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Life forward

Real voices, better choices

Embedding lived experience in policies for noncommunicable diseases and mental health

September 2025

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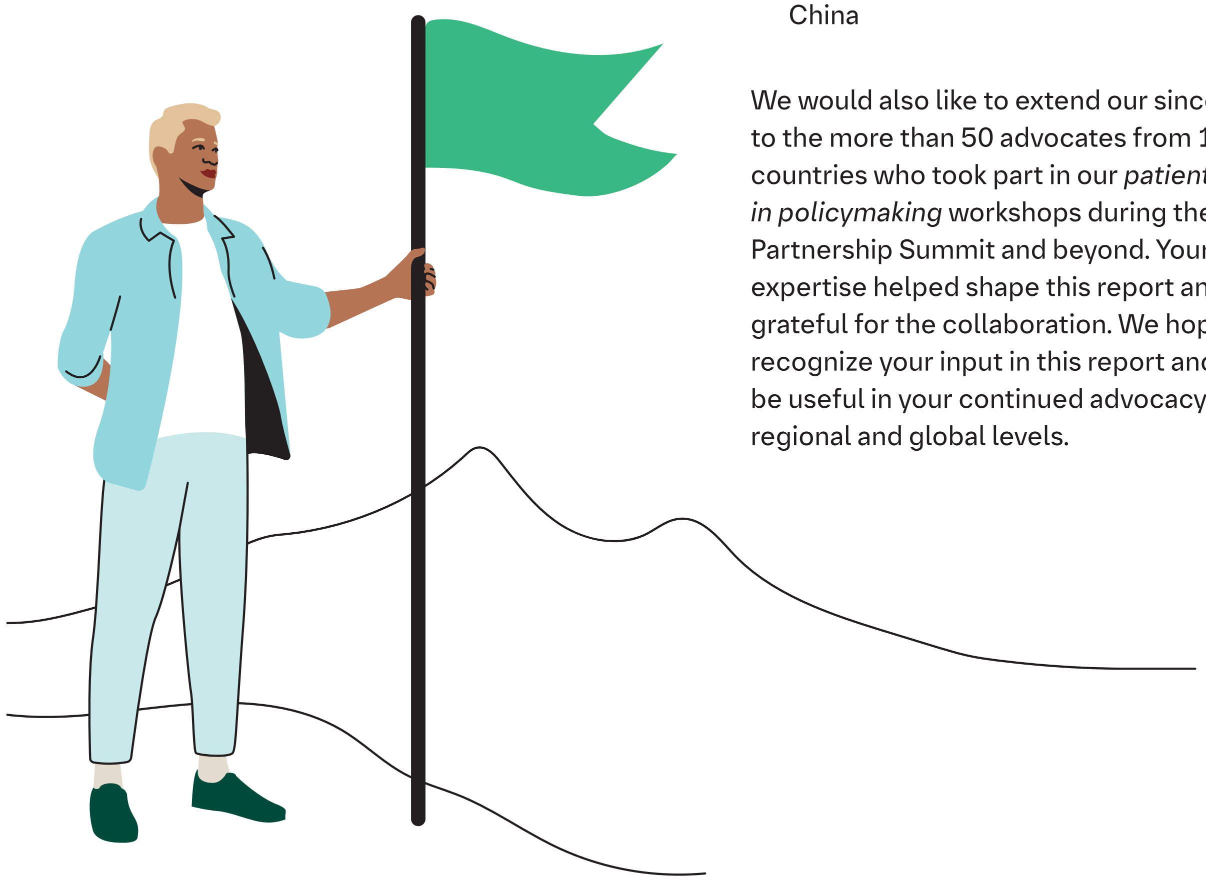

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Foreword

Three quarters of all deaths worldwide are caused by noncommunicable diseases (NCDs). Behind this staggering statistic are millions of people living with chronic conditions, mental health challenges and the daily reality of navigating health systems that too often fail to meet their needs and preferences. Yet their voices remain largely absent from the policy tables where decisions about their care are made.

This exclusion is not just morally wrong and unfair, but also risks undermining governments' economic and political goals. When policies are developed without meaningfully engaging people with lived experience, they miss critical insights that could improve outcomes, reduce costs and save lives. Patients and their families understand the gaps in care pathways and the real-world impact of policy decisions in ways that data alone can never fully capture.

The global burden of NCDs and mental health conditions continues to escalate, creating profound inequalities within and between countries. The UN High-Level Meeting on NCDs and Mental Health represents an unprecedented opportunity to commit to transformative action, guided by a Political Declaration that sets the impetus and targets for change.

But Declarations and targets are only as strong as their implementation. The critical question is not whether countries will commit to action – the *2024 WHO resolution on social participation for universal health coverage, health and well-being* clearly illustrates governments' ambitions. The urgent challenge is how they will turn those commitments into policies that genuinely improve lives.

That is the basis for this report.

By emphasizing the need to embed lived experience into policymaking – a cornerstone of the social participation agenda, and fundamental to IAPO's work – this report illustrates how vital national resources can be saved and how economic outcomes, beyond healthcare, can be improved. The report provides examples of how lived experience has informed policymaking, with the aim of showcasing good practices that can be replicated or adapted across different contexts.

For IAPO and the global patient organization movement, this report represents more than best practice guidance. It is a call to action for genuine partnership between people with lived experience and policymakers. IAPO extends its gratitude to Boehringer Ingelheim for commissioning this work and recognizing that amplifying patient voices is fundamental to creating inclusive, innovative, and effective health policy. It exemplifies the kind of partnership needed to transform health systems and drive meaningful change.

The path forward is clear, and the tools are at hand. Now is the moment to ensure that no policy affecting people with NCDs and mental health conditions is ever again developed without them. Now is the time to take decisive global action to fight back the rise of NCDs and mental health conditions.

This report serves as a roadmap for policymakers and decision-makers, guiding the implementation of the Political Declaration and informing other health and care policies and practices worldwide. Together, we can transform health systems and ensure that every voice is truly heard.

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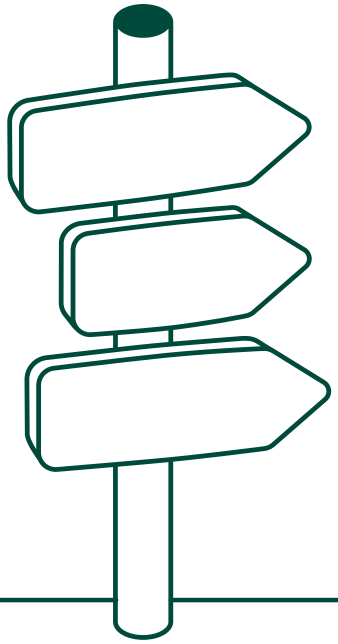

Executive Summary

Noncommunicable diseases (NCDs) and mental health conditions place enormous pressure on countries across the globe. This includes:

An estimated **$3 trillion** in lost economic productivity and health system costs

43 million lives lost to NCDs every year, with up to 80% of these deaths being preventable[i]

Disruption of livelihoods and quality of life, for patients, caregivers and other loved ones

Policymakers around the world have turned their attention to NCDs and mental health as the focus of the 2025 UN High-Level Meeting. Now is the time to create and implement effective national policies, led by lived experience.

Embedding lived experience in NCD and mental health policies can save vital national resources and improve economic outcomes beyond healthcare. It can improve the uptake of national policies, enabling a more efficient and targeted approach to health spending. Policies led by lived experience can also improve quality of care and health outcomes, which supports people to live well and contribute to the economy for longer.

This report aims to ensure that people with lived experience (patients and caregivers) and their advocates are at the core of national policies on NCDs and mental health. It provides examples and implementable solutions and details a pathway that all countries can follow.

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[i] https://ncdalliance.org/explore-ncds/ncds

Regardless of their starting point, every government has an opportunity to strengthen their policies with lived experience.

Widening the involvement of patients and caregivers in policymaking

- **Policymakers** should develop legal frameworks and implement initiatives that formalize the participation of people with lived experience in policy discussions
- **Advocacy groups** should campaign for initiatives and legislative change that embed lived experience in policymaking
- **Health system leaders** should champion the expertise of people with lived experience and advocate for their involvement in decision- and policymaking processes

Deepen and strengthen involvement through collaboration

- **Policymakers** should support collaboration with and between advocacy organizations, allocating adequate budget to involve people with lived experience and advocacy groups in policymaking
- **Advocacy groups** should identify strategic opportunities for collaboration on NCDs and mental health (e.g. with clinical societies, research institutes, media outlets)
- **People with lived experience** should get involved with relevant national advocacy groups, if they are able

Leveraging the unique strengths and capabilities of advocacy groups

- **Policymakers** should implement existing principles and guidance for participation in policymaking, such as those from the World Health Organization
- **Health system leaders and medical societies** should collaborate with advocacy organizations to identify system-wide change needed for NCDs and/or mental health conditions (e.g. through data generation projects)
- **Advocacy organizations** should call for and pursue training and capacity-building programs focused on data generation and policy engagement to ensure lived experience is considered in national policies

Ensuring transparency within formal mechanisms to better embed accountability and partnership

- **Policymakers** should embed transparency and accountability in decision-making processes, so people can understand how their input shapes outcomes
- **Advocacy groups** should call for more transparency and feedback in the development of national action plans for NCDs and mental health, for continued involvement in policymaking
- **Health system leaders** should drive transparency in the implementation of national policies on NCDs and mental health in clinical practice

