions, groups, organisations, networks, geographies, cultures, political lines, movements, social media
	Setting up new organising structures		New organisations, coalitions, groups, associations, funds, networks of people/organisations/networks, formal/informal, varying scales, helping other people organise, coordinating a volunteer workforce
	Enabling		Sharing lived experience, bringing people together who would otherwise not meet, networking, knowledge-sharing, problem-solving, opportunity creation, exhibiting strength in numbers, achieving specific tasks, bridge-building, "moving things out of the way," developing a common voice, campaigning, getting a seat at the table, providing a "consumer voice," joining legal action
	Building	Empathy	Listening to people, talking to people, empathising with what matters to people, going where the people are, learning from people about what is working, asking questions, cultivating relationships, responding to a need, perceiving risks people face, cultivating relationships, filling in knowledge gaps
		Solutions	Treatments, products, processes, services, care models, information resources, training courses, legislation, policies, new ways of thinking, new ways of working together, a magic bullet

		Evidence	"Taking control of the developing evidence base," advising on studies, leading an evaluation, running intervention studies, developing evaluation approaches
		Movements	Mobilisation strategies, campaign strategies, frames, tactics, complementary movements
	Contributing	How people are contributing	Voluntarily, openly, rapidly, generously, how they can, in diverse ways
		What people are contributing	Skills, knowledge, experience, expertise, money, mutual support, advice, social connections, time
		Serving on various levels	Sharing stuff on social media, giving small pockets of time, taking on roles and responsibilities (e.g., formal/informal), building a career, a way of life
	Adopting	Adopting new role	Proactively adopting a new role, being asked to take on a role, reversing roles
		Adopting opinions	More powerful people, peers
		Adopting a new norm	Safer drug usage, safe sex; smoking as bad
		Adopting a new behaviour	Using clean syringes, using condoms, quitting smoking
		Adopting solutions	Individually adopting, system adopting; rapidly; diverse types

### Learning

Learning how to combat loneliness, to prevent HIV/AIDs, to deliver mental health services to a large section of the world – these were explicit goals people expressed in their interviews. Learning how to do something, and delivering what works, can require learning new skills, new identities or roles as well as becoming interested in new areas. Therefore, learning “as you go along” (“Jonas”) felt like a hallmark feature of the social movement experience. “Magnus” describes having to learn how to generate evidence for a project they “knew was a good thing” but for which they didn’t know how to generate evidence for. “Tannhaus” describes becoming interested in new areas as they became relevant to drug harm reduction, including how drug users were solving their own problems.

I got very interested in how people do harm reduction rather than being told to do harm reduction because it’s the people that do it rather than the experts. The experts can facilitate it... in NYC... a friend of mine... said that from the... mid 80s / early 90s onwards... drug users were already adopting risk prevention behaviours in NYC in the context of HIV/AIDs... I became interested in how people did that and how drug users sort of told others about it... how they cascaded that message and became... outreach workers.

The data also illuminates who people were learning from, including their peers, ancestors and people in other social movements. For instance, the previous chapter revealed social care professionals learning from their peers, “Winden” consulting a Victorian philanthropist on how to do restorative practice and global mental health activists learning from the HIV/AIDs movement.

We can examine what people were learning from each other. A self-organised group of transgendered sex workers in Toronto were adamant about using their time together to learn how to stay safe. “Magnus” shares what it was like to work with them:

I’m not sure they quite got... what we meant by community-based research because... they didn’t want to do the study, they just wanted to communicate the knowledge... they kept saying, “The most important thing is to get the learning out not bring the learning in.” I’d say, “I can see why you’d feel that way” ... one of the people in my group said, “Martin, you’re working with a bunch of... you didn’t expect to be in control, did you?” They were talking to each other... their customers... they knew enough... they’d been around the block a few times and... frankly, the ones who knew how to put the condom on, they really knew how to put a condom on... that was a skill that they could uh share... and... the ones who knew how to avoid getting beaten up and arrested... they could share those skills pretty well... in the end, for that group, at that time, that mattered more than me getting a nice report with content.

“Magnus” later shared that other research groups produced more “classically useful” data reports. In this situation, he also learned a valuable lesson about building relationships.

They paid me back hugely a year or two later when it was a big World AIDs conference in South Africa... they put me in the wrong panel... sex workers... I was... with really top-level academics... here was I... like 25... I hadn’t finished my masters... I’d dropped out cuz AIDs activism was more important than behavioural economics... which is probably about right... and I was literally ready to vomit... a colleague had a bucket behind the screen for me because I was so, so nervous... what happened was this whole group of transgendered prostitutes in Toronto rushed the front row... and then they started singing, “Go Martin! Go Martin!” giving me a kind of rotating gig... with a crowd behind you like that, you just can’t fail... yup, they paid me back big time.

Participants stress the importance of learning about the evidence related to the problems they were trying to address. “Tannhaus” shared that, “A good number of vaping activists are extremely well-versed in the evidence, better than many public health commentators!”

### *Influencing*

Participants were attempting to influence people, policy and institutions in diverse ways. These ways included educating, forging relationships, raising awareness, building credibility, demanding, working through people, framing issues and exercising voice. Actions to educate others included developing trainings as well as connecting people who can educate each other through experience. In terms of forging relationships, the EIP movement had to build strong and trusting relationships with researchers to generate evidence rapidly so that it could use that evidence to influence national policy.

We didn't have the strong evidence base that we have now... we had to grow that very fast... that required appealing to researchers to move away from paranoia... insulism... to... release data early... collaborate across research teams... we did that through narrative and heart... that proved very, very successful... and we tried to help people to see that there were gains... so we were able to profile research... before it was complete... and that worked very well in terms of fast-growing evidence.

This early access to evidence enabled the EIP movement to raise awareness of EIP and get the issue into the national policy framework. Participants also describe spending considerable time learning the evidence and exhibiting familiarity with it to funders and decision-makers to build credibility. Credibility secured two organisations – Initiative to Reduce the Impact of Schizophrenia (IRIS) and the New Nicotine Alliance (NNA) – a “consumer voice” in decision-making. The EIP movement used IRIS as a credible organisation to demand change from the orthodoxy anonymously. “Jonas” explains, “... we used [an organisation] as an out-of-the orthodoxy place... whenever we wanted to challenge.”

Participants also describe influencing by working through “global allies” and “middle ground” people. “Jonas” describes how she built a relationship with an “unlikely ally” who later influenced in “rooms and corridors” she felt she would never have access to:

There were people in government we appealed to... there was someone very well-respected... evidence driven... thoughtful... he'd probably never been out of Whitehall. [My colleague] came up with this bright idea... why don't you come and meet... families and hear what it's about... so he did... we picked him up from Birmingham International... [we] didn't have any funding... we took him to a Wacky Warehouse<sup>54</sup>... we probably disabled him and put him out of his comfort zone. I arranged tea with a lad with psychosis... talking about... getting back to uni... and this civil servant sat having tea and cake... it appealed to heart... and he was a head man... then he used his head in places he sat... later on at my retirement, he came with an umbrella and a bottle of champagne and I cried... he was just such a lovely man and such an unlikely ally.

Understanding how to approach who you want to engage is important, as “Mikkel” describes:

You need to have a good sense of... the... contributors that you want to engage with... the networks associated with those people... it's often about not approaching somebody yourself but... through somebody you know who is trusted in that network.

In influencing, “I think there's something about... getting the right balance between challenge and collaboration... enough challenge to detach and encourage a portion of people from the establishment... to want to engage with you... but not so much challenge” (“Mikkel”).

Finally, participants were influencing by framing issues. For instance, in terms of anti-smoking, “Agnes” was involved in reframing smoking as a workers' rights issue. She explained that, “... everyone has the right to a smoke-free workplace... if you work in a pub or a bar... you're low-paid... you don't have much choice about where you work... ventilation doesn't work... it's about... worker's rights... you need legislation.” A pivotal point in the debate about legislation in pubs and bars was the harm principle.

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<sup>54</sup> Wacky Warehouse (2020) is a soft play area for children in the UK.

Joshua Mill and the harm principle... liberal philosophy... underpins a lot of public... and parliamentary thinking around what is appropriate for government to do... if it harms others, it gives the State the right to intervene... how you define that is the subject of a lot of debate but it's quite an important principle. ("Agnes")

Furthermore, by framing the issue as a debate, rather than a one-sided issue, anti-smoking activists caught the attention of the media.

We started the campaign... it was difficult to get media coverage... people weren't interested... 'There's no chance of legislation, why should anyone care about this?'... the media are always interested when there's an argument... if it's a simple story one way, who cares?... suddenly, journalists found that their letter pages got lots of answers... we were getting phoned up from journalists on a regular basis... have you got an angle for us?

"Agnes" believes that the harm principle is also critical to the debates about vaping in public places, "... that's why we don't support... extending the legislation to include... vaping... the evidence of harm is just not there... it actually undermines the value of legislation."

### *Organising*

From bringing colleagues together, through convening local meetings, to coordinating volunteer workforces and engaging people online, many participants were organising people and resources, often across traditional boundaries, sectors and movements. There was a general sense from most participants that the issues they work on cannot be solved alone. The impetus for organising was generally addressing a social issue or believing in a common vision, mission, aim, or ideology. More granular motivations for organising included bringing people together who would otherwise never meet, exhibiting strength in numbers and coordinating people to achieve specific tasks such as campaign, fundraise or conduct research. Participants were setting up a range of organising structures such as charities, advocacy organisations, coalitions, groups, associations, funds and networks at various scales – local, regional, national

and international. Some of these organising structures evolved into sustainable organisations, as “Magnus” shared.

I founded the first charity in the UK that was dealing specifically with male sexual violence... back in the 1980s and still going strong... the charity... some 30 years later... it was very much the beginning of that movement when... people were only beginning to talk about the issues... and some of the big cover-ups were still pretty well underway.

Organising did not always happen at “the grassroots.” “Claudia” shares how helpful it was to organise a governance group of senior leaders, “We setup a governance group... we accounted back to... we called those meetings... and they acted as people who... moved things out of the way for us... a powerful role to play... very helpful to us.”

Participants report dedicating a lot of time and energy to helping people with lived experience to organise. “Egon” shared, “We spent a lot of time trying to organise... people with... psycho-social disabilities... mental illnesses... to coordinate themselves to be advocacy organisations even forming a national organisation and trying to get a seat at the table at the national disability federation.” Similarly, “Tannhaus” worked on persuading vapers in the UK, and in other countries, to start consumer activist organisations. Many of these organisations are now a first resort for the media wanting a “consumer voice.” Professionals like “Egon” talked about the power of organising coalitions that campaign with a common voice. “There's something more powerful than just ‘the voice of service users’ campaigning for their own issue... and separately the psychiatrists... the NGOs... it's important in a historically fragmented field that people also have a common voice across the sectors,” said “Egon.”

Social movements can, for a moment, mobilise the time, energy and resources of people from other movements to achieve an aim that impacts on multiple movements. For instance, FundaMentalSDG “unified” and “connected” people and organisations advancing multiple

mental health movements across the globe to achieve the inclusion of a mental health target in the UN post-2015 SDGs.

### **Building**

Movement-builders build. They build amidst limited resources and knowledge as well as insufficient or non-existent solutions. When mothers of children with autism were dissatisfied with the support they received, they took it upon themselves to build solutions, often together with other mothers as well, as “Egon” shares:

I would say the most successful movement in mental health is autism... absolutely totally outstrips everything else by a factor of 10... the power of mothers... being so incredibly committed. I went to the first meeting... at the WHO... starting a new programme around... autism and childhood developmental disorders which subsequently... resulted in an intervention called Parents Skills Training... which is really good... it was... mothers of people with autism... they'd found them through their national autism society in their parent country. They all had same the same story which was basically... I had a child with autism... no one knew what it was... I had a load of quacks that I wasted money on... and they even probably did harm to my child... then I read up a bit more about it... trained myself and started this organisation... a special school... now I run a big national organization... it's the same story for all of them... just amazing...

According to the data, participants were building products, processes, services, evidence, identities, networks, care models, information resources, training courses, legislation and policies. They were also building complementary social movements and innovative ways to grow their movements such as mobilisation strategies, campaigns and tactics.

Building often happened collectively and began by talking to people. When “Regina” first heard about e-cigarettes, she decided to go to an e-cigarette conference and talk to vapers.

I... was absolutely convinced after those conversations that this was something really positive... that would help stop smoking rates in the UK. I wasn't thinking at that time about... the rest of the world... I was just keen that in our local service, we could really do something... so we started asking questions... the manager of a vape shop... we asked him along to one of our team meetings and there was definitely an air of mutual



suspicion when we first started talking but he was so passionate about all the same goals that we wanted... like helping people to stop smoking... the enthusiasm in the room really grew as people started asking him more and more questions about flavours and strengths and devices and cost... health... anything that people wanted to know, he was able to answer... this was in late 2013... we have kept close contact with him and a number of other vape shops... we have cultivated relationships that have helped us fill in the knowledge gaps... I encourage the team to not be afraid of the vaping culture just because they don't know much about it but to help themselves with better knowledge, share information, talk to their service users who are vaping and gather those anecdotal stories and bring them back to the team so that we can all benefit.

By talking to vapers, members of Regin's stop smoking service were able to listen, ask questions, dispel their fears about vaping, discover shared intentions, fill in knowledge gaps and ultimately, conceive of an e-cigarette friendly smoking cessation service.

Coming together and talking about the issues can really energise people and give them hope to find solutions. "Mikkel" shares that the #socialcarefuture movement responded to a need they saw to energise people.

We're looking to energise people, aren't we?... many of whom have been feeling, "I can't see a way forward... there's nothing that anybody's come up with that makes me think... 'that's a solution'... or that I can be part of a solution... one of the things I'm hearing from people is that they're fed up just talking about how shit everything is... people really need some hope now. They've got to a point where they've had 10 years of it being bad... and nobody's come along with a big wodge of cash to sort that.

Social Care Future offers a way to "be part of a solution" and to "attach myself to something that at least is saying there is a solution."

Participants were also using diverse problem-solving strategies to build solutions such as "having multiple things on the go" to attempt to solve an issue from multiple angles simultaneously.

We had multiple things on the go... all aimed at having an impact around loneliness but coming at it in different ways... so, we did three things... a campaign around trying to

demonstrate the impact of the arts... trying to develop a food movement that was about using food to address loneliness... and a small grants programme. ("Claudia")

Multiple participants believed that innovations need space and time to develop and demonstrate potential. This belief manifested in social movement groups seeding innovations. One of the HASM groups established a micro-grants programme to support the development of ideas that would make a difference to people locally.

The small grants programme was about investing in communities to... develop ideas they had around what would make a difference where they lived... some of those were individuals living in the community, others were you know... Stroke Association wanting to do something... we funded around 47 small projects that got between 500 and 2,500 pounds to do something around loneliness.

Following this initial exploratory phase, a mobilisation phase would follow, supporting people to further develop, pilot or implement effective solutions.

### *Contributing*

Participants were contributing their skills, knowledge, expertise, money and social connections to addressing the issues they care about. People were contributing at various commitment levels. Commitment levels ranged from clicking a "like" button on Facebook to taking on voluntary responsibilities to building a career around an issue. For "Jonas," the EIP movement became a "way of life" for a while.

I can't tell you at what point the narrative reached my heart, but it did... and I became passionate about it... and would put in hours way beyond the call of duty... it became, for a while, a bit of a way of life... it was selfless... you would do lots for other people for no particular gain for yourself... so I did supervision over Skype for people in Japan... in Nigeria... trying to move a social movement... early intervention in their countries... there were... lots of late hours... some of those connections and friendships still exist.

According to the data, people were contributing in relational ways, often voluntarily and generously. They were sharing their experiences, offering support and advice and spending time with other people.

There's a beautiful study... RCTs [randomized control trials] in Glasgow... where people diagnosed with... lung cancer... who have... declined the help [to quit smoking] ... are offered e-cigarettes, advice and support on how to use them. Advice and support comes not from the researchers or the public health people but from vaper volunteers who have... training... they go out... sometimes they'll drive for hours to the home of somebody with cancer... they'll sit with them... spend time with them... share experiences... they're very powerful... persuading and helping people... replace their smoking with vaping... they get a lot out of that... everybody does. ("Magnus")

This account is another example of social movements as "peer-to-peer" and "putting the solutions in the hands of people who lack access," both discussed in Chapter 4.

### *Adopting*

Participants were adopting new roles, identities, opinions, norms, behaviours, evidence, and innovations. Participants chose to adopt a new role on their own accord or due to peer pressure. For instance, "Egon" agreed to lead a new network when there was simply no one else to lead it. Adopting a new professional role can sometimes require adopting a new identity.

In 2004... I was at [a university] ... it was not very much attuned to the kind of public health I was interested in... I suddenly thought, I don't want to do this anymore... I jumped into running an advocacy organisation... it was just me and a half-time administrator... its task was to ensure that the UN agencies supported drug harm reduction... we worked with, sometimes against, the UN... I suddenly found myself in an advocacy role which was very usual for me because I'd never seen myself in that role. ("Tannhaus")

Taking on multiple roles and identities simultaneously was common in social movement work. In the HIV/AIDS movement, activist researchers "reversed roles:"

I used to joke that we were very community-based... our volunteers included both social researchers, health researchers and strippers. Unfortunately for us, or fortunately perhaps, the strippers wanted to do the research and the researchers wanted to do the stripping. ("Magnus")

In social movements, people are influencing other people to adopt their opinions and approaches, for example, about how to address a particular issue such as loneliness. One of the HASM group leaders had a particular interest in utilising the arts to address loneliness and therefore, the group adopted a "strong arts and culture-based element" ("Claudia"). "Claudia" acknowledged that if that person had not been there, this focus probably would not have happened.

In Chapter 4, we learned about social movements driving "wide-scale norms change" by encouraging people to adopt new norms and behaviours, with adopting new norms intimately interlinked with adopting new behaviours. We will discuss social movement members adopting innovations, or "innovative solutions," in Chapter 6.

### *Enacting a mindset*<sup>55</sup>

It is too early to fully characterise the mindset people were enacting but some of its features include: embracing humour, comfortable with ambiguity, accepting failure, following your intuition, adapting to the context, not letting hurdles stop you as well as being committed, entrepreneurial, opportunistic, resourceful, willing to let go and willing to get your hands dirty. "Magnus" embraced humour when peers criticised their research group on HIV/AIDs and behaviour change which departed from RCTs, a dominant approach at the time: "... some researchers said, 'How dare you call that research?'... that debate... so we called it *Queery* which didn't solve many problems."

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<sup>55</sup> This section relates to the section in Chapter 4 on, "A mindset."

## Facing

Study participant narratives illuminate the social, political, cultural and institutional challenges they were facing in their pursuit of social movement goals.

**Table 5.1: Data structure for how people make sense of social movements as experience (continued)**

Category	Clusters	Second-level codes	First-level codes
Facing	Social challenges	Struggling with	Letting go, feeling of failure, a lost opportunity, uncertainty, how to do something, how your actions will have an impact
		Interpersonal issues	Trust issues, uncomfortable power dynamics, imposing ideas, strong egos, paternalism, judgmental attitudes about people, criticism from peers
		Impediments to participation	Stigma, nature of social condition, lacking right to speak out
	Political challenges	Political association	With political charged issues
		Dissent	Opposition, hostility, criticism
		Political interests	Shifting political interests, conflicting stances, political divides, a plethora of frames, fragmentation, political divides, manipulation
	Mobilisation challenges	Social health condition	Impacting on ability to mobilise (e.g., reverse social gradient enabling mobilisation of resources, lack of motivation inhibiting participation)
		Stigma as overarching issue	Impacting on willingness to disclose and talk about lived experience of stigmatized issues, impacting on willingness of social movement groups to interact with more stigmatised groups they might be able to help
	Cultural challenges	Cultural diversity	Diverse conceptions health conditions, cultural diversity delaying movement emergence
		Cultural beliefs	Appropriate responses to health conditions, views of autonomy, collective decision-making
		Cultural baggage	A history of adopting Western ideas
		Cultural denial	"Buddhists do not have smoking problems"
	Institutional challenges	Lack of institutional support	Lack of engagement, hostility
		Institutions asserting control	Government "drafting" people in, using evaluation, having to "entertain" conversations professionals want to have, pressure to product outputs
		Lack of motivation to innovate or change	Getting stuck on one approach, ideas about reform unchanging, lack of investment in advancing technology
	Social movement lineage	"Inheriting a worldview"	Understanding of how society works
		Inheriting language	Discourse (e.g., enabling/hindering consensus), name of social movement
		Experiencing lineage perpetually	"Standing on the shoulders of giants," emerging like "Russian dolls"

### *Social challenges*

Participants talk about their personal struggles within social relationships. Personally, participants talked about their struggles with “letting go,” ceding control, failure, loss and feeling the right to speak out.

Interpersonally, people faced issues such as uncomfortable power dynamics, trust issues and having strong ideas imposed on them. In terms of uncomfortable power dynamics, “Mikkel” reflects on the state of the social care field:

There’s quite a lot of paternalism...well, more than a lot... and a lot of judgmental attitudes about people and, you know, their agency and their trustworthiness. It’s never quite said, but it’s often in and about that... I really want to challenge that...

In terms of trust issues, “Tannhaus” shares how public health professionals felt when tobacco companies started getting into the e-cigarette business. The professionals really questioned the motivations of these companies, given the harm they had induced historically.

[Tobacco companies are] ... forced... for economic reasons... to get into the e-cigarette business which actually benefits everybody... something that many public health people and people in tobacco control can’t really bear thinking about... that these companies that cause so much misery are now coming up with the solutions... there’s all this suspicion still about whether tobacco companies are really in it to do both.

In terms of having ideas imposed on them, according to “Egon,” mental health organisations in Africa were having strong ideas imposed on them from their peers in Western organisations. These organisations were successful at determining which ideas were relevant to them.

Initially... there was a very quick... exposure to very strong ideas that were actually quite foreign and then a reaction to them and... successful feedback...

### *Mobilisation challenges*

The nature of social health conditions can introduce mobilisation challenges for social movements. "Egon" thinks that autism has been so successful as a social movement because:

... autism... it's the only mental condition that has a reverse social gradient... every other one, the poorer you are, the more likely you are to have a mental condition... so middle-class people have autism in their families... and they are able to mobilise resources and be well-organised... time to volunteer and all of that so... that's my theory... most others are much more common in poorer populations... the exception is eating disorders...

"Egon" also shares how the nature of depression impacts on participating productively in social movements.

It's been quite a challenge... there are inherent things about mental illness that's a bit different from other disabilities... it affects the mind... your motivation... how much work you can get done... and the fact that you relapse and you're off the grid for three months... not a reliable contact for people who want to find out more information about your organisation and all of that... and also stigma, it's just so huge.

As we have touched upon, stigma is an overarching issue within the mental health field and is also a barrier to mobilising people. Stigma impacts on people's willingness to talk about their lived experience of mental illness with others, as "Egon" describes:

I was having a conversation with [a person] ... he felt really low... he wanted to kill himself... when I asked him the question, "Do you have mental health consequences from this?" ... "No, no, no, no, no" ... my colleague who was sitting next to him said, "... but, you said you felt really sad" ... "Yes, but I wasn't mad" ... and this is the problem... that the person who is mad is the person walking down the street talking to himself laughing... you don't want to admit having any problem at all... because it puts you in the same camp as that person... that's a major problem for us... people being more reluctant to talk about themselves... their mental health problems.

Stigma can also impact on whether social movement groups are willing to work together.

According to "Egon," a group of people with physical disabilities did not want to associate

with people with mental illness as they felt that it could negatively affect their status and reputation.

I had a meeting... at... [association of people with disabilities] and it was all about saying... we have these self-help groups around the country... they're really well-organised ... they could learn from everything you know about organising and advocating for disability and they said, "We're already so excluded. Why would we want to associate ourselves with mad people?" ... so, there's a sense that... it was just going to drag them down in terms of their status and reputation... so it's been a real challenge...

### *Political challenges*

Participants report facing political opposition from people, the media, institutions and other movements. "Agnes" shared how her campaigning organisation navigated political fragmentation and creatively influenced political interests to get smoking on the legislative agenda and realise smoke-free laws.

... different agents wanted different things... the tobacco industry didn't want legislation but if it was going to have legislation, it would prefer... local not national... from the Labour Party's point of view where they were worried about national legislation because of the fight they'd been having on fox hunting... we floated the idea of... allowing local areas to do it themselves... they then put that in the consultation... around what was going to go into the manifesto... once that idea took hold, it wasn't ever going to be the solution... so, getting it on the agenda meant it became a real option... subject to massive debate... it also meant that we could split off different sectors... from the hospitality trade point of view... you've got big companies owning pub chains and restaurants... they didn't want to have one set of rules in Liverpool... another set in Manchester... so we were able to say... I went and gave a speech to a big hospitality trade group meeting... you either come on board and support national legislation or you're going to be stuck with local legislation... one by one, they did... actually, when we were trying to put the legislation in Parliament, the British Pubs Association and their [Members of Parliament] ... they wanted a consistent approach... they wanted a consistent approach... by that time, they'd sort of been moved away from their previous position...



The Labour Party, which traditionally speaks on behalf of the working classes where smoking rates are higher, was worried about another “vociferous” battle with one of their voter groups after a recent political battle with fox hunters.

### *Cultural challenges*

Participants noted three cultural challenges. First, that “There are a lot of conceptual hurdles to get over... whether mental illness is the same in every country” (“Egon”). Second, that there are culturally embedded beliefs about appropriate responses to mental health conditions. “Egon” shares his reactions to listening to a member of a Kenyan organisation talk about autonomy and collective decision-making.

... decisions being made for you... a big issue for people with... mental illness... [people in Africa] would disagree with... people in this country... how decisions should be taken with your family... I think most people in Africa would say... it's really important that your family is involved... that does go too far... there's a huge amount of abuse by families who just assume that they should take over that person's finances... not allow them to inherit... to marry... have children... because there's sort of an over-exercised sense of preventive responsibility... whereas in this country, there's a very strong backlash against that... most 18 year-olds would tell their parents to “fuck off” if they wanted to intervene in their financial or marital affairs.

Third, that there can be “cultural denial” about the existence of health issues. For instance, with regards to smoking, “Tannhaus” notes hearing, “We’re Buddhists, we don’t have these kinds of problems... we’re not like that in the West.”

### *Institutional challenges*

Participants note numerous challenges related to institutions, including a lack of support from institutions and institutions exhibiting behaviours such as apathy, hostility and asserting

control.<sup>56</sup> In terms of lack of support from institutions, when lung practitioners proposed solutions to government in response to research on the scientific link between smoking and lung cancer, the government was unresponsive, leaving doctors no choice but to setup a campaigning organisation. In the data, an apathetic response from institutions can come from a lack of understanding or profit incentive. "Egon" explains that, "Mental health doesn't pay... I'm fighting a battle with my own organisation towards mental health." Other times, it can come from a lack of motivation to innovate. "Tannhaus" shares that with regards to nicotine and smoking cessation, "...it's like technology didn't move on for 100 years." Nicotine replacement therapies (NRTs) have a failure rate of 95%, he explains, and the tobacco project kept saying:

... we've got tried and tested treatment... NRTs just stayed boring... gums, patches, inhalators... there wasn't an innovative drive there by the pharma companies to deliver nicotine in new ways... public health in the West had decided that you could beat smoking by bashing smokers and tobacco companies... most of the interventions are all "sticks"... ban at point of sale... a lot of this is good stuff but it's all negative... deliberate stigmatisation... there are some fields where stigmatisation strategies are used as a positive strategy but it's rare... having come from AIDs... the tobacco project got... hung up on making it difficult to smoke with no end game for tobacco companies... BATs [British American Tobacco companies] got \$60 billion pounds... they're not going to be nationalised or closed down...

As the excitement around e-cigarettes rose, the public health establishment was not only apathetic towards engaging with the emerging practice but outwardly hostile. As "Tannhaus" described, "There was hostility from public health... of the 150 public health directors in the UK, only 2 or 3 have come out with some very glowing, positive statement around e-cigarettes which is very different than in the age of HIV/AIDs where they all signed up."

Participants also report institutions trying to assert control over their activities, such as through co-opting people. Amidst a growing need for information about HIV/AIDs, the government

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<sup>56</sup> These behaviours are consistent with Goldner's (2004) strategic organisational responses to activism (Table 2.4).

drafted volunteers from the successful London Lesbian & Gay Switchboard to run the competing National AIDs Helpline, as “Magnus” explained:

I got... drafted in... I suppose that’s reasonably well described. The way I got into that was the government setting up its National AIDs Helpline... and so they needed people who knew what HIV was and how to spell it... and there weren’t that many of us... I was a volunteer with London Lesbian and Gay Switchboard... so the [name of other helpline] and the... Switchboard were the two ways that the National AIDs Helpline was staffed in the first instance.

Institutions also tried to assert control through evaluation. For instance, “Magnus” and his peers “... started doing [an HIV/AIDs intervention] on [their] own as volunteers... we’d attracted funding from local health bodies... increasingly... it was running away with itself... and [the NHS] wanted to assert control and one of the ways they wanted to assert control was through... evaluation.” By controlling the evaluation, the NHS could control not only how the intervention was evaluated but also how that evidence was disseminated and communicated.

### *Social movement lineage*

“Here’s what I would say to history,” said a women’s rights activist, “Thank you, but fuck you” (“Hannah”). The data suggests that social movement actors have a paradoxical and contentious relationship with history, which can constrain and enable social movement activity. When I asked “Magnus” to define innovation, he said:

It is... a... worldview... an understanding of how society works that you are kind of brought up on... that communities can act and change the world around them... is there anything really new in that?... I guess because you’ve always perpetually... on the shoulders of giants... it’s a cross between you know Russian [Matryoshka] dolls and shoulders of giants... like ever higher kind of stacked up.

This passage illuminates two phenomena happening simultaneously: of people standing on the shoulders of giants and descending from their social movement ancestors. “Perpetually” implies these phenomena repeating through time and generations, even “higher kind of stacked up.” Lineage within a social movement context requires further investigation. The data reveals that lineage in different forms affects social movement activity. For instance, “Egon” reflects on working with service user organisations in Africa to develop mental health coalitions. According to him, it has been much easier to develop coalitions in Africa than in the UK due to the absence of historically well-developed discourses.

In Africa, there's generally this enormous gap... just a nothingness in terms of formal services... there's a... cultural... treatment response to mental health problems... if you bring people together... naturally... unforced... they would like to see more access to good quality, not oppressive, basic services... less biomedical... more talking therapies... broadly, psychiatrists would agree... psychologists... NGOs... service users. I would say much easier to... have a common consensus than in this country [the UK].

Participants observed strong “divisions” between social and medical support in mental health services. To provide another example of social movement lineage, prior to the early 2000s, practitioners referred to “cultural mental health,” not global mental health. The term received quite a lot of backlash as critics were sceptical about whether conceptions of mental health can cross cultural borders. “Egon” feels that the name change to “global mental health” frees the field from some criticism but not from historically strong “divisions” between people who think mobilising across cultures to address mental health is possible versus not.

## **Sensing**

The previous chapter examined how study participants make sense of social movements as a concept. This section broadens the frame to making sense of *what is happening* in social movements and identifies four sensing clusters: relating, identifying, evaluating and feeling.

**Table 5.1: Data structure for how people make sense of social movements as experience (continued)**

Category	Clusters	Second-level codes	First-level codes
Sensing	Relating	To people	Sharing interpretations of what is happening, sharing narratives
		To other social movements	Getting inspired, actively learning from, benchmarking, spotting parallels, relating across time
		To other social movement struggles	Sensing other social movements playing out alongside, broader, narrower, smaller, competing, criss-crossing, overlapping in issues/approach/goals
		New to old activism	Identities forming around different issues, organising around memes and slogans, politically active, not physically organised
		To other social change forms	Associating social movements with activism, referring interchangeably (e.g., community improvement, activism, fields, organising, networks, coalitions, campaigns, advocacy), assuming multiple change forms simultaneously
	Identifying	Identifying with	Group, profession, expertise, role, health condition, education level, age, shared family history, majority, minority, personality trait, what I am doing now, profession, lived experience
		Identifying with a social movement	Involved, part of, active in, ally, member of
		Avoiding identifying	Core identity not representative, feeling ashamed "secret vice," desiring to be identity-less ("keeping your nose clean")
		Embodying multiple identities	Assuming different identities in different contexts, having guises, experiencing incompatible identities
		Identity opens or constrains	Acceptable priorities and actions, opportunities
		Identity impacts on	Relationships, behaviours, sense of self, self-esteem, perceived agency, perceived motives
		Assigning identities	To groups of people (e.g., niconistas)
		Characterising identities	Resonance, accuracy, representation, representing what I am, representing what I do, compatible, incompatible
	Evaluating	Personally	Experiencing self-fulfilment, helping people change behaviour, experiencing good health, building agency, transforming identity
		Collectively	Learning how to work together with people who have shared values, connecting people who would not have met otherwise, wide-scale norms change, experts cannot achieve what people have, transforming identities, becoming a field leader, becoming a fast-growing research area
		Politically	Raising the profile of a social issue, changing the global discourse, getting an issue on the legislative agenda, succeeding at influencing legislation, not costing the government, becoming a national policy/priority
		Financially	Reducing costs, achieving hundreds in research money
	Feeling	Positive feelings	Fulfilled, appreciated, supported, enthusiastic, proud, fortunate, privileged, nostalgic, passionate, joy
		Negative feelings	Unheard, grief, frustration, unsafe, afraid, overly critical of themselves, obligated, angry, envious, guilt, shame, despair, helpless

**Relating**

As we saw in Chapter 4, one way that participants make sense of social movements is by relating their social movements to other movements. Participants had a visceral sense of other struggles playing out alongside their own, some of which were broader, narrower or

overlapping. For instance, “Ulrich” talked about experiencing Zimbabwe’s struggle for independence playing out alongside the emerging disability rights movement in the 1980s.

