



# We change the world

What can we learn  
from global social  
movements for health?

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## Health as a Social Movement

Building on the agenda set out in the NHS *Five Year Forward View*, Health as a Social Movement is a three-year programme, launched in early 2016, to support social movements in health and care. Funded by NHS England, the programme has involved **Nesta**, the **New Economics Foundation**, the **RSA** and six new care model vanguards:

- **Royal Free London NHS Foundation Trust** (Acute Care Collaboration)
- **Wellbeing Erewash – Your Life Your Way** (Multispecialty Community Provider)
- **Stockport Together** (Multispecialty Community Provider)
- **Accountable Cancer Network** (Acute Care Collaboration)
- **Better Care Together** (Morecambe Bay Health Community, Integrated Primary and Acute Care System)
- **Airedale and Partners** (Enhanced Health in Care Homes)

This programme is also working with the wider vanguard network and beyond.

This report was produced as part of the programme. Further publications from the Health as a Social Movement programme will share learning from the sites and contain additional practical guidance for health institutions wanting to take action, and will be hosted on the RSA website.

It builds on a report produced by Nesta in September 2016, *The Power of People in Movements for Health*, which laid out the value of social movements and the need for new models of engagement between health institutions and movements.

Thank you to all people who provided their insights and expertise into this report, including the people in social movements who provided their perspectives and the Health as a Social Movement partners and grantees. We also want to acknowledge Annie Finnis and Christina Cornwell from Nesta's Health Lab who provided important input into shaping this report.

## About Nesta

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# Foreword



**By Halima Khan, Executive Director, Nesta Health Lab**

Across the globe, we are seeing extraordinary examples of people driving change through social movements. Whether it is marginalised groups fighting for their rights, people dedicating their time and resources to issues that matter to them, or local communities coming together to support each other - people in social movements are changing the world.

We are excited about the potential of social movements to improve the health and wellbeing of people and communities in particular, and contributing to change that is so urgently needed. As the NHS *Five Year Forward View* set out, social movements represent a clear opportunity to harness the renewable energy of people and communities.

This report forms part of a larger Health as a Social Movement programme, funded by NHS England and working alongside a set of committed organisations and professionals, to understand how people in movements bring communities together to drive change. In the first year of the programme, Nesta published *The Power of People in Movements for Health*<sup>1</sup> which explored the value of social movements in health and proposed the need for new models of engagement between health institutions and social movements.

In this second report we focus on a small number of international case studies which have influenced and impacted health systems globally. We have included examples that repeatedly demonstrate the capacity of people with courage and determination to work together to change not just healthcare, but the wider world.

We have focused on more mature social movements, to understand how they work and how they have become influential over time. And we have drawn out insights that we hope will also be of interest and value to people at an earlier stage of their journey - aspiring to start or grow social movements in the UK and beyond. We are also hoping that the insights will be helpful to people working in institutions who want to work better with movements. In both ways, we hope it will be useful to people who want to mobilise to improve health - and to change the world.

# Executive summary

## What can we learn from global social movements for health?

The report presents practical insights about how social movements grow. The insights are based on interviews with over 40 people at the heart of global social movements impacting health. We look primarily at four movements - HIV/AIDs, global mental health, disability rights, rare disease - and a diverse set of additional examples are signposted throughout. The report is intended to be of practical value to people starting or growing social movements as well as those desiring to work, understand or interact with them better.

The examples were chosen because they have scaled globally, have impacted on health issues, and are relatively mature and so potentially a great deal can be learned from them. The insights are not prescriptive or formulaic but can serve as a valuable resource and source of inspiration for people and communities eager to make change using the principles of social movements. They can offer inspiration and powerful lessons to people everywhere, including the UK.

Insights around three themes emerged through the research - how social movements get off the ground, who they involve and how they influence through relationships.

- 1 Kickstarting action**  
Emerging and building momentum
- 2 Nurturing voices**  
Cultivating diverse interests and motivations
- 3 Influencing and interacting**  
Navigating a complex array of relationships

Below is a brief overview of each theme and our main findings:

## 1. Kickstarting action: emerging and building momentum

Successful movements usually focus on an important set of early actions. These include cultivating leaders and early members, nurturing a diverse set of collective actions, developing effective messages, utilising assets and resources creatively and coordinating activity within and outside of the movement. When a social movement grows, it spreads a vision and set of collective actions to attain it, as opposed to traditional change programmes which encourage the adoption of an intervention, product, service or programme.

**Successful social movements aren't always about large numbers, they grow in influence by engaging the right people in the right places at the right time.**

## 2. Nurturing voices: cultivating diverse interests and motivations

Our research revealed five 'voices' which contribute to a social movement's success: people with lived experience, pioneers of knowledge, subject experts, spokespeople and institutional supporters. People with lived experience illuminate what needs to change; they might become pioneers of new knowledge and expertise. Subject experts contribute their expertise in influential ways and often advance their own work in the process. Spokespeople are the 'face' of a movement, inspiring hearts and minds as well as demanding collective action and institutional responses. Institutional supporters garner support from within institutions and often dedicate significant resources and skills to movements. All people involved in movements, irrespective of their role, are united by a passion for change.

**Successful social movements understand the value of a diverse set of voices, as well as cultivating the unique experiences, energy and skills they bring.**

## 3. Influencing and interacting: navigating complex relationships

Social movements influence, and are influenced by, a complex web of relationships with informal and formal groups, including institutions, funders, dissenters, public opinion, the media and other movements. These relationships influence the structure, activities and future of movements. Institutions can support or oppose movements. They often hold the power to negotiate if, how and when change will happen. Both institutions and funders can offer or block access to funds, resources and people. Dissenters oppose movements or their viewpoints; this can stall progress but may also be useful in exploring alternative perspectives and areas for improvement. Public opinion and media can influence movement support and shift public conversations. Movements often compete with other movements for resources and attention, and some find that joining up with other movements can lead to complementary efforts or unique opportunities to share resources.

**Successful social movements often make smart trade-offs about where and how to invest their energy in relationships to achieve the highest level of influence and impact.**

## Looking forward

We hope this report will help people starting or growing social movements learn from others who have gone before them and take inspiration from their victories. In particular, we hope this report will spark useful debate about how social movements and the health system might meaningfully engage with one another, in ways that capitalise on their differences, so that there are more opportunities for positive change.

*"Pursuing social change is more of an art than a science.*



*There is no fixed model.  
No curricula. No rules.  
No guarantee. It's about  
reading power. Building  
relationships. Framing issues.  
Honing messages. Mobilising  
supporters. Bringing  
pressure to bear. All of this  
in an increasingly complex,  
networked society in which  
assumptions that held even  
a year ago no longer hold."*

# Introduction

In our conversations with people starting or growing social movements, time and time again we hear the question, “*What can we learn from social movements like HIV/AIDs?*”

There is no blueprint for a social movement. Every movement grows out of a different set of circumstances and must find its own ways of making change. However, there is much to be learned from social movements that have gone before us and have achieved victories, large and small.

