

MEANINGFULLY INVOLVING PEOPLE LIVING WITH NCDs

What is being done and why it matters



An initiative by the NCD Alliance
and people living with NCDs



Acknowledgements

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 Edited by the NCD Alliance, October 2018

Cover pictures, top right clockwise – Chris Agbega from Ghana speaking at Our Views, Our Voices high-level reception on margins of 71st World Health Assembly, Geneva, May 2018; Tara Lisa Persaud from Barbados speaking at NCD Alliance side event on margins of UN third High-Level Meeting on NCDs; Mexico City community conversation; bottom left – Chikhulupiliro Ng'ombe from Malawi speaking at Our Views, Our Voices workshop in Geneva, October 2017; Our Views, Our Voices workshop in Geneva, May 2018; middle shot - Benda Kithaka from Kenya.

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1. Executive Summary

Key Take-Aways

Why Meaningful Involvement?

→ People living with Non-Communicable Diseases (NCDs) offer Unique, Invaluable Insights

Effectively addressing NCDs requires understanding how these diseases affect people and the challenges and needs that people face as they navigate healthcare systems and daily life. Learning from the lived experience and first-hand know edge of NCDs is essential to improving policies, services, programmes and social beliefs.

→ Meaningful Involvement Drives Results

Organisations that carry out genuine meaningful involvement activities stand to benefit in many ways. Whether it be greater legitimacy for civil society organisations, [advocacy wins](#) (see page 21), government transparency and accountability, [more effective use of public funds](#) (see page 27) for health or concrete [improvements in health service delivery](#) (see page 31), the rationale for meaningful involvement is clear.

→ Meaningful Involvement is Everybody's Business

Meaningful involvement is not confined to civil society, or any other single sector. All sectors can meaningfully involve people living with NCDs to improve NCD prevention and control initiatives.

What makes Meaningful Involvement work?

→ Start Small, Build Buy-In, Show Results

The concept of meaningful involvement is endlessly adaptable, and can generate value at different levels, ranging from one-off surveys or focus group discussions to executive board appointments and collaborative partnerships.

→ Create Mutual Development Pathways

People living with NCDs will come from a variety of backgrounds, professions, and present with a variety of existing skills. Always consider what support people will need to be able to fulfil their role. There are many examples of involvement that do not require people living with NCDs to have specialised skills or knowledge to participate. However, building long-term relationships and providing training and resources to develop new skills will unlock potential for substantial collaboration and co-production initiatives.

→ Create a Culture of Involvement

As organisations increase their activities involving people living with NCDs and benefits are realised, the recognition of the value of the lived experience and planning for inclusivity becomes part of the organisational culture. Staff and organisational representatives who may be living with NCDs themselves may become more outspoken about their lived experience and become role models for involvement.

It's Time to Get Started!

Planning your first meaningful activity does not necessarily require a great deal of time or resources. To help you get started, take a look at our [simple five-step guide](#) (see page 34) for some tips and inspiration.

The meaningful involvement of people living with NCDs is a critical element of an effective NCD response. From policymaking to awareness raising, clinical trials, academic research, advocacy, organisational governance, and more, people living with NCDs can contribute to many different facets of the NCD response and act as role models breaking barriers to inclusion.

Promoting meaningful involvement requires recognition of its importance and the creation of enabling environments, including dedicated spaces for involvement. This review lays out some definitions of key concepts and explores what meaningful involvement of people living with NCDs currently looks like within [Civil Society \(see page 15\)](#), [Government \(see page 24\)](#), and [Health Care Delivery \(see page 29\)](#).

What is 'meaningful involvement of people living with NCDs'?

The meaningful involvement of people living with NCDs is possible when professionals, organisations, or institutions recognise the value of the lived experience. It requires the use of appropriate mechanisms to leverage this value by accessing the knowledge, skills, and insights of people living with NCDs.

Meaningful involvement avoids tokenism by building a reciprocal relationship with people, ensuring that they also benefit from the experience of being engaged and become role models to strengthen meaningful

involvement. It is not prescriptive and can take place at different levels, from participation to collaboration and co-production, which are applicable across a wide range of different sectors and activities.

“

On what isn't meaningful involvement — My government issued an invitation on a Tuesday to a stakeholder involvement meeting on the Wednesday for a report coming out on Friday (already written) – you tick the box.”

Our Views, Our Voices workshop participant,
May 2018, Geneva.

“

For me, meaningful involvement is two-pronged: The first would be to be empowered (with information, knowledge, resources, support etc.) to make informed choices and decisions about my own healthcare. The second would be systematically having a collective patient voice in shaping and implementing policies and programmes that really bring positive change to how people live every day.”

Tara Lisa Persaud,
Our Views, Our Voices 2018 Global Advisory Committee

Meaningful involvement is...

- Listening to people living with NCDs to understand their views and priorities
- Inviting people living with NCDs to play an active role in projects
- Recruiting people living with NCDs to take responsibility over projects

Meaningful involvement is not...

- Designing or implementing NCD projects without engaging people living with NCDs directly
- Consulting people living with NCDs after a decision has already been made
- Collecting inputs from people living with NCDs without making changes to reflect the findings

Multi-Level Engagement: The Ladder of Involvement

People living with NCDs can be engaged at different levels – spanning from participation (where people have little power over outcomes) to collaboration and to the highest form of involvement, co-production. These different levels can be seen in the [‘Ladder of Involvement’](#) (see page 12) which serves as a useful framework against which to consider involvement activities.

The three levels are illustrated in this review by 15 concrete case studies of what civil society organisations, governments, and health care providers from 13 countries all around the world are currently achieving through their meaningful involvement initiatives.

These real-world examples help illustrate what the concept of meaningful involvement looks like in practice. They also illustrate the concrete benefits that various NCD stakeholders and people living with NCDs stand to gain from working closer together. Whether it be greater legitimacy for civil society organisations, government transparency and

accountability, or improved hospital service quality and safety, the rationale for meaningful involvement is clear across sectors.

“

People living with NCDs have similar needs, challenges and priorities and are continuously striving to accept the situation and devise coping strategies. If they can be given a platform to collectively raise a voice they will be able to share from their experiences the loop holes and opportunities which will help control NCDs and their risk factors.”

Chennai, India,
2017 Our Views, Our Voices Community Conversations

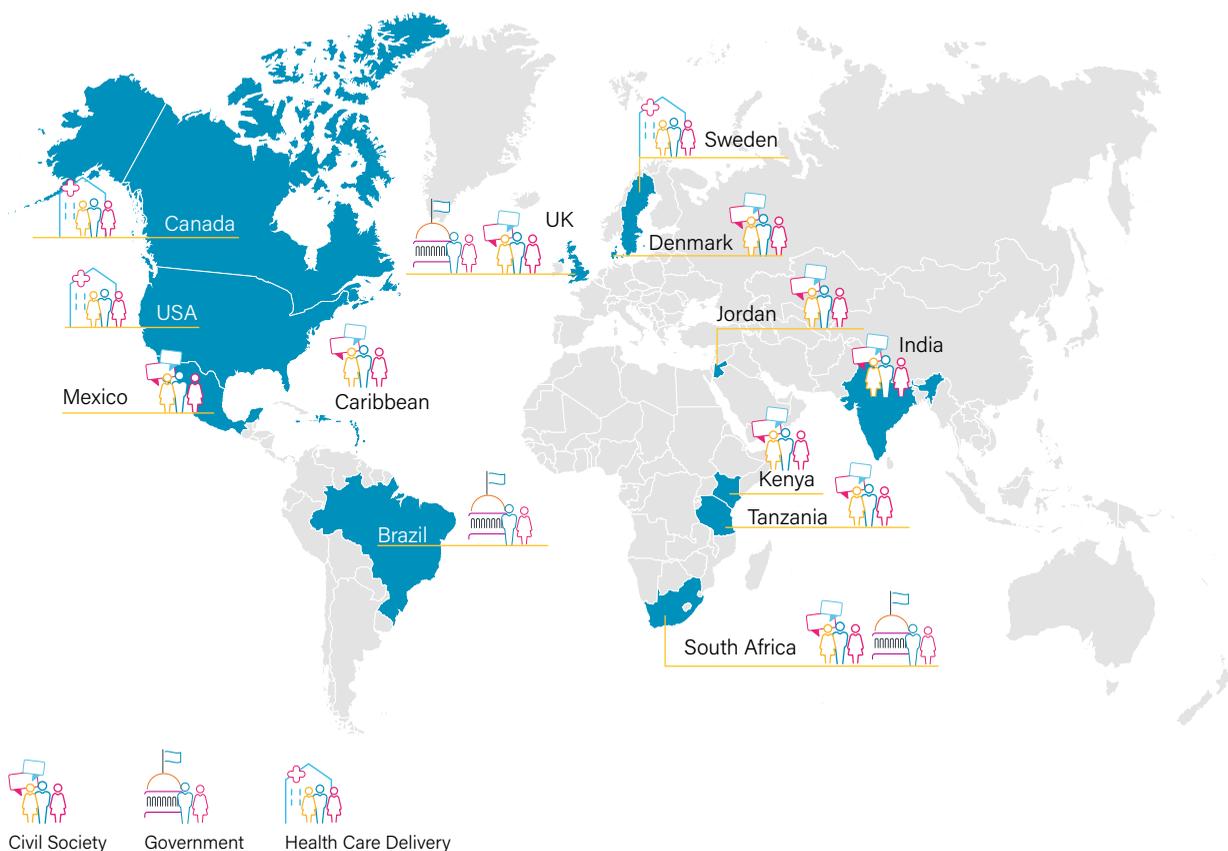


Figure 1. Case study countries of meaningful involvement listed in this review.