Our definitions

- **Noncommunicable diseases (NCDs),** also known as chronic diseases, tend to be long in duration and are the result of interconnected genetic, physical, environmental and/or behavioral factors. People of all age groups, regions and countries are affected by NCDs.[1] Examples include cardiovascular disease, cancer, chronic respiratory disease, diabetes and chronic kidney disease.
- **Mental health** encompasses overall mental wellbeing[2] – a state that enables people to cope with life's stresses and function effectively – as well as serious conditions, such as depressive and anxiety disorders.
- **Lived experience** is the expertise gained by living with NCDs and/or mental health conditions, or by supporting and caring for people living with those conditions. This report, where appropriate, favors person-centered terminology like "person with lived experience" and "person living with..." over diagnosis-centered terms like "patient". Their individual insights and lived expertise are vital when looking at concepts like care quality and service delivery.
- **Advocates and advocacy groups** refers to the formalized groups that represent people with lived experience. These terms are used instead of "patient advocacy group" and "patient advocate" to include other important stakeholders (e.g. caregivers). Advocacy groups can help identify patterns across large groups of patients and caregivers (population-level data), which can help map burden of disease and inform decision-making.
- **Policymakers** are people with the standing and power to directly influence national or local government policy and/or decision-making processes. Some examples include elected officials, policy advisors and advisory committees, and civil servants.
- **Health system leaders** are people within national health systems that can directly implement, or closely influence the implementation of, national policy across national and local contexts.
- **United Nations High-Level Meeting (UN HLM) on NCDs and Mental Health** – Meeting held in September 2025 between Heads of State and Government, during the UN General Assembly in New York. This meeting resulted in a **Political Declaration on NCDs and Mental Health,** which outlines commitments agreed by UN Member States to drive progress to 2030 and beyond.

NCDs and poor mental health place a heavy and growing burden on people, economies and healthcare systems across the globe. NCDs are a major driver of global disability and death, with 18 million people dying prematurely in 2021 alone – 82% of these deaths are in low- and middle-income countries.[3,4] The global economic burden of poor mental health is estimated to cost up to 4% of GDP; driven by healthcare costs as well as an estimated $1 trillion of lost economic productivity per year.[5,6] The combined impact of NCDs and poor mental health can drain national resources and damage the long-term resilience of health and financial systems, the impacts of which are disproportionately felt in low- and middle-income countries.

NCDs and mental health outcomes are inextricably linked. People living with NCDs have a 15% to 27% higher risk of experiencing depression.[7] NCDs share many key determinants and risk factors with mental health and neurological conditions, including tobacco and alcohol use, lack of access to healthy foods and physical inactivity.[8] Mental illness is likely to affect one in two people in their lifetime and the linkage between NCDs, mental health, and their combined effect on health system resourcing and national economies cannot be ignored.[9] Furthermore, the challenges for healthcare systems to effectively manage mental health needs can exacerbate existing inequalities.[10]

Lived experience must be part of the evidence that drives national policy and action on NCDs and mental health. People with lived experience are best placed to understand their condition and the policies that will enable them to live well and that may prevent others from developing the condition. This includes developing formal pathways to embed lived experience in policymaking; enabling patients, caregivers and NCD and mental health advocacy groups to meaningfully participate, including defining priorities to address unmet needs, and determining who is appointed to represent the community at-large. No single advocacy organization or advocate can be all-encompassing of an entire community. It is essential that individual patients and their caregivers are included as experts with lived experience in policymaking at every phase – from consultation, to planning and implementation.

While there is encouraging national and global progress to better involve people with lived experience in policymaking, it remains the exception rather than the global norm. Recent years have seen several major global policy initiatives to guide global efforts to better integrate lived experience in health-focused policymaking. Some examples include:

- The 2023 *World Health Organization (WHO) Framework for Meaningful Engagement of People Living with Noncommunicable Diseases and Mental Health and Neurological Conditions*, which provides a pathway for how Member States can meaningfully engage these lived experience experts to guide policies, programs and services[11]
- The 2024 *WHO Resolution on Social Participation*, which urges Member States to implement, strengthen and sustain regular and meaningful social participation in decision-making processes for health[12]
- The global Patient Movement Catalyst, which is a group of patient representatives, lived experience experts and patient engagement champions seeking to accelerate progress towards a world where lived experience drives the design and delivery of healthcare[13]

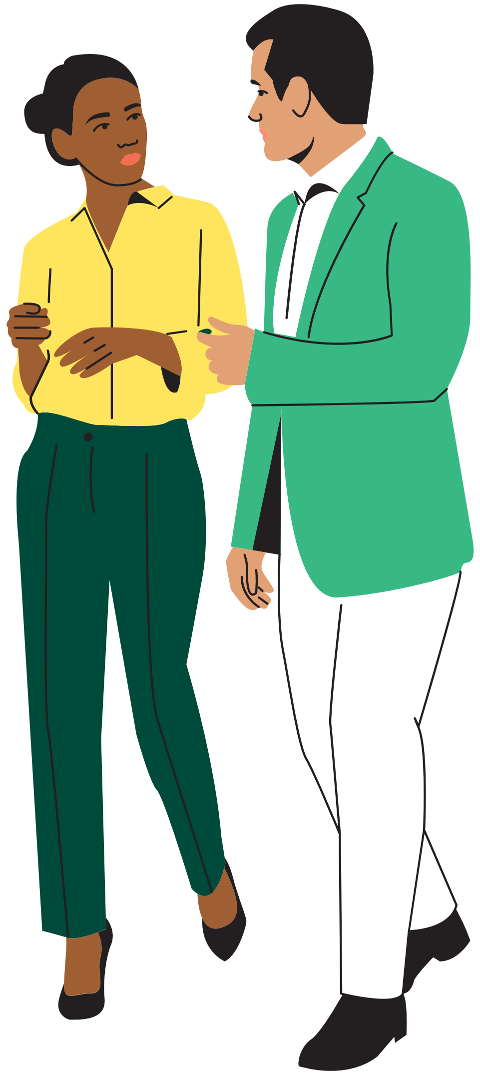
Building on these initiatives, the purpose of this report is to ensure that people with lived experience (patients and caregivers) and their advocates are at the core of national policies on NCDs and mental health. It provides solutions for how people with lived experience can and should be at the center of policy discussions and implementation. Building on global commitments secured at the UN HLM on NCDs and Mental Health, this report aims to be a useful tool for national decision-makers looking to better incorporate lived experience in policies on NCDs and mental health; and for advocacy groups as a means of sharing learnings and promising practices.

Our opportunity to embed lived experience in NCD and mental health policies

2025 marks a pivotal year for global health policy, with significant attention on NCDs and mental health. The 2025 UN HLM, and resulting Political Declaration on NCDs and mental health, provide a set of global targets and cost-effective, evidence-based actions for Member States to take forward. Progress in the prevention and control of NCDs and the promotion of mental health now falls to national governments, which are responsible for implementing the Political Declaration.

There is a real opportunity to advance evidence-based national policies on NCDs and mental health. Latest data shows that policy action to address NCDs and mental health is lagging: 43% of countries have yet to fully develop national guidelines to manage NCDs in primary care,[i] 46% of countries do not have a national strategy to mitigate risk factors for NCDs,[ii] and 33% of countries do not have a standalone mental health strategy.[14] While the Political Declaration is a major milestone in driving change, the global recommendations rely on national-level implementation led by Member States. Implementation and achievement of the shared goals require clear plans for action at a national level, bolstered by evidence-based decision-making and investment. The HLM and Political Declaration offer a rare opportunity to capitalize on political buy-in for NCD and mental health policies.

Capitalizing on this moment to embed lived experience in NCD and mental health policies can save vital national resources and improve economic outcomes beyond healthcare. The inclusion of lived experience in policy can improve the effectiveness and uptake of national policies and enable a more efficient and targeted approach to health spending.[15,16,17,18,19] It can also help improve quality of care and health outcomes, which enable people to live well and contribute to the economy. By better addressing NCDs and mental health conditions, policymakers can work towards alleviating the combined $3 trillion[iii] in estimated lost economic productivity per year.



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[i] Full indicator: develop evidence-based national guidelines/protocols/standards for the management of major NCDs through a primary care approach, recognized/approved by government or competent authorities.

[ii] Full indicator: an operational multisectoral national strategy/action plan that integrates the major NCDs and their shared risk factors

[iii] Lost economic productivity due to mental health conditions is estimated to be $1 trillion, and $2 trillion for NCDs.

The building blocks of lived experience-led policy for NCDs and mental health

This paper takes a strengths-based approach, emphasizing that people with lived experience are best-placed to guide policies and decisions that directly impact them or those at risk of NCDs and mental health conditions. In addition, these experts and their advocacy groups hold the knowledge and experience required to broaden meaningful participation in policymaking. This extends to areas like healthcare delivery, research and clinical trial design and government policy.

Governments vary in how extensively they involve people with lived experience in policymaking. There are some useful examples to draw from, whilst also recognizing differences in culture, societal norms and available resources can impact how lived experience can be embedded in national systems. This report also recognizes that health and political systems are not universal. It details a pathway that countries can follow no matter their starting point. Broadening involvement of lived experience in policymaking is a process of engaging, trialing, reflecting and adjusting to find the best route forward. This report aims to be a useful resource for policymakers, health system leaders, lived experience experts and advocacy groups alike.