This report contains practical insights about how people and groups have grown social movements - their dilemmas and tradeoffs as well as their strategies and tactics. The insights are based on interviews with over 40 social movement leaders, members, allies and dissenters. They represent four relatively mature social movements, selected based on their ability to scale across the world, impact on health issues and tackle issues such as power, stigma, resource imbalances, injustice and discrimination. A snapshot of each of these four movements is described below:

- **HIV and AIDS** achieved mass grassroots mobilisation, rapidly bringing people with lived experience together, and engaging a range of institutions across the globe to fight for equal access to treatment for all.
- **Global mental health** is a vast group of people and organisations, in overlapping and often conflicting movements, fighting to improve the lives of people with a diverse array of mental illnesses. Some of their aims include generating evidence, closing the treatment gap for people in low-income countries and promoting human rights.
- **Rare disease** is a tapestry of intersecting efforts to improve conditions for people affected by the over 7,000 identified rare diseases, often by leading research, sharing knowledge and organising peer support.
- **Disability rights** has promoted the participation of disabled people in policy and service delivery globally and has helped bring the world’s attention to the human rights of disabled people internationally.

**Interviews were conducted with people primarily based outside of the UK in an attempt to learn from other contexts as well as to understand how movements are often connected to a much larger set of interrelated or historical movements.** Applying learnings from elsewhere can be challenging, requiring adaptation and translation. Taking time to reflect and ask, “*Is this applicable to me? How?*” can be fruitful and is often the first step. And, despite a focus on health, we suspect the insights are applicable much more broadly, especially to movements that address the social determinants of health.

This report does not describe the history of any one movement. Instead, it looks across these four movements to understand and identify factors which social movement leaders *themselves* feel have contributed to small wins and long-term successes. The aim is to bring these insights to life through stories and to make them actionable. Please read about our methodology in Annex I.

These examples represent a small sample of social movements aimed at health and wellbeing, so we also signpost to many other examples throughout the report. We include nascent movements, such as adverse childhood experiences (aiming to prevent and reduce the effects of childhood trauma shown to impact on adult health and life expectancy) as well as early-stage UK-based initiatives, such as parkrun (a network of volunteer groups organising free weekly five kilometre runs in local parks across 18 countries) which have ‘movement-like’ characteristics.

**The intention is that the insights are of practical value to people starting or growing social movements, large or small, who want to achieve greater influence and impact, as well as those desiring to work, understand or interact with them better.**





1

# Kickstarting action

Emerging and building  
momentum

# 1 Kickstarting action

## Emerging and building momentum

This section looks at what activities have helped people grow their social movement in the early stages. The activities include mobilising leaders and early members, nurturing a diverse set of collective actions, developing effective messages, using assets and resources creatively and coordinating activity within and outside of the movement. Below we discuss each of these factors.

### Mobilising early leaders and members

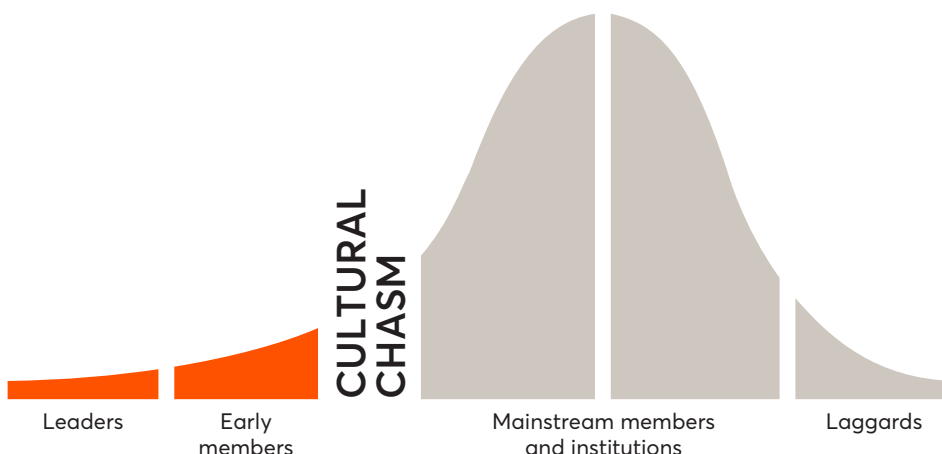
*"You need to get to the point where you are so exhausted by a problem that you are willing to dedicate everything to a solution."*

Melissa Creary (Assistant Professor, University of Michigan School of Public Health) Speaking at Genetic Alliance's 30th Anniversary Meeting: Co-Creating A Healthy Future

Social movements often start when impatient people have had enough of the status quo and there is an opportunity to join together to change it. They might not know how to change it but they know that change is needed. An initial group of people coming together around common vital interests often expands to more people who find it easy to identify with the interests of the group.

Social movements spread by promoting a vision for the future and a set of collective actions for attaining it.<sup>2</sup> The vision for HIV and AIDS was that a plague affecting gay men, ethnic minorities and intravenous drug users was worthy of attention. Collective actions included fundraising for research funds, researching cures and adopting safe sexual behaviours.

As social movements grow, however, they are at risk of falling into a "cultural chasm."<sup>3</sup> This is when there is a failure to widen their influence beyond leaders and early members, which means that they dwindle rather than bring about widespread change in culture or mindset. This can happen because the people required to bring about large-scale change are not aligned with the movement's vision or goals. Insights on how to "cross the cultural chasm" are explored below.



## Nurturing a diverse set of collective actions

*"With all social movements... letting one thousand flowers bloom can be truly transformative."*

Mike Podmore, Director, STOPAIDS

Social movements recognise the power of disrupting the status quo and doing things differently. They often use loose and dynamic networks to encourage many different approaches simultaneously to raise their profile and address the problems they fight for. Especially in the early stages of a movement, creating an environment of experimentation, where any person or group can try out new ideas and tactics, utilising their unique strengths and skills, can be critical for success. This philosophy can feel uncomfortable or unproductive from the perspective of traditional health and care, but can actually accelerate success and save costs associated with getting locked into any one path too early.

## The importance of inclusive leadership in the HIV and AIDS movement

Early on, ACT UP, an international campaign to impact the lives of people with AIDS, was primarily led by gay men. As the disease spread and the movement grew, it became clear that the original focus of the campaign, *"getting drugs into bodies"* was too narrow and inadequate. In the words of activist Ray Navarro, the campaign, *"simply [didn't] account for the historical oppression [of gay people] or people of colour or women."* The documentary *United in Anger: A History of ACT UP* portrays the campaign's shift from *"getting drugs into bodies"* into a broader set of issues, interests and goals.<sup>4</sup>

Around that time, 300 groups across the US came together to change the definition of AIDS to include diseases specific to women and intravenous drug users. A diverse group of people joined the movement and led on issues important to them. Inclusive leadership became increasingly important, with leaders creating space for sub-networks and sub-movements to thrive as well as for people to experiment with different types of collective actions and solutions.

