Social Movements for Health

What the programme taught us

Helen Bovey, Helen Carr, Nicola Stenberg
November 2020

nesta

Authors

Helen Bovey, Helen Carr, Nicola Stenberg – **Icarus**

About Nesta

Nesta is an innovation foundation. For us, innovation means turning bold ideas into reality and changing lives for the better. We use our expertise, skills and funding in areas where there are big challenges facing society. Nesta is based in the UK and supported by a financial endowment. We work with partners around the globe to bring bold ideas to life to change the world for good.

nesta

Social Movements for Health

What the programme taught us

nesta

Foreword

For more than ten years, Nesta has been researching, funding and championing 'people powered health', a vision of health created by people, with people, for people. Our Social Movements for Health programme grew out of conversations with the Dunhill Medical Trust. Together, we wanted to learn more about the journeys that social movements go on and the ways that funding organisations can support them. We hoped that we could help emerging movements build momentum and find ways to support one another, as part of a growing number of 'people-powered health' movements.

As we designed this programme, we hoped that we would be able to help each of the movements, and the people within them, build the skills, ambition, scope and reach they need to achieve their goals. Only time will really tell if we achieved this, but despite different starting points and experiences, they have all left the programme more united, clearer about their aims, and more confident about their ability to make progress.

As funders, we learnt a great deal about how we could be at our best in support of the social movements and we tried to capture this in a short report specifically about the funding of social movements. This report goes further looking at every aspect of the programme and offering insight into the way movements emerge and the elements that help and hinder their progress.

This short programme has taught us much about the ways in which social movements grow and develop. The passion, energy and commitment of the people involved in the programme was inspirational. We are indebted to Icarus for this thorough and comprehensive evaluation of the programme and the work that went into it. We are sure this will be helpful to Nesta, to the Dunhill Medical Trust and to other funders and organisations in the future.

**Damian Hebron and Sally Zlotowitz,
Programme Managers, The Social Movements for Health Programme, Nesta**

1

Introduction

1.1   About the programme

The Social Movements for Health Programme was initiated and funded by Nesta and Dunhill Medical Trust in response to emerging evidence about the potential of social movements to create positive change in health and health and social care and extending this theme of 'people powered health'. Building on two reports previously published by Nesta, *The Power of People in Movements for Health*[1] and *We Change the World: What can we learn from global social movements for health?*[2] the programme aimed to better understand the journey that social movements take as they grow. In particular, there was a desire to learn more about the forms of capacity-building, funding and support that can build social movements and enable them to bring about social change.

Defining social movements can be challenging: they have diverse visions, complex interconnected networks and widely varying methods to bring about change. They are, by nature, spontaneous and unpredictable, emerging from the bottom-up and represent the collective passion of people for change. One way to think about a social movement for health is when people;

"Come together to promote or resist change in the experience of health or the systems that shape it. They unite people around a common vision and they grow networks to amplify their message and challenge society, institutions and elites to think and act differently. Often they bubble up outside formal institutions, but they can also come from within."[3]

Health social movements seek to promote or resist change in the experience of health and the systems that shape it. Their impact on health and social care can take different forms:

- Bringing about changes in the experience and delivery of health care.
- Improving people's experiences of disease, disability or illness.
- Promoting healthy lifestyles.
- Addressing socio-economic and political determinants of health.
- Democratising the production and dissemination of knowledge.
- Changing cultural and societal norms.
- Proposing new health innovation and policy-making processes'.[1]

---

1. https://www.nesta.org.uk/report/health-as-a-social-movement-the-power-of-people-in-movements/
2. https://www.nesta.org.uk/report/we-change-the-world-what-can-we-learn-from-global-social-movements-for-healt
3. https://www.nesta.org.uk/project/social-movements-health/open-call/

1.2   The social movements

Seven groups were selected to be part of the programme, receiving funding and support over a 12-month period from April 2019-March 2020. They were all in the early stages of development, however, within this there was wide variation in leadership, purpose, structure, experience, geographic location and knowledge. The programme aimed to support emerging movements focused on issues that are typically under-resourced, under-developed or marginalised. All of the groups selected (or some could be conceived of as networks) aspired to use social movement building principles to grow and achieve their goals. However, not all of the groups neatly fit within the definition of a social movement as outlined above. Those not aligning with the criteria of a social movement were selected to be part of the programme because they had ambitions to become movements rather than just projects, networks or organisations. In addition, for some groups, the programme provided an opportunity for reflection and led to a decision that other forms of coalition building and social change would be the best way to pursue their ambitions, at least in the shorter term. Below is a brief outline of the seven groups. For the purpose of this paper, we shall refer to them as 'movements' whilst acknowledging the different stages the groups were at.

"We mobilise bi/gay and or trans men of African descent in the UK to work together to address shared challenges, create platforms for our voices, build networks to support our aspirations, and enable us to play a more active role in the communities of which we are part – 'we are the heroes we've been waiting for'."