We shouldn’t forget that at the same time in 1980... Rhodesia became Zimbabwe... disabled... citizens... had just witnessed by struggle the change in nationhood... I was invited to the stadium, the Rufaro Stadium, when they became independent as a guest of the new incoming government... so I was able to share those stories of being there... many of the disabled people... hadn’t been there... it kind of felt that we were all on the same side... facing in the same direction... that was very exciting and motivating to be part of, a movement... I remember... sitting in a taxi prior to going into the stadium... the taxi driver said, “Where are you going?” ... I explained about my disabled comrades... he stopped the car, got out... gave me a hug and then put me back in the car. It was his feeling of his “won” struggle... criss-crossing with another struggle... much as he had been oppressed himself by white... so you get this sense of multiplicity...

Participants also relate newer forms of activism to older forms:

... a new kind of community activism... which wasn’t based around community organising but... around social media... vapers who were agitating against the... what was then the Tobacco Products Directive<sup>57</sup>... this was... grassroots activism which wasn’t organised... it was rather disorganised... around concepts... so those slogans were circulating... it was really out there... vapers as... clicktivist, atomized individuals... it wasn’t organised in any... way... we usually understand community activism to be organised... it wasn’t people in organisations with strategies and so on... (“Tannhaus”)

Activism is re-inventing itself through new communication technologies while activists are updating their skills to stay current.

### *Identifying*

Participants identified with social movements in five ways: part of, a member of, active in, involved in, an ally or doesn’t self-identify. According to “Magnus,” people avoid identifying

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<sup>57</sup> The Tobacco Products Directive limits the sale and merchandising of tobacco and tobacco-related products in the European Union.

with social movements because either the identity does not represent them, “it’s just not the thing they do... not the thing they are” or it makes them feel ashamed due to its association with a behaviour or “secret vice.” They might also fear the social or professional ramifications of identifying with a particular social group. For example, in the early days of the HIV/AIDS movement, some “professionals... were keeping their nose clean at work, and going out clubbing at night, but weren’t really involved in the politics.”

As “Tannhaus” points out, social movement identities do not necessarily represent everyone signed up to a practice or behaviour such as vaping. “The advocates are not necessarily representative of the 2.8 million...” he shares. There are advocates and then, there’s, “... everybody else who’s gone to a corner shop or the supermarket who don’t self-identify.” At numerous social movement meetings, I observed disgruntled activists voicing their desire to define their own identity rather than having someone else define it for them. At a conference in San Francisco in 2019, domestic violence survivors said, “People call us activists when in fact we are survivors” (Othering & Belonging Institute at UC Berkeley, 2019).

Participants described holding multiple identities, some of which were relevant to their social movement participation. These identities revolved around a group, profession, expertise, role, health condition, lived experience, behaviour, organisation, education level, age, personality trait or shared family history.

The data also highlighted other phenomena related to identifying such as people “having guises” or “shifting their identities” by assuming different identities in different contexts. In the early days of HIV/AIDS, “Magnus” shares that, “The people doing the academic studies were our mates... and our volunteers in a different guise.” “Claudia” felt that being institutionally “identity-less” or unaffiliated with an organisation opened opportunities to build trusting relationships with people who might have otherwise been concerned about her motives and priorities. It also gave her group the freedom to act in alignment with their own values and priorities rather than those of any one institution.

I think what the architects of this programme... felt was that... having people working in systems would be problematic... so... I was working freelance... alongside [my colleague] who was also a freelancer... using our own email addresses... so we weren't system-based... and actually reflecting on that... that was actually a really, really good move because we didn't belong to an organisation... I think if we'd had an NHS e-mail address, it would have been a different project... I think we would have been bound by different priorities... we wouldn't have been able to do some of the things that we did... it changed the relationship with people that we met along the journey... had we been associated with either... people would have approached us quite differently and been more concerned about our motivation.

Participants felt that social movements can support identity formation and transformation, as highlighted in Chapter 4 (e.g., vaping activists redefining the emerging vaper identity to ensure it has "a more empowered stance" and that vapers are not subjected to the same rules as smokers such as being "chucked out into the world of smokers" outside establishments).

### *Evaluating*

Evaluating the impact on their actions was critical to some participants. "We used to evaluate everything," said "Magnus" because, "... you had to learn from it... right from the start... mistakes... it's a crime not to learn from them." Participants note their social movement activity having an impact on them personally as well as on political and financial outcomes.

Personally, social movements can teach people about themselves. For instance, starting a social movement through HASM helped "Silja" realise that he is a "connector."

I've always done stuff that has questioned and challenged... I've gone on marches at the drop of a hat... that... network of relationships... the potential of that network... for doing different stuff... I think I'm a connector... and I hadn't realised that before...

Collectively, the EIP achieved a collective victory when it became one of the fastest-growing research areas in mental health as well as when it got a repeat of a national priority.



We're an international field leader in terms of... repeat national policy... and a repeat of a national priority... it was a priority in 2002-10... then, we were able to get it back into policy in 2016 in the access and wait time... that's unusual... that was part of our thing about how do you sustain something when the eye moves off the ball... after it moved off the policy agenda in 2010, we saw rapping of early intervention services, reductions in funding... then worked... to get it back in the policy agenda... the funding hasn't quite come in as government said... so there was a meeting to look at, again, how we hold government... accountable. ("Jonas")

Politically, social movement activity was influencing legislation, getting issues on the policy agenda and changing the global discourse. For instance, disability movements in low-income countries changed perspectives on mental health in low-income countries amongst members of a credible global network.

Historically... the membership was entirely made up of European and North American national member associations... now, there's a Pan-African network of people with psycho-social disabilities... strong Indian and Asian groups that sit on the board of the world network... that changed the discourse quite a lot from what was historically a very anti-psychiatry organisation that's mainly about changing the law to make it less oppressive for people with mental disorders... the low-income countries are all about increasing access to services which is... the opposite argument... they've had a real influence... the leadership... said... our perspective of the situation... is not shared by people in low income countries... evolving movements...

Financially, the success of the vaping movement has led to a drop in the number of people consulting smoking cessation services. The e-cigarette "doesn't cost the government anything... it's all smokers... in their hands and their pockets" ("Tannhaus"). We also saw in Chapter 4 how "Egon" valued the hundreds of millions in research money that non-communicable disease professionals have been able to achieve by "organising."

### *Feeling*

The narratives of study participant were rich with positive and negative emotions. I shared these emotions with participants as they expressed them. I felt "Magnus'" joy and nostalgia when 200 men sang happy birthday to him at a sexual abuse conference; "Doris'" anger and

despair when he retold the story of his daughter receiving extraordinarily poor care during a psychotic episode; “Torben’s” enthusiasm for drug harm reduction as well as “Jonas’” pride in developing a new model of psychosis care, one which has led to a significant reduction in suicide right across the UK. I might not feel these emotions in the same way or with the same magnitude, but I felt them. Some participants described their feelings overtly. “Egon” described how fortunate he felt that the global mental health field has “taken off” and enabled him to build a career. He also shared the ongoing pressure he was experiencing within the global mental health field to “develop a common message” and not “overcomplicate things.”

## Planning

In terms of code frequency, the study data is weighted towards acting, facing and sensing. However, planning does arise prominently in the form of aspiring, strategizing, negotiating interests and making complex decisions.

**Table 5.1: Data structure for how people make sense of social movements as experience (continued)**

Category	Clusters	Second-level codes	First-level codes
Planning	Aspiring	For themselves	To achieve wider social change, change the status quo, change something that affects me, go beyond “my own little area”
		For social issues	Social issues (e.g., eliminating smoking, better mental health in the world, zero suicide, reducing stigma and discrimination against people with mental illness, making it possible to talk about mental health, combatting loneliness, a new model of psychosis care, to include mental health in the SDGs, empowering carers of people with dementia, greater health through social movements, greater health), how they work on social issues (e.g., systematically, collectively)
		For social movements	Building agency and ownership, mobilising people, supporting behaviour change, driving investment and attention, having momentum, having sustainability, pressuring for change, learning, tackling overarching issues impacting on health, inclusivity, improving health, scaled impact, aligning movements, accelerating change
	Strategizing	“Assessing opportunities”	Dynamically, identifying gaps (e.g., in organisations that protect and represent people, in professional fields), short/medium/long-term, looking to the future (e.g., predicting trends, extrapolating, envisioning new possibilities)
		Seizing opportunities	Opportunities to do something differently, political opportunities

		Creating new strategic choices	Proactively, courting opportunities with funders, affiliating with many people, organisations and networks to explore opportunities, mobilising people to develop new ideas and collaborative opportunities
	Negotiating interests	Organising people around common goal	Broad common goal, creating space for broad and crystallised goals, balancing a trade-off between membership size and goal specificity
		Acknowledging diverse interests	Dissimilar identities co-existing around converging goals
	Making complex decisions	Drivers in decisions	Driven by values, beliefs, professional principles, evidence, a worldview
		Grappling with tough questions	Complex, moral, steep cost of inaction, incomplete information
		Facing indecision	Goals, issues framings, collective actions
		Taking on risks	Personal, professional

### Aspiring

As we saw in Chapter 4, some participants see social movements as aspirational. Participants held aspirations for themselves, social change issues and social movements. Personally, participants spoke about aspiring to change something that affects them or other people. “Egon” talked about desiring to go beyond “my own little area” to come together to achieve “wider social change.” Within the context of social movements, aspirations people have for specific social issues manifested as both the change they wish to see in the world and the way they desire for people to realise it (e.g., systematically and collectively).

Participants aspire for social movements to build agency, mobilise people, pressure for change, build momentum, accelerate change, learn how to combat a social issue, drive investment and attention in an issue, tackle overarching or “contaminating” issues impacting health, improve health, support behaviour change and scale impact. “Noah” aspires for FundaMentalSDG to “connect” and “align” all mental health movements.

Mental health... there’s a lot going on in very small bits here and there... lots of people are doing the work... oftentimes, people who work... in the same area... are not even aligned. Everyone is basically doing, more or less, their own thing... FundaMentalSDG has been trying... with a really specific aim and target... to align those movements... if you’re a knowledge broker... who connects... on-going movements... hindering those diffusion of innovations is really this fragmentation of mental health...

“Noah” also aspired for FundaMentalSDG to mobilise organisations doing work that impacts on mental health but perhaps, do not see mental health as a central focus in their work. In Chapter 4, we also heard participants aspiring for a social movement to be the solution to better health such by fostering social connectedness amongst people experiencing loneliness.

### **Strategizing**

Strategizing manifests in the study data as a dynamic process of assessing and seizing opportunities as well as proactively creating new strategies choices. When reflecting on the process of accessing and seizing opportunities, “Agnes” says, “We don’t make the weather... we have to use the wind... at every stage... it was a dynamic process... what are the potential opportunities, what are the challenges?” Accessing opportunities involved identifying gaps in existing fields (e.g., a lack of organisations that “protect and represent” people) as well as identifying short, medium- and long-term opportunities. It also involved looking into the future by predicting trends, extrapolating and actively envisioning new possibilities.

Participants were proactively creating new strategic choices by affiliating with many diverse groups of people, having influence in multiple places and courting opportunities with funder. The study data describes leaders of a loneliness movement mobilising people across Manchester into a “Movement of Movements” to explore creative ways to address loneliness in the community, plan collective actions and develop new areas for collaboration.

### **Negotiating interests**

“Social movements can’t be as simple as somebody saying, ‘I’m in that social movement’ and we all identify as having the same interests...” as “Peter” insightfully shares. Participants refer to social movements organising people around common goals. Yet, arriving at a common goal can be challenging especially for groups with diverse interests such as the field of global

mental health. “Torben” describes a broad unifying goal supported by “constellations” of activity pursuing related goals.

There are now 100s of people around the world who are working together in various sort of constellations of activities essentially pursuing the sort of broader idea of better mental health in the world... and sometimes it's as broad as that, sometimes it's more specific, saying it should be better mental health services or the quality of mental health care should be better or more people who have mental health difficulties should be getting better treatment. Sometimes it's crystallised, sometimes it's broad but it's around those sorts of ideas.

Sometimes, the “constellations” represent other social movements which vary in membership size, scope and scale. Within Social Care Future (#socialcarefuture), “Mikkel” describes the concept of “converging goals.” He says, “I know plenty of people who wouldn't identify with me or what I'm trying to do, but... are probably largely convergent in terms of goals... they might not like me, but... their goals are not too dissimilar to mine, you know?” Thinking of social movement member interests converging is practically helpful when balancing goal specificity and membership size.

### *Making complex decisions*

Participants were grappling with complex questions, such as: Can the field of global mental health mobilise across cultures where there are diverse cultural conceptions of, and responses to, mental health? “Egon” shares one of the steep downsides to inaction:

[Culture] is a massive issue that we really need to address but that shouldn't stop us from doing anything... people were saying you can't do this... culture is so different... we were willing to pay the price... allowing people to continue to be chained in their communities which was happening for... years.

Participants shared taking on personal and professional risk if it meant doing the “right thing.” “Jonas” and her colleague almost became unemployed when she contested legislation emerging from another arm of government that could negatively impact millions of people:

One arm of [our organisation], a different arm to ours, was producing mental health legislation. The way the draft was put out would have quite negative implications... so we wrote a criticism of it... we sent comments in... we almost lost our jobs... we were definitely yellow carded... almost red carded... we'd broken a rule... it was a member of the club criticising another member of the club's activities... even worse, we wrote it on [letterhead] paper... we went right to the top... we had to go and see very senior people and were duly told off... and had to be very penitent for a while... luckily, we had a good boss who was very supportive and knew what we were trying to do... one of the joke things that he always said was... most people, when they do something wrong... are genuinely penitent and... really do try to change their behaviour... I haven't... seen that with either you or [your co-lead].

Participants decisions were driven by values (e.g., honesty), beliefs (needing to uphold the value of legislation), professional principles (e.g., the needs of the people matter most), worldviews (e.g., that people can act and change the world) and evidence (e.g., scientific, lived experience). "Ulrich" talked about risking a trusted relationship with an organisation to meet with its beneficiaries who were feeling patronised by the way in which they were being treated.

I remember sitting in Zimbabwe in a room... like a train garage... seats on one side... seats on the other... you face each other... that was the whole room... we were there unbeknownst to the paternalistic disability organisation that I was a guest of... they were an organisation "for" disabled people... talking about an organisation they wished to create "of" disabled people... so those two little words... "for" and "of" then became... a major prescription for me in terms of what I felt was important... they were physically disabled people... they were not intellectually or mentally ill... rebelling against the organisation... "for" them... that they were beneficiaries of... yet, the patronising way in which they were being treated as adults had really left them feeling bad.

## Summary

This Chapter provided an experiential view of health social movements. After investigating how study participants refer to "experience" in the interviews – as expertise, lived experience, learning and the impetus for a social movement – we explored the emerging conceptual categories of the social movement experience. Chapter 7 explores the explanatory power of

theories of experience in light of our study data. Chapter 8 opens exciting avenues for deepening the social movement experience concept. In terms of where we are in the research journey, investigating the social movement as *experience* provides one lens through which to examine a social process such as innovation.

## Chapter 6: How people make sense of social movements as innovation

### Introduction

A conceptual and experiential view of social movements enables us to look more deeply at innovation through the eyes of study participants. We are now in a position to respond to the research question, “How do people make sense of social movements as innovation?” This Chapter presents how study participants perceive innovation and identifies twelve of social movement actions that aid innovation development and diffusion. Just as innovation often requires an “initial leap of faith that can be validated or discarded on the basis of results” (Fusar-Poli et al., 2017), identifying the twelve actions required viewing the data through an innovation practitioner lens and then, consulting the social movement and innovation literatures to explore their explanatory power in light of study findings. The discussion surrounding consulting the existing literature is reserved until Chapter 7 to maintain clear boundaries between data reporting and analysis.

Table 6.1 organises findings into a data structure with five levels of abstraction – first-level codes, second-level codes, clusters, categories and concept with first-level codes representing line-by-line codes. The words of study participants are retained to maintain their voices in the analysis and presentation of study findings. When possible, findings are also phrased as gerunds to maintain a focus in the data analysis on actions and on what is happening (Charmaz, 2018).



**Table 6.1: Data structure for how people make sense of social movements as innovation**

Concept	Categories	Clusters	Second-level codes	First-level codes
Making sense of social movements as innovation	Perceiving innovation	Innovation as "new"	Newness valued over "what works"	In this category, the "clusters" represent first-level codes. The second-level codes were identified only after the "clusters" were grouped into the category, "perceiving innovation." Overall, this process represented a top-down data analysis process.
			Galvanises excitement for innovations	
			Results in people "dressing up" solutions as new	
		Innovation as having "lineage"	Places value on solutions that work	
			Acknowledges social change ancestors	
		Innovation as a "magic bullet"	Supports search for "one-size-fits-all" solutions	
			Search for magic bullet presides over scaling solutions	
		Innovation as progressive	"Working with people is cyclical"	
			Understanding of social issue incrementally improves	
		Innovation as "profit-generating"	Supports search for profitable solutions	
			Innovations constrained by profit requirement	
		Innovator as lone genius	Creates unrealistically high expectations for innovation	
			Innovator identity alienates people	
	Innovation as tied to scaling	Innovation prioritised over addressing urgent needs		
		Innovation development and diffusion as intertwined		
	Innovation as an obligation	Innovation creates pressure to innovate		
		Minimises the value of solutions that work		
	Identifying actions supporting innovation	Making sense of lived experience	Making sense of own lived experience	Sharing stories, relating, understanding
			Empathising with the lived experience of other people	Listening, understanding, identifying
			Identifying needs from lived experience	Articulating needs, understanding needs
		Raising the profile of an issue	Associating higher profile issues with	Monetary resources, public awareness/attention/interest
			With the purpose of	Securing resources, raising awareness, attention, interest, solving issues urgently, getting on policy agenda
		Setting aspirational innovation goals	Inspiring people to get involved in innovation	Developing, improving, implementing innovations
			Counteracts mindsets inhibiting innovation	Low expectations, outdated, fixed, incremental
		Spreading an optimistic mindset for reform	Supports resource recruitment to innovation	People, funding
			Counteracts mindsets inhibiting innovation	Pessimistic, transitory
Inspires on-going participation in innovation			Incremental, transformative, scaled	
Contagious scale shifting geographically			Nationally, internationally	
Contagious scale shifting to other social issues			Spurring reform and movements, adapting innovations	
Identifying with thinking differently		Thinking differently as a "feature of identity"	Individual, collective	
	Thinking differently from	Establishment, status quo		
	Thinking differently by	Building on the ideas of others, putting ideas together differently		

	Thinking differently to	Respond rapidly, address a social problem in a new way
	Searching for other people who	Want to think and do things differently, can do things differently
Maintaining an informal identity	Informality as a feature of identity	Individual, group identity
	Informality enabling	Recruitment, inclusivity, unscripted conversation, rehearsing arguments, developing ideas, spotting implications, avoiding institutional interference
Contributing to an evolving "commonwealth of skills and knowledge"	People sharing their skills	Voluntarily, openly, rapidly, generously
	People joining up with people to	Combine skills, complete specialist tasks, develop solutions
	People seeing their skills repurposed	For unexpected purposes, in unexpected ways
Making strong and weak ties	Making strong ties	Acting in solidarity, experiencing shared conflicts and victories, developing trust, building lasting relationships, showing support, appreciating people, identifying similar values
	Making weak ties	Exchanging ideas, sharing knowledge
Forming and acting in communities and networks	Forming and belonging to communities	Common lived experiences, issues, identities, belonging
	Forming and participating in networks	To connect, share a common interest, build bridges, complete tasks requiring collaboration, manpower
	Simultaneously acting in communities & networks	Mental Health Innovation Network – community of innovators sharing resources & ideas for innovations
Framing issues and debates	Framing what?	Social issues, debates surrounding social issues
	Framing to?	Shift public discourse/perception, shift self-perception, raise awareness, alter social norms impacting on collective action, build consensus
Developing ideas and "innovative" solutions	Developing ideas and solutions	For themselves, collectively, beating the odds
	Developing solutions to grow the movement	Identities, campaigns, tactics, symbols, communication and mobilising strategies, evaluation approaches
	Developing solutions to social issues	Products, health services, care models, training, workshops, information resources, legislation
	Utilising problem-solving approaches	Letting a thousand flowers bloom, "having multiple things on the go," DIY experimentation.
	Supporting idea and solution development	Setting up funding programmes, innovation networks
Advocating for "innovative" solutions	Advocating for	Solution engagement, solution adoption, a voice in innovation development, the right to innovate
	Advocating for solutions by	Creating organisations, working through powerful people and institutions, demanding assistance

## Perceiving innovation

“How would you describe a horse galloping on a tomato?” I often start my innovation workshops by asking participants this question. Participants start responding – a giant circus horse galloping on a tiny tomato or a horse galloping across a tomato red sea. Their answers highlight the subjective nature of ideas – that two people can see the same idea very differently. Asking people to describe “innovation” is no different than asking people to describe a horse galloping on a tomato. People innovate across a range of settings and for diverse purposes, leading to different conceptualisations and practical applications of the term. Understanding how study participants perceive innovation is our first point of departure. Their perceptions converge around eight themes – innovation as new, having lineage, a magic bullet, progressive, profit-generating, lone genius, tied to scaling and an obligation.

### **Innovation as new**

Participants often refer to innovation as something new, whether it be new ideas, products, services, approaches or new ways of thinking and acting. “Novelty... is... in the eye of the beholder” according to “Magnus.” “Adam” shares that, “Innovation to me is about new ideas and ways of doing things.” On more than one occasion, participants interpreted my questions about “innovation” as referring to what was “new” about what they were doing. For instance, “Magnus” said, “I try to keep coming back to your question about what was new.” For some participants, doing something “new” meant doing something for the first time. “Tannhaus” talked about when a group of heroin users (“junkies”) in Rotterdam setup the first needle exchange scheme to protect against hepatitis B (Friedman et al., 2007).

The drug users were ahead of the experts... the first needle exchange scheme in the world was setup by the junkie bond drug user union... in 1981. They were demanding the city provide them with syringes. They were doing it before anybody else thought of doing it.

The junkiebond drug user union was setup in reaction to a proposal to detoxify drug users by force (Friedman et al., 2007). The underground needle exchange programme quickly gained widespread public support with local authorities deciding to implement it at scale six years later in 1987 (Jong, 1987; Jong & van Noort, 1987).

Going back to innovation as new, for other participants such as “Adam,” innovation does not necessarily need to be novel, “... it can just be saying... this is an approach that has worked in the learning and disability field... let’s try it in a different disability field... if it doesn’t work well there, you’d probably still learn something.” In other words, innovation can involve applying an existing approach in a new setting, becoming innovative in its application versus its content. Similarly, “Adam” illuminates that innovation might involve excavating approaches from other fields or combining multiple approaches and testing them in a new field or setting.

The innovation... the BasicNeeds model<sup>58</sup>... is a collection of approaches that have been used for decades, if not millennia... in the development field and in other fields... what [the founder] did was say, I’m going to apply these to mental health... people at that time, didn’t even see it as an area of need or if they did, they thought it was... too... complex to be worth trying... what [the founder] did was demonstrate that something could be done at relatively low cost that would have a positive impact and hadn’t been done before in that sector... self-help groups and livelihoods... all the other bits and pieces of the... model... have been used across... every geographical setting and for decades.

Within the field of restorative practice, “Winden” worries about health professionals referring to something as “new” because he recognises that most ideas emerge from prior approaches.

We’re pretending that we’ve invented something new... I think there’s a real danger in saying we’ve suddenly invented something that’s never existed before. The truth of it is that this is as old as... any social work practice or social pedagogy... if you look at the

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<sup>58</sup> The BasicNeeds model consists of capacity-building, community mental health, livelihoods, research and collaboration; as an organisation, BasicNeeds has enabled over 650,000 people with mental illness and/or epilepsy across 12 countries in Africa and Asia to access treatment, earn an income and successfully re-integrate themselves into their families and communities (Mental Health Innovation Network, 2020b).

Victorian philanthropists and their writings... Mary Carpenter in 1863 was saying... with the child... don't do things to them. She was absolutely restorative in her approach.

Referring to something as "new" could be perceived as naïve especially if a solution stems from a much longer lineage.

### **Innovation as having lineage**

"Magnus" references AIDS map as another example of an innovative solution having lineage. AIDS map is an information resource developed in the 1970s by people volunteering for the London Lesbian and Gay Switchboard, one of the first UK helplines for people with HIV/AIDS. The volunteers developed AIDS map in response to a growing demand for information regarding the unknown disease and to help people stay up to date on the rapidly proliferating knowledge base.

As the effect on our communities became apparent, we collated and maintained a detailed manual of the latest and most up-to-date information available. We not only shared this with the many frightened callers to our helpline but also with the general public. (Switchboard LGBT+, 2020)

By the 1980s, the helpline had become the "leading source of information on the new and unknown disease" (Switchboard LGBT+, 2020).

What was designed as the health manual for the Switchboard went on to become the National AIDS Manual and now, AIDS map. It's a very... innovative HIV/AIDS information resource... from the outside... looked innovative and new but it had a... lineage... you could trace it back... through various other... groups... through, you know, the feminist movement, the gay and lesbian movement of the early 1970s. ("Magnus")

Innovations do not always feel innovative to people like "Magnus" who are aware of their much longer history. Furthermore, innovations can influence future innovations and innovators.

A new EIP care model, for instance, is influencing future EIP innovations and innovations in analogous issues such as anti-stigmatisation, suicide prevention and mental health literacy.

The development of early psychosis services is expected to be a breakthrough for many issues in Japan, such as the anti-stigmatization movement, the prevention of suicide in younger generations, and the development of early interventions for psychosis itself and the promotion of mental health literacy in general. ("Jonas")

The above passage suggests that innovations have continuity in the sense that they are influenced by past innovation and influence future innovations.

### **Innovation as a magic bullet**

Participants working in mental health and restorative practice referred to innovation as the search for a "magic bullet." "Egon" feels that this search detracts from getting solutions to people who lack access to and urgently need them.

When we talk... about innovation, we haven't scaled... hardly anything... we need to put a bit more energy into refining and investing in scaling the best of what we already know... and not constantly falling over ourselves trying to find some magic bullet.

"Egon" also proposes why the search for a magic bullet is fruitless in a mental health context.

Mental health is a bit different from... other areas of medicine because there's unlikely to be a magic bullet... these are socially derived problems... they're in-built into our humanity some of them... our behaviour... our genes... very diverse mental health problems in communities... from general distress in a population after... a horrible accident or rape or... war... to people with severe schizophrenia who need medical support... drugs.

Social movements are social and often address socially derived problems embedded in relationships.

### **Innovation as progressive**

Some participants, such as “Winden,” perceive innovation as progressive, yet:

The whole of intervention with people is cyclical... if you look at house building or the development of iPhones... it's... progressive whereas working with people, we change what we're doing because of the political, economic, social climate of the time rather than saying, “We're doing it better”... aggregated improvement... if you talk to people who've been around... they'll say, “Yeah, we did that in 1983”... we've suddenly come back to it... we might call it different... it might be better in terms of understanding... it might feel a lot better... but actually, the intervention's the same.

Social and relational problems demand social and relational solutions. As “Noah” said, “The solution to people is people not things!” The value of these social and relational solutions is not necessarily measured through incremental performance improvements.

### **Innovation as profit-generating**

Some participants talked about drawing on for-profit innovation frameworks in their work.

These frameworks proved problematic for practitioners such as “Egon.”

One of the biggest challenges with putting an innovations framework onto mental health is the whole profit issue. That might be covered by frugal innovation but... it's quite a lot of talk around the money side of things which is really important actually but... we're fairly unlikely to get... something that actually turns a profit... that makes it [mental health] ... a more difficult area to grow.

“Winden” says that social problems require “relational” solutions: “The intervention has to be based around a relationship.” Therefore, social and relational solutions are not always “marketable” or “profitable” (“Egon”). As “Winden” says, “I cannot give you a box of relational practices... I can't sell you the value of working with people. It isn't a marketable thing!” What he can give, he says, are principles about how to approach relational practice.

Profit constraints can also prematurely weed out effective solutions. Thrive UK utilises social therapeutic horticulture, an approach rooted in scientific evidence which brings people together to reap the health benefits of gardening. If Thrive's founder had limited himself to solutions that generate a profit, he would have missed the opportunity to introduce horticulture and ultimately, improve so many lives.

### **Innovator as lone genius**

Just as people associate social movements with charismatic figures such as Dr. Martin Luther King, they associate innovation with figures like technologist Steve Jobs.

[Innovation] can be a bit... loaded... people can see innovators as the Jeff Skolls and Steve Jobs of the world... that can make it feel so big... people don't think they can ever be an innovator... they just think that is something other people do. "Katarina"

Associating "innovation" with luminary figures can inspire people but also, create unrealistically high expectations for innovation, making it feel unattainable and inaccessible to most.

### **Innovation as tied to scaling**

"Egon" describes "facing a curse of innovation" where innovation is happening for "innovation's sake." This curse, for example, leads to prioritising mental health innovation over scaling existing solutions to every person who needs them across the world.

There's a little bit of a curse of innovation going on... the ideas that we have about what is needed in reform, about how that might be done, basic tenets of our movement... hasn't changed in about 15 years... global health is largely about equity... access... cultural appropriateness... acceptability of treatment... the 2001 WHO report *Mental Health: New Understanding, New Hope* said we need to de-centralize services, close down institutions, give people more rights, do something about the horrible abuse... make sure the best evidence-based care is available... in an affordable, locally appropriate way... we need to... have clinicians available in most primary care



centres... we're only doing it in a quarter of the world... if that... so innovation is a good thing but not just for the sake of innovation.

Instead of seeing innovation and scale as mutually exclusive, "Torben" suggests that innovative thinking can be directed to scaling mental health innovations.

They're not so separate things [innovation and scale] ... even if one said rather mechanically, "We know what to do... let's just do it... we don't need innovation... we don't need more money spent on new things." We actually don't know how to scale up... very precisely or reliably. One could say, "Let's ensure that forms of effective screening are available in primary care to people who have TB [tuberculosis] or HIV/AIDs around the world." There's still the question about developing innovative ways in which that could be achieved... it's not as if... there's old knowledge and new knowledge because they're inter-twined so intricately.

"Tannhaus" describes that the design of an innovation, such as a nicotine delivery device, can impact on its adoption rate.

You've got e-cigarettes, but you've also got heat not burn... [which] makes it easier to switch from smoking... the taste is very similar to tobacco... the hit... the blood nicotine levels... emulates the 5-minute cigarette. The e-cigarette is more grazing... so people might take 300 puffs of an e-cigarette per day without having a burst... that's why it doesn't work immediately for everybody... because you've got to learn a new way of using... if you're moving onto something else, you're looking for that.

Developing an innovation which offers a similar experience to smoking can make it easier for people to use it, adopt it or switch to it.

### **Innovation as obligation**

Feeling an obligation to innovate, such as from funding organisations, can lead health professionals to mask their work as innovative to ensure funding for work that is essential to people and that might not otherwise get funded, as "Katarina" describes.

Most of the time in social care in the UK... you would have to “dress up” what you were already doing as innovative... for funders to put money into it... it just felt like a game... to get ongoing funding, you had to... scratch your head and think about some aspect... that could be presented as being innovative... or bump onto it... to make it look innovative just to keep the core service funded.

This obligation to innovate can undermine, or minimise the importance of, solutions that work.

I’ve worked in a lot of sectors where we didn’t need innovation... we just needed something that worked... that’s valued by the people... they don’t want... something new and sexy and innovative... they just want what we know works... and that’s... typically in social and mental health services... groups of people coming together who can give one another support in some way... and that’s not sexy and exciting.

That brings us to the end of our contested tour of participant perceptions of innovation. The data reveals obvious discomforts, especially amongst health professionals, with the term “innovation.” Chapter 7 will investigate the implications of participant perceptions. Now, we turn to identifying participant actions aiding innovation.

## Identifying social movement actions aiding innovation

This section identifies twelve social movement actions aiding innovation development and diffusion. I identified them by reviewing the data through an innovation practitioner lens, coding actions relating to innovation and organising those actions into more abstract categories.

