European **Patients'** Forum

Barometer

2026

1st Edition

Measuring the involvement of patient organisations
in health policy at national level

EPF European Patients Forum

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List of participating organisations

We would like to express our sincere thanks to the 27 national coalitions of patient organisations that provided the essential information and data on which this report is based.

- AOPP – Association for the Protection of Patients' Rights (Slovakia)
- BAG Selbsthilfe (Germany)
- BAPD – Bulgarian Association for Patients' Defence (Bulgaria)
- KZZ – Confederation of Heath Protection (Bulgaria)
- COPAC – Coalition of Patients' Organisations with Chronic Diseases (Romania)
- CyFPA – Cyprus Federation of Patients' Associations (Cyprus)
- EPIK – Estonian Chamber of Disabled People (Estonia)
- FEP – Spanish Patients' Forum (Spain)
- France Assos Santé (France)
- Greek Patients' Association (Greece)
- HAPO (BEMOSZ) – Hungarian Alliance of Patient Organisations (Hungary)
- KUZ – Coalition of Associations in Healthcare (Croatia)
- LPOT – Latvian Network of Patient Organisations (Latvia)
- LPOAT – Council of Representatives of Patients' Organisations of Lithuania (Lithuania)
- MHN – Malta Health Network (Malta)
- NAPO – National Association of Patients' Organisations (Czechia)
- Netherlands Patients' Federation (Netherlands)
- PRAK – Patients' Rights Association in Kosovo (Kosovo)
- UPS – Patients' Association of Serbia (Serbia)
- POP – Plataforma de Organizaciones de Pacientes