BlackOutUK

"We are a resident-led social movement fighting for fairness in our city by demanding better health and quality of lives for the people in our community and challenging the health inequality experienced by people in East Brighton. Causewayed is encouraging residents to work together to bring opportunities to their area through supporting each other to develop local activities and events. These include improving access to fresh fruit and vegetables through cooking, eating and growing projects, holding music and science-based community events and supporting community-led groups to form around sports and physical activity."

Causewayed, East Brighton

"We are led by people who have lived experience of mental distress, many of whom have been bereaved by suicide, campaigning on the lack of investment in counselling services and reducing waiting times for a therapeutic intervention. The COVID-19 pandemic has exposed and entrenched the intensity and scale of inequalities, we are developing alliances and COVID-19 recovery plans in response to this".

Mental Health Rights Movement in Northern Ireland

"We are care workers demanding the professionalisation of care work including improved pay, training, regulation and support that reflects the skilled nature of care work and the mental and emotional demands of that work."

National Association of Care and Support Workers

"We are campaigning to ensure that people with learning disabilities are at the heart of decision making in all areas of society and life. The Self Advocacy Together movement brings together leading regional self advocacy hubs to coordinate efforts to campaign for the rights of people with learning disabilities."

Self Advocacy Together

"A broad coalition of service user groups and professional organisations of social workers and clinicians is connecting together to challenge traditional approaches to mental health. Our demand is for mental health investment and services to focus more on addressing social inequalities, social justice, social support and rights. Our aim is to create solidarity and support for change across different parts of the mental health system, driven by the perspectives of people using and needing services."

The Movement for Social Approaches in Mental Health

"We are medical students with an aim to integrate social prescribing into early clinician training and bring about medical education reforms across the UK."

Students for Social Prescribing

1.3   Programme overview

The programme funders and partners, Nesta and Dunhill Medical Trust, contributed in different ways to the programme. Nesta was the lead organisation, with overall responsibility for managing the programme and working alongside the social movements. This work was undertaken at Nesta by two Programme Managers each spending approximately three days per week on the programme, plus input from senior leadership, communications, finance and legal teams. Dunhill Medical Trust were involved in the selection and awarding of grantees and then met regularly with Nesta to reflect on progress and provide input as a 'critical friend' as well as attending events and training with the movements.

The programme provided three forms of support to the social movements; tailored funding, movement building support and connection to social movement peers.

I.   **Tailored funding** – Nesta worked with the social movements during the early stages of the programme to understand their vision and aspirations for growth and impact and agree broad objectives and milestones. Each movement was awarded a grant of between £20,000 and £50,000 for the one year period.

II. **Movement building support** – Social movements could access specialist support from people with extensive experience of campaigning and movement building, in areas such as framing, tactical development, network formation and engagement strategies (c. £8,000 per movement on this support.)

III. **Connection to social movement peers** – The programme created a community of peers across the social movements and provided opportunities for connecting with like-minded people facing similar opportunities and challenges, sharing ideas and exploring the scope for collaborative working. One key mechanism for this was via periodic cohort meetings attended by every social movement.

1.4 About this paper

This paper reflects on the learning from the Social Movements for Health programme. It considers how being part of the programme has helped social movements to grow their networks, spark new ideas and develop skills and tactics to enable them to bring about change. It provides insight into the impact of the different elements of the programme on building social movements and reflects on the outcomes for the groups taking part. Within the context of a 12-month programme, where the emphasis is on growing social movements that are in the early stages of their development, the programme did not aim to measure health or social care related impacts. Nevertheless, there are accounts of progress and success within the case studies that are presented within this paper. There is also a second and separate paper that reflects on lessons for funders supporting social movements.

It is worth noting that the final stages of the programme were significantly impacted by the COVID-19 pandemic. This dramatic change in context had implications for the approach to programme management and the work of the social movements. At the programme level, it was not possible to bring the social movements together for a final cohort meeting and some of the learning and insight activities were not completed as planned. Over this period, Nesta shifted its focus to providing extra resources and support to their partners and grantees to enable them to pivot and do what was needed as part of their response to the pandemic. In the case of this programme, this included both the availability of new funds and enhanced flexibility for the social movements to adapt their activities in response to COVID-19 and away from their agreed plans and funding milestones.

For the social movements, the pandemic has been both a catalyst for change and a disruptive force. It has brought into sharp focus some of the societal and institutional inequalities that the movements are working to challenge (Health Foundation, 2020[4], Nesta, 2020[5]). While for others, the change in context has meant that progress on strategic planning has been paused, campaigns have been rendered inappropriate and a loss of momentum became a risk. On a practical level, many of the individuals who are active within the social movements have been restricted in what they can do during the period of lockdown due to their own health conditions. Countering this has been an increase in the use of video-calling which has resulted in increased interactions, conversations and team building for some of the social movements. Responding to the current and changing social, political and economic environment has inevitably been a priority for some of the social movements. For example, the Black Lives Matter movement also had a significant impact during this period, raising awareness and accelerating action against racial injustice by individuals and institutions across the UK and internationally.