Key Skills Required

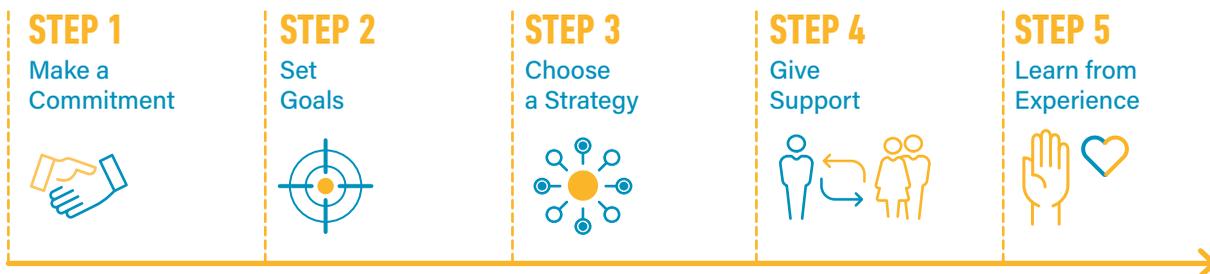
Specific skills are often necessary to ensure that people living with NCDs are able to make the most of the involvement opportunities available. These differ greatly depending on the level of engagement – for example, taking part in an online survey may require knowledge of the subject matter, but serving as a board member is a far more skill-intensive activity. However, drawing from general lessons extracted from the case studies and inputs from NCD Alliance's *Our Views, Our Voices group of people living with NCDs*, key skills have been summarised.

- ➔ **Connecting personal experience with collective asks:** When taking on advocacy roles, it is necessary for individuals to ground 'asks' with personal experiences. Training in public speaking and storytelling can support advocates.
- ➔ **Being a spokesperson:** Moving from the personal to the collective entails being able to speak as a representative of a larger group and to fully understand what it means to be a spokesperson on behalf of people living with NCDs and conveying that 'representativeness'. It requires being able to articulate ideas clearly and listening closely to the experiences of others and finding common group priorities.

- ➔ **Diplomacy and negotiation:** Individuals in advisory roles will need diplomacy and negotiating skills to build consensus and find constructive solutions. In some cases, people may need to be supported to build their confidence in order to speak openly and debate or disagree with those with power, questioning the status quo.
- ➔ **Leadership:** Being able to resolve conflicts, mediate between opposing views, collaborate with people from different backgrounds, and lead others are skills that are required by individuals in planning committees/boards/advisory roles.
- ➔ **Ability to offer constructive insights:** It is often necessary for individuals to be able to think beyond problems and focus on solutions and offer constructive suggestions for improvement.

Key Steps to Making Meaningful Involvement Happen

The different steps involved in embarking on meaningful involvement projects from start to finish are very similar regardless of sector or issue at hand. [The Making Meaningful Involvement Happen section](#) (see page 34) lays out five key steps, below, and provides guiding questions to consider at each stage.



In summary, this review is designed to contribute to the body of knowledge available to stakeholders interested in promoting meaningful involvement of people living with NCDs by sharing a sample of what is taking place around the world. It offers a way of understanding different levels of involvement, an overview of key skills to be mindful of, and a brief guide to getting started.



“

We want a person living with NCDs to represent us because they are the only ones who know what we go through. They should involve us in trainings in the health centres like the health volunteers. When they are recruiting health volunteers they should have a representative of PLWNCDs.”

Kariobangi Health Center, Kenya
2017 Our Views, Our Voices Community Conversation

2. Introduction

2.1 The Importance of Meaningfully Engaging People Living with NCDs

While the power of the people's voice is a touchstone of democracy, the evolution of the concept of 'meaningful involvement' of people with lived experiences in socio-political movements broadly, and the health and human rights discourse in particular, can be traced to the disability rights movement of the 1980s and 1990s.

The expression '*Nothing About Us Without Us*', which has been extensively invoked by disability rights advocates over the years and made popular by James I Charlton's book by the same name¹ in 1998 encompasses the principle that people living with certain conditions, whether disabilities, HIV, or NCDs know what is best for them and their communities. Today, the expression continues to resonate across movements.

In the early 1990s, the concept of meaningful involvement also began to take hold within the HIV/AIDS movement. At the Paris AIDS Summit of 1994, 42 governments adopted in its Declaration the principle of 'greater involvement of people living with or affected by HIV/AIDS (GIPA)', recognized as being critical to 'effective national responses to the epidemic.' GIPA is emblematic of the important contribution that people living with or affected by HIV/AIDS can make in the response to the epidemic and the need for creating space within society for their involvement and active participation in all aspects of that response².

The understanding of GIPA, which set out to create enabling political, social and legal environments for involvement of people living with HIV/AIDS, has also evolved into the meaningful involvement of people living with HIV or MIPA, a term often preferred to GIPA because it acknowledges people living with HIV as *active and equal agents of change, not passive recipients of services*.³

In recent years, there has been growing recognition of the importance of meaningful involvement of people living with NCDs in the NCD response. The dementia movement, in particular, has widely adopted the slogan 'nothing about us, without us' to advocate for the rightful and equal inclusion of people living with dementia in policymaking, research and care efforts⁴. While the broader NCD movement has begun calling for 'person-centered' approaches, simultaneous efforts must be made to deepen an understanding of the concept and mechanisms of meaningful involvement in this field. The collective role of governments, policymakers, multi-lateral agencies, civil society, healthcare providers, relevant private sector entities, and people living with NCDs is imperative for creating an enabling environment to promote meaningful involvement and truly 'put people first'.

Who are people living with NCDs⁵?

The term People living with NCDs (PLWNCDs) refers to a broad group of people who have or have had one or more NCD, as well as those who are closely connected to someone with an NCD – such as relatives, close friends, and care partners (sometimes also referred to as carers or caregivers).

The main NCDs include cancer, cardiovascular disease, chronic respiratory diseases, and diabetes in addition to a range of other diseases and conditions, including mental health disorders, neurological disorders (such as dementia), autoimmune and inflammatory disorders (such as psoriasis, lupus, and endometriosis), bone and joint conditions (such as osteoporosis and arthritis), renal, oral, eye and ear diseases, as well as injuries and disabilities.

¹ Charlton, J. I. (1998). *Nothing about us without us: Disability oppression and empowerment*. Berkeley, CA: University of California Press, Accessed 3 August 2018

² UNAIDS (1999). *From Principle to Practice. Greater Involvement of People Living with or Affected by HIV/AIDS (GIPA)*. http://data.unaids.org/publications/irc-pub01/jc252-gipa-i_en.pdf. Accessed 3 August 2018

³ UNAIDS Policy Brief: *The Greater Involvement of People Living with HIV (GIPA)*. http://data.unaids.org/pub/briefingnote/2007/jc1299_policy_brief_gipa.pdf. Accessed 3 August 2018

⁴ Williamson, T. (2012) *A stronger collective voice for people with dementia*. <https://www.jrf.org.uk/report/stronger-collective-voice-people-dementia>. Accessed August 16 2018

⁵ This definition was agreed to with the guidance of the 2017 Global Advisory Committee of Our Views, Our Voices and by people living with NCDs present at the Our Views, Our Voices workshop in Geneva in May 2017 who were compiling the Advocacy Agenda of People Living with NCDs.

In May, 2018, a group of 19 people living with a wide range of noncommunicable diseases (NCDs) from 13 countries gathered for an NCD Alliance training on how to be effective advocates and spokespersons and leverage their lived experiences to build a public narrative on tackling NCDs. Each of these participants had a powerful personal story to tell and an instinctive understanding of why it is crucial to meaningfully involve people living with and most affected by NCDs in any initiative or policy that directly impacts their lives.

Several participants emphasized that people living with NCDs offer a unique and powerful insights into the issues and challenges of tackling NCDs on a day-to day basis. Individuals living with NCDs, their care partners and relatives grasp the issues and challenges they face the best, which gives them first-hand knowledge that cannot be replaced by technical expertise. Others spoke of the way meaningful involvement fosters partnership and empowers people, as opposed to objectifying them. Another made the simple yet profound observation that meaningful involvement contains an element of democracy, as it can remove barriers between citizens and decision makers. The group also had clear ideas as to what type of engagement does not qualify as

meaningful involvement. These included simply telling people living with NCDs what to do, or asking people to take part in deliberations after a decision has already been made.

These perspectives were echoed and reinforced by the collective views of nearly 2000 people living with NCDs from 76 countries who took part in a virtual or in-person consultations leading up to the creation of the [Advocacy Agenda of People Living with NCDs](#), which powerfully articulates a collective demand for and the rationale of meaningfully engaging people living with NCDs (see box below) in the NCD response.

The value of the lived experience can compel others to act, whether it is motivating others to tell their story or building a public narrative for action. The importance of creating 'shared purpose' through one's own story or lived experience and translating values to action is captured in Marshall Ganz's theory of Telling your Public Story: *Story of Self, Us and Now*. Ganz explains, "by telling our personal stories of challenges we have faced, choices we have made, and what we learned from the outcomes we can inspire others and share our own wisdom."⁶

Advocacy Agenda of People Living with NCDs: Meaningful Involvement

No measure of technical knowledge can replace the insight of the lived experience.

Our knowledge is undervalued in NCD programme development, implementation, and policy-making. In general, we are under-represented as leaders in organisations, and largely silent in decision-making processes on policies that directly affect us.

As people living with NCDs, we are experts in our own right, and we can speak for ourselves. We call for an urgent and fundamental shift in the NCD response, with the full and meaningful involvement of people living with NCDs placed at its heart.

