



International Alliance of
Patients' Organizations



INITIAL GUIDANCE DOCUMENT

for Implementing the
Global Patients' Charter
on Social Participation



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INTRODUCTION

The **Global Patients' Charter on Social Participation** is a global commitment to guide the implementation of the **World Health Assembly Resolution on Social Participation** and ensure meaningful engagement of patients, people with lived experience, their organisations and communities in shaping health and related policies, services, and systems.

This guidance document outlines steps to implement the Charter through national and sub-national actions.



The WHA Resolution on Social Participation opens a unique global window to **redefine power, participation, and health equity**. Use the Charter strategically and build on it. Demand your seat. And ensure that policies are made with patients, people with lived experience, patient organisations and communities not just for us.

Statement during the first consultation meeting



PURPOSE AND SCOPE

This guidance document is designed to:

- Support patients, people with lived experience, their organisations and communities and informal networks to promote and operationalise the Global Patient Charter at different levels.
- Provide practical workable actions and examples aligned with human rights, equity, and Universal Health Coverage (UHC) goals.
- Support patient organisations in encouraging the institutionalization of social participation as a sustainable, inclusive, and accountable mechanism, democratising health.

The document is tailored towards **patients, people with lived experience, their organisations and communities, in their own environments and contexts** aiming to:

- Equip them to **implement** the Global Charter
- Enable them to **advocate for institutional and legislative change** at local, national, and collectively at regional and global levels.
- Strengthen **patient voice and leadership** in health governance, policies, and systems.

It will be complemented by additional specific tools and resources to support further the implementation of the Charter, based on the on-going needs expressed by patient communities in different regions.



WHAT IS THE PATIENT CHARTER ON SOCIAL PARTICIPATION?

It is a statement of **principles, commitments, and expectations** that:

- Outlines the **rights and responsibilities of patients, people with lived experience, their organisations and communities** to participate in health governance.
- Defines the **responsibilities of institutions** to enable meaningful participation.
- Serves as a **springboard for advocacy, accountability, and transparency**.

ROLES

The Role of Patients, People with Lived Experience, Patient Organisations and Communities

All play a unique role in:

- **Raising awareness** about the right to participate.
- **Building coalitions** within/across disease areas and demographics and with other stakeholders.
- **Advocating** for legal and institutional reforms.
- **Representing diverse voices** at local, national, and global levels.
- **Monitoring** implementation and equity of participation mechanisms.



STEP-BY-STEP GUIDANCE

for Implementation

STEP 1

Understand the WHA Resolution and its implications

- Read and interpret the WHA Resolution on Social Participation
 - Translate it into the **national context and patient rights**.
 - Host internal discussions to **align your strategy with the resolution**.
-

STEP 2

Endorse and integrate the Global Patient Charter in your work, and / or develop or adapt your own Charter as appropriate

- Where deemed necessary and useful, co-create a **National Patient Charter on Social Participation** using, linking and endorsing the Global Patient Charter as a framework.

Note – creating a national charter is an optional step which may bring added value in reflecting your national context and reality.

Include:

- » Vision and values (equity, inclusion, rights-based)
 - » Rights and responsibilities of patients
 - » Specific demands towards your government and institutions
- Base it on co-creation and **inclusive consultations** with your members/community/network.
 - See in the annex a 'model' Charter, as a starting point.



STEP 3

Build awareness and capacity

- Using IAPO and other resources, inform your team, members, volunteers and community leaders on:
 - » The importance of social participation per se
 - » Patients Rights
 - » Health system basics and UHC, including health system budgeting and financing
 - » National and Global legal and policy frameworks
 - » Tools for advocacy, dialogue, and negotiation
 - Facilitate peer-to-peer learning and community-led education.
 - Adapting the resources included in the annex of this guide, develop **toolkits, infographics, and explainer videos**, and signpost to existing material.
-

STEP 4

Engage in dialogue with Governments and stakeholders

- Map entry points for participation (e.g. health councils, advisory boards).
 - Request formal representation in these spaces.
 - Submit the Global Charter and, eventually, your charter to the **Ministry of Health or Parliamentary Committees**.
 - Build alliances with other civil society and professional bodies.
-



STEP 5

Encourage the institutionalisation of participation

- Encourage and Advocate for:
 - » National guidelines, policies or legal frameworks on patient participation.
 - » Dedicated government units for social participation.
 - » Funding for participation platforms and patient organisations.
 - » Patients and people with lived experience, patient organisations and their communities' meaningful participation in
 - ◇ Health priority-setting
 - ◇ Budgeting and planning
 - ◇ Programme design and service delivery
 - ◇ The development of digital tools to facilitate engagement
 - ◇ Scientific congresses and high-level policy events
 - » Monitoring, evaluation, and accountability feedback loops that are functional and acted upon.
 - Advocate for **legal guarantees** of patient involvement in decision-making.
-

STEP 6

Monitor, evaluate, and report

- Using indicators co-produced with the community, track:
 - » Inclusion of patient voices in decision-making processes.
 - » Policy changes influenced by patient inputs.
 - » Diversity and equity in participation. (See annex for generic examples of indicators)
- Use community led monitoring and accountability tools such as hearings.
- Share this information on progress and gaps to feed into the Global Patient Charter Review Committee.