## Developing effective messages

Messages help movements recruit the right members and foster the right actions. Effective messages can be challenging to develop due to diverse, and often conflicting, ideologies and approaches within a movement. Members of the Adverse Childhood Experiences movement<sup>5</sup> are tackling childhood trauma from various vantage points, including healing and prevention. A broad set of stakeholders across health and care, education, criminal justice and public policy has made it difficult to agree on a single goal; ACEs is a public health issue but could be framed as an education or social justice issue.

One effective tool to address these challenges is framing, a dynamic process of developing communication messages which speak to the interests and motivations of specific audiences. Throughout the 1990s, the breast cancer movement successfully used framing to reach the right people and raise funding.

## How the breast cancer movement successfully used framing

In the 1990s, the breast cancer movement in the United States used three frames to redefine breast cancer from an individual problem to a major public health crisis in demand of federal funding. During this time, federal funding increased from \$89 million to \$430 million.<sup>6</sup>

- **Breast cancer as an epidemic** created a sense of urgency around the disease. Messages stressed the economic impact of the disease and the irresponsibility of institutions. Activists argued that the government's funding priorities were focused on military defence at the expense of women's lives. Surgeon Dr Love said, *"Why can this country find \$380 million for an obsolete defence project, but is unable to find \$300 million to save women's lives?"*
- **Breast cancer as a gender inequity issue** in research and funding. Nancy Chilcote, head of the Ohio branch of National Breast Cancer Coalition (NBCC), said, *"If some part of a male organ were being cut off at a rate of one in nine men, the world would stop rotating until we found a cure. Because it's a female disease, no one really cares."*
- **Breast cancer as a threat to family stability**, a message that was timely in the context of American politics. This frame cast families as victims, saying that the *"family is under attack by breast cancer."* Testimonies included lines like, *"I am a mother, a wife and a breast cancer survivor"* to emphasise women's multiple identities.

The Frameworks Institute, a non-profit in Washington DC, has extensive experience working with advocates to frame social issues and devise communications strategies.<sup>7</sup> Their 'Hall of Frames' features work on the social determinants of health which encourages a shift away from outdated 'charity' models to integrated human services.<sup>8</sup> Their *Gaining Momentum* communications toolkit challenges American advocates to reframe the conversation on ageing - so, rather than current cultural idioms such as 'fighting' ageing or valuing 'staying young,' they advocate positioning ageing as a process with forward momentum, highlighting the untapped potential of an ageing population and the risks associated with bypassing that potential. A test of how this metaphor affects people's implicit bias has showed it reduced people's subconscious ageism by 30 per cent.<sup>9</sup>

## Utilising resources and assets creatively

Resources and assets are often scarce in the early stages of a movement. Therefore, movements often need to be extraordinarily resourceful and creative in achieving their aims, including inspiring people to draw on their unique skills. Early AIDS activism was marked by stockbrokers coordinating protest action on trading floors and sex workers collaborating with journalists to write safe sex guides.

### A father utilises his computing skills to advance research on his son's rare disease

Many of the 7,000 identified rare diseases are barely understood; families hit by an unexpected diagnosis often find little information or support. The lack of established care pathways leads families to mobilise every resource they have to search for information and cures.

Matt Might had just completed his PhD in computing when his child Bertrand was born. By six months old it was clear Bertrand had little to no motor control. More minor but equally baffling symptoms such as a total lack of tears would emerge over the years, but no one could provide answers. Years of tests, culminating in genome sequencing, eventually discovered Bertrand was the first child ever identified with a NGLY1 deficiency. But for the diagnosis to be confirmed and studies to continue, more patients would need to be identified.

Might wrote a provocative post on his blog titled *Hunting Down my Son's Killer* which spread rapidly, reaching mainstream news, and helped him identify 15 other people with the same disease as his son. In a further attempt to speed up research, Might used his academic networks and programming expertise to develop Mark2Cure, a platform where people read and tag biomedical texts on topics related to NGLY1, making it easier for researchers to search papers and identify patterns that could lead to new knowledge, treatments and cures.

## Coordinating activity within and outside of the movement

As movements grow, they often need to establish ways of coordinating and communicating across disparate groups and at varying scales. At first, they often look to informal ways of organising. As they mature, they often spawn social movement organisations (SMOs) to run specific activities, such as fundraising, managing assets, and running public interest campaigns. Many organisations have their roots in social movements – such as Stonewall, the largest LGBT rights charity organisation in Europe, formed after the Stonewall riots in New York City in 1989.

## Questions to spark action

Important actions in the early stages of a social movement often include mobilising leaders and early members, nurturing a diverse set of collective actions, developing effective messages, using assets and resources creatively and setting up structures to coordinate activity within and outside of the movement. Drawing on the examples and insights from this report, here are some questions which movement leaders might benefit from asking.

### Mobilising leaders and early members

1. Who is leading the movement and is the leadership representative of the larger vision?
2. How is decision-making happening? Are there ways to make it more inclusive, open and shared with the people whose opinions are needed?
3. Consider the role of sub-groups and sub-movements. How can you make space for them to grow?

### Developing effective messages

1. How are you currently framing your social movement? Do you feel these frames are reaching the appropriate groups? Encouraging the intended actions?
2. What movements, either in your field or in analogous fields, could you learn from in terms of how they have framed their messages? Are there historical frames, cultural or political narratives you might be able to use or tap into?
3. How can you test your frames and generate evidence about which ones are effective at attracting new members, influencing people and triggering specific behaviours?

### Using resources and assets creatively

1. What assets and resources do you have access to or could you get access to? How can you deploy them creatively?
2. What asset-based approaches can you utilise to grow your movement?

### Coordinating activity within and across movements

1. Would your movement benefit from coordinating with others to help facilitate activities within and outside of your movement?
2. As your movement grows, what activities might benefit from more formal procedures and processes? What networks or organisations might you need to set up?

Here is one example of an early-stage UK initiative that is bringing people and communities together to grow a network of social movements.

### **Greater Manchester: a 'call to action' around a network of social movements**

Stockport, working together with neighbouring boroughs Oldham and Tameside, have joined up to create a Health as a Social Movement Project. Their aim is to bring together people and groups across Greater Manchester with an interest in living more socially connected and healthy lives.<sup>10</sup>

In March 2017, members of #LiveWellMakeArt, local food movements and people supporting social isolation and loneliness met in a 'call to action' to assemble a group or network of people, resources, assets and relationships working across Greater Manchester for greater health and wellbeing.

