Nesta...

Health as a Social Movement

THE POWER OF PEOPLE IN MOVEMENTS

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Foreword

by Anu Singh, NHS England's Director of Patient and Public Voice and Insight

The challenge is clear and well understood. The NHS faces challenges of unprecedented scale and urgency in the form of escalating costs, shrinking budgets and the growing and changing needs of the population.

The response is also clear - it's not a question of whether the NHS will change, but how and with whose interests and needs at its heart.

I firmly believe that we need to do much more to connect with wider communities and be more proactive in providing informal care in informal settings that will prevent people from needing more formal healthcare. This shift - from formal to informal - is the key to the future of the NHS.

In the Health as a Social Movement programme we are attempting to understand the power of people in movements to drive transformational change. The examples in this report from around the UK and the world repeatedly demonstrate the capacity of people with courage and determination working together to change not just healthcare, but society; of how marginalised people can articulate and fight for their rights in the face of enormous obstacles; of how communities can identify problems and lead change in care at the end of life, in mental health, for rare diseases and more; and of how local communities come together to make changes in their care and their lives.

The capacities of the public are extraordinary; they understand communities' needs and can identify solutions because they **are** those communities; they **are** experts of experience. Their support is mission-critical to developing a sustainable healthcare system and culture that delivers for all.

The key site of healthcare has moved from the hospital into the community; from fixing acute problems to meaningful relationships and choices we make about our health. We have to adapt long-established structures to be more open and responsive to communities and to work together to create change.

The challenge is existential in scale, and the solution will be too: requiring change both in structure and systems, and in interpersonal relationships; how professionals go about their work and how we engage much more intensively with communities and community organisations, if we are not to 'kill what we commission'.

We do not have all the answers, but we know that the best solutions are often created through deep engagement and collaboration, and we look forward to developing this programme with humility, in partnership with the people who the NHS has served for over half a century.

Preface

by Halima Khan, Executive Director, Nesta Health Lab

Nesta health lab

Dramatic social change has been driven time and again by groups of ‘thoughtful, committed citizens’ coming together to change the world, in the words of Margaret Mead. People have come together to fight for rights, solve problems, shift how people think, support each other and demand what they need throughout history. It is important that we remember, indeed honour, the movements that have preceded us.

In their purest form movements are messy, vibrant, spontaneous and uncontrollable. They bubble up outside of formal institutions and from beyond established power structures. They challenge and disrupt. They are restless and determined. They often make society, elites and institutions deeply uncomfortable as they challenge accepted values, priorities and procedures.

Which is why it is extraordinary, and potentially unprecedented, for the leader of a major public institution like the NHS - a system that is understandably highly controlled, with clear hierarchies, rules and protocols - to actively call for more social movements.

But this interest in social movements does also coincide with what could be called a crisis in the founding principles of formal health systems.

The limits of a ‘treat and cure’ model are well and truly established. Excellent clinical care is both essential and absolutely not enough for the complex issues we face. There is a consensus that we need to move upstream to prevent ill health. But this requires a whole set of actions that are beyond the reach of traditional formal services and which move into the social sphere; indeed into the private lives of people. In this context, it is unsurprising that the language of social movements becomes attractive.

As we explore in this report, social movements in health represent a huge opportunity to think differently about how to develop and support health and wellbeing. There is the potential to combine the energy and dynamism of movements with the need for radical institutional change. This creative tension between people and institutions lies at the heart of our work on People Powered Health.

But this collision of worlds also creates challenges. How can formal institutions work with something as restless and intangible as a movement? Who is accountable to whom? Can shared purpose be created without co-opting citizen-led change? What are the limits of social movements?

We know that this report cannot be comprehensive; so we seek instead to provide some clarity over the ways in which social movements in health are being referred to, and some examples of how they have contributed. For every example included, there are many more that are not - so please forgive all omissions. It is also clear that while there are many mature movements in health, practice within the formal health system - such as CCGs themselves - is at a much earlier stage of development; over time this work may contribute to larger and wider movements in health.

We hope that this report shines a light on the value and implications of social movements in health - to foster further debate, experiments and development of a practice around movements. Because if there’s one thing we know, it’s that the health and care system needs radical change. And people-powered movements may contain the seeds of just the kind of change that is needed.

1. Executive summary

"In 1983, the time between diagnosis to death from HIV/AIDs was six months. Thirty years later, when we look at standard antiretroviral therapy, the anticipated life expectancy is over 50 years. How did we get there? We got there by clinicians not accepting the inevitability of a death sentence... the entire community coming together and saying we need to figure out what is going on so we can intervene."

Nadine Burke Harris, CEO and Founder, Center for Youth Wellness

The pace of social and technological change is accelerating in the UK and worldwide. In health and care, a confluence of factors are challenging the boundaries between formal health institutions and the environments where health is developed and experienced, including people desiring deeper involvement in choices related to their health and wellbeing, the traditional medical model falling short of addressing the wider determinants of health, and increasing recognition that hierarchical institutions alone can no longer adequately address local and global health challenges.

Social movements have been gaining increased attention as an effective bottom-up approach to change. They put pressure on societal systems to accelerate transformation, respond directly to the needs of people and communities and have the potential to diffuse widely across populations through interpersonal relationships.

A health social movement is a persevering people-powered effort to promote or resist change in the experience of health or the systems that shape it

Social movements are not a panacea or an answer to all of our health and care concerns. They can be messy, turbulent, and risky, leading us down experimental paths without immediate benefit. Yet, they represent one approach to the system-level transformation so urgently needed in health and care.

Simon Stevens, the Chief Executive of NHS England, states that scaled social movements are, "mission critical to the future of the NHS." In early 2016, as a response to the Five Year Forward View, NHS England launched a three year programme, Health as a Social Movement, to support social movements in health and care. Working initially with six new care model vanguards, the programme is developing, testing and spreading effective ways of mobilising people in social movements that improve health outcomes. The NHS has appointed three national partners: the New Economics Foundation, Nesta and Royal Society of Arts to provide the overarching learning, development, support and evaluation for the programme.

The purpose of this report is to bring greater clarity to social movements in health, explore their potential value, stimulate further debate and propose a platform of action going forward. This report illuminates the value and power of people working together in movements to improve health and healthcare. It aims to foster further debate, experiments and development of a practice around social movements for health.

How social movements impact health and care

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
6. Change cultural and societal norms
7. Propose new health innovation and policymaking processes

Communicating the value of movements

There is no definitive definition of a social movement. Yet, it is possible to sharpen understanding and communication around the term to make it useful to a UK health and care context. Current NHS communication around social movements focuses on the NHS as a social movement and on movements supporting NHS services, fostering cultural change and driving large-scale systems change. It is critical to sharpen the communication around social movements to capture the breadth of their potential value as well as refine it to reflect depth of understanding.

A social movement empowers

Understanding how social movements behave is critical to engaging with them. We suggest that a social **EMPOWERS**:

- **E**mpathises with the issues of people, carers and communities
- **M**obilises the strengths, capabilities, resources and knowledge of people
- **P**owers people by building leadership and agency
- **O**rbits existing health, political, and societal systems to change them
- **W**aves and recurs in intensity over time
- **E**xperiments with new ideas and approaches
- **R**ages and roars for issues that matter
- **S**elf-governs their activities

Productively engaging with movements

There are inherent challenges in established organisations like the NHS working alongside more emergent practice like movements. For example, it is difficult to design structures for social movements to 'dock into' health services without them collapsing under the burden of bureaucracy, and which do not control or pressure movements to change. These challenges surface a healthy tension.

How can the NHS, social movements and health and care organisations engage with each other most productively?

We propose the need for a new model of engagement that draws effectively on both the efficiency and scale of institutions and the dynamism and agility of movements. This model of engagement can be developed by:

1. Identifying and engaging on shared priorities
2. Developing appropriate decision-making infrastructure
3. Encouraging effective communication between formal and informal groups
4. Promoting facilitative leadership and inclusive engagement
5. Driving accountability and responsibility
6. Creating appropriate social movement evaluation methods
7. Better recognising the value of UK health social movements

Further work is needed to understand how social movements could better flourish, the outcomes of health movements and how to evaluate their impact as well as how movements scale, especially in 'crossing the cultural chasm' between early adoption and mainstream practice.

Movements are integral to a healthy and thriving society. Ultimately, whether and how they achieve their aims depends in part on the ability of institutions to listen and effectively respond to movements. So to realise the transformative and innovative potential of social movements there needs to be agile and responsive institutions and a commitment on both sides to engage and create better ways of doing things.

2. The time is ripe for social movements in health

There is a unique power to people in social movements - one in which purposeful citizens have the *determination* and *courage* to stand up and speak out for the issues that matter to them and their loved ones.

Issues of health are built into the social fabric of our daily lives. Many of the changes we have seen in how we experience health have been brought forward by social movements.

Social movements are grounded in the lived experiences of people and communities. Their members *are* the people managing chronic health conditions or adhering to complex medication regimes, the people who have grievances with the status quo and can translate them into inspirational visions of a better life and society. The AIDS movement, the breast cancer movement and the disability rights movement aimed to transform people's experiences of their own health conditions and circumstances as well as create cultural shifts in how society responds to sexuality, gender and ableism.

People's voices and determination in movements illuminate powerful ways for society to operate and live. Their role is to seek out alternative approaches, pathways, and ways of living which challenge or reject the status quo. Ultimately, they buffer us against any extreme, including dehumanised services, marginalisation, inequality, inequity, and the rigidity and constancy of entrenched institutions.

A health social movement is a persevering people-powered effort to promote or resist change in the experience of health or the systems that shape it

Social movements directed at health and care issues have been gaining increased attention as effective forms of civic engagement putting pressure on health and care systems. They aim at a broad array of social, cultural and political changes such as promoting healthy lifestyles, creating dialogue around stigmatised health issues and experimenting with new approaches to knowledge creation, innovation, and policymaking.

A confluence of factors in health and care, and UK society at large, are challenging the boundaries between formal health institutions and the environments where health is developed and experienced:

People love the NHS and want to support it: A 2015 British Social Attitudes survey revealed that about 1.7 million people are actively volunteering, and that 24 million would volunteer, in health and care in England.[1] People supporting services and actively co-designing future care offerings, could reduce pressure on NHS services and help ensure the system is meeting people's needs.

Healthcare needs to be people powered: The traditional medical model works effectively in acute situations but is failing to address health issues requiring significant lifestyle change or tackling the wider determinants of health. People-powered health addresses the underlying social drivers of health and puts the person at the centre of care and in relationships which are empowering and lead to better health and wellbeing.

This era of change needs new types of power: A hierarchical structure of 'command and control' across health systems has benefits, facilitating management efficiencies and safety in care provision. But, new types of power and associated forms of leadership are increasingly being recognised as relevant and potentially complementary; power which is communal, open, shared, and relational. We need to utilise bottom-up approaches, such as building networks for change and engaging people informally, whilst retaining the hierarchical and top-down approaches that work.

Our current health challenges require widespread behaviour change: We need behaviour change at scale to respond to the rise in chronic disease. New types of approaches are needed which reduce unhealthy behaviours, such as smoking, and increase healthy behaviours, such as exercising.

People at the grassroots and frontline can see and solve problems in new ways: It is tremendously difficult to change systems from within, using the same understanding of the problem that designed current solutions. The creative ingenuity of people outside the system can bring new pathways for health systems globally.

Globalisation is changing modes of discourse and the nature of collaboration: Through global communication networks, people can connect and communicate informally across national borders, accelerating the development and spread of new ideologies, solutions, and change tactics.