ROLES AND RESPONSIBILITIES

in the implementation of social participation

Stakeholder	Roles
Ministries of Health	Lead implementation, coordination, resource allocation, and oversight.
Local Governments	Operationalize participation platforms at the community level.
Patients, PWLE, POS& Civil Society	Actively participate, advocate, monitor, and hold duty-bearers accountable
Health Providers	Create enabling environments for patient voices in service design implementation and feedback.
Development Partners/Donors	Provide technical and financial support for system strengthening and mechanisms for participatio
Private Sector	Create, advocate for, and support opportunities for social participation
Resource mobilization	Advocate for dedicated budgets for social participation structures. Mobilize external support for capacity-building and innovation. Leverage community-based resources and volunteers.



CHALLENGES AND MITIGATION STRATEGIES

Challenge	Mitigation strategy
Limited understanding / awareness, value of social participation, what are their rights Resource constraints and lack of capacity, remuneration	Advocate for sustainable financing and capacity building resources and integration into existing systems
Tokenism, ad hoc or superficial engagement	Build genuine co-designed processes and feedback mechanisms
Power imbalances	Support marginalized voices through facilitation and safe spaces
Limited awareness of participation rights	Conduct public campaigns and community outreach
Lack of data on participation outcomes	Collaboration with academic or civil society partners to document impact
Draw on good practice in relation to the effective implementation of 'similar' resolutions	Create, advocate for, and support opportunities for social participation



POTENTIAL ADVOCACY ACTIONS

for Patient Organisations

Action	Description
Build a coalition	Bring together disease-specific and cross-cutting organisations.
Hold an online advocacy campaign	Get endorsements to the Charter from different stakeholders
Organize a national summit	Invite government, donors, and civil society to launch the Charter.
Engage the media	Use storytelling and real patient experiences to highlight the need.
Use international forums	Together with IAPO, advocate through WHO, UN, and global health alliances.
Mobilize community leaders	Train and activate local champions for participation.

EXAMPLES OF POTENTIAL TOOLS AND TEMPLATES

(see annexes)

Sample National Patient Charter on Social Participation

Template: Letter to Government Authorities

Dashboard: Indicators to Track Participation

Training Toolkit: "Patients as Policy Advocates"

Communication Package (social media, press release, infographics)



POSSIBLE MECHANISMS for Participation

This non-exhaustive list highlights possible mechanisms for participation, to support dialogue between patient organisations and health authorities exploring how to optimise the engagement of people with lived experience in health governance structures.

Community Health Assemblies: Local platforms of people with lived experience and citizens to voice needs and goals, and to co-develop priorities and solutions.

Health Councils, Committees, Panels, Working Parties with formal representation of patients and people with lived experience in health policy discussion with voting rights as applicable.

Digital Participation Tools: Online platforms for consultation, feedback, and dialogue.

Citizen Report Cards & Social Audits: Tools for people to assess and report on service quality.

The UHC Compass to enable patient organisations to understand universal health coverage in their countries, and how they can engage effectively with governments and other stakeholders to advance UHC and align on core priorities.

Permanent dialogue roundtables between governments, the private sector, and patient organizations



CASE STUDIES

Examples from the field

At a glance:

Brazil:

Health councils at every level of the SUS (Sistema Único de Saúde) with strong patient and community representation. <https://pmc.ncbi.nlm.nih.gov/articles/PMC8005309/>

Madagascar

Madagascar is in the early stages of establishing meaningful social participation for health mechanisms. A bottom-up, participatory planning system across all regions and districts. For example, efforts to strengthen social participation in district health committees in Madagascar found that use of Malagasy as opposed to French, more accessible meeting locations, and creating safe spaces away from hierarchies helped to adjust power imbalances and promoted greater appreciation of the value of participation among both the government and the communities themselves.

This initiative seeks to develop localized health development plans that articulate priorities, goals and expected outcomes in alignment with the national health strategy and annual state budget.