The event was appropriately held at the People's History Museum featuring a rich history of past and current social movements. People engaged in creative activities to develop strategies around aspects of each movement. It also featured performances by The Anti-Loneliness League, a multi-media superhero music theatre show about the experiences of people facing loneliness through theatre, comedy and live music.

This call to action is at an early stage, using many social movement tactics to create momentum and shared purpose, building on existing relationships and initiatives.

2

# Nurturing voices

Cultivating diverse interests  
and motivations



## 2 Nurturing voices

### Cultivating diverse interests and motivations

An important part of understanding how social movements make change is who participates and why. Our interviews with people in social movements revealed five voices contributing to social movements. The voices are not mutually exclusive; any one person might occupy multiple roles. This section describes these five voices, the knowledge and experience they bring, as well as how social movements have cultivated their involvement.

1. **People with lived experience** are at the heart of social movements. Their perspectives living with a particular health condition or facing a gap in healthcare provision often motivate a movement to begin and persist.
2. **Pioneers of knowledge** often develop new knowledge and expertise while managing and researching their own health issues. They can breakthrough silos, inspire new solutions and challenge power dynamics.
3. **Subject experts** are motivated by their exposure to an issue and can offer their unique expertise to a social movement. They might work within or outside of an institution, lead research, offer strategic advice or participate in the movement.
4. **Spokespeople** speak on behalf of a social movement in the media and in public spaces. They might be elected by social movements directly, trained to focus on delivering key messages or arise organically.
5. **Institutional supporters** have power and platforms. They use their voices to amplify the impact of a social movement by partnering on scaled solutions and helping the movement achieve wider recognition and awareness.

#### 1. Lived experience

People with lived experience are and should be at the heart of any social movement. Their perspectives and opinions are critical to ensuring the movement develops aims and actions that improve their lives. By actively participating in movements, people with lived experience connect with people with similar experiences, deepen their understanding of their situation and exchange resources, ultimately helping them move from passive to active participants in their own health and care.

Many interviewees told us that joining a movement made them feel empathy for others, and helped them feel less isolated. The experience often illuminated that more action was needed and that they could play a part:

*"While my son was in the hospital, a doctor gave us a contact address for an organisation. We wanted to learn more about the condition, to connect with people... because at first, you feel like the only person in the whole wide world going through this. It was really good to talk to other families, to learn what their path was, and how to incorporate this condition into your life. And so we decided we needed to do our part."*

Jana Monaco, Rare Action Network State Ambassador for Virginia of the National Organization for Rare Disorders (NORD)

For institutions and those delivering public services, examining the 'voices' of lived experience can help to understand what matters to people, and inform the development of new programmes and services, ensuring they meet the needs of the people ultimately using them. People with lived experience surface issues that others can miss - the gaps in care pathways, where systems fail and real impact goes unmeasured.

*"In clinical trials for Duchenne's muscular dystrophy, they often use the six-minute walk test as a measure of success [of drugs and therapies ameliorate to the degenerative effects of the condition], but when we ask the boys themselves, they say they would rather be tested for how long they can type so they can communicate with their friends. That was stunning to the doctors."*



Sharon Terry, President and CEO, Genetic Alliance

Professor Linda-Gail Bekker, Deputy Director of the Desmond Tutu HIV Centre, encountered a group of HIV positive women who changed her perception of their needs:

*"There was an almost puritanical 'your life has been saved therefore you will not have sex with anyone again' approach by the research community. But after seeing a popular TV soap in which an HIV positive woman become pregnant, South African women came to me and said they wanted to safely conceive. It was almost an awakening for those of us in the field, we are saving people's lives so they can lead normal lives and that includes having sex and being able to reproduce."*



## How lived experienced strengthened the HIV and AIDS movement and influenced research

Early in the HIV and AIDS movement, members recognised that the voices of those living with AIDS were missing, and in some cases, actively excluded from institutional responses. In 1987, the campaign for global microbicides (GCM) started as a "bottom-up, citizen-led coalition of individuals and non-profit organisations,"<sup>11</sup> to build support for woman-initiated tools for HIV prevention. Over 14 years, it built a global advocacy network to increase political will and investment in adding the voices of women to research.

Discussing the need for women to adequately protect themselves from HIV, Lori Heise, Executive Director of the STRIVE Research Consortium, tells the story of a woman in Uganda who asked, "If they can put a man on the moon why can't they produce something that women can use?"<sup>12</sup> In seeking a usable product, GCM has changed the conversation about the health needs of women and moved research towards engaging more collaboratively with affected communities.

## 2. Pioneers of knowledge

People with lived experience of a health condition often find themselves becoming leaders of their care – creating new knowledge, assembling disparate professions and seeking new forms of support. They develop practical insights from which others can benefit, including people attempting to address the issues they face, people reimagining care pathways, evidencing the need for structural change and informing scientific practice.

For example, parents of children with a rare disease can find themselves becoming pioneers of knowledge – learning the exact metabolic pathway or genetic mutation undermining their child's health, the latest research on drugs affecting it, the bureaucracy of getting support, the people working on drug trials and the barriers to joining them.

*"Suddenly out of necessity I was immersed in a world of enzymes and proteins, DNA and RNA, good laboratory practices, clinical trials, bioethics."*

Abbey Meyers, Founder and past President, National Organisation for Rare Disorders (NORD)

Movements can also help disseminate the knowledge and solutions created by their members, providing more people with information and solutions to help themselves. Technology plays a big part in dissemination and the creation of patient and expert networks. This redistribution of knowledge and power can help people have more effective interactions with clinicians and researchers, including what adequate support means to them.

## 3. Subject experts

People with knowledge and skills relevant to a social movement can apply their expertise in positive and useful ways as well as advancing their own work.

Early in the HIV and AIDS movement, chemist Iris Long PhD, decided she could not sit on the sidelines. Misinformation, infighting, systemic failures and prejudice were crippling progress towards developing treatments. Despite hesitancy as a public speaker, she started talking about biomedical and regulatory issues at ACT UP meetings, offering insights that advanced the group's aims and tactics. *"If there's one catalytic person who bears a lot of that credit [saving eight million lives], it's Iris Long,"* said David France in *How to Survive a Plague*.<sup>13</sup>

In special cases, experts might decide to dedicate themselves entirely to an issue and create new social services or business offerings which fill a gap in the market.

## How one person's expertise is improving the lives of people with disability

*"We sued New York's subway system... they were renovating one of their subway stations... spending \$22 million dollars... they were not going to put in an elevator which they are required to do under the law. We won and that elevator is now in... we got off at the subway platform, the doors opened, and out from the elevator came a woman pushing a baby carriage, an elderly woman with a big shopping cart and a tourist with his huge suitcase. That elevator helps everybody."<sup>14</sup>*

Sid Wolinsky, Co-Founder, Disability Rights Advocates

Sid Wolinsky went from big business into disability rights law co-founding Disability Rights Advocates, a US non-profit run by and with disabled people advancing equal rights and opportunities nationwide. Sid is an expert at using strategic litigation for disability rights, having served on over 400 cases, including going up against Kaiser Permanente, a large hospital system, on how it treats disabled people. He finds disability advocacy important not only for disabled people but for society at large.