Note on methodology

This report was developed with insights and feedback from 52 advocates from 16 countries across South and North America, Asia, Oceania, Africa and Europe. Full methodology can be found in **Appendix A.**

Regardless of their starting point, every government has an opportunity to strengthen their policies with lived experience. Embedding lived experience into policymaking is an iterative process with several building blocks (see Figure 1). It involves moving along a pathway, from widening involvement of people with lived experience as active contributors, through to embedding transparency and accountability within formal mechanisms. Each of these blocks is equally important and progress is made by building one on top of the other. The pathway involves trialing, evaluating and amending approaches to find what works best based in local contexts. Even countries with advanced policy frameworks for participation have room for improvement on this pathway, acknowledging that existing policies do not always guarantee equitable and widespread implementation.[i] Underpinning the entire pathway is a foundation of political leadership and support, where policymakers actively push for progress in working with people with lived experience.

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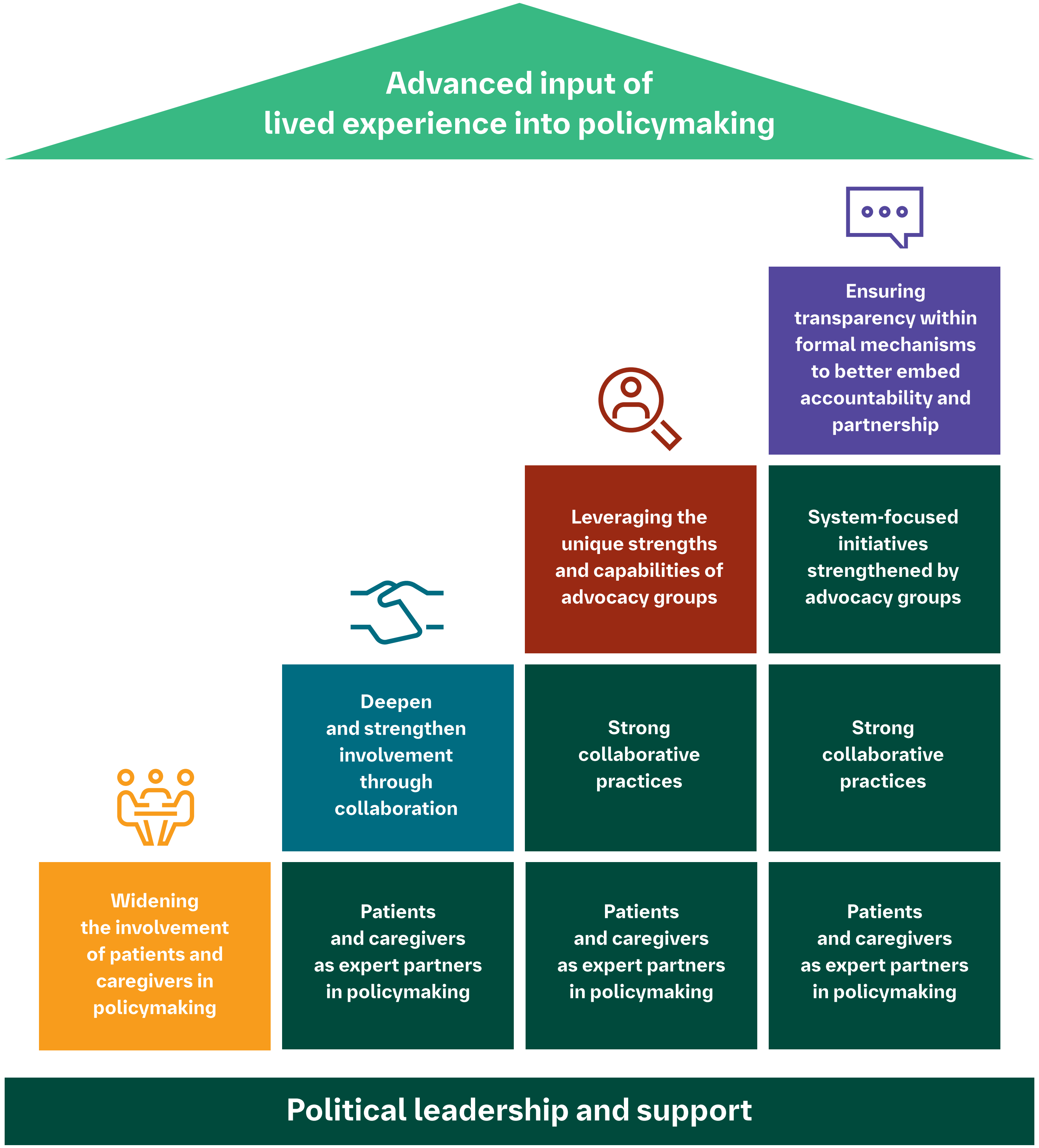
[i] Framework developed through insights gained as part of the Global Patient Participation Summit Workshops

Figure 1: The building blocks of lived experience-led policy



Widening the involvement of patients and caregivers in policymaking

Governments can only create evidence-based policy by recognizing and engaging patients and caregivers as equal partners in policymaking. Lived experience is key data.[21] It can guide improvements in care and investments in health systems, track performance and progress on policy implementation, and shape the services covering NCDs and mental health.[22,23,24] For this expertise to be embedded in national action, policymakers, clinicians and health system leaders must champion a culture where people with lived experience (patients and caregivers) are actively recognized and engaged as experts.

Cultural and societal norms can place people with lived experience into a more "passive role" compared with other stakeholders, such as clinicians and policymakers.[25] Where this is the case, the starting point should be to shift this perception and embed lived experience into a culture of collaboration and engagement. Some participation opportunities may exist, but they are reported to be sporadic, voluntary and poorly resourced – this makes it difficult to retain patients and caregivers as experts over time and risks perpetuating inequality between advocates (those with means and those without).[26] It also risks entrenching inequality within the system itself. While some advocacy groups have successfully found their political champions, government turnover and short-term focus in policymaking can hinder their ability to advance progress on participation.[27]

Legislation and legal frameworks can create the continuity and guidance needed to widen involvement of people with lived experience in policymaking. These tools can outline the rights that patients and caregivers have in healthcare settings and how they should be involved in policymaking processes. While laws cannot guarantee implementation of patient participation in policymaking, it can contribute to cultural shifts that enable lived experience to become more systemically embedded in health policies. They also provide accountability structures to advance progress, even during political transitions. A notable example of this includes *The Patient Basic Act* in South Korea (see **CASE STUDY 1**), which formally defines "patient" and "patient organizations" and stipulates their medical and treatment rights and responsibilities.

Other examples from Europe highlight that standardized legal frameworks for the role of lived experience in policymaking is a necessary starting point for widening the involvement of this expertise in policy- and decision-making. Formalizing the role of lived experience in policymaking has improved health outcomes across the continent.[28] It also sets the standard for true partnership and collaboration, including the need to pay people with lived experience for their expertise and time, in line with other experts (e.g. clinicians, researchers).[29]

Beyond legislation, governments can also opt for established involvement approaches to kickstart their collaboration with patients, caregivers and advocacy groups. One example includes a Citizens' Jury, which brings together a group of 12 to 24 people – reflective of the wider population - to discuss an issue, find common ground and brainstorm potential solutions.[30] Another includes a Citizen Advisory Group, with 10-30 members of the public who sit on a committee to inform and advise decision-making over an extended period of time – South Korea's Patient Policy Bureau (see **CASE STUDY 1**) is a good example of this approach.

CASE STUDY 1

The Patient Basic Act and the establishment of the Patient Policy Bureau in South Korea

Introduced in December 2024, the **Patient Basic Act** looks to protect patient health, support treatment journeys, enhance patient rights and foster a patient-centered healthcare environment. Existing laws (such as the Medical Service Act and the Patient Safety Act) were deemed insufficient in consistently and comprehensively guaranteeing patient rights. To help deliver components of the Patient Basic Act, a **Patient Policy Bureau** is being developed to focus on patient care and rights advocacy, with divisions such as Patient Policy, Patient Safety, and Patient Remedy. It will be responsible for developing and improving patient-related policies and systems. As of August 2025, the enactment of the Patient Basic Act has been included as a national agenda item, with active discussions ongoing between the government and the National Assembly.

The **Korea Alliance of Patients Organizations (KAPO)** is driving efforts to enact the Patient Basic Act and create the Patient Policy Bureau within the Ministry of Health and Welfare, helping to ensure that people with lived experience can become active participants in healthcare policy and decision-making. The goal is for the Bureau to advise the government on pursuing person-centered policies in a more integrated and systematic manner, while the Patient Basic Act is expected to serve as the overarching framework that covers foundational patient rights and support.

The Patient Basic Act implemented several key provisions that:

- Define patients and patient organizations and stipulate their rights and responsibilities, including participation in policymaking
- Requires the **Minister of Health and Welfare** to establish and implement a basic patient policy plan every **five years**
- Mandate a nationwide survey on patient policy every **three years**, with results to be made public
- Establish a **National Patient Policy Committee** to deliberate and decide on patient-related policies
- Calls for the creation of **Integrated Patient Support Centers** and the strengthening of patient support systems

Shifting cultural and societal norms requires long-term and sustained action. Legal and legislative frameworks can both catalyze change and ensure it is maintained, while Citizens' Juries and Advisory Committees offer solutions that can be implemented in the shorter-term. In other countries, the development or expansion of citizen juries – either at national or regional levels – provide a systematic mechanism to recognize lived experience within policymaking.

While the legal framework and/or engagement approach should be tailored to the national context, it should recognize patients and caregivers as informed and active participants in decisions about their care (in clinical and policy settings).