The purpose of this report is to bring greater clarity to health social movements, explore their potential value and propose a way forward for the Health as a Social Movement agenda. This report does not seek to be comprehensive; it is intended to stimulate further debate and practice. The examples illustrated in this report are symbolic of the nature and scale of change that movements are capable of achieving.

We must remember that social movements are not a panacea or an answer to all of our health and care issues. They can be messy, turbulent, dangerous, and risky, leading us down experimental paths without immediate benefit. Taken in imbalanced doses, they could swing society towards instability. Yet, they represent one timely approach to the system-level transformation so urgently needed in health and care. As work on social movements in the NHS continues, we hope to continue to glean ever more powerful ways to engage with them and ensure they have the chance at bringing forward new realities for how we see our own health, and the institutions and systems which shape it.

> *“Social movements are a hope and power out of our current predicament.”*
>
> Helen Bevan, Chief Transformation Officer, Horizons Group, NHS England

3. How social movements impact health and care

> *“[The NHS] is the biggest single experiment in social service that the world has ever seen”*
>
> Aneurin Bevan, Minister for Health, 1948

Over the past half-century, the NHS has made significant progress delivering excellent clinical treatment for acute and infectious disease. An analysis by the Commonwealth Fund deemed the NHS the top health system, scoring the highest on access, quality and efficiency in comparison to the highest income countries globally.[2] Yet, its success has created new challenges: people are living longer, often with multiple long-term conditions and at greater expense to the health system. In England, 15 million people, or a quarter of the population, live with long-term health conditions, accounting for £7 of every £10 spent on health and social care.[3]

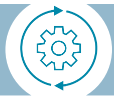
One could say the NHS was founded on a social movement pursuing the ideology that *“good healthcare should be available to everyone.”* It was an ambitious reframing of the relationship between State and Individual in healthcare provision, stressing equity, inclusion, accessibility and equality.[4] Prior to 1948, the availability and quality of care had generally been dependant on citizens’ ability to pay. Voluntary hospitals for taxpayers existed, yet coverage was incomplete and quality varied. World War II set the scene for radical system change. It produced the first centralised Emergency Hospital Service and left a shared sense that healthcare should be a right not a privilege.

Since 1948, the NHS has been responding to shifting patient needs and disease patterns as well as incorporating the latest technology and life science advancements. These shifting external factors have led to a continual restructuring of the service throughout the 20th century. While much change has come from within, movements have continually stretched the NHS from the outside. In this sense, the UK health system could be thought of as a **persevering ‘health movement’** which continues to evolve through engagements with movements. The following timeline gives just a few examples of how social movements have influenced health and care in the UK and worldwide.

A historical glimpse into the influence of social movements on health and care

Year	Event
1840s	Dorothea Dix, a retired teacher, founds the mental health movement to change how people with mental health conditions are viewed and treated.
1863	Founding of the International Red Cross movement, proposing voluntary national relief societies trained to help in times of war.[5]
1877	Formation of St. John Ambulance Association to teach first-aid to the public.
1948	Founding of the National Health Service.
1951	Rise of the disability rights movement, setting out to achieve equal rights and opportunities for disabled people.
1952	The link between smoking and lung cancer identified, leading to the tobacco control movement to increase public awareness about the harmful effects of smoking.
1961	The introduction of the contraceptive pill, a driving force behind the UK women's liberation movement,[6] as 'sexual liberation did not always mean women's liberation'.
1967	The opening of St. Christopher's Hospice, the first in London, marking a success of the UK hospice movement to radically change the approach to death and dying.
1970s	The patient rights movement gives rise to hospital-based patient advocates.
1980	Formation of the Alzheimer's Association, starting the Alzheimer's movement.
1987	ACT UP members march on Wall Street to demand access to AIDS drugs and a national policy to fight the disease.
1980s/1990s	The breast cancer movement takes off after the invention of the mammogram in 1966 enables screening and identification of breast cancer.
Early 2000s	Social movement thinking is applied to building an NHS Improvement movement.
2013	NHS Change Day runs for the first time, gaining 200,000+ pledges for change.
2014	*The Five Year Forward View* refers to the NHS as a 'social movement.'
2016	The NHS launches the 'Health as a Social Movement' programme.

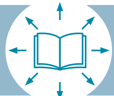
What social movements in health aim to achieve


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

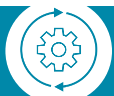
4. Address socioeconomic and political determinants of health


5. Democratise the production and dissemination of knowledge

6. Change cultural and societal norms

7. Propose new health innovation and policymaking approaches

The list that follows builds on the work of sociologists Phil Brown and Stephen Zavestoski in their research on examining social movements in health.



1. Bring about change in the experience and delivery of health care

Social movements emerge to challenge the status quo. They bring about incremental changes in service provision or more transformative changes in health policy, regulation and delivery systems. The influence of social movements can rival that of heads of state, scientists, and corporate executives.[7] The most revolutionary movements often start out knowing what they want to do, but not *how* they are going to do it. The UK hospice movement is a good example of this.

The UK hospice movement

"You matter until the last moment of your life. We will do all we can, not only to help you die peacefully but to live until you die."

Dame Cicely Saunders, founder of the UK hospice movement

The hospice movement started with a vision to bring dignity to dying. Dame Cicely Saunders started working as a volunteer nurse in 1948. She spent over a decade training as a doctor to understand issues surrounding death. This led her to opening the first hospice centre in 1967. Hospice centres are medical, teaching and research facilities providing specialist care and dedicated to the holistic care of patients. Hospices provide palliative care as well as support for carers and family members.

A worldwide movement has grown out of the hospice care movement and is radically changing the approach to death and dying. Now, the model has evolved with multidisciplinary teams offering dignity, peace and calm at the end of life. The UK hospice care sector supports at least 360,000 people with terminal and life-limiting conditions each year, including their family members.[8]

Movements can also reject the status quo. The NHS' decision to temporarily close a local hospital led to a community protest in Millom. The local NHS vanguard responded by enlisting the community to lead a successful general practitioner (GP) recruitment effort.

The Alliance between Community and Better Care Together at Millom

"The NHS is really listening to the community, and I don't think anything like this has been done before."[9]

Newspaper quote from Local Millom Action Group Member

In 2014, 2,000 people marched through Millom, the most geographically isolated town in South Cumbria, in protest of the temporary closure of the local community hospital. Over the years, local services had been gradually reduced and the town's 8,000 residents were taking 17,600 journeys out of town every year to a clinic, A&E or hospital. These trips took 50 minutes by car or a costly taxi trip. An 18-month campaign to hire replacement GPs had failed to attract a single candidate.

In response, the local NHS vanguard (Better Care Together) invited the protest group to help with the recruitment effort. The Millom Health Action group produced a recruitment video, which attracted 5,000 views a week and successfully recruited three GPs. Better Care Together is now working with the group to use new technologies, better partnership working as well as creative community-led endeavours such as health information leaflets, support groups such as 'Hope and Cope' and 'Diabetes Type 2', volunteering initiatives and many more to deliver more services and information where people are.

2. Improve people's experience of disease, disability, or illness

People experiencing a particular disease, disability or illness often mobilise to change the experience and perception of their illness and gain greater control over their bodies and care. This might involve reducing cultural stigmas, achieving medical recognition for their disease, or fighting for research around diagnosis, treatment, and prevention. The illness might be 'contested,' unexplained by current medical knowledge, or have environmental explanations that are often disputed. In society, collaboration within and across these groups has increased, indicating a potential health consumer movement.[10]

In this movement, people are valuing their bodies and health choices. As users of health services, they are increasingly insisting on their rights (understanding themselves as 'consumers' of healthcare). This means forging meaningful and personable relationships with members of their care team, defining and making choices about their health priorities, and having concerns recognised even when diagnosis is not straightforward. Others prefer to frame these rights in the context of citizenship and human rights, rather than consumer rights; and major movements, such as the disability movement, can contain elements of both approaches or may be characterised by one in particular.

The Alzheimer's Society's Dementia Friends programme is the largest UK initiative attempting to change people's perceptions of dementia. It aims to transform the way the nation thinks, acts and talks about the condition. The Airedale NHS vanguard is hoping to draw on the success of Dementia Friends to improve understanding of dementia in their local community.

Looking at the evolution of the breast cancer movement shows how a movement can influence societal perception of a health issue over time. One researcher looked at how one woman's cancer experience changed between the 1970s and 1990s.

The impact of the breast cancer movement on the disease experience[11]

In 1979, Clara Larson received her first diagnosis of breast cancer. She was 37, living in San Francisco. At that time, surgeons were 'king' in the medical system and the only role available to her was one of compliant patient. At that time, regulations did not require surgeons to give patients the choice to have a mastectomy. Thankfully, Clara was given a choice. When she sought out fellow patients, she found only stigma and isolation. Summarising the experience in the late 1970s:

"People didn't talk about it then. And I think that's probably the most global thing that I can say about having breast cancer in 1979. People Didn't. Talk. About it. Period."

"Certainly, the women's movement... in the 70s gave me words and concepts to be able to understand how I felt... if you don't have the words to express how you feel, you're really kind of stuck..."

In 1997, she received her second diagnosis. By that time, the clinical encounters and public perception of the disease had completely transformed. She was treated in a feminist, lesbian-friendly cancer centre where she participated in a healthcare team and had medical alternatives. She was met with support groups, resources, and access to patient education. Breast cancer survivors were, 'heralded as heroes rather than pitied as victims.'

3. Promote healthy lifestyles

Lifestyle movements challenge predominant cultural norms and promote alternative lifestyles. They encourage change at the individual level - in the choices, daily practices, consumption habits, leisure activities and conscious experiences of people's lives. For example, the voluntary simplicity movement promotes reducing material possessions to reduce the environmental footprint. For health and care, these movements are a compelling opportunity to explore behaviour change at scale, empowering people to take control of their health and seek to ease pressure on NHS services.[12]

Veganism: a growing lifestyle movement

Veganism is one of the fastest growing lifestyle movements in the UK; the number of vegans in Britain has risen by 360 per cent over the last ten years.[13] Some of the factors potentially driving the trend include the perceived health benefits of the diet as well as welfare and environmental issues related to animal-sourced food. Veganism challenges cultural norms around dieting and consumption. A study by Ipsos MORI confirmed that a majority of British vegans live in urban or suburban areas and almost half are aged 15-34.[14]

Lifestyle movements consciously and actively promote a way of life to foster social change at a broader level. In other words, individuals are not part of a lifestyle movement if they adopt the lifestyle solely for personal benefits - health, mental, financial. When compared to protest action aimed at deep structural change, lifestyle movements may seem less influential. However, they can create the energy and momentum to generate behaviour change at scale. One caveat here is that individual changes in behaviour might not add up to the same scaled effect. However, for people uncomfortable with engaging in contentious politics, these movements can offer a more personally aligned way of pursuing social change. Research also shows that individual-level action can also create the foundation for people engaging more deeply in other collective action forms.

4. Address socioeconomic and political determinants of health

Health is developed and experienced in context with socioeconomic and political conditions influencing distributions of disease and health outcomes.

Income inequality and poverty, housing and employment conditions, marginalisation and discrimination based on race, ethnicity, gender, sexuality, and class have enormous impact on individuals' health, the choices available to them, their care, and outcomes. Economically disadvantaged communities campaigning on economic issues may be a hugely effective means of improving physical and mental health outcomes.

Economically disadvantaged communities campaigning on economic issues may be the most effective means of directing energy towards improved physical and mental health. The living wage campaign describes itself as 'A Citizens Movement'[15] and was founded by two parents living in East London. They found that despite working two or more jobs on minimum wage, they struggled to pay rent and bills, and had no time for family life. This began a series of publicity campaigns to document life on minimum wage[16] and direct action such as occupying retail spaces of companies paying less than the living wage. In 2005, the Greater London Authority established the Living Wage Unit to calculate the London Living Wage. By 2016 the campaign had generated nearly £210 million in additional wages for UK low-paid work.