This strategy and these reforms will make their health governance more inclusive and representative and ensure community needs and priorities are funded. Ultimately, it will ensure people's access to the health and care services they need, when and where they need them. https://cancermissionhubs.eu/wp-content/uploads/2025/01/voice-agency-empowerment_handbook-on-social-participation-for-universal-health-coverage.pdf

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CASE STUDIES

Examples from the field

South Africa

Community health workers and patient groups represented in primary healthcare governance structures.

<https://pmc.ncbi.nlm.nih.gov/articles/PMC8128020/>

Thailand:

The National Health Assembly institutionalized community and patient input into national health policy since 2008. Established in 2008, with a mandate to ensure diverse participation in policy making processes & build civil society capacity to meaningfully engage in these processes. Since its establishment, social participation for health in Thailand has improved, and government resources have been strategically directed toward community-identified priorities, maximizing the impact and return on investment of these funds. <https://en.nationalhealth.or.th/nha/>



CASE STUDIES

More detailed

Name of the initiative	STITCH – Strengthening the Integrated Treatment and Care for People with Hepatitis in Vietnam and the Philippines
Brief Description	A 5-year project to co-design, implement and scale / sustain a people-centred model of care for hepatitis B and C among primary care facilities in the two countries. Input from patients and people with lived experience was sought from the beginning and strengthened throughout the course of the project in response to evolving needs, feedback and growing capability among all stakeholders.
Legal Framework, if applicable	None – although the Philippines has a strong culture of patient organizations having input into programme design, this does not extend to the provincial / district level as far as we are aware.
Responsible Organisation(s)	Harvard Medical School Program in Global Primary Healthcare, University of the Philippines Manila, local governments and health facilities in Tarlac and Quezon City, the Philippines; and Thai Binh and Hung Yen Provinces in Vietnam.
Challenges	<p>Establishing ‘patient friendly’ expectations and environment within project activities (e.g. research, design and progress workshops, healthcare provider training), to enable genuine participation and input, especially in Vietnam where community input is relatively restrictive, and culture is hierarchical</p> <p>Fear of confidentiality breach, and / or discrimination if patients disclose their status to healthcare providers or government officials, especially in the Philippines where stigma was more prominent</p> <p>Ensuring equitable and adequate compensation and recognition for patients / advocates time and effort supporting the project work, especially where CSOs operate on a volunteer basis (or patients are not ‘organised’ at all)</p>



Lessons learned	<p>Importance of 'graded' or phased involvement and capacity building over time – for example, Yellow Warriors from the Philippines began as research subjects / referrals for interviews, and now are the ones conducting interviews in expansion sites; in the initial workshops they just answered when called upon, but eventually began hosting / leadings sessions for healthcare workers</p> <p>Safety in numbers, where possible, so that patient voices are not dominated by healthcare workers or policy-makers. This was easier in Philippines than Vietnam because of established structures.</p> <p>Directly acknowledging and addressing any tensions or power dynamics that come up to avoid any confrontation and maintain productive friction; anticipating this by creating spaces for conversation that are deliberately 'provocative' but not personal (e.g. fishbowl)</p> <p>Social activities and relationship building among the different stakeholders to get them outside of their professional hats</p>
Links and references	<p>Our website is currently being migrated, which has the most public information, but some other links in the meantime and can provide other documents as needed</p> <p>https://magazine.hms.harvard.edu/articles/viral-hepatitis-project-engages-community-transform-care</p> <p>https://globalhealth.harvard.edu/event/global-health-coffee-sessions-stitch/</p>



Name of the initiative	Brazil's Health Councils & Conferences (Sistema Único de Saúde, Brazil)
Brief Description	Institutionalized councils and conferences at municipal, state and national levels. Citizens, health workers and managers discuss health policies & budgets. Proposals shaped in conferences can influence state / national policy.
Legal Framework, if applicable	Brazil's 1988 'Citizens' Constitution' recognises health as a right and guarantees the public's participation in health governance; health councils are legally empowered to inspect public accounts and influence resource allocation.
Responsible Organisation(s)	Ministry of Health, state & municipal health secretariats, local health councils, diverse civil society groups.
Challenges	Representation can be uneven; councils may be dominated by political elites. Effective participation depends on supportive public managers, strong civil society and transparent councillor selection processes.
Lessons learned	Open, inclusive selection of council members and participatory techniques improve diversity; strong ties with political structures lead to more effective councils and better policy influence.
Links and references	Powercube case study on Brazil's health councils (2009)