Calls to action

To widen the involvement of patients and caregivers in policymaking for NCDs and mental health, we call on:

- **Policymakers to** develop legal frameworks and implement initiatives that formalize the participation of people with lived experience in policy discussions, comparable to other expert groups. This should be incorporated into efforts to strengthen governance and national action plans for NCDs and mental health, using a whole-of-government approach (across Health and Social Care, Finance, Education, Justice and Interior ministries; recognizing the widespread impact of NCDs and mental health).
- **Advocacy groups to** ensure initiatives are designed and built in collaboration with those with lived experience thereby strengthening campaigns for initiatives and legislative change that embed lived experience in policymaking, building on learnings from other countries. These campaigns can then better highlight that input from people with lived experience is necessary to effectively implement the targets in the Political Declaration on NCDs and Mental Health at national level.
- **Health system leaders to** champion the expertise of people with lived experience and advocate for their involvement in decision- and policy-making processes. When invited to participate in policymaking processes, ask whether people with lived experience and advocacy groups will also be invited.

Deepen and strengthen involvement through collaboration

Strong involvement practices create a national policy environment that recognizes people with lived experience as experts and creates clear spaces for collaboration. This includes collaboration between people with lived experience, advocacy groups, and policy- and decision-makers. Integrating the perspectives of multiple stakeholders helps tailor policy interventions to the local context and the desired health outcomes.[31,32] Collaborative approaches to policy can also create new links between siloed policy areas, such as NCDs and mental health. For advocates, collaborative involvement practices can enable the pooling of resources, stress-test messaging and policy asks, and create wider networks for policy engagement and public campaigns.[33]

Collaborative practices can be hindered by limited national resources, which can create competition between advocacy groups and blur opportunities for collaboration. Advocates highlight growing demands on their time and pressures in terms of funding and workforce. Even where formal mechanisms exist, advocates may not have the resources to meaningfully take part in policy processes (e.g. resources to cover travel, logistics and staff time).[34] Cultural and language barriers, disease-related stigma, a lack of unified patient voice and limited financing make it harder for lived experience to be incorporated into policy. Without sustained funding and coordination, efforts will remain siloed and inequitable.

CASE STUDY 2

Patient and organizational involvement in fiscal policies in South Africa

“Sin taxes” have been a success story in South Africa due to advocacy efforts from scientists, civil society and patient organizations, health economists and similar ethical groups working together and leveraging their unique strengths. This created a unique lobbying effort around Sin Taxes, which led to the eventual passing of legislation.

Both the Tobacco Sin Tax and the Sugar Sweetened Beverage Tax were backed by evidence, including the fact that the legislation has worked well in other countries. This formed a core part of lobbying efforts from researchers and health economists, along with patient voices represented by advocacy group, such as the Heart and Stroke Foundation South Africa.

Key outcomes achieved include the implementation of a Tobacco Sin Tax and Sugar Sweetened Beverage Tax, which have shown to reduce the prevalence of NCDs.[35,36] Funds collated through these taxes are placed into a Health Promotion Levy Fund. In 2025, the Fund has yet to release resource to advocacy groups doing health promotion and disease prevention work, but work continues to improve this connection while the Fund continues to raise money.

CASE STUDY 3

Patient and Caregiver Charter

In 2020, the HeartLife Foundation – a Canadian patient-driven charity working to improve outcomes in heart disease – launched a Patient and Caregiver Charter that articulates a disease-agnostic national standard of rights to encourage the development and delivery of best-practice care.

The Charter began with a patient journey map, which helped the HeartLife Foundation understand lived experiences across the country. What began as an exercise to improve care in Canada was then used to drive awareness for heart failure globally, as the Charter was translated into 17 languages and endorsed by 33 groups willing to amplify their shared message.

Building on the recommendations in the Charter, the HeartLife Foundation set out to develop a compelling case for change for policy audiences. It partnered with the Canadian Institute for Health Economics to develop the economic evidence base to support the Charter.

Working with policy experts, the HeartLife foundation worked to translate the health economic case and Charter into an actionable policy framework, focused on diagnosis, screening and management. It included national messaging, as well as more local messaging and key data points. The asks were endorsed by clinical and professional societies, further strengthening the case for legislation on heart failure (currently moving through Canadian Parliament).

Government and private sector funding for collaboration and spaces for dialogue between advocacy organizations can help overcome some of the challenges. Support for umbrella networks and cross-disease coalitions has been shown to reduce fragmentation, enable evidence sharing, and present cohesive policy asks; for example, in Canada where leading advocacy organizations and professional societies are collaborating on a campaign to lower the screening age for colorectal cancer.[37] Working closely with other stakeholders (e.g. clinical societies and professional associations) on shared advocacy priorities can also help organizations build their profile and expand their network of policy influencers, as evidenced in **CASE STUDY 3**. Government funding should also take the shape of specific budget lines directed to the implementation of legal frameworks and legislation as described in building block 1.

Effective policymaking and the strengthening of health outcomes and care delivery relies on collaboration. System-focused initiatives have a real opportunity to further strengthen ties between different advocacy organizations and their approach to engaging with national policies.

Calls to action

To deepen and strengthen involvement through collaboration, we call on:

- **Policymakers to** support collaboration with and between advocacy organizations, allocating adequate budget to involve people with lived experience and advocacy groups in policymaking. For example, by providing opportunities for multi-stakeholder groups and coalitions to input into the design of national policies. Policymakers should also ensure that legal frameworks created to embed lived experience in policy is properly financed with dedicated budget. This approach will help stress-test government policies with all relevant stakeholders, thereby creating evidence-based policies that are fit-for-purpose at local and national levels.
- **Advocacy groups to** identify strategic opportunities for collaboration with other advocates that share their interest in NCDs and mental health (e.g. patient and caregiver groups, clinical societies, research institutes, media outlets). By leveraging their political strength in numbers, they should signal to policymakers the need for urgent action, including the importance of involving people with lived experience in policymaking.
- **People with lived experience to** get involved with relevant national advocacy groups, if they are able. Opportunities may look different in each country, but can include lending time and expertise to support research, guide policy messaging and engage with policymakers on meeting the targets set for the Political Declaration on NCDs and Mental Health.

Leverage the unique strengths and capabilities of advocacy groups

Advocacy groups often have unique access to the insights of people with lived experience, which is vital system-wide data that can strengthen national policies on NCDs and mental health. Advocacy groups with strong data generation capabilities and an understanding of the policy landscape (also known as *policy fluency*) can take part in policy discussions more comfortably – they can identify opportunities for improvement and table solutions, based on patient and caregiver insights. When datasets are detailed and tailorable (e.g. based on local, state and federal levels), advocacy groups can help policymakers understand the burden of specific conditions within their constituency/locality and guide targeted investment to drive progress.[38] With this information, advocacy and educational campaigns can also be tailored based on the needs of the local population.[39]

CASE STUDY 4

End Dialysis by 2050 – Kidney Health Australia

Kidney Health Australia's launch of their bold vision to *End Dialysis by 2050* was purposefully directed to key government stakeholders, with a clear message built on several principles:

1. Driving early detection and diagnosis
2. Highlighting the improvements in innovation and the importance of access to new treatments in kidney health to slow or stop progression of the disease to kidney failure
3. Fostering greater investment in future research and innovation to make dialysis a treatment of the past. This includes a focus on new treatments and technologies, kidney transplantation, increasing living kidney donation, and reducing wait lists via early intervention strategies

This message was delivered by people living with chronic kidney disease (CKD) to highlight the daily reality of dialysis and the critical need for earlier intervention. By ensuring the experiences of those living with and supporting a loved one with kidney disease was front and center, it added real-life experience to the important message delivered to government. To bring the aspiration to life, lived experience was paired with economic impact data from a Deloitte report, commissioned by Kidney Health Australia, which found that investment in early detection could significantly benefit health system savings as well as quality of life years for those with CKD. For example, access to new medications that slow the rate of decline in kidney function can be directly linked to this bold vision to End Dialysis by 2050. This is similar for early detection and awareness programs.

This advocacy gained much attention for the realities facing those living with kidney disease. Kidney Health Australia continues to work with government on finding solutions to address the kidney health emergency. Having a well-defined goal and clear steps to "end dialysis", together with measurable and achievable outcomes and a bold "person-centric" campaign that resonated with key stakeholders and generated significant media pick-up.

CASE STUDY 5

Utilizing collaborative approaches to improve affordable access to treatments in Japan

In 2025, the Japanese government announced an increase in the upper limit of the high-cost medical care system's burden, which meant that many patients in Japan would not be able to afford the optimum treatment for their conditions. Advocacy groups highlighted that people with lived experience and their representative organizations had not been consulted on these changes.

The Japan Association of Intractable and Rare Diseases (JPA) launched an emergency campaign with the National Federation of Cancer Patient Organizations and Izumi Association for Chronic Myeloid Leukemia Patients and Families to oppose the new upper limit. Within three days, the campaign collected responses from more than 3,600 people with lived experience, healthcare professionals and members of the public through an online questionnaire. These results were then presented to the Prime Minister.

As a result, advocacy groups had an opportunity to engage in dialogue with ministers and the planned increase in the co-pay ceiling was temporarily postponed. Furthermore, a bipartisan caucus was organized to discuss this issue on an ongoing basis.

The success of this campaign was driven by the large-scale collaboration between two advocacy organizations who often have differing activities and perspectives; as well as the volume of responses received to the questionnaire (only possible through this collaboration). An additional factor was support from other academic and professional societies/groups who also objected to the raise, as it lent greater awareness and credibility to the issue.