## 4. Spokespeople

Spokespeople provide a 'face' for a social movement and help amplify and spread its messages. In some cases, spokespeople are actively sought out. In others they arise organically with people standing up and speaking out about their personal experiences.

Mental health is an area which has benefitted from celebrity spokespeople raising awareness. Notable names include Stephen Fry who has publicly discussed his experiences with bipolar disorder and depression. More recently Prince Harry also disclosed to a journalist that after years of shutting down his emotions surrounding his mother's death he sought counselling to move forward.

## 5. Institutional supporters

Institutional supporters might come from inside the NHS, the wider world of health and care, public service infrastructure, or even other groups impacting health and care. An example of an NHS institutional supporter of Health as a Social Movement is Andy Knox, a GP in Morecambe Bay at Better Care Together. He developed a set of videos to help people manage common conditions such as a sore throat, earache and eczema. Patients can watch the videos from anywhere and avoid the travel costs of making a trip to the GP. Knox says, *"It will be fantastic to have a whole library of local knowledge available as a first port of call for our patients."*

People in institutions can use their platform to raise awareness and support as well as forward a movement's aims through their work. For example, Kofi Annan, 17th UN Secretary-General has acknowledged the movement and the need to better involve communities and people living with HIV and AIDS. He also called for a war chest of a size far beyond what is available.<sup>15</sup> His speech gave political leaders financial targets to mobilise around and highlighted where change can happen, increasing international political will and leading to official development assistance, scientific progress and new institutions.<sup>16</sup>

Many successful rare disease advocacy groups stress the importance of working closely with researchers and clinicians within institutions, whose work aligns with the movement's efforts:

*"You've got to find someone who is an out of the box thinker. I have had a few doctors say we were waiting for someone like you to give us a challenge to put us on the map. It's a mutual thing; when you take something so ultra rare it's exciting. That was how we built our team; it is mutualistic and we all have a common goal."*

Monica Weldon, President and CEO, Bridge the Gap - Syngap

The involvement of institutional supporters often requires advocacy. Rare disease researchers have had to turn away from work they love because it does not always fit into journals' remits and might cover multiple bodily systems, failing to fit within siloed research domains. To fight these barriers, disease advocacy groups have helped arrange for prestigious journals to run special issues on rare diseases, develop patient registries, recruit patients to trials, collect DNA/tissue samples and take creative approaches to fundraising - crowdfunding, viral campaigning, and presenting business cases to health providers.

## Questions to spark action

Our research has shown that successful social movements understand the value of cultivating five voices - people with lived experience, pioneers of new knowledge, subject experts, spokespeople and institutional supporters. They acknowledge when specific voices are nonexistent, unheard or excluded from activities, and work to overcome barriers to participation and inclusion. First and foremost, you might start by listing the voices that are part of your social movement. Who is not part of the conversation who should be? Drawing on the examples and lessons from this report, here are some questions which movement leaders might benefit from asking.

### People with lived experience

1. Are there barriers to incorporating people with lived experience into the movement? If so, how might you counteract those barriers?
2. In what ways can you help bring people with lived experience together?

### Pioneers of knowledge

1. Who is developing new knowledge, expertise or innovations?
2. How might your movement create or support environments where new knowledge, expertise or innovations are developed?

### Subject experts

1. Whose expertise does your social movement need?
2. How might you recruit these subject experts?

### Spokespeople

1. Who are the spokespeople for your social movement?
2. How might you enable more people to speak out (eg. partnering with a media outlet or running a social media campaign)?

### Institutional supporters

1. Who could support or advance your movement from within an institution? Specifically, think about influential people who could represent your movement, advance the evidence base or provide access to networks, sources of funding or other resources.
2. How can you recruit these institutional supporters to your movement?

Here is one example of an early-stage UK initiative which is drawing in a range of voices to grow a movement.

### **Unlimited Potential: working with fathers in Salford**

Unlimited Potential has been working in Salford for more than 15 years. They have reached an average of 7,000 people a year through their work, which draws on the collective strengths and insights of local people to explore challenges and develop solutions.

Unlimited Potential worked with a 'council of dadz' made up of fathers with disadvantaged backgrounds to co-develop the Dadly Does It programme. This improved the wellbeing of fathers through the creation of male-friendly environments where positive role models talk openly with each other and try out fun, dad/child activities that enable bonding.

A social return on investment study of the Dadly Does It project found that £1 invested yielded approximately £2.25 potential savings to children's services alone, and £14 of wellbeing value for fathers involved.

Dadly Does It amplifies the voices of fathers struggling with complex issues including mental health problems and long-term unemployment. In Salford, young people read adult participant statements aloud such as, *"I felt alone. I felt a failure as I had no one to measure up against. I was very depressed ... Everyone needs someone to turn to, to say "Am I doing this right?", It's not just women who can open up; men can be sensitive too, we just don't get the chance."*<sup>17</sup>

3

# Influencing and interacting

Navigating a complex  
array of relationships



## 3 Influencing and interacting

### Navigating a complex array of relationships

Social movements influence not in isolation but through a complex web of relationships with people and institutions. Our interviews revealed five 'external actors' that movements interact with in fundamental ways. This section describes how social movements have effectively engaged with these actors. A more impactful movement does not just mean more people supporting it. It is about getting the right people, from the right places, at the right time to adopt it so that the right actions can happen.

1. **Institutions** can support or oppose social movements. Their platforms, people and resources can be a huge support for movements to grow their reach and impact at scale.
2. **Dissenters** oppose social movements. They can function negatively, stalling a movement's progress, or positively challenge movement members to strengthen their arguments and demands. Sometimes, dissent is so strong that it results in a counter-movement.
3. **Funders** can influence the structure and activities of a social movement. Movements can receive funds from a range of sources, including citizens, foundations, businesses and governments.
4. **Public opinion** can get behind social movements, helping influence institutional change or the actions of politicians.
5. **Media** influences public opinion and can amplify a movement's success, spreading awareness, disseminating research, winning support for movements and triggering widespread collective action.
6. **Other movements** can be complementary or conflicting, especially those vying for the same sources of support. Yet, umbrella organisations enable movements to join up into 'families of movements,' sharing resources and working together towards similar goals.