Name of the initiative	Southcentral Foundation's Nuka System of Care (Alaska, USA)
Brief Description	A relationship-based, customer-owned health system serving Alaska Native / American Indian people. Board of directors & workforce include community members; objectives and performance metrics are co-developed with community, and care is provided through integrated services.
Legal Framework, if applicable	Southcentral Foundation was created under the tribal authority of Cook Inlet Region Inc., established by the Alaska Native Claims Settlement Act; the Nuka model embodies principles of the Indian Self-Determination and Education Assistance Act
Responsible Organisation(s)	Southcentral Foundation (non-profit), board of directors comprised of Alaska Native customer-owners, tribal authority via Cook Inlet Region Inc.
Challenges	Transforming a bureaucratic, centrally controlled system into a community-owned model; sustaining relationships and continuous quality improvement across a large network.
Lessons learned	Community ownership & relationship-based care yield better outcomes; engagement via community-defined objectives, satisfaction surveys and a community board fosters accountability and equity.
Links and references	<u>K. Gottlieb et al., "The Nuka System of Care: improving health through ownership and relationships" (2013)</u>



Name of the initiative	Community Scorecards in Eastern Democratic Republic of Congo
Brief Description	Part of a community-driven reconstruction project, community scorecards were used to promote transparency and accountability at health facilities. Stories of change collected from community members & providers revealed improvements in patient-provider relationships, access to services & infrastructure.
Legal Framework, if applicable	Implemented through project agreements rather than specific legislation; used within local development committees and health facility management structures.
Responsible Organisation(s)	Village development committees, health committees, community members, healthcare providers, supported by NGOs.
Challenges	Weak health system due to conflict, limited resources, corruption and user fees; building trust between communities and providers.
Lessons learned	Scorecards provide structured spaces for communities & providers to exchange information; change arises through provider responsiveness, community pressure and joint action; locally accessible solutions can be implemented to improve quality.
Links and references	<u>Ho et al., "Effects of a community scorecard on improving the local health system in Eastern DRC" (2015)</u>



Name of the initiative	Social participation mechanisms in Kosovo Patient Councils, Community Scorecards & Municipal Health Action Plans (Kosovo)
Brief Description	Multiple mechanisms were examined in a primary health care study: patient councils acting as liaison bodies for complaints; community scorecards involving representatives to voice preferences; and municipal health action plans where community representatives participate in planning. Levels of participation ranged from low to moderate.
Legal Framework, if applicable	Mechanisms operate within Kosovo's public healthcare system; formal legal basis is weak or unspecified.
Responsible Organisation(s)	Municipal health authorities, primary health centres, community and patient representatives.
Challenges	Inclusiveness and influence varied; patient councils often had limited decision-making power; capacity constraints affected community scorecard use.
Lessons learned	Shared platforms between service users and providers can sustain moderate social participation; community scorecards amplify community preferences; increasing inclusiveness and decision-making influence is essential for meaningful impact.
Links and references	<u>Hoxha et al., "Social participation in health – case studies from primary health care in Kosovo" (2024)</u>



Name of the initiative	Grounded Citizens' Jury for Health Needs Assessment (North-West England, UK)
Brief Description	A Primary Care Group convened a week-long citizens' jury with 12 local residents to deliberate on health needs in an area with health inequalities. The jury acted as a grass-roots health needs assessment and led to the establishment of a community health centre governed by community members & local agencies.
Legal Framework, if applicable	UK policies such as the 2000 NHS Plan and subsequent 2001 legislation require trusts and health authorities to involve and consult patients and the public in planning and reviewing services.
Responsible Organisation(s)	Primary Care Group (north-west England), local community members, local health authorities and agencies.
Challenges	Traditional consultation approaches can be tokenistic; recruiting diverse participants; sustaining the outcomes beyond the jury process.
Lessons learned	Grounded citizens' juries emphasising deliberation, integration, sustainability & accountability can empower residents to shape health services; the process can lead to tangible outcomes like community-run health centres.
Links and references	<u>Kashefi & Mort, "Grounded citizens' juries: a tool for health activism?" (2004)</u>



Name of the initiative	Banner University Health Plan Member & Community Engagement (Arizona, USA)
Brief Description	The BUHP health plan engages members and communities through multiple structures: member advisory councils, cultural competency committee, and neighborhood advisory committees. Semi-annual 'Community Conversations' bring members, non-members, local leaders and service organizations together to identify local health priorities and solutions.
Legal Framework, if applicable	State-managed care contracts and federal Centers for Medicare & Medicaid Services regulations require Medicaid health plans to establish beneficiary advisory councils.
Responsible Organisation(s)	Banner University Health Plan (BUHP); Office of Individual and Family Affairs; member advisory councils; neighbourhood advisory committees.
Challenges	Ensuring engagement goes beyond contractual compliance; reaching non-member community voices; sustaining engagement and translating input into action.
Lessons learned	Combining formal advisory councils with informal community conversations enhances engagement; local solutions identified through conversations can be funded via community reinvestment programs; cross-sector participation strengthens equity initiatives.
Links and references	<u>Sridharan & Fitzgerald, "Comprehensive Member and Community Engagement: A Multi-Tiered Approach by a Safety Net Health Plan" (2024)</u>