4. Health Foundation (2020). https://www.health.org.uk/sites/default/files/2020-05/Will%20COVID-19%20be%20a%20watershed%20moment%20for%20health%20inequalities.pdf

5. Nesta (2020). https://www.nesta.org.uk/blog/striving-more-inclusive-approach-public-health-research-and-innovation/

2

Research methodology

At the start of the programme, research consultants Icarus worked with the programme team to develop a research framework to guide the capture of learning. This focused on understanding the changes and outcomes for the social movements and for the individuals within them, as well as building knowledge about how funders can support the growth of social movements.

Table 1 below outlines the research methods. It should be noted that some of the research activities planned for the end of the programme could not go ahead due to COVID-19.

Table 1: Learning framework

Methodology	Purpose	When	Attendance/participation
Individual survey	To measure the impact of the programme on individual participants	Survey 1: June-July 2019	All 7 movements, 44 people in total
		Survey 2: March 2020	Survey did not go ahead due to COVID-19
Initial and final focus groups at cohort events	Capture learning about expectations movement-building, changes in health and wellbeing and contribution of programme	Round 1: April 2019	Key people from all 7 movements
		Round 2: March 2020	Cancelled due to COVID-19
Initial and final learning workshop	For movements to self-assess stage of movement building in each of the four areas, discuss contextual factors and aims in relation to the seven pillars of health	June-July 2019	Key people from all 7 movements
		March 2020	Key people from 4 social movements (other social movements were not available for interview due to COVID-19)
Observations and reflections captured at cohort events	To understand the impact of peer-support, learning activities and support from programme leaders	April 2019	All 7 movements
		July 2019	All 7 movements
		November 2019	All 7 movements
Social movement diary (written or audio/ video) followed by telephone interviews	Capture learning about movement-building, changes in health and wellbeing and contribution of programme	Sept 2019	Key people from all 7 movements
		May 2020	Key people from 4 social movements
Funder diary/ reflections and follow-up telephone discussion	To capture the learning for funders in supporting social movements	Sept 2019	2 Nesta staff and 1 DMT staff
		Nov 2019	2 Nesta staff
		Dec 2019	1 Nesta staff and 2 DMT staff
		Feb 2020	1 Nesta staff
		May 2020	3 Nesta staff and 2 DMT staff
Learning activity supplier interviews	To understand the experience of suppliers involved in the programme and their reflections on the programme and the movements with which they had worked.	May 2020	4 suppliers

3

Social movement building

3.1 Four areas of social movement building as a basis for programme design

The programme team identified four key areas of social movement building as a way of framing what the programme could offer and the work of the social movements over the duration of the Social Movements for Health programme. Based on Nesta's previous research on social movements and the issues and priorities expressed by the movements during the selection process, these four areas were: leadership and purpose; measuring impact; growing awareness and mobilising new people; and sustainability.

The social movements were encouraged to use these four areas to shape their plans for the 12 month programme. They were also a useful reference point for facilitating discussions about and measuring change within the social movements. The kinds of changes anticipated as a result of participation by the social movements in the programme were articulated by Icarus in a set of 'change statements' for each of the areas, drawing on insights from other research about movement building.[6] The four areas and corresponding statements are outlined in Table 2 below.

Table 2: The four areas of movement building and change statements used in the Social Movements for Health programme

Leadership and purpose	Sustainability
• We know why the social movement exists/what we are trying to change. • Messages about our social movement are reaching the right people. • Our strategy and tactics for the long term are clear. • We have enough resources to do what we want to do. • Our approach to decision making ensures that everyone has an opportunity to contribute to decisions about the work of our social movement	• Leadership comes from a number of different people in the movement. It is not dependent upon one or two individuals. • Across our social movement we have people who bring the kinds of attributes we need, such as: vision/credibility/ expertise/connections/ passion. • We are addressing any skill needs within our social movement • We are involving people who can make things happen. • We have a structure around our social movement that will help to ensure it continues its mission after this programme is over.
Growing awareness and mobilising new people	Measuring impact
• We ensure that people are aware of the issues we are seeking to challenge • We have tactics for involving people within our movement • We have tactics and strategies for challenging key people • We have tactics and strategies for making allies with key people	• We understand if our social movement is getting stronger • We know how to measure the impact of our social movement • We have the support and resources that we need to measure change and capture our learning

6. (GEO, 2013; Masters & Osborn, 2010; Pastor & Oritz, 2009). – details to be added

3.2 Were the 'four areas' a useful way to understand social movement building?

It is worth reflecting on whether these four areas of social movement building proved to be a useful tool in guiding the programme and in helping to understand the progress that the social movements were making.

Overall, they provided a good basis to understand, discuss and communicate different aspects of social movement growth. Social movements were able to align their growth priorities with the four areas and use the change statements to assess their stage of development. In summary, defining four areas of social movement building offered a number of advantages.

- **Prioritisation** – it enabled social movements to be clear about their movement building goals over the lifetime of the programme.

- **Reflection** – discussing and reviewing progress using the four areas provided an opportunity to track and reflect on achievements and sticking points.