Our involvement needs to be comprehensive, and not tokenistic. We must be treated as equal partners. We must be involved in policy making and accountability processes, help shape and monitor programmes and services that affect our lives, play an active role in the governance and leadership of international and national organisations, and be on the front line of NCD advocacy.

This is about realising the rights and responsibilities of people living with NCDs, and we strongly believe it will positively benefit the response as a whole.

In order for us to take a more active role in the response, we need supportive political, legal, and social environments that give all of us the opportunity to speak up, especially those most vulnerable and disenfranchised. Our involvement and empowerment does not take place in a vacuum, and we need political action to prioritise this.

We are ready to take action, and we share the same goals - let us work together.⁷

⁶ Marshall Ganz. 2007. Telling Your Public Story: Self, Us, Now (Worksheet) Kennedy School of Government [accessed 3 August 2018]

⁷ This text of the Advocacy Agenda was finalised at an [Our Views, Our Voices workshop](#) held in October, 2017 involving 34 people living with NCDs from 22 countries.

Why is it so important to tell stories? What is the role of emotion in decision making? What inhibits action? Check out this [lecture on Public Narrative](#) and the Story of Self, Us, and Now.

Ganz defines public narrative as a 'leadership practice of translating values into action'⁸ that is created by linking one's own 'story of self' with the 'story of us' (the shared experiences or motivating values that will enable collective action) and the story of now (the urgent action one is calling for).^{9,10}

The 'experience of storytelling', complimented by 'strategy' (or the evidence-base and analysis) together result in action (see Figure 2).

In addition to an appreciation of the value and importance of sharing one's lived experience to enable action on NCDs, it is useful to set a common understanding of what meaningful involvement of people living with NCDs entails in practice. The following section attempts to contribute to the body of knowledge by offering some key definitions and outlining a framework of assessment and classification of different examples of meaningful involvement in action.



Figure 2. Adapted from the works of Marshall Ganz, Harvard University.¹¹

⁸ Marshall Louis Ganz, 'Public Narrative, Collective Action, and Power', in *Accountability Through Public Opinion: From Inertia to Public Action*, 2011 <https://dash.harvard.edu/handle/1/29314925> [accessed 23 July 2018].

⁹ Marshall Ganz. 2009. What Is Public Narrative: Self, Us & Now (Public Narrative Worksheet). Working Paper [accessed 3 August 2018]

¹⁰ The NCD Alliance's own Our Views, Our Voices training is based on Marshal Ganz's theory.

¹¹ Marshall Ganz, Serena Zhang, and Voop de Vulpillieres, 'Public Narrative Participant Guide' (Harvard Kennedy School) <https://www.ndi.org/sites/default/files/Public%20Narrative%20Participant%20Guide.pdf> [accessed 13 May 2018].

2.2 Defining Meaningful Involvement: From ‘Participation’ to ‘Collaboration’ and ‘Co-Production’

Many definitions of ‘meaningful involvement,’ referred to by a range of expressions and phrases, have been articulated over time. Within the context of health care, Morrison and Dearden define it as ‘the opposite of tokenistic’ and ‘the ability to impact decision-making.’¹² Adopting a similar line of reasoning, Ocloo and Matthews define it ‘as an activity that is done “with” or “by” patients or members of the public rather than “to,” “about” or “for” them.’¹³

Generally speaking, the meaningful involvement of people living with NCDs is possible when professionals, organisations, or institutions recognise the value of the lived experience. It requires the use of appropriate mechanisms to leverage this value by accessing the knowledge, skills, and insights of people. It avoids tokenism by building a reciprocal relationship with people living with NCDs, ensuring that they also benefit from the experience of getting engaged. It is not prescriptive and can take place at different levels, from participation to collaboration and co-production, which are applicable across a wide range of different sectors and activities.

Many parallels can be drawn between the concept of meaningful involvement of people living with NCDs and that of ‘co-production.’¹⁴

Co-Production

‘A relationship where professionals and citizens share power to plan and deliver support together, recognising that both partners have vital contributions to make in order to improve quality of life for people and communities.’¹⁵

Co-production offers a radical critique of public service delivery based on several arguments, including that ‘professionals’ (such as doctors, policymakers, civil society leaders) need clients (or people living with NCDs) to be effective just as much as the reverse is true.¹⁶ However, to help make sense of the wide array of mechanisms that civil society organisations (CSOs), governments, and health care providers have at hand to engage people living with NCDs, it is useful to place co-production within a wider framework, encompassing a larger spectrum of involvement.

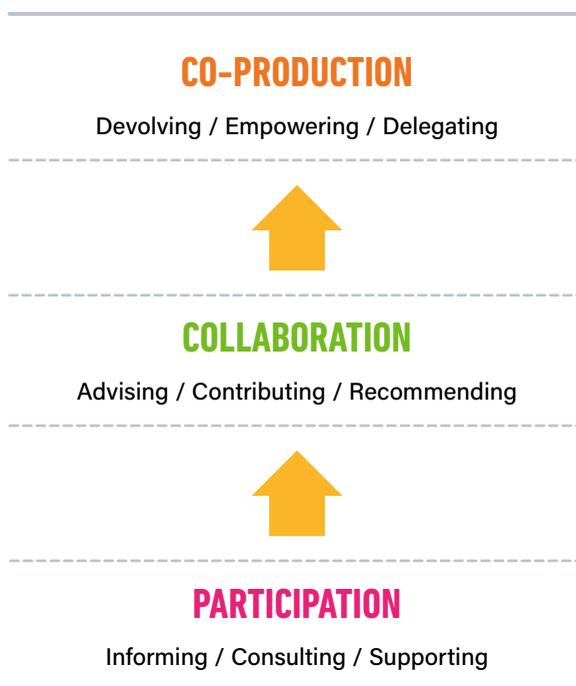


Figure 3. Ladder of Involvement of People Living with NCDs¹⁷

¹² Cecily Morrison and Andy Dearden, ‘Beyond Tokenistic Participation: Using Representational Artefacts to Enable Meaningful Public Participation in Health Service Design’, *Health Policy*, 112.3 (2013), 179–86 <https://doi.org/10.1016/j.healthpol.2013.05.008>.

¹³ Josephine Ocloo and Rachel Matthews, ‘From Tokenism to Empowerment: Progressing Patient and Public Involvement in Healthcare Improvement’, *BMJ Qual Saf*, 2016, bmjqs-2015-004839 <https://doi.org/10.1136/bmjqs-2015-004839>.

¹⁴ Josh Ryan-Collins and Lucie Stephens, *Co-Production: A Manifesto for Growing the Core Economy* (New Economics Foundation, 2008) <https://neweconomics.org/upload>

¹⁵ Ryan-Collins and Stephens.

¹⁶ Ryan-Collins and Stephens

¹⁷ Sherry R. Arnstein, ‘A Ladder Of Citizen Participation’, *Journal of the American Institute of Planners*, 35.4 (1969), 216–24 <<https://doi.org/10.1080/01944366908977225>>.

The 'Ladder of Involvement' (see Figure 3) is one such framework. It draws from Arnstein's influential 1969 paper on citizen participation, which has since been re-created in many forms by many others¹⁸. Although it was originally conceived as a way of describing levels of involvement in policymaking, it is equally useful in describing a wide array of mechanisms in different sectors. For instance, National Health Service England's 'ladder of engagement' for patient and public participation efforts is firmly grounded in Arnstein's framework of involvement.¹⁹

As the case studies in this review make clear, the specific mechanisms that may be used by a government differ from those that may be employed by a civil society organisation or hospitals. Nevertheless, this three-tiered ladder can help describe where on the scale of meaningful involvement a particular initiative is ranked. **The higher up the ladder, the more influence people living with NCDs have in determining the outcome of action and the more meaningful their involvement.**

Despite the hierarchy created by the Ladder of Involvement, the implication is not that collaboration and participation are not worthwhile.

Indeed, it is often necessary to begin at lower levels of the involvement in order to build the capacity and skills of people living with NCDs to engage at higher levels – a process which can take time and resources. Similarly, an organisation may also develop its approach to meaningful involvement of people living with NCDs over time, as it builds its own capacity to do so.

Meaningful involvement applies to everything from the design and implementation of new policies and programmes, to advocacy campaigns, clinical trials, research projects and media portrayals of health issues to name a few. However, this review will focus on exploring some of the existing mechanisms for meaningfully involving people living with NCDs within **civil society, government, and healthcare delivery** around the world.

The following sections illustrate some common mechanisms belonging to each level of involvement used within these three sectors in the meaningful involvement of people living with NCDs through real-world case studies. Recognising the importance of building peoples' capacity to engage, a spotlight on the key skills people living with NCDs need to make the most of such opportunities is also included.

Co-Production

Co-Production is the highest level of involvement, representing initiatives that are 'done with' people living with NCDs. It entails sharing decision-making power with people, or providing them an equal role to play in delivering what they have produced.

Examples

Representation in decision-making bodies, staff or leadership positions, power over resources.

Collaboration

Collaboration provides a greater scope for people living with NCDs to take part in the designing or implementing of initiatives, which can roughly be described as 'done for' people living with NCDs. However, collaboration operates within boundaries set by professionals – in other words, people living with NCDs do not have a final say on decisions or outcomes.²⁰

Examples

Inclusion in policy recommendation committees, advisory councils, reference groups.

Participation

Participation represents the lowest form of involvement and can risk being tokenistic in nature. Initiatives that belong to this category can be described as 'done to' people living with NCDs. They may involve exchanging information with people, but do not create the opportunity to shape decisions or outcomes.