### **Making sense of lived experience**

When Clara was diagnosed with breast cancer, she found herself waking up from a biopsy with her doctor looming over saying, “Well, it’s cancer! Do you want me to cut it off now or in a couple of days?” Feeling outraged, she chose the second option. After the surgical procedure, she recounts the follow-up appointment with her doctor:

"You really need to have reconstructive surgery." And I said, "Why?" And he said, "I have seen many a marriage founder on the shoals of a mastectomy." And I thought, "Okay. I'm gay. Now how do I explain this to a guy in a way that doesn't make it sound like my body's not important in this relationship... and I got so confused trying to figure out how I should respond to him... that I lose the opportunity... if I had not been a lesbian... I probably would have killed myself or started drinking." (Klawiter, 2004)

Twenty years later, Clara reflected:

My body was my body. And certainly I went through all the consciousness-raising groups in the seventies and... certainly, the women's movement and all that stuff that we were going through in the seventies gave me the words and concepts to be able to understand how I felt about this stuff... and if I hadn't been freed from it by the women's movement, then I just would have... I wouldn't have questioned it... if you don't have the words to express how you feel, you're really kind of stuck with the feeling. And that's what I got out of those early years and it definitely... definitely created my response to the cancer experience. (Klawiter, 2004)

Mobilising can give people the chance to share their experiences and listen to the experiences of others. It can also help people understand their own experiences and develop an understanding of their own needs. I experienced this personally when I attended ACEs movement meetings where I encountered people at various stages in their healing with whom I developed a bond. One person said to me, "Jackie, just by being here, you are doing the work." A leader of a UK charity organisation recently asked me to name a bottom-up movement that had "actually" been successful. I was stunned by the question because in healthcare, we talk a lot about helping people manage their own health and well-being. Participating in these groups helped me, and so many others, do just that. The way that leader measures success is incongruous with the way a person participating in a social movement might measure it.

Participants shared their strategies for empathising with people such as working with people, listening, building relationships and putting people at the centre of their work. "Magnus" exhibited empathy by acknowledging all risks people were facing in addition to the risk of HIV

transmission: "If you were cruising... there was only one risk you faced [HIV transmission]... but getting queer bashed... or... arrested were probably more front of mind... we want to look at all those risks." Formal research also aided empathy-building such as research on understanding how people develop and navigate their strategies for safe sex.

You decide... how safe you want to be... it's not up to the doctor or charity to determine that for you...so, we had this survey about what people's pre-contemplated strategies are... and how well they were able to adhere... and what their failure rate was... to our surprise... people who had the most rigid strategies had the lowest relapse... oh yeah, "I always know the status of the person I'm having sex with"... oh right, "Gosh, does that work out for you?"... the more... nuanced AIDs strategy, the lower the level of adherence or the higher the level of relapse. ("Magnus")

### **Raising the profile of an issue**

According to "Noah," Time to Change and other mental health movements have helped raise the profile of mental health as an issue.

What we see in the UK in the last 10 years... campaigns that de-stigmatize and raise awareness of mental health... are gaining traction and have helped put mental health on the agenda. Yesterday, there was on BBC, biggest of its kind. Impressive... the media is more and more willing to pick the subject up.

Participants associated higher profile issues, and the success of their social movements, with more attention and resources as well as whether an issue makes it onto a policy agenda. The autism rights movement emerged when mothers of children with autism took it upon themselves to learn about the condition, raise awareness and fundraise to start their own organizations. A global mental health researcher, "Egon," comments, "You know... its hundreds of millions of research money. We haven't been able to do that at all in other areas of mental health." If an issue makes it onto a policy agenda, the challenge then becomes "sustaining it as a target" ("Jonas"). Aspirational goal setting and communication can help achieve this.

### **Setting aspirational innovation goals**

Participants held many aspirational goals, such as achieving zero suicide. Sometimes, these aspirational goals are directed towards developing innovations. In the early days of the EIP movement, “Jonas” shares that “a group of 5 of us... really wanted to set out a model for psychosis care.” They used this aspirational goal to get people invested and involved in achieving it. It also gave people permission to think differently and was facilitatory in helping them achieve it. At an EIP event in 2018, sponsored by NHS England and NHS Improvement, the new EIP model was referred to as, “The great innovation of the last 10 years... the most positive development in mental health services since the beginning of community care” (Rethink Mental Illness, 2018). Innovating a new EIP model helped people let go of mindsets inhibiting reform. It provoked hope and dissolved pessimism, doubt and fear. “Innovation is a vital ingredient if we are to dispel the ‘soft bigotry of low expectations’ and the palliative mindset of traditional mental health care” (McGorry, 2015).

### **Spreading an optimistic mindset for reform**

The mental hygiene movement in the 1920s generated only “transient and illusory optimism” for early intervention in psychotic disorders. Up until the 1990s, psychotic disorders were still, “the furthest thing from the minds of clinicians and researchers;” in the early intervention field, “deep pessimism had reigned” before groups of practitioners dedicated themselves to changing the field (McGorry, 2015). The EIP movement not only became associated with the creation and adoption of a new EIP model but also, the diffusion of an optimistic mindset supporting reform which drove participation and commitment to the overall effort (McGorry et al., 2008). That optimistic mindset, coupled with the EIP care model innovation, has spread nationally and internationally and is inspiring continued reform in EIP as well as in other mental health disorders.

Since the early 1990s, this hitherto barren landscape [for EIP], has seen the growth of an increasingly rich harvest of evidence, and widespread national and international efforts for reform in services and treatment approaches, setting the scene for more serious efforts in early intervention in other mental disorders. (McGorry et al., 2008)

Social movements for other mental disorders have emerged, spurring innovation in issues such as suicide prevention (McGorry et al., 2008). Professor McGorry, an EIP leader from the UK, was invited to speak at the 104<sup>th</sup> Japanese Society of Psychiatric Association where the meeting organiser shared, “We hope that the message... will become an epoch-making event for future early intervention movements in our country” (Mizuno et al., 2009).

### **Identifying with thinking differently**

Numerous participants shared their stories of connecting with other people who wanted to think differently from the establishment or status quo. “Magnus” said that thinking differently was “crucially important” to the HIV/AIDs movement and that “... it was all about thinking differently.” Thinking differently, he said, was “an identifying feature” and “a feature of our identity.” To him, thinking differently meant, “... having the same bits of information but putting them together in a different way... the way you allow ideas to bubble up.” To other participants, thinking differently meant building on the ideas of others.

The impetus for thinking differently was solving issues in new ways, sometimes *urgently*. During the height of the HIV/AIDs crisis, people were rapidly inventing new ways to make an impact such as by delivering workshops for men in saunas to reduce HIV transmission risk.

One guy who used saunas said, “Well look, this is good, but we need something different for saunas cuz the risks are different, and the opportunities are different.” And then somebody said... “If we’re gonna run a training course for... men having sex in saunas... why don’t we run it in a sauna?” For public health at the time, it seemed really... off the wall... and innovative to be doing that kind of workshop... but we were working with what we had and getting our hands dirty, literally in some cases.

A thinking differently identity facilitated new ways of working and responding to dynamic situations. "Magnus" reflects that some of the processes his group used decades ago to generate ideas outside of the establishment are still in use today *within* the establishment.

I still use some of those... with my team in Public Health England... to... write up ideas in a succinct way. I've been using them for 30 years... so they're older than that but at the time... it was fairly different from... the banks... councils... places where we worked.

A thinking differently identity also mobilised people who wanted to think differently. EIP movement members not only mobilised people wanted to do things differently but also, people who could do things differently in similar ways across cultures, as "Jonas" describes.

We used the same... tactics for trying to grow early intervention in Japan... a hierarchical, controlling system... working with people who could operate like us in terms of how we work with families... professionals who were willing to step out and do things differently.

"Claudia" believed that mobilising people who think differently can lead to new outputs: "If you get creative people who can scope something... and then, they connect with other creative people that between you, you can construct something... build something." For instance, the HIV and AIDs movement attracted researchers who wanted to think differently about how to do evaluation, as "Magnus" describes:

The researchers would go native... they were so excited by the stuff that we were doing... they would look for equally innovative ways of evaluating... we... started off in a stall... then we got an ice cream van... we'd park in the parking lot... guys... would be offered condoms and lube... we used to produce these very sexy postcards with sexy images on one side, and safe sex information on the other... people would... collect the set so we would release different ones through the summer... I remember people complaining about not having anything to keep them together... so we put a wrap-around... I remember someone said, "Why don't we have a questionnaire on the wrap-around?" ... we could have people fold it up and send it by free post... so we did that... we could make contact with 2000 men in a single night... it was before internet-dating... guys would be queuing up... and also hanging around to chat.

The data shares numerous instances where researchers and activists worked closely together to develop innovative forms of evaluation.

Sunday afternoons... we would get a group of volunteers up to Heath with bean bags and picker-uppers and... clear out the condoms that had been left there from the night before... so... the people who were evaluating... they wanted to... observe our interactions... see how people were responding to us being there... but then they saw these bags... full of used condoms and they said, "This is gold dust... this is data, you've got bean bags full of data." They opened the bin bags on the floor of their offices... sorted them by what proportion of the materials... were coming from us versus elsewhere. ("Magnus")

### **Maintaining an informal identity**

Informality was yet another identifying feature of social movements, for some participants. EIP movement leaders felt that informality aided recruitment and inclusivity as it made people feel comfortable and welcome.

We never said no to anyone. If someone came arbitrarily, we just said, "Come along." We weren't exclusive saying oh... we can only have the regional leads. Sometimes we'd be at a meeting and I'd say we're going onto an EIP meeting and someone would say, "How'd do you get to that?" I'd say, "Well, come along and see." It had an informality to it... very inclusive. ("Jonas")

According to the data, informal spaces also give people the chance to refine their thinking, build consensus and play out the implications of potential solutions. "Winden" echoes that informality allows for "unscripted conversations."

One of the things I believe in is... the notion of unscripted conversation as a way to come to a different view of how we do things. I deliberately didn't want to be... we'll do this and then we'll do this... what's important is people saying yeah, that's interesting... they can actually talk to each other. I think the other thing is... if we formalize stuff too much, all we do is we hand over a really interesting idea to... an organization who... they have their organizational norms... rules... governance... they... see how it works... and they start trying to market something... let's just talk to each other in a way that develops work with children... families... adults... communities.



In this case, informality also enabled groups to avoid institutional interference or early co-option of their ideas. In other cases, informality enabled building a collective vision and “rehearsing” arguments that would eventually become part of the orthodoxy. As “Jonas” shared:

The power was... in the arguments we were rehearsing and the sort of vision we set out was... influencing one of the people in that group who made a meteoric rise to the Department of Health... he took that with him and eventually... two years later maybe... he rang up and said, “You know... you called it Emperor’s Clothes, how would 50 million sound to you?” He’d taken all of the ideas as a new way of doing [EIP]... and so we became part of the orthodoxy.

### **Contributing to an evolving commonwealth of skills and knowledge**

As the HIV/AIDS epidemic intensified, more people got involved in the HIV/AIDS movement, bringing their skills and knowledge.

When their friends began to get sick, they began to think, “I’ve got to do something here.” They were doctors and lawyers and retailers... they brought their skills and their commitment more than their money... but then again, they also brought quite a lot of rich friends. (“Magnus”)

People shared their skills and knowledge voluntarily, openly, rapidly and generously. They contributed to specialist tasks such as producing printed materials to educate people about the disease or designing a survey to better understand risky sexual behaviours. They also joined up with other people to respond to opportunities requiring a combination of skills and knowledge. For instance, people with knowledge of bondage safety joined up with training experts to produce the first of its kind Bondage for Beginners course. The London Gay & Lesbian Switchboard was one of many places where people collaborated with other people as well as repurposed their skills.

There was... a commonwealth of skills and knowledge that were... getting shared rapidly... so the London Gay and Lesbian Switchboard was a kind of a hothouse... warehouse exchange place for skills where people were bringing skills from other parts of their lives and kind of repurposing them and sharing them out again. ("Magnus")

It was not uncommon for people to see their skills used for unexpected purposes.

It was interesting how the skills got spread around... one woman was particularly generous in the way that she shared her skills. She was an equal opportunities trainer... black lesbian woman... had she known that her skills were going to... be... used to run gay men's masochism training, she probably would have been surprised. ("Magnus")

This passage relates to the metaphor in Chapter 4 – that starting a social movement is like "kindling a flame." When a person contributes voluntarily to a social movement, they might also let go of how their contributions evolve and spread.

### **Making strong and weak ties**

Through their social movement involvement, participants made both strong and weak ties. Strong ties are intimate relationships, possibly long-lasting, with whom ones spends time regularly; they enable tacit knowledge exchange and high degrees of trust (Dal Fiore, 2005; Fagerberg, 2013; Ghoshal et al., 1994; Granovetter, 1973; Hansen, 1999; Rost, 2011; Szulanski, 1996; Uzzi, 1996). They can foster feelings of solidarity and a commitment to collective action (Della Porta, 1988; Diani & McAdam, 2003; Krackhardt, 1992). Weak ties are people outside personal and professional networks (Granovetter, 1973; see also Fagerberg, 2013). They offer access to diverse information sources, perspectives and opportunities (Dal Fiore, 2007).

As a researcher, I experienced some of the strong ties between people in social movements. Two study participants had been through a lot together, from almost getting red carded to strategizing in pubs to taking a Whitehall politician to a Wacky Warehouse. The way they talked

about one another suggested that their common victories and struggles had brought them closer together, with one asking me to send a text to the other during their interview saying, “You’re a country bumpkin!”

To “Claudia,” the value of starting a social movement was in meeting people outside of her network with whom she shared similar values.

I met all kinds of people like you... people who I wouldn’t have ever really met who... I will continue to... work with... I think that was the real value.....and it shows me that the strong thread about this is... how people work together who have shared values.

Some of the relationships “Claudia” formed have continued beyond the life of her social movement involvement, with weak ties transforming into strong ties.

As we saw in Chapter 4, TTC is facilitating social contact, or weak ties, amongst people with mental health conditions. Since TTC began, an estimated 66,911 people have made a friend outside of the mental health sector, enabling people to expand their social networks outside self-help groups (Time to Change, 2011). Furthermore, the story about celebrity activist Liz Taylor being connected to one of the founders of Gay Men Fighting AIDs (GMFA) is another example of a weak tie in the sense that, according to the grey literature, Liz opened up numerous opportunities for the HIV/AIDs movement through her celebrity platform such as by setting up a programme to distribute experimental HIV medication in the early 1990s and raising millions of dollars for the cause.

### **Forming and acting in communities and networks**

Participants were active in both communities and networks operating at various levels of scale – locally, regionally, nationally and globally. The data suggests that communities form when people come together who have a common identity or lived experience. Communities of people also shared similar backgrounds, such as politically active parents, or attributes such as

being young or well-educated. "Magnus" talked about being involved in an effort to form communities.

One of the conspicuous innovations I was involved with was the... community mobilisation approach, as we called it... in my case, the London... gay male community... in changing... the crisis it faced... popular academic things like Jeff Kelly's Gay Heroes study... a randomised control trial at the level of the small city... you had to have a population of at least a quarter of a million... like 60 miles from the nearest other city of comparable size... they... randomly allocated... got a standard information thing and the others got a... process design doc identifying community opinion leaders, training them up and getting them to act as advocates.

The Mental Health Innovation Network (MHIN) refers to itself as both a network and "community of mental health innovators... sharing innovative resources and ideas to promote mental health and improve the lives of people with mental, neurological and substance use disorders" (Mental Health Innovation Network, 2020a). It is supporting the development, testing and accelerated scaling of ideas and innovations. Anyone can submit an innovative resource or idea to an open-source website or innovations database. Each resource or idea goes through a selection process.

We have standards. We expect certain things like measurement of outcomes... but... you don't have to have a randomized control trial (RCT)... which is really important because most good work isn't done by RCTs... it's done by people who have a 20-year history of working with people in Southwest Nigeria... no one's ever bothered to ask them what they do and how they do it... we provide them with a theme... an accessible enough way of writing something up... that asks some... questions... does it work? how much does it cost?

MHIN is attempting to break down power dynamics and interrogate Western research standards. It is also stressing the importance of developing innovations

## Framing issues and debates

In the interviews, participants were contemplating how to reframe global mental health to secure greater investment. The Lancet Commission published some of these reframes, such as framing global mental health as a rights-based, wellbeing, early intervention, social determinants, prevention, wellbeing or happiness issue (Patel et al., 2018). One participant felt that multiple frames can co-exist to achieve specific purposes.

Frames can influence the power dynamics between social movement groups. For example, when I asked how ACEs relates to global mental health, “Egon” reflected:

I think it's very powerful research. It has been demonstrated over and over again in many ways and has been echoed in the social determinants of health work on mental health... but it is focusing on children in the context of homes and schools... we're just widening that out... there are much wider influences that also have an impact on mental health... a much broader frame... different sub-movements can bolster the cause.

The global mental health movement is perhaps trying to absorb the ACEs movement into its “broader” frame.

In addition to framing issues, participants talked about framing debates. Smoking cessation and vaping movement members talked about the need to reframe the debate around smoking, both to shift the public discourse and a smoker’s sense of self. “Agnes” shared that the debate needs to make, “... smokers feel empowered... so they feel the right to speak out.” She expressed the need to reframe nicotine as beneficial to specific groups: “Nicotine as a drug... for some people is a coping mechanism... for some people, it makes them feel better.” “Tannhaus” feels the need to reframe nicotine as pleasurable.

There’s a prospect of nicotine becoming like caffeine... something people aren’t that fussed about... they’ll be more recognition of nicotine as a recreational consumer drug like coffee... we’ll move away from a pre-occupation with addiction... acknowledging pleasure... which public health finds... difficult... because it’s all downsides... you’re

eating too much... drinking too much... smoking too much... therefore, you're addicted... not realising that people are wired to enjoy things, aren't we?

### Developing "innovative" solutions

Participants talked about developing "innovative" solutions directed at solving social issues such as developing a new model of psychosis care, assembling an information resource of people with HIV/AIDs or developing a pill cutter for antiretroviral drugs; others, about solutions directed at growing social movements such as innovative ways of mobilising communities or transforming identities. Most people were motivated to develop solutions for themselves or a loved one.

Participants also shared their strategies for developing solutions, such as "having multiple things on the go" and DIY experimentation. Participants believed that having "multiple things on the go" could increase the probability of finding a solution, especially when solutions do not exist and are urgently needed, as well as support simultaneous development pathways for problems with no "one-sized fits all" solutions. DIY experimentation was vibrant in the early stages of the vaping movement when people were modifying the e-cigarette design, mixing their own nicotine blends and sharing their creations with other vapers.

In the early days... vapers were doing a lot of DIY stuff... buying a litre of nicotine from China... mixing their own blends... some of those people were running vape shops... they were innovating on the tastes and flavours... device design... adding batteries, chips... different kinds of coils and tanks... you've got the early manufactured e-cigs called cigalites... they look like cigarettes... colour filtered white stem... glowing... second generation were more like a fat cigar with a clear tank that you could fill... some of those are now closed... or relatively closed systems... a bit like a fountain pen... so the company making it protects its sales... the third generation called Mods which are modifiable devices... open tank systems... you might buy a battery from one place... a tank from another place... a coil from another place and a mouthpiece from somewhere else... so, you can boom it up... it's like the early days of motoring... I say it's a bit like Jeremy Clarkson... there's been a lot of innovation at that level. ("Tannhaus")

DIY generated interest around vaping and encouraged people to try e-cigarettes. Solutions can also run away with themselves in the context of social movements. The development of the GMFA pill cutter is a ripe example:

The GMFA pill cutter... started off as a thing for people who wanted to take their dose of... antiretroviral medications but in lower doses... really quickly... this became very popular in clubs... didn't take us long to work out why... I remember when... queues of young lesbian clubbers wanting to get a GMFA pill cutter... it wasn't antiretrovirals that they were cutting... what it did allow you to do was to cut your party pills in a reliable way instead of just breaking them in your teeth and passing them on... so you could cut them in half or even quarters... share them in a predicable way would be much better... a pretty classic harm reduction approach. ("Magnus")

Just as people lack control of social movements, they can lose control over the solutions they develop within the context of social movements.

### **Advocating for "innovative" solutions**

In the data, participants were advocating for innovative solutions in a number of ways, including forming organisations to promote solutions, helping solutions work by acting as solution advocates and putting solutions in the hands of people who lack access. For example, in the issue of "tobacco and health" which has been around for centuries (Davies, 1992). The discovery of the scientific link between smoking and lung cancer has a contested history, with German scientists identifying the link as early as the 1920s (Proctor, 2000, 2001). In 1954, Doll and Hill published a preliminary report on the *British Doctors' Study*,<sup>59</sup> bringing the topic into view for the UK scientific and medical community. "Agnes" expands:

If you were a lung specialist working in the early part of the 20th century, you rarely saw lung cancer... suddenly, it developed into this epidemic... we now knew the manifestation of the disease... could be 20-30 years later... and it's a horrible disease, it

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<sup>59</sup> The *British Doctors' Study* ran from 1951 to 2001 as a prospective cohort study and identified the statistical link between tobacco smoking and increased risk of lung cancer (Doll & Hill, 2004).

kills your patients in a really horrible way... so they cared about it and wanted to do something about it... they wanted government to take action.

In 1962, a group of lung specialists with the Royal College of Physicians (RCP) published a report (1962) proposing solutions to the UK government, such as greater education, campaigns and taxes.<sup>60,61</sup> Then, “they sat back and waited for government to do something, but nothing happened” so they setup an organisation to advocate for solutions (“Agnes”). In addition to directly advocating for solutions, study participants talked about bringing innovative solutions into health services, acting as early adopters and helping the solutions work:

The innovator... she came to a conference on e-cigarettes and then... started to make her service e-cigarette friendly... to introduce e-cigarettes into her service... she sort of cadged and borrowed and persuaded local companies to donate because she didn't have a budget for providing them so she wanted to give people a starter kit... it very soon appeared that... their numbers stopped declining... their success rate increased and Public Health England has got data showing that smoking cessation services which are e-cig friendly are now getting better success... so that has rolled out... been emulated by other smoking cessation services. (“Regina”)

“Regina” also describes how people in her smoking cessation service made a deliberate effort to introduce the e-cigarette to people who need it most.

From a niche interest where you have to wait for people to discover it [the e-cigarette] to putting it right in front of people who may have carried on smoking forever... and give them options that they wouldn't necessarily have looked for... only the affluent... well-educated... moved from smoking to vaping... we helped put it in the hands of the most needy in our communities... in terms of the movement, by widening out access... getting it to people who... quite frankly would be dead in a few years if they didn't quit... they would succumb to cancer or cardiac disease or respiratory disease. Similarly, “Tannhaus” shared that in the early days of needle exchange schemes, members of the Rotterdam drug user movement would “take out syringes to give to their friends,” people who the schemes were struggling to reach, and “then bring the dirty ones back in.”

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<sup>60</sup> The RCP is one of the oldest and recognised British medical organisations. It played a major role in the inception of the NHS.

<sup>61</sup> According to “Agnes,” the report later had influence on the tobacco control movement in America.



Vapers experimented with new e-cigarette designs. Their experimentation made their own experience more enjoyable and invited more people to experiment too. For some, it became a serious hobby. Others, a fun way to spend time with friends. At the E-Cigarette Summit in London in 2017, Sarah Jakes, a passionate vaper and Chair of the New Nicotine Alliance, shared that vapers also pressurized industry to improved e-cigarette designs:

Passionate vapers are a diverse crowd... but we do all have some things in common. We want to share our experiences and we want to protect something that we love... we want lawmakers to understand why that regulation that they think is such a wonderful idea really isn't. We understand this because we created this. It was vapers who took the original e-cigarette, pulled it apart and turned it into something that works. Through thousands of informal channels like forums and YouTube reviews, we pushed industry to improve the designs and the options on offer and we still do that today. The independent vaping industry has always been incredibly sensitive to the needs of consumers... you know why? Because they are us. The only difference between us and them is the fact that their enthusiasm took them the extra step of setting up in business... so, when you see our rowdy revolution, remember that what you are seeing is just people who are stopping you from fucking it all up.

Vapers' successful development of viable solutions, coupled with their advocacy, secured them a sustained voice in the industry innovation process – a voice many still exercise today.

## Summary

This chapter illuminated how study participants perceive innovation and identified twelve social movement actions aiding innovation. In the next chapter, we explore these actions in light of the innovation and social movements literature. The study data suggests that the relationship between social movement and innovation actors requires deeper investigation. This investigation could reveal where and how their relationship is practically synergistic.

SECTION III:

# Interpretation & Implications

## Chapter 7: Integrative interpretation

### Introduction

We have reached the exciting point in the research journey when we discuss and interpret the study findings. This chapter reflects on the findings from each empirical chapter and then, offers integrative thoughts across them. At this point in the constructivist grounded theory journey, it is appropriate to consult outside literature in light of study findings to explore its explanatory power and excavate new insights (Charmaz, 2008). I draw on literature aligning with each empirical chapter concept – conceptualising, experiencing and innovating – as well as the social movement theoretical literature from Chapter 2. The chapter ends by reflecting on the research methodology.

### Making sense of social movements as a concept

In Chapter 4, we examined how people make sense of social movements as a concept, motivated by an arising need to understand what people think social movements are and how people develop meaning around the concept. Some study participants exhibited low levels of familiarity, awareness and understanding of social movements, despite experience with them. For others, social movements were a backdrop to their professional and personal lives.

### **Reflecting on how study participants make sense of social movements**

The data surfaced diverse ways people make sense of social movements as a concept, including utilising metaphors as well as characterising, deliberating on, relating to other social movements and valuing social movements. This section reflects on these diverse ways and consults the sensemaking literature for explanatory power.

### *The development and diffusion of the social movement concept across England*

“Claudia” feels that the social movement concept is not well-developed or diffused across England, a finding that is curious because according to scholars, social movements were invented in Britain during antislavery (Tilly, 2004c). Chapter 8 discusses the practical implications of this finding, including its potential impact on social movement spread and collaboration, and suggests that sensemaking tools could aid greater social movement awareness, understanding and experience.

### *Metaphors as cognitive resources for social movements*

In the sensemaking literature, metaphors are “cognitive resources,” offering “discursive opportunities” and aiding mental model development (Hill, 1995; Patriotta & Brown, 2011). “By connecting realms of human experience and imagination, metaphors guide individuals’ perceptions and interpretations of reality” (Cornelissen, 2006; Gibson & Zellmer-Bruhn, 2001). In the data, metaphors aided study participants in individual and collective sensemaking, enabling people to map the social movement concept onto more familiar ones (Misoczky, 2009). The “sailing craft” metaphor helped people navigate and cope with uncertainty within the EIP movement (Hill, 1995; Patriotta & Brown, 2011). Metaphors can also offer a reference point “of what is being constructed, of what is-not-yet” (Misoczky, 2009). Within the HASM programme, comparing the act of starting a social movement to “kindling a flame” helped people understand the experience of starting a social movement and how it differs from some of their other social change experiences. The social movement literature tells us that metaphors can legitimise social action (Patriotta & Brown, 2011), create movement “cohesion” (Eidlin, 2013) and evoke emotion across communities, such as in the use of the “tide” in Spanish society (Romano & Porto, 2018).

Social movement scholars have also utilised metaphors to aid sensemaking. A study of social movement networks proposed three metaphors for their networked patterns – fluids, webs and

rhizomes (Misoczky, 2009). Scholars such as Case (2018) also note the value, implications and unintended consequences of metaphors in a social movement context. For instance, Case discusses the Social Movement Ecology metaphor, which promotes “diversity” and “mutualism” in strengthening social movements, and its successful usage in Black Lives Matter Minneapolis as well as its focus on environmentalism (Ayni Institute, 2017). Yet, as Case (2018) also notes, it introduces challenges associated with drawing boundaries around movement ecologies, assessing the value of individual agency alongside ecosystem behaviour and balancing interactions rooted in competition for limited resources and cooperation for survival.<sup>62</sup> Chapter 8 further illuminates how social movement actors and educators could utilise metaphors to aid social movement sensemaking and sensegiving.<sup>63</sup>

### *Characterising social movements*

The social movement characteristics presented in Chapter 4 do not sufficiently capture the range of words people used to describe social movements. Appendix IX depicts qualitative variables that study participants use to refer to social movements, including motivation, purpose, driving force, origin, leadership, characteristics, behaviour, structure, targets, function, scale, stage, status, classification, formality, supporters, metaphors and value. Appendix VIII presents how study participants refer to the groups they mention in the interviews.

### *Returning to the scholarly definition of health social movements*

Armed with what we have learned about social movements in a health context, we can reflect on what the data illuminates with regards to the definition of HSMs. For reference, HSMs are:

Collective challenges to medical policy, public health policy and politics, belief systems, research and practice which include an array of formal and informal organisations,

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<sup>62</sup> Case (2018) refers to these challenges as the boundary, agency and interaction problems.

<sup>63</sup> “Sensemaking” refers to the act of understanding and “sensegiving,” to the act of communicating understanding (Hill, 1995).

supporters, networks of co-operation and media. HSMs make many challenges to political power, professional authority and personal and collective identity. (Brown & Zavestoski, 2004)

This definition is presented alongside a preliminary typology of HSMs according to the issues they address, including: 1) Access to healthcare and improved provision of services, 2) Disease, disability or illness, and 3) Health inequalities or inequities (Table 1.1). Our existing definition of HSMs captures what and who they challenge but not how. As we learned in Chapter 2, “contentious performances, displays and campaigns” (Tilly, 2004c) and “frequent and varying forms of protest” (Della Porta & Diani, 1999) are central to social movements (Tilly, 2004a) and feature prominently in social movement definitions. The study data also suggests that social movements challenge a much wider range of phenomena than “medical policy, public health policy and politics, belief systems, research and practice,” including lifestyles, human rights and health institutions. A typology of what and how HSMs challenge could organise a diverse range of challenge targets and tactics, serving as an analytical and practical tool.

The definition of HSMs captures the “antagonistic” and perhaps “political” nature of social movements. Additional characteristics from Chapter 4 that might be worthwhile to consider include “driven by values” and “peer-to-peer.” These additional characteristics classified social movements into subtypes (e.g., mass movement), were preferable to participants (e.g., inclusive), were phase-dependent (e.g., early-stage) or referred to the dynamic nature of social movements, including that they wax and wane, change form, persist across time, operate at various levels of scale simultaneously as well as expand and contract in membership. It might also be important to interrogate the “supporter” identity within the current HSM definition in terms of whether it encompasses how most individuals identify with social movements. None of the participants identified as a social movement “supporter” but rather as an “ally” or “resource holder.” Additional actors emerged as well such as “communities.”

### *Deliberating on social movements*

It is not surprising that study participants expressed quite a few “deliberations” about social movements given that there is no single definition of a social movement (Tilly, 2004b; see also Karl-Dieter, 2009) and social movements are socially constructed phenomena (Stammers, 1999). In the data, deliberations about social movements centered around who can start a social movement in a health context (e.g., people with lived experience, service users, medical professionals, scientists), the structures that social movements can assume (e.g., organisations, funded programmes), whether there is such a thing as a “real” social movement and using the term “social movement.” Exploring these deliberations could assist social movement actors in making strategic decisions about their movements and in exploring their own biases. For instance, according to the data, the belief that professionals cannot lead social movements is unfounded for two reasons. First, there are no rules about who, and who cannot, start and lead social movements, which was shared by “Regina.” Second, the boundary between professionals and people with lived experience is not clear-cut as we saw with professional members of TTC talking about how their lived experiences motivated them to enter the mental health profession. To offer another example, I have observed professionals dismiss social movement approaches out of fear for the implications of with term on their initiatives. By employing social movement thinking within their groups, these professionals can avoid using the term publicly while reaping the benefits of a social movement approach.<sup>64</sup>

“Is it a real social movement?” is a question I often heard amongst funders trying to identify groups that fall under the remit of a social movement. An example of a “fake” social movement is an “astroturf front group,” which is defined as a group posing as a social movement such as to promote business interests (Cho et al., 2011). For study participants,

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<sup>64</sup> In 2009, the NHS Institute for Innovation and Improvement proposed “social movement thinking” as a perspective that could “reinvigorate and redefine both large-scale improvement efforts and local front-line change initiatives” in healthcare organisations (Bibby et al., 2009). According Bibby et al., social movement thinking is built on social movement theory and about “connecting with people’s core values and motivations, and mobilising their own personal energies and drivers for change.”

“fake” social movements are groups that do not meet the participant’s criteria for a social movement but that refer to themselves as such. Just as there is no single definition of a social movement (Tilly, 2004b; see also Karl-Dieter, 2009), there are no predefined criteria for a social movement. The absence of global criteria for identifying social movements has methodological implications, as mentioned in Chapter 2. We observe it also having practical implications for people trying to build social movements who might be seeking to model their activity after social movement exemplars. The Junior Doctor’s strike utilised a particular set of social movement characteristics (Bate et al., 2004) to develop strategies for their “Check a Box. Save a Life” campaign (Carson-Stevens et al., 2013). Of course, criteria could also constrain social movement group activity by perpetuating a reliance on expertise.