- **Transformational thinking** – it helped to maintain a focus on the process of building a social movement. This contrasts with more conventional funding programmes where the focus is often on the achievement of an end result and an agreed set of outputs.

- **Shared understanding** – it provided a shared language between funder and social movement, enhancing communication about goals and the types of support needed to enable progress.

Learning from the programme also highlighted some limitations of this approach. Whilst three of the areas are distinct, 'sustainability' overlapped with the other areas, for example, developing a clear strategy for the long term (leadership and purpose) is closely linked to having a structure that will ensure the movement continues after the programme is over (sustainability).

Self and collective care was also not reflected in the four areas and yet it was highlighted as a necessary condition for growth. People recognised that the work they do as a member of a social movement can be emotionally challenging and that it places significant demands on people's time in addition to their work, caring and other responsibilities. Support structures that enable people (who are traditionally marginalised) to build, grow and shape a movement are necessary within this context.

This suggests that there is merit in identifying broad areas of change within social movement building programmes, however, it is important to clearly define and explicate the terms that are used.

Recommendations

1. Consolidate sustainability into the areas of leadership and purpose and growing awareness and mobilising new people.

2. Separate leadership and purpose into discrete movement building areas. Other models of social movement building such as Masters and Osborn (2010)[7] suggest 'leadership' and 'vision and ideas' are distinct in their five-part framework. Both elements are central to the development of the movement and require different skills and experience. Leadership within social movements is complex with both collective and individual leadership often in need of developing. Equally, development of a common narrative in the form of a vision that can inspire and connect people is key to the progress of a social movement. Therefore, two separate areas of 'Leadership' and 'Vision and Purpose' would facilitate better prioritisation, reflection and shared understanding when movement building.

3. A final recommendation would be to ensure that creating capacity for self- and collective care is included within the framework. This could sit within mobilising new people, with the recognition that in order to build and sustain a base of movement members, self and collective care is required to prevent burnout.

7. Masters and Osborn (2010) 'Social Movements and Philanthropy: How Foundations Can Support Movement Building'. The Foundation Review: Vol. 2: Iss. 2, Article 3.

4

Social movement outcomes

4.1 The social movement starting points

The diversity in the purpose, structure, leadership and stage of development of the seven social movements meant that each started from a unique position. Additionally, different political, cultural and societal factors affected each of the social movements. For example, some had the relative advantage of their cause being high up the current political agenda with policy makers and institutions displaying an appetite for change, while others strived to challenge issues with low political and cultural rhetoric. Some had relative advantages in terms of privileges afforded to them by their identities (such as their whiteness) whilst some movements had to face the challenges of intersecting oppression.

Despite these differences, the social movements shared some goals for their participation in the Social Movements for Health programme. Over half of the social movements wanted to focus on creating a structure that would ensure the movement is sustainable long term. In addition, all of the social movements were unconfident about measuring the impact of their movement, with just under half of them also choosing, at least initially, to focus on this as a priority area. One explanation of this could be that people recognise the importance of measuring impact for future funding, sustainability and movement development and that this, combined with the knowledge that they are least confident in this area, drives the desire to address it as a priority.

4.2 Change across the social movements

Over the course of the 12 months there have been significant developments for each of the social movements, with change being reported across three of the movement building areas. Consistent with the priorities identified by the movements at the start of the programme, most change happened in relation to sustainability and leadership and purpose.

Leadership and purpose outcomes

Development of vision and purpose

Time spent consolidating the purpose and aims of the social movement allowed groups to grow their strategy and tactics for the long term. Social movement members collectively discussed the structure and positioning of the movement and also engaged with external support to aid development of their vision and strategies.

⊗ For example...

In the early stages of the programme, the Movement for Social Approaches in Mental Health spent time clarifying their identity and purpose, working together to agree on a shared vision. This was important in allowing them to move forward and understand their approach as a social movement. *"It enabled us to agree on our methodology for influencing ongoing debates, our target audience, allies and opponents."*

⊗ For example...

The Causewayed Movement worked on the language they used to describe their aims as a result of working with the Frameworks Institute. This session helped them to think about strategic messaging and ensured the movement could respond to changing contexts.

Increase in shared decision making

Some groups took the opportunity to review and build processes to enable more members to participate in decision-making. The examples below demonstrate the emergence of two different ways of engaging people within the movement, both of which led to increased involvement, support and trust across the movement.

⊗ For example...

The Causewayed Movement as a group developed decision-making processes that enabled them to make some decisions when only some of the group were present, reserving big decisions for everyone to be involved. This speeded up their processes and enabled them to take advantage when new opportunities emerged. Many of the core group were able to attend most fortnightly meetings but this clarity helped build trust and cohesion in this newly formed group.

⊗ For example...