Examples

Newsletters, focus groups, citizens' panels, surveys.

¹⁸ Arnstein.

¹⁹ NHS England, 2014. Bite sized guides to Participation. <https://www.england.nhs.uk/publication/bite-size-guides-to-participation> [accessed 3 August 2018]

²⁰ These definitions borrow from the framework laid out in New Economics Foundation, 'Co-Production in Mental Health', 2013. <http://neweconomics.org/2013/11/co-production-mental-health/> [accessed 13 May 2018].

3. Methodology

This review was produced mainly through desk research of the grey and academic literature on the subject of citizen involvement. Inputs from experts on patient engagement in the UK National Health Service context were also called upon in the process of identifying an appropriate theoretical framework.

Simultaneously, valuable inputs were gathered from people living with NCDs participating in two NCD Alliance events, one in October, 2017 and the second in May, 2018. Both of these discussed the value of and definitions of meaningful involvement, which were instrumental in the process of shaping this review.

In addition to desk-based research, an open call for submissions of initiatives demonstrating meaningful involvement undertaken by national or regional NCD alliances resulted in 31 examples from 19 countries. The Our Views, Our Voices group of advocates living with NCDs also submitted 22 initiatives from 14 countries.²¹ Several of the case studies submitted appear in the Civil Society and Government sections below, illustrating that much is already being done that can be scaled up or replicated elsewhere.

Final case studies were selected for illustration purposes of the different levels and allowing for geographic diversity.

The submissions also shed light on some general trends and the key skills that CSOs and people living with NCDs felt were needed to make the most of the initiatives they have taken part in. These informed the compilation of 'Key Skills' summaries that are included for each of the three sectors.

Among the limitations of this review is the relative absence of examples of the involvement of people living with NCDs as a unified group, which has resulted in a reliance on disease-specific case studies, although these do provide a solid foundation.

Finally, conducting interviews with each of the organisations responsible for the case studies included could have resulted in much greater granularity and additional lessons learned. Delving deeper into specific cases in order to extract more insights could be an avenue to pursue further in future.



Participants of the Our Views, Our Voices workshop of May 2018.

²¹ These calls for submissions took place between April and May, 2018.

4. Civil Society

Case Study Guide



Participation

		Key Features
Kenya <i>See page 17</i>	Sharing Information and Tools for Better Self-Management of Diabetes	Support Groups Education Sessions Peer Educators
Global / India <i>See page 18</i>	Consulting People Living with NCDs to Identify Needs and Priorities	Online Survey Focus Groups Working Group
South Africa <i>See page 18</i>	Collecting Stories to 'Humanise' Cancer through Photovoice Narratives	Photovoice Exhibitions Research Papers

Collaboration

		Key Features
Caribbean <i>See page 19</i>	Appointment of a Technical Adviser to Guide Policy and Strategy	Advisory Role Public Speaking Opportunities External Representation
Tanzania <i>See page 20</i>	Inviting People Living with NCDs to Speak Up at Annual General Assembly Meetings	Awareness Sessions Trainer Training General Assembly Invitations
Jordan <i>See page 20</i>	Helping to Design and Implement A Campaign to Tackle Stigma	Focus Groups Fundraising Roles Media Exposure

Co-Production

		Key Features
UK <i>See page 21</i>	Campaign Ambassadors Advocating Directly to Decision Makers	Direct Lobbying Ambassador Roles
Mexico <i>See page 22</i>	Working in an Alliance with Patient Organisations for Joint Campaigning	Organisational Partnership Social Media Campaigning Direct Advocacy Outreach
Denmark <i>See page 22</i>	People Living with NCDs as Executive Board Members	Consultations Advisory Roles Executive Board Roles



4.1 Introduction

Civil society has long contributed towards promoting public health from the national to the global levels, providing a critical connection to local contexts. NCD civil society's role encompasses access, awareness raising, advocacy, and accountability. With an increasing recognition of the need for a whole-of-society approach to tackling health issues in general, and NCDs specifically, civil society is uniquely positioned as a valued stakeholder and enabler.²²

Definition of Civil Society

“Wide array of non-governmental and not-for-profit organisations that have a presence in public life, expressing the interests and values of their members or others, based on ethical, cultural, political, scientific, religious or philanthropic considerations. Civil Society Organisations (CSOs) therefore refer to a wide of array of organisations: community groups, non-governmental organisations (NGOs), labour unions, indigenous groups, charitable organisations, faith-based organisations, professional associations, and foundations” (World Bank).

Comparisons with the HIV response have called attention to the low involvement of people living with NCDs in civil society action, partly due to the absence of one common voice amongst the many different conditions included under the NCD umbrella. This contrasts with powerful ‘grassroots community activism led by those affected’, which was instrumental in driving progress in the response to HIV.²³

CSOs stand to gain a great deal from adopting meaningful involvement of people living with NCDs as a norm. Advocacy asks and campaigns are far more compelling and incisive when informed by those with first-hand experience of the issues being tackled. Moreover, civil society is often relied upon ‘to give

expression to the marginalised and those who often are not heard’²⁴. Given this role, organisations that effectively involve and represent people living with NCDs earn greater legitimacy in the eyes of decision makers as well as the public.

In recognition of the value of meaningful involvement of people living with NCDs and the need to promote its relevance and application in the NCD response, the NCD Alliance included “Put People First” as a campaign priority for the 2018 UN High-Level Meeting on NCDs.²⁵

While more can and must be done, excellent examples of meaningful involvement spanning participation, collaboration, and co-production can already be seen making an impact on NCD civil society activities globally.

It is important to note that CSOs engage in a wide range of activities – from advocacy campaign planning or implementation, monitoring and evaluation, media outreach, public awareness campaigns and much, much more. Consequently, the case studies included below (much like those presented with reference to government and health care delivery) are not intended to be exhaustive. Instead, they are designed to illustrate common mechanisms at three different levels of involvement.

“

It is important to highlight that these conditions can affect anyone in the society ... This role can be best played by civil society as they are close to people and have the ability to reach out to every corner of the country.”

Madras Diabetes Research Foundation;
HRIDAY; India 2017 Our Views, Our Voices Community Conversation

²² The value of civil society contributions are recognised in the ‘Global Action Plan for the Prevention and Control of NCDs 2013-2020’, WHO. http://www.who.int/nmh/events/ncd_action_plan/en/ [accessed 16 February 2018].

²³ Anton Palma and others, ‘Can the Success of HIV Scale-Up Advance the Global Chronic Non-Communicable Disease Agenda?’, *Global Heart*, 11.4 (2016), 403–8. <https://doi.org/10.1016/j.ghheart.2016.10.012>.

²⁴ ‘WHO | Civil Society.’

²⁵ ‘NCD Alliance Campaign Priorities: 2018 UN High-Level Meeting on NCDs | NCD Alliance’ <https://ncdalliance.org/resources/ncda-campaign-priorities-2018-un-high-level-meeting-on-ncds> [accessed 26 July 2018].

4.2 Participation

The cases below illustrate how CSOs around the world engage people living with NCDs by providing key information, consulting individuals to learn about their priorities and recommendations, and by collecting their stories for use in advocacy among decision makers and dissemination among wider audiences.

CASE 1

Sharing Information and Tools for Better Self-Management of Diabetes

	Organisation	Kenya Defeat Diabetes Association
	Country	Kenya
	Duration	2015-2018

DESCRIPTION

Recognising that people living with diabetes are, in effect, experts in their own conditions, the Kenya Defeat Diabetes Association (KDDA) set out to supply information and training to improve self-management skills.

A key objective of the initiative was to raise awareness about the condition and how to best manage it. Simultaneously, people living with diabetes were also encouraged to form support groups, screened for early diagnosis of eye conditions, and provided with syringes and testing devices.

In total, 406 support groups were created in 32 counties of the country. Approximately 127,000 people living with diabetes were supplied with accurate information about how to manage their conditions, and general awareness raising messages reached an estimated 2.9 million Kenyans.

Moving further up the ladder of involvement towards the level of collaboration, KDDA also trained 746 people living with diabetes to be peer educators.

BENEFITS

According to KDDA, the initiative has helped to tackle stigma and discrimination, improved adherence to treatment, and paved the way to working closer together with new stakeholders.

“

Don't speak for us, let us speak for ourselves.”

Vicki Pinkney Atkinson,
NCD advocate living with multiple diseases, Our Views,
Our Voices workshop, Geneva



CASE 2

Consulting People Living with NCDs to Identify Needs and Priorities



Organisation **NCD Alliance**



Country **Global**



Duration **2017**

DESCRIPTION

The NCD Alliance launched the Our Views, Our Voices global consultation in 2017. In total, 16 countries hosted community conversations, or focus group discussions, involving 935 people living with different NCDs to discuss their needs and recommendations regarding treatment, care, and support, prevention, social justice, and meaningful involvement. An online survey covering the same topics simultaneously reached 958 people from all over the world. Results were turned into interactive online dashboards to amplify their reach. These inputs formed the Advocacy Agenda of People Living with NCDs.

Several country alliances have taken this work forward by continuing to create opportunities for participation. The NCD Alliance of Kenya (NCDAK), for example, in consultation with 52 people living with NCDs and a range of stakeholders at a national meeting in early 2018 has built the Advocacy Agenda of People living with NCDs in Kenya. Likewise, the Healthy India Alliance (HIA) plans to develop a National Advocacy Agenda of People Living with NCDs based on the inputs of those who took part in the five community conversations held in the country.

HIA also reports that it is assembling a Working Group on patient engagement and using the insights collected from the community conversations to inform its strategic planning for the next 3-5 years. This is a good illustration of how participation-level initiatives can help pave the way to collaboration and beyond.