A grassroots movement to address adverse childhood experiences (ACEs)

The Adverse Childhood Experiences (ACEs) research, conducted by Kaiser Permanente and the Center for Disease Control in the U.S., was a large public health study conducted with 17,000+ patients. Patients responded to a survey about traumatic childhood events; responses were matched to their medical records. The study found strong correlation between ten adverse events and major chronic diseases and negative health behaviours, such as smoking and alcohol abuse.[17]

ACEs are common: nearly two-thirds (64 per cent) of U.S. adults have at least one. High doses of adversity in early life affect brain structure and function, the developing immune system, and the way DNA is read and transcribed, putting children on a path of lower life expectancy. Failing to address this problem early is expensive to society - according to a CDC study, one year of cases of child maltreatment costs $124 billion over the lifetime of the child.[18]

A grassroots movement is exploring solutions across society – pediatricians are developing treatment protocols, school teachers are introducing compassionate curriculum, and journalists are telling stories of trauma. However, healthcare has been the slowest sector to respond. The UK Children's Commissioner has made protecting children from harm a priority.[19]

"When key influencers begin to speak out, this issue will move forward."

Marcia Stanton, Senior Injury Prevention Specialist, Phoenix Children's Hospital

5. Democratise the production and dissemination of knowledge

Health movements can aim to improve the experience of a person with a particular disease or condition. We see this happening in a variety of ways. People with specific health conditions are being valued for their knowledge and insight by professionals. For example, people with autism are co-designing appropriate methods of engagement alongside professionals. Professionals are looking to peer-support networks to understand the lived experience, such as in the SUN project in Croydon.

We also see citizens and institutions rallying for new medical research by putting forth research priorities, suggesting reshifting of funding priorities and promoting new research approaches. The rise of the citizen science movement is marked by a desire for more patient-led healthcare research. Patients can be frustrated with the speed and direction of research. With massive amounts of data now able to be produced, owned, and controlled by patients, citizens can more actively contribute. Patient associations, such as AKU, see themselves as part of a larger movement to engage patients in medical research – maintaining patient registries and raising funds for clinical trials.

The AKU Society: supporting a wider movement to engage patients in clinical research[20]

“Getting patient groups more involved in clinical research - that’s a movement.”

Oliver Timmis, CEO, AKU

AKU Society is a charity serving people with Alkaptonuria (AKU), a rare genetic disorder causing damage to bones, cartilage, and tissues. Its mission is to transform the lives of AKU patients through support and treatment. They have successfully raised EU funding to measure the effectiveness of the first potential treatment, established a National Centre of Excellence, and united patients through platforms like PatientsLikeMe. Their programmes foster relationships between patients, researchers and clinicians; keeping patients at the centre of cutting edge research, not simply as a moral duty, but because AKU believes it leads to more effective research and faster access to better treatments. For example, a pharma company developing an injectable treatment for eczema asked a patient for feedback. The patient said, *“This is ridiculous! My skin is too sensitive, I can’t use this!”* The company made a cream instead.

“When the patients see their voice is being heard, they’re more involved, more willing to travel to give samples… and, they understand more.”

Dr Ranganath, Co-founder and Medical Director, AKU

AKU research requires highly activated patients - they must be willing to take off-label drugs and adhere to strict diets. While one visit to the national centre may replace several to experts, it means lengthier journeys, often complicated by pain and disabilities caused by the condition. Sometimes, patients also contribute research funding from their own personal networks.

The charity sees itself as part of a larger movement to encourage the adoption of patient-centered research for a wider set of rare genetic conditions. It is encouraging this philosophy on Findacure, an organisation building disease communities around research.

“Studying rare disease can lead to some discoveries around more common diseases as well.”

Oliver Timmis, CEO, AKU

6. Change cultural and societal norms

Social movements are uniquely capable of expressing the needs and interests of communities because they are those communities. Vitally, they are often members of marginalised groups who do not have access to other sources of power to drive change. For these groups, stating that their bodies and choices matter can be a radical political act, requiring a swell of grassroots energy, even in matters of life and death.

On October 15, 1982, at a White House press briefing, reporter Lester Kinsolving asked Press Secretary Larry Speakes about a horrifying new disease called AIDS ravaging the gay community.

"What's AIDS?" Speakes asked.
"It's known as the 'gay plague,' " Kinsolving replied.
Everyone laughed.
"I don't have it," Speakes replied. *"Do you?"* The room erupted in laughter again.[21]

The activist group ACT UP had specific practical aims that could not be achieved without profound cultural change. As a marginalised and stigmatised group, the LGBTQ+ community had to fight for recognition that their bodies and lives mattered. Similarly, disability rights and feminist campaigners had to fight for the right to participate in decisions about their care.

Social movements are often uncomfortable for incumbents because people often express sentiments of anger and pain through them. For the most marginalised groups, simply asking for a recognition of their problems and adequate care can be a radical political act, as often their community's needs and interests can be deeply taboo, or disregarded.

7. Propose new health innovation and policy-making approaches

Movements can promote public participation in social policy and regulation as well as democratisation of organisations influencing policymaking and research. There has been a rise in the study of grassroot innovation movements promoting alternate forms of innovation and encouraging inclusivity in the innovation process. This is also reflected in the increasing use of challenge prizes and other 'open innovation' methods in a health context. Nesta is currently running the Longitude Prize on antibiotic resistance,[22] which was chosen by public vote, and OpenIDEO is enabling anyone in the world to contribute new ideas to global challenges on their innovation platform.

OpenIDEO: The potential of an open innovation platform to bring energy to movements

OpenIDEO is a global community designing solutions to the world's biggest challenges. An online innovation platform enables anyone in the world to contribute to challenges. Challenges are devised by IDEO, the international design and consulting firm, in collaboration with sponsors.

A recent challenge asked, *"How might we reimagine the end-of-life experience for ourselves and our loved ones?"*[23] Participants were invited to contribute to a phased creative process - inspiration, ideas, feedback, refinement, and final feedback. 'Top Ideas' were chosen for their potential to be developed, piloted, and implemented. Top Ideas included: systems to personalise the ICU experience, death education in schools, and providing 'breaks' for stressed carers.

The challenge has been the most successful to date. The OpenIDEO platform has shown its potential to catalyse global conversations around the end-of-life issue and contribute to the persevering movement on death and dying. Challenge sponsors included Sutter Health, a nonprofit health system in California, and HELIX, a design studio at St. Mary's Hospital in London.

Health and care: status quo or change?

Social movements are an integral part of a healthy and thriving society. Taken collectively, movements can have synergistic effects - sharing resources and enabling disproportionately positive outcomes. High social movement activity can imply: an engaged citizenry, a diversity of movements, high mobilisation around a common set of causes, or a plethora of grievances with the state of affairs. How can institutions take advantage of high social movement activity? In the context of the NHS, we propose a framework suggesting that crossing high social movement activity and with institutional agility could lead to new levels of innovation, transformation, and growth co-led by people and institutions. Low institutional agility and high social movement activity would still lead to change but amidst an environment of societal discontent, agitation, and protest. Low social movement activity means that change is either institution-led, or, that fatalism occurs.

High Social
Movement Activity

PEOPLE-LED CHANGE: DISCONTENT AGITATION, PROTEST

CO-LED CHANGE: INNOVATION TRANSFORMATION GROWTH

Low
Institutional
Agility

High
Institutional
Agility

FATALISM: REPRESSION OR APATHY

INSTITUTION-LED CHANGE: SATISFACTION OR APATHY

Low Social
Movement Activity

4. Communicating the role of movements

How NHS leaders communicate the value and role of social movements can influence their impact. Currently, NHS leaders talk about the value and role of social movements in four primary ways.

1. The NHS as a social movement

The Five Year Forward View refers to the 'NHS as a social movement', and this has been reiterated by Simon Stevens and other health and care leaders in interviews and speeches. This is sometimes linked to the NHS as a facet of people's personal and cultural identity:

"The NHS is a social movement and not just a healthcare service… It is part of what it means to be British."[24]

Simon Stevens, Chief Executive, NHS England, interview with *The Guardian*, October 2014

In some cases, the NHS workforce itself is explicitly included as part of the NHS as a social movement:

"We need to get out into the community and deliver care where patients are. We need flexibility for the demographics of the workforce and to make sure the health service makes the most of all its staff. Every doctor must feel empowered in a social movement. We need to empower, educate, engage, and focus on equality and diversity."[25]

Simon Stevens, Chief Executive, NHS England, interview with *The Guardian*, June 2015

"My vision is of public health as a movement, owned by everyone, for everyone's benefit. A movement which unites those who have been trying to prevent ill health with those responsible for treating it. A movement which not only transforms the way we deliver public health, but also revolutionises the way we think about it."[26]

Andrew Lansley, then Secretary of State for Health, speech to Faculty of Public Health, December 2010

Framed in this way, social movements could empower and ensure the commitment of doctors, NHS staff and volunteers to create better health for all.

2. Social movements as supportive forces working alongside the NHS

Social movements have also been framed as an effective complement to NHS services. Referred to in this way, social movements tend to be associated with community-based activity to support health, such as peer-support networks and neighbourhood-level health groups. In recent speeches, Simon Stevens has noted that *"social movements have the power to tap into the fabric of the country in ways the NHS might never be able to do."*[27]

"... the NHS can't do it alone. Because the NHS isn't just a care and repair service, it's a social movement. We're going to need active support from patients, the public, and politicians of all parties."[28]

Simon Stevens, Chief Executive, NHS England, NHS Speech, May 2015

"Since the first Prime Minister's Dementia Challenge was launched we've seen real progress in the fight against this devastating condition, and the beginnings of a social movement to rally people behind that fight."[29]

Hilary Evans, Chief Executive, Alzheimer's Research UK, March 2016

"The NHS is as much a social movement as a health service. That is why it is so vital to secure its founding principles and set out the rights and responsibilities of patients, public and staff."[30]

The Rt Hon Alan Johnson MP, then Secretary of State for Health, in *High Quality Care for All*, NHS Next Stage Review Final Report, June 2008

Volunteers as supporting forces: the volunteering movement in health and care

"People who love the NHS are desperate to support it. We have to show them how to do it."

Bev Taylor, Volunteering Development Manager, Public Participation Team, NHS England

David Buck, Senior Fellow of Public Health and Inequalities at the King's Fund, calls volunteering, 'the quiet force for change.' A 2015 British Social Attitudes (BSA) survey revealed that there are about 1.7 million active health and care volunteers in England, Scotland, and Wales. Furthermore, 24 million British adults, about half the population, would consider volunteering for health, representing an extremely powerful resource of supporters of health and care.

Through the Helping in Hospitals programme,[31] with support from the Cabinet Office and Department of Health, Nesta worked with ten hospital trusts in England to support the creation of impact volunteering roles. These roles enable people to engage in their local communities; for example, a 'Hospital to Home' service in which volunteers help discharged patients settle at home. The programme measured the impact of hospital volunteering on patient, staff, trusts and communities through methodologies such as matched comparison groups. The evidence showed promising results, with statistically significant positive impact on patient experience, mood, anxiety levels, nutrition and hydration, and releasing nurses' time to care. Such programmes do not simply represent the NHS drawing on the energies of the community, but actively developing that community's ties, skills and energy alongside NHS professionals.

"For me, I find it a very satisfying experience [supporting patients who are discharged from hospital and helping them back into their home and community]. From someone that was withdrawn and not wanting to talk, to someone who leaps out of bed with a smile on his face - that is very satisfying."