## 1. Institutions

Institutions can have a variety of responses to social movements. How an institution responds to and works alongside a movement can have a significant impact on a movement's influence. Sociologist Melinda Goldner refers to five ways an institution can respond to a social movement.<sup>6</sup>

### Institutional responses to social movements

Strategy	Description	Behaviours
Acquiesce	Institution sees the movement as a threat	Habit, Imitate, Comply
Compromise	Institution complies but with some resistance	Balance, Pacify, Bargain
Avoid	Institution does not change or feel the need to	Conceal, Buffer, Escape
Defy	Institution resists or openly attacks the movement	Dismiss, Challenge, Attack
Manipulate	Institution tries to dominate the movement	Co-opt, Influence, Control

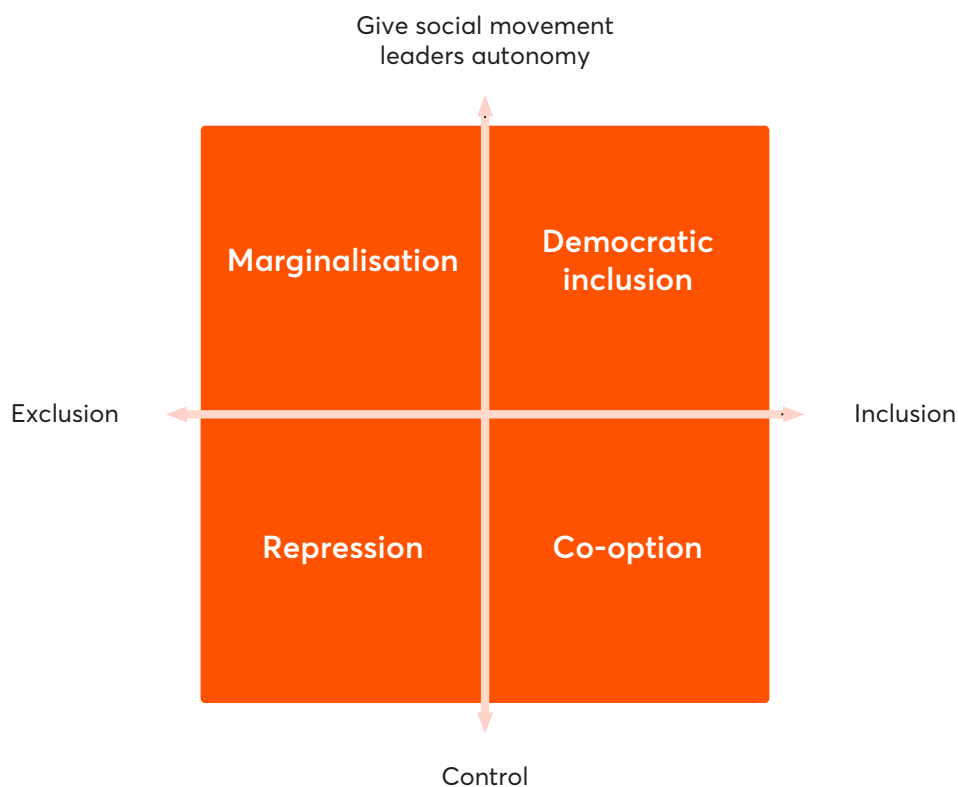
Manipulation is the most dangerous strategy as it leads to a loss of voice by social movement members. Institutions can also co-opt activists (hiring social movement members but restricting their activities) or their ideas (adopting ideas but not social movement members) - both are problematic for social movements.

When an institution decides to adopt a social movement, it faces two decisions:<sup>18</sup>

- 1. Inclusion or exclusion:** To include or exclude the people in a social movement proposing the change.
- 2. Autonomy or control:** To grant people in social movements continued autonomy over their efforts or to attempt to take control.

These decisions are reflected in the diagram that follows. Movements being able to trust that their ideas will be listened to will go some way, as a first step, to developing stronger ways of working between movements and institutions. However, staff working in institutions can also be supported to go further than this - to interact with social movement members in ways that enable social movements to stay autonomous, and avoid co-option.

### Institutional decisions in response to social movements



### How the WHO is nurturing the mental health advocacy movement

Institutions and governments can play an influential role nurturing movements. In 2005, the WHO published, *Advocacy for mental health: roles for consumer and family organisations and governments*,<sup>19</sup> recommending actions to support the mental health advocacy movement. Ministries of Health are advised to work across government ministries to ensure mental health and human rights are baked into related agendas, and to integrate community groups in drafting new policies and evaluating mental health facilities; government officials to foster cross-sector activity at varying scales, particularly between mental and general health workers.

In the UK, the Department of Health has been involved in several public information campaigns involving professional organisations and advocacy groups. The campaigns have changed population attitudes over a five-year period, with statistically significant reductions of stigma associated with several mental health problems.<sup>20</sup>

Social movements can partner with institutions to test new ideas. The OpenNotes movement started by introducing a pilot programme in hospitals. Evidence of its success and strong clinician adoption has led to it spreading to seven million patients and thousands of doctors across the US.

## How the OpenNotes movements is partnering with healthcare organisations

In 2007, Steve Keating volunteered to participate in a scientific research study. An MRI scan revealed a brain abnormality which later developed into a massive tumour. Since his diagnosis, he has become an activist in the OpenNotes movement, encouraging doctors to share medical records with patients and patients to participate in their own care. *"No one really sees the problems involved in getting your own data until you're in the hot seat... How come, as a patient, we're last in line to our own data?"*<sup>21</sup> says Steve.

*"When I suggested this to my colleagues, half of them thought I'd lost it... we wanted to offer ready-access to patients for those things that we write about them. The law gives them access to it. But we've made it as difficult as humanly possible for them to access it,"*<sup>21</sup>

Tom Delbanco, MD, Co-Founder, OpenNotes, Harvard Medical School

An experiment involved three hospitals, 100 doctors and 20,000 patients. Twelve months later, none of the doctors wanted to it turn off. Seventy per cent of patients reported feeling more in control.<sup>22</sup> In December 2015, three foundations invested \$10 million to reach 50 million patients over three years.<sup>23</sup>

## 2. Dissenters

Dissent is at the heart of social movements. Many movements start out by challenging existing systems, offering points of view counter to mainstream opinion. As social movements grow, they often spawn dissent - people and groups who oppose or offer critiques of their vision or activities. Dissent can be expressed through many channels - on the street, over social media, in speeches or in research.

Sometimes, dissent can be so strong that it results in a counter-movement. For the past century, a multitude of conflicting ideologies have been at the heart of the global mental health movement, issues such as institutionalisation or de-institutionalisation, pro-psychiatry or anti-psychiatry as well as mental health being classified as a psychosocial disability within disability rights.