BlackOut UK created an app which allows members who have downloaded it to interact directly with decision-making about the movement's actions and responses to challenges and opportunities. Core members can ask questions of the wider membership and receive instant feedback and support. *"It's not just the three of us anymore, it feels like a movement that has a chance of being extended."*

Sustainability outcomes

Improved leadership distribution

Social movements worked to increase the number of leaders, for example, by creating working groups and sharing responsibilities. While for some social movements this was successful, others found it a challenge. For those that found engaging new leaders difficult, the time commitment required was reported as a barrier. In addition, for some, there was an underlying challenge of members looking to others to carry the leadership rather than the responsibility being spread throughout the movement. Engaging with learning activities was found to be helpful, enabling and encouraging members to see where they could take on leadership roles.

Q For example...

The Mental Health Rights Movement invited experienced activist Dan Glass[8] to come and speak to movement members giving concrete examples of action and helping to stimulate thinking about a relevant action the group could do to raise awareness. As plans were made individual members took on leadership roles and became clearer about how they could define, shape and drive a planned public action.

Development of sustainable structure

Some of the social movements are hosted within a lead organisation to allow the movement to receive funding. Whilst the benefits of having a 'host' organisation were acknowledged, it was also recognised that there are challenges associated with this. For example, social movements highlighted the need for the movement to be independent of the lead organisation whilst simultaneously being dependent on it for sustainability. This is particularly relevant where it might be problematic for the host to be associated with disruptive movement activities such as direct action. Some groups took the opportunity to discuss and consider this in relation to the future structure and sustainability of the movement.

Q For example...

The Mental Health Rights Movement considered the type of organisation where the social movement is hosted. *"We are just wondering about NGOs – they are not a good fit with social movements – they put restrictions on this. Our natural inclination is that direct action has to be independent of an NGO but how do you resource it, support it and keep it going, especially when you are dealing with mental health. It's something we have to keep an eye on so that we are not building something up that we then have to drop after the second direct action."*

8. https://www.theglassishalffull.co.uk

Growing awareness and mobilising new people outcomes

Increased membership and mobilisation

Being part of the programme has enabled social movements to increase the number of people within their networks, primarily as a result of having greater resources to reach out to and connect with people.

Q For example...

BlackOut UK ran online social events during the pandemic (The Lockdown Get Down) which raised visibility of the movement and drove traffic increasing downloads of its app dramatically.

Q For example...

The Self-Advocacy Movement members were pleased with the action they took in response to the rights of people with learning disabilities by getting involved in a national demonstration.

"I was pleased to see that 4 of the 5 self advocacy groups who are movement members supported demonstrations around the country in response to the abuse scandal at Whorlton Hall."

Q For example...

The Causewayed Movement ran a number of local fun community events to raise awareness of their work including everything from arts and crafts activity, sports and fitness training through to inclusive astronomy.

Challenging key people

During the course of the programme, the social movements increased their knowledge of tactics and strategies to engage with and challenge key people. Learning at cohort events and individual sessions led to greater confidence in the use of language and positive framing to pursue their cause with people in power.

Q For example...

Following a session with Stephanie Leonard at Act Build Change, the Social Prescribing Student Champion Scheme better understood what they needed to do in order to challenge medical institutions and the people in power. *"Stephanie completely opened my eyes to how you can build a social movement. It just completely shifted the way I think about a social movement and the way in which parity works."*

Q For example...

NACAS were pleased with the success of Professional Care Workers Day in September *"We were trending on twitter the whole day and lots of providers got involved. We also had very good support from many major social care stakeholders for the day."*

Q For example...

The Mental Health Rights Movement had success in challenging key people with their *"declare an emergency"* campaign. Utilising what they had learnt about direct action, framing and language during the programme they were successful in getting the attention of key people. *"It was the quick succession of the direct action and the public letter followed by the ministerial coffee – you saw that the language we used was being integrated into people's vocabulary. People that had no relationship with us were talking about the idea of an emergency. This part of the training around popularising a narrative was getting us somewhere."*

Measuring impact outcomes

Throughout the programme, measuring impact has been the movement building area with the least change. This perhaps reflects that the focus for social movements has been on planning and strategic development and the delivery of social movement activities. As highlighted in the previous section some social movements demonstrated a desire to improve in this area at the start of the programme, however support and learning activities for measuring impact came later in the programme and this may go some way to explaining the slower progress in this area. It is also likely that the challenging nature of measuring change brought about by social movements has prevented progress on this within the 12-month period. For some social movements, concrete outcomes, for example changes in policy, are an aspiration or can be seen and therefore easily evidenced. But for others the work of the social movement is long term, about changing perceptions and eventually behaviours, making measuring the impact of the movement very difficult without significant expert time and resource.

4.3 How the programme helped facilitate these changes

Over the course of the 12 months there have been significant developments for each of the social movements, with change being reported across three of the movement building areas. Consistent with the priorities identified by the movements at the start of the programme, most change happened in relation to sustainability and leadership and purpose.

Tailored funding

Flexibility – There has been an in-built flexibility at the heart of the Social Movements for Health programme. It was acknowledged that as the social movements evolved their needs would change and that the funders should be able to respond accordingly. Grant agreements were kept as open as possible; the social movements were given time to identify their support needs and the expertise they wanted to access – and they have been able to change their minds. Flexibility has brought challenges too.