Name of the initiative	Development of a code of expectations for health entities' engagement with consumers and whānau (New Zealand)
Brief Description	The code sets the expectations for how health entities must work with consumers, whānau and communities in the planning, design, delivery and evaluation of health services.
Legal Framework, if applicable	Developed as secondary legislation and required under section 60 of the Pae Ora (Healthy Futures) Act 2022.
Responsible Organisation(s)	All health entities are responsible for following the code. Health entities are defined as Health New Zealand, New Zealand Blood Service, Pharmac, and the Health Quality & Safety Commission. Each must act in accordance with the code and report annually on how it has given effect to the code.
Challenges	Implementation requires dedicated resources, and these have been reduced.
Lessons learned	The code was developed with patients, consumers, the community, clinicians, professional bodies, government, and many others. If you involve all stakeholders early and can describe what is required as succinctly as possible, it is more likely that you will get traction, particularly in a stretched health system context.
Links and references	A BMJ editorial is forthcoming, and this will be a useful link to describe the challenges of patient engagement more broadly, using the code as an example.



Name of the initiative	Committee for the Promotion of the Rights of Persons with Disabilities, Ministry of Health and Welfare, ROC (Taiwan)
Brief Description	Composed of representatives from government agencies, scholars and experts, and organizations of persons with disabilities. The Committee holds regular meetings to integrate planning, research, consultation, and coordination efforts to promote the rights of persons with disabilities.
Legal Framework, if applicable	<u>People with Disabilities Rights Protection Act</u> , Article 10. Guidelines for the Establishment of the Committee for the Promotion of the Rights of Persons with Disabilities, Ministry of Health and Welfare
Responsible Organisation(s)	Social and Family Affairs Administration, Ministry of Health and Welfare
Challenges	Currently, the regulations do not specify the proportion of representatives with disabilities, nor do they include participation of children with disabilities. Therefore, the 2025 draft amendment to the Act stipulates that persons with disabilities must account for at least one-fourth of all members, and adds representatives of children or youth with disabilities.
Lessons learned	Through regular meetings, the Committee effectively collects opinions from persons with disabilities and their representative organizations, facilitates cross-ministerial coordination, and follows up on areas for improvement, such as enhancing accessibility in medical institutions and providing health promotion services for wheelchair users.
Links and references	<u>https://www.sfaa.gov.tw/SFAA/Pages/List.aspx?nodeid=917</u>



Name of the initiative	Pharmaceutical Benefit and Reimbursement Scheme Joint Committee, PBRs, ROC (Taiwan)
Brief Description	Handles the formulation of reimbursement items and payment standards for pharmaceuticals under the National Health Insurance.
Legal Framework, if applicable	National Health Insurance Act, Article 41. Regulations for the Joint Formulation of Pharmaceutical Benefit and Reimbursement Scheme under National Health Insurance, Articles 4 and 7.
Responsible Organisation(s)	National Health Insurance Administration, Ministry of Health and Welfare
Challenges	Expanding and empowering patient participation in meetings where medical information is complex and often communicated using highly technical or professional terminology remains a challenge.
Lessons learned	Patient participation in deliberations and decision-making helps build trust and recognition within the healthcare system and enhances policy implementation and social support.
Links and references	National Health Insurance Act https://law.moj.gov.tw/LawClass/LawAll.aspx?PCode=L0060001 Regulations for the Joint Formulation of Pharmaceutical Benefit and Reimbursement Scheme under National Health Insurance https://law.moj.gov.tw/LawClass/LawAll.aspx?PCode=L0060030



Name of the initiative	Patient Opinion Sharing Platform, ROC (Taiwan)
Brief Description	Encourages patients to share opinions on their disease conditions, treatment experiences, and experiences using new drugs/medical devices and caregiving.
Legal Framework, if applicable	-
Responsible Organisation(s)	National Health Insurance Administration, Ministry of Health and Welfare
Challenges	Not all patient voices and experiences can be collected, and some patients still need to further build their knowledge and capacity in order to provide effective input for policy decision-making.
Lessons learned	Patient opinions are collected and presented to the Pharmaceutical Benefit and Reimbursement Scheme Joint Committee.
Links and references	https://med.nhi.gov.tw/isPe0000/ISPE0000S01.aspx

Name of the initiative	SPAN-HNC – Screening, Patient Awareness and Nutritional Support for Head & Neck Cancer Patients (India)
Brief Description	Our organisation partners with hospitals to provide counselling and nutritional support to cancer patients. As part of this collaboration, we proposed supplementary patient experience sessions such as yoga and music therapy, aimed at improving quality of life for patients. These activities were included in the Memorandum of Understanding (MoU) signed with the hospital.
Legal Framework, if applicable	MoU signed between our organisation and the government hospital.