In terms of the relationship between organisations and social movements, research at the intersection of institutions, social movements and organisations reveals that social movements are important sources of institutional innovation (Hargrave & Van de Ven, 2006) and change (Lounsbury et al., 2003). Social movements enable industry creation through the “de-institutionalization of field frames” which support the persistence of existing practices and ways of organising (Lounsbury et al., 2003). They can also spawn and work through social movement organisations (SMOs) that support social movement goals but are not organisations in themselves (Armstrong & Bartley, 2007); conversely, “Single organizations may be a part of social movements but are not movements in themselves” (Zoller, 2005). The study data revealed people setting up formal and informal organisations as well as other organising structures to support social movement activity at varying levels of scale and for a variety of purposes.

### *Valuing social movements*

Study participants articulated what they value about social movements, including that they contribute to specific outcomes, serve specific functions, offer benefit to people or simply, “make life exciting.” In the interviews, participants were not used to articulating the value of



social movements to themselves, social issues or wider society. As discussed in Chapter 2, assessing the outcomes and consequences of social movements has methodological challenges (Figure 2.6). “Jonas” also talked about issues with appraising value in healthcare confounding issues with appraising the value of social movements. A more systematic investigation of how social movement actors value social movements, or perceive their value, would be practically useful to social movements actors and health systems.<sup>65</sup>

### *Towards collective sensemaking*

The findings about how people make sense of social movements represent the views of individuals shared through semi-structured interviews. Yet, social relationships are central to the construction and perception of meaning (Weick, 1999). Collective sensemaking methods, such as participatory sensemaking, could move “the onus of social understanding” from the individual to the collective and offer an “enactive account of social cognition” (De Jaegher & Di Paolo, 2007). Collective sensemaking methods could generate insights about how social movement groups adopt, apply, shape, negotiate and act upon the social movement concept, including when and how they use the concept explicitly. We know that how collectives, such as social movement groups, adopt and apply the social movement concept can impact on collective action (Oh et al., 2015).

### *The place for “health” in making sense of social movements*

Health as an issue area was practically absent in how study participants make sense of social movements as a concept. Scanning Table 4.1 reveals that health does not feature in the clusters and categories except for the section on “valuing social movements.” In that category,

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<sup>65</sup> Our research at Nesta revealed that health social movements: 1) Bring about change in the experience and delivery of health care, 2) Improve people’s experience of disease, disability or illness, 3) Promote healthy lifestyles, 4) Address socioeconomic and political determinants of health, 5) Democratise the production and dissemination of knowledge, 5) Change cultural and societal norms and 6) Propose new health innovation and policymaking approaches (del Castillo et al., 2016).

participants talked about how social movements can be the solution to health issues such as loneliness. In the section on, “Mobilisation challenges” in Chapter 5, participants also talked about how social health issues can impact on social movement mobilization.

### *The “social” in social movements*

“Social” can take on different meanings in an innovation context (Cozzens & Sutz, 2014). It can refer to the goal of problem-solving such as addressing “the water problem” versus “a water pump” where less of a focus is placed on the “marketability” of an invention. It can also refer to the “values and activities” unaccounted for economically. Within the study data, “social” took on three meanings. First, “social” refers to a social process of mobilisation, of people coming together, interacting and building social relationships. Second, it refers to social movements addressing “social problems” often through “social solutions.” Finally, it refers to the social lineage of social movements across time and in terms of language, discourse and relationships as we saw in Chapter 5.

### *Why it is challenging to answer the question, “What is a social movement?”*

The study data reveals at least four reasons why it is challenging to answer the question, “What is a social movement?” First, social movements are “dynamic” – waxing and waning as well as moving in and out of “social movement status” – making them impossible to capture what a social movement is at a single point in time because once you analyse it, it is already gone. Second, the meanings people assign to social movements are varied. They are socially situated and depend on factors such as values, cultural context, identities and past social movement experience. Third, social movements do not have the “right” to govern behaviour. There is also no “invisible hand” (Weick, 1999) influencing how people make sense of social movement experience. As “Regina” says, “There are no rules in social movements.” Fourth, and most importantly, “social movements are not things” (“Claudia”). This viewpoint is consistent with Hegel’s (1979) view that “experience cannot be captured by means of a noun that denotes a

thing.” In other words, if a social movement is an experience, it is not a thing, and it becomes theoretically impossible to answer the question, “What is a social movement?”

### *Who decides what a social movement is?*

“Definitions belong to the definers, not the defined” according to American novelist Toni Morrison. According to this ideal, social movement definitions currently belong to sociologists. Who should they belong to? Who decides what a social movement is? Related questions abound such as: Who is at liberty to decide? Who has the power to decide? Is that power mindfully embraced, seized or willingly given? How would social movement participants like to be involved in defining a social movement? What methods do we have to define concepts democratically?

Karl Marx and Friedrich Engels (1848) are perhaps relevant in this instance, “The history of all hitherto existing human society is the history of class struggles.” The history of academia is also a history of class struggles, reproducing social stratification and class hierarchies (Jewel, 2008) as well as leading to unhealthy everyday practices for some, if not all, social groups (Acker & Armenti, 2004). Investigating how class struggles play out within, as well as impact on, social movement research could help contextualise and characterise the relationship between social movement theorists and activists as well as illuminate opportunities for collective action.

### *Reliance on expertise to make sense of social movements*

The health field exhibits a strong reliance on expertise and evidence-based medicine (Brown & Zavestoski, 2004). During the formal study interviews and my informal practical engagements with social movements, I saw a tendency for health professionals to rely on expertise to make sense of social movements and devise social movement strategies. I first observed this tendency in the formal interviews when “Torben” asked me to validate his comments about social movements, “Right... so am I in the kind of right territory?” In my social movement

support role, I similarly experienced health professionals asking, “Is what we’re doing a social movement?” and “Can you send me a blueprint for a social movement?” Alongside sending relevant resources, I tried to challenge this reliance on expertise by suggesting to people that “it is only a social movement if you think it is” and “there is no blueprint for a social movement... social movements are what you make of them.” In some cases, perpetuating a reliance on social movement expertise can undermine the unique role that social movements play and the ways in which people within them challenge the status quo.

### **Sensemaking as social change**

Sensemaking is not just a process through which people make sense of the world, it is a process of social change, a process between “order” and “chaos,” a “process by which humans make and unmake, develop, maintain, resist, destroy and change order, structure, culture, organization, relationships and the self” (Jacobson, 2000). Sensemaking also differs from other forms of social change.

One way in which sense-making differs from other approaches is that it explicitly, and necessarily, privileges the ordinary person as a theorist involved in developing ideas to guide an understanding of not only her personal world but also collective, historical and social worlds... Sensemaking requires us to focus on power by attending to forces that facilitate movements and forces that inhibit and constrain movement. (Jacobson, 2000)

In the sensemaking frame, every social movement actor is involved in theory-building (Jacobson, 2000). Actors advance an understanding of the world by collaborating with the past, present and future.

## Experiencing social movements

This section explores the analytical power of theories of experience as well as reflects on the theoretical and practical value of studying the social movement as experience. It also illustrates the power of relating the social movement experience to analogous experiences.

### Exploring the analytical power of experience theories

Traversing existing experience theories in light of the data surfaced new insights and raised new questions. This section discusses study findings in terms of two conceptions of experience: experience as continuity and interaction as well as experience as learning, development and transformation. It then highlights broader insights illuminated through experience theories.

#### *Experience as continuity and interaction*

American philosopher John Dewey dedicated much of his life to theorising “experience.” His theory of experience has enduring theoretical value (Muhit, 2016) and is particularly relevant to social movements. Dewey felt that experiences could inspire people to alter their future. According to Muhit, Dewey saw people as “agent patients” and desired for philosophical ideas to have practical value:<sup>66</sup>

Better it is for philosophy to err in active participation in the living struggles and issues of its own age and times than to maintain an immune monastic impeccability, without relevancy and bearing in the generating of ideas of its contemporary presence. (Dewey, 1908)

At the heart of Dewey’s theory of experience are two principles: continuity and interaction. Continuity refers to an experience as a “continuous flow.” The present moment is both influenced by past experiences and influences the nature and quality of future ones (Dewey,

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<sup>66</sup> I share Dewey’s belief that philosophy can assume an active role in our evolving reality, helping us address social issues.

1934). Vygotsky similarly describes experiences as “temporally unfolding” societal relations across space and time (Vygotsky, 1935). Particularly intriguing is the related concept of “experience as a moving force” where “its value can be judged only on the ground of what it moves toward and into” (Dewey, 1938, 2008). This conception implies that social movements can only be evaluated according to what they aspire towards. In this instance, we might return to how study participants were “Valuing” social movements in Chapter 4 or how they were “Aspiring” and “Evaluating” in Chapter 5.

Interaction, the second principle in Dewey’s theory of experience, refers to “transactions” and mutual adaptations between “actors” and “subjects” of an experience as well as with their physical and social environment. Dewey proposed a view of experience *of* and *in* nature, rejecting existing philosophical traditions promoting a dichotomy between experience and nature (Muhit, 2016). In Dewey, the environment includes both tangible and intangible aspects such as ideas or memories (Dewey & Bentley, 1999; Muhit, 2016) which is particularly relevant to social movements that involve intangible aspects such as values, identities, beliefs, ideologies, social norms and cultures.

Experience includes what men do and suffer, what they strive for, love, believe, and endure, and how men act and are acted upon, the ways in which they do and suffer, desire and enjoy, see, believe, imagine – in short, processes in experiencing. “Experience” denotes the planted field, the sowed seeds, the reaped harvests, the changes of night and day, spring and autumn, wet and dry, heat and cold, that are observed, feared, longed for; it also denotes the one who plants and reaps, who works and rejoices, hopes, fears, plans, invokes magic or chemistry to aid him, who is downcast or triumphant. It is “double-barrelled” in that it recognizes in its primary integrity no division between act and material, subject and object, but contains them both in an unanalysed totality. “Thing” and “thought”... are single-barrelled; they refer to products discriminated by reflection out of primary experience. (Dewey, 1958)

Perhaps Acting, Facing, Sensing and Planning are “processes in experiencing.” Experience as the “planted field” and “sowed seeds” also reminds me of the “seed” metaphor in Chapter 4.

Experience is a constructive process, a “collision” of interests, because “in this dialectic between doing and receiving, agency and reception are set in co-constitutive motion” (Roth & Jornet, 2014). Acknowledging experiences as “relations-in-the-making” makes it possible to examine both its “agential” and “pathic” dimensions, including how transactions are reproduced across time (Roth & Jornet, 2014). Dewey saw people as active, not just passive recipients in experiences; in experiences, people “act, suffer and enjoy” and experience “doings” (Muhit, 2016). Recent phenomenological research positions human beings as “subjects of experience but also subject and subjected to” (Romano, 1998; Waldenfels, 2011), “living through” and “undergoing” experience (Waldenfels, 2011).

The data illuminates instances of continuity and interaction. In the data, I observed continuity in the interactions between people, especially amongst “strong ties” that persist across time, as well as between people and specific organisations. The data illuminates interactions across a range of actors, including amongst social movement peers as well as between social movements and *what* they challenge such as health institutions, values, norms and lifestyles.

The principles of continuity and interaction interrelate in Dewey’s theory as “continuous transactions.” Vygotsky noted these interrelationships by describing a developing child. The child is both born out of and interacts with its environment; Vygotsky eloquently states that, “Something which is only supposed to take shape at the very end of development, somehow influences the very first steps in this development” (Vygotskij, 1935, 2001). Similarly, a social movement is both born out of and interacts with its environment. The social movement and the status quo co-determine one another. They are part of the same experience, transacting, acting on and influencing one another. Therefore, we can avoid the temptation to draw the boundaries of the social movement experience only around the people participating in it.

Experience as “continuous transactions” creates practical conundrums. First, where does one social movement experience end and another begin? According to the data, study participants

“dip in and out” of social movement activity over time, creating discontinuities in their own social movement experience. Second, people generally associate “experience” with “participation in events or activities” (Roth & Jornet, 2014) such as protest events rather than perceiving other aspects such as introspection and personal growth as part of their social movement experience. Third, Dewey believed that experiences are overlapping (Roth & Jornet, 2014). In Chapter 5, we saw overlapping experiences in the data, including lived experience of disease (e.g., breast cancer), its associated social movement (e.g., the breast cancer movement) and related social movement experiences (e.g., the women’s movement).

### *Experience as learning, development and transformation*

Scholars, such as Welton (1993) and Kilgore (1999), identify new social movements as sites of learning, offering both individual and collective learning opportunities.<sup>67</sup> The data is consistent with this view; study participants reported both personal and collective learning such as learning about their lived experience as well as about how to work with people who have shared values, respectively. Multiple participants felt as if they were “learning as they went along” with learning happening through experience.<sup>68</sup> Furthermore, only some participants knew what they wanted or intended to learn. According to Dewey, “The greatest of all pedagogical fallacies is the notion that a person learns only the particular thing he is studying at the time” (Dewey, 1938, 2008). What people learn through experience can extend beyond what is intended or expected (Marion, 2010; Roth, 2012). “Claudia” felt that, “Everyone takes something away from a movement.”

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<sup>67</sup> To more deeply understand these learning opportunities within the context of social movements, Kilgore (1999) proposes a theory of collective learning to explore the interrelationships between individual and group development by examining identity, consciousness, sense of agency, sense of worthiness and sense of connectedness as well as collective identity, group consciousness, solidarity and organisation, respectively (Choudry & Kapoor, 2010).

<sup>68</sup> Education scholars examine how experience impacts on learning but rarely, how learning impacts on experience (Pugh, 2011). The social movement experience offers context to examine both phenomena.



In experience lies opportunities for transformation; actors can transform themselves and the “objective conditions under which experiences are had” (Roth & Jornet, 2014). Experience can transform both person and environment “in the course of practical activity” (Garrison, 2001).

Experience, in its fundamental sense, is that which, by putting us in play ourselves, modifies us profoundly in a way that after having crossed, endured, traversed it, we will never be the same again: undergo an illness, mourning, joy, loving, traveling, writing a book, painting are “experiences” in the first philosophical sense, surely simple, but nevertheless trivial. (Romano, 1998)

In transformative experiences, “the old self is put off and the new self is only forming, and the form it finally takes will depend upon the unforeseeable result of an adventure” (Dewey, 1929). Experience can either encompass change or mark the start of a “transition.” The social movement experience as the start of a “transition” would be consistent with the social movement lifecycle where the height of collective action marks the start of system adaptation, a process which can outlive the social movement. According to Roth and Jornet (2014), not all experiences necessarily become significant or lead to transformation. As we learned in Chapter 2 regarding social movements, a transformation is not guaranteed to happen or to sufficiently meet the demands which set the transition or transformation in motion. Broadly, however, experience as transformation has profound implications for studying social movements. It suggests that within social movements, we can investigate what is transforming *in* and *through* them as well as how transformation is happening in the course of “practical activity” and “everyday life.”

### ***Experience encompassing what, how and who is experiencing***

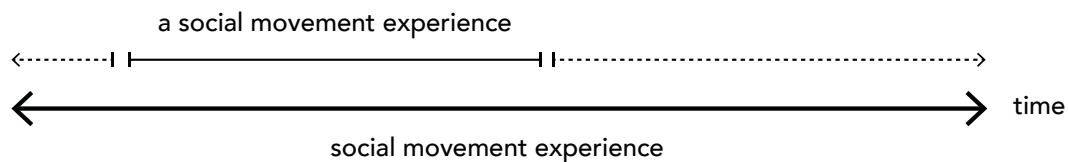
The data in Chapter 5 reveals an important distinction between *what* they are experiencing in relation to social movements (Acting, Planning, Facing) and *how* they are experiencing it (Sensing). According to Dewey, experience also encompasses the experiencers, including every actor acting on, and getting acted upon, by social movement activity (Muhit, 2016).

### *Experience in, with and of social movements*

Roth and Jornet (2014) talk about experiences “in, with and of” science. These three words – in, with and of – resonate with what I saw in the data; that there are experiences in, with and of social movements. Study participants identifying as “part of” a social movement are having experiences *in* social movements whereas people identifying as “allies,” experiences *with* social movements. Participants engaging in specific social movement activities, such as a convening, are perhaps having experiences *of* social movements. These distinctions could assist with identifying the types of engagements people have with social movements as well as how people identify with them.

### *An experience versus experience*

The experience literature distinguishes between experience and having an experience, which stands out as significant within a continuous flow of experience (Roth & Jornet, 2014). Figure 7.1 depicts this distinction, where a social movement experience stands out as significant within a continuous flow of social movement experience. A social movement experience has book ends, perhaps representing an experience with a particular social movement or a particular type of interaction with social movements. Although the line is solid, a social movement experience might have discontinuities caused by, for example, a movement going dormant or a person taking a break from social movement participation.



**Figure 7.1: Differentiating between an experience and experience**

### *Falling out of step, recovering unison*

Experiences can represent a “falling out of step with the march of surrounding things:”

Life itself consists of phases in which the organism falls out of step with the march of surrounding things and then recovers unison with it – either through effort or by some happy chance. And, in a growing life, the recovery is never mere return to a prior state, for it is enriched by the state of disparity and resistance through which it has successfully passed. If the gap between organism and environment is too wide, the creature dies. If its activity is not enhanced by the temporary alienation, it merely subsists. Life grows when a temporary falling out is a transition to a more extensive balance of the energies of the organism with those of the conditions under which it lives. (Dewey, 1934)

As the data revealed, the social movement experience can be one of struggle, survival, resilience and growth. It is in experiencing “collision” and “contradiction” (Veresov, 2010) that change happens. The resilience people build in response can be a force to be reckoned with.

### *Experience and control*

Experience does not belong to anyone; it flows through interactions “in and across space and time within irreducible person-in-setting units” (Roth & Jornet, 2014). Everyone is experiencing as an agent and patient, facing events not under their control (Roth & Jornet, 2014). The inability to control experience limits the extent to which people can plan the outcomes of experience (Wagenschein, 1999). Experiences are spontaneous and unpredictable; they are “something to be swept-up in” (Girod et al., 2003) rather than something that is planned. The social movement as an experience which cannot be controlled supports why some participants believe that no one can control social movements. Theoretically, “The idea that human experience involves elements beyond our intentional control” (Wong, 2007) is “underestimated and under-theorized” (Roth & Jornet, 2014).

### *The accumulation and transferability of social movement experience*

Study participants described having “experience” with social movements, raising questions about whether social movement experience accumulates or is transferable across social movement contexts. “Claudia” was unsure as to whether her experience with a social movement led to a deeper understanding of social movements. The experience literature suggests why “Claudia” might feel this way – that what is learned in terms of skills or understanding through experience is not necessarily “automatically mobilized later, especially under conditions unlike those in which they were originally experienced” (Lave, 1988). For instance, aspects of a social movement experience in Manchester might be transferrable to a social movement experience in London but not to one in San Francisco. Understanding what social movement experience constitutes, as well as whether and what aspects are accumulated or transferable and under what conditions, could assist people in better understanding their contributions and experience.

### *Experiences as overlapping*

In Dewey’s theory of experience, experiences can be “overlapping, merging and fragmenting;” in fact, “Life consists of a series of overlapping and interpenetrating experiences, contexts, or situations, each of which has its internal qualitative integrity” (Muhit, 2016). The data suggests that people often participate in multiple movements simultaneously as we saw in the memo in Chapter 3 on “movement multiplicity.” It also suggests that the social movement experience can intersect with other types of experiences, such as lived experience of an illness or a care, adverse, professional or social change experience. In Chapter 5, we got a sense of social movements playing out alongside one another. Social movements can overlap in many ways such as in their goals. For instance, the domestic violence movement has historically focused on survivor healing which is also a focus of the ACEs movement where domestic violence is defined as an ACE (Public Health Scotland, 2020).

## The theoretical and practical value of studying social movement experience

Understanding the social movement experience could contribute to renewed scholarly interest in the experience concept and to people desiring to practically understand social movements.

### *Contributing to a renewed scholarly interest in the experience concept*

There is a renewed interest in studying the experience concept, especially within psychology and education (Hohr, 2012; Muhit, 2016). Within psychology, the concept addresses a central question of “unit of analysis” within recent sociocultural and situative theories examining how people and environments “mutually determine each another” as well as understanding “situational and continuous aspects of knowing and learning” (e.g., Greeno, 2006; Hamza & Wickman, 2009; Lidar et al., 2010; Rogoff, 1955; Roth & Jornet, 2013, 2014). Within education, “experience” is widely referred to in relation to learning (Roth & Jornet, 2014). Yet, “what experience is and how it is related to learning and change remains untheorized” (Roth & Jornet, 2014; Wong et al., 2001). Studying social movements as *experiences* could contribute to a deeper understanding of not only *what* experience is but also *how* experience relates to learning and change.

As we saw in Chapter 2, cultural research has investigated how societal culture impacts on, and is impacted by, social movements as well as how culture impacts on social movement emergence and diffusion. At the end of his life, Dewey expressed regret for not replacing “experience” with “culture” in his book *Experience and Nature* (1929); he thought the change would shift the “experience” concept away from “individualistic” and “mentalist” concerns towards “social” concerns (Alexander, 1987; Hohr, 2012).<sup>69</sup> Although I understand his intention, it would have been a shame for culture to bury the concept of experience or “eat experience

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<sup>69</sup> Advancements in cultural psychology in the 1990s align with Dewey’s work at the end of life (Cole, 1996; Shweder, 1990).

for breakfast.” Experience supports relatability, giving meaning to the continuous flow of everyday transactions, and retaining the “inherent uncertainty that is an integral part of human experience” (Roth & Jornet, 2014).

### *Implicating all actors and subjects in the social movement experience*

Studying the social movement *as experience* acknowledges both actor and subject in a dialectical change process encompassing their interactions, negotiations and conflicts. Social movements are usually described in terms of the people doing the challenging (e.g., “collective challenges”). Yet, according to Dewey and Vygotsky, experience is “the minimum analytic unit that retains all the features of the whole” (Dewey, 1938, 2008; Miettinen, 2000; Vygotskij, 1935, 2001).<sup>70</sup> It encompasses the set of people and transactions with their physical and social environments (Roth & Jornet, 2014). In social movement experience, every individual *experiencing* a social movement is part of the dialectical change process. There can be a tendency amongst funders to see themselves as external actors in relation to social movements. Sometimes, funders want to be actors in the change process but are pushed out by movement members themselves. Elkind (2015) feels that “major funders of movements are themselves movement actors.” Framing the social movement *as experience* might help all actors see themselves as a part of the same dialectical change process and may also create more inclusive environments for social change.

### *Social movement experience fostering relatability and understanding*

Study participants shared that social movements such as HIV/AIDs can sometimes feel grand, that they could never be like “great figures” like Dr. Martin Luther King. The social movement experience concept could enable people to project themselves onto it and relate to the everyday experience of social movements, to the “actions” and “sufferings” of social

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<sup>70</sup> In cultural psychology, the basic unit of analysis is the interaction between a person and culture where “culture is at the same time both psychological and collective” (Miettinen, 2000).

movement actors. To offer an analogy, people with lived experience of a health condition can help other people understand their own lived experience. They can also help health professionals more deeply understand the lived experience of a condition, enabling more informed care. Similarly, social movement experience could help people make sense of their own experience, anticipating what it could be like to be part of one and learning from people who came before them. It could also help policymakers and funders more deeply understand social movements, enabling more informed support.

### *Relating the social movement experience to analogous experiences*

Relating the social movement experience to other types of experiences could surface new insights about it. For instance, emotions such as hope can take on various meanings in the cancer experience: “Hope of being cured, hope of living as normally as possible, a presence of confirmative relationships and reconciliation with life and death” (Benzein et al., 2001). Furthermore, many people with cancer find that their intimate social relationships are negatively affected (Muzzin et al., 1994). Perhaps, emotions such as hope can take on varied meanings for people in the social movement experience. The data revealed that the social movement experience can also negatively impact on social relationships. For instance, “Jonas” described her relationship with her partner suffering while she participated in a particular social movement due to her extreme commitment and it becoming a “way of life.”

### Innovating within social movements

We now pivot to interpreting the findings on how people make sense of social movements as innovation. This section reflects on how study participants perceive innovation, explores the twelve social movements actions aiding innovation in light of innovation literature and investigates what the data reveals about the interrelationships between social movement and innovation development and diffusion. It wraps up by reflecting on what this study reveals about social movements as innovation experiences.

## Reflecting on how study participants perceive innovation

Some study participants clearly have a contested relationship with innovation. This relationship seems to stem, in part, from interacting with innovation funders as well as with for-profit innovation theory and practice. Participants reported struggling with applying for-profit innovation frameworks which are not designed for the types of social issues they address. It is unclear to what extent participants draw on social innovation frameworks or have an awareness of innovation's lineage of being rooted in the firm.

The data revealed positive and negative implications to participant perceptions of innovation. First, that framing innovations as having lineage could place greater value on solutions that work over new ideas but jeopardise the positive energy gained from developing new ideas. Second, that innovation research has tended to prioritise studying innovation diffusion over development (Dal Fiore, 2007; Ruef, 2002). In fact, the innovation literature is inconsistent about how innovation development relates to diffusion with diffusion scholars identifying innovation development or "research and development" as "pre-diffusion" (Rogers, 2003). In my experience, design practitioners often relegate diffusion to "implementation" rather than acknowledging it as a critical phase of the design process. Progressive designers promote designing *for* diffusion by designing diffusion mechanisms into an innovation (Stanford ChangeLabs, 2020). Third, innovation as "lone genius" can alienate underrepresented groups, compounding the exclusion of their ideas, knowledge and experience into innovation processes. According to Cozzens & Sutz (2014), to study innovation in informal settings, shifts are needed in both how scholars view innovation and in "the perception of actors for whom these new empirical insights [about informal innovation] can have practical relevance." In social movements, identities can shift possibilities for individual and collective action (Della Porta & Diani, 2006). Social movements could play a role in shifting perceptions of innovation.



## **Exploring the twelve social movement actions aiding innovation**

This section draws on the social movement and innovation literatures to discuss each of the twelve social movement actions aiding innovation. In the process, it surfaces new insights, validates findings and characterises the links between social movement action and innovation. Table 7.1 provides an overview of insights derived from triangulating the study data against my researcher lens as well as the social movement and innovation literatures.

Table 7.1: Exploring the power of the social movement and innovation literatures

Action	Study data findings	Insight from researcher innovation lens	Insight from the literatures
Making sense of lived experience	<ul style="list-style-type: none"> <li>Connecting and relating to people with shared lived experiences through sharing your own story.</li> <li>Empathising with other people such as by listening to them tell their story.</li> <li>Helping people gain a deeper understanding of their own needs and inspiring them to address them.</li> </ul>	<ul style="list-style-type: none"> <li>Lived experience impacts each phase of the innovation process, including understanding human needs, framing problems as well as developing and testing solutions.<sup>71</sup></li> <li><b>Hypothesis from researcher:</b> Social movement actors are not well-recognised by innovation theorists or practitioners as sources of lived experience or ethnographic practice.</li> </ul>	<ul style="list-style-type: none"> <li>Lived experience gives a perspective “unavailable to others” (Brown &amp; Zavestoski, 2004).</li> <li>Sharing and talking about lived experiences aids deeper understanding (Della Porta &amp; Diani, 2006).</li> <li>Social movements articulate needs that have never been named as well as deepen an understanding of them (Mulgan, 2006).</li> <li>Lived experience is the most important source of innovation in all contexts (Lundvall, 1988; von Hippel, 2007).</li> <li>Social innovation begins with a need derived from human experience (Mulgan, 2006).</li> </ul>
Raising the profile of an issue	<ul style="list-style-type: none"> <li>Raising the profile of an issue by getting an issue on the policy agenda, raising awareness amongst the public and within communities as well as raising interest in solving social issues.</li> <li>Associating higher profile issues with greater monetary resources and public awareness.</li> </ul>	<ul style="list-style-type: none"> <li>Raising the value of the problem to be solved, incentivising people to innovate and generating momentum for the innovation effort.</li> <li>Raising the profile of an issue can refer to raising it on the political agenda, policy agenda, within the public sphere and within communities.</li> </ul>	<ul style="list-style-type: none"> <li>Social movements raise the profile of an issue by challenging people to address their demands (Goodwin &amp; Jasper, 2009).</li> <li>The profile of an innovation “challenge” can raise public awareness, momentum and incentives to work on it (Richardson, 2020).</li> <li>“A valuable problem to solve” is an ingredient for successful innovations (de Jong et al., 2015).</li> </ul>
Setting aspirational innovation goals	<ul style="list-style-type: none"> <li>Setting an aspirational goal to develop an innovation.</li> <li>Counteracting mindsets inhibiting innovation (e.g., outdated, fixed, incremental, low expectations).</li> </ul>	<ul style="list-style-type: none"> <li>Gives people the permission and right to think differently. This permission is extremely important in environments that more strongly resist change such as health.</li> <li>Motivates and inspires people to dedicate time, energy and resources to innovation.</li> <li>Aspirational communication increases dedication to an innovation goal, especially those requiring long-time horizons.</li> </ul>	<ul style="list-style-type: none"> <li>Aspirational goals impact positively on all phases of the innovation process (Stetler &amp; Magnusson, 2015).</li> <li>Aspirational goals give people clarity, possibility and motivate behaviour with low- and high-clarity goals leading to more innovative ideas (Stetler &amp; Magnusson, 2015).</li> <li>Aspirational communication increases dedication to an issue (Hattaway &amp; Hart, 2013).</li> </ul>

<sup>71</sup> I originally identified this insight from my practical experience but later, found the supporting evidence for it in a paper I have read many times throughout my career (Patnaik & Becker, 2010). I highlight this point about process to underscore the iterative nature through which I assembled this table.