- Flexibility can be confused with prevarication or disorganisation. Some social movements would have initially preferred more structure, along the lines of menus of choices, rather than the option to spend time considering their needs.
- Existing funder processes were at times slow to respond.

"The flexibility of the programme has allowed social movements the space to adapt and change course from their original plan and has been vital for the success of some social movements."

Dunhill Medical Trust staff member

"We were really grappling in the dark and to be honest, without the funding, the movement really would not have continued. It has enabled us to build an infrastructure, a vision and a coherent organisation to pursue this going forward."

Social movement member

Movement building support

High level of engagement – A high level of funder engagement throughout the Social Movements for Health programme was a deliberate approach that aimed to build trust between the funders and the social movements. There has been a conscious effort to, as much as possible, step away from the conventional language of grant making that is transactional in nature – 'grantees, funding agreements, milestones, beneficiary numbers' etc. Communications have instead been relational – the funders have been mindful of their power and privilege in the way it communicates with the social movements.

The application process consisted of a number of steps that gave the funders an opportunity to engage with and understand the applicant social movements – submission of an expression of interest, taking part in a webinar, attending a briefing workshop, development workshops for shortlisted applicants, submitting a full proposal. Face to face engagement between the funders and applicants was regarded as a positive feature of the application process by the funders.

Communication between the funders and the social movements has been deliberately frequent – regular, small goals were added to grant agreements to ensure communication between the two happened at regular intervals.

Q For example…

The Self Advocacy Movement communicated with Nesta about how best to support participant involvement in training. Changes were made to the structure of training, to the food that was available and to how communication was shared. Sometimes though, it wasn't possible to support training for all the movements to be delivered in a way which worked for everyone.

The funders have attended key meetings and events with social movements, and have facilitated the cohort meetings (see below). This approach has created some challenges.

- Goals and review points were deliberately small and frequent as a way of making sure that there was regular contact between the funder and the social movements but in practice the frequency meant that most conversations between the two parties had a transactional element that became an obstacle to open communications. This reinforced the funder's 'power' as the party released funding on the achievement of milestones.

- Some of the social movements in the programme did not engage with the funders to the same extent as others. Trust was not established to the same degree and the scope to maximise the value of the relationship diminished as a result.

"The more the social movements have engaged with us, the more we have been able to develop their trust and therefore offer them more."

Nesta staff member

Solidarity versus philanthropy – The funders have sought to 'act in solidarity' with the social movements. The language of the programme was that of collaboration and that related to how the funders stood alongside grant recipients, avoiding a top down dynamic as much as possible. However, the funders have their own charitable purposes to fulfil. Ensuring the programme contributed towards these, while eschewing a top down approach to a significant degree, was challenging.

"At its best this relationship would be that of an ally to the cause or movement, moving from being a financial backer ("I'm right behind you") to a fellow traveller ("I'm right beside you")."

Nesta staff member

Q For example...

The Mental Health Rights Movement planned a public demonstration to disrupt the monthly board meeting of Northern Ireland's Public Health Agency. The movement discussed the possible risks to Nesta as the funder, should things go wrong. Nesta's Communications team devised a reactive press policy to prepare for this eventuality. The policy was supportive of the movement while acknowledging the legal distinctions of the funding and clarifying what the funding was for. The press policy was shared with the movement to maintain trust and prepare them in the event it needed to be activated. This required effective and close working between movement and funder.

High level of support – Social Movements for Health aspired to be a high support, high challenge programme. A framework of suppliers was established prior to the programme launch. This comprised people and organisations with expertise and skills relevant to emerging social movements in this field and meant that it was often possible to pair a social movement to a supplier quickly. Social movements could access suppliers from this framework, or request other suppliers if necessary.

The funders referred to the social movement peers as experts too – the focus was not solely on securing support and advice from external suppliers.

Social movements identified the support they needed, with appropriate levels of challenge from the funders to think broadly and creatively.

Q For example...

The Social Prescribing group of students were encouraged to engage with a parallel group of student activists to learn from these peers and consider the breadth and scope of their campaign and to explore other ways of challenging the curriculum.

This was key to ensuring that the support met their needs and was appropriate for their stage of development and helped build sustainability. In contrast, the danger with a funder suggesting what is needed is that grant recipients can accept the help, regardless of whether it is needed, as they believe it is a funder requirement.

"The direct-action session was the preparation for the series of actions that we did take forward. It felt like we were taking the decision together and we needed external validation and expertise to facilitate that discussion. This worked brilliantly."

Social movement member

High level of challenge – It was the funders' intention to stimulate the social movements to tackle difficult issues and to think broadly and creatively about their purpose, their membership and their journey. For example, this has included conversations about how to open up the leadership role in social movements to others. The funders have acted in a critical friend role, moving away from the mostly transactional relationship between traditional funders and grantees.

High challenge requires a nuanced approach. For example, the funders are conscious of: other demands on people's time; the potential for burn out of key individuals. With the latter example, the funders supported leaders to think about how to recruit and absorb new members, delegate and draw on community organising principles of 'leaderful' networks. This was still a struggle for some of the movements because of capacity. As the programme progressed the issues of 'self and collective care' of social movement members grew in profile.