'Hospital to home' volunteer at Derbyshire Community Health Services

3. Social movements as a force for cultural change and mind set shift

NHS leaders often refer to social movements in the context of society becoming more health focused; adopting healthy behaviours and recognising the social, as well as clinical, determinants of health. Used in this way, the term implies much more profound cultural change, with the NHS at the heart of a society whose cultural norms are rooted in good health and wellbeing.

Bromley-by-Bow Centre[32]

The Bromley by Bow Centre is an innovative charity operating in East London. Over the past 30 years it has worked to transform people's lives from some of the most deprived neighbourhoods in the UK. It focuses on unlocking the talents and skills within deprived communities and has supported the founding of 57 businesses which provide goods and services to the community, employ over 300 local people and have a combined turnover in excess of £4 million.

The Bromley-by-Bow Centre provides a holistic range of integrated services: primary care; community health services; social care; public health and community based mental health programmes; together with a wide range of services that build skills and improve the wider determinants of health. Services are designed to meet immediate needs and build longer term resilience. Services include programmes to reduce social isolation, promote healthy lifestyles and behaviours, and offer social welfare and legal advice (particularly benefits, debt and housing). The Centre is accessed by thousands of people each month as both users and contributors. Each year the Centre enables the realisation of dozens of resident-led community projects that support healthy living initiatives in local neighbourhoods.

4. Social movements as an approach to large-scale scale systems change

In the early 2000s, most healthcare improvement efforts had relied on top-down change approaches. Yet, evidence from policy and social science suggest that *"bottom-up, locally-led, grassroots movements could offer a complementary approach to healthcare improvement thinking and practice."*[33] Under the leadership of Helen Bevan, Chief Transformation Officer, the NHS began studying social movement thinking with the aim of applying it to NHS improvement as well as utilising it to enrich and extend NHS thinking in relation to large-scale, system-wide change.

"Ultimately, if we were going to enable improvements for people who use our services across the whole country, we needed to build a movement of at least a million change agents. What could we, in the healthcare improvement community, learn from the leaders of the great social movements: the Women's Suffrage Movement, the American Civil Rights Movement, the environmental campaigners of the 1970s? These were leaders who had no hierarchical power and few resources in a conventional sense but were able to mobilise for action that literally changed the world."[34]

Helen Bevan, Chief Transformation Officer, Horizons Group, NHS England

The Improvement Movement and NHS Change Day

In 2013, a group of young doctors in a leadership course shared their frustrations about driving change in the NHS. In March 2013, they launched NHS Change Day, asking the 1.3 million people who engage with the NHS, including clinical and administrative staff and volunteers, to publicly make 'pledges' for change. In a few months, 200,000 pledges were captured. A pediatrician agreed to *"work with the hospital pharmacy to improve the taste of medicines prescribed to children."* Another example is the CEO of an NHS Trust to *"visit patients in our hospitals who do not have any other visitors."* Change Day runs annually through NHS Improving Quality. An evaluation of Change Day was conducted by CECAN (Centre for the Evaluation of Complexity Across the Nexus). That evaluation and a year's work of evaluating bottom-up change approaches led to the development of a new evaluation approach, 'Revaluation'[35] for measuring change involving participatory methods, one which goes beyond looking at 'what works' to 'what is going on.'

Broadening how movements are understood

Current NHS communication around social movements focuses on their role in relation to the NHS - as the NHS being a movement, as supportive forces of NHS services, and as an approach to large-scale systems and cultural change. However, it currently does not capture the full breadth and extent of their potential. Across all fields, social movements are:

Innovators	Social movements can be innovations in themselves, or create the spaces for innovative activity to occur. Movements are also sources of cultural innovation giving rise to culture shifts and new organisational forms.
Forms of democratic engagement	Social movements enable alternative forms of participation. They can be a particularly powerful motivator for those who lack conventional routes to power or mainstream political discourse.
Community and resource mobilisers	As social movements emerge and grow, they mobilise people into strong collectives for action. Through those collectives, people invest and commit resources in the form of talents, skills, capabilities. Assets, networks, and 'social capital' is also built. This infrastructure is often utilised by future movements to facilitate other types of collaborative action.
Knowledge producers	Movements challenge the strengths and weaknesses of established practice and experiment with alternate solutions, generating knowledge highly relevant to policymaking. Forms of knowledge might include ethnographic (i.e. unmet needs, living conditions), instrumental (i.e. skills required to implement solutions), and critical (i.e. allies or gatekeepers).
Awareness raisers and conversation starters	Movements bring awareness to the issues they fight for. The conversation may centre around stigmatised issues or specific communities whose needs have historically been underrepresented such as women, LGBTQ+ communities, people with mental health conditions, or those living with long-term conditions and/or disabilities.
Empowerment builders	Movements empower people to become agents of change. They build individual and community-level agency which can be utilised for future community development endeavours. People in movements often undergo a personal transformation. The experience of being part of a movement provides a new role and lens through which to experience the world - to be motivated by the vision, recruit members, establish new relationships and see issues in new ways.

Change accelerators	People in movements accelerate change in issues not advancing through mainstream practice. As Dr. Ranganath, Co-founder and Medical Director, of the AKU Society expressed, *"If we didn't have the AKU society, what we have done in seven years would have taken 30."*
Power redistributors	Movements arise from informal and flexible organisational structures which distribute power across people and networks, enabling real-time communication and data-sharing. They facilitate interactions between power holders and people lacking formal representation to change the distribution or exercise of power.
Relationship builders	Social movements build and strengthen relationships. These relationships can emotionally and practically support people in managing ongoing health conditions and responding to new health and care wellbeing issues before they get to a crisis point.
Diffusors of new ideologies	When movements diffuse through society, they spread their ideologies and tactics, including protests and riots. Understanding how movements spread and scale are topics of great interest to researchers.

Viewpoints from health and care leaders

People working in health and care have shared some of their perceptions and perspectives surrounding social movements. Their opinions and viewpoints are important sources of insight for guiding the communication around social movements.

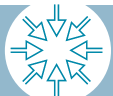
Perception or perspective	Reality
"It's as if we've just discovered social movements and it's some shiny new thing."	Social movements are not new; they have existed for centuries. It is important to acknowledge the role of social movements throughout history; and stress the value they could bring to addressing current challenges.
"This seems like community development wrapped up in new words."	NHS professionals are concerned the term, 'social movements' could be used in ways that fail to acknowledge the work community leaders have been doing for decades. Social movements should be positioned as a complementary, rather than competing, approach to community-centered development and other change approaches.
"For the NHS to say, 'this is how we should run social movements'... that would be a big mistake."	By definition, a social movement cannot be governed by the institution it seeks to reform or revolutionise. Health leaders and those working in the health system need to resist the urge to manage social movements; institutions and organisations can, however, nurture movements by connecting different social movements to each other and to necessary resources.
"There's a danger that this term will get applied to pedestrian and familiar things." *"To what extent is the term, 'social movement' giving civil society activity a useful label."*	If every initiative with 'movement-like' qualities is deemed a social movement, the approach is in danger of becoming a 'policy fad.' Charles Tilly, a pre-eminent sociologist, says there are two ways to get the analysis of social movements wrong: to see social movements everywhere and to search for general laws of how they work.[36] We should continue to develop deep and effective practice around social movements.
"The message needs to continue to be behind the goal."	It is important to understand what is trying to be achieved through movements and to be open to other approaches that could achieve the same aims - rather than positioning social movements as a 'silver bullet'.

5. Social movement fundamentals

For over a century, scholars have been examining how social movements emerge, grow, and reshape society. Studying their impact is challenging as it can take years, even decades, for the outcomes of social movements to manifest. However, much is known about what *triggers* them and how they *behave*. An understanding of their behaviour will assist institutions like the NHS in engaging with them as emergent, dynamic, and turbulent forces.

We suggest that a social movement **EMPOWERS**:

Empathises with the issues of people, carers and communities

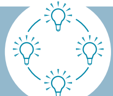


Mobilises the strengths, capabilities, resources and knowledge of people

Powers people by building leadership and agency

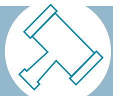
Orbits existing health, political, and societal systems to change them

Waves and recurs in intensity over time



Experiments with new ideas and approaches

Rages and roars for issues that matter



Self-governs their activities

Through movements, people bring their attention, skills and capabilities to the issues that matter to them and their communities. We describe each behaviour below.

Empathises

Social movements are informal groups made up of people with direct or indirect experience of an issue; they understand their own grievances and context as well as the causes or contributing factors. This understanding makes movements inherently empathetic, and enables them to draw on people's direct experience of an issue to understand how to fundamentally change it. As the VCSE Review shows, informal charities, community groups and social enterprises draw from the experience and insight of communities as well as develop them, functioning as a 'glue' holding communities together.

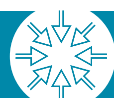
The Voluntary, Community and Social Enterprise (VCSE) Review

VCSE organisations are often uniquely able to offer support which looks at the whole person and whole family, thinking preventatively and across the whole lifetime.[37]

The Voluntary, Community and Social Enterprise (VCSE) Review was undertaken to map out VCSEs activities and their relationships with health and care agencies. The report found that charities, community groups and social enterprises support people that mainstream healthcare struggles to reach. Due to values such as being 'holistic, long-term, relational and locally-rooted,' they were able to develop deeper relationships with individuals and communities and could respond sensitively to ongoing needs, working on direct health problems as well as the wider context, including the social determinants of health.

Alongside an urgent call to embed the VCSE sector into decision-making, the Review includes a warning not to pressure VCSEs into growing and professionalising in such a manner that they become indistinguishable from mainstream healthcare, and so lose their community roots, the relationships, expertise and experience that make them so valuable and effective.

The review was co-produced by the public and the VCSE sector, with an advisory body of community organisations, social enterprises, senior NHS members, the Department for Health and other government bodies.



Mobilises

"A social movement in health to me is about how people can get together and collaborate with each other to create a healthy society and an NHS that works for us."

Dr Brian Fisher, vice-chair, New NHS Alliance

As movements emerge, they mobilise people and resources for collective action. Mobilisation is aided by factors internal and external to the movement. Internal factors include availability and access to resources, pre-existing networks of potential supporters, a shared sense of identity among target members and leaders with the right capacities. External factors include political and economic opportunities as well as a technological or life sciences discovery, such as a new diagnostic, drug, or research finding. Political or economic opportunities, such as a State-level crisis, can slacken the resistance movements face from the State, creating opportunity for collective action. A discovery can catalyse further momentum and research around the issue it addresses. For example, with the invention of the mammogram in 1966, women could be screened for breast cancer, advancing the need and urgency for treatment research.

There is increasing interest in the context of the NHS in identifying and building community assets through, for example ‘asset mapping’ processes and approaches that actively build confidence, social relationships and community-based leadership and change, and continuing to build the evidence of how these approaches make a difference.

“A growing body of evidence shows that when practitioners begin with a focus on what communities have (their assets) as opposed to what they don’t have (their needs) a community’s efficacy in addressing its own needs increases, as does its capacity to lever in external support. It provides healthy community practitioners with a fresh perspective on building bridges with socially excluded people and marginalised groups.”[38]

Assembling coalitions of activated healthcare consumers to build social movements

The Jewish Health Foundation (JHF) in the United States believes that coalitions of activated healthcare consumers are key to starting a social movement in health.[39] Specifically, activated consumers see their wellbeing as an asset. They seek out information to support health choices, track their progress towards their health goals, and desire meaningful relationships with their providers. *Health Affairs* recently published a study showing that activated[40] consumers achieve better health outcomes at a lower cost than passive counterparts.