BENEFITS

The construction of the Advocacy Agenda of People Living With NCDs has made it possible to present the needs and recommendations of people to decision makers and experts at global events. This serves to inject the voices of those directly affected into technical policy discussion and formulation.

CASE 3

Collecting Stories to 'Humanise' Cancer through Photovoice Narratives



Organisation **Cancer Association of South Africa**



Country **South Africa**



Duration **2016-2018**

DESCRIPTION

The Cancer Association of South Africa (CANSA) launched an initiative to collect 300 stories of people living with cancer, including photographs that capture their daily experiences. The findings have been used to inform the development of a South African Advocacy Toolkit developed by the organisation.

The inputs have been disseminated widely with the public, academic audiences, government officials, and other stakeholders. For example, the collected materials have been used to create public exhibitions at conferences, materials for advocacy meetings with national and local government departments, and for written educational and support resources.

Several research papers contributing to the existing body of knowledge and evidence on cancer in the country have also resulted from this initiative (including one on childhood cancer experiences, another on the emotional challenges of cancer, and a final one on grassroots feedback about cancer challenges).

BENEFITS

This project served to create an original body of evidence for use in CANSA's advocacy with decision makers.

4.3 Collaboration

The cases presented in this section, originating from the Caribbean, Tanzania, and Jordan, all illustrate how people living with NCDs are making substantive contributions to the work of NCD CSOs and coalitions. They include the appointment of a technical adviser on meaningful involvement, campaign planning collaboration, and the involvement of people living with NCDs at general assembly meetings.

CASE 1

Appointment of a Technical Adviser to Guide Policy and Strategy

 Organisation **Healthy Caribbean Coalition**

 Country **Caribbean Region**

 Duration **2017 to Present**

DESCRIPTION

In 2017, the Healthy Caribbean Coalition engaged Tara Lisa Persaud as an 'Our Views, Our Voices Technical Advisor' to help ensure that the voices of people living with NCDs are reflected in all aspects of its work.

As a Technical Adviser, Tara Lisa was nominated to attend the Second Global NCD Alliance Forum in December, 2017 and reflected on her experience in a blog post published by HCC. Since the Forum, Tara Lisa has been invited to serve on two global bodies that provide platforms to amplify the voices of people living with NCDs, and also began serving on the Advisory Committee of the Our Views, Our Voices initiative helping to guide its development by advising NCD Alliance staff.

Tara Lisa has also engaged directly in HCC events. In 2018, she co-chaired the closing session of a multi-stakeholder NCD forum attended by over 100 delegates, during which people living with NCDs spoke about their experiences.

BENEFITS

Thanks to Tara Lisa's knowledge and experience around securing access to essential cancer medicines, she has not only become active in advocacy on the topic but also helped HCC to build connections with a leading high-level political advocate who works on this issue.



“

For me one of the most important things is the recognition that you are not alone. (...) It's a little like you've suddenly found your 'tribe'. People that understand more. But more than that, they are ready to strive to make a difference in the things that affect your every day. That 'tribe' is more valuable than I can explain”

Tara Lisa Persaud



CASE 2

Inviting People Living with NCDs to Speak Up at Annual General Assembly Meetings



Organisation **Tanzania NCD Alliance**



Country **Tanzania**



Duration **2012 to Present**

DESCRIPTION

The vision and mission statements of the Tanzania NCD Alliance (TANCDAA), which prominently mention 'human rights for people with NCDs' and 'improving welfare of people with NCDs,' place a clear emphasis on people at the core of the organisation's work.

TANCDAA runs programmes to support people living with NCDs and advocates for quality care as a human right at the national level. In addition, it provides people living with NCDs with training in order to deliver awareness raising and educational sessions within communities and schools.

In addition to providing support, however, people living with NCDs are invited to attend TANCDAA general assemblies to make sure their voices are heard during decision-making processes.

Going beyond the collaboration level towards that of co-production, TANCDAA, also requires each of its members to appoint someone living with NCDs to their board. This ensures proper planning and ensuring person-centred advocacy campaigns.

BENEFITS

This initiative reportedly made an impact in tackling stigma around NCDs, and allowed the CSOs involved to gain a much clearer understanding of what people living with NCDs actually need, and what they face on a daily basis. It also helped to deepen trust between people and organisations representing them.

CASE 3

Helping to Design and Implement a Campaign to Tackle Stigma



Organisation **King Hussein Cancer Foundation**



Country **Jordan**



Duration **2007 to Present**

DESCRIPTION

Since its establishment, at a time when the topic of cancer was steeped in taboo, the King Hussein Cancer Foundation (KHCF) has been working with people with lived experience to change public perceptions of the disease.

One example of this is the KHCF's Jordan Breast Cancer Program, a nationwide awareness raising campaign is launched every October. Cancer survivors play a role in both planning and implementing this initiative.

During planning, consultancy workshops and focus group discussions with women who have experienced breast cancer are held to elicit ideas for everything from campaign messages to advertisement tools.

BENEFITS

Participating women aid staff by actively contributing to the initiative in valuable ways. For example, they help to raise the profile of the event by addressing the media and general public, and they conduct outreach by delivering lectures in the local community (among many other activities). Finally, they also contribute to fundraising activities to support screening services for less privileged women.

4.4 Co-Production

These examples demonstrate how CSOs in the UK, Mexico, and Denmark are working alongside people living with NCDs to co-produce advocacy initiatives. They span the work of campaign ambassadors lobbying local MPs, to organisations forming alliances with people living with NCDs to advance pressing health issues, to the appointment of executive board members who themselves have a lived experience of the conditions being targeted.

CASE 1

Campaign Ambassadors Advocating Directly to Decision Makers



Organisation **Cancer Research UK**



Country **UK**



Duration **Ongoing**

DESCRIPTION

Cancer Research UK provides an extensive range of involvement opportunities, ranging from contributing to social media campaigns and surveys to mobilising political campaigns targeting local Members of Parliament (MP) through the 'Cancer Campaigns Ambassadors' initiative.

Ambassadors can make a tangible difference by lobbying their politicians directly, especially considering the fact that a key part of a politician's role is to listen to constituents and understand their priorities. Moreover, the conversations Ambassadors have with politicians in their home communities can affect national legislation.

BENEFITS

Over the years, CRUK Ambassadors have achieved numerous successes, including campaigns on sunbed restrictions (to help beat skin cancer), tobacco control, and have secured extra investment in early diagnosis.²⁶

²⁶ CRUK, *Involve Innovate Inspire*, 20 October 2017 <<http://www.cancerresearchuk.org/support-us/volunteer/patient-involvement-at-cancer-research-uk/impact-of-patient-involvement>> [accessed 17 April 2018].



CASE 2

Working in an Alliance with Patient Organisations for Joint Campaigning

 Organisation	Red de Acceso (Access Network)
 Country	México
 Duration	March to July 2018

DESCRIPTION

Red de Acceso (Access Network) is an alliance of 15 civil society organizations and patients living with different diseases that represent the main causes of mortality in Mexico (such as cancer, diabetes, hepatitis, and HIV), as well as low prevalence diseases. For many years, the alliance has advocated on the need for people-centred initiatives to strengthen the health system. A recent campaign coincided with the Mexican presidential elections held in July 2018. The National Electoral Institute (INE) organizes debates between the candidates during every election. This time, three debates were organised between March and June. However, the subject of health had not been included in any of them. Red de Acceso argued that, by omitting this issue, a great opportunity to inform the electorate about what the candidates' health plans and proposals would be missed.

In this context, the alliance members, including people living with NCDs, sent over 40 letters to the INE authorities asking that health be included and considered as a priority in the debates. They also started a targeted social media campaign to create awareness on the absence of health in the debates with the hashtag #SaludEnElDebate (#HealthInTheDebate).

Ultimately, INE officials expressed their interest in knowing more about Red de Acceso's work and demands. They agreed to receive proposals for questions from patient organizations to be included in the third presidential debate, which has held on June 12, 2018, in the city of Merida, Yucatan. This debate included questions on topics like health financing and obesity. The INE even invited the members of the alliance to attend as guests.

BENEFITS

The campaign resulting from this collaboration achieved an impact of more than 87,000 total impressions and almost 10,000 total interactions on Twitter. It brought the issue to the attention of opinion leaders, and even that of the INE authorities.

CASE 3

People Living with NCDs as Executive Board Members

 Organisation	Danish Cancer Society and Danish Diabetes Association
 Country	Denmark
 Duration	Ongoing

DESCRIPTION

The Danish Cancer Society and the Danish Diabetes Association (founders of the Danish NCD Alliance) both engage people living with NCDs in most of what they do. The organisations' work is focused on the needs of people living with these conditions, and through their activities recognise the unique insights gathered by working with those who deal or have dealt with them every day.

In light of this recognition, both organisations engage people living with NCDs in their executive boards. In these posts, they have the same roles and responsibilities with regards to organisational governance as all other executive board members. They also guarantee representation on almost all established working groups and similar entities.

BENEFITS

This high-level involvement ensures that the information produced and general engagement activities adopted by the organisations are as relevant and user-friendly as possible. Ultimately, this form of co-production makes it much easier for organisations to make sure they always consider the views of people living with NCDs before making recommendations or advocacy campaign decisions.