This approach can create challenges itself, for example, when a programme participant does not respond to challenge.

"It felt like Sally, Damian and the team were looking out for us in terms of specialist training and things like that they thought might be useful. Sally kept suggesting really good ideas for training and regular emails from Damian about webinars and ways Nesta can support us."

Social movement member

Embedding learning – With a Research Partner (Icarus) in place for the lifetime of the programme, there was a clear focus on reflection and learning, for both the social movements and the funders. The Research Partner has worked alongside the programme and provided insights into progress at regular intervals, informing its on-going work.

Connection to social movement peers

Funding as a cohort – The intention was always that the social movements in the programme would be considered as a cohort rather than seven individual grant recipients. Their shared characteristics were: social movements focused on improving health and care of people living in the UK; emerging social movements in the early stages of development and with some existing momentum; and the ability to engage with and actively take part in the programme.

The key advantage of a cohort approach is the potential it gives for fostering peer support. The cohort works effectively when the participants within it want to actively engage both with the programme and with each other – this has not always been the case for all of the social movements.

Cohort meetings – Three cohort meetings were held during the lifetime of the programme, bringing the funders together with the social movements for a couple of days each time. For social movements the benefits included: building relationships within their movement, building relationships with other social movements, sharing of learning, building relationships with the funders, and being inspired by external experts and programme participants. The key benefits for the funders were the opportunity the cohort events presented to catch up with the social movements' progress and check that their thinking about the programme was up to date and relevant.

Q For example...

At the November 2019 cohort event, the issue of self and collective care emerged as a key challenge through conversations and informal discussions. This highlighted the importance of these face to face meetings and the informal, relational nature of these events (eating together, lots of time for teas, coffees, people staying in the same hotel/accommodation) in building a trusting relationship in which these vulnerabilities could be aired.

"I have bonded even more with colleagues from my own movement."

"The realisation that there were other groups, tackling similar issues, generated a real feeling of togetherness and positivity amongst the group."

"It allows for serendipitous discovery of ways you can help the movements that may not become apparent through remote contact."

"Meeting more of the participants in the movement is really positive – them being able to put a face/identity to us I think helps too. It means that it is not just us liaising with one or two people from each movement."

4.4 Factors that impacted on social movements participation and growth

Throughout the programme, the social movements and the funders have reflected on what has enabled them to progress the growth of the movement and also what has slowed them down or prevented them from moving forward. We have analysed the combined data and arrived at some of these themes for what facilitated and constrained movement building on this programme.

Factors facilitating movement building	Factors constraining movement building
Focus Social movements shared that being part of the programme has brought about the structure and change of pace needed to progress the movement. Some of the movements recognise that the changes would have happened anyway, but that the programme enabled them to happen more quickly. **Collaboration** The collaborative style of working was recognised by both social movements and funders as an important part of enabling social movement building. Walking alongside movements, providing challenge and a critical friend role in contrast to a traditional transactional funder-grantee relationship gave movements the support they needed to develop without constraints or placing extra burden on them. **Funder flexibility** This was key in allowing social movements the freedom to move in the direction they needed to as they developed without being held to a rigid plan. It was highly valued by social movements and appreciated as a unique element of the programme. **Inspiration from and solidarity with peers** Feedback from social movements and funders suggests that social movements did not connect and network as much as expected. However, time with peers at cohort events was important due to the value it gave in providing inspiration and solidarity. Following events, movement members took away a renewed energy to continue the work of their movement. Equally, movements reflected that the sense of solidarity helped them to feel supported in tackling issues, knowing that others were experiencing the same challenges. Appendix 1 is a summary from the November 2019 cohort meeting where social movements worked on themed issues. **Space for reflection** A central part of movement building is to reflect on the direction and purpose of the movement and what is required to move it forward. Social movements found that the cohort events gave this space and time for reflection. Being away from the member's usual location and exposed to different ideas enabled reflection, consolidation and validation of the purpose and actions of the movement.	**Short programme length** The short-term nature of the programme meant that for some, the pressure to work within the timescale of the programme to achieve their goals constrained the attention given to some areas of movement building. A longer programme would enable a more balanced approach. However, some movements did report that the short programme length contributed to the focus and motivation described opposite. **Unfamiliarity with transformational funders** Whilst a collaborative working style is essential in facilitating social movement building, the change in funder relationship took some time for some social movements to adapt to. For example, some found it difficult to know what help was available to them and to identify which of the learning activity suppliers would help them to address their skills and knowledge needs. Support to carry out an early and in-depth analysis of skill/knowledge gaps alongside a clear outline of the support available may aid the transition to a transformational working style for those less familiar with it. **Capacity** Nearly all social movements reported that finding the time required to successfully develop the social movement had been a challenge. For some there was a feeling of missed opportunities due to not having the capacity to respond to situations as they arose. Diverse geographical locations and time required away from family, work or study has meant that face to face meetings of the movements have not happened as much as they would like, slowing down progress **Personal cost** The political nature of the work of social movements can put members at risk of personal criticism and stress. This sometimes leads to people either stepping away from the movement or being reluctant to be involved in the first place, constraining the ability to grow the movement. Strategies could be put in place which help to alleviate this barrier to movement building such as having defined and varied roles within the movement so that there are multiple ways in which people can contribute, ensuring that it is not always the same people involved in high profile campaigns. This underlines the importance of developing good support and self-care opportunities for movement members. **Power dynamics** Differences in power between members of a social movement can create tensions and be a barrier to building the movement. Being part of the programme has required there to be a main point of contact and therefore created a hierarchy of knowledge. Power dynamics between host/supporting organisations and the social movement have also created challenges. For example, needing to adhere to the financial processes of the organisation holding the programme funding.