JHF believes that to make scaled changes in behaviour, policy, and culture, one needs a diverse coalition. In 2004, the JHF invited 70+ activated healthcare consumers, philanthropists, medical providers, economists, and technology experts to Pittsburgh to design campaigns to start social movements around population-level health issues. Teams worked on housing choices for senior citizens, coping with depression, and promoting healthy eating habits, for example.[41]

Powers people

“Research shows that just being a mobiliser doesn’t create a long-term sustainable movement. It’s about developing people and leaders that can organise and change things.”

Helen Bevan, Chief Transformation Officer, Horizons Group, NHS England

Movements build individual leadership and agency by getting people actively involved, and providing ways for communities to demonstrate, develop and enforce the changes they want to see in their homes, communities, and environments. For example, social prescribing is a system of collaborative referral and prescription that incorporates social models of support in local communities, such as peer-support groups. It provides patients with non-medical support, complementing care from a healthcare professional. It acknowledges that people should be at the centre of their health and supports them in accessing opportunities in their communities to live a healthy lifestyle, including physical activity, learning new skills, and finding new social connections.

Relationships built on trust are central to social movements. In the absence of formal hierarchies or written obligations, voluntary commitment to movements can only be built through relationships. Nesta’s work on People Powered Health[42] has emphasised the importance of relationships across networks of citizens, the voluntary, community and social enterprise sector and the formal health and care system.

Creating a People Powered Health Movement

Nesta's Health Lab believes the answer to the challenges facing the health and care system lies in creating a health system that is for people, by people and with people. This means providing healthcare when people need it, enabling them to manage health in their everyday life, and connecting them into networks for peer support. Nesta argues that this approach to health will require new relationships, networks and knowledge powered by digital technologies. The core principles of People Powered Health are:

- **People**: citizens living well with health conditions in their everyday life, at the centre of their health and care decision-making and connected to others in networks of support.
- **Powered**: people working together as partners with a motivated workforce and in ways that enable them to have more control over their own health.
- **Health**: creating behaviours and social contexts that improve health, and recognising the social (as well as clinical) dimensions of health and wellbeing.

Empowering and collaborative relationships are central to a People Powered Health system. For example, collaborative clinical consultations focus on what's most important to the person with a health condition and peer-support networks provide emotional and practical support between people with shared experiences and concerns.

Nesta is also developing a method that improves relationships between professionals, with the Rapid Results Institute. People Powered Results is a structured innovation method that uses 100-day sprints to help unlock the expertise and passion of leaders, frontline professionals and service users, and to accelerate change and innovation in complex systems.

Orbits

Movements often operate at the margins or 'fringes' of society, orbiting mainstream institutions and practices and writing their own rules. The meaning of the word 'orbit' in this context, comes from Gordon MacKenzie, who describes the need to 'orbit the hairball' to succeed in the corporate world:

"A hairball is an entangled pattern of behavior. It's bureaucracy, which doesn't allow much space for original thinking and creativity. It's the corporate tendency to rely on past policies, decisions, and processes as a formula for future success. All of this creates a Gordian knot of corporate normalcy — an entanglement that grows over time. As its mass increases, so does its gravitational pull. And what does gravity do? It drags things down. But hairballs can be effective. They provide a necessary stability. It's not the job of the hairball to be vibrant, alive, and creative."[43]

As proponents of new and transformative ideas, social movements tend to 'orbit' the NHS. Orbiting does not mean complete detachment. It means finding creativity, originality, and autonomy while following established norms and potentially benefiting from the resources and scale of institutions. Mark Swift is an example of an 'orbiter' who left his job at the NHS to found Wellbeing Enterprises.

Wellbeing Enterprises CIC[44]

While working for the NHS in 2005, Mark Swift noticed the need for even more robust evidence around mental health programmes. He decided to explore a model of health which would integrate the insight of community members into a social model of health. He teamed up with a few other passionate people to explore a model they would later call 'Wellbeing Enterprises CIC:'

"We noticed people had a lot of the answers to their health problems; and, that there were sparkly-eyed people willing to help."

Mark Swift, Founder and CEO, Wellbeing Enterprises CIC

In the early days of Wellbeing Enterprises, Mark describes it as a 'coalition of the willing,' a group of passionate people fighting for a better community. There were no boundaries or exclusions as to who could join. Everybody was welcome and had a contribution to make. And, most importantly, Wellbeing Enterprises was accountable to the community.

Wellbeing Enterprises CIC is now an award-winning social enterprise with a mission to empower happier, healthier, and longer lives in Halton and surrounding areas. It has a presence in all 17 GP practices in Halton funded by Halton CCG. They link people, through GPs and other health professionals, to wider community resources, a social prescribing programme, community resilience training (including an Ignite for Life! programme which teaches people how to use laughter and music to overcome adversity), community navigation, volunteering, peer support and asset building. The culture is one of experimentation where people are encouraged to think creatively and constantly try new things through social action. They find innovative ways to spread their reach, including training hairdressers to spot depression and stand-up comedians to talk about resilience!

"Wellbeing is for people who want to challenge things. We were on the periphery of the system innovating. Now, it feels like we've moved back into the centre and are developing our next set of lofty goals. Organisations like ours are pushing the boundaries."

Waves

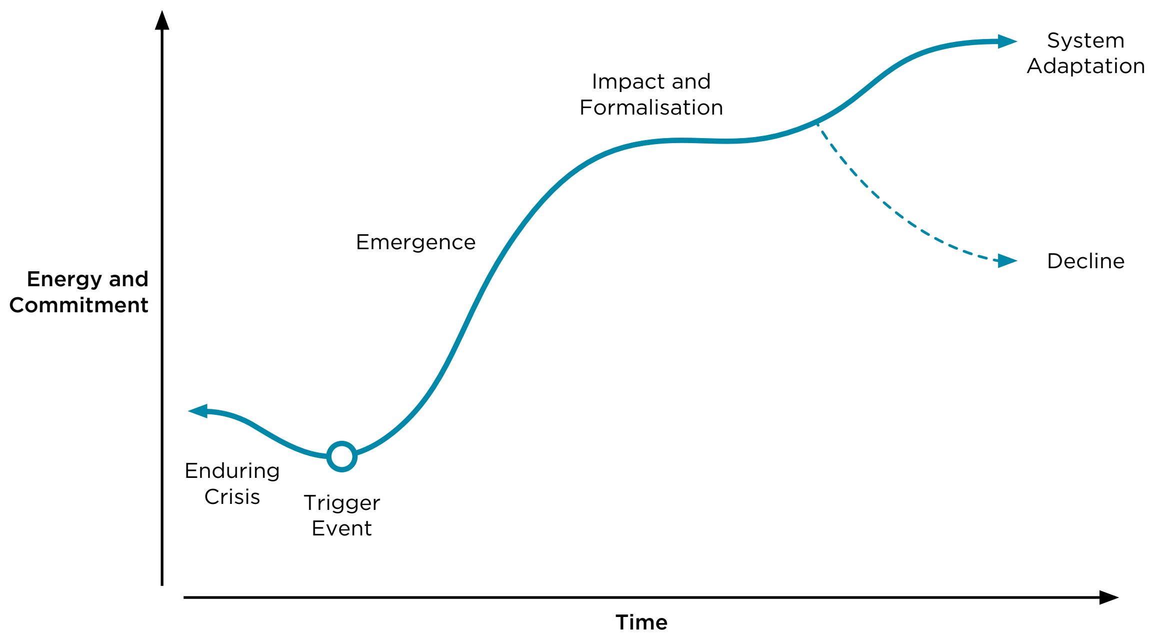
Most social movements go through 'waves' characterised by a set of phases: Enduring Crisis, Emergence, Impact and Formalisation, and System Adaptation or Decline.[45] These phases are depicted and described in further detail below.

During the Enduring Crisis phase, grievances intensify and the urgency for change builds. A 'Trigger Event' like a campaign or protest often inspire a movement to emerge. Emergence happens when members start mobilising, committing resources, and building a collective identity. Leaders refine movement ideology and devise strategies and tactics to achieve desired goals. During Impact and Formalisation, collective action is taking place. At this point, movements might create organisations (SMOs) to support movement activities. In the end, a movement either gets integrated into the system or declines. A movement might Decline if authorities try to undermine or destroy it, if movement leaders shift their focus, if it runs out of resources or loses cohesiveness through factionalism.

It is worth noting: not all movements follow this trajectory - some skip phases and others define their own. Some movements achieves their aims swiftly; others persist for decades going through multiple 'waves', intensifying when collective action becomes opportunistic, or, adapting

to new successes and aims. For example, the feminist movement has been going on for decades and each 'wave' has built on the previous - it has continued to thrive after women achieved the vote, were admitted to university, and became heads of state. The battleground changes, but the fight continues.

The social movement wave



Experiments

Social movements experiment with alternative solutions in spaces outside formal institutions. As agile entities, they can quickly pivot and redirect their activities in response to feedback. Furthermore, social movements often operate under extreme resource constraints, rarely having access to the resources that defenders of the status quo do. In this way, they can be a powerful source of cost-effective or frugal innovations.

The synergistic relationship between frugal innovation and social movements

Frugal innovation, the ability to do more with less and for many people, is a topic gaining increased attention within healthcare.[46] Frugal innovation is a practice at play in movements, where leaders and members rely on their creative ingenuity to develop effective strategies that meet resource constraints and reach large numbers of people.

Social movements also support the creation of markets by increasing awareness of a product, service, or approach. Coalitions of people - academics, foundations, and global policy - are promoting market creation around frugal innovations that are meeting the needs of the underserved. Reverse innovation is another trend taking place in healthcare which represents the learning from, or diffusion of, innovation from low-income countries where those innovations have been developed and potentially scaled.[47] The trend is supporting the market for frugal innovations, representing the potential of frugal innovations to be translated and adapted to the needs and settings of developed countries searching for lower cost and sustainable alternatives.

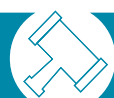
Rages and Roars

Movement members are incredibly passionate about the issues they care about. They participate in activities to raise awareness, visibility and urgency. Putting pressure on institutions often requires visible actions that command a response, including protests, sit-ins, and social media campaigns. For example, AIDS advocacy group ACT UP engaged in taboo-defying public action, promoting powerful slogans such as 'drugs into bodies', to pressure action around AIDS.

Advocacy to raise the urgency and pressure for action around AIDS

The 1980s saw an explosive growth in cases of AIDs, primarily in gay men, with a mounting death toll and silence from authority figures. By the time US President Reagan first mentioned AIDS publicly in 1985, over 36,000 people had been diagnosed and 20,000 had died. At a Gay Men's Health Crisis meeting, Larry Kramer, frustrated by the slow pace of change, stood up to tell attendees that two-thirds of them would die of AIDS within five years and asked them to join a new group devoted to political action, called ACT UP. Three hundred people came to the first meeting.

Over time, the group mobilised hundreds of members from the New York LGBT community around the slogan 'drugs into bodies,' and 'silence = death' setting out a strategic roadmap of taboo-defying public action, challenges to the regulatory system, and targeting pharmaceutical companies controlling prices and access to drugs. Activists wore business suits to blend in as they entered the New York Stock Exchange, only to chain themselves to the VIP balcony and unfurl a banner reading 'SELL WELLCOME' referring to Burroughs Wellcome, the pharmaceutical sponsor of the AIDS drug AZT priced at $10,000 per patient per year. Within days, the price lowered to $6,400 per patient per year.



Self-governs

"It's about people coming together to say what can we do to make a healthy community... It's not something you can commission or order."

