



International Alliance of
Patients' Organizations



THE GLOBAL PATIENT CHARTER ON SOCIAL PARTICIPATION

Co-produced by IAPO, its membership and its allies
across health civil society and multilateral organisations



INTRODUCTION

This Charter is a set of advocacy principles for social participation co-produced to help patients and people with lived experience, patient organisations and their representatives, informal patient networks and communities, governments and health stakeholders to work together. It is particularly timely as we witness and anticipate fundamental changes in health policy architecture at many levels.

Our goal is to promote locally rooted, context-sensitive social participation, to ensure the meaningful participation of people with lived experience in health decision-making processes at all policy levels, and to support patient organisations in reaching their advocacy goals.

This Charter is complemented by the following supporting advocacy tools:

- A Guide on how to use the Charter in different settings/geographies/socio economic realities and optimise its reach and impact on the ground.
- A metrics framework on the dissemination and socialisation of the Charter.



PREAMBLE

- 1. Welcoming the World Health Assembly (WHA) Resolution on Social Participation for universal health coverage (UHC), health and wellbeing¹**, which aims to institutionalise social participation within health governance and previous initiatives in the areas of social participation²: This charter underlines the central role of patients, people with lived experience and communities in this process, shaping health policies and systems. In contexts where governments or territories are not represented in WHO mechanisms, patients organizations and civil society should be supported to engage through alternative regional or global networks, ensuring that no communities are excluded from the Charter's processes.
- 2. Affirming principles of human rights, equity, inclusivity, accountability and transparency** in health governance, and design and strengthening of health systems.
- 3. Building on the Declarations of Alma-Ata and Astana**, the participation of people and communities in decisions about their health care is recognized as a fundamental right and a key principle of primary health care.
- 4. Acknowledging the importance of patients, representatives of patient organisations, people with lived experience, and communities** across the globe to be engaged and to contribute to better health outcomes.
- 5. Welcoming the synergies between the Resolution on Social Participation and other pillars of work driven by WHO**, notably the WHO Charter on Patient Safety Rights and the WHO Healthy Aging Strategy
- 6. Recognising the role of patient organisations as knowledge-brokers** between patients and policy makers.

1 <https://www.who.int/news/item/29-05-2024-world-health-assembly-endorses-resolution-on-social-participation>

2 [Sustainable Development Goal 16.7](#): This goal (adopted in 2015) calls for "responsive, inclusive, participatory and representative decision-making at all levels" and provides a foundational commitment for many social participation initiatives.

[Declaration of Astana \(2018\)](#): This declaration emphasizes the empowerment of people and communities as part of the primary health care approach, which inherently requires social participation.

[Rio Political Declaration on Social Determinants of Health \(2011\)](#): This declaration highlights the importance of public, community, and civil society participation in achieving health equity.



VISION AND OBJECTIVES OF THE CHARTER

VISION

All patients and people with lived experience and their carers and families across the globe are informed and are able to shape health systems and services that affect our lives, resulting in more people-centred, compassionate, accessible, timely, and affordable care.

OBJECTIVES

- 1** **To promote** inclusive, equitable, diverse and sustained participation of patients and people with lived experience in health systems' governance.
- 2** **To ensure** effective mechanisms for meaningful representation of patients and people with lived experience in the co-design of health system planning, policymaking, implementation, and monitoring and evaluation, resulting in health systems' strengthening and resilience and better health outcomes.
- 3** **To uphold** the dignity, rights, responsibilities and goals of patients and people with lived experience in and through participatory processes.
- 4** **To build** trust, transparency, and mutual accountability between health policy makers, institutions, healthcare professionals, patients and people with lived experience, and other stakeholders.



GUIDING PRINCIPLES

Equity & Inclusiveness: with particular attention to under-served and underrepresented groups, and Low- and Middle-Income Countries, leaving no-one behind.

Recognition and respect for patients and people with lived experience as experts and indispensable stakeholders.

Cultural Relevance: The Charter and accompanying documents and resources are intended to be applicable and adaptable in different cultural settings across the globe, reflecting the diversity and reach of patient organisations and informal communities.

Transparency: Open communication and accessible and accurate information on plans, proposals, policies and their implementation and impact, through objective monitoring and evaluation.

Accessibility: Patients and people with lived experience should be able to participate on an equal basis in health governance and policy decision-making, with guaranteed accessibility to the physical environment / transportation, and access to health literacy programmes, quality information, and public services.

Accountability: Commitment and shared responsibilities between governments, health institutions, healthcare professionals and other stakeholders, including representative patient organisations.

Respect for Autonomy: Recognition of patients and people with lived experience as agents in their own care and their unique role in health system shaping.