Advocacy groups and policymakers face several challenges in leveraging these strengths and capabilities. Firstly, data generation requires time and resource – a challenge reported by most advocacy groups, regardless of their size. Even with high-quality evidence and messaging, operating across several governmental levels (national-regional or local-state-federal) can be difficult. Focusing on only one part of the system becomes more resource-intensive in the long-run.[40] For example, new policies may only be implemented at local level, with further advocacy required at state or federal level. Similarly, policymakers may also have limited experience in engaging with lived experience data or implementing system-led initiatives to support meaningful participation in policymaking (beyond simple consultative mechanisms).

There are great examples and guidelines available to bolster policy fluency and data generation capabilities in the advocacy community. One good example is the European Patients' Academy on Therapeutic Innovation (EUPATI), which aims to help patients understand how medicines are developed by offering clear, accessible education and training. This includes capacity-building for terminology, methodology and key concepts within health innovation, enabling people to contribute to research design, clinical trials and overall medicines development (including regulation and Health Technology Assessment).[41] Examples from Australia (see **CASE STUDY 4**) and Japan (see **CASE STUDY 5**) show where advocacy groups have used data and evidence to strengthen their case for change to policymakers.

Similarly, guidance such as the WHO's *Advocacy Toolkit on Social Participation for Universal Health Coverage, Health and Well-being* and *Framework for Meaningful Engagement of People Living with NCDs and Mental Health and Neurological Conditions* can provide clear examples and practices for how policymakers can better support advocacy groups in engaging with decision-making processes.[42]

By relying on existing tools and examples, policymakers do not need to "start from scratch" in leveraging the strengths and capabilities of advocacy groups. Supporting advocacy groups with policy fluency and data generation helps leverage their unique strengths and capabilities and strengthens national policies on NCDs and mental health.

CASE STUDY 6

Embedding lived experience in NCD and mental health screening in India

During the COVID 19 pandemic, marginalized communities in India faced compounded risks from both communicable disease and under diagnosed NCDs like hypertension and diabetes, which exacerbated COVID severity. These groups also experienced heightened stress and mental health burden, yet traditional health services remained inaccessible or untrusted.

Swasti adapted its flagship i4We (Invest4Wellness) model to co-locate NCD screening and psychosocial support at COVID 19 vaccination camps, leveraging trusted community institutions and frontline workers drawn from the affected communities. Community members and self help groups informed camp location, timing, and design. Community health workers (trusted peers) conducted awareness, screening, and referrals. Mental health was addressed via sensitization, counselling availability on-site, and follow-up community engagement.

From planning to execution, community representatives guided messaging, identified languages and mediums that resonated culturally, and signaled local concerns (e.g. stigma, loss of wage). Their voices shaped the decision to offer quick NCD checks during the waiting period before/after vaccination, transforming a logistical pause into a critical health opportunity.

This model led to higher uptake of both vaccination and NCD screening among marginalized populations. Early detection of hypertension and diabetes enabled timely referrals, medical counselling, and connection to low-cost generic medicines via government schemes like Jana Aushadhi Kendras. Simultaneously, on-site mental health counselling and respectful care protocols reduced anxiety and built trust in formal health services.

Calls to action

To leverage the unique strengths and capabilities of advocacy groups, we call on:

- **Policymakers to** implement existing principles and guidance for participation in policymaking for NCDs and mental health, such as the WHO's *Resolution on Social Participation*, the *Political Declaration on NCDs and Mental Health* and the WHO's *Framework for Meaningful Engagement of People Living with NCDs and Mental Health and Neurological Conditions.* This will allow policymakers to better leverage the strengths of advocacy groups and write evidence-based policies that are scale-able across national policy contexts.
- **Health system leaders and medical societies to** collaborate with advocacy organizations to identify system-wide changes needed to improve the lives of people living with NCDs and/or mental health conditions. This could be through consultation exercises, data generation projects and/or workshops to build joint policy asks to create more inclusive and impactful health-promoting environments.
- **Advocacy organizations to** call for and pursue training and capacity-building programs, focused on policy engagement and using data to ensure lived experience is considered in national policies. This is especially important for national action plans on NCDS and mental health.

Ensure transparency within formal mechanisms to better embed accountability and partnership

Transparency and accountability help people with lived experience, advocacy groups and policymakers in collaborating to create better policies. A system with two-way dialogue (also described as a *feedback loop*) is essential to encourage trust between policymakers and people with lived experience. Feedback is vital for patients, caregivers and their advocacy groups to understand how best to contribute to the policymaking process – this includes an understanding of what information is helpful, where gaps still exist and how their efforts fit into the broader policy and stakeholder landscape. Insights from people with lived experience and population-level information from advocacy groups provide invaluable detail to guide smart, cost-effective and targeted interventions for NCDs and mental health.[43] This is especially important within the current climate of fiscal constraints and instability.

Even in systems with consistent patient participation, there is a lack of follow-up on how feedback eventually shapes policy. Advocates report that seeing the final result without an explanation on how their input was used can make participation feel tokenistic, creating a sense of mistrust in the system. Even in countries where there are formal mechanisms for lived experience input, advocates report feeling unsure about the value and impact of their contributions, which limits their opportunity to build and learn from this policymaking experience.[44] In some cases, advocacy groups report that the legal requirement for inclusion has evolved into a “box-ticking” exercise.[45] Meaningful integration of lived experience in policymaking must include transparency and feedback about decision-making processes.

Some health technology assessment (HTA) examples show how this feedback loop can be built into decision-making systems for healthcare. The involvement of lived experience has been shown to enhance HTA decision processes with greater and more relevant evidence. Some countries have formal mechanisms that actively support the inclusion of people with lived experience in their decision- and policymaking processes. This often includes support for patients and other members of the public involved in the process,[46,47,48] and guidance for decision-makers to incorporate lived experience into their processes.[49,50] An example from Canada’s Drug Agency (**CASE STUDY 7**) shows how feedback loops help advocacy groups and people with lived experience strengthen policy knowledge and future contributions to policymaking processes.

There are still opportunities for improvement within HTA processes and beyond. In many countries, actionable guidance on effective partnership working and feedback mechanisms on how lived experience is incorporated into decision-making is still a missing puzzle piece.[51,52,53] Providing such guidance and feedback enables both policymakers and advocacy groups to evolve and grow in their practices – strengthening existing partnerships and delivering incrementally better results over time.

CASE STUDY 7

Enhancing transparency in Health Technology Assessment (HTA) – Canada’s Drug Agency

Canada’s Drug Agency (CDA, formerly CADTH) works with patient organizations to ensure lived experience evidence is considered in national HTAs. In the past, patient groups often submitted input without knowing how it influenced final recommendations, creating frustration and eroding trust in the process.

In response, CDA – guided by HTA International’s (HTAi) Values and Standards – introduced a formal feedback process. Every patient group that contributes to a Common Drug Review or pan-Canadian Oncology Drug Review now receives an individual thank-you letter outlining which parts of their submission were most valuable and how they informed the final assessment. For oncology reviews, verbal or in-person feedback is also offered.

This approach closes the transparency gap by showing contributors the tangible role their input plays in shaping decisions. It also strengthens future submissions, as groups receive clear suggestions for improvement. Recognized internationally as good practice, the CDA model has been recommended for wider use across all HTA activities, from Optimal Use projects to Horizon Scans.

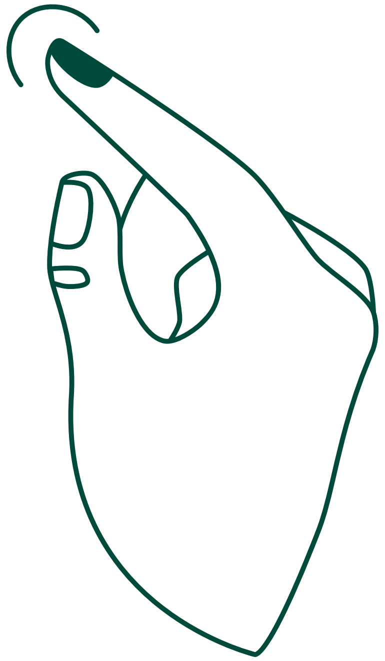
By embedding this feedback loop, CDA has built trust with patient communities, improved the quality of evidence it receives, and demonstrated that patient participation can directly shape national policy decisions.

Calls to action

To ensure transparency within formal mechanisms to better embed accountability and partnership, we call on:

- **Policymakers to** embed clear, transparent decision-making processes and close the feedback loop so people with lived experience see how their input shapes outcomes. This is particularly important within the context of national action plans for NCDs and mental health, which pose a complex and growing challenge for national governments.
- **Advocacy groups to** call for more transparency and feedback from governments developing national action plans for NCDs and mental health, underpinned by an ambition for continued involvement in policymaking. Draw from existing models in HTA and regulatory processes and explore whether these may be transferable to other policy contexts.
- **Health system leaders to** drive transparency in the implementation of national policies on NCDs and mental health; ensuring that the feedback loop is incorporated into clinical practice across national contexts.

Advancing input of lived experience in policymaking: our calls to action



The involvement of lived experience in policy- and decision-making can improve health outcomes across NCDs and mental health. There are strong examples of lived experience-led policies that decision-makers can learn from especially for governments beginning to incorporate lived experience into their policy processes. For those further along, there is still room for improvement – most importantly, this means ensuring transparent feedback for lived experience experts in formal mechanisms. To truly meet the targets and ambitions of the Political Declaration on NCDs and Mental Health, countries must ensure that lived experience is incorporated into their policies.