Academic research can offer productive dissent, shedding a light on where movements could be more effective and keeping them accountable. Stefan Ecks of the University of Edinburgh wrote *Ethnographic Critiques of the Global Mental Health Movement*, to show the potential of ethnographic evidence to inform the development and implementation of global mental health policy and programmes.<sup>24</sup>

Dissent can also strengthen existing arguments and unite people. In South Africa, during the Thabo Mbeki presidency, AIDS denialism was actively supported; policies denying people treatments were put in place. Discussing how this brought scientists and activists shoulder-to-shoulder Professor Linda-Gail Bekker remarked: *"There's nothing stronger than bad politics to unite a group of people around a particular movement."*

Some actors maintain a neutral stance for the benefit of contributing knowledge to the entire field, such as editors of academic journals. One editor of a major journal shares, *"As an editor, I can bring things into the discussion. It is not my job to be an unquestioning advocate."*

### 3. Funders

*"How do we make sure we don't kill what we commission?"*

Carey Bamber, Director, CBA and Project Manager, Stockport, Oldham and Tameside Health as a Social Movement Project

There are advantages and disadvantages to social movements receiving funding from external groups such as foundations, businesses, and government.<sup>25</sup> Institutions can nudge movements towards goals which forward their agendas and away from a movement's original mission. Even with the best of intentions, the burdens of funding agreements can take leaders away from important movement-building activities. Stringent objectives can hollow out the dynamism and creativity that built a movement in the first place.

One person we interviewed asked, *"Are movements fundable?"* She said her group crafted an overarching movement strategy but sought funding from disparate sources for individual aspects of it. This is a pragmatic approach, but could potentially undermine a holistic movement-building strategy.

Some foundations, such as the Robert Wood Johnson Foundation (RWJF), actively seek a pivotal role in funding social movements. The RWJF have spotted and funded opportunities where cross-sector collaboration and community mobilisation were necessary to make progress on an issue. For example, they funded an eight-year study that one researcher claims launched the end-of-life movement, funding collaborative relationships across hospices, home health agencies, hospitals, and managed care organisations.<sup>26</sup> RWJF is also funding the Adverse Childhood Experiences (ACEs) and OpenNotes movements. Their recent strategic shift to supporting a 'Culture of Health' suggests that social movements, as a mechanism for culture and lifestyle change, is a core element of their work.

The New World Foundation, a public charity in New York City, has funded movement-building for over 50 years. They see social movements as long-term investments, requiring risk-taking. Based on their experience, they share ten recommendations for movement grant-making:

### Tips for funding social movements from the New World Foundation<sup>27</sup>

1. Identify the stage of the movement and what support is needed at that stage.
2. Fund across organisational partners and peer networks rather than isolated groups. Will the funding promote collaboration and mutuality or division?
3. Avoid narrow issue silos and rigid programme areas, which often reward special interest advocates but punish base-building around a broad, multi-issue empowerment agenda.
4. Look for opportunities to build long-term infrastructure - leadership development, staff training, exchanges among peer organisations, research capacity, media outreach.
5. Look at lines of accountability in organisations and grantee collaborations, so that funding does not impose leadership or partners on grassroots groups.
6. In assessing collaborations, look at the relative costs of collaboration for each partner, including qualitative costs like: who is bridging the cultural divides, who is risking resources or credibility, who's accruing the new capacity. Consider funding the costs of partner groups - lost staff time, travel, competing programme needs.
7. Fund internal organisational efforts to increase sustainability and capacity. General support and long-term grants are key, as are supplemental grants for technical assistance, management training, leadership transmission, sabbaticals and education, evaluation, alternative fundraising.
8. Move the grant-making focus along the movement cycle: where grassroots grow, fund anchor organisations; where anchors grow, fund organisational capacity building; where capacity is shared, fund networks; where scope and scale enlarge, fund new partners; when the movement arrives, fund a stream or a spectrum; when the moment passes, fund implementation and the next generation.
9. Small funders can utilise a social movement lens to help the 'missing pieces' gain the visibility and capacity needed to become coalition partners and movement leaders.
10. Join with other funders to reduce redundant demands on grantees, expand complementary grant-making, and build a shared knowledge base.

## 4. Media

The media plays an important role in spreading awareness, influencing public opinion, disseminating research, winning individual and organisational support and triggering widespread collective action. Social movements often get media coverage of their community events and protests. They can also strategically partner with media outlets to achieve specific aims. The tobacco control movement in India designed one 'big bang' to put the issue centre stage.

*"Cricket has a huge influence on the country - when India plays cricket nobody does anything else that day. But the cricket team at that time was sponsored by the biggest tobacco company in India and players had branding on their uniforms. So we filed a Public Interest Litigation arguing that sponsoring sporting events has nothing in common with tobacco products. Sport is about fitness, sport is about health, sport is about energy and what tobacco does is completely different, it spreads only illness and disease."*

Bhavna Mukhopadhyay, Chief Executive of Voluntary Health Association of India

A campaign centered around the national sport received widespread press coverage as well as support from cricket associations globally. At every cricket match and court hearing, the story was highlighted in the media; activists highlighted the impact of smoking on health and how the tobacco company was targeting young people with advertising. Awareness and support built across the country. Eventually the high court stated the need for more regulation around sponsorship and sport, and the tobacco company withdrew sponsorship.

## 5. Public opinion

Movements can engage with public opinion to influence people and institutions who are resisting calls for change, combat stigma, raise awareness or change perceptions. Politicians also publically represent and are influenced by public opinion, and those in their constituency.

### The power of public opinion in rare disease drug development

The first attempt to create a law incentivising pharmaceutical companies to invest in rare disease ended in failure, despite being led by Henry Waxman, one of the most powerful people in American health policy. He initiated a congressional hearing on orphan drugs. Pharmaceutical companies refused to give testimony or even attend. During the testimony, the room was empty aside from half a dozen family members and a young man seemingly asleep at the back.

Henry Waxman shared:

*"After the hearing I asked Bill Corr, 'What happens next?' He answered, 'Get public opinion on your side, get newspaper and magazine stories about orphan drugs, and the public will eventually demand that something should be done.'"*

The young man in the back turned out to be a journalist who wrote in the next day's paper. A Quincy show producer read it, who himself had a rare blood cancer, and offered to work on an episode; it featured a man with Tourette's unable to access treatment, his frustrated doctors and FDA staff standing up against pharmaceutical companies concerned with profits.

After the episode, thousands of letters poured in. Volunteers helped connect writers with local support groups and compiled mailing lists for targeted campaigning. People were encouraged to tell their stories to local newspapers and TV stations, building enormous coverage nationwide. The second congressional hearing was packed with people with rare diseases, supporters, press and Congress members; pharmaceutical companies could not avoid testifying, despite continued denial. Months of mass protest and targeted campaigning ensured the bill passed.

## 6. Other movements

Several interviewees explained that other movements, especially those with closely aligned aims, can often be a significant obstacle to change. Other movements might attempt to capture resources from similar pools, thus creating competition between movements for members, resources and funds. Abbey Meyers of the rare disease movement said she was asked to not incorporate her organisation, the National Organization for Rare Disorders (NORD), as a non-profit because another coalition feared it would split the available resources and membership. It took many phone calls and meetings with members of the coalition to convince them that in fact, this was not a zero sum game; that NORD's progress on all rare diseases would improve the situation for the coalition for neurological diseases.