Key Skills Required for Meaningful Involvement in Civil Society

While certain tasks call for specialised skills, there are several general competencies that people living with NCDs need to make the most of opportunities such as the ones presented above. Naturally, much more is demanded of people involved in co-production as compared to collaboration or participation initiatives. However, several cross-cutting skills can be identified:

→ Ability to connect personal experience with advocacy asks

In order to contribute meaningfully to a large-scale advocacy campaign or to the functioning of a civil society organisation, an advocate living with NCDs must be confident in going beyond a retelling of their personal lived experiences. Returning to the theories of Marshall Ganz introduced above, a powerful public narrative needs to progress from a 'story of self' to a 'story of us' and a 'story of now' in order to motivate others to action.²⁷ Confidence in this form of public speaking requires training and time to develop. Moving from the personal to the collective also entails being able to speak as a representative of a larger group and fully understanding and conveying that 'representativeness'.

→ Ability to articulate ideas clearly

Particularly where the involvement activity entails acting as a spokesperson on behalf of people living with NCDs in public fora, whether that be a general assembly meeting or a media interview, the ability to convey advocacy asks and priorities in an accurate and compelling way is essential.

→ Ability to assimilate new information quickly

Advocacy campaigns are fast-moving and multifaceted. People living with NCDs, particularly those who are getting involved for the first time, may need training or support (resources, briefings, FAQs) to be able to understand the concepts and evidence behind the advocacy asks being pursued.

→ Identifying and leveraging areas of shared purpose

Working alongside people living with other conditions requires advocates to be able to listen closely to the experiences of others and find common priorities or recommendations in order to represent people living with NCDs as a group.

→ Collaboration and teamwork

At all levels of involvement, advocates living with NCDs require excellent interpersonal skills. At the higher level of co-production, the ability to collaborate with organisation staff or leadership becomes even more critical.

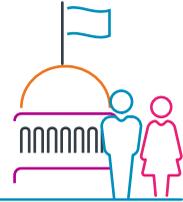
→ Dedication and commitment

Involvement initiatives led by CSOs often operate on a voluntary basis. Consequently, it is extremely important to work with individuals who have a passion and commitment to the cause in order to ensure that projects are successful and sustainable in the long term.

²⁷ Marshall Louis Ganz, 'What Is Public Narrative: Self, Us & Now', 2009 <https://dash.harvard.edu/handle/1/30760283> [accessed 23 July 2018].

5. Government

Guide to Cases



Participation

Key Features

South Africa
See page 25

Involving People Living with NCDs in Awareness Days Co-Hosted by Provincial Governments

Consultation Meetings
Screening Services
Awareness Raising

Collaboration

Key Features

Brazil
See page 26

Representation on Health Councils to Monitor and Advise Government

Council Representation
Progress Monitoring

Co-Production

Key Features

UK
See page 27

Devolving Power to People through Personal Health Budgets

Legal Duty to Involve
Spending Power

5.1 Introduction

Goal 16 of the 2030 Agenda for Sustainable Development calls for the promotion of just, peaceful and inclusive societies with a target dedicated to the creation of 'responsive, inclusive, participatory and representative decision-making at all levels'.²⁸ Within this context, the meaningful involvement of people living with NCDs in government can be understood as part of a larger global priority for achieving sustainable development.

The rationale behind this goal is clear. Including civil society, including people living with NCDs, makes it possible for officials to become aware of citizens' needs and demands, which in turn increases transparency and accountability while potentially making people more supportive of government decisions.²⁹

The idea of co-production in this sector strives towards greater democracy in the design and delivery of public services, so as to allow citizens a higher degree of

“

The Ministry of Health I think needs to reach out to the survivors, when they are coming up [sic] with their strategic plans and their various policy documents.”

2017 *Our Views, Our Voices* Community Conversations, Cancer Support Group, Aga Khan University Hospital; Kenya

influence over the decisions that impact their daily lives. It has been argued that co-produced services improve outcomes by increasing efficiency while being relatively low-cost to implement.³⁰

²⁸ 'Sustainable Development Goals: 17 Goals to Transform Our World' <http://www.un.org/sustainabledevelopment> [accessed 16 February 2018].

²⁹ Martha Gabriela Martinez and Jillian Clare Kohler, 'Civil Society Participation in the Health System: The Case of Brazil's Health Councils', *Globalization and Health*, 12.1 (2016), 64. <https://doi.org/10.1186/s12992-016-0197-1>.

³⁰ 'Co-Production'. <https://www.local.gov.uk/topics/devolution/engaging-citizens-devolution/approaches-civic-and-democratic-engagement/co> [accessed 31 July 2018].

The OECD's Observatory of Public Sector Innovation classifies different ways of involving citizens in shaping public services as co-commissioning, co-design, co-delivery, and co-assessment.³¹ While this highlights the great diversity of potential approaches for involvement by government, the same 'ladder of involvement' typology can still be applied. The three cases below

briefly outline concrete mechanisms falling under the categories of participation, collaboration, and co-production. They range from CSOs acting as bridges between people living with NCDs and local governments, health councils that directly advise governments, and finally devolution of spending power through Personal Health Budgets.

5.2 Participation

CASE

Involving People Living with NCDs in Awareness Days Co-Hosted by Provincial Governments

	Country	South Africa
	Duration	2014

DESCRIPTION

South Africa has experienced a disjuncture between the national NCD plan and its implementation in the provinces in terms of resource allocation and action. To help remedy this situation, the South African NCD Alliance (SANCDAs) undertook an initiative to capacitate and mobilise selected provinces to share NCD knowledge and best practices across sectors.

Three provincial governments agreed to co-host NCD awareness events for health care workers and civil society actors in their respective jurisdictions. The one-day events were held with 200 delegates at KwaZulu-Natal, 100 delegates at Northern Cape, and 250 delegates at Gauteng.

In each case, planning began with on-site meetings of the organizing committee comprising of the provincial team, SANCDAs, and its local partners. People living with NCDs, who are often bypassed, were given a voice by being invited to participate in programme planning. The events were also designed to create a space for NCD screenings and subsequent referrals to appropriate services. The programme for each workshop started with a NCDs awareness building exercise, followed by NCD presentations with interactive question and answer sessions. Topics ranged from community involvement to obesity and oral health.

Group tasks were designed to enable participants to share their personal experiences related to NCDs. They expressed their challenges in accessing NCD services in urban areas and the need for increased human resources for health in the districts. A rapporteur from each group gave feedback at a plenary session with more input encouraged from delegates. The implementation of the initiative followed a model of shared responsibility with the provincial government and civil society partners. This helped develop a low-cost model that utilized provincial government facilities and reach, with civil society offering technical and management assistance to maintain standards for optimal outcomes.

BENEFITS

This was the first interaction that government officials had with people living with NCDs in such a capacity. Their participation and voices on this occasion provided an honest, apolitical, and independent representation of the reality of life in these provinces, which resulted in far more fruitful discussions.

³¹ 'CitizenPoweredCities: Co-Producing Better Public Services with Citizens - OPSI' <https://www.oecd.org/governance/observatory-public-sector-innovation/blog/page/citizenpoweredcitiesco-producingbetterpublicserviceswithcitizens.htm> [accessed 31 July 2018].



5.3 Collaboration

CASE

Representation on Health Councils to Monitor and Advise Government

	Country	Brazil
	Duration	Ongoing

DESCRIPTION

Brazil's 'Citizens' Constitution' of 1988 laid the foundation for the construction of institutionalised mechanisms for citizens to engage with government at all levels (national, state, and municipal). The constitution also enshrined health as the right of all, and guaranteed the right of citizens, including people living with NCDs, to participate in health governance³².

One mechanism for involvement took the form of Health Councils, which operate at different levels of government including in most of Brazil's municipalities (over 5,000 of them)³³. They were set up to monitor the public and private health sectors, monitor and approve the country's health budget and allocations, and to assist in the implementation of national health policy³⁴.

Membership of the councils is divided between different sectors. 'Users' of the healthcare system, which includes people living with NCDs and representatives of CSOs, are allocated 50% of seats. The remaining 50% is split evenly between healthcare representatives and government representatives.^{35,36}

The way the Councils operate in reality, however, has drawn criticism that suggests their actual impact on policy may be quite limited. For example, Councils have no legal authority to make sure that their recommendations, decisions, and resolutions are actually implemented. They have also been criticised for membership guidelines that make it harder for smaller and less well-established civil society representatives to be included, as well as limited training for those who do secure a seat.^{37, 38, 39}

BENEFITS

According to some accounts, the Councils have resulted in cases of strong influence.³⁸ A study from 2014 even found that council experience is correlated with reductions in the incidence of corruption in public health programmes.³⁹

³² 'Taking a Seat on Brazil's Health Councils', OpenDemocracy. <http://www.opendemocracy.net/andrea-cornwall-vera-schattan-p-coelho-alex-shankland/taking-seat-on-brazils-health-councils> [accessed 27 July 2018].

³³ 'Municipal Health Councils (Brazil)', Participedia. <https://participedia.net/en/cases/municipal-health-councils-brazil> [accessed 27 July 2018].

³⁴ Martinez and Kohler.

³⁵ Martinez and Kohler.

³⁶ Antonio Augusto Dall'Agnol Modesto, Ana Costa, and Bahia Ligia, Health and Social Determinants in Brazil: A Study on the Influence of Public Participation on the Formulation of the Expanded Concept of Health and Liberating Practices (WHO) <http://www.who.int/social_determinants/resources/isa_public_participation_bra.pdf.

³⁷ Martinez and Kohler.

³⁸ 'Taking a Seat on Brazil's Health Councils.'

³⁹ George Avelino, Lorena G. Barberia, and Ciro Biderman, 'Governance in Managing Public Health Resources in Brazilian Municipalities', *Health Policy and Planning*, 29.6 (2014), 694–702. <https://doi.org/10.1093/heapol/czt003>.