Responsible Organisation(s)	DakshamA Health and the hospitals
Challenges	<p>While the counselling and nutrition programme was implemented smoothly, the supplementary sessions faced approval challenges. Responsibility for decisions shifted between the Head of Department, Dean, and Medical Superintendent, with no single authority clearly accountable. Most discussions happened in person, but outcomes were rarely documented in writing, making it difficult to establish a clear record of the process.</p>
Lessons learned	<p>Importance of formal documentation in institutional partnerships to ensure credibility and accountability.</p> <p>Establishing a culture of written communication (e.g. meeting notes, written approvals/refusals) would support greater transparency and trust between hospitals and patient organisations.</p> <p>For patient groups, documenting conversations and decisions internally is also a useful strategy to maintain continuity and evidence of engagement.</p>
Links and references	



Name of the initiative	Chilean Financial Protection Model for High-Cost Diagnosis and Treatment: A Guiding Framework (Chile)
Brief Description	<p>The Prioritized Recommendation Commission (CRP) is the key technical body in the process of including new benefits to the SPF.</p> <p>A. Main Function: Evidence-Based Prioritization</p> <p>The CRP acts as a Health Technology Assessment (ETESA) filter, but with a prioritization approach. Its process is as follows:</p> <ul style="list-style-type: none">• Evidence Analysis: Analyzes ETESA's public scientific reports prepared by the Undersecretary of Public Health.• Priority Establishment: Establishes an order of priority (priority) for candidate diagnoses and treatments with prioritization criteria.• Basis for the Decision: The recommendations of the CRP, together with the budgetary availability defined by the Ministry of Finance, serve as the basis for the Ministry of Health to issue the decree that incorporates the benefits into the System. <p>B. The Citizen Pillar: Citizen Commission for Surveillance and Control (CCVC)</p> <p>The Citizen Commission for Surveillance and Control (CCVC) is the body that confers on the Chilean system a higher standard of transparency and accountability. Its existence is a reflection of the organized social demand that drove the law and makes it a differentiating asset.</p> <p>Essential Function: Monitoring and Advisory</p> <p>The CCVC is an external and independent body of the Ministry of Health. Its main functions are:</p> <ul style="list-style-type: none">• Monitoring of Performance: Supervise how the Financial Protection System operates in practice.• Technical Advice: Advise the Ministries of Health and Finance through the preparation of reports and recommendations that identify gaps and propose improvements in the application of the law.



Legal Framework, if applicable	<p>Chile's Law No. 20,850, popularly known as the Ricarte Soto Law, establishes a Financial Protection System (SPF) for high-cost diagnoses and treatments, based on scientific evidence, social value, and citizen transparency. This model is a valuable reference for other nations seeking to ensure universal access to expensive therapies.</p> <p>A central and differentiating element of the Chilean model is the architecture of its Advisory Commissions, which combines technical expertise with citizen vigilance.</p>
Responsible Organisation(s)	Chilean Government
Lessons learned	<p>The integration of the CCVC into the Chilean model demonstrates that organized citizen participation is not only a symbol of transparency, but also an indispensable technical tool for the sustainability and quality of the system. It gives citizens an active and binding role in the monitoring of scientific evidence and the correct use of public funds.</p> <p>Elements of Governance for Effectiveness</p> <ul style="list-style-type: none">• Balanced Composition: Although its core is experts (doctors, scientists, economists), it must include the voice of the beneficiaries. The Chilean CRP maintains two representatives of patient groups.• Promotion of Participation: To ensure the quorum and the dedication of external professionals, the payment of a per diem (fees) per session was implemented.• Operational Flexibility: Sessions have been allowed to be held remotely (telematics), facilitating the attendance of experts from different regions or with complex agendas.• Quorum Optimization: The reduction of the total number of experts (from twelve to five) seeks to make convening and decision-making more efficient.