Spreading an optimistic mindset for reform	<ul style="list-style-type: none"> <li>• Counteracting mindsets inhibiting reform (e.g., pessimistic, transient, fixed).</li> <li>• Supports resource recruitment to innovation.</li> <li>• Inspires on-going participation in innovation.</li> <li>• Contagious scale shifting to other social issues.</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Hypothesis from researcher:</b> An optimistic mindset, coupled with demonstratable results, supports current and future reform efforts as well as scale shifts to related issue areas.</li> </ul>	<ul style="list-style-type: none"> <li>• Optimism is critical to innovation (Cvitanovic &amp; Hobday, 2018).</li> <li>• There are limitations of an optimistic mindset such as unrealistic expectations and irrational risk-taking; realistic optimism coupled with a learning mindset and prototyping approach is most effective (Clapp &amp; Swenson, 2015).</li> </ul>
Identifying with thinking differently	<ul style="list-style-type: none"> <li>• Thinking differently as a group identity.</li> <li>• Building on the ideas of others, putting ideas together in a different way, thinking differently from the establishment or status quo.</li> <li>• Responding rapidly to an emerging situation, addressing a problem in a new way.</li> <li>• Mobilising people who think differently or desire to, including cross-culturally.</li> </ul>	<ul style="list-style-type: none"> <li>• A thinking differently identity gives people the space and permission to think differently.</li> <li>• Thinking differently is a critical skill throughout the innovation process, especially during the idea generation phase.</li> <li>• <b>Hypothesis from researcher:</b> The tendency of social movements to foster a “thinking differently identity” makes them a likely site for innovations.</li> </ul>	<ul style="list-style-type: none"> <li>• Thinking differently is the bridge between an innovative environment and the rise of new innovations (Dal Fiore, 2007; Ruef, 2002).</li> <li>• Identity construction is a social process, according to the social movement literature (Berger &amp; Luckmann, 1966; Billig, 1995; Della Porta &amp; Diani, 2006; Moscovici, 1981).</li> </ul>
Maintaining an informal identity	<ul style="list-style-type: none"> <li>• Informality as a feature of group identity.</li> <li>• Enabling “unscripted” conversations, sharing and developing ideas without institutional interference, inclusivity as well as rehearsing vision and arguments.</li> <li>• There is a disconnect between how social movement groups and health institutions “appraise” value.</li> </ul>	<ul style="list-style-type: none"> <li>• Informality enables freewheeling conversations and scrappy development procedures.</li> <li>• Maintaining informality enables groups to avoid pre-mature co-option of ideas by larger, more powerful institutions.</li> </ul>	<ul style="list-style-type: none"> <li>• Informal spaces enable listening to people;</li> <li>• Informal and collective innovation processes require dialogue and conflict-solving processes, requiring people to have a stronger motivation for interaction;</li> <li>• Informal environments can face pressure to formalise as well as deregulated activity (Cozzens &amp; Sutz, 2014).</li> </ul>
Contributing to an evolving commonwealth of skills and knowledge	<ul style="list-style-type: none"> <li>• Bringing diverse skills and knowledge; sharing them openly and generously.</li> <li>• Enabling rapid problem-solving as well as developing solutions requiring people to combine skill sets and knowledge domains.</li> <li>• Seeing skills repurposed in unexpected ways.</li> </ul>	<ul style="list-style-type: none"> <li>• Creating a hotbed for novel ideas, as disparate skillsets and knowledge bases come together.</li> </ul>	<ul style="list-style-type: none"> <li>• Radical innovation happens at the intersection of fields, disciplines, skillsets and diverse experiences (Johansson, 2004).</li> </ul>
Making strong and weak ties	<ul style="list-style-type: none"> <li>• Making strong ties – facing struggles and victories together, meeting a new friend during the course of social movement activity, meeting new people with whom ones shares similar values and continues to work with, building trust.</li> <li>• Making weak ties – meeting people outside current networks to exchange information and ideas; weak ties opening opportunities.</li> <li>• Transforming strong ties into weak ties.</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Hypothesis from researcher:</b> The nature, strength and arrangement of ties impacts on how social movement actors develop and spread ideas as well as the types of ideas that emerge from and through social movements.</li> <li>• <b>Hypothesis from researcher:</b> Social movements, as entities featuring strong ties embedded in weak network architectures, are fertile grounds for innovative solutions.</li> </ul>	<ul style="list-style-type: none"> <li>• Social movements foster new and deeper ties between people especially mobilised against a common enemy (Della Porta &amp; Diani, 2006).</li> <li>• Strong ties contribute to innovation diffusion; weak ties, to innovation development (Dal Fiore, 2007; Rost, 2011); strong inter-movement ties to tactical innovation spread (Banaszak, 1996).</li> <li>• Strong ties embedded in weak tie networks enable more innovative solutions (Rost, 2011).</li> </ul>

Forming and acting in communities and networks	<ul style="list-style-type: none"> <li>• Belonging to communities sharing common lived experiences and identities.</li> <li>• Forming and acting in networks to connect with people who share a common interest or endeavour, share information and knowledge, develop opportunities, share ideas, build bridges or complete tasks requiring collaboration.</li> <li>• Simultaneously acting in communities and networks.</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Hypothesis from the literature:</b> Significant social change happens through hybrid forms of communities and networks (Dal Fiore, 2007).</li> <li>• <b>Hypothesis from researcher:</b> Social movements potentially represent a hybrid social container drawing on the benefits of how communities and networks support the development and diffusion of innovations as well as facilitating the diffusion of radical ideas.</li> </ul>	<ul style="list-style-type: none"> <li>• Communities and networks facilitate incremental and radical innovation, respectively. Communities facilitate innovation adoption by creating a sense of belonging and utilising confirming communication. Networks facilitate innovation development through information and idea sharing across diverse communication channels, enabling expansive and creative conversations (Dal Fiore, 2007).</li> </ul>
Framing issues and debates	<ul style="list-style-type: none"> <li>• Framing social problems.</li> <li>• Framing discourse and debates around social problems.</li> <li>• Utilising frames to change the way people see themselves, raise awareness, foster consensus, change public discourse, alter public perceptions, secure legislation, alter the social norms impacting on collective action.</li> </ul>	<ul style="list-style-type: none"> <li>• It is worth exploring if and when greater benefit could be achieved if the framing efforts of social movement actors and innovators were explicitly aligned as well as what both groups could learn from one another about framing.</li> <li>• This initial look at the literature suggests that perhaps, social movements utilise framing for broader aims than innovators.</li> </ul>	<ul style="list-style-type: none"> <li>• Social movement actors utilise frames to share grievances, mobilise actors, set collective action goals, press claims on targets and alter public perceptions (Givan et al., 2010).</li> <li>• Innovators utilise frames to generate novel problem framings, altering the range of potential solutions (Seelig, 2013) as well as work towards solutions and principles for creating intended value (Dorst, 2011).</li> </ul>
Developing “innovative” solutions	<ul style="list-style-type: none"> <li>• Developing new ideas and solutions, often to their own problems and against the odds. Study participants refer to a diverse range of solutions as “innovative” (Table 6.1).</li> <li>• Solutions emerge from or are impacted by social movement activity.</li> <li>• Problem-solving strategies include allowing many flowers to bloom, DIY and supporting innovations. Study participants utilised the first strategy to increase the probability of finding a solution.</li> </ul>	<ul style="list-style-type: none"> <li>• There is potential alignment in the types of problems and problem-solving processes that social movements actors and external innovators use to develop “innovative” solutions. It is worth exploring if and when greater benefit could be achieved if activities were explicitly aligned.</li> <li>• Study participants do not refer to intangible outputs (e.g., norms, cultures, narratives) themselves as “innovative” but rather, to innovative ways to realise them.</li> </ul>	<ul style="list-style-type: none"> <li>• Social movements play a role in the development of institutional (Hargrave &amp; Ven, 2006), tactical (Wang &amp; Soule, 2016) government and commercial innovations (Mulgan et al., 2007).</li> <li>• The best way to have a good idea is to have a lot of ideas (Olson, 1980). Multiple groups solving the same problem can increase the probability of rapidly finding solutions as well as ensure experimentation prior to getting locked into paths too early (Thrane et al., 2010).</li> </ul>
Advocating for “innovative” solutions	<ul style="list-style-type: none"> <li>• Advocating for engagement and adoption of “innovative” solutions.</li> <li>• Advocating for the right to innovate and for representation in the innovation process, such as by securing a voice in development.</li> <li>• Innovation adoption as a collective action supporting social movement diffusion.</li> </ul>	<ul style="list-style-type: none"> <li>• <b>Hypothesis from researcher:</b> As social movements spread, collective actions spreads, supporting innovation adoption; conversely, innovation adoption becomes a social movement symbol, supporting spread.</li> <li>• It is worth exploring what innovators could learn from social movement actors about meeting the inevitable resistance to new ideas as well as addressing unjust innovation diffusion.</li> </ul>	<ul style="list-style-type: none"> <li>• Every new idea that becomes mainstream faces “ridicule” and “opposition” prior to “acceptance” (Mulgan et al., 2007). In healthcare, ideas are particularly slow to diffuse especially preventative innovation (Rogers, 2002).</li> <li>• Social movements diffuse through frames and collective actions (Givan et al., 2010).</li> <li>• Symbols are powerful resources for social movement emergence and diffusion (Zani, 2016).</li> </ul>

### *Making sense of lived experience*

Lived experience “gives people with the disease or condition a lived perspective that is unavailable to others” (Brown et al., 2004). Social movements often emerge when people come together around shared lived experiences, such as a lived experience of a disease, disability or illness (Brown & Zavestoski, 2004). Talking about one’s own lived experience, and listening to the experiences of others, can lead to a deeper understanding of their own lived experience (Della Porta & Diani, 2006). In the study data, we saw people making sense of their lived experiences by mobilising and interacting with other people in social movements as well as employing strategies to empathise with others.

According to social movement research, social movement participants use a collective understanding of lived experience to identify needs, develop solutions, make claims and motivate action (Benford & Snow, 2000; Brown et al., 2004; Fleischer & Zames, 2001; Morgen, 2002; Silvers et al., 1998; Snow et al., 1986). Through these activities, the collective identity of a social movement becomes rooted in the lived experiences of its members, helping recruit new members as well as transform public perceptions, norms and beliefs.

Lived experience is the most important source of innovation in all contexts (Fagerberg, 2013; Fagerberg et al., 2005; Lundvall, 1988; von Hippel, 2018). It contributes to all aspects of the innovation process, including defining human needs, framing problems, developing, testing and diffusing solutions (Patnaik & Becker, 2010). Every innovation process also begins with a need derived from human experience (Mulgan, 2006). Sometimes, a human need is not immediately apparent or understood until it is named and articulated. Social movements play a pivotal role in developing an understanding of issues and needs that are not well-recognised, articulated or understood as well as raising public consciousness around them (Mulgan, 2006). In this way, social movements are one of the origins of innovation, representing where an understanding of lived experience germinates. Furthermore, innovation is “likely to be most successful when there is close involvement of people with the strongest understanding of

needs” (Mulgan, 2006) such as social movements. Yet, social movements are not well-recognised by innovation practitioners as sources of lived experience or as potential participants in innovation efforts.

The needs of people endure much longer than the solutions (Patnaik & Becker, 2010). Many social movements persist for long periods, waxing and waning as well as evolving in their identification, understanding and expression of human needs. The solutions to these needs are almost never sufficient, as we learned in Chapter 2, as they represent an evolving dance and compromise between those with unmet needs and those with the power to address them.

### *Raising the profile of an issue*

Social movements raise the profile of an issue to be solved by challenging more powerful people and institutions to address their demands (Goodwin & Jasper, 2009). Study participants refer to raising the profile of an issue within policy, the public sphere and within specific communities. Kriesi et al., (1995) offers insight into the strategies social movements use to raise the profile of issues on political agendas, with higher profile issues exhibiting five factors in greater intensity: resources, challenges to power, probability of government survival, public perception and the ability of a government to meet demands (Giugni, 2004). The innovation literature tells us that raising the profile or value of an issue to be solved (e.g., through an innovation challenge such as a challenge prize<sup>72</sup>), can raise public awareness of the issue and motivate people to work on it (Richardson, 2020). “A valuable problem to solve” is one of three ingredients for successful innovation (de Jong et al., 2015). Therefore, by raising the profile of an issue, social movements could raise the perceived value of a problem to be solved.

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<sup>72</sup> A challenge prize is “a series of incentives with a final prize to whoever can first or most effectively meet a defined challenge.” They are often used to address well-defined problems with unknown solvers and solutions or aspects of complex and urgent problems that cross boundaries and where progress is difficult to measure (Richardson, 2020).

### *Setting aspirational innovation goals*

An important first step in creating transformational change is setting ambitious and achievable goals (Hattaway & Hart, 2013). Aspirational goals motivate and inspire people to dedicate their time, energy and resources to them as well as give people a sense of what is possible (Hattaway & Hart, 2013). When aspirational goals relate to developing innovations, such as a new EIP care model, they can motivate and inspire people to dedicate time, energy and resources to developing that innovation as well as give people a sense that its development is possible. In the case of developing a new EIP care model, an aspirational innovation goal was pivotal to countering the mindsets inhibiting innovation as well as giving people the permission and right to think differently. This permission is particularly important in healthcare environments that inherently resist change, as “Jonas” noted. Furthermore, continued aspirational communication increases the likelihood that people will stay dedicated to a goal, which is especially important when addressing complex or systemic problems which often require longer time horizons to bear fruit (Hattaway & Hart, 2013).<sup>73</sup> We also know that aspirational goals impact positively on all phases of the innovation process and that high-and low-clarity goals lead to more innovative ideas than mid-clarity goals (Stetler & Magnusson, 2015). The EIP movement exhibited both aspiration and high clarity in developing a new EIP care model.

### *Spreading an optimistic mindset for reform*

The data reveals study participants spreading an optimistic mindset, especially to counter mindsets inhibiting reform such as pessimism. Optimism is critical to innovation (Cvitanovic & Hobday, 2018). Yet, it also important to acknowledge that optimistic mindsets can create unrealistic and unfounded expectations as well as fuel irrational decision-making and risk-taking; realistic optimism coupled with a learning mindset and prototyping approach is most

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<sup>73</sup> Aspirational and emotional language represent 80 percent of Dr. Martin Luther King’s “I Have a Dream” speech with 5 only percent focusing on solutions (Hattaway & Hart, 2013).

effective (Clapp & Swenson, 2015). For the EIP movement, demonstratable results, coupled with an optimistic mindset, supported current and future reform efforts as well as scale shifts to related social issues such as a suicide prevention. Crane & Crane (2007) also illustrate the effectiveness of “dispositional optimism” on entrepreneurial success where dispositional optimism represents the “expectation that good things will be plentiful in the future and bad things scarce.” Perhaps, dispositional optimism has a similar effect on social movement success.

### *Identifying with thinking differently*

Thinking differently is utilised at every stage of the innovation process, from finding new ways of understanding the needs of people, framing problems in new ways, brainstorming ideas and testing concepts with people. It is the bridge between an innovative environment and the rise of innovations (Dal Fiore, 2007; Ruef, 2002). According to the data, thinking differently can be a feature of social movement identity, mobilising people who desire thinking differently from the establishment or the status quo. These abilities to foster a thinking differently identity as well as mobilise people who think differently make social movements a likely site for the rise of innovations.

Furthermore, we also know that identity formation influences social movement mobilisation (Fominaya, 2010) and that identity construction is a social process (Berger & Luckmann, 1966; Billig, 1995; Della Porta & Diani, 2006; Moscovici, 1981). More deeply understanding how a thinking differently identity influences social movement mobilisation as well as how a thinking differently identity is formed in social movement groups are two ripe areas for future research. This understanding could inform how to practically build and spread this identity, or desire and capability to think differently, within social movements.



### *Maintaining an informal identity*

Study participants also viewed informality as a feature of their identity. They felt that maintaining an informal identity helped them operate inclusively, recruit people, have “unscripted conversations,” avoid institutional interference and co-option as well as develop ideas, visions, arguments and implications. According to informal innovation research, informal settings are places where people live and work; they enable listening and “a respectful attitude towards what other people know,” whereas formal, top-down innovation strategies “crowd people out” (Cozzens & Sutz, 2014). People within informal settings, “need to have a strong motivation to interact” because “the more collective the innovative process, the more it will require dialogue, conflict-solving procedures, and ultimately innovation-related governance issues” (Cozzens & Sutz, 2014). The data revealed instances of people exhibiting this “strong motivation to interact” and a willingness to engage in conflict to solve an issue that needed to be solved; in fact, some embraced healthy dialogue and conflict. Still, informal spaces lack regulation with problematic situations often going “under the radar” (McCaskie, 2008). The data revealed someone selling drugs on a volunteer support helpline and using the proceeds to buy office furniture, exhibiting what can arise when people “work from their own wounds,” said “Magnus.” Furthermore, informal environments can face institutional co-option of ideas and people as well as pressures to formalise (Cozzens & Sutz, 2014). We need to further understand these pressures and how social movement actors negotiate them.

### *Contributing to an evolving commonwealth of skills and knowledge*

People contributing to an evolving commonwealth of skills and knowledge has implications for both the development and diffusion of new ideas. First, rapid skill and knowledge sharing at the height of the HIV/AIDS crisis enabled people to problem-solve and accelerate a response, responses that might not have been possible through formal development channels with prescribed processes and procedures. Second, a diverse commonwealth of skills and knowledge facilitated the creation of solutions requiring multiple skillsets, knowledge domains,

professional fields and lived experiences. The innovation literature tells us that radical innovation happens at the intersection of fields (Johansson, 2004). When social movements mobilise diverse groups of people across boundaries (Wang et al., 2018), they facilitate new channels for information flow, novel combinations of skills and knowledge as well as a cauldron of ideational choices, becoming hotbeds for radical innovation.

### *Making strong and weak ties*

Social movements foster new and deeper ties, or bonds, between people, especially those mobilised against a common enemy (Della Porta & Diani, 2006) or reacting to a conflict in solidarity (Fantasia, 1988; Snow, 2004). According to Della Porta (2020), “Social movements create and recreate ties: they build upon existing networks but also, in action, they connect and multiply them.” The data showed study participants making both strong and weak ties as well as weak ties transforming into strong ties. In the innovation literature, strong and weak ties have implications for the development and spread of new ideas well as how innovative the ideas are that emerge. Weak ties assist in the development of new ideas; strong ties, in the spread of innovations (Dal Fiore, 2007). In Banaszak's (1996) study of the women's suffrage movements in the US and Switzerland, the American suffragists encouraged strong ties between state leaders to spread local innovations. Strong ties with other movements, such as the temperance and abolition movements, also helped spread tactical innovations such as hiring paid organisers.<sup>74</sup> The Swiss movement lacked strong internal and external ties and was unable to diffuse innovations and innovative tactics as effectively. A lively debate exists about whether strong or weak ties have more value in the creation of innovations (Burt, 1992; Coleman, 1990). Recent research suggests that strong and weak ties can have synergistic benefits – that people with strong ties come up with more innovative solutions when embedded in weak architectures such as structural holes and peripheral network positions

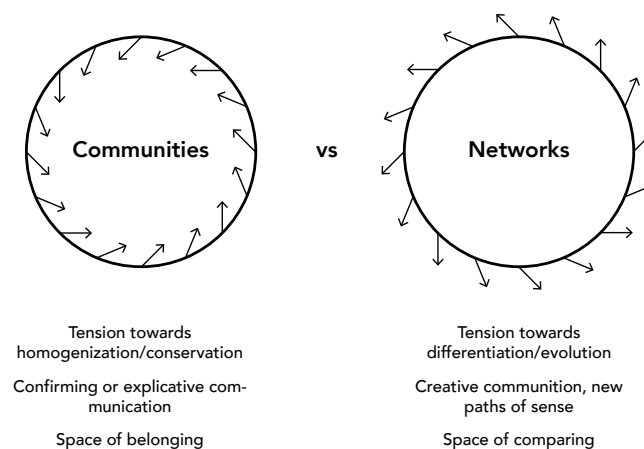
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<sup>74</sup> Susan B. Anthony, an American suffrage movement leader, utilised what she had learned in the temperance and abolition movements to suggest using paid organisers to travel and organise (Banaszak, 1996; Snow, 2004).

(Rost, 2011). Two hypotheses emerge. First, that perhaps the nature, strength and arrangement of ties within social movements can impact on how social movement actors develop and spread new ideas as well as how innovative the ideas are that emerge from and through their activity. Second, that social movements feature strong ties embedded in weak network architectures, are fertile grounds for more innovative solutions. Furthermore, social movement studies is in need of theories that link micro- and macro levels of sociological theory such as a strong and weak ties (Granovetter, 1973). The theory of strong and weak ties could inform future theoretical work at the intersection between social movements and innovation studies.

### *Forming and acting in communities and networks*

Communities and networks represent social containers that facilitate different kinds of innovative ideas and actions (Dal Fiore, 2005). Yet, the innovation literature, alongside the communities of practice and knowledge management literatures, have used the community and network concepts interchangeably depriving them of explanatory and heuristic power within an innovation context (Conway & Steward, 1998; Dal Fiore, 2007; Hildreth & Kimble, 2004; Koku & Wellman, 2002). Figure 7.2 illustrates the implications of communities and networks for innovation development and diffusion, based on a speculative attempt to place communities and networks on two separate poles of the same axis (Dal Fiore, 2007).



**Figure 7.2: Differentiating communities from networks (Dal Fiore, 2007)**

Communities represent people coming together around a common obligation (Dal Fiore, 2005; Postman, 1993). They facilitate the adoption of new ideas through a sense of belonging, homogenisation and confirming communication (Dal Fiore, 2007). Networks represent “interconnected value-free nodes,” enabling the development of innovations through information and idea sharing across diverse communication channels as well as expansive and creative conversations (Dal Fiore, 2007).

The data describes people forming and acting in both communities and networks, often simultaneously. According to Dal Fiore (2007), “In the end, significant social change would originate thanks only to a combination of communities and networks.” It is possible that a social movement context represents a “hybrid social container” (Dal Fiore, 2007) facilitating the development and diffusion of innovations through networks and communities, respectively.

### *Framing issues and debates*

Study participants described framing problems, discourse and debates. Little data emerged about *how* social movement actors develop frames, such as through cognitive liberation and political learning processes discussed in Chapter 2 (Givan et al., 2010; McAdam, 1982).

Participants used frames to change the way people see themselves, public perception and discourse as well as the social norms impacting on collective action. The “social construction of collective action frames” can also assist with crafting “persuasive communication” and “consciousness raising” (Klandermans, 1997).

Both social movement actors and innovators engage in framing. For innovators, framing represents “the process of creating novel perspectives to view problems” (Dorst, 2011; Schön, 1983). A problem frame reflects a shared understanding of the problem from diverse views and directs subsequent concept generation (Dorst, 2011; Schön, 1983). Frames can represent needs, gaps, pain points, opportunities or challenges. Re-framing a problem can dramatically alter the range of potential solutions (Seelig, 2013) by opening the imagination to new

possibilities. For instance, when a team of Stanford designers set out to design a low-cost baby incubator for the developing world, they re-framed the challenge to “a low-cost baby warming device,” opening the imagination to alternate manifestations of baby warming. Ultimately, the team landed on a sleeping bag design utilising phase-change material to regulate a baby’s body temperature and costing a tenth of the price of traditional incubators. Similarly, a simple problem reframe, “How can I design a safer and alternative way of consuming nicotine?” led to the invention of the e-cigarette, which disrupted the entire smoking industry and eventually led to the emergence of a social movement (Stimson et al. 2014). Therefore, the ability to frame and reframe problems is one of the most valuable contributions and forms of impact that an innovation lab such as the Helix Centre can make alongside influencing who is involved in the innovation process and embedding results into practice (Gaventa, 1980). Framing is also unique to innovation processes requiring abductive reasoning such as design; designers develop novel framings of complex problems and then use those framings to develop working solutions and principles to create intended value (Dorst, 2011).

There are clear synergies between the activities of social movement actors and innovators with regards to framing. Social movement actors could promote the development and adoption of innovations aligned with their own frames. Innovators could also root idea generation in social movement frames as well as align innovation diffusion strategies with those frames. Social movement actors and innovators could also jointly develop frames and learn from each other about how to frame.

### *Developing “innovative” solutions*

Study participants refer to a diverse range of solutions as “innovative” some of which they report being involved in developing. Social movements contribute to a range of innovation types, including institutional (Hargrave & Ven, 2006), tactical (Wang & Soule, 2016; McCammon, 2003), democratic (Felicetti & Della Porta, 2017) and social innovations (Cornish et al., 2014; Munch, 2006; Raphael, 2009; Scambler & Kelleher, 2006). Social innovations have

included British antislavery campaigning methods, such as “mass membership, demonstrations, petitions, consumer boycotts, logos and slogans” as well as “innovations in governments, commercial markets and NGOs” during the 1960s (Mulgan et al., 2007). A literature review could enumerate innovation types to which social movements contribute.

Study participants were often developing solutions collectively because they needed other’s skills and expertise as well as political and mutual support. This collective approach to solution development is perhaps consistent with innovation as “interactive” and “an expression of collective action” (Cozzens & Sutz, 2014) where collective action arises “when the efforts of two or more individuals are needed to accomplish an outcome” (Sandler, 1992). This collective view of innovation aligns with social movements addressing “contaminating issues” (“Torben”) such as stigma that impact on all solutions addressing mental health. In other words, stigma is everyone’s problem to solve.

Social movement and innovation processes intersect in terms of the types of problems they solve and their approach. Social movement and innovation efforts in this study primarily concerned themselves with social, societal and “socially derived” problems (“Egon”). The study data reveals situations where study participants know what value they want to create but the “what” and “how” are opaque in terms of “what” the problem is and “how” to solve it. Situations like these benefit from abductive reasoning where the “what” refers to a solution and the “how” refers to a working principle that ensures value creation. Design thinking, for instance, is an innovation approach that relies heavily on abductive reasoning to address complex, wicked challenges through framing (Dorst, 2011). Third, Figure 2.6 in Chapter 2 revealed the overlaps between the effects of movement actions, the effects of outside events and actions as well as the impact on movement claims. Exploring how innovation processes, outputs and outcomes impact on movement claims would illuminate ways that innovation aids social movement emergence, diffusion and impact.

Social movements, as dynamic and emerging entities with porous boundaries, shifting allegiances, and diverse organisational forms – are not easily located. Innovation activity that relates to social movement activity becomes even more complicated to locate. Our initial examination of social movement actions aiding innovation reveals that it is more appropriate to talk about innovations emerging *through* social movements rather than *within* social movements. The word “through” encompasses innovations emerging from social movement activity as well as innovations influenced by social movement activity.

### ***Advocating for “innovative” solutions***

In healthcare, innovations are comparatively slow to diffuse taking 17 years on average to reach mainstream adoption, with preventive innovations facing longer timescales (Rogers, 2002). Every new idea that eventually becomes mainstream faces “ridicule” and “opposition” during its diffusion process prior to “acceptance” (Mulgan et al., 2007). Social movements employ tactics to promote or resist change (Wang & Soule, 2016) and therefore, potentially play a role in overcoming this “ridicule” or “opposition” and accelerating innovation adoption. The data surfaced tactics that study participants used to advocate for solution adoption, including working through powerful people and institutions, as we saw when lung practitioners mobilised and acted through the Royal College of Practitioners, as well as creating organisations such as ASH to advocate for smoking cessation solutions.

### **Noticing temporal relationships between social movement and innovation activity**

What comes first, the social movement or the innovation? The data suggests both possibilities – that an innovation can be the impetus for a social movement and that social movements can spawn innovations. For instance, the e-cigarette gave rise to the vaping movement (Stimson et al., 2014) with people mobilising on online forums, in vape shops and at vape fests. These people were also innovating on the experience of consuming nicotine as well as encouraging the adoption of the e-cigarette, as we learned in Chapter 6.

The rapid adoption of tobacco harm reduction has been market-enabled and consumer-driven... it's fascinating because vapers find out about vaping from other vapers or online. It's not been... in any way a top-down intervention. It's a public health intervention in capitals... without public health... because public health has actually been antagonistic... what you have here is word-of-mouth... people learning from others... the e-cigarette forum in the UK has 10,000 visits a day... if I'd gone and said to public health, "I want to setup a website... to persuade the world to use e-cigarettes... I'm going to get over 10,000 hits a day. It's a forum, it's a chat." They'd have said, "Yeah, you're crazy." ("Tannhaus")

In the second instance, the Rotterdam drug user movement contributed to the development and diffusion of the first needle exchange programme; it later went onto playing a leading role in stabilising HIV rates by utilising pre-existing relationships and experience-based prevention materials to stimulate discussions about HIV amongst users, develop solutions and rapidly influence policy responses (Friedman et al., 2007). Both of these examples point to a potentially temporal and cyclical relationship between social movements and innovation.

### **Social movement as innovation experience**

The data suggests that the social movement in itself, can be an innovation experience exhibiting continuity and intersection. Innovation in the context of social movements can have continuity. For instance, the successful development of a new EIP care model happened within the context of an EIP movement and is influencing future innovation in EIP as well as in related issues such as anti-stigmatization, suicide prevention and mental health literacy promotion.

The development of early psychosis services is expected to be a breakthrough for many issues in Japan, such as the anti-stigmatization movement, the prevention of suicide in younger generations, and the development of early interventions for psychosis itself and the promotion of mental health literacy in general.

The new EIP care model was also developed through interactions amongst people in the EIP movement, including people inside and outside of health and care. As Cozzens & Sutz (2014) suggest, "The kind of interactions supporting or leading to innovation will depend on the



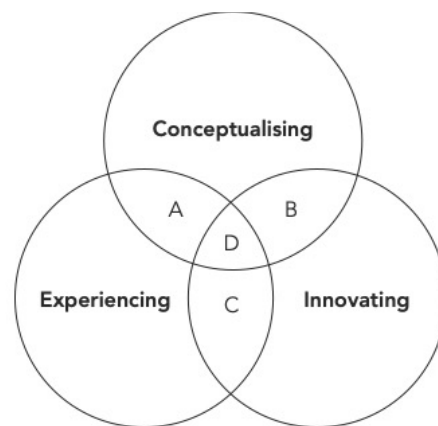
specific settings where the process of innovation is taking place and the actors involved... the strength of these interactions; how horizontal or hierarchical the exchanges in which they are based are; and how wide the net of participants is, are all heavily context-dependent and innovation-specific." In terms of the process of innovation within a social movement, "Torben" felt that social movements do not subscribe to any one method of innovation.

Global mental health... it's a title applying to a... wide range of activities... it's not as if it's an organisation deliberately doing things or... adopting any particular methodology for its... organisation, aims, goals... how it's going about its work... it doesn't have a sort of a method of innovation.

Social movements can create space for multiple innovation methods to co-exist simultaneously.

### Conceptualising, experiencing and innovating

In this study, we examined how people make sense of social movements through three lenses – as a concept, as experience and as innovation. Inspired by a constructivist grounded theory approach, we took notice of "what is happening" in the data and framed emerging concepts as gerunds (Charmaz, 2018). We could also view these lenses as actions – conceptualising, experiencing and innovating – and as processes dynamically interacting with one another in diverse ways. The data has started to illuminate their interrelationships, depicted in Figure 7.3.



**Figure 7.3: Conceptualising, experiencing and innovating social movements**

According to the data, engaging with social movements can involve conceptualising, experiencing and innovating them, sometimes simultaneously or in synergistic ways. At intersection A, part of experiencing social movements is conceptualising them. Conversely, in conceptualising a social movement, a person might already be experiencing social movements. At intersection B, conceptualising a social movement can involve innovating on what a social movement is and what it does. Chapters 5 and 6 illuminated innovations people developed to grow their social movements. Social movement actors could also utilise innovations that help them sense what they are “Facing.” We saw ways in which “organising in the age of the Internet” is changing the nature of activism. At intersection C, we see how innovating social movements could change the way we experience them. Part of experiencing social movements could be “facing” the changing nature of social movements or experiencing social movement innovation. At intersection D, all three actions – conceptualising, experiencing and innovating – are happening simultaneously, bringing forth multiple possibilities such as conceptualising the social movement innovation experience or experiencing innovating on the social movement concept.

## Reflecting on the research methodology

This section now turns to reflecting on the research methodology. It reflects on challenges emerging during the research process, utilising constructivist grounded theory within a PhD programme and inviting an innovation practitioner lens into the data analysis.

### **Reflections on challenges emerging during the research process**

A number of challenges emerged while collecting and analysing data, including identifying study participants, balancing researcher and practitioner identities as well as mapping participant actions to social movement activity.

### *Identifying study participants*

As described in Chapter 3, I chose study participants from an initial list of people who publicly identify with or influence a social movement groups related to a UK public health issue. The social movement literature suggests asking all study participants what social movements they identify with and how, rather than presuming their association. In their responses, participants revealed a range of ways they identify with social movements. Enumerating these identities would be useful to other studies desiring to account for how people identify.

### *Balancing researcher and practitioner identities*

During some of the interviews, I noticed myself relating participant responses to the literature and to my experience with social movements in my mind. For instance, one participant talked about expecting a social movement to “take off” on its own after it was setup. I thought, “Where does this assumption come from – that a social movement is like a product you can assemble, turn on and expect it to run on its own?” Instead of challenging the views of this participant or imposing my own, I chose to ask probing questions such as, “How do you envision the movement taking off?” and “What role do you see yourself playing in the movement?” I held back on probes if they could potentially bias future participant responses. During some of my practical engagements with social movements outside of the formal research setting, I felt tempted to share research findings prematurely especially when I felt they could be valuable.

### *Mapping participant responses to social movement activity*

When asked about his involvement in social movements, “Magnus” responded, “HIV advocacy in the 1980s for sure.” Furthermore, “Torben” referred to TTC as both a “new dynamic social movement” and a “campaign.” As these examples highlight, study participants interchangeably refer to social movements and other change forms such as advocacy and

campaigning. For this reason, it took careful consideration to map participant responses to social movement activity. Revisiting the original framing of a question often helped confirm the mapping. When it was not possible to map participant actions, the findings were not included in the data analysis. This scenario highlights a methodological challenge resulting from the lack of widespread adoption of Diani's (1992) global characteristics discussed in Chapter 2. Those characteristics were intended to assist researchers in distinguishing social movements from related concepts.

### **Utilising constructivist grounded theory within a PhD programme**

Constructivist grounded theory can have institutional, practical and personal barriers within the context of a PhD programme (Urquhart, 2017). In terms of institutional barriers, at Imperial, writing a literature review prior to starting data collection was a necessary "marker of progress" (Urquhart, 2017) during the PhD programme but risked early exposure to relevant literatures.<sup>75</sup> As described in Chapter 3, early exposure to literatures can "contaminate" the analysis and "divert attention from the methodology's subversive potential... to push pass disciplinary boundaries" (Martin, 2006). I circumvented this barrier by producing a "non-committal literature review" (Urquhart & Fernandez, 2006) on theories of social movement emergence, spread and impact to produce a theoretical background on social movements rather than expose myself to relevant innovation literature prior to starting inductive coding. Traversing the experience and innovation literatures commenced only after the initial conceptual categories of the social movement experience were identified.

Practically, the time constraints of a PhD programme meant that I had insufficient time to conduct more than two rounds of theoretical sampling on conceptual categories or the linkages across them, such as across the categories of the SMExp or across social movement

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<sup>75</sup> On occasion, I was asked what theories I would apply to the study data but resisted the temptation to adopt specific theories.

conceptualising, experiencing and innovating. As described in Chapter 3, I chose to conduct a second round of interviews based on two theoretical samples to deepen my understanding. Further rounds of theoretical sampling would have moved this research towards theory-building.

Personally, constructivist grounded theory requires patience and “detailed, painstaking analysis” to surface concepts (Urquhart, 2017). My design thinking and systems thinking experience had prepared me to “trust the process” and “embrace ambiguity.”