*"Someone from [a coalition for neurologic diseases] called and asked Marjorie to stop NORD from moving forward because they were afraid that NORD might lure their members away... I assured Marjorie that could not possibly be true."*

Abbey Meyers, Founder and past President of the National Organization for Rare Disorders (NORD) in Orphan Drugs: A Global Crusade



## Questions to spark action

Our research has shown that successful social movements understand the value of interacting with external groups to grow their influence. They might join forces to win support, or oppose activities which undermine their progress. Social movements often make tough trade-offs about where and how to invest their energy in these external relationships to achieve the highest level of impact. Drawing on the examples and lessons from this report, here are some questions which movement leaders might benefit from asking.

### Institutions

1. How are institutions responding to your movement? How can you proactively respond?
2. How can you partner with institutions to grow your movement?
3. Which institutions are nurturing your movement? How? Which institutions could nurture your movement and how might you encourage them to do so?

### Dissenters

1. Which people and groups oppose your movement? Are their claims legitimate, and how might you respond?
2. How might you use research as a tool to generate evidence, insight or support for your movement?

### Funders

1. If you are in the early phases of your movement, how might you manage your dependence on external organisations to avoid early co-option of your efforts?
2. Who might fund your social movements in small, but critical ways, such as providing meeting space and covering marketing expenses?
3. How might institutions invest, fund and support your social movement?

### Media and public opinion

1. Which media outlets and activities can help you reach your target audiences?
2. Which media partnerships will best help you encourage people to take specific actions as part of your movement?
3. How can you encourage people to tell their stories - not just as part of the movement, but in every appropriate outlet?

### Other movements

1. Are there movements in your local community you could partner with on specific activities to extend your reach and influence? What is the best way to approach them?
2. Could your movement act as a 'bridge' between movements or groups which have traditionally remained separate? Are there other groups you might partner up with to create a 'social movement family' (a set of social movements which complement one another)?

Here is an example of a UK-based initiative which has networked and engaged in successful relationships to grow across the country and internationally.

### **parkrun: successful relationships for growth and impact**

A useful example of a group with 'movement-like' characteristics that is engaging successfully with external actors such as institutions, funders and public opinion is parkrun.<sup>28</sup> parkrun organises free, weekly, 5k timed runs in areas of open space around the world. There are also junior parkruns for children aged 4-14 years old. People of all backgrounds, ages and abilities can take part in these local, welcoming and accessible volunteer-led events. There is no pressure to run, those that want to walk are just as welcome.

Founded in 2004, parkrun has grown from one event to almost 100,000 events in the UK supported by tens of thousands of volunteers. In 2016, the number of participants at UK events alone reached one million. So much more than an event organiser, parkrun brings communities together with tangible impacts on health and wellbeing through physical activity, volunteering, community cohesion and access to open space.

parkrun works with a number of 'partners' and 'supporters' who have helped to sustain growth, including other charities and companies. These relationships are carefully considered, in that they must be in line with parkrun's mission, *"Our partners are an extremely important part of the parkrun family, which is why we select them so carefully. Each of our partners has a deep understanding of the culture and ethos of parkrun and the values that are close to our heart. That's why we are proud to support them in return."*<sup>28</sup>

There have also been successes with parkrun contributing to the reshaping of public debates around uses of public space and the health and wellbeing of communities, including through Government consultations, such as the Department for Culture, Media & Sport's *A New Strategy for Sport* in 2015 and The Communities and Local Government Committee inquiry into public parks in 2016.

parkrun is working closely with the health sector, at the national and local level. One doctor, who regularly prescribes parkrun during consultations, has described the positive impact parkrun participation has had on his staff and patients. *"It's a win-win situation for my patients and the NHS. My patients are healthier, happier and on fewer medications, and the NHS saves a fortune on unnecessary drugs and dealing with their side effects."*<sup>29</sup> parkrun has also partnered with the Advanced Wellbeing Research Centre (AWRC) at Sheffield Hallam University, to further research the health and wellbeing impacts.

## Future work

**Social movements assemble the people, resources and relationships necessary to achieve great things in the world. This report reflects some learning about how people in social movements act in ways that influence and change health in the broadest sense. We hope it can be a resource, navigation guide and source of inspiration for people and communities eager to make change using the principles of social movements.**

There is still much to learn from health social movements in the UK and across the globe. At Nesta we are interested in the power of social movements to create social change. In particular, what helps movements succeed and what gets in the way, how institutions can build stronger bridges with social movements that could ultimately benefit the people they serve, and how society creates and supports an environment where social movements lead to greater positive societal change.

Future work must look at how each of us can contribute. How might the NHS, and the wider world of health and care, nurture and support social movements? How can we move from 'letting it happen' to 'helping it happen'? What specific actions can we collectively take to support a social movement for our own health and the health of others? We'd love to hear from you.

[socialmovements@nesta.org.uk](mailto:socialmovements@nesta.org.uk)

# Annex I: Research approach

**This report features practical learnings from over ten social movements which have spread and scaled nationally and internationally. We cover four historically significant movements in depth and look to additional movements for specific lessons - often nascent movements operating in today's political and social climate.**

For each social movement, we conducted background research and semi-structured interviews with people who identify with the social movement, or whose work is affiliated in other ways. We sought a diversity of perspectives including leaders, activists, institutional supporters, academic experts, funders, policymakers and dissenters. Research spanned countries where activism is particularly high, including the UK, US, South Africa and India.

During the interviews, we aimed to understand the dynamics of a social movement's growth and decline - including challenges and opportunities for future growth, how activists got involved, who was involved in shaping the movement's direction, interactions with institutions, and tensions within the movement. The role of sub-movements - such as suicide prevention in the case of mental health - came up within our conversations and is discussed throughout.

## Movement selection

To select social movements, we asked the following questions: Is the movement aiming to improve health or wellbeing, either directly or indirectly? Are people referring to it as a social movements (versus an organisation or initiative)? Is it challenging existing norms, beliefs, institutions or systems? Has it changed form or scale, moving from grassroots to policy to institutions to law? Does it claim to have shifted values and norms? Or, contributed to system change?

## Interview selection

We selected interviewees based on whether they identify with the social movement or whether their work seemingly impacted the growth of the movement. We then employed a snowball sampling strategy by asking: Are there other people we should speak to who you think have been influential in growing the movement? People within institutions who have been supporters of this movement?

In total, we conducted over 40 interviews: 7-10 for each of the four movements covered in depth and 7-10 interviews for additional movements (combined). We also spoke with two experts on the topic of how social movements and institutions interact. We selected those experts based on their contributions to the topic in academic research.

# Annex II: Acknowledgements

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**Dr. Sally Witcher OBE**, Chief Executive Officer, Inclusion Scotland

## Annex III: Endnotes

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