We call on:

Policymakers

- **Develop legal frameworks and implement initiatives that formalize the participation of people with lived experience in policy discussions, comparable to other expert groups.** This should be incorporated into efforts to strengthen governance and national action plans for NCDs and mental health, using a whole-of-government approach (across Health and Social Care, Finance, Education, Justice and Interior ministries; recognizing the widespread impact of NCDs and mental health); thereby widening the involvement of patients and caregivers in policymaking.
- **Support collaboration with and between advocacy organizations, allocating adequate budget to involve people with lived experience and advocacy groups in policymaking.** For example, by providing opportunities for multi-stakeholder groups and coalitions to provide feedback on and input to the design of national policies. Policymakers should also ensure that legal frameworks created to embed lived experience in policy is properly financed with dedicated budget lines. This approach will help stress-test government policies across multiple interlinked perspectives, thereby creating evidence-based policies that are fit for purpose at local and national levels.
- **Implement existing principles and guidance for participation in policymaking for NCDs and mental health,** such as the WHO's *Resolution on Social Participation,* the *Political Declaration on NCDs and Mental Health* and the WHO's *Framework for Meaningful Engagement of People Living with NCDs and Mental Health and Neurological Conditions.* This will allow policymakers to better leverage the strengths of advocacy groups and write evidence-based policies that are scale-able across national policy contexts.
- **Embed clear, transparent decision-making processes and close the feedback loop so people with lived experience see how their input shapes outcome.** This is particularly important within the context of national action plans for NCDs and mental health, which pose a complex and growing challenge for national governments.

Advocacy groups

- **Ensure initiatives are designed and built in collaboration with those with lived experience thereby strengthening campaigns for initiatives and legislative change that embed lived experience in policymaking,** building on learnings from other countries. These campaigns can then better highlight that input from people with lived experience is necessary to effectively implement the targets in the Political Declaration on NCDs and Mental Health at a national level.
- **Identify strategic opportunities for collaboration with other advocates that share their interest in NCDs and mental health** (e.g. patient and caregiver groups, clinical societies, research institutes, media outlets). By leveraging their political strength in numbers, they should signal to policymakers the need for urgent action, including the importance of involving people with lived experience in policymaking.
- **Call for and pursue training and capacity-building programs, focused on policy engagement and using data to ensure lived experience is considered in national policies.** This is especially important for national action plans on NCDs and mental health.
- **Call for more transparency and feedback from governments developing national action plans for NCDs and mental health,** underpinned by an ambition for continued involvement in policymaking. Draw from existing models in HTA and regulatory processes and explore whether these may be transferable to other policy contexts.

Health system leaders

- **Champion the expertise of people with lived experience and advocate for their involvement in decision- and policymaking processes.** When invited to participate in policymaking processes, ask whether people with lived experience and advocacy groups will also be invited.
- **Collaborate with advocacy organizations, alongside medical societies, to identify system-wide changes needed to improve the lives of people living with NCDs and/or mental health conditions.** This could be through consultation exercises, data generation projects and/or workshops to create joint policy asks to create more inclusive and impactful health-promoting environments.
- **Drive transparency in the implementation of national policies on NCDs and mental health;** ensuring that the feedback loop is incorporated into clinical practice across national contexts.

People with lived experience

- **Get involved with relevant national advocacy groups, if they are able.** Opportunities may look different in each country, but can include lending time and expertise to support research, guide policy messaging and engage with policymakers on meeting the targets set for the Political Declaration on NCDs and Mental Health.

Appendix A: Methodology

This report was developed using extensive desk research and in close consultation with advocacy organizations focused on NCDS and mental health.

Phase 1 started with a systematic literature review, examining patient participation in health – covering clinical trials, access and delivery of medicines, patient-focused research, health policy, clinical characteristics and healthcare insurance.

Phase 2 built on the findings of the literature review, gathering insights from advocacy groups about their experiences in engaging with policymakers about NCDs and mental health. As part of Boehringer's Global Patient Partnership Summit, we hosted two large workshops to:

- Map priority challenges that need to be addressed to improve patient participation in policymaking
- Gather examples of promising practices, policy levers and target stakeholders to engage in policy and advocacy work for NCDs and mental health

These workshops collated insights from more than 52 advocates across 16 countries, covering Asia, Oceania, Africa and Europe. Further virtual workshops were hosted to gather insights from advocates in North and South America. Several advocates were asked to share further information to build our library of promising practices (see Appendix B).

Phase 3 involved combining the desk research and advocacy insights in this report and its recommendations. This process was guided by an expert Editorial Board, consisting of advocacy leaders with experience in the policy space for NCDs and mental health. They provided feedback on the skeleton and several drafts of this report, and took part in a virtual meeting to align on terminology, sharpen policy asks and share examples of promising practices to include.

Appendix B: Examples of promising practices

Widening the involvement of patients and caregivers in policymaking

The Patient Basic Act and the establishment of the Patient Policy Bureau in South Korea

Introduced in December 2024, the **Patient Basic Act** looks to protect patient health, support treatment journeys, enhance patient rights and foster a patient-centered healthcare environment. Existing laws (such as the Medical Service Act and the Patient Safety Act) were deemed insufficient in consistently and comprehensively guaranteeing patient rights. To ensure the specific provisions of the new law can be realized, efforts are also underway to establish a **Patient Policy Bureau**, which would be dedicated to patient care and rights advocacy, with divisions such as Patient Policy, Patient Safety, and Patient Remedy. It will be responsible for developing and improving patient-related policies and systems. As of August 2025, the enactment of the Patient Basic Act has been included as a national agenda item, with active discussions ongoing between the government and the National Assembly.

The **Korea Alliance of Patients Organizations (KAPO)** is driving efforts to enact the Patient Basic Act and create the Patient Policy Bureau within the Ministry of Health and Welfare, helping to ensure that people with lived experience can become active participants in healthcare policy and decision-making. The goal is for the Bureau to advise the government on pursuing person-centered policies in a more integrated and systematic manner, while the Patient Basic Act is expected to serve as the overarching framework that covers foundational patient rights and support.

The Patient Basic Act implemented several provisions that:

- Define patients and patient organizations and stipulate their rights and responsibilities, including participation in policymaking
- Requires the **Minister of Health and Welfare** to establish and implement a basic patient policy plan every **five years**
- Mandate a nationwide survey on patient policy every **three years**, with results to be made public
- Establish a **National Patient Policy Committee** to deliberate and decide on patient-related policies
- Calls for the creation of **Integrated Patient Support Centers** and the strengthening of patient support systems

Deepening and strengthening involvement through collaboration

Patient and organizational involvement in fiscal policies in South Africa

“Sin taxes” have been a success story in South Africa due to advocacy efforts from scientists, civil society and patient organizations, health economists and similar ethical groups working together and leveraging their strengths. For these taxes and the Tobacco and Electronic Devices Bill – which is going through the South African Parliament – multi-sectoral collaboration enabled a greater mobilization of action and lobbying efforts around the bills and the subsequent passing of the legislation.

Both the Tobacco Sin Tax and the Sugar Sweetened Beverage Tax were premised by evidence, including the evidence that the legislation has worked in other countries with subsequent positive health impacts. The patient voice was largely represented through civil society organizations such as the Heart and Stroke Foundation South Africa.

Specifically for the Tobacco Sin Tax, this was increased within the 2025 South African budget. Excise duties on cigarettes, cigarette tobacco, and vaping products will rise by 4.75%, while pipe tobacco and cigars will see a 6.75% increase. These increases are part of a broader strategy to raise revenue and discourage consumption of these products.

Key outcomes achieved include the implementation of a Tobacco Sin Tax and Sugar Sweetened Beverage Tax – both of which have shown to reduce the prevalence of NCDs – which are collected and placed into a Health Promotion Levy Fund. The fund has not to date materialized or transferred to patient or advocacy organizations doing the health promotion and disease prevention work, but work continues to improve this connection while the fund continues to raise money.

Patient and Caregiver Charter

In 2020, the HeartLife Foundation – a Canadian patient-driven charity working to improve outcomes in heart disease – launched a Patient and Caregiver Charter that articulates a disease-agnostic national standard of rights to encourage the development and delivery of best-practice care. The charter is an example of how lived experience-led initiatives can drive improvements in health policy, and how collaborative approaches can drive policy outcomes.

Work on the Charter began with a patient journey map to understand lived experiences across the country. What began as an exercise to improve care in Canada was then used to drive awareness in care for heart failure globally as the Charter was translated into 17 languages, endorsed by 33 groups and united many advocacy groups to amplify a shared central message.

While the Charter itself is a useful advocacy tool, it was recognized that further collaboration was required to support the implementation of the policy changes it called for. This was achieved through partnership with the Canadian Institute for Health Economics to develop a comprehensive report on the health economic case of the Charter. In this way, the Institute of Health Economics acted as the credible evidence generator partner for the advocacy messages in the Charter.

Working with policy experts, the report was then narrowed down into a clear set of asks within a policy framework, focused on diagnosis, screening and management. It included national messaging, as well as more local messaging and data points. The asks were endorsed by clinical and professional societies, further strengthening the case for legislation on heart failure (currently moving through Canadian Parliament).

Critically, this collaborative effort created awareness for the heart failure community and built the profile and reputation of HeartLife in Canada. The cross-sector collaboration is a great example of how to secure cut-through with a policy audience.