GUIDING PRINCIPLES

Collaboration, Co-creation & Co-production: Health decisions at all levels are developed with—not for— patients and people with lived experience.

Specificity: In policy / programme development and decision-making in a specific condition / disease area, the representative should be ideally an individual living with that condition, or with a personal connection to that condition.

Continuity and comprehensiveness: Participation strengthens a health systems' ability — especially within primary health care — to provide comprehensive, continuous and coordinated care that meets people's needs over time.

People-centredness: Social participation is essential for ensuring that health services are designed around the needs and preferences of people and communities.



RESPONSIBILITIES

Responsibilities of Patients and People with Lived Experience who commit to engage, and our representative organisations, informal platforms and communities

To **actively participate** in available public forums, consultations, and co-creation & co-production initiatives relating to health decision-making and service delivery.

To **speak on behalf of patients and people with lived experience**, sharing authentic perspectives and actively participating in policy drafting and the design, delivery, monitoring and evaluation of health services.

To safeguard and **ensure diverse voices are represented**.

To **consult the communities that they are representing effectively** in order to convey a powerful voice in decision-making settings, reflecting the views and needs of patients and people with lived experience.

To be a **genuine partner** and provide constructive, evidence-based and workable feedback and uphold **shared accountability**.

To **disclose conflicts of interest** particularly when working with entities with vested financial interests and ensuring that our actions are always aligned with the best interests of the broader patient community, drawing on the [International Consensus Framework for Ethical Collaboration](#)¹.

To contribute to research and the **generation of evidence and data from lived experience**, to improve policies and services, and their efficiency and effectiveness.

1 <https://www.iapo.org.uk/consensus-framework-ethical-collaboration>



RIGHTS

Rights of Patients and People with Lived Experience and our organisations

Patients and People with lived experience and our organisations, informal platforms and communities have the right to:

Accessible and accurate information in various formats to enable us to consider and consult on critical questions, proposals and decisions, and their implications, through the lens of our communities.

Be invited to participate from **the beginning of the design** of research/policy/programmes/proposals, rather than at a later stage just to corroborate what was decided.

Adequate resources: access to information, financial and capacity-building support.

Capacity Building: to enable us to understand the 'mechanics' of engagement and engage effectively on an equal basis with other stakeholder and convey our experiential knowledge and expertise.

Participation in Decision-Making: to have an equal role in a decision-making context and voting rights as applicable.

Non-Discrimination: to not be discriminated against on the grounds of health / socio economic status, nor any other grounds (sex, racial or ethnic origin, religion or belief, disability, age, or sexual orientation) and for people with disabilities to be guaranteed reasonable accommodation to ensure equal participation.

Feedback: to receive feedback on the input and insights we have provided, and how these have been taken on board, or not, and why.

Compensation for our time and expertise equivalent to other contributors: compensation at fair market value on for our unique and vital contributions.



IMPLEMENTATION FRAMEWORKS

To implement the Resolution on Social Participation and this Charter, the following are our key requests to governments:

Legal and Policy Integration

Social participation rights and mechanisms should be embedded into national legal and policy frameworks to ensure sustainability, equity, and enforceability. In some countries and regions, this will require a phased approach.

- **Legislation:** Enact or revise national health laws to recognize the right of patients, people with lived experience and communities to co-create & co-produce health policy and decision-making processes.
- **Policy Alignment:** Ensure that national health strategies integrate social participation mechanisms as part of good governance. This includes incorporating participation principles in health systems and services, research, planning and delivery.
- **Rights-Based Approaches:** Align with human rights treaties and the UN Universal Declaration of Human Rights. Participation should be guided by the principles of this Charter – see above.
- **Decentralisation Policies:** Integrate social participation into decentralised health governance policies—supporting community input at sub-national levels.
- **Ongoing monitoring and evaluation** of the effectiveness of adopted legislation and policy and a systematic review for improvements—considering the public policy cycle.



Institutional Mandate

There is a need to establish or strengthen institutions and mechanisms that are formally mandated to support the participation of patients, people with lived experience and communities.

- **Formal Structures:** Set up or empower permanent bodies such as **Health Assemblies, Citizen Councils, Patient Forums and Patient-centred Care Committees in hospitals** at national and local levels. These should be apolitical, have transparent governance structures with clearly defined roles and membership election and rotation processes. They should be co-created & co-produced, with patients and people with lived experience and their communities involved in decision-making processes, including approving or vetoing health policy decisions where these are not made by consensus. Where feasible, digital and hybrid participation models should also be considered. *Further mechanisms for participation at global, regional and national level are explored in greater detail in the accompanying guide.*
- **Multisectoral Collaboration:** Create institutional mandates that require collaboration between ministries (health, finance, local government, education, research etc.) to ensure participatory processes are crosscutting.
- **Capacity Building:** Mandate institutional support for capacity building among patients, people with lived experience and communities and policy makers to ensure meaningful dialogue. This includes training on participatory methodologies, rights, and inclusive facilitation.
- **Partnerships and shared decision – making with Civil Society Organisations and Patient Organisations and platforms:** Institutions should be mandated to collaborate to ensure the diverse representation of underserved and underrepresented groups.
- **Mechanisms for on-going monitoring, evaluation and accountability** of established bodies to ensure their objectives are being met and not distorted, while also maintaining a technical vision of the health system.