5.4 Co-Production

CASE

Devolving Power to People through Personal Health Budgets



Country

UK



Duration

Ongoing

DESCRIPTION

One key government responsibility is to decide how to allocate public funds. In most cases, choices are made by officials within ministries or other positions of authority within the government. By contrast, the case of Personal Health Budgets in the UK presents one example of a government devolving part of this power to people, including people living with NCDs.

The National Health Service England (NHS) provides publicly-funded health services to approximately 54.3 million people.⁴⁰ Although a recognition of the value of meaningful involvement of patients can be traced to its foundation, recent legislation has resulted in more concerted efforts to step up involvement activities.

For example, the National Health Service Act of 2006 made it a legal duty for NHS bodies to involve people in planning, amending, and making decisions that impact services.⁴¹ The act specifically states that the Board must 'promote the involvement of patients, and their carers and representatives (if any), in decisions which relate to the prevention or diagnosis of illness in the patients, or their care or treatment.'⁴² It also sets out requirements with respect to general public consultation and involvement. This sharing of decision-making power in itself is evidence of co-production.

Within this context, Personal Health Budgets are a concrete example of the involvement of people in decision-making when it comes to their own health. They are intended to provide people with more control by allocating them NHS money to spend any services (there is no set list) they decide would be most beneficial for their health.⁴³

BENEFITS

Pilots of the scheme between 2009 and 2012 showed greater positive effects on quality of life and psychological well-being than commissioned services, alongside a reduction in the use of unplanned care.⁴⁴ Further studies have shown other benefits relating to cost-effectiveness and quality of life.⁴⁴ By 2014, approximately 60,000 people with complex health care needs had the formal right to a personal health budget.

⁴⁰ N. H. S. Choices, 'About the National Health Service (NHS) in England - NHS Choices', 2016. <https://www.nhs.uk/NHSEngland/thenhs/about/Pages/overview.aspx> [accessed 27 July 2018].

⁴¹ 'People in Control of Their Own Health and Care', The King's Fund, 2014. <https://www.kingsfund.org.uk/publications/people-control-their-own-health-and-care> [accessed 29 July 2018].

⁴² The National Archives, 'National Health Service Act 2006'. <http://www.legislation.gov.uk/ukpga/2006/41/contents> [accessed 29 July 2018].

⁴³ Reform, Expert Patients, 2015. <http://www.reform.uk/publication/expert-patients> [accessed 29 July 2018].

⁴⁴ Vidhya Alakeson and others, 'Debating Personal Health Budgets', *BJPsych Bulletin*, 40.1 (2016), 34–37. <https://doi.org/10.1192/pb.bp.114.048827>.

⁴⁵ 'People in Control of Their Own Health and Care.'



Key Skills Required for Meaningful Involvement in Government

→ Public speaking

Being heard by decision makers at gatherings such as the Health Council meetings in Brazil requires strong public speaking skills, including an ability to frame asks in ways that are persuasive and compelling in front of a large audience.

→ Ability to learn and adapt quickly

Engagement fora, especially at higher levels of the ladder of involvement, are likely to operate their own set of rules and procedures which would require time and effort to learn. Moreover, technical policy discussions are likely to require more in-depth knowledge on specific topics than most people would have before stepping into their role as advocates.

→ Diplomacy and negotiation

Debates on policy matters can easily become heated and conflict-ridden as opposing sides disagree. To succeed in such an environment, people living with NCDs who engage must be able to rely on their diplomacy and negotiation skills to build consensus and find constructive solutions.

→ Confidence

Meaningfully engaging in co-production of public services is likely to involve debating or disagreeing with those in power. This requires confidence which can take time to build.

→ Leadership

Being able to resolve conflicts, mediate between opposing views, collaborate with people from different backgrounds, and lead others are skills that would be extremely beneficial in the context of government involvement projects.

6. Health Care Delivery

Guide to Cases



Participation

Sweden

See page 30

Capturing Patients' Experiences through Interviews and Focus Groups

Key Features

Interviews
Focus Group Discussions

Collaboration

Canada

See page 31

Shaping Hospital Services with the Help of a Patient and Family Advisory Council

Key Features

Advisory Council Roles
Staff Committee Representation
Trainings

Co-Production

USA

See page 32

Nominating Patient and Family Advisers to Serve on Hospital Executive Councils

Key Features

Training
Advisory Council Roles
Executive Roles

6.1 Introduction

Meaningful involvement within health care delivery settings takes place when professionals cease to view people as passive 'patients' but as valuable contributors to the process of improving services with unique insights into current problems and potential solutions.

In this context, people living with NCDs (or 'service users'), can be engaged in designing or improving services through surveys about their experiences, serving as advisors, or joining governance committees.⁴⁶

The perils of not involving people in health care delivery are great. In the UK, for example, a series of reports compiled in reaction of adverse events demonstrated that, in most cases, significant harm could have been prevented and costs saved if organisations had listened to those in their care.⁴⁷

A recent systematic review of patient advisors on healthcare outcomes also points towards benefits, and highlights a large number of concrete examples,

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Listening to people living with NCDs is the key to learning their real necessities, not only medical but emotional needs as well. Free peer support groups established at places accessed by people living with NCDs; hospitals, consultations, and organizations, can create a community care model, a special place where they can share their feelings and propose new ideas to other NCDs stakeholders about their specific needs.”

Francis Zaballa Roquero, *Our views, Our Voices 2018*
Global Advisory Committee

⁴⁶ Laurel Liang and others, 'Patient Engagement in Hospital Health Service Planning and Improvement: A Scoping Review', *BMJ Open*, 8:1 (2018), e018263. <https://doi.org/10.1136/bmjopen-2017-018263>.

⁴⁷ 'People in Control of Their Own Health and Care.'



while also acknowledging the difficulty of evaluating the concrete impacts of such models.⁴⁸ It is important to note that this systematic review of the literature, yielding 639 articles, resulted in relevant case studies exclusively from High Income Countries. This suggests that this type of intervention (or scholarship on this topic) are relatively lacking in Low- and Middle-Income countries at this stage.

The cases presented below describe the efforts of three organisations that have worked to promote the meaningful involvement of their service users at the three levels of participation, collaboration, and co-production. The high impact and multiple uses of advisory councils are conveyed clearly in these experiences. Although the following cases may not all specifically relate to people receiving treatment for NCDs, the mechanisms involved are highly relevant and adaptable.

6.2 Participation

CASE

Capturing Patients' Experiences through Interviews and Focus Groups



Institution

Skaraborg Hospital Paediatric and Women's division



Country

Sweden



Duration

2014

DESCRIPTION

Communication between hospital staff and patients is a crucial first step to successful 'experience-based co-design' initiatives. At the Skaraborg Hospital Paediatric Hospital in Sweden, information was not frequently transmitted between these two groups until an involvement intervention took place in 2014.

The 'participation' level involvement of patients took the form of capturing mothers' and partners' experiences through extended interviews, during which they were asked open-ended questions to gain a holistic view of their views and opinions regarding services.

Interviews were followed by focus group meetings between parents and between a mixture of parents and staff. This gathering of insights from the first-hand perspective of service users is a key hallmark of participation.

A small number of healthcare professionals, including nurses, midwives, and nursing assistants took part in a similar process to identify areas of overlap or disagreement between the different groups.

The initiative then went beyond participation, as families worked with staff to make recommendations for improvements – which included providing better breastfeeding advice to new mothers along with 18 other priorities.

BENEFITS

Three months after the process, many of the 'simple' problems identified had actually been resolved. For example nurses received extra training and the ward beds for fathers were upgraded. Importantly, patients felt that the process of sharing their experiences and helping to make suggestions was a rewarding one.⁴⁹

⁴⁸ Anjana E. Sharma and others, 'The Impact of Patient Advisors on Healthcare Outcomes: A Systematic Review', *BMC Health Services Research*, 17 (2017). <https://doi.org/10.1186/s12913-017-2630-4>.

⁴⁹ Susanne Maria Kristina Gustavsson, 'Improvements in Neonatal Care; Using Experience-Based Co-Design', *International Journal of Health Care Quality Assurance*, 27.5 (2014), 427–38. <https://doi.org/10.1108/IJHCQA-02-2013-0016>.



6.3 Collaboration

CASE

Shaping Hospital Services with the Help of a Patient and Family Advisory Council

	Institution	Kingston General Hospital
	Country	Canada
	Duration	2010 to Present

DESCRIPTION

The Kingston General Hospital set out to implement an 'Interprofessional Collaborative Practice Model' as a key mechanism by which to 'transform the patient experience,' which was made a pillar of its strategic plan. By instituting this new model, the hospital expected to be able to deliver safer, higher quality care.

The Patient and Family Advisory Council was formed in January 2010 after it became clear that the input and advice of patients are essential if a patient- and family-centred approach to care was to be sustained.

The Council is formed of former patients or their family members working in partnership with leadership and staff. It ensures that patients and families are involved in every aspect of care, safety, and general improvement projects. It also gives them a seat at the table when decisions are made, a feature that goes beyond 'collaboration' and adds a clear 'co-production' element to this case.

As patients and families became increasingly involved, a paradigm shift took place within the organisation, transforming it from one that does things 'to and for' patients to one that partners with patients to meet their health needs.

Experiencing the benefits of this approach, the scale of involvement quickly grew. Beginning with 3 'patient experience advisors' in 2010, there were over 55 by 2014. The advisers even began joining staff on committees, hiring interview panels, and in continuous improvement trainings.