OneVoiceILD in the UK

OneVoiceILD is a transformational movement uniting the interstitial lung disease (ILD) community comprising people with lived experience, doctors and other health care professionals to address system-wide challenges in care such as slow and inaccurate diagnosis, inequity of access to support services, and lack of access to pharmaceutical treatments to slow the disease. The OneVoiceILD movement is committed to strengthening ILD services across the UK to meet the priorities of people with the disease.

By reimagining the current model of care, OneVoiceILD is working to build a future where ILD services meet the specific needs of people living with ILD. The initiative is driving strategic, large-scale change to improve healthcare delivery, patient outcomes, system efficiency, and workforce capacity.

Patient voice is at the heart of OneVoiceILD. Every decision and action is shaped by the lived experience and insights of those directly affected. This patient-led approach forms the foundation of the initiative’s strategy and structure. It is driven by a Lived Experience Panel covering a wide range of experiences of ILD and caring for someone with the disease. Through collaboration with over 200 healthcare professionals and those with lived experience, OneVoiceILD harnesses collective expertise to design innovative, sustainable solutions with long-term impact. In areas where the OneVoiceILD ‘Optimum ILD Care Pathway’ has been implemented, improvements have already been seen in significantly lower wait times and reduced need for patients to travel – both vital to the patient experience.

The initiative is supported by a Secretariat provided by Action for Pulmonary Fibrosis (APF), which has extensive experience in amplifying lived experience and building strong ILD patient networks.

UN Treaty Body Reviews and the role of civil society: the case for tobacco control and women’s rights in Spain

The United Nations has a system of treaty bodies – committees of independent experts – that are responsible for monitoring how countries implement the international treaties they have ratified. One such body is the Committee on the Elimination of Discrimination Against Women (CEDAW Committee), which oversees the implementation of the CEDAW Convention. Civil society plays a crucial role in this process. NGOs and other organizations bring ground-level evidence, independent research, and often the voices of affected communities to the attention of the Committee. This ensures a more accurate and holistic understanding of the human rights situation in a country.

Public consultations also strengthen transparency, accountability, and democratic participation in international human rights monitoring.

MÁS QUE IDEAS Foundation – which works to enhance individual and collective action from the different stakeholders in healthcare, in collaboration with the National Committee for Tobacco Prevention (CNPT) and Action on Smoking and Health (ASH) – brought together in May 2019 a group of 25 experts in tobacco control, public health, feminism, and human rights to discuss this issue. As a result of that meeting, they produced a report, supported by 20 other organizations, which was submitted to the United Nations Human Rights Council. This report was considered during Spain's Universal Periodic Review (UPR) on Human Rights (January 2020), with the aim of encouraging the Spanish government to implement new measures to protect the population's health from the harms of tobacco.

Through this initiative, they were able to raise awareness and engage many organizations that do not actively work in tobacco control. Individuals and entities from the fields of education, healthcare, civil society, media, human rights, and feminism took part in this effort, which aimed to bring a new approach to health activism—one grounded in a human rights perspective. This approach makes it possible to use new institutional channels to influence government policies and measures, as well as to ensure their proper implementation.

The greatest success of this initiative has been bringing together individuals and organizations from diverse sectors to work on one of the most pressing global public health issues: tobacco use. The power and influence of the tobacco industry demand a collective effort and the sharing of resources to promote effective tobacco control policies and to develop new approaches that can help shape healthier, more sustainable, and environmentally friendly societies.

Working in health from a human rights perspective is an innovative approach that opens up new ways of working and creates opportunities to influence the agendas of institutions actively engaged in human rights.

Leverage the unique strengths and capabilities of advocacy groups

End Dialysis by 2050 – Kidney Health Australia (KHA)

Kidney Health Australia's launch of their bold vision to End Dialysis by 2050 was purposefully directed to key government stakeholders, with a clear message built on several principles:

1. Driving early detection and diagnosis
2. Highlighting the improvements in innovation and the importance of access to new treatments in kidney health to slow or stop progression of the disease to kidney failure
3. Fostering greater investment in future research and innovation to make dialysis a treatment of the past. This includes a focus on new treatments and technologies, kidney transplantation, increasing living kidney donation, and reducing wait lists via early intervention strategies

This message was delivered by people living with chronic kidney disease (CKD) to highlight the daily reality of dialysis and the critical need for earlier intervention. By ensuring the experiences of those living with and supporting a loved one with kidney disease was front and center, it added real-life experience to the important message delivered to government. To bring the aspiration to life, lived experience was paired with economic impact data from a Deloitte report, commissioned by Kidney Health Australia, which found that investment in early detection could significantly benefit health system savings as well as quality of life years for those with CKD. For example, access to new medications that slow the rate of decline in kidney function can be directly linked to this bold vision to End Dialysis by 2050. This is similar for early detection and awareness programs.

This advocacy gained much attention for the realities facing those living with kidney disease. Kidney Health Australia continues to work with the government on finding solutions to address the kidney health emergency. Having a well-defined goal and clear steps to "end dialysis", together with measurable and achievable outcomes and a bold "person-centric" campaign that resonated with key stakeholders and generated significant media pick-up.

The campaign was successful for several reasons:

- Lived experience of kidney failure is the focus behind this ambition and the rise in kidney disease is the driving force behind this strategy
- The solution and the steps to "end dialysis" are made clear, measurable and achievable
- As kidney disease is a silent killer, creating a bold "person-centric" vision is impactful and resonated with key stakeholders and generated good media pick-up
- Governments are looking for tangible steps to solve complex problems

Utilizing collaborative approaches to improve affordable access to treatments in Japan

In 2025, the Japanese government announced an increase in the upper limit of the high-cost medical care system's burden, which meant that many patients in Japan may not be able to afford the optimum treatment for their conditions. Advocacy groups highlighted that people with lived experience and their representative organizations had not been consulted on these changes.

To combat this, the Japan Association of Intractable and Rare Diseases (JPA) launched an emergency campaign with the National Federation of Cancer Patient Organizations and Izumi Association for Chronic Myeloid Leukemia Patients and Families in opposition to the proposed upper limit. Within three days, the campaign collected responses from more than 3,600 people with lived experience, healthcare professionals and members of the public through an online questionnaire. These results were then presented to the Prime Minister.

As a result, dialogue between ministers and advocacy organizations were held and the planned increase in the co-pay ceiling has been temporarily postponed. Furthermore, a bipartisan caucus has been organized to discuss this issue on an ongoing basis.

The success of this campaign was driven by the large-scale collaboration between two advocacy organizations who often have differing activities and perspectives; as well as the volume of responses received to the questionnaire (only possible through this collaboration). An additional factor was support from other academic and professional societies/groups who also objected to the raise, as it lent greater awareness and credibility to the issue.

Patient advocacy to drive action on building comprehensive screening programs

A coalition of patient advocates, physicians, and researchers joined forces to push for improvements to provincial screening programs in Canada. Working with credible experts nationally and internationally, they produced modelling that showed the lives saved and healthcare costs reduced through earlier detection.

Patient leaders ensured the evidence reached decision-makers directly, using one-to-one meetings with health ministers, targeted social media, and media engagement to maintain visibility. They were ready to address objections, from program capacity to competing policy priorities, drawing on examples from other jurisdictions to show feasibility.

Partnerships with grassroots movements, clinical societies, and economic experts added weight to the case, helping to overcome system inertia. By combining credible, patient-driven evidence with strategic engagement, the coalition shifted the policy conversation – moving screening expansion higher up the political agenda. It has also now launched a study with primary care physicians to better uncover their understanding of colorectal cancer and begun campaigning to lower the screening age in Canada from 50 years old to 45.

Embedding lived experience in NCD & mental health screening via a community-led vaccination program in India

During the COVID-19 pandemic, marginalized communities in India – especially urban slum populations – faced compounded risks from both communicable disease and under-diagnosed Non-Communicable Diseases (NCDs) like hypertension and diabetes, which exacerbated COVID-19 severity. These groups also experienced heightened stress and mental health burden, yet traditional health services remained inaccessible or untrusted.

Swasti adapted its flagship i4We (Invest4Wellness) model to co-locate NCD screening and psychosocial support at COVID-19 vaccination camps, leveraging trusted community institutions and frontline workers drawn from the affected communities. Community members and self-help groups informed camp location, timing, and design. Community health workers (trusted peers) conducted awareness, screening, and referrals. Mental health was addressed via sensitization, counselling availability on-site, and follow-up community engagement.

From planning to execution, community representatives guided messaging, identified languages and mediums that resonated culturally, and signaled local concerns (e.g. stigma, loss of wage). Their voices shaped the decision to offer quick NCD checks during the waiting period before/after vaccination, transforming a logistical pause into a critical health opportunity.

This model led to higher uptake of both vaccination and NCD screening among marginalized populations. Early detection of hypertension and diabetes enabled timely referrals, medical counselling, and connection to low-cost generic medicines via government schemes like Jana Aushadhi Kendras. Simultaneously, on-site mental health counselling and respectful care protocols reduced anxiety and built trust in formal health services.

By centering community and patient voice in program design, Swasti's model achieved greater outreach, relevance, and trust. It demonstrated that embedding lived experience in health systems planning not only enhances NCD screening but also improves mental health responsiveness within broader primary care interventions. This offers a replicable, policy-relevant blueprint for UN-level advocacy: ensuring peoples' lived realities shape health service design and leads to more equitable and effective outcomes.

VaxNow's implementation in Bagepalli showcases a strong partnership between the community, healthcare workers, CAC, and government officials to ensure timely and smooth vaccine delivery. Working closely with local governments, the team adopted a hyperlocal, saturation-based approach tailored to community needs. Local leaders and influencers were engaged to boost participation, while district and block-level coordination strengthened execution. The collaboration also helped the administration use data more effectively and solve logistical challenges.