Catherine Wilton, Director Coalition for Collaborative Care (C4CC)

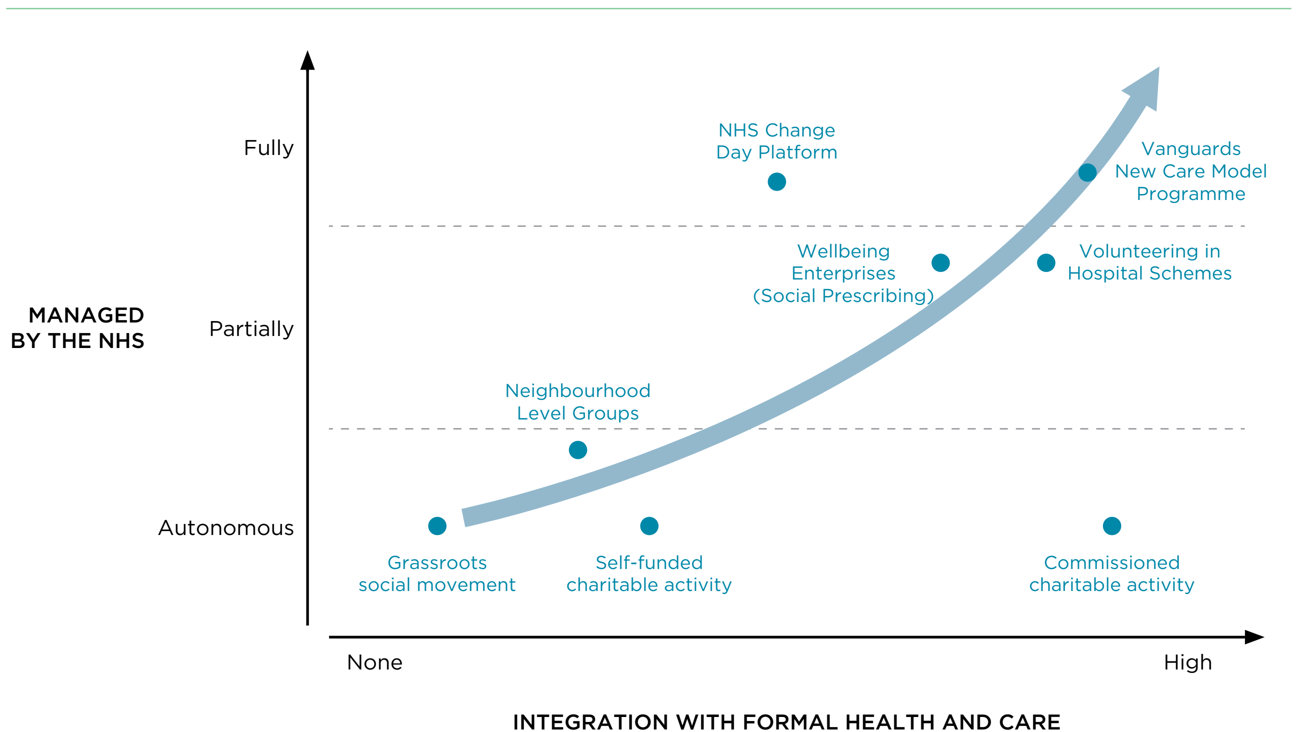
Social movements govern their own activities. The autonomy gives them the freedom and flexibility to act without adherence to bureaucracy - to decide who to recruit, how to control resources, and what actions to pursue. As social movements grow and formalise, they often create structures or spawn organisations to run specific functions of the movement or to achieve higher levels of coordination and organisation overall. For example, the EEA (European Environment Agency) was formed in the context of the environmental movement to provide independent environmental information to people shaping environmental policy and the public at large.

Due to this autonomy, the NHS cannot commission or manage social movements. However, the NHS could support the integration of movements into the NHS, health and care services or society at large. Over time, a social movement can, for example, become a sustained part of the NHS through the process of 'institutionalisation'. A movement institutionalises when it embeds

some change (e.g. service, solution, belief, pattern of behaviour, norm) into an organisation, social system or society at large. One path is illustrated below.

Informal grassroots groups progress towards greater formalisation and institutionalisation, potentially spawning an organisation to support its scale. Some organisations will 'dock' into formal NHS services by sharing management responsibilities (e.g. Wellbeing Enterprise's Social Prescribing programme), others will remain more autonomous. Still others might form and run groups or departments within the NHS organisational structure. Movements aimed at changing cultural and political norms and institutions might follow a different trajectory to institutionalisation and resist formalisation and incorporation. Further work is needed to map the different trajectories to institutionalisation, diffusion and scale; for initial discussion, the following diagram plots some illustrative examples along one path.

Path to institutionalisation



The elements of a social movement

Every movement sits within a wider context of social, political, economic, cultural, and environmental issues. Within that context, each movement utilises several elements, including frames, strategies, spaces, pathways, and encounters.[48]

Frames	Framing involves deciding which issues and goals a movement will focus on and how to communicate those issues to engage important members.	Identifying grievances and root causes, engaging in debates and coming to a consensus on movement goals. It also involves crafting external communication to engage new members.
Strategy and tactics	Movements utilise strategies and tactics to attempt to reach their goals.	Direct action such as protests or boycotts, publicity campaigns, education programmes.
Spaces	The physical or digital spaces in which movement activity happens.	Public meetings in town halls, discussions over social media or forums like PatientsLikeMe.
Pathways	The routes to solving the issues set out in the frames.	Setting up a clinical trial, investing in the development of a new product or service, disseminating a new treatment, creating a new policy.
Encounters	Interactions movements have with the institutions or systems they are trying to change or resist change in.	Meetings between staff and management at the picket line of a protest, or every appointment someone with a contested disease has with clinicians.

Framing the issue: Through frames, movements articulate and communicate their collective struggles.[49] Framing is an art, where issues are re-stated often using different arguments and premises to influence how people react to them. They result from a lively debate about which critiques of mainstream institutions and alternative visions will be at the centre of a movement's aims. Frames recruit and attract movement members as well as influencers and adopters. Most movements have multiple frames which can be a source of flexibility in advancing the movement in different directions. As movements develop, frames evolve depending on the opportunities that become available for movement advancement.

Framing the problem

For a parent with a child suffering from a rare genetic disorder, their immediate problems may be lack of information, confusing care pathways, difficulty getting a diagnosis, or a lack of treatments and cures.

Despite the 7000 rare diseases collectively affecting 3.5 million people in the UK, only 400 of these conditions have treatments.[50] This is because rare diseases are not attractive to pharmaceutical companies investing in developing new drugs. Less funding makes it harder for researchers to focus on rare conditions, and leaves patients with little hope of ever receiving treatment.

For Findacure,[51] a charity working with rare disease communities, a vital part of improving care is working on the way rare diseases are perceived, and the environment in which care and research is carried out. Findacure works to reframe rare genetic diseases as fundamental diseases and pushes researchers to treasure our exceptions, describing genetic disorders as gateways to understanding common conditions and human physiology. This repositions genetic disorders as valuable and worthy of research rather than as inconveniences, or as unprofitable niche markets. They work to empower the rare disease patient communities so they can be powerful partners for research and are setting up a non-profit drug development programme to motivate more research into these overlooked conditions.

Devising strategies and tactics: Strategies open up spaces for social movement activity. Below are a collection of strategies and tactics used by social movements to achieve their aims:

Strategies and tactics used by social movements

- **Protests** bring attention to one specific issue, often at a local level. Examples of protests include riots, sit-ins, and strike action.
- **Campaigns** are utilised to achieve very specific goals within a social movement. Examples include publicity, marketing, and political campaigns; increasingly campaigns use digital platforms including social media, such as the #HelloMyNameIs and #iwill campaigns. Social media campaigns have also been used in recent NHS industrial disputes, alongside more traditional media and out-reach.
- **Social networks** can be an integral part of social movements, assisting the spread of a movement, aiding communication between members, raising awareness, and supporting distributed leadership through online influencers.
- **Advocacy or activism**: Activists challenge systems from the outside, whereas advocates aim to change systems from within. Social movements can utilise both approaches.
- **Industrial disputes** are conflicts between employer and employees over specific disagreements, resulting in strikes, picketing, or other forms of protest. They can be part of larger movements for change, such as worker rights or labour movements or anti-privatisation movements.
- **Nonprofit or civil society organisations**: Organisations can launch movements as well as support and advocate on behalf of movements. Movements can also evolve into organisations.
- **Political parties** have regular access to political power and influence. Movements might forge relationships with political parties who can influence political leaders or can also turn into political parties (e.g. the worker rights movement leading to the Labour party in the UK).

Establishing spaces for movement activity: Spaces are the physical and virtual spaces social movements rely on to coordinate and conduct their activities. They might include municipal buildings, neighbourhood and community venues, co-working spaces, research institutes, or online social networks. Strategies and tactics are often aimed at helping social movements gain access to spaces.

Pathways for action: For any given issue, there are a multitude of potential approaches. Pathways represent the approaches social movements decide to pursue. Pathways chosen are often based on opportunities made available to movements through relationships, a given set of resources, or other strategic opportunities. Pathways which reinforce existing power structures or institutional priorities often gain considerable momentum. Enduring pressure to change from social movements groups can enable new types of power structures and priorities to arise.

The social prescribing movement

"I found I was being asked to give anti-depressants in situations where it was obvious that they weren't going to make anything any better. For some groups of patients, the problem was that they were long term unemployed, or couldn't read – or that their housing was making them sick, or they were in debt or dealing with some other crushing social situation which they were unable to escape from."[52]

Social prescribing, provides patients with non-medical support, complementing support from a healthcare professional. It ensures that people are at the centre of their health and wellbeing and the decision-making around that. It identifies what is important to the person, wider factors that are affecting their health (such as debt) and what support they need to improve their health and wellbeing. The person is then actively supported to access opportunities in their communities to live a healthier lifestyle, including physical activity, learning new skills, and finding new social connections, as well as services and support to address underlying issues such as housing.

Encounters with institutions: Encounters are where social movements meet mainstream institutions and systems. They are the subject of the next chapter.

How movements propagate and scale

"We see social movements as communities. They are small by nature. At Altogether Better, we've learned that if we can work in GP practices, we start there. Then, we can link them together into a hub and spoke model and go national."

Alyson McGregor, Director, Altogether Better

To fully understand movements, we must look at how they grow and expand across society. Movements spread across two dimensions: actions and ideologies. In action-oriented diffusion, movement strategies and tactics are spread to other sites so that people in other locations can adapt and replicate them with similar effects. In ideological diffusion, movements spread their ideologies and the frames defining the issues, goals, and aspirations they are fighting for. In both cases, movement propagation and scale is highly dependent on relationships, including interpersonal connections and informal networks.[53]

Spreading the peer support movement

Peer support involves people sharing knowledge, experience or practical help with each other. It can be facilitated by face-to-face interactions between individuals but also through online social networks, through phone calls and community meetings. People around the world with specific problems are connecting and helping each other without asking a professional. The groups they form are often creating bridges between healthcare organisations and community-based organisations. It is a very vibrant model and one which can reduce pressure on NHS services. Nesta compiled information from 1,000 studies to make the case for peer support to organisations and commissioners and concluding *"Peer support is worth investing in."*[54]

As broad, diffused and disseminated as peer-support programmes are, they can be siloed. Programmes and networks for people with specific conditions (e.g., liver disease) are not always aware of each other and so do not share findings, approaches or resources. Peer-support experts and leaders, are working to help make these groups aware of each other so that peer support becomes a more coherent movement in the eyes of health system leaders.[55]

Social movement leadership

"Research shows that just being a mobiliser doesn't create a long-term sustainable movement. It's about developing people and leaders that can organise and change things."