	<p>A crucial improvement to the model, proposed to strengthen citizen evaluation and control, is to give it a function with direct action on scientific evidence:</p> <ul style="list-style-type: none"> • Evidence Review Warning: The health authority is granted the power to publicize the existence of new antecedents that justify reviewing the efficacy or safety of a High-Cost Diagnosis or Treatment already included in the SPF. • Precautionary Objective: With this attribution, the CCVC contributes directly to ensuring that public resources continue to be allocated only to therapies with up-to-date favourable scientific evidence, allowing the timely exit of those benefits whose evidence has been weakened.
<p>Links and references</p>	

<p>Name of the initiative</p>	<p>Institutionalising meaningful participation of people with lived experience in Malaysia</p>
<p>Brief Description</p>	<p>Following the launch of a national Advocacy Agenda for People Living with Noncommunicable Diseases in Malaysia, NCD Alliance Malaysia called for the meaningful participation of people with lived experience of NCDs within policy making bodies at the Ministry of Health. This commitment has been institutionalised through the formalisation of a partnership with the Ministry of Health Malaysia via a Memorandum of Understanding between NCD Alliance Malaysia and civil society organisations representing people living with NCDs, who are members of the alliance. The Ministry of Health already holds town hall meetings to discuss healthcare issues, policy changes, and system improvements. These are large meetings though, so not all voices are heard. This MoU will ensure the priorities of people with lived experience of noncommunicable diseases are accounted for in policy and programme decision-making at the national level via two mandated meetings every year, one at the start of the fiscal year and one just before the government budget is agreed.</p>



Legal Framework, if applicable	This is not a legal framework – MoU’s are typically statements of intent, not formal contracts but it is a way of formalising participation of those with lived experience.
Responsible Organisation(s)	Ministry of Health Malaysia, NCD Alliance Malaysia and 12 close affiliates (civil society organisations) who are members of the alliance.
Challenges	<p>Even though the MoU is not legally binding, the Ministry of Health needed to consult with their legal department which requires time.</p> <p>If a member of the Malaysian NCD Alliance wanted to be a separate signatory in the MoU they needed to register as a legal entity in Malaysia which is a process that also takes time and resulted in some delays to the agreement and final MoU.</p>
Lessons learned	<p>Planning ahead is important as negotiating formal agreements with government to enable participation take time.</p> <p>It was important for the alliance to properly brief their members on the process and requirements to be a signatory to the MoU.</p>
Links and references	https://www.ourviewsourvoices.org/involve/involvement-reports/202412-meaningful-involvement-of-people-living-with-ncds-strengthen#:~:text=The%20process%20received%20support%20from,to%20NCD%20prevention%20and%20control



Name of the initiative	Inclusive and integrated decision-making for noncommunicable diseases (NCDs) in Kenya
<p>Brief Description</p>	<p>NCD Alliance Kenya and people with lived experience have contributed to the co-creation of policies, their implementation, and community-led social accountability. In 2023, during the elections, the alliance’s caucus of people with lived experience advocated for their priorities to be included in the County Integrated Development Plans and asked for prioritization of NCDs through increased NCD budgets; increased prioritization of NCD prevention; improvement of NCD service delivery; and financing through the National Health Insurance Fund (NHIF) and universal health coverage. These plans are now being monitored, through county chapters of people living with NCDs to mark progress on the commitments made by duty bearers. The alliance also successfully advocated for people with lived experience to be part of the NCD Intersectoral Coordinating Committee (NCD ICC) which supports implementation of the National NCD Strategy. The Strategy also recommends the creation of NCD Technical Working Groups (NCD TWGs) at the county level, to mimic the functioning of the NCD ICC. NCD Alliance Kenya has played a key role in establishing NCD TWGs in 6 counties, all of which include lived experience participation.</p>
<p>Legal Framework, if applicable</p>	<p>National NCD strategies are generally considered policy documents or plans of action; they are not inherently binding legal frameworks themselves. However, they can and often do lay the foundation for, or exist alongside, specific, legally binding national laws and regulations.</p>
<p>Responsible Organisation(s)</p>	<p>Ministry of Health Kenya, NCD Alliance Kenya and the caucus of people living with NCDs.</p>
<p>Challenges</p>	<p>Some key challenges preventing or limiting the participation of people with lived experience in Kenya have been social and structural issues (e.g. stigma, power imbalances), the risk of tokenistic participation, and practical limitations such as a lack of resources.</p>



Lessons learned	National and sub-national networks of people with lived experience offer a way to sustain and strengthen engagement, multiplying reach into the community, amplifying messages and keeping abreast of changing community needs. To ensure that the value of the lived experience is considered in policy and decision-making, it is essential to advocate for formal mechanisms for people living with NCDs and communities to have a 'seat at the table'.
Links and references	https://www.ourviewsourvoices.org/involve/involvement-reports/202412-inclusive-and-integrated-decision-making-ncd-prevention-and



CONCLUSION

Social participation is a cornerstone of people-centred health systems and democracy in health governance. Implementing the Patients' Charter is not just a box-ticking exercise—it is a transformative process that can build trust, improve health outcomes, and ensure equity.

IAPO is honoured and proud to have coordinated this work. Should you have any questions, need support or would like to share news about your work on social participation, please contact: info@iapo.org.uk.



ANNEXES

Tools and Resources with a Navigation Guide

Note: these tools will be co-developed and tested during the course of 2026 once the guide has been agreed.