BENEFITS

As a result of this new approach, improvements were seen in the quality of patient care as well as quality of work life. Survey results of patients show that they are more aware of the plans relating to their care, that care is coordinated, and that they feel listened to and safe at the hospital.⁵⁰

⁵⁰ This case study based on Anndale McTavish and Cynthia Phillips, 'Transforming the Patient Experience: Bringing to Life a Patient- and Family-Centred Interprofessional Collaborative Practice Model of Care at Kingston General Hospital,' Patient Experience Journal, 1.1 (2014), 50–55.



6.4 Co-Production

CASE

Nominating Patient and Family Advisers to Serve on Hospital Executive Councils



Institution

Spectrum Health



Country

USA



Duration

2012

DESCRIPTION

Recognising that the traditional methods of surveys and focus groups are not sufficient in achieving a deep level of involvement, Spectrum Health has instituted a system of Patient and Family Advisory Councils to play an essential role in hospital governance and service delivery.⁵¹

Given this high level of responsibility, the process of selecting advisers is quite a rigorous one. Prospective advisers undergo a thorough interview process to determine if they possess the required skills and their level of commitment. Once selected, they receive training on, for example, how to speak up and share views on specific issues. Overall, selected advisers must represent the patient population with regards to age, gender, race, and socioeconomic status.

The system is composed of 11 Patient and Family Councils, each representing different service lines such as cardiovascular or oncology. While the Council sizes vary, each meets monthly and all members are asked to sign commitment papers to remain engaged for one year.

There is also a separate Executive Council, which includes 8 advisers nominated from the different Patient and Family Councils, who serve alongside top hospital executives. These 8 advisers also join systemwide committees dealing with, for example, biomedical ethics and medication safety. Since they are also chairs of their respective Patient and Family Councils, they also serve as the link between the two bodies, which is key to ensuring continuous feedback.

Importantly, the changes suggested by Councils do go on to implementation. To track and measure progress, Councils each have clear goals and implementation plans which are reviewed annually.⁵²

BENEFITS

The Patient and Family Advisory Councils roles and responsibilities are wide-ranging and assist staff in many valuable ways. For example, council members assist system leaders in prioritising actions; participate in the development of policies; provide feedback on communications to ensure information is relevant and understandable; assist with the design of facilities; and work to ensure access to information and resources.

⁵¹ Spectrum Health is an integrated health system of nine hospitals in the Michigan, USA.

⁵² This case study is based on Kristine White, 'Engaging Patients to Improve the *Healthcare Experience*', *Healthcare Financial Management: Journal of the Healthcare Financial Management Association*, 66.7 (2012), 84–88.

Key Skills Required for Meaningful Involvement in Health Care Delivery

→ Ability to offer constructive insights

Advisers are most effective when they are able to transform any negative experience they have had at a facility into a constructive suggestion for improvement, as opposed to simply using engagement opportunities to voice grievances.

→ Ability to question the status quo

The experience of Spectrum Health revealed that the most incisive and valuable comments came from advisers who were able to question the status quo by asking questions like ‘how come? What if? Why not? Who says?’⁵³

→ Commitment and dedication

Patient Advisers, for example, are often asked to repeatedly return to the facility where they received care long after having been discharged – sometimes without remuneration. To sustain a meaningful engagement given these constraints, it is important to identify advisers who have the right level of commitment and dedication to the goal of improving services for other patients.

→ Communication

As with any form of engagement, the ability to express views, opinions, and recommendations in a clear and compelling way is critical for maximising impact.

→ Willingness to learn

Whether it be the terminology and technical jargon used by hospital staff and management, or the details of involvement processes available at the institution, or detailed descriptions of healthcare processes, a keen willingness to learn is an important quality of effective advisers in a health care delivery context.

→ Collaboration and teamwork

Most involvement opportunities beyond the participation level often require teamwork with other patients or hospital staff, which is made far easier with a collaborative attitude and good interpersonal skills.

⁵³ White.

7. Making Meaningful Involvement Happen

The steps towards making meaningful involvement happen are simple and similar across sectors and levels of involvement. Although it may seem daunting to set up a first activity, there is a vast body of knowledge and experience to draw from.

Below are five key steps that can be followed and adapted by any organisation seeking to set up meaningful involvement initiatives for the first time.

STEP 1



Make a Commitment

Before planning the first activity, it is important for the organisation to make a formal or informal commitment to meaningfully involving people living with NCDs. An assessment of the organisation's capacity for meaningful involvement at different levels should be undertaken, and any evident barriers identified.

KEY QUESTIONS TO ANSWER

- Is there a broad organisational commitment to the principle of meaningful involvement?
- Are staff members confident when it comes to planning and implementing projects that involve people living with NCDs?
- Are there any foreseeable barriers to involvement? For example, are there barriers to the interest or ability of people living with NCDs to be involved (e.g. social/cultural stigma attached to an NCD condition; lack of financial support)? Is there a need for staff training or additional resources to complete a new project?

STEP 2



Set Goals

Decide what needs to be accomplished through meaningful involvement of people living with NCDs. For example, organisations may wish to step up advocacy campaigns on a particular topic, or improve their services to users.

KEY QUESTIONS TO ANSWER

- What are the main objectives of the meaningful involvement activity?
- What is the envisaged scope and duration?
- Does the organisation already have contact with people living with NCDs to involve in the planning process?

For an alternative checklist, take a look at the [International Alliance of Patients' Organisations 'Guidelines for Patient Involvement'](#)!

STEP 3



Choose a Strategy

Determine which specific mechanism would be most appropriate in achieving the activity's objectives with the resources available. This requires insight into the interests and skills of those the organisation wishes to engage.

KEY QUESTIONS TO ANSWER

- What level of engagement would be most feasible: collaboration, participation, or co-production?
- Given the available time and interests of those being engaged, what would be the best way of motivating action?
- Will the planned activities be inclusive, accessible by those with disability, and sufficiently representative?

STEP 4



Give Support

Once the project is in full swing, it is important to provide continuous support to those wishing to get involved. The extent of support necessary will differ based on the level of engagement taking place, and may range from providing simple FAQ sheets to in-depth training.

KEY QUESTIONS TO ANSWER

- Will effective involvement in your activity require specialised knowledge or skills?
- Is there a mechanism in place for people living with NCDs to reach out for information or other support?
- For any in-person activities, are there any special requirements to accommodate in terms of venue accessibility, catering, or timings?

STEP 5



Learn from Experience

After the activity has taken place (or after some time interval in the case of ongoing activities), evaluation is key to ensuring that objectives are being met, and to discerning any weaknesses in the approach that can be improved in future. Don't forget to recognise and celebrate successes!

KEY QUESTIONS TO ANSWER

- Are there appropriate mechanisms in place for gathering feedback from people living with NCDs involved?
- Have those involved been informed of the activity's results or final outcomes?
- In what ways can people living with NCDs involved be recognised for their time and contribution?

8. Conclusion

The meaningful involvement of people living with NCDs can occur in numerous different instances within a wide variety of sectors, including civil society, government, and health care delivery. As this review has outlined, involvement can take place at different levels depending on the objectives of the initiative and the interest, ability and opportunity of people living with NCDs to take part. These levels range from participation, where people have no decision-making power, all the way to co-production, where people have a significant role in shaping final outcomes.

While there is no universal formula for successful involvement initiatives or models, the 15 case studies presented in this review illustrate a number of mechanisms that can potentially be applied to different contexts and broadened to promote more meaningful involvement. Despite their diversity, they do reveal a number of general trends:

→ Combine different levels of involvement

Several case studies demonstrated that multiple mechanisms (belonging to different levels of involvement) could be deployed at once. For example, participation may be called for in conceptualising a campaign, but co-production can be taking place simultaneously within the initiative's leadership.

→ Participation can evolve to higher levels of involvement

Beginning at the lower levels of the ladder of Involvement, for example by consulting or surveying people living with NCDs, can naturally lead the way to more sustained collaboration as organisations see the clear benefit of engagement. Organisations new to this approach may also first need to establish contacts with advocates living with NCDs, and as the partnership evolves, advocates are then able and willing to contribute more.

→ Give and take

To be meaningful and sustainable, involvement initiatives must ensure to 'give recognition' to the people living with NCDs who volunteer their time and efforts. There are many ways of achieving this. For example, if surveying people, it is important to feedback results, share information, and explain the impact of the work they have contributed to. Training, exposure to new networks and opportunities, and peer recognition are also ways of giving back.

→ Success requires time and training

Particularly at the higher levels of involvement, certain skills are required of people living with NCDs. Stakeholders who commit to meaningful involvement need to identify what skills are needed for their particular initiative, and make allowances for the time and training that will be required to support people living with NCDs.

→ Establishing a new norm

To ensure sustainability and maximise impact, there needs to be a paradigm shift among stakeholders in order to establish meaningful involvement as a norm, not an exception. This will make it more likely for arrangements and processes to be put in place to ensure that involvement is effective and sustainable.

This review has set the stage for further investigations of success stories to extract lessons and illustrate the impact of meaningfully involving people living with NCDs. More work can be done to create guidelines and practical tools to help organisations build their own capacity to make the most of these mechanisms and explore additional possibilities.

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The meaningful involvement of people living with noncommunicable diseases is a critical element of an effective NCD response. From policymaking to awareness raising, clinical trials, academic research, advocacy, organisational governance, and more, people living with NCDs can contribute to many different facets of the NCD response and act as role models breaking barriers to inclusion.

Promoting meaningful involvement requires recognition of its importance and the creation of enabling environments, including dedicated spaces for involvement.

This review lays out some definitions of key concepts and explores what meaningful involvement of people living with NCDs currently looks like within Civil Society, Government, and Health Care Delivery.



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