Patient insights to shift primary care practice on early-onset colorectal cancer

In Canada, patient advocates set out to address diagnostic delays in early-onset colorectal cancer. Surveys of people with lived experience revealed patterns of symptoms being dismissed or attributed to less serious causes, highlighting a gap in primary care awareness.

Using these findings, advocates collaborated with clinicians to create the My Symptoms Matter program – an educational tool to help primary care physicians (PCPs) recognize potential warning signs and refer for further investigation sooner. The program was built into CME-accredited training, ensuring it counted toward physicians' professional development.

By embedding patient stories and lived-experience data into medical education, the initiative challenged traditional power dynamics between patients and providers, fostering a more equal and collaborative approach to care. The combination of credible evidence, direct patient input, and alignment with professional standards made it harder for the issue to be overlooked.

As a result, more PCPs are now equipped to recognize possible colorectal cancer symptoms earlier, helping to reduce time to diagnosis.

Establishing quality standards for rare diseases in the UK

The initiative was led by the Independent Advisory Group (IAG), formed from the UK-wide Rare Diseases Forum. The group includes patient organizations (e.g., Scleroderma & Raynaud's UK, Ataxia UK, Salivary Gland Cancer UK), clinicians and researchers (e.g., Dr Peter Lanyon, Dr Graham Shortland, Dr Robin Lachmann), representatives from The National Institute for Health and Care Excellence (NICE), NHS England, and Health Improvement Scotland (HIS), lived experience representatives from across the four UK nations, and project support from Principle Consulting and JLA. The group is chaired by Sue Farrington, Co-Chair of RAIRDA and Chief Executive of Scleroderma & Raynaud's UK.

Despite the UK Rare Diseases Framework, there were no measurable standards to track progress in improving care for people with rare diseases. Key issues included lack of transparency and accountability in service delivery, stigma and inequity in access to care, absence of capacity-building tools for healthcare providers, and no consistent quality benchmarks across the UK nations.

The initiative led to the formation of a steering group with cross-sector and cross-nation representation, development of a project protocol and scoping review to identify gaps and themes, drafting of quality statements across key domains such as diagnosis, mental health, patient experience, and access to technology, engagement with NICE and HIS to align outputs with national standards, and a roadmap for Delphi consultation and consensus workshops to finalize statements.

The success of the initiative was driven by patient-led leadership, collaborative governance, evidence-based methodology, strategic alignment with NICE's criteria, and clear advocacy efforts. The inclusion of stakeholders from all four UK nations ensured broad buy-in and a rigorous scoping review and thematic analysis guided the development of quality statements.

Elevating psoriatic disease in Argentina – a collaborative, data-driven approach

Psoriatic disease, which includes both psoriasis and psoriatic arthritis, is a chronic, systemic condition that significantly impacts patients' quality of life and is associated with a range of serious comorbidities, including cardiovascular disease and diabetes. Despite its prevalence and burden, psoriatic disease has historically been under-recognized in national and global health policy frameworks.

To address this, the International Federation of Psoriasis Associations (IFPA), in partnership with NCD Alliance (NCDA), launched a global initiative to advocate for the formal recognition of psoriatic disease as a chronic systemic condition. Argentina became a key national example of how this global strategy could be implemented locally to drive policy change and improve patient outcomes.

A major barrier to progress was the lack of comprehensive national data. In response, IFPA collaborated with the Dermatology and Rheumatology Societies of Argentina to launch a national screening campaign. This initiative provided patients with free, dual-specialist consultations – allowing them to see both a dermatologist and a rheumatologist in a single visit. The campaign was supported by a digital app designed to collect patient feedback and clinical data, enabling the creation of a robust evidence base to inform advocacy efforts.

The data collected through these campaigns has been used annually to engage with both provincial and national health authorities, including the Ministry of Health. These discussions have focused on the prevalence of comorbidities among patients with psoriatic disease and the economic and human costs of delayed diagnosis and treatment. Evidence from Argentina has shown that early and appropriate treatment, particularly with biologic therapies, can significantly reduce the risk of developing psoriatic arthritis.

As a result of these sustained advocacy efforts, biological medications were included in Argentina's national mandatory medical program (Programa Médico Obligatorio, PMO). While not all treatments are yet covered, this inclusion marked a critical first step toward broader access to innovative treatments.

Looking ahead, stakeholders in Argentina are closely following the development of a national Health Technology Assessment (HTA) agency. The proposed agency, ANEFiTS (Agencia Nacional de Evaluación de Tecnologías Sanitarias e Innovación), aims to centralize and formalize HTA processes across the country's fragmented healthcare system. If successfully implemented, ANEFiTS could provide a transparent and evidence-based mechanism for evaluating and incorporating new treatments into national coverage schemes.

Ensure transparency within formal mechanisms to better embed accountability and partnership

Enhancing transparency in Health Technology Assessment (HTA) – Canada's Drug Agency

Canada's Drug Agency (CDA, formerly CADTH) works with patient organizations to ensure lived experience evidence is considered in national HTAs. In the past, patient groups often submitted input without knowing how it influenced final recommendations, creating frustration and eroding trust in the process.

In response, CDA – guided by HTA International's (HTAi) Values and Standards – introduced a formal feedback process. Every patient group that contributes to a Common Drug Review or pan-Canadian Oncology Drug Review now receives an individual thank-you letter outlining which parts of their submission were most valuable and how they informed the final assessment. For oncology reviews, verbal or in-person feedback is also offered.

This approach closes the transparency gap by showing contributors the tangible role their input plays in shaping decisions. It also strengthens future submissions, as groups receive clear suggestions for improvement. Recognized internationally as good practice, the CDA model has been recommended for wider use across all HTA activities, from Optimal Use projects to Horizon Scans.

By embedding this feedback loop, CDA has built trust with patient communities, improved the quality of evidence it receives, and demonstrated that patient participation can directly shape national policy decisions.

The NICE process and support for patient involvement in England

The NICE is responsible for producing evidence-based guidance and advice for health, public health, and social care in England. A core part of its mission is to ensure that patients, caregivers, and the public are meaningfully involved in shaping healthcare decisions – particularly through its Technology Appraisal (TA) process, which evaluates the clinical and cost-effectiveness of new treatments.

NICE has developed a formal, transparent process that embeds patient and public involvement at every stage of the technology appraisal lifecycle. This approach is designed to ensure accountability, inclusivity, and partnership with patient communities throughout each phase of the HTA process, as outlined below.

1. **Scoping Phase – Co-creating the right questions where patient organizations are invited to contribute to defining the scope of each appraisal. This includes identification of:**
   - Relevant patient populations and subgroups
   - Outcomes that matter most to patients (e.g. quality of life, mobility, mental health)
   - Unmet needs and equality considerations

   This early involvement ensures that the appraisal reflects real-world concerns from the outset. For example, the presentation highlights how patients are asked whether the treatment is usually given alone or in combination, and what comparators are currently used.

2. **Evidence Submission – Capturing the lived experience, where organizations and individuals submit written evidence describing:**
   - What it's like to live with the condition
   - The impact of treatment on daily life
   - Advantages and disadvantages of current and proposed treatments

   This qualitative evidence complements clinical and economic data, offering a fuller picture of value. NICE provides templates, training, and even reviews draft submissions to support contributors – demonstrating a commitment to accessibility and partnership.

3. **Committee Participation – Ensuring patient voices are heard**

   Two patient experts are invited to attend appraisal committee meetings as individuals. They share personal or community-wide experiences and respond to questions from the committee. Their role is not to advocate but to inform, anchoring discussions in the human impact of decisions.

   In these committees, patient experts often highlight issues overlooked by clinical data – such as the burden of side effects, challenges with medication storage, or the emotional toll of treatment.

4. **Public Consultation – Transparent drafting and feedback**

   When draft guidance is not a clear "yes," NICE opens a public consultation. This allows stakeholders – including the public – to challenge assumptions, correct inaccuracies and provide additional evidence. This mechanism enhances transparency and ensures that decisions are not made behind closed doors.

5. **Appeals Process – Formal accountability where stakeholders can appeal final decisions on two grounds:**
   - NICE failed to act fairly or exceeded its powers
   - The recommendation is unreasonable in light of the evidence

   This formal route reinforces NICE's accountability and provides a safety net for stakeholders who feel their input was not adequately considered.

Developing feedback loops to advance mental health programs in India

Worldbeing's Youth First program provides an integrated, school-based resilience and adolescent health training program to improve mental health and physical wellbeing; support school performance and engagement; and cultivate self-advocacy and social skills. It operates in Bihar, which is one of India's poorest and most densely populated states.[54]

It was developed in line with India's 2020 National Education Policy, which highlights good mental health as a key component of overall positive health and better learning.[55] The program worked closely with educators and students to build an evidenced-based approach to addressing mental health issues in Bihar.

Using the ambitions of existing national policy, the Youth First program trained local school teachers to lead mental health education sessions to improve students' understanding of mental health and the tools available to manage mental health challenges.

The program has since been scaled up to train nearly 1,000 government Master Trainers and 100,000 teachers to incorporate wellbeing programming in their classrooms, reaching 4.7 million students annually in nearly 30,000 schools at scale, in partnership with the Bihar State Council for Education Research and Training (SCERT).[56]

The program incorporates an ongoing feedback loop between teachers, students, and trainers which ensures the program can adapt to meet students' and teachers' needs. This also ensures that the program remains relevant in delivering its objectives.

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