Annex A	Sample Patient Charter (customizable)
Annex B	Stakeholder Engagement Mapping Template
Annex C	Monitoring Framework with suggested indicators in a dashboard format
Annex D	Glossary of Terms (Social Participation, Co-Creation, Patient Engagement etc)
Annex E	Training Toolkit: “Patients as Policy Advocates” including practical country-level adaptation guidance for low- and middle-income countries
Annex F	Communication Package (social media, press release, infographics)
Annex G	Relevant International Frameworks and References <ul style="list-style-type: none">• WHO Handbook on Social Participation for UHC https://cancermissionhubs.eu/wp-content/uploads/2025/01/voice-agency-empowerment_handbook-on-social-participation-for-universal-health-coverage.pdf• WHA Resolution 77/A77 on Social Participation https://apps.who.int/gb/ebwha/pdf_files/WHA77/A77_ACONF3-en.pdf• UHC Compass https://www.iapo.org.uk/node/15718• WHO Patient Safety Rights Charter https://www.who.int/news/item/18-04-2024-who-launches-first-ever-patient-safety-rights-charter• NCD Alliance Charter on Meaningful Involvement of People Living with NCDs https://ncdalliance.org/what-we-do/capacity-development/our-views-our-voices/global-charter-on-meaningful-involvement-of-people-living-with-ncds• International Consortium for Health Outcomes Measurement Patient Charter https://www.ichom.org/wp-content/uploads/2024/01/Patient-Charter_Final.pdf



Annex H

Examples of possible indicators to evaluate and monitor the implementation of the WHA Resolution on Social Participation.

These will be developed once more information has been received regarding WHO's approach to monitoring the implementation of the Resolution

Structure

1. Legislation or policy framework enacted on social participation that is inclusive patients, people with lived experience and civil society in health decision-making.
2. Adoption of specific institutional measures to promote participation of patients, people with lived experience, their organisations and communities and informal network.

Process

1. Frequency and scale of government-organized multi-stakeholder consultation meetings
2. Percentage of participation by underserved or vulnerable groups (patients, people with disabilities, minority groups)
3. Accessibility of information for participants (language, accessible formats)
4. Number of training and capacity-building activities provided to patients, people with lived experience and their related organisations and communities to strengthen their participate across all phases of health governance and decision-making.
5. Proportion of financial support allocated to and spent on patients, people with lived experience and their related organisations and communities to strengthen their capacity to participate in health governance and decision-making processes, out of the entire budget allocated to and spent on supporting civil society organizations.



Annex H (cont.)	<p>Outcome</p> <ol style="list-style-type: none">1. Percentage of recommendations adopted into policy after participation.2. Number of health policies revised or newly introduced as a result of public participation.3. Results of surveys on civil society/patient satisfaction with the participation process. (to be updated in line with future WHO guidelines) <p>The SDG-CRPD Resources Package – Article 29 provides a set of indicators (covering structure, process, and outcome), which could be considered when looking at metrics which could also inspire how to frame indicators in a way that is both practical and aligned with existing human rights monitoring tools. See https://www.ohchr.org/en/disabilities/promoting-rights-persons-disabilities-through-sustainable-development-goals-resource-package-sdg</p>
Annex I	<p>Examples of possible indicators linked to the dissemination, socialisation and uptake of the Global Patient Charter on Social Participation.</p> <p><i>These will be converted into an easily applicable metrics framework to accompany the Charter and the Guide</i></p> <ul style="list-style-type: none">• ‘Clicks’/downloads of the charter itself (tracking where/who is doing this?)• Citations – on government and CSO’s websites, in high-level meetings/minutes, national policies/documents• Targeted advocacy campaigns utilizing the Charter• Reported outcomes/outputs of those who use the charter as part of advocacy campaigns• Number of national and regional organizations endorsing and or adapting the Charter.• Number of countries translating or adapting the Charter.• Availability of accessible versions of the Charter (e.g., easy-to-read versions, large print, audio, sign language, digital accessibility).



Annex I (cont.)

- Number of events, webinars, or training organized on the Charter.
- Number of governments or institutions formally referencing the Charter in policy or program documents.
- Qualitative feedback from patient organizations on awareness and perceived usefulness.
- Webinars held, participant numbers
- Toolkits used/downloaded
- Case studies being created
- Number of workshops or national consultations held.
- Diversity of participants (disease areas, gender, region, socio-economic status).
- Number of formal spaces (health councils, advisory boards) integrating patient representatives after the Charter's launch.
- Media and social media visibility metrics (mentions, engagement, reach).
- Level of awareness among patients, people with lived experience, and communities regarding the Charter.



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