Constructivist grounded theory delivered on many of its promises. First, it enabled a middle-range approach to sociological theory construction, offering the ability to examine specific aspects of social movements, including how people make sense of them as concepts, experiences and innovation, without the need for an overarching theory of social change (Rootes, 2010). Second, it is particularly well-suited to studying experiences (Charmaz, 2018), which was serendipitous because the decision to study social movement experience was not pre-determined.<sup>76</sup> Third, it enabled exploring social movements and innovation as complex social phenomena and as processes which are “relational” and “situated” (Pilny, 2015). Fourth, it allowed the relationship between the findings and the data to be emerging which enabled inductive work and the discovery of new concepts, conceptual directions and rich insight. Fifth, its “subversive potential” of enabled transcending the disciplinary boundaries of two fields – social movements and innovation – to discover SMExp and widening the “relevant” literature (Martin, 2006) to experience theories. Finally, it enabled applying an innovation practitioner lens to the data and adopting a reflexive practice to reflect on power, privilege and politics issues (Olesen, 2007).

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<sup>76</sup> In July 2018, I attended a two-day workshop on constructivist grounded theory conducted by Dr. Kathy Charmaz at Lancaster University. A group of researchers were utilising grounded theory to study health experiences which conjured up a discussion about utilising grounded theory to study experiences more generally.

### **Inviting an innovation practitioner lens into the data analysis**

As an innovation practitioner, crossing over into the social movements field enabled excavating empirical insights, hypotheses and future research opportunities at the nascent intersection of social movements and innovation. The interviews yielded insights in the language of social movement actors. My researcher lens brought in language from innovation theory and practice. As described in Chapter 3, an equally exciting point of departure for this study would have been, “How does innovation aid social movement development and diffusion?” A study involving interviews with innovators would yield insights in the language of innovation actors and bring in language from social movement theory and practice. Conducting this alternate study would also enable a more in-depth understanding of the interrelationships between social movements and innovation.

### **Summary**

This chapter discussed and reflected on the study findings from the empirical chapters (Chapters 4, 5, and 6). It also explored the explanatory power of the social movement, innovation and health literatures from Chapters 1 and 2 as well as literature on sensemaking and experience. We also started to consider the interrelationships between making sense of social movements as a concept, experience and innovation as well as the temporal and cyclical relationship between social movements and innovation. The chapter concluded by reflecting on the research methodology in preparation for Chapter 8 which discusses the study impact and limitations well as presents implications for research, practice, policy and education.

## Chapter 8: Impact, limitations and implications

### Introduction

I hope this research study has taken you on a journey, and that the voices of study participants have revealed a world that is either deeply familiar or delightfully novel. Inevitably, the journey was uniquely yours. I also hope it conjured up more questions than it answered. The study findings pose some exciting and critical implications for the way we understand and realise social change. This chapter reflects on the impact and limitations of study findings, converging on implications for research, theory, practice, policy and education. It opens new avenues for research, summarised in Chapter 9, and offers personal reflections on the research journey.

### Impact of the study

This study makes a number of theoretical contributions. Table 8.1 organises these contributions utilising a framework (Walsham, 1995) which was adapted by grounded theory researchers to suit their purposes (Diaz-Andrade, 2009; Urquhart, 2013). The framework positions each “type of contribution” as an “analytic generalisation.” These generalisations offer explanations for phenomena arising from the study data but are not “wholly predictive of future situations.” They simply represent valuable starting points for future empirical work (Walsham, 1995). This section reflects on each type of contribution while reviewing how the study responds to gaps in the literature and impacts on the researcher lens. The implications for research, theory, practice, policy and education are covered in sections that follow.

**Table 8.1: Theoretical contributions (Walsham, 1995; Diaz-Andrade, 2009; Urquhart, 2013)**

Type	Contribution
New concepts	<ul style="list-style-type: none"> <li>• Social movement experience (SMExp)</li> <li>• Conceptualising-Experiencing-Innovating social movements</li> </ul>
Conceptual directions	<p>Social movement lineage, social movement innovation</p> <ul style="list-style-type: none"> <li>• Innovation repertoires (from “tactical repertoires”), social movement and innovation opportunities structures (from “political opportunity structure”)</li> </ul>
Implications for research and theory	<ul style="list-style-type: none"> <li>• Embracing “theory for all” in producing theories by, with and for people building social movements</li> <li>• Assessing the theoretical value of social movement experience as an analytical tool for research and an avenue for deepening experience theories within psychology, education and cultural studies</li> <li>• Moving towards a theory of social movement experience (e.g., linkages between conceptual categories)</li> <li>• Embracing alternate lenses through which to study social movement experience</li> <li>• Refining how to study innovation in relation to social movements (e.g., utilising conceptions of social movements to study innovation, utilising the SMExp as a foundation for empirical investigation)</li> <li>• Further investigating social movement actions, identities and mindsets aiding innovation</li> <li>• Characterising interrelationships between social movements and innovation (e.g., temporal, cyclical, drivers)</li> <li>• Exploring studying innovation as experience</li> </ul>
Implications for practice	<ul style="list-style-type: none"> <li>• How people make sense of social movements impacts on practical action</li> <li>• Some study participants were unaware of the socially constructed nature of social movements</li> <li>• Social movement actors desiring a more conscious process of learning from other movements</li> <li>• SMExp concept enabling people to relate to others and learn practically about building social movements</li> <li>• SMExp informing approaches to measuring social movement progress</li> <li>• Offering insight on practical movement-building strategies</li> <li>• Study participants designing social movements to have specific functions and elements</li> <li>• Applying entrepreneurial marketing and innovation approaches to “designing” social movements</li> </ul>
Implications for policy	<ul style="list-style-type: none"> <li>• Offering a “people’s perspective” or “experiential view” of social movements to inform funders and policymakers in situating social movements within a wider social change landscape, developing ways for social movements and institutions to productively engage as well as devising support programmes</li> </ul>
Implications for education	<ul style="list-style-type: none"> <li>• Social movement learning by doing</li> <li>• Developing a social movement case study method</li> </ul>
Contributions to rich insight	<ul style="list-style-type: none"> <li>• Raising a question about whether social movements are well-diffused across England</li> <li>• Revealing ways people make sense of social movements, including utilising metaphors as well as characterising, deliberating on, valuing and relating to other movements. The findings reveal different familiarity levels with social movements in terms of awareness, understanding and experience.</li> <li>• Experience theories offering insight into issues such as whether social movement experience is accumulated and transferrable, that there is a distinction between social movement experience and an experience with social movements as well as on why there is not definitive answer to, “What is a social movement?”</li> <li>• Identifying social movement actions aiding innovation, including making sense of lived experience, raising the profile of a social issue, setting aspirational innovation goals, diffusing an optimistic mindset for reform, identifying with thinking differently, contributing to an evolving commonwealth of skills &amp; knowledge, framing issues and debates, making strong &amp; weak ties, forming and acting in communities &amp; networks, developing “innovative” solutions and advocating for “innovative” solutions</li> <li>• Observing a distinction between innovative social movement diffusion elements and innovative solutions to social issues emerging through social movement activity</li> <li>• Observing a temporal, cyclical and driving relationship between social movements and innovation development and diffusion activities, illuminating eight phenomena</li> <li>• Social movements can be the solution to health issues such as loneliness through fostering social connection</li> <li>• The nature of social health issues impacts on social movement mobilisation</li> <li>• Health does not feature prominently in how study participants make sense of social movements</li> <li>• Suggesting that innovation exhibits Dewey’s concepts of experience – continuity and interaction</li> <li>• The study data illuminates complex interrelationships between conceptualising, experiencing and innovating social movements, all of which could offer new vantage points through which to study social movements</li> </ul>



### Discovering new concepts and conceptual directions

When you discover a salient concept in the data, there can be a sudden realisation that it has “been there all along” and “you start to see it everywhere” because it has conceptual weight (Charmaz, 2008a, 2018). When I discovered the social movement experience it not only became visible in the data but also in my everyday life, which only increased my confidence in its existence and potential value. The study also pointed to a number of new conceptual directions, including social movement lineage and social movement innovation which require further elaboration. It also identified concepts within the social movement literature such as “political opportunity structures” and “tactical repertoires” which could offer theoretical and practical value to the innovation field. Investigating social movements through three lenses – conceptualising, experiencing and innovating – illuminated their interconnectedness, offering new interdisciplinary spaces for investigation.

### Contributions to rich insight

This study makes a number of contributions to rich insight. First, it revealed ways that people make sense of social movements as a concept, including the use of metaphors as well as characterising, deliberating on, valuing and relating to other social movements. The findings reveal different familiarity levels with social movements in terms of awareness, understanding and experience, raising questions about whether the social movement concept is well-diffused across England. Second, the study discovers the social movement experience through a bottom-up analysis of how study participants describe acting within social movements. Experience theories help us make the distinction between social movement experience and an experience with social movements. They also raise questions such as whether social movement experience is accumulated and transferable. Finally, experience theories suggest that it is potentially impossible to definitively answer the question, “What is a social movement?”

Finally, the findings identify twelve social movement actions that aid innovation development and diffusion, illuminated through a synergistic dance between the study findings, my innovation practitioner lens and the innovation literature. Broader considerations emerged, including that there is a temporal, cyclical and driving relationship between social movement and innovation development and diffusion, with eight phenomena emerging, as well as that there is a distinction between innovative social movement diffusion elements and innovative solutions to social issues emerging through social movement activity.

From a health perspective, the findings suggest that social movements can be the solution to health issues such as loneliness through fostering social connection. The nature of social health issues also impacts on social movement mobilisation. Perhaps surprisingly, health did not feature prominently in how study participants make sense of social movements. The data suggests that innovation exhibits Dewey's concepts of experience – continuity and interaction – and therefore, could be studied as experience. It also illuminates complex interrelationships between conceptualising, experiencing and innovating social movements, all of which could offer new vantage points through which to study social movements and innovation.

### **Responding to gaps in the literature**

This study responded to a number of theoretical, methodological and practical research gaps and trends in the literature as outlined in Table 2.5. It contributes to health as an underrepresented area within social movement research by generating empirical insights from people identifying with or influencing UK social movements in a health context. It triangulated and supplemented their viewpoints with observations of social movement meetings and document analyses of UK social movement activity as well as contextualised extant literature through UK health examples. Interspersed within the empirical findings are insights about how people build social movements impacting on health, offering practical value to social movement actors. Grounded theory was utilised systematically, responding to the need for a

more systematic application of grounded theory method within social movement studies (Peters, 2014). This systemic approach came at the expense of conducting additional rounds of theoretical saturation as well as establishing links between conceptual categories. It also ensured that the voices of social movement actors are imbued within the findings. Finally, the study also built theoretical and practical bridges between the social movement and innovation fields. Although this study pivoted away from the original research question, it illuminated potential ways that social movement actions aid innovation development and diffusion as well as broader patterns about the interrelationships between social movement and innovation development and diffusion. This initial understanding opens avenues for future research and opportunities for shared practice between social movement actors and innovators working on common social issues.

### **Impact on the researcher lens**

I have discussed how my researcher lens shaped this study but not how this study impacted on me. This study challenged my view of innovation (Godin, 2015), revealing that existing innovation research emerged from the firm, not from people innovating health and care. Therefore, we must continue to understand innovation from the perspectives of people whose voices have not been comparatively prioritised in research and theory-building. I also became more aware of my own innovation lineage and baggage. Dr. Yasser Bhatti alerted me to a quote by T.S. Eliot, "And the end of all our exploring will be to arrive where we started and know the place for the first time." This quote captures how I feel at the end of this study which has given me a more critical view of the innovation field and a deeper understanding of its shortcomings, blind spots and opportunities. I also exit it with a renewed recognition of the necessity of social movements in fighting for more equitable innovation theories, policies, processes and practices.

## Study limitations

Every study comes with limitations (Ross & Bibler Zaidi, 2019). This section discusses the limitations of the study design as well as those that emerged during its implementation.

### Biases

Biases could have entered the study from at least five vantage points. First, by the researcher whose lens represents a particular innovation repertoire, including design thinking, human-centered design and systems innovation; the associated mindsets, processes, frameworks and sensibilities of these traditions are likely to be reflected in the study findings. Second, some scholars might say that studying a subject for which I am deeply passionate could skew the findings; that, researchers offering a more neutral stance would produce more objective results. Yet still, an interest in a subject matter can also lead to findings more attuned to the views and environments of study participants. Third, every sense maker is a “parliament of selves” with selves expressing themselves differently across various social relationships (Mead, 1934). Study participants likely adjusted their views, consciously or subconsciously, based on their perceptions of my role, position, experience, gender and cultural background. It would be challenging to assess how each of these factors introduced biases. Most study participants were aware of my affiliation with Nesta which funds UK health and care activity. Although I explained to every participant that the interviews were being conducted in my researcher role, some participants might have viewed the interview as an opportunity to build a funding relationship. Fourth, the interviews were conducted in the wake of the *NHS Five-Year Forward View* (2014) with its section on “The NHS as a Social Movement.” It could have been useful to ask study participants how familiar they were with that section and whether they were involved in initiatives directly responding to it. Finally, looking at how the social movement groups in this study were resourced and supported could reveal any hidden agendas biasing or influencing study participant views and actions.

### **Sympathising with social movements**

Social movement scholars tend to study social movements they are “sympathetic to,” sharing the concerns of those they study (Klandermans & Staggenborg, 2002). Researching a social movement one cares about can make it difficult to produce objective results. An early research design involved conducting a case study on how the ACEs movement is enabling and hindering the development and diffusion of ACEs innovations. As my interest in social movements grew more broadly, I gently shelved this idea, realising that studying how social movements spread could meaningfully inform the ACEs movement as well. Studying multiple movements also meant I was less likely to become invested in any one movement.

During this study, I came across Dewey’s sentiment that “man is essentially an agent, an experimenter... where... the character of his activity is affected by what he experiences” (Muhit, 2016). A person experiencing childhood abuse faces a higher likelihood of becoming a perpetrator (Felitti et al., 1998), mirroring Dewey’s sentiment that what a person experiences impacts on the character of future experiences. I realised I had not stopped to ask, “What is an adverse childhood *experience*?” Nor had I heard anyone raise this question. I wonder how deliberately the ACEs investigators chose the word, “*experience*.” Theories of experience could yield new insights about both ACEs and the ACEs movement as *experience*.

### **Transferability not generalisability**

The study findings represent the people and social movements under investigation and are not generalisable to other social movement contexts such as other social issues, geographies or cultures. However, this chapter identifies pathways for testing the transferability of findings to other contexts sharing similar characteristics (Heist, 2012) such as to other people organised into other HSMs social movements in the UK or in other geographies.

### **Perceptions not innovation processes**

This study set out to understand how social movements aid innovation development and diffusion. The initial semi-structured interviews with people identifying with or influencing UK social movements were originally intended to surface innovations associated with specific social movements. The development and diffusion of these innovations could then be followed, or retrospectively investigated, such as in the Minnesota studies where researchers identified specific innovations and followed them within the context of organisations (Van de Ven et al., 1989). However, during the first few interviews, it quickly became apparent that study participants held varied conceptions of social movements and innovation and that understanding innovation in relation to social movements requires understanding how people organised into social movements make sense of these concepts. In reaction, the study pivoted towards understanding their perceptions as described in Chapter 3. Proceeding with the original study design would have turned a blind eye to participant perceptions, some of which clash with dominant views of innovation and therefore, offer opportunities for new insight. A deeper understanding of these perceptions aids designing more appropriate ways of studying social movements and innovation that take into account the views and language of people. Methods are also needed to identify innovations within a social movement context. Within social movements, plans to develop solutions are not necessarily readily available or scoped with clear milestones to enable studying the development of an innovation within a reliable timeframe.

### **Attending to the meso- and macro-level contexts**

This study focused on the social movement micro-level context, generating empirical insights from the perspectives of people. It situated insights in a social movement meso-level context. This study was conducted shortly after the introduction of the *NHS Five-Year Forward View* (2014) and its section on “The NHS as a social movement” as well as amidst a contentious

trend towards healthcare privatisation (Pushkar, 2019). A dedicated focus on the social movement meso- and macro-level context would lead to a deeper understanding of the social movement experience as well as of how social movements enable and hinder innovation.

### **Completing the constructivist grounded theory journey**

This study was designed to surface new opportunities at the nascent intersection of social movement and innovation studies. With discovery dominating the research agenda, most of my energy was spent on making sense of the research journey and responding to new realisations. In fact, discovering and refining appropriate research questions in inductive research can take up to 10 years (Wiedner & Ansari, 2017). This exploratory process left little time for completing the constructivist grounded theory journey within the context of a PhD, including characterising linkages between categories, which is identified as future research in Chapter 9.

### **Implications for research and theory**

After discussing the study impact and limitations, it is time to identify implications for research and theory, including a “theory for all” agenda to produce theories by, with and for social movement actors, the social movement experience as a new analytical tool, approaching the study of innovation in relation to social movements and studying innovation as experience.

### **Theory for all**

In *Einstein’s Dreams* (1993), Lightman describes seven definitions of time alongside what a world would look like if time were defined in each way. For instance, in a world where time moves slower at higher altitudes, people build their homes on stilts on the mountains. Along similar lines, in a society where theory represents the views of all people, anyone could easily create and use theory – theory for all.

According to Crothers (2010), “Theory is necessarily produced by elites – but that is not to say that theory is necessarily elitist, that it can only be appropriated by elites, or that its employment can only lead to elitist results.” Theory for all perhaps refers to theory appropriated by all and benefiting all. The voices of people who have historically had less power remain relatively absent in theories about and concerning them. Within health, the scientisation of decision-making is leading to the devaluation of people in making decisions about their own health and in the design of health services. Within social movement research, there is an urgent need for greater representation in terms of gender, race and ethnicity.<sup>77</sup> Inclusive and accessible theory-building processes that break down barriers to engagement would ensure more representative theories appropriated for social movement actors. When do we want theory for all? Now! Generating and testing the value of the social movement experience concept with social movement actors is an appropriate next step towards realising “theory for all.”

### **The social movement experience as a new analytical tool**

Chapter 7 proposed that the social movement experience could serve as an analytical tool for social movement research and for deepening experience theories within psychology, education and cultural studies. Fully realising the value of the SMExp requires moving towards theory, including conducting additional rounds of empirical work to surface and deepen conceptual categories as well as characterising linkages across them. At this point, we might also choose to embrace alternate lenses through which to study social movement experience.

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<sup>77</sup> The need for greater representation of women and Hispanics in social movement research is a continual source of inspiration.

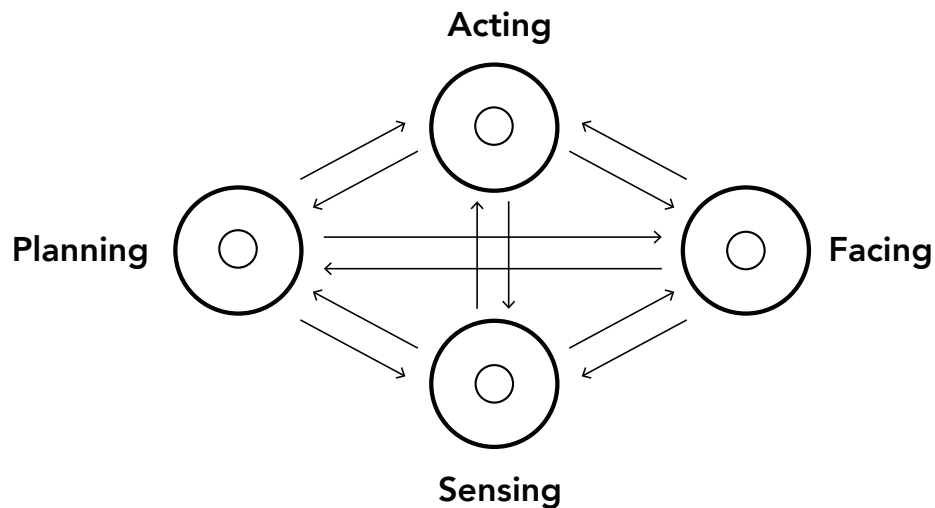


### *Surfacing and deepening social movement experience conceptual categories*

There are a number of ways to surface and deepen the social movement experience conceptual categories. First, to explore unanswered questions raised by the data such as, “When does a social movement experience start and end?” Second, to explore unanswered questions raised by the extant literature such as, “Is social movement experience accumulated?” Third, to conduct additional rounds of data collection and analysis through new theoretical samples. Fourth, to continually apply experience theories to the data.

### *Characterising the linkages between social movement experience conceptual categories*

I have started to document and characterise the linkages across conceptual categories of the social movement experience (Figure 8.1). Additional rounds of data collection and analysis, out of scope for this study, will enable further understanding of these linkages. It would also be useful to analyse the density of the four conceptual categories in relation to one another in terms of their frequency and observe whether patterns emerge across linkage sets.



**Figure 8.1: Linkages across social movement experience conceptual categories**

### *Embracing alternate lenses through which to study social movement experience*

Studying social movements as a lived experience, system or robotic paradigm could offer deeper insight into the social movement experience. Studying the social movement experience as a lived experience would help us understand what binds and separates the experiences of people with social movements. For instance, phenomenology concerns itself with “the empirical realm of everyday lived experience,” focusing on gathering “other people’s experiences because they allow us to become more experienced ourselves” (van Manen, 2015). Heidegger (1971) and Ricoeur (1991) also stress the importance of language in understanding lived experience and surfacing diversity across experiences. Embracing a phenomenological approach would aid identifying the “experiential structures” of the social movement experience (van Manen, 2015).

If experience represents “actors” and “patients” interacting within their physical and social environments, then the analytic tools of systems thinking would be appropriate to studying the social movement experience. Henderson (1993) says that, “The conceptual tools of non-linear systems dynamics, chaos, and complexity modelling are appropriate tools for citizen movements.” Analysing social movements as systems would enable researchers to identify and characterise its actors, relationships and environments. It could also offer practical value to social movement actors. Movement actors could utilise systems thinking to plan collective actions and identify points of collaboration with other movement groups. Resource-holders could identify the needs of social movement groups and make investments that respond to them as well as strengthen the social movement system terrain (Bartley, 2007).

The first iteration of the social movement experience was Sense-Think-Act.<sup>78</sup> Googling, “Sense-Think-Act” revealed an early robotic paradigm, Sense-Plan-Act (SPA) which identifies the three

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<sup>78</sup> In the first iteration of the SMExp, “Act” included what actions people “Face” and “Think” included “Plan.”

capabilities of an effective robot and how they interact to process and distribute sensory data (Brooks, 1986). In sub-paradigms of SPA, reactive and behaviour-based control paradigms, sensory data is processed and distributed from the bottom-up with the behaviour-based control paradigm accounting for interpretative freedom (Arkin, 1998). These two robotic paradigms could be applied to social movements as bottom-up, social and distributed phenomena. For instance, framing the components of the social movement experience as capabilities, and placing them in relationship with one another, could also offer insight into how sensory data is processed and distributed within them.

### **Approaching the study of innovation in relation to social movements**

I refrained from proposing “social movement innovation” as a new area of innovation research prematurely. It felt important to first understand how social movement actors perceive social movements and innovation as well as determine where innovation theory and practice is most needed in a social movement context. Studying innovation in relation to social movements requires its own set of preconditions and assumptions, including that are social movements emerging as well as that they involve people organising into hybrid forms such as communities and networks. The findings reveal three areas for understanding how to approach studying innovation in relation to social movements. First, to utilise social movement characteristics to study innovation in relation to social movements. Second, to conduct further empirical work on social movement actions aiding innovation as well as other social movements aspects such as identities and mindsets aiding innovation. Third, to characterise the interrelationships between social movement emergence and diffusion as well as innovation development and diffusion.

### ***Utilising social movement characteristics to study innovation in relation to social movements***

Chapter 4 revealed how study participants characterized social movements. We could conduct a literature review of innovation theories exhibiting those same characteristics such as bottom-

up or informal innovation. I have started to acquaint myself with innovation traditions relevant to social movements. For instance, studying social movements as “emerging innovation systems” would enable mapping the system of innovation actors in social movements, tracing innovation resource flows through social movements as well as characterising relationships within social movements which aid or hinder innovation. Yet, it could also create boundary, agency and interaction problems as is the case with The Social Movement Ecology metaphor (Case, 2018).

### *Conducting further empirical work on social movement actions aiding innovation*

Conducting further empirical work on social movement actions aiding innovation might involve:

1) Expanding the dataset of social movement actions to further investigate the 12 social movement actions and surface additional actions, 2) Looking at social movement actions hindering innovation, 3) Distinguishing between social movement actions aiding innovation development and those aiding innovation diffusion, 4) Looking at other aspects, beyond social movement actions, aiding innovation such as identities and mindsets, 5) Testing the hypotheses in Table 7.1, and 6) Experimenting with mapping the 12 social movement actions onto the social movement experience (SMExp).

How social movements aid innovation development and diffusion also requires understanding the nature of the problems people are trying to solve, the types of “innovative” solutions emerging within and through social movement activity as well as the role of social movements in a wider innovation development and diffusion ecosystem. Case studies of social movements and innovations would assist this understanding. For instance, tracing the diffusion of an innovation through social movement activity would assist with understanding where social movement and innovation development and diffusion activities intersect. Examining a single social movement and identifying innovations associated with that movement’s activity would also yield valuable insights about the role of social movements in aiding the development and diffusion of these innovations.

### *Characterising interrelationships between social movements and innovation*

The data revealed a potential temporal and driving relationship between social movements and innovation with Chapter 7 identifying eight phenomena. To characterise their interrelationships, we might first complete a literature review to identify how social movements and innovation interrelate such as social movements spreading a culture of innovation (Dean, 2013) and removing innovation barriers (Carson-Stevens et al., 2013). We might also expand the dataset of social movements and innovations. This database would enable activities such as plotting social movement and innovation development and diffusion events across time.

### **Studying innovation as experience**

The experience concept could contribute to innovation theory-building in multiple ways. First, studying innovation as experience could demystify the everyday experience of innovation, helping people better relate to the concept.<sup>79</sup> Second, researchers could apply the experience concept to understanding the development of experiences in healthcare such as patient experiences. Through an experience frame, researchers could interrogate the meaning of experience in these contexts and investigate how a deeper theoretical understanding of experience would impact on innovation practice.<sup>80</sup> Third, positioning the innovation practitioner as an *experiencer*, someone who “acts” and “suffers,” could be valuable in examining the development of intangible innovations, such as how a person comes to adopt a new norm, as well as in understanding the benefit of participating in an innovation process. For instance, social entrepreneurs who have experienced traumatic childhoods can draw value from designing innovative solutions (Barendsen & Gardner, 2004).

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<sup>79</sup> Chapter 6 revealed that some study participants perceive innovation as “something other people do.”

<sup>80</sup> As a designer in health and care, I had never interrogated the meaning of “experience” in phrases such as “transform the experience and delivery of health care” (Mayo Clinic Center for Innovation, 2020).

## Implications for practice

This section outlines practical implications of this study for social movement actors and innovators.

### **Social movement sensemaking having implications for practical action**

Understanding how people make sense of social movements is critical to understanding how people act within them and in relation to them. After all, "Human beings act toward things on the basis of the meaning things have for them" (Blumer, 1969). Study participants revealed instances where their perceptions and beliefs about social movements have implications for practical action. For instance, when health professionals believe they can organise people into social movements, it can have negative implications for lasting change, as "Egon" shares.

We don't want to force people to organise themselves in certain ways and have certain types of messages and... organisational structures... because its artificial... as soon as that money goes, it collapses... this has happened over and over... you do have to let things go.

Many study participants viewed social movements as challenging to the orthodoxy. Yet, the health field is not very open to challenge. As a result, the data shows health professionals in social movements adopting strategies such as "getting their ducks in a row" prior to introducing projects perceived as challenging to institutions or setting up outside organisations to challenge power anonymously.

Some study participants were not familiar with social movements despite clear associations with groups referring to themselves as such. My social movement meeting observations reveal that some people are unaware of the socially constructed nature of social movements. As one clear indicator, the question, "What is a social movement?" continually resurfaces like a

“broken record” in practical conversations about social movements. Understanding that the social movement concept is a social construction would illuminate one reason why “What is a social movement?” is impossible to definitively answer. Asking different questions about social movements could aid deeper understanding of them. For instance, “What do you want a social movement to do?” or “Why do you want to start a social movement?” could set up a productive strategizing conversation about what people want their social movement to achieve. Table 8.2 proposes a range of questions and their anticipated value.

**Table 8.2: Questions for generating a deeper social movement understanding**

Question	Anticipated value
What is a social movement?	Identifying subjective perceptions, descriptors and characteristics
How do social movements behave?	Characteristics of social movement rising, thriving and declining
How would you describe your social movement experience?	An experiential view of social movements
What is a social movement to you?	Relative meaning of a social movement
What do you want a social movement to do?	Intended role of a social movement

Identifying and developing occasions for meaning creation would be valuable future practical work and aid social movement understanding. Two immediate opportunities for meaning creation include directly applying the ways people make sense of social movements in Chapter 4 and utilising digital sensemaking tools within social movement groups. For instance, SenseMaker® utilises insights from complex adaptive systems theory to conduct “distributed ethnography” and enable collective sensemaking (Van der Merwe, 2019). The NHS has been utilising SenseMaker® in the NHS to baseline and measure narrative shifts, generate meaning around large-scale systems change and look at “what is needed, where, and who for.” In 2016, 286 NHS staff stories of change were collected across four NHS organisations with contributors electronically submitting and coding their own stories (Bevan Commission, 2016).<sup>81</sup> There is opportunity to apply SenseMaker® within social movement groups outside the NHS.

<sup>81</sup> The prompt was, “Think about a time when something changed or needed to change in work.”

## Learning from other social movements

In Chapter 4, we saw study participants trying to learn from other social movements. Yet, as “Egon” shares, “Beyond that original idea,” of the MGMH learning from HIV/AIDS activists, “I don’t think there’s been a really conscious process of studying other movements... of knowing what they can do... that’s an opportunity.” I made a similar observation in 2016 when an Arizona ACEs movement activist asked, “What can we learn from other social movements such as HIV/AIDS?” I have heard this question multiple times in the US and UK, such as at the E-Cigarette Summit as part of this study, illuminating that social movement groups could benefit from a more systemic process of learning from one another which may involve going beyond the “usual suspects” such as HIV/AIDS. Harris et al., (2018) found that what health professionals learn depends on where they look. Enumerating where social movement members look, and what they look for, could reveal untapped sources for learning as well as shed light on what social movement actors want to learn from other social movements. For instance, “Mikkel” desired learning, “What’s the best we know about how to... make a movement work?” Identifying dimensions along which social movement groups can look for relevant learning – beyond looking for social movements working on related “issues” or in the same “locality” – could offer more relevant and untapped sources for learning. For instance, the ACEs movement is contemplating how to transform ACEs from a private into a public issue. The breast cancer movement was successful at this endeavour and therefore, could offer insight into relevant strategies.

## Measuring social movement progress

Social movement actors have historically struggled to measure their progress. Making sense of social movements as experience offers an explanation as to why it is problematic to measure social movement progress. As Hohr (2012) shares, “It is clear that some aspects of experience can be measured. But experience as an integral event is beyond such an approach.” Identifying what aspects of a social movement can be measured, as Hohr suggests, would be



practically useful for social movement actors and resource holders who need to report on the impact of their investments. This endeavour would inform a conversation about whether measuring those aspects is feasible, cost effective and valuable to inform action. A social movement experience measurement framework could be adapted to specific contexts. Appendix IX depicts variables that study participants use to refer to social movements. These variables offer a starting point for developing a measurement framework that is rooted in how study participants perceive and value movements, rather than in how external actors, such as funders or policymakers, perceive and value them. The variables could facilitate tracing the progress of a single social movement as well as conducting cross-movement studies such as through qualitative comparative analysis (QCA).

### **Developing movement-building tools**

Some scholars feel that social movement theories of emergence and spread inform a social science rather than a social movement activist audience (Irons & Tseng, 2019). “Mikkel” thinks of himself as “principled pragmatist” and is, “... frustrated by people working stuff out theoretically and... not taking it anywhere... I like the combination... thinkers and doers.” Engaging with people in social movements over the past five years – through this study and other practical engagements – illuminated many of the challenges and opportunities they face, such as identifying target audiences, framing issues and designing effective tactics. Some health and care professionals desire blueprints for building social movements. There is no single blueprint for a social movement, but this desire reveals an appetite for movement-building tools. According to Sunrise Movement advocates,<sup>82</sup> grounding their strategies in social movement research was one of four factors contributing to their momentum alongside a bold vision, narrative and idea such as the Green New Deal (Willcox & Barnett-Loro, 2019).<sup>83</sup> Working with social movement activists to co-develop useful and effective movement-building

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<sup>82</sup> The Sunrise Movement is a “youth movement to stop climate change and create millions of good jobs in the process” (2020).

<sup>83</sup> Green New Deal public policy proposals address climate change alongside other social issues (Green New Deal UK, 2020).

tools is an important applied research agenda. Two immediate opportunities for an applied research agenda include exploring the applicability of entrepreneurial marketing tools and designing social movements utilising innovation approaches.

### *Exploring the applicability of entrepreneurial tools to social movements*

Social movements and technological innovation are two drivers of societal change. Yet, our understanding of how people build social movements is limited in comparison to what we know about how entrepreneurs build technological innovations. During my PhD programme, I explored the applicability of entrepreneurial tools to movement-building, tools to craft go-to-market strategies and strategies to cross the chasm.