Helen Bevan, Chief Transformation Officer, Horizons Group, NHS England

Understanding the how of social movement work can only be understood through the lens of relational leadership. Relational leadership builds people's ability to act strategically in combination with others by focusing on their skills and confidence to do so. Effective social movement leaders typically possess a unique set of capacities, and, they must be able to develop them in others.[56]

The five primary capacities of effective social movement leaders

"The role of leadership in social movements goes well beyond that of the stereotypical charismatic public persona with whom they are often identified."

Marshall Ganz, Senior Lecturer in Public Policy, Harvard Kennedy School of Government

1. **Forging new relationships**: Relationships are central to social movements as they are the building blocks of cohesion and collaborative action. The movement also scales and grows through relationships as existing members are encouraged to recruit and train new members.
2. **Framing issues to ensure broad commitment**: Social movement leaders must be able to frame issues in ways that speak to the emotions and values of people they are trying to recruit or influence. In Helen Bevan's recent work on 'social movement thinking,' framing was found to be one of the most important aspects to change leaders.
3. **Devising strategies**: Given that social movements are emergent, strategy building is an ongoing creative process of translating resources into collective action, navigating ambiguity and adapting to new conditions. Leaders who build an open and entrepreneurial spirit across the movement see members contributing ideas for strategies and tactics.
4. **Catalysing action**: Leaders must know how to mobilise and deploy resources in ways that translate strategy into action. Commitments from movement members - time, skills, and effort - are essential to collective action. One of the most critical capacities of a social movement leader is managing both the formal and informal aspects of movements - the often loose, informal structure of its membership as well as the more formal network of leaders requiring access to timely information to organise and implement movement activities.

5. **Developing others**: Recently, Wellesley professor Hahrie Han investigated what makes activist organisations successful. She found three kinds of activists: the lone wolf, the mobiliser, and the organiser. The lone wolf is the charismatic leader with good intentions and excellent skill but operates in isolation. Mobilisers are good at encouraging people to get out and take action. Organisers collaborate with others and develop other people's capacity to lead change for themselves. The research shows that mobilisers don't create a long-term sustainable movement, organisers do.[57]

"Organising develops the capacity of people to act on their own behalf ... As circumscribed functions, advocacy and mobilisation are essential."[58]

Kathryn Perera, visiting fellow at the Ash Center for Democratic Governance and Innovation at Harvard

6. Productively engaging with movements

> *"The government needs to be very mindful of how its role in this space will require new models of how it does things."*

Edwin B. Fisher, PhD, Global Director of Peers for Progress

There are inherent challenges in established organisations like the NHS working alongside more emergent practice like social movements. Challenges arise from their very different and sometimes conflicting priorities, structures, decision-making processes and communication styles. Please see Annex II for a comparison of the worlds of social movements and healthcare institutions.

A relatively rigid organisational structure is common across healthcare systems for good reason; it facilitates efficiencies in management, safety in care provision, complex decision-making, and the careful development of biomedical knowledge. However, processes can become bureaucratic, slowing action and response times as well as stifling more disruptive and transformative innovation. The interests of the organisation often end up being prioritised which can lead to a failure to take advantage of the human ingenuity, talents, and skills of the workforce as well as to innovate outside immediate priorities.[59] Yet, the scale of institutions can help movements bring their ideas into the mainstream.

Social movements arise informally to address issues unsolved by formal groups. They interrogate the strengths and weaknesses of established practice and are often disruptive in their stance; experimenting with alternate approaches and generating knowledge highly relevant to policymaking.[60] Operating outside institutions, or, where the rules, regulations, and priorities are relatively relaxed, movements can better venture into uncharted territory. They value the community's needs over building knowledge for posterity[61] and often create more culturally appropriate solutions.[62]

Discussing social movements in the context of the NHS surfaces can be described as a 'Healthy Tension'.

How can the NHS, social movements and health and care organisations engage with each other most productively?

The scale and structure of the NHS makes it challenging for it to be highly responsive and adaptive to the dynamic nature of movements. It is difficult to design structures for social movements to 'dock into' health services without them collapsing under the burden of bureaucracy. Forced conformity can distort or destroy radical ideas, or have their successes rendered invisible under the scrutiny of existing metrics. At the same time, engagement needs to be meaningful for formal institutions, which are already under pressure and have limited resources, as well as for social movement groups which have the agility and momentum to push change and innovation.

Efforts to draw effectively from both the resources, stability and scale of institutions as well as the dynamism, agility and resilience of movements, will need to be co-produced, transparent and long-standing. This section sets out our initial thinking on how the NHS might engage with social movements, including five thematic areas of work and tangible proposed next steps.

1. Experiment with new forms of engagement between the NHS and social movements

"If we're trying to change the health system, the tension between movements and institutions has to exist. It's not about less hierarchy and more movement."

Helen Bevan, Chief Transformation Officer, Horizons Group, NHS England

A tension like this one creates a space for innovative forms of engagement to emerge which respect the unique characteristics of each group. Creating forms of engagement that work for both institutions and movements is a messy and important area and one which has not yet been fully explored in the context of the NHS. The Health as a Social Movement programme is one experiment in engaging with and supporting mobilised communities and needs to be followed up with further experimentation and practice in this field. Below are four aspects of engagement which demand further work to enable the value of health social movements to be more fully realised.

Identifying and engaging on shared priorities

"Historically, governments have been conspicuously unsuccessful at initiating social movements."[63]

The NHS can't initiate or manage social movements to achieve certain ends. However, it can create the conditions to nurture them and to engage productively with them, especially when both groups are working towards shared priorities or purposes. This will require innovation to create new ways for movements and institutions to identify and work on shared priorities. This work should draw on the experience of existing practice including NHS Change Day and NHS Citizen which encourage staff and citizens to voice and act on priorities they feel are important.

Developing an appropriate decision-making infrastructure

This agenda requires further development of the decision-making infrastructure so that it underpins effective engagement between the NHS and social movement groups. Decision-making should consider issues such as how to surface and address grievances, being clear about constraints and boundaries, negotiating solutions, and developing pathways at different stages of a social movement's trajectory and potential engagement with the NHS.

"The NHS gets a budget it has to live within, and that won't be congruent with giving all the care that might appear reasonable. That needs to be on the table in discussions about the role of the health service and the wide range of other groups and other organisations that influence population health."

Dr. Edwin B. Fisher, Global Director, Peers for Progresss

Encouraging communication between formal and informal groups

Effective communication is a critical part of a productive relationship between the NHS and social movements. As encounters between social movements and the NHS continue, we will witness complex negotiations between these two groups. Effective communication and engagement will require a deeper understanding of the goals, ways of working and constraints on both sides. This can be supported through recruiting for specific skills and attributes, skills building, actively supporting new forms of leadership and creating a culture of openness and exploration. Creating ways of observing, capturing and reflecting on these encounters will also serve as insight into better navigating them.

"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."

Geoff Mulgan, Chief Executive, Nesta

The linguistic work of Altogether Better[64]

Altogether Better is an award-winning NHS national network organisation bringing citizens and services together in productive conversations to do things that matter. They have worked with more than 24,000 citizens who gift their time to make a difference to the health and wellbeing of people in their community and to the services they work alongside. It is a collective, asset-based approach, where citizens are invited to be partners in co-producing services that meet the non-fixable, non-medical challenges the NHS faces of supporting people who are isolated, lonely and struggle to manage their long-term conditions.

In delivering this work Altogether Better came to understand the very real challenges of working in what they describe as 'liminal space' - the space between the formal institutional world of the NHS characterised by roles, qualifications, processes, pathways and systems and the informal 'lifeworld' of citizens characterised by relationships, stories, human interaction and emergence. Director Alyson McGregor describes:

"We understood that the conversation and the relationships between citizens (Practice Health Champions) and staff were key and wanted to understand why the work was good in some places and not in others. So we commissioned a linguistic analysis of the conversations between champions and staff. The analysis provided us with an understanding that people occupy either one world view or the other. The work we do at Altogether Better is to bring citizens and services together in the liminal space between the two worlds. This liminal space, can be best understood if you think about the beach. The beach lies between the land and the sea, it is different from both the land and the sea – and there are norms and ways of being on the beach that we all understand and follow. Just like the beach, liminal space is an exciting place to be, full of possibilities, but as normal rules are suspended in this space, we need to find different, fit for purpose norms and ways of being that allow the work to flourish."

Promoting facilitator leadership and inclusive engagement

Developing models of engagement between social, political and cultural institutions and social movements must be an ongoing process of collaboration and experimentation with social movement groups. In other words, it should not be something done by, or dominated by, statutory institutions alone. Furthermore, facilitative leaders with a passion for this agenda and the ability to navigate formal and informal realms should be selected to grow this work further.

Ensuring accountability and responsibility

Accountability and responsibility are essential to achieving sustainable transformation through movements. Movement leaders must be accountable to their members and the growth of a movement requires responsibility and follow-through from many people. Accountability and responsibility are also critical in health care in the context of patient safety and clinical risk. Exploring how these concepts differ both in the context of movements as well as between movements and established practice is an important area of work.

2. Better recognise the value of UK health social movements and what they need to flourish

Movements bring a broad range of value to society. They mobilise communities, build trusted and consensual relationships, bring new forms of democratic engagement, and generate knowledge highly relevant to policymaking. As knowledge builders, they might generate knowledge that is ethnographic, illuminating unmet needs, or, instrumental, describing what is required to implement solutions. Annex II gives an overview of their roles. Identifying, valuing and working out how to utilise the more intangible assets of movements is a challenge but a worthy pursuit.

Actively engaging with social movements requires empathy for their origins, grievances, motivations, goals, and challenges. Successful engagement will always, therefore, be more than a narrow 'technical exercise'. It will also be important to understand the particular perspective and needs of those who are most active in movements. Thus far, we have learned that movement leaders desire connections to other leaders, entrepreneurship education, assistance with building awareness and achieving scale, greater investment and access to expertise. A deeper understanding of the needs of leaders and movements is critical.

Movements addressing deeply complex issues often go through multiple 'waves', with each 'wave' leveraging the success of the previous to facilitate greater progress. Therefore, understanding social movements in the context of their larger history is also important so that the insight and learning gained from past efforts can be acknowledged as well as unlocking intangible assets, such as consensual relationships and networks, which could facilitate collaborative action of all kinds.

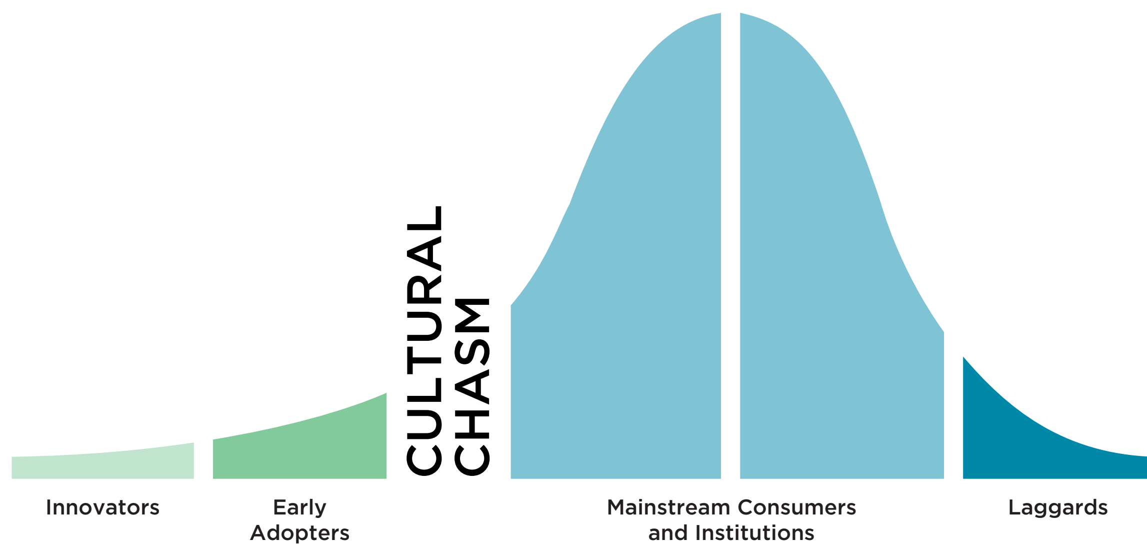
3. Support the scaling of social movements and especially to 'cross the cultural chasm' between early adoption and mainstream practice

"Scaled social movements are mission critical to the future of the NHS"

Simon Stevens, Chief Executive, NHS England

When social movements spread across a population, they face a challenge in reaching critical mass. Two cultural strategists, Douglas Holt and Douglas Cameron, deem this challenge, *"crossing the cultural chasm."*[65] They compare it to the challenge that technology companies face in reaching a mainstream market, which management and marketing expert Geoffrey Moore calls *"crossing the chasm."*[66] A new technology innovation is usually adopted fairly quickly and easily by fellow innovators and early adopters but can fall into a 'chasm', failing to reach adopters in the mainstream market.