5

Individual outcomes

Alongside the changes social movements have experienced as a result of being part of the Social Movements for Health programme it is also the case that individuals within those social movements have experienced change over the course of the year. While the evidence about this is incomplete, we know that at the start of the programme, there was a desire amongst many to gain improved skills such as leadership and communication, increased self-confidence and expanded networks and social contacts. By the end of the programme, the evidence that exists suggests that those hopes had become a reality for some members of the social movements, in addition to some further changes as described below.

Challenging individual perspectives and practice

"In some ways, if I'm honest, I didn't want the workshops, particularly the frameworks workshop, to work because I wanted to be proven right that it was all just another waste of time. I am pleased that I was wrong and that I had the opportunity to challenge my prejudice and see that these processes can help create change."

"It's made me think and helped me learn about my organisation. All the comms, framing work, thinking about where we position ourselves and how people understand us was really useful. I think it's helped with lots of different bits of work and thinking about relationships and facilitating and not managing, all of that."

"I just remember going home (from the Framing session) and rang so many friends and said I can't believe what I've just had. I've learnt so much that I'd never even considered ever."

Increased networks and improved relationships

"I wouldn't have the relationships I've got with the self-advocacy groups if we hadn't done this programme. It's really nice to understand what they are doing."

"Becoming closer with the team at Nesta, contacts and relationships has been a really good thing throughout all of this as well."

"It brought me into contact with some members of the community that I never knew and had never worked with and some that I knew but had never really worked with."

Inspiration

"I found people's passion inspiring, the don't give up attitude."

"Morale boost! Hearing about the amazing work these movements are doing reinforces why you love your job."

"I found it inspiring seeing how other people do things."

6

Conclusion

The social movements for health programme has delivered a significant opportunity to deepen the understanding of 'people powered health' and learn how social movements can be supported to promote positive change in health and health and social care. Arguably, most importantly it has allowed seven social movements to build on their ideas and strategies for challenging and improving health care experiences and the wider determinants of health across the UK.

Whilst variations in the starting point, structure and purpose of each movement have resulted in each taking away something from the programme that is unique to them, the movements have collectively grown their abilities to pursue their goals and maintain long term momentum. They have each developed their vision and have got to grips with their purposes, some have stronger leadership with a greater distribution of decision making between social movement members. Others have built a structure that will enable them to continue to flourish and have learnt tactics that will empower them to challenge key people.

Alongside supporting the growth of the movements, the programme held significant value as a facilitator of positive change for the individuals taking part. The flexible, high support nature of the programme and the trusting relationships developed between programme managers and social movement members led to personal growth and development of professional working practices. Key elements of the programme such as constructive feedback, exposure to new ideas and perspectives and opportunities to reach outside of normal comfort zones are necessary conditions for this type of growth providing a catalyst for people to reflect, learn and develop.

The programme has also provided meaningful lessons in ways to structure and tailor support for social movements. In addition to the lessons outlined in *Funding Social Movements: The Key Lessons*,[9] the four areas of movement building; leadership and purpose, sustainability, growing awareness and mobilising new people, brought value as a tool for a shared understanding of social movement development. It eased communication by shaping conversations and allowing focused discussion of ambitions for growth. The four areas also provided social movements with a framework for reflection and prioritisation of ideas and work streams.

Perhaps though, the key overarching lesson from the programme is that time, patience and flexibility are the most important elements forsuccessfully supporting social movements. For the movements, time and space to consider the sometimes difficult and thorny issues related to growing a social movement was highly valued. Taking a break away from juggling other work and life responsibilities at cohort events, for example, has provided the conditions needed to tackle the challenges they faced. For funders, providing transformational rather than transactional support has highlighted that meeting social movements where they are – working within their terms and framework, at their speed is essential. The tensions of working in this way while fulfilling funder organisational needs and processes have been exposed, however the programme has demonstrated that ultimately it can be done. Funders can adapt and flex to fit the human and unformed elements of social movements and support them on their journey to 'people powered health' in a new style of collaborative partnership.

9. https://www.nesta.org.uk/report/funding-social-movements-key-lessons/

nesta

58 Victoria Embankment
London EC4Y 0DS

+44 (0)20 7438 2500
information@nesta.org.uk

@nesta_uk
www.facebook.com/nesta.uk
www.nesta.org.uk