In Chapter 4, we observed study participants having a bias towards mass movements – that in order to be “real,” movements must have mass mobilisation. Yet, it is not always necessary, and potentially counterproductive, for movements to set their mobilisation targets infinitely large, especially amidst limited resources. A case-in-point is the EIP movement which targeted people who could deliver a new model of psychosis care. Entrepreneurs identify target markets by assessing their total available market and serviceable available market, TAM and SAM respectively (Blank & Dorf, 2020). In similar fashion, social movement groups could benefit from assessing their total available base and reachable available base, TAB and RAB respectively.

Just as high-tech products can face a “chasm” when trying to reach mainstream customers (Moore, 2002), social movements can face a similar “cultural chasm” when trying to reach influencers who can realise a social movement’s change programme (del Castillo et al., 2016). In my practical engagements with social movement actors, the concept of a “cultural chasm” resonated with them. In response, I adapted the Technology Adoption Lifecycle and Bowling Pin Strategy to create the social movement adoption lifecycle (SMALC)(Figure 8.2) and Social Movement Bowling Pin Strategy to assist social movements in crossing the cultural chasm.

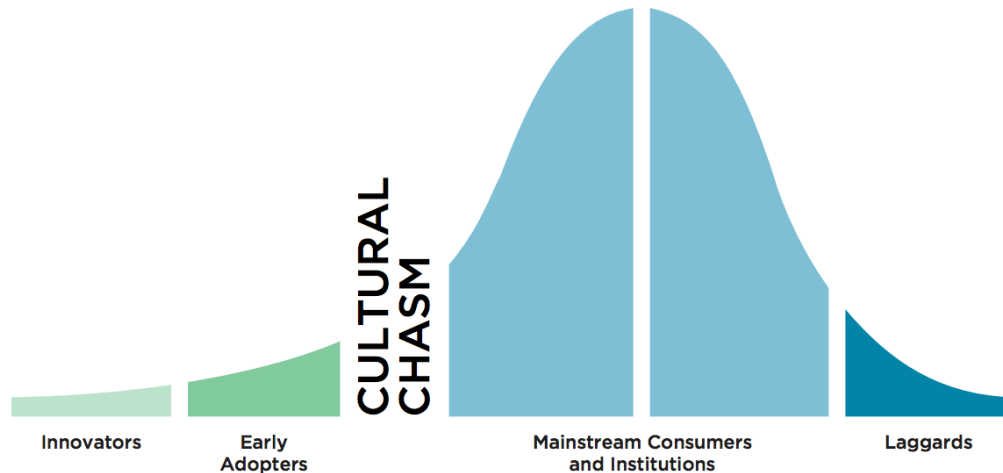


Figure 8.2: The Social Movement Adoption Lifecycle (SMALC)(del Castillo et al., 2016)

### *Designing social movements utilising innovation approaches*

“Can you engineer a social movement?” has led to a lively debate on multiple occasions. To what extent does a social movement – as dynamic, emerging and spontaneous – lend itself to a design process? Within the design field, we talk about designing and prototyping systems. Why not design and prototype social movements? Social movement design is not a well-developed or diffused practice and therefore, represents an opportunity for new practice.

Amongst study participants, “Torben” believes that social movements can be “designed” to have specific elements and for specific functions.

The reason I would refer to [Time to Change] as a social movement... is because it’s deliberately designed to go much wider and to have momentum much longer than the core funding applies... it’s a... nucleus designed to motivate... inspire... accelerate change and engagement... it’s a point of recruitment... congregation... of people who want to join in... quite often you’ll need... a core nucleus... as a platform which is then multiplied or accelerated by others to join in... that’s one model.<sup>84</sup>

<sup>84</sup> It would be useful to deconstruct these social movement “models.”

This debate inspired me to develop an interactive workshop on *Designing Social Movements* where people work collectively to design a social movement through an orchestrated and interactive process which draws inspiration from design thinking. Since 2016, I have delivered this workshop to over 500 graduate students in public health, medicine, health policy, design and business at Imperial College London, the Royal College of Art and Oxford Saïd Business School as well as with U.S. and UK health professionals at Mayo Clinic *Transform* (Sparks, 2017) and Nesta's *The Future of People Powered Health* (Nesta, 2018) conferences. The workshop has received positive feedback and resulted in emerging social movements as well as a research programme on *Movement of Movements* at the University of Oxford. An innovation action research approach could support the systematic development of social movement design tools (Kaplan, 1998).<sup>85</sup> Research to identify social movement diffusion elements that can be designed, such as identities, tactics and symbols, is underway.<sup>86</sup>

### **Social movements for just innovation development and diffusion**

Innovation has historically exacerbated inequalities. It has widened the gap between those who have the right to develop innovations and those who have the right to access their benefits (Sveiby et al., 2012). Over the last decade, scholars have been calling for an account of "justice in innovation" (Buchanan et al., 2011) and "unjust innovation diffusion" processes and policies (Papaioannou, 2011). This study opens up opportunities to build social movements for "just innovation diffusion" and to research related topics such as how vapers pressurised industry to adopt their e-cigarette designs and over time, sustained a voice in industry innovation.

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<sup>85</sup> Innovation action research offers a theory for developing new management tools such as the balanced scorecard (Kaplan, 1998).

<sup>86</sup> Study participants felt that some social movement elements cannot be designed. "You can't invent charismatic leaders," for instance ("Egon"). Digital communication tools offer ways to mobilise and bring into question the necessity of a charismatic leader (Carty, 2015)

### **Innovation by, with and for**

More health professionals are embracing the principles of “by, with and for” in their innovation processes such as the Helix Centre (2020) and Kraftens Hus (2019), a social innovation project designed by, with and for people affected by cancer. As “Ulrich” described, a single word such as “by” or “for” can have vast implications for how innovations are ultimately developed and adopted. They can also shape interactions between people participating in innovation processes, influencing the freedom to act, self-esteem, self-determination and balance of power between innovators and beneficiaries. Solutions design “for” people, and imposed on them, reduce their intrinsic motivation, with self-esteem and self-determination suffering (Ostrom, 2005). The balance of power between innovator and beneficiary must be further interrogated if innovation approaches are to assist in achieving a more equitable world. Shifting power to people who have been exploited or marginalised is not enough. Equitable innovation must start and end with the needs of people - it must be *by, with and for* us all.

### **Implications for policy**

Broadly, this study offers a much needed “people’s perspective” or “experiential view” of social movements to inform policymaking. The findings hold implications for situating social movements as part of a wider social change landscape, navigating the liminal space between social movements and institutions as well as supporting social movements.

### **Situating social movements as part of a wider social change landscape**

Participant responses indicate a fuzzy understanding about how social movements relate to other mechanisms of social change such as policy advocacy, campaigning and field-building. A framework that situates social movements within a wider landscape of social change approaches would enable policymakers and funders to devise support strategies that support

the unique way that social movements create change. I have observed the tendency for movement-building funders to widen the definition of movement-building to other mechanisms of social change such as community development, which risks diluting the term and contributing to social movements becoming a policy fad. Decades ago, sociologist Charles Tilley said, “One way to get social movements wrong is to see them everywhere.” A social movement policy fad could lead to people creating “social movements for social movements sake” or misusing the term, perhaps even to cloak other interests. Since the publication of the *NHS Five-Year Forward View* (2014) and as a result, greater funder interest in social movements, more and more groups have been starting or referring to themselves as social movements, sometimes without thoughtful consideration as to why.

### **Navigating the liminal space between social movements and institutions**

The study data reveals instances of institutions attempting to control, co-opt or crush social movements, such as a health institution drafting people from the HIV/AIDs movement to setup a competing national hotline. This phenomenon is well-documented, with social movements and institutions finding it challenging to interact (Goldner, 2004). Social movements are dynamic and emerging, operating by their own rules and on their own time scales, making it difficult for formal institutions to work with or alongside them (del Castillo et al., 2016). Institutions can also become politically charged by associating with social movements. Yet, social movements can benefit from the scale and resources of institutions; and institutions, from the ideas and knowledge of social movements (Smith et al., 2014).

Social movements often change the world but they’re also fluid, messy, complex and unpredictable. Civil services and professionals need to learn new skills to engage with them well in authentic conversation, whether responding to their demands, pushing back or working together to solve problems. (del Castillo et al., 2016)

Healthcare institutions can foster more productive engagements with social movements, such as by engaging on shared priorities as well as fostering communication across both formal and informal divides (del Castillo et al., 2016).

Patient and Public Involvement (PPI) initiatives are rising in the UK and internationally; yet, PPI can be resource-intensive and health systems can lack appropriate ways of measuring their value despite their promise to centre healthcare services around patient needs (Pizzo et al., 2015). The HASM programme explored how the NHS can engage with social movements that offer alternate visions of the future and that could contribute to accelerating new ideas into the NHS. There is tremendous promise in this type of approach, but a dedicated effort is needed to understand how a health institution can better work alongside social movements that are challenging and how to appraise the value of this type of partnership from both perspectives. In addition, it would be helpful to pinpoint how a programme such as HASM complements or challenges existing PPI efforts as well as NHS innovation and transformation activities.

As we saw in Chapter 4, study participants held reservations about referring to their groups or initiatives as social movements, especially pre-maturely. More work is needed to understand the positive and negative perceptions associated with designating an initiative as a social movement at various stages in a social movement's development. Critics of health social movements warn of governments and corporations "co-opting the language of social movements" to sell future healthcare plans to the public and "cloak" private interests (Land, 2018).

In the fight for universal healthcare systems, flashy headline offers and buzzwords must be subject to careful examination, and the implications – how these policies are likely to pan out in practice – explored and disseminated. Policies that sound positive to the public may be a misleading representation of profit-focused models that are not in the best interests of patients. (Land, 2018)

India's Modicare private health insurance scheme refers to itself as "Swasth Nagrik Abhiyan" or "Social Movement for Health" (Land, 2018). NHS England's HASM programme was criticised as potentially yet another "rendition of the Big Society" (Benson, 2016).

### **Supporting social movements**

Funders can be important fuel for social movements such as by connecting social movement organisations sharing complementary aims and aiding field professionalisation (Bartley, 2007). Yet, supporting social movements can require uncomfortable shifts for funders, such as embracing emergent ways of working and reflecting on issues such as power and control (Grantmakers for Effective Organizations, 2013). Study findings offer a "people's perspective" on how people make sense of and experience social movements, a perspective which is valuable to funders devising social movement support.

Groups such as science, technology and innovation institutions (STIs) play a role in incubating technological innovations (Fressoli et al., 2014). Yet, the value and role of analogous groups in incubating social movements is relatively unexplored. While at Nesta in 2018, I worked with colleagues to devise a social movement incubation programme – designed by, with and for people building social movements – in response to health and care professionals desiring to learn more about how to build social movements from their peers and practical research (Nesta, 2018). Our hypothesis was that providing "protective space" for social movements in their early stages could assist their growth and survival (Smith & Raven, 2012). A formal research programme to design and test early-stage social movement incubation support could surface early-stage support needs and interrogate the value of support to diverse actors.

Empirical evidence suggests that one of the most influential ways that funders can invest in social movements is by strengthening the social movement ecosystem (Bartley, 2007). Systems thinking tools could also offer value in this area. Funder collaboratives can offer joint and



leveraged support as well as catalyse social movements. For instance, Robert Wood Johnson Foundation has been catalysing a movement their building a Culture of Health programme (Trujillo & Plough, 2016).

In Chapter 4, we discussed whether funded programmes can be social movements. Believing funded programmes can be social movements could lead funders to place expectations on initiatives to become social movements. It could also lead them to construct pre-defined criteria for programmes to earn social movement status. Empirical work on how social movements actors experience working with funders, as well as applied research to devise new rules of engagement, would support the social norms change that is critical to future funder and grantee relationships (Grantmakers for Effective Organizations, 2013).

## Implications for education

The social movement experience has profound implications for education. As Miettinen (2000) shares, "Through its humanistic connection (with people), the concept of experience... has an ideological function: faith in an individual's innate capacity to grow and learn. This is what makes it particularly attractive for adult education theorists and for the idea of life-long learning." Framing a social movement as experience opens up opportunities for social movement "experiential education" (Quay, 2003) where people learn about social movements by participating in them. This section highlights two opportunities for educators: social movement "learning by doing" and developing a social movement case study method.

### **Social movement "learning by doing"**

"If you could start a social movement, what movement would you start?" This is often the first question I ask students when I conduct a workshop on social movements. After a few minutes of reflection, I ask for volunteers to share their ideas. Then, students are asked to self-organise into groups, according to the ideas, where they proceed through interactive exercises to

design a social movement. All of this takes place in just over 60 minutes, illustrating how rapidly we can all act collectively and strategically on issues we care about. This snippet is an example of social movement “learning by doing” where groups of people learn by engaging in real-world social movement activity – either to start a social movement, such as how students might start an enterprise, or participate in an existing social movement. After all, joining a social movement could ultimately have more impact than starting one (TED, 2010). Social movement “learning by doing” is a return to Dewey’s ideas that “experience is transformation” and that we can promote democracy within education (Muhit, 2016). After all, to fully grasp what it is like to voice a grievance, understand your own story, listen to the pain of others, demand change, navigate ambiguity, overcome steep hurdles, be courageous and achieve small victories, people must *experience*.

### **Developing a “social movement” case study method**

The case study method is a learning method which asks students to adopt the role of a character in a business scenario with the instructor assuming the role of “a planner, host, moderator, devil’s advocate, fellow-student, [or] judge” and orchestrates a process where a classroom develops the solution together and reflects on the process (Christensen Center for Teaching and Learning, n.d.). In a social movement case study method, students could adopt the role of a character in a social movement scenario with the instructor assuming the role of organiser, dissenter, movement peer and institutional gatekeeper, for instance. The case study method has been under criticism recently for contributing to a “narrow, instrumental, amoral, managerial perspective on business where making decisions which maximise profit is all that matters” (Bridgman, 2010). A social movement case study method would address some of these criticisms and offer a new application of the method. It would expose students to “the art of managing social change,” giving them a sense of how collective victories are won which maximize social good. Asking students to design their own social movement case study would also give them yet another way to experience social movements.

## Researcher reflections

This research experience, and the social movement experience, have transformed me in ways I could have never anticipated. Most importantly, they helped me reclaim the personal power I never knew I had or deserved. I am grateful for the time to learn as well as the time to explore a topic that continues to fuel my passion, imagination and intellectual interest.

### **Embracing a researcher mindset**

I will never forget George Kembel at the Stanford d.school filling an entire white board with 50 ideas in 5 minutes. He taught me that thinking differently is a muscle requiring exercise! My entire career has revolved around thinking differently, around discovering new ways to frame problems, solve problems and devise actions. At the onset of this research journey, I struggled to embrace a researcher mindset because as a divergent and lateral thinker, I saw possibilities infinitely expanding at every stage of the research process. My excitement around these prospects inhibited my ability to focus at times. My initial attempts to write looked like “idea scraps,” a smattering of disparately connected ideas lacking logical flow. In the past, I have been known to ask my closest teammates to help me order my thoughts into a linear sequence for a talk or presentation. Furthermore, as a systems thinker, tunnelling down into a specific topic felt contrary to solving systems problems requiring attending to the integrated nature of things. As the research journey progressed, I learned to better cultivate deep focus, capturing and parking new ideas as they emerged and cultivating a structured mind.

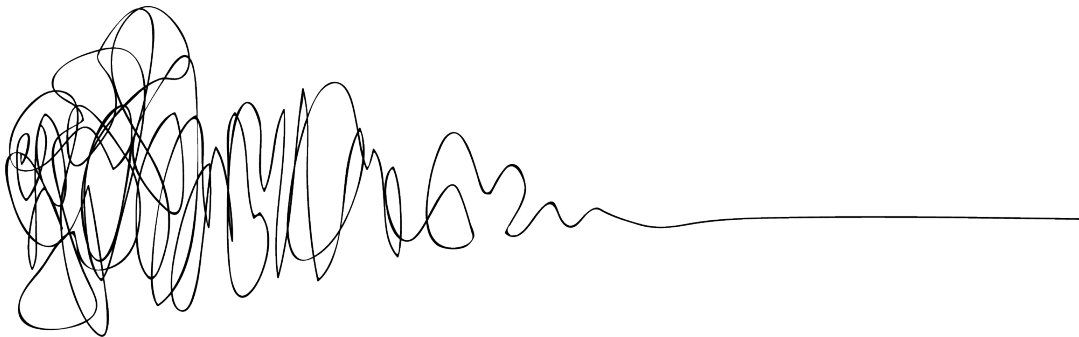
To me, becoming a social scientist means learning to think like one. It means redirecting the lateral mind to think deeply rather than differently about qualitative insights. It also means becoming attuned to “What is happening?” rather than identifying needs, solving problems or making recommendations, and finding your voice.

## Boundary-spanning

Crossing over into a new field – social movements – was challenging and rewarding. Insights from this boundary-spanning journey could be useful to other scholars crossing into the social movements field and even other fields more broadly. Personally, it was challenging to grasp social movement concepts for which I had no practical experience. As I gained relevant practical experience, concepts started taking on meaning. I recommend anyone crossing into the social movements field to get engaged in social movements, if you have not already.

## Design squiggling

The trajectory of this research journey mimicked the Design Squiggle, depicted in Figure 8.3.<sup>87</sup> Embracing an inductive research process enabled pivoting to respond to insights emerging from the voices of people as well as my own observations. It also involved hitting conceptual dead ends as well as converging and diverging to find conceptual clarity.



**Figure 8.3: The Design Squiggle (Newman, 2002)**

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<sup>87</sup> The Design Squiggle is licensed under a CC BY-ND 3.0 US License (Newman, 2002).

### **Theoretically grounding my innovation and social movement practices**

This research offered a theoretical foundation for my ongoing practical involvement in innovation and social movement efforts. Frequently, I would read something in the literature and realise that it helped me make sense of what I had been doing in my practical career. An example that stands out is Dorst's (2009) "layers of design practice."

### **Becoming an activist**

A colleague recently said, "You know what happens when you study movements?" He chuckled. "What, I asked?" ... "You become part of them." This research put me on a journey of becoming an activist, to taking on something larger than myself with other people on issues I care about. One of my students recently asked, "If you had to give one piece of advice to an activist, what would it be?" I instinctively responded, "If you aren't struggling, your cause is not big enough."

### **Summary**

This chapter presented the impact of the study in terms of new concepts, conceptual directions and rich insight. It also discussed the study limitations as well as implications for research, theory, practice, policy and education, all pointing to exciting future research summarised in the next chapter. This study suggests that perhaps, social movements and innovation are social change cousins. There is much for scholars in each field to learn from the other, enlarging individual scopes of understanding as well as exploring work at this nascent intersection.

## Chapter 9: Charting future research

The sun has set on this research journey. New questions have emerged for future research that is potentially of theoretical and practical value to social movement researchers and actors.

### Future research agenda

A rich future research agenda (Table 9.1) has surfaced to advance our understanding of the social movement concept, social movement experience and social movement innovation.

**Table 9.1: Future research agenda**

Concept	Future research	Brief description
Social movement concept	Valuing social movements	Develop a typology of how people value social movements
	Deliberating on SMs	Further empirical work to identify and understand social movement deliberations
	Characterising SMs	Further empirical work to identify how people characterise social movements
	What SMs challenge	Develop a typology of what health social movements challenge and how
	SM expertise	Investigate whether SM experience is accumulated and transferrable as expertise
	SM as a mindset	Investigate the social movement as a mindset
	SM learning	Identify what SM actors learn from other SMs
	Biases about SMs	Identify and examine biases held by health professionals about SMs
Social movement experience	Cross-cultural conceptions	Investigate conceptions of SMs cross-culturally
	SMEExp theory development	Develop SMEExp categories & linkages; engage actors in theory development
	Value of SMEExp	Examine the value of the SMEExp to people and professionals
	SM lineage	Develop the SM lineage concept through theoretical sampling
	SMEExp through new lenses	Investigate the SMEExp as a lived experience, system or robotic paradigm
Social movement innovation	SMEExp as unit of analysis	Identify variables of a SMEExp that enable the measurement of progress
	Innovation conceptions	Conduct theoretical sampling on SM actor innovation conceptions
	Innovation in relation to SMs	Identify innovation traditions relating to SMs; conduct a review of these traditions
	SM innovations	Identify the types of innovations influenced by social movement activity
	SMs actions aiding and hindering innovation	Expand dataset of SMs and innovations to conduct further empirical work on SM actions aiding and hindering innovation, test Table 7.1 hypotheses
	SM case study	Explore a social movement and its impact on associated innovations; explore an innovation and its development or diffusion through SM activity
	Temporal relationships	Explore the eight temporal relationship between SMs and innovation; develop the social movement and innovation opportunity structure concepts
	Designing SMs	Utilise innovation action research to further develop SM design tools
SM incubation	Identify incubation support needs of early-stage social movements	
Innovation as experience	Investigate innovation as experience	

This study resulted in a dataset of 40 UK health social movements which can be utilised to glean insights on new research questions. It can also be expanded to conduct deeper analysis on specific topics such as movement-building strategies.

## Collaborating with the past, present and future

“The beginning is the end and the end is the beginning... yesterday, today and tomorrow are not consecutive, they are connected in a never-ending circle” (Müsch et al., 2017–2020). In 2013 and 2014, I contributed to a systems innovation course with Banny Banerjee which he aptly named, “Collaborating with the Future: Launching Large-Scale, Sustainable Transformations” (Stanford ChangeLabs, 2020). As this research revealed, realising social change requires collaborating with the past, present and future. Social movement actors occupy the liminal space between the status quo and alternative futures, a space where boundaries blur, cultures merge and relationships grow.

This research study contributes to health as an underrepresented issue area within social movement research, a people’s perspective of social movements and a desire amongst innovation scholars to understand social movements. The social movement experience offers a new analytical lens through which to understand social movements. This research also offers theoretical insights on how to study social movement innovation and practical insights on how to build social movements that improve the experience of health and care for all.

Together, we face a timely opportunity to act creatively and strategically about how to realise health for all. In the words of Margaret Mead, “Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has” (Lutkehaus, 2008).

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## Appendix

### Appendix I: Public launch announcement of the National Health Service

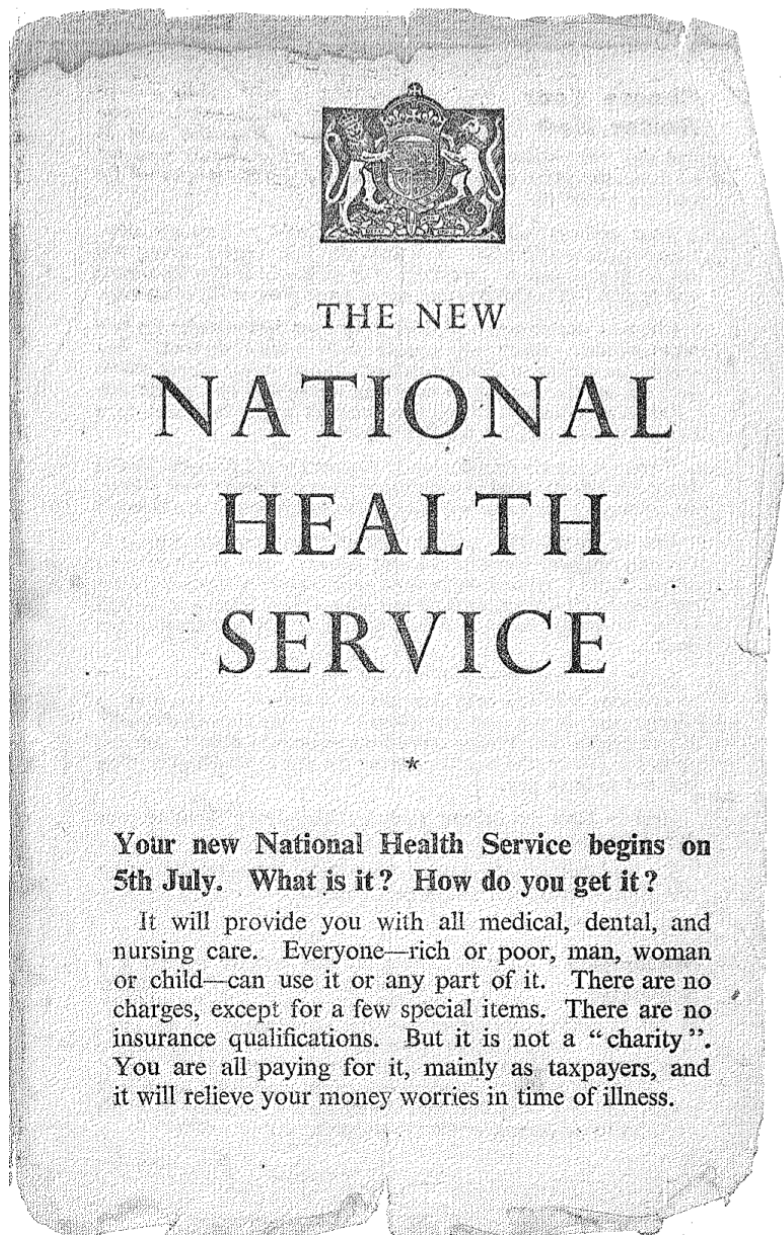
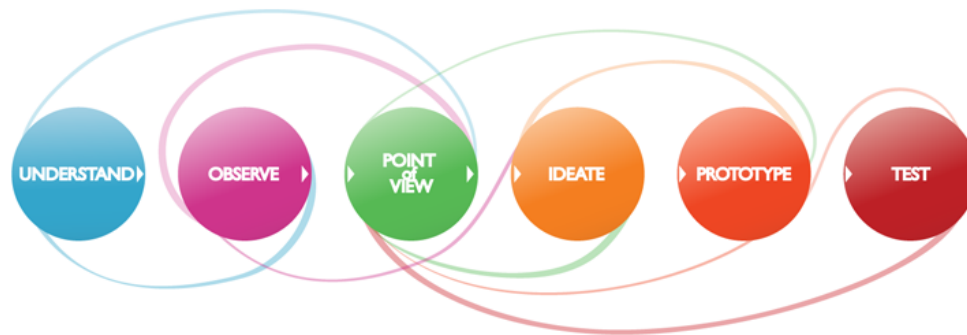


Figure A: Public launch announcement of the National Health Service  
(Ministry of Health, and the Central Office of Information, 1948)

## Appendix II: Researcher innovation approaches

As a practitioner, I have utilised a range of innovation approaches, including design thinking at the Stanford Hasso Plattner Institute of Design (Figure B) and the Mayo Clinic Centre for Innovation (Figure C) as well as human-centred design at the Helix Centre for Design (Figure D) and Nesta's innovation spiral (Figure E). This appendix depicts each approach.

The Stanford Hasso Plattner Institute of Design is “a hub for innovation, collaboration and creativity” in the heart of Silicon Valley (Stanford d.school, 2020). It has pioneered the application of design thinking to solving real-world challenges and cultivating creativity.



**Figure B: Design thinking at Stanford d.school (2020)**

The Mayo Clinic Center for Innovation (CFI) was established in 2008 and was one of the first innovation groups embedded within an academic medical center. Multidisciplinary teams of service designers, project managers, clinicians and other stakeholders utilised design thinking to develop innovations that “transform the experience and delivery of health care with a patient-centered focus” (Mayo Clinic Center or Innovation, 2020).



**Figure C: Design thinking at Mayo Clinic (2017)**

The Helix Centre is an innovation lab at St. Mary’s Hospital in London, UK and promotes collaboration amongst patients, clinicians, staff and students. It translates research into products that improve health outcomes and advances human-centered design in healthcare.

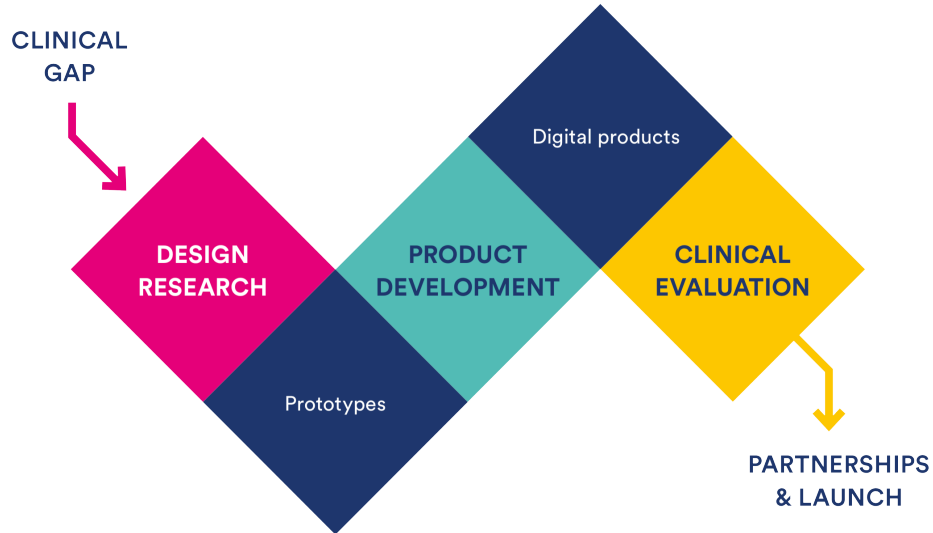


Figure D: Human-centred design at Helix Centre (2020)

Nesta is a UK innovation charity which brings “bold ideas to life to change the world for good.” The Nesta innovation spiral depicts seven stages through which innovations advance. More information about each stage can be found on the Nesta website (Nesta, 2017).



Figure E: Nesta innovation spiral (2017)

## Appendix III: Additional UK social movement groups related to health

<b>Social Movement Group</b>	
1	Active Birth Movement
2	Alzheimer's Movement
3	Antibiotic Resistance
4	Anti-Vaccination Movement
5	Arts, Health and Wellbeing as a Social Movement
6	Better Conversation as a Social Movement
7	BlackOut UK
8	Breast Cancer Movement
9	Change4Life
10	Consumerism
11	Co-operative Movement
12	Doctors for Extinction Rebellion
13	East Brighton Campaign for Health Inequality
14	Greater Manchester Cancer Vanguard
15	Health Freedom Movement
16	Health through Rights Self-Advocacy
17	Hello My Name Is (#hellomynameis)
18	International Red Cross and Red Crescent Movement
19	Junior Doctors' Strike
20	Hospice Movement
21	Keep Our NHS Public
22	LGBTQ Movements
23	Mental Health Rights Movement
24	Natural Childbirth Movement
25	NHS as a Social Movement
26	NHS Volunteering
27	Organic Movement
28	Park Run
29	Patient Rights Movement
30	Psychiatric Survivors Movement
31	Professionalising Care Work
32	Rare Disease
33	See Me
34	Social Approaches in Mental Health
35	Social Care Future (#socialcarefuture)
36	Social Movement for Health Equity
37	Social Prescribing
38	UK Health Consumer Groups
39	UK Mental Health User and Survivor Movement
40	UK People's Health Movement
41	Veganism
42	Women's Health Movement
43	Women's Liberation Movement
44	Young Health Movement

## Appendix IV: Description of social movement groups included in the study

This Appendix describes 11 of the 22 UK-based social movement groups, which make up the raw study data. They are not case studies but rather offer background context to the empirical findings of Chapters 4, 5 and 6. Study participant data provides the scaffolding for these descriptions. Academic articles, public websites, formal reports, meeting notes and conference materials provide additional detail, nuance and narrative. In my experience, every social movement consists of more and less powerful voices as well as competing interests and ideologies. I ask the reader to keep these truths in mind. Great care was taken to express study participant views while also highlighting contested issues, diverse interests and historical baggage at the heart of these groups. A lively debate within social movement research exists around whether researchers can be truly “value free.” In response, I take inspiration from C. Wright Mills: “I have tried to be objective. I do not claim to be detached” (Mills, 1962). Yet, the viewpoints described are not my own.

### Global Mental Health

Congressman Patrick Kennedy said, “Until a cause becomes a (social) movement, authentic, even transformational change, will not occur. The 60s gave us the Civil Rights Movement, the 90s the Aids Movement.” Let us make mental health the 21st Century Movement. (Goetzke, 2014)

Over the past decade, an international mental health movement has emerged to address mental health disparities worldwide, specifically in low- and middle-income countries as well as amongst vulnerable populations in high-income nations (Horton, 2007; Patel & Prince, 2010). It is also giving rise to a new field of global mental health research and practice (Patel, 2014), which is generating evidence for the burden and impact of untreated mental disorders globally (Cooper, 2016). The field aligns with the global health field which is contributing scientific and ethical evidence advocating for a global approach to health; global mental health practitioners focus on “the promotion of evidence-based interventions, human rights, and novel frameworks for scaling-up mental health services, such as task sharing” (Cooper, 2016).

It is important to distinguish between global mental health as a movement and the Movement for Global Mental Health (MGMH). According to “Tannhaus,” the global mental health movement refers to the “broader array of people who are doing work in that field” whereas the MGMH is “one of the networks” some of whose members are associated with the broader movement.