Crossing the cutural chasm: the social movement adoption lifecycle



Similarly, a social movement is usually adopted fairly quickly by members who believe in the movement's ideologies and goals. However, these strategies often fail to convince the people and influencers required to implement social movement goals. The movement might threaten their personal interests, clash with those of their organisations, or fail to reach them entirely. Therefore, a different set of strategies is often needed to reach these people and 'cross the cultural chasm.' Borrowing methods from management and marketing might aid movements in reaching different types of audiences. Large institutions like the NHS could provide insight into why social movements are not reaching key stakeholders or implementers and help them diffuse or scale.

MIND[67]

The mental health charity, Mind, uses a federated model to align its national and local efforts. National Mind develops strategy, engages with policymakers, and runs large-scale fundraising campaigns. Every local Mind chapter operates autonomously, involving service users in decision-making and tailoring services to local communities. The services focus on the social determinants of health, not medical or professionally therapeutic interventions, including peer support, access to housing, employment, emergency grants, advice on managing budgets and stress, and social opportunities for vulnerable or lonely community members.

The Time To Change campaign, created by Mind, aims to end the stigma and discrimination faced by people who experience mental health problems. Over time, this campaign has gained its own momentum and done a great deal to change social attitudes towards mental health. For example, since Time to Change began in 2007, there has been an overall 8.3 per cent improvement in public attitudes to people with mental health problems.

4. Invest in a deeper understanding of movement outcomes and evaluation methods

From a practical point of view, social movements often struggle with achieving greater buy-in, which would enable resources for growth and scale, due to the challenge of gathering, monitoring and evaluating qualitative impact. Traditional evaluation methods, aimed at measuring direct outcomes around 'what works,' are not always relevant to measuring the success of social movements which are emergent, participatory and dynamic. Existing evaluation methods utilised in health and care can hinder support for experimenting with new solutions and approaches. Furthermore, the standards for generating evidence can be prohibitively expensive and burdensome for small and informal groups. More appropriate approaches are needed to measure the value and impact of social movements in health.

Few studies have been conducted on the effectiveness of social movements and how they achieve their aims. Investigators have favoured looking at their origins and trajectories, looking less at their impact on social, environmental and political conditions. A richer understanding of movement outcomes in the context of health in the UK would contribute to an appropriate engagement between movements and institutions more suitable to the UK context.

Furthermore, the consequences of social movements are often different from what was intended. Therefore, it would be important to compare originally intended outcomes with final outcomes.

Pinkwashing

The pink ribbon has become an internationally recognised symbol of support for women with breast cancer. Thousands of themed 'pink ribbon' products are produced and sold every year. In 2005, 3M donated $300,000 to research from pink Post-it sales. Yet, companies have used the ribbon inappropriately (pinkwashing) to sell products with minimal donations. Campaigns like Think Before You Pink encourage greater consumer awareness and transparency of funds.

7. Proposed future work

This section lays out a summary of proposed future work based on themes in the previous section. We suggest each of the next steps be embedded with the context of existing programmes or built out as new programmes within broader work on social movements in health.

1. **Experiment with new forms of engagement between the NHS and social movements**
   - **Build programmes which engage with movements originating or operating outside the health and care system**, such as mid-stage movements with some proposed integration with NHS services or early-stage grassroots movements by community leaders that are not connected, integrated, or managed into NHS services.
   - **Further develop models for engagement and decision-making** between informal movements and formal institutions. These mechanisms should address social movement grievances, visions and priorities, and be co-produced[68] with movements. This should draw on the experiences of existing models, including NHS Change Day, NHS Citizen and co-production.
   - **Link work with social movements to a broader NHS learning agenda**. Integrate learning into ongoing NHS improvement and cultural transformation efforts as well as professional training and leadership development both inside and outside of the NHS.
   - **Create digital and non-digital communication structures** facilitating informal and distributed discourse with movements, effectively feeding into more formal communication, and aiding in movement scale. For example, the NHS might explore the viability of a platform (e.g. NHS Movements) where people could share the issues they are fighting for and tell their stories of impact.

2. **Understand, recognise and utilise the value of health social movements in the UK**
   - **Conduct qualitative research on what UK social movements need and want in terms of support**: Understanding the needs of leaders and members are equally important. Movements are as strong as their members and supporters who engage and commit resources.
   - **Recognise the transformative work of movement leaders** such as profiling their stories, or creating an NHS Movement Award.
   - **Provide resources for innovative movement activity** that aligns with NHS current and future priorities, on a 'no strings attached' basis.

3. **Support social movements to scale both inside and outside of the NHS, especially to 'cross the cultural chasm' between early adoption and mainstream practice**
   - **Devise strategies and methods** for 'crossing the cultural chasm', including understanding how to supplement, integrate and support movements to be effective (e.g. through on-going action learning sets).
   - **Examine successful and unsuccessful examples of movement diffusion and scale**. Why did some succeed or fail to 'cross the cultural chasm?'
   - **Explore how the NHS can facilitate** sharing of infrastructure and resources across movements as they grow, interact and scale.

4. **Invest in a deeper understanding of social movement outcomes and evaluation methods**
   - **Develop and pilot new movement evaluation approaches**, including adapting 'bottom-up' change evaluation methods that are congruent with movement behaviour, such as participatory evaluation methods or adaptive measurement methods.
   - **Qualitatively study UK movements in health** to refine the typology of movement outcomes. Scholars advise looking at the sequence of events giving rise to outcomes (versus causes).
   - **Build the evidence for social movements** through evidence of community-based approaches with relevant outcomes like community mobilisation or agency. This might require linking up information and data across programmes (e.g. through communities of practice).

The NHS has appointed three national partners: New Economics Foundation, Nesta and Royal Society of Arts to provide the overarching learning, development, support and evaluation for the Health as a Social Movement programme. Partners will continue to work together on supporting current efforts as well as exploring the next steps posed in this section.

8. Closing

The speed and scale of change affecting the health system has brought us to the point where profound change is recognised as necessary. At the same time, people are already working together with energy, imagination and empathy to drive changes in the healthcare system and wider society to improve their own, their loved ones, their communities' and neighbours' health.

If the NHS is to adapt and sustain, it needs to engage more deeply with the people it serves and be part of a shift in thinking about health which supports people in improving and protecting their health in ways that address what is important to them.

This will be both challenging and necessary. But the determination of people both within and outside of the formal health system to work for positive change is a tremendous resource. And perhaps the most powerful lesson to take from social movements is to resist fatalism.

Positive change is always possible.

Your experience, insight, response and involvement is important, please contact us at:
movements@nesta.org.uk

Annex I: Health as a Social Movement programme

Building on the agenda set out in the 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.

Working initially with six new care model vanguards across England, NHS England and partners will develop, test and spread effective ways of mobilising people in social movements that improve health and care outcomes and show a positive return on investment. This programme is also working with the wider vanguard network and beyond to support the development and spread of social movements in health and care.

By the end of the programme, vanguards will be able to:

1. Connect with communities, hear and act on their priorities for health and wellbeing.
2. Nurture volunteering, social action and an influential third sector to prevent long-term conditions, reduce social isolation and find ways for communities to support each other.
3. Improve community development skills for staff and communities.
4. Evaluate what works best in supporting communities across vanguard sites.
5. Build evidence for intelligent commissioning, which reduces system pressures.
6. Share learning across health and care on how to nurture social movements in health.

Six local vanguards will receive national support and funding:

Wellbeing Erewash aims to shift investment and energy 'upstream' to encourage thriving communities, where people feel confident and supported to choose healthier lifestyles, stay well, know how to get help and person-centred support when needed. Approaches include supporting time banking, building young people's resilience and asset-based community development work.'

The Royal Free Foundation Trust is an Acute Care Collaboration vanguard. As part of this, this project brings together Hillingdon, The Royal Brompton and Harefield, Moorfields and Imperial hospitals to work with the Healthy London Partnership on supporting staff health and wellbeing. This work focuses on the priorities of lower-paid staff, who have traditionally been less involved with health and wellbeing programmes.

Stockport Together Multi-Speciality Community Provider has partnered with neighbouring areas Oldham and Tameside to focus its health as a social movement work around themes of loneliness, food and arts. Working closely with community-led and third sector organisations, the programme builds on local work developed with Nesta to deliver people powered health approaches.

Great Manchester Cancer Vanguard wants to harness the energy of communities and the third sector to improve cancer prevention, recruiting 20,000 cancer champions and expert patients to promote healthy choices and early detection. They will explore the potential of digital technologies to support self-care, create and connect social networks for people affected by cancer.

Airedale and Partners' Enhanced Health in Care Homes aim to improve health, wellbeing and care and enable connections between care homes and the wider community through technology and rolling out telemedicine across 248 care homes. With the Alzheimer's Society, they will empower dementia friends, connect residents to local communities and support them to be involved in decisions about their health.

Better Care Together integrated primary and acute care system vanguard in Morecambe Bay will build on existing support where local residents have formed action groups to improve GP recruitment, created health promotion magazines; promoted pharmacy schemes; led health surveys and taught children how to use the NHS.

Annex II: An overview of health social movements and health and care systems

	Health social movements	Health and care systems
Protagonists	Local communities, patients, caregivers, activists, civil society organisations, social entrepreneurs, cooperatives, non-health social movements.	Hospitals, A&E, GP practices, hospices, care homes, government and public bodies, university and other research centres, entrepreneurs, industry, investors.
Priorities	Community social and cultural values, culturally appropriate solutions, wellbeing, inclusion, participation in decision-making.	Clinical outcomes, codified and biomedical knowledge, growth, sustainability, competitiveness, care provision.
Incentives and drivers	Community needs, voluntarism, cooperation, participation.	Patient safety, expert authority, reputation, market demand, statutory duties, regulation.
Assets and resources	Social capital, distributed leadership and networks, public finance, charitable and social business funds, grassroots ingenuity, local knowledge, voluntary and community sector expertise.	Public finance, corporate investment, venture capital, scientific and professional expertise and training, formal leadership and accountability, analytical and technical capacity.
Locations of activity	Local towns and neighbourhoods, community venues and projects, non-health social movements.	Formal healthcare settings, laboratories, R&D centres, boardrooms, ministries, markets.
Forms of knowledge and dissemination	Situated and tacit knowledge captured through knowledge commons, media and voluntary and community sector networks.	Scientific and technical knowledge captured through intellectual property, scientific journals, licensed technologies, policy and regulation.

Adapted from Smith et al., 2016 and Fressoli et al., 2014

Annex III: Additional resources

Some additional reading on social movements and social movements in health.

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