Monitoring & Evaluation

There is a need to develop robust M&E systems to assess the quality, effectiveness, and inclusiveness of social participation mechanisms.

- **Participatory M&E:** Involve patients, people with lived experience and communities in designing and implementing M&E frameworks, including process and outcome indicators, explored further in the accompanying guide.
- **Feedback Loops:** Institutionalize mechanisms to ensure that community feedback leads to policy response and change.
- **Global Reporting:** Align M&E systems with international reporting frameworks such as UHC2030, SDG 16 (inclusive institutions), and WHO's Accountability Framework on Social Participation.

Funding & Resources

Sustainable and adequate funding is needed for the implementation and operationalisation of participatory mechanisms.

- **Dedicated Budget Lines:** Allocate specific funding in national and sub-national health budgets for participatory processes. This should cover: Facilitators, translators, logistics; capacity-building initiatives, community-led M&E; compensation at fair market value.
- **Cost Benefit Analysis:** Develop a cost benefit model on investing in the implementation of the Resolution on Social Participation and the Patient Charter, to demonstrate the significant economic in addition to the fundamental and intrinsic human value of social participation. This should incorporate social return on investment indicators to evaluate non-monetary benefits (improved patient engagement and health outcomes, service uptake, accountability and trust). This analysis should be multisectoral and led by the Ministries of Health.
- **Donor Coordination:** Engage international donors to support participatory systems, especially in low-income countries. Donor support should complement—not substitute—national investment. This should align with national health sector priorities and should



use existing country systems to avoid duplication. Support should focus on capacity transfer and system strengthening to ensure sustainability (after/beyond funding cycles).

- **Equity-Focused Investment:** Prioritize funding for inclusive processes, especially targeting underserved and under-represented groups (e.g., persons with disabilities, indigenous populations, rural communities).
- **Sustainability Plans:** Integrate funding plans into national health sector development plans and medium-term expenditure frameworks.





OVERSIGHT AND REVIEW

Oversight and Review of the Global Patients' Charter on Social Participation

IAPO will establish a multi-stakeholder **Patient Charter Review Committee** led by patients and people with lived experience to:

- Monitor the dissemination and socialisation of the Charter according to agreed indicators, primarily through the lens of patients and people with lived experience.
- Receive reports of non-participation / non-engagement and reflect on how this could be addressed effectively, applying good practice from other countries and regions as appropriate.
- Partner with other organisations monitoring the implementation of the WHA Resolution on Social Participation.
- Propose amendments to the Charter based on emerging needs and global political socio-economic developments.

The terms of reference of the Committee will ensure the independence of patients' voices in such a committee.

The Committee will update the World Health Organization's Civil Society Commission on a regular basis.





ADOPTION AND ENDORSEMENT

The Global Patients' Charter on Social Participation was officially adopted by IAPO at its 11th Global Patient Congress in Manila in November 2025.

Sister patient organisations, civil society allies, institutions, and national governments are invited to endorse the Charter and use it as a complement to their other resources on social participation.

IAPO will lead a widespread dissemination, socialisation and social media campaign amongst its membership and sister organisations promoting the use of the Charter, together with an accompanying **Guide** and **Metrics Framework**.

This will be launched on Patient Solidarity Day. Additional capacity building resources will be co-produced during the course of 2026.





METHODOLOGY AND ACKNOWLEDGEMENTS

The Global Patients' Charter on Social Participation was officially adopted by IAPO at its 11th Global Patient Congress in Manila in November 2025.

The Global Patients' Charter on Social Participation and accompanying guide was co-produced by a Task Force composed of IAPO member organisation leaders who volunteered to be part of this work, and global sister patient organisations.

A group of advisors also contributed toward the reflection and drafting process. Three online meetings and three rounds of written consultation took place during summer /early autumn 2025.

IAPO also reached out to its entire membership and other partners to glean their input on an advanced draft and held a consultation session with the members of the World Health Organization Civil Society Commission.



WARMEST THANKS TO

IAPO expresses its deep appreciation to all those involved for their engagement, commitment and important contributions, and for their ongoing support in the outreach and implementation of the Charter.

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