## The Movement for Global Mental Health

The Movement for Global Mental Health (MGMH) is an international network of people and organisations that aim to “improve services for people living with mental health problems and psychosocial disabilities worldwide, especially in low- and middle-income countries where effective services are often scarce” (Mental Health Innovation Network, 2020a).

The MGMH emerged in 2007 when a group of people joined together to “close the treatment gap for people living with mental disorders worldwide” (Lancet Global Mental Health Group et al., 2007). The voluntary network has grown to over 10,000 people and 200 institutions worldwide, including people and families affected by mental health problems, activists, policymakers, researchers, decision makers and health care providers. The coordination of the movement has been shifting across continents for over a decade. It is currently coordinated by Charlene Sunkel in South Africa. Individuals and institutions can join the movement on its website, serving as an expression of commitment, as well as connect, share ideas and knowledge, campaign and attend a bi-annual summit.

## Smoking Cessation

The issue of “tobacco and health” has been around for centuries (Davis, 1992). In 1954, Doll and Hill published a preliminary report on the *British Doctors’ Study*,<sup>88</sup> bringing the topic into view for the UK scientific and medical community. “Agnes” expands:

If you were a lung specialist working in the early part of the 20th century, you rarely saw lung cancer... suddenly, it developed into this epidemic... the manifestation of disease... could be 20-30 years later... and it's a horrible disease... it kills your patients in a really horrible way... so [lung specialists] cared about it and wanted to do something about it... they wanted government to take action. (“Agnes”)

In 1962, a group of lung specialists at the Royal College of Physicians (RCP) published a report *Smoking and Health*, proposing solutions to the UK government. According to “Agnes:”

They published this report... talking about the need for education... for... campaigns... to increase prices... to increase tax... it was the first report... it got a lot of publicity... and they sat back and waited for government to do something, but nothing happened.

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<sup>88</sup> The *British Doctors’ Study* ran from 1951 to 2001 as a prospective cohort study and identified the statistical link between tobacco smoking and increased risk of lung cancer (Doll & Hill, 2004).



In response, the specialists setup Action on Smoking and Health (ASH) to campaign and advocate for solutions. The report was later referred to as “seminal” in the 1964 report by the U.S. Surgeon General’s Advisory Committee and had influence on tobacco control in America, giving rise to the anti-tobacco movement.

## Health as a Social Movement

Health as a Social Movement was a three-year programme exploring how the NHS England can support social movements in health and care (NHS England, 2016). The programme was inspired by the *NHS Five-Year Forward View* (2014) and its section on “The NHS as a social movement” in chapter two, “What will the future look like?” A new relationship with patients and communities.” An open application process identified six new care model vanguards across England to participate in the programme based on an assessment of their social movement activity. Social movement activity focused on issues such as workplace health and wellbeing, nurturing emotional wellbeing, cancer prevention and improving the lives of people with dementia in care homes.

The programme also engaged three organisations to provide support, learning and evaluation, including Nesta, the New Economics Foundation (NEF), and the Royal Society of Arts (RSA). The programme raised critical questions about the relationship between a government health service, sites of local health provision, communities and people mobilised into social movements. Three reports captured the learning and posed new questions (Arnold et al., 2018; Burbidge, 2017; del Castillo et al., 2016).

## Ears Against Loneliness

Ears Against Loneliness is a “social movement and participatory arts project” challenging people to act against loneliness by donating active listening time (Made by Mortals, 2020). It emerged in the wake of NHS England’s HASM programme (NHS England, 2016) when a group of people who had met during the programme desired to creatively respond to the rising epidemic of loneliness in the UK and the way it links with physical and mental health problems. The initiative utilised a social media campaign and participatory forum theatre piece to mobilise and inspire people to act. The campaign asks people to post an “ear selfie” on social media (#EarsAgainstLoneliness), alongside what they are doing to listen, as a symbol of their commitment to tackle loneliness. The participatory forum theatre piece invites audiences to act and make change in the issue of loneliness. The piece premiered in Manchester, UK in November 2018 at the Social Care Future (#socialcarefuture) conference.

We know that listening to people (particularly vulnerable members of society) can be a daunting prospect and we’re not asking people to do anything they’re uncomfortable

with. However, we know that when a person feels listened to, they know they exist, and they know they matter. Small things can make a big difference. It might be as simple as greeting someone you often see on your morning commute, having a chat with a neighbour or calling a relative who lives alone. (Made by Mortals, 2020)

### **Call to Action: Movement of Movements in Greater Manchester**

In March 2017, 148 people gathered at the People’s History Museum in Manchester, UK for an event, *Call to Action: Movement of Movements in Greater Manchester*. The goal of the event was to build the momentum of social movement activity and research across Greater Manchester as well as assist groups in identifying potential collaborations. The event organisers invited people who they felt had been “actively involved in building more socially connected and healthy lives within communities,” such as #LiveWellMakeArt, Catalyse and Food as a Social Movement. The gathering featured talks, creative workshopping, performances and films. A “low-fi network” wall promoted connections and “opportunities to contribute to mini movements and creative inspiring ‘moments’ throughout the day.”

As the “national museum of democracy,” the People’s History Museum (2020) was a fitting venue for the event. It is home to numerous social movement collections, including women’s suffrage movement posters and working-class material of the Communist Part of Great Britain after its disbandment. It prides itself as a place where a “radical past can inspire and motivate people to take action – to shape a future where ideas of democracy, equality, justice and co-operation are thriving” (People’s History Museum, 2020).

### **Vaping Movement**

The e-cigarette was invented in 2003 by pharmacist Hon Lik. According to one study participant, the e-cigarette was met with a lukewarm reception in England. At that time, public health professionals cited the lack of evidence of its long-term health effects which is still inconclusive despite a 2015 report by Public Health England finding vaping to be 95 per cent less harmful than smoking. E-cigarette adoption has grown rapidly into an estimated 12 billion industry with a range of product customizations from devices with interchangeable parts to slim pens to an infinite choice of flavours (Usborne, 2019).

“E-cigarettes, and alternative nicotine products more generally, are changing the landscape of smoking cessation and tobacco control” (Dunand, 2016). According to the study data, vapers are offering peer advice to one another, rather than having to consult public health experts. For some, the quitting experience has shifted from a person struggling in stigma and guilt to an enjoyable hobby and lifestyle. The “frontline” of smoking cessation is no longer NHS smoking cessation services but e-cigarette users, vaping stores, social media forums and e-

cigarette makers of which there are nearly one million (Dunand, 2016). E-cigarettes are almost twice as effective as nicotine replacement therapy (NRT) products (Hajek et al., 2019) and allow users to gradually lower their nicotine usage over time. E-cigarette sales have now surpassed NRT use with smoking cessation services losing business. The intervention is essentially free to the government, wiping out the 513 per person smoking cessation cost, and involves minimal public health expertise other than conducting research on their safety and informing policy.

A professor of neuropsychopharmacology at Imperial College describes e-cigarettes as “the greater health advance since vaccines” and “a massive potential public health prize” (Usborne, 2019). Public health social scientist and expert on harm reduction believes that vaping is a “remarkable social movement – a consumer led market solution to a health problem” (Dunand, 2016). Yet, vaping is a contested political issue with the public accusing e-cigarette companies of targeting new generations of non-smokers and tobacco companies contributing to the R&D of a product meant to undo the very health crisis it created (Usborne, 2019). Several countries have banned e-cigarettes entirely with Britain banning sales to under-18s (Usborne, 2019). Responses from public health still range from negative to cautious to positive.

### **Social Care Future (#socialcarefuture)**

Don't we all want to live in the place we call home with the people and things we love, in communities where we look out for one another, doing the things that matter to us? That's the #socialcarefuture we see. (Social Care Future, 2020)

Social Care Future (#socialcarefuture) is an “emerging movement” of people acting together to imagine and create a new future for social care.<sup>89</sup> Believing that social care ultimately impacts on the wellbeing of everyone, this group aims to:

- Co-author a shared story of change and learn how to use it to inspire the wider public to support the future we seek;
- Underpin this story with examples of the approaches that exemplify this future and work with others to grow and to spread them;
- Challenge and change the present through action at all levels to close the gap between the positive ambition of the Care Act 2014<sup>90</sup> and reality on the ground (Social Care Future, 2020)

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<sup>89</sup> Social care in England covers a range of services from end of life care to child protection. For more information about what social care and how it works, please visit: <https://www.kingsfund.org.uk/projects/what-is-social-care>

<sup>90</sup> The Care Acts place a responsibility on local authorities to promote individual wellbeing by placing them at the centre of decision-making.

This voluntary, networked group is made up of “people with lived experience, families, professionals, managers, support providers, user-led organisations, politicians, commissioners, community groups and others” (Social Care Future, 2020). The group administration is provided by a single organisation.

Members of Social Care Future believe that achieving their aims will require a highly engaged public, changing the narrative (Crowther, 2020), political support, changes in how social care works as well as building power within communities requiring less of a focus on institutional practices; for their “glimpses” of the future, please visit their blog (Kendall, 2019).

## **FundaMentalSDG**

FundaMentalSDG emerged in 2014 with a single policy demand – to include mental health in the 2030 United Nations Sustainable Development Goals (UN SDGs) – where SDGs are goals, targets and indicators that all UN member states commit to utilising in their respective political agendas (FundaMentalSDG, 2020). The adoption of mental health into the SDGs would acknowledge the impact of mental health on health globally and on other SDGs intertwined with mental health such as poverty and economic development. It would also motivate governments and organizations to mobilise resources and take action for mental health development (Votruba et al., 2014). As part of FundaMentalSDG, people from around the world came together to draft a mental health target and two indicators for inclusion in the SDG Health Goal.

Mental health target:

“The provision of mental and physical health and social care services for people with mental disorders, in parity with resources for services addressing physical health.”

Mental health indicators:

1. “To ensure that service coverage for people with severe mental disorders in each country will have increased to at least 20% by 2020 (including a community orientated package of interventions for people with psychosis; bipolar affective disorder; or moderate-severe depression).”
2. “To increase the amount invested in mental health to at least 5% of the total health budget by 2020, and to at least 10% by 2030 in each low- and middle-income country.”

On September 2015, the UN adopted three targets and two indicators for mental health into the SDGs. FundaMentalSDG not only achieved its demand but for the first time, succeeded in rapidly mobilising global mental health actors with diverse priorities (Votruba et al., 2016). It

also fuelled conversations about the importance of mental health to other critical agendas such as conflict reduction.

### Early Intervention in Psychosis

In 2002, five people joined together to respond to the experience of a 16-year-old girl receiving care for a psychotic episode in the West Midlands.

I mean... she went into an adult psychiatric ward at 15... with 40-year old men... she didn't make a good or quick recovery... and no one seemed to bother that she wasn't doing any exams... that she wasn't mixing with her peers... that she was mixing with totally inappropriate... no one worried she was in an 8-bed ward with just curtains as a 15-year old in an adult ward... and instead of being reassured that she was being treated, they worried for her safety... eventually she was rehabilitated to a rehab ward in an old asylum and um and basically left there really... and she was 17... and no one seemed to be worrying about either her education, employment prospects, social prospects, her interests. They just seemed pleased that they'd moved her from an acute ward to a rehab ward and that she was effectively now being rehabilitated. ("Jonas")

The girl's father, a psychiatrist in the NHS, shared his anger and dissatisfaction with many colleagues. The narrative quickly reached people outside of the West Midlands and across the UK, inspiring many to respond. What started as a small group grew into a national network, mental health charity and international movement (Shiers & Smith, 2014) as well as one of the most pioneering efforts in mental health reform worldwide. Helen Bevan, Chief Transformation Officer of the Horizons Team at NHS England, referred to Early Intervention in Psychosis as "an exemplar of major health care change achieved through a social movement" (Byrne & Rosen, 2014).

### Time to Change

Time to Change (TTC) is a mental health initiative started in 2007 by Mind and ReThink Mental Illness, two non-profit organizations in England. Smith (2013) refers to it as the "largest-ever programme in England designed to reduce stigma and discrimination against people with mental health disorders." What started as a programme of work, funded by the Big Lottery Fund and Comic Relief,<sup>91</sup> evolved into a campaign and social movement. The initial campaign ran for four years between 2009 and 2012 and later received government funding for showing initial success in reducing stigma and discrimination in those years.

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<sup>91</sup> The original grant was £20.5 with £7.5 allocated for a social media marketing campaign.

The initial TTC evaluation,<sup>92</sup> conducted by King's College London Institute of Psychiatry, revealed a 5% reduction in stigma and discrimination towards people with mental illness across England in the first 12 months and an overall improvement in behaviours and attitudes over four years (Evans-Lacko et al., 2013). The evaluation utilised a best practice stigma model targeting knowledge, attitudes and behaviours; Smith (2013) refers to the evaluation as "exemplary... a milestone in international stigma research," showing that "systematic, insightful and multifaceted campaigns can be implemented and tested at scale." Yet, some believe that the programme fell "short of the wholesale shift in attitudes that is needed" (Smith, 2013).

The TTC website refers to the initiative as a "social movement for change" and a "growing movement changing... the way people think and act about mental health problems" (Time to Change, 2020). On the website, people are asked to join "thousands of campaigners in workplaces, schools, communities and online who are making stigma and discrimination a thing of the past." On the *Joining the Movement* page, website visitors can select how much time they want to dedicate – minutes, hours, longer – and where they want to act – workplace, school, online, community or with friends. Hitting the "Inspire Me" button produces a list of potential actions.

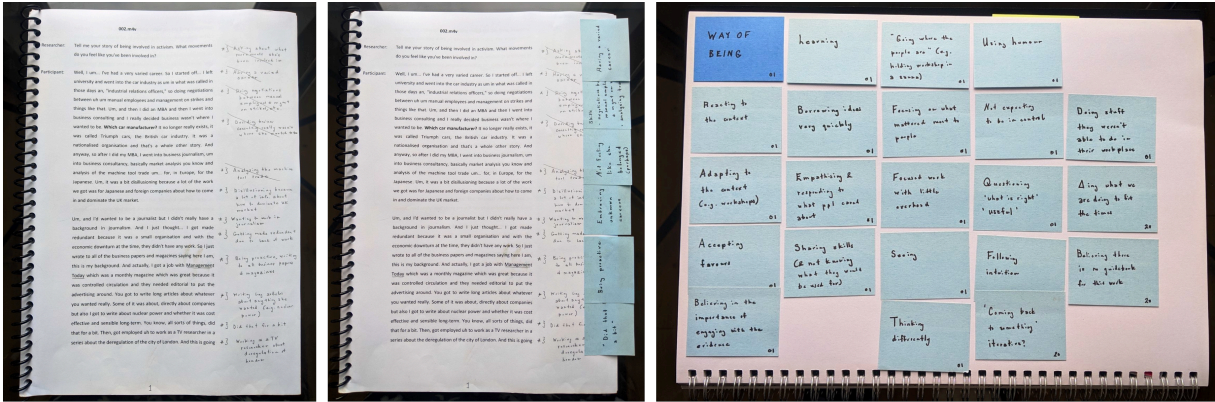
The National Social Marketing Centre refers to TTC as "building a movement for change" (2017). It presents a list of achievements, including over 117 organisations running activities (e.g., trusts, NHS primary care trusts, local councils, police forces, student unions, charities), Members of Parliament (MPs) pledging support (e.g., 45 MPs in 2009), celebrity involvement, citizen engagement (e.g., 11,000 pledging to end mental health prejudice; 27,000 participating in "Time to Get Moving" events) and a social media following (e.g., 31,000 Facebook fans). TTC is one of several national-level stigma campaigns globally, including "Open the Doors" of the World Psychiatric Association, "Like Minds, like Mine" of New Zealand, "See Me" of Scotland, "What a different a friend makes" of the United States and "Opening Minds" of Canada (Smith, 2013).

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<sup>92</sup> The study involved analysing the longitudinal trends of a nationally representative sample of people in England. The research team developed an annual Viewpoint survey, a Discrimination and Stigma Scale (DISC) and other research tools that are included in the Attitudes to Mental Illness Survey commissioned by the Department of Health (Evans-Lacko et al., 2013).

# Appendix V: Visual depiction of the coding process

This Appendix visually depicts the coding process.



### 1 Line-by-line coding

- » By hand on printed transcripts
- » Using gerunds and in vivo codes

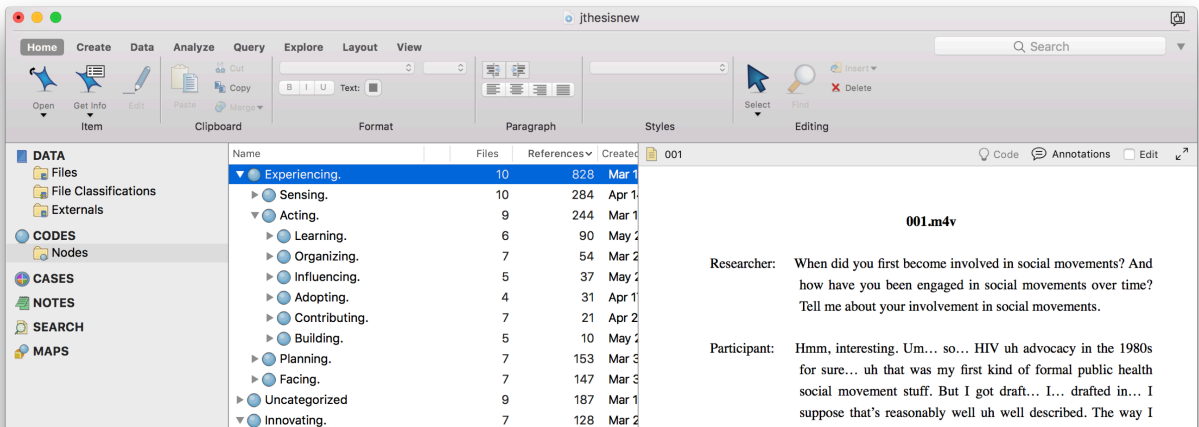
### 2 Refining line-by-line codes

- » With post-its on printed transcripts
- » Rephrasing codes

### 3 Focused coding to produce higher level codes

- » Physically copying and placing focused codes on larger pads
- » Abstracting focused codes into higher level codes

← **Triangulating** with supplementary documents and observation notes



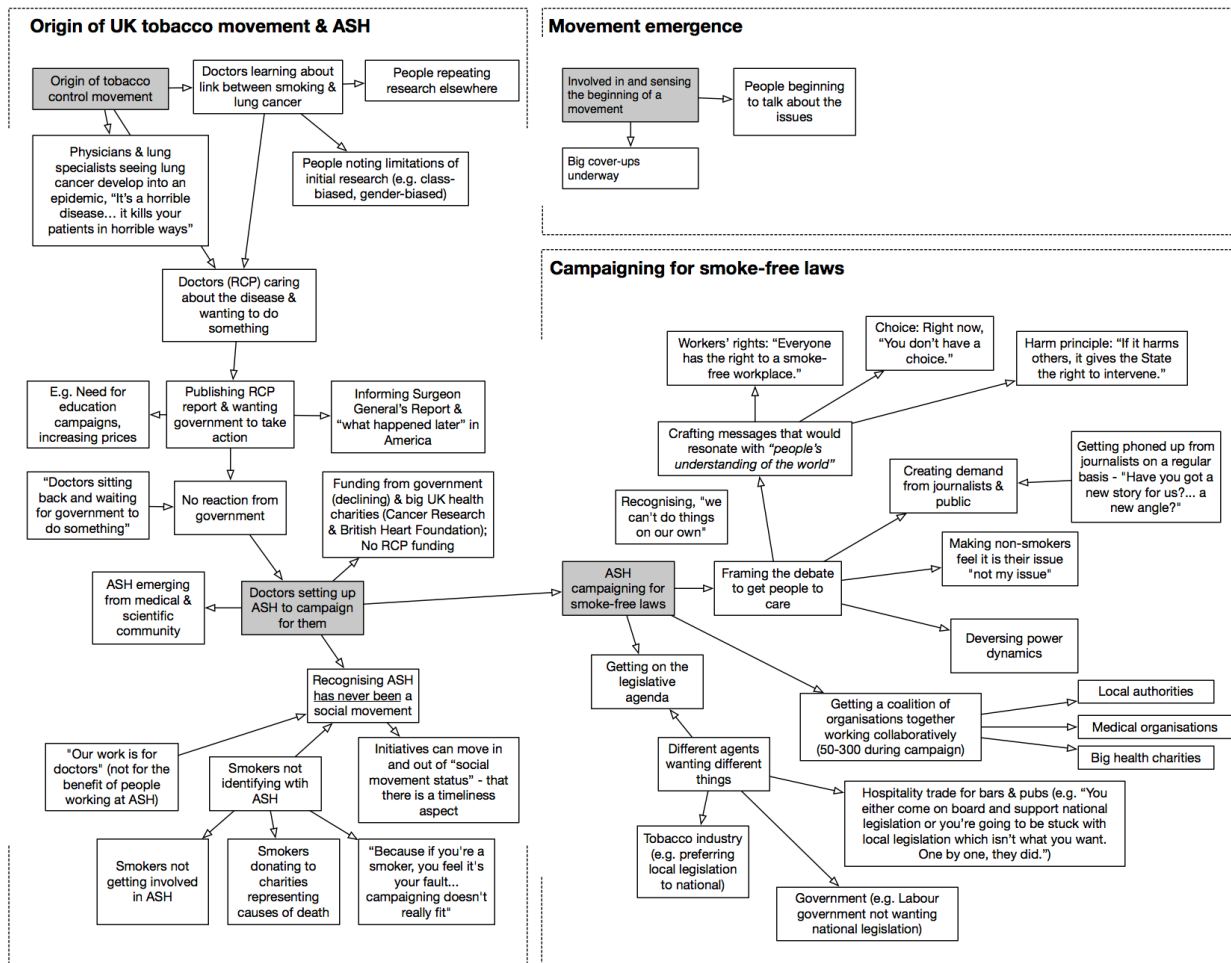
**2,000+** line-by-line codes    **120** clusters    **18** categories    **3** concepts



## Appendix VI: Sample conceptual maps

This Appendix depicts two sample conceptual maps, one from a single interview and another about how study participants refer to social movements.

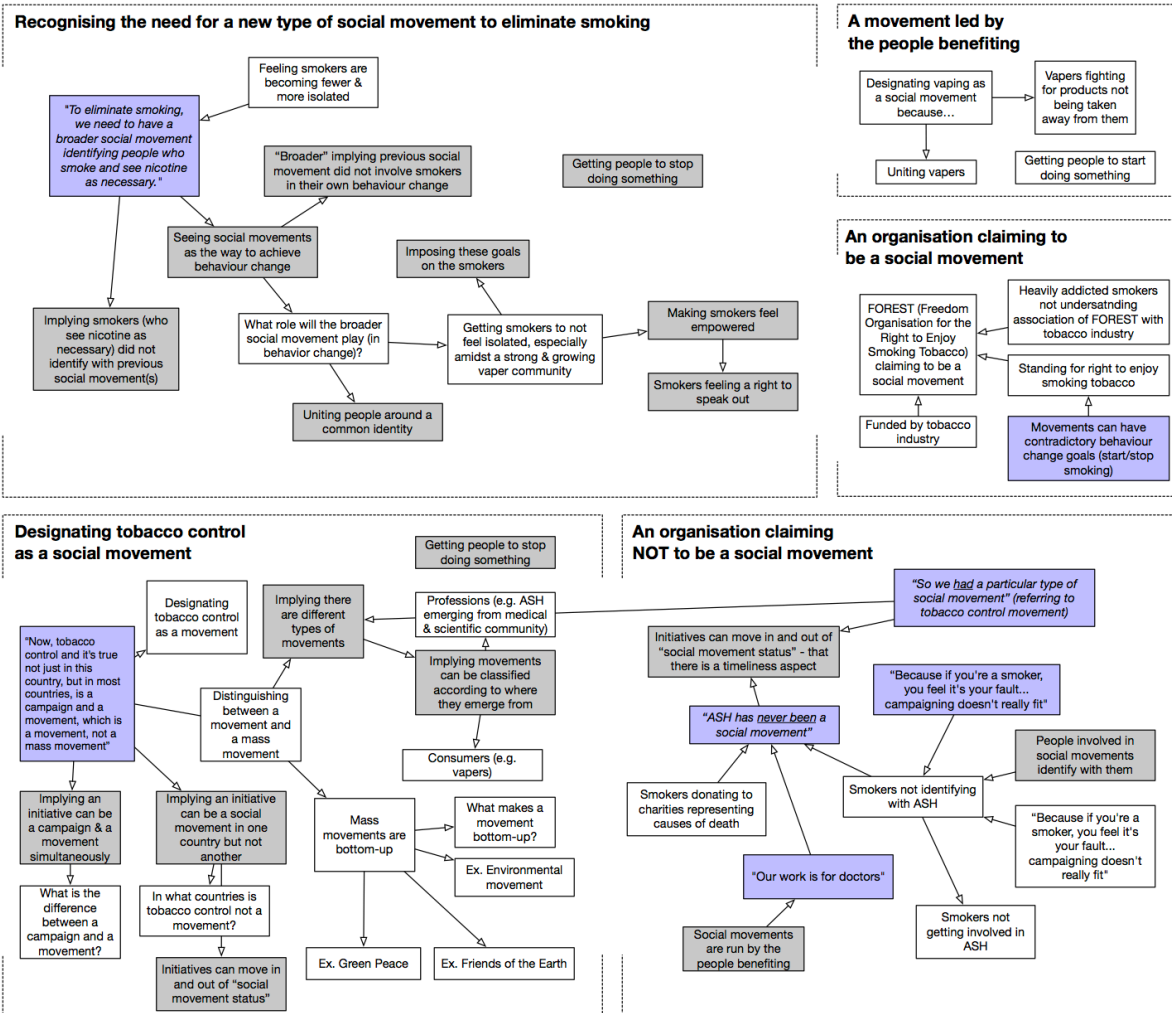
### Conceptual map from a single interview





Conceptual map about how study participants "refer to social movements"

Referring to social movements



## Appendix VII: Ethical approval from Imperial College Research Ethics Committee

**Imperial College  
London**

**Imperial College Research Ethics Committee**  
Imperial College London  
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[researchethicscommittee@imperial.ac.uk](mailto:researchethicscommittee@imperial.ac.uk)

Dr Jacqueline Del Castillo  
Research Postgraduate  
Institute of Global Health Innovation  
10<sup>th</sup> Floor, QEQM building, St Mary's Hospital,  
Praed Street,  
London W2 1NY

Date: 02/08/2017

Dear Dr Del Castillo

**Study Title:** How social movements aid the development and diffusion of innovations.

**ICREC reference:** 17IC4331

The above study was approved by your Head of Department on date and by the Joint Research Compliance Office on date.

Under the Imperial College Research Ethics Committee process, a study that has been reviewed by the Joint Research Compliance Office and Head of Division/Department (or Principal), where no significant ethical issues have been identified in the protocol or ethics application, can be approved without requiring it to go to full committee.

### Documents

The documents reviewed were:

- ICREC Application form
- Interview Protocol version 1.0 21/07/17
- PIS Version 1.0 28/07/17
- Consent Form Version 1.0 28/07/17

Yours sincerely,



Gary Roper,  
Head of Regulatory Compliance,  
Imperial College London

## Appendix VIII: How study participants refer to groups in the interviews

<b>Group</b>	<b>This group is:</b>	<b>This group is not:</b>
1 The Movement for Global Mental Health	<ul style="list-style-type: none"> <li>• A network</li> <li>• Part of the field of global mental health</li> <li>• Coordinated by a rotating global leader</li> </ul>	<ul style="list-style-type: none"> <li>• Led by service users</li> <li>• A mass movement</li> </ul>
2 The field of global mental health	<ul style="list-style-type: none"> <li>• A social movement</li> <li>• A broad array of people</li> <li>• A constellation of activities around crystallized &amp; broad goals</li> <li>• A network of networks</li> </ul>	
3 Early Intervention in Psychosis	<ul style="list-style-type: none"> <li>• A social movement</li> <li>• Antagonistic</li> <li>• Credible</li> <li>• Values-driven</li> <li>• Driven by anger &amp; dissatisfaction</li> <li>• Emerging</li> <li>• Peer-to-peer</li> <li>• Narrative &amp; evidence-driven</li> <li>• Led by medical &amp; scientific professionals</li> </ul>	<ul style="list-style-type: none"> <li>• Accepting status quo</li> <li>• Top-down</li> <li>• Performance-managed</li> <li>• Fear-driven</li> <li>• Control-driven</li> <li>• Evidence-driven</li> </ul>
4 Time to Change	<ul style="list-style-type: none"> <li>• A social movement</li> <li>• A funded programme of work</li> <li>• A nucleus designed to motivate, inspire, accelerate change and engagement</li> <li>• A point of recruitment &amp; congregation</li> <li>• A platform, "then multiplied or accelerated by others to join in."</li> </ul>	<ul style="list-style-type: none"> <li>• User-led</li> </ul>
5 FundaMentalSDG	<ul style="list-style-type: none"> <li>• Global</li> <li>• Hibernating/stopped</li> </ul>	
6 Zero Suicide	<ul style="list-style-type: none"> <li>• A movement</li> <li>• A group</li> <li>• A mindset</li> <li>• Ambitious</li> </ul>	<ul style="list-style-type: none"> <li>• Peer-to-peer</li> </ul>
7 Tobacco Control	<ul style="list-style-type: none"> <li>• A campaign</li> <li>• A movement</li> <li>• Emerging from the scientific and medical community</li> </ul>	<ul style="list-style-type: none"> <li>• A mass movement</li> <li>• Led by smokers</li> </ul>
8 FOREST	<ul style="list-style-type: none"> <li>• An organisation that calls itself a social movement</li> <li>• Funded by tobacco industry</li> <li>• Standing for right to enjoy smoking</li> </ul>	<ul style="list-style-type: none"> <li>• A movement</li> <li>• Led by heavy smokers</li> </ul>
9 Vaping	<ul style="list-style-type: none"> <li>• A movement</li> <li>• Bottom-up</li> <li>• Fighting for products not being taken away from them</li> <li>• Led by people</li> <li>• Uniting vapers</li> <li>• Encouraging people to quit smoking</li> </ul>	
10 Action on Smoking and Health (ASH)	<ul style="list-style-type: none"> <li>• A small charity</li> <li>• An organisation</li> <li>• Funded by health charities &amp; government</li> <li>• Led by medical &amp; scientific professionals</li> </ul>	<ul style="list-style-type: none"> <li>• A movement</li> <li>• User-led</li> <li>• Resourced by smokers</li> </ul>
11 HIV/AIDs	<ul style="list-style-type: none"> <li>• A movement</li> <li>• Bottom-up</li> <li>• User-led</li> <li>• Informed by the gay liberation movement</li> </ul>	

## Appendix IX: Sampling of variables &amp; values related to social movements

Variable	Values that study participants assign to variables in the interviews
Motivation	Anger & dissatisfaction (e.g., poor health service experience), research uptake (e.g., adverse childhood experiences), behaviour change goal (e.g., smoking cessation), a mindset (e.g., minimalism), right (e.g., enjoy vaping in public places), value (e.g., health access), visionary target (e.g., zero suicide), innovation adoption (e.g., e-cigarette)
Purpose	Physical, mental, spiritual, social determinants, health systems, policy
Origin	People, service users, professionals, indigenous, bottom-up, top-down
Leadership	People, professionals, organisations, no central polarity of leadership
Characteristics	Driven by values, emerging, bottom-up, dynamic, antagonistic, inclusive, a mindset, peer-to-peer, go beyond traditional boundaries, political, aspirational
Behaviour	Emerging, waxing & waning, evolving, persisting, polymorphic, opportunistic, organic, fluid, unforced, spontaneous, flexible, going beyond traditional boundaries and sectors, inclusivity
Structure	Group, community, organisation, network, network of networks, interconnecting networks, funded programme of work, coalition, consortium, complex
Targets	Medical community, medical policy, public health policy, health systems, health institutions, research, values, belief systems, human rights, social norms, lifestyles, personal behaviour, mindsets, culture, narratives, discourse, the establishment, status quo, ourselves
Function	Mobilising large numbers of people, uniting, engaging, organising, motivating, inspiring, aspiring, advocating, accelerating change, antagonising the orthodoxy, changing mindsets
Scale	Neighbourhood-level, local, regional, national, international
Stage	Emerging, evolving, plateauing, declining
Status	Active, inactive, stopped, hibernating
Classification	Real, fake, astroturf
Formality	Formal, informal, elements of both
Supporters	Social movement members, charities, government, industry, narratives, evidence
Metaphors	Kindling flame, seed, sailing craft, nucleus, amoeba-like flowing, constellations of activities, brand, march of the oppressed, swelling, a lot of little fiefdoms, tribes
Value	Purpose and fulfilment, identity formation and transformation, making life exciting, recruiting resources to an issue, putting an issue on the agenda, creating spaces for unscripted conversation, working on contaminating issues, pressuring persistently, wide-scale norms changing, serving as a status symbol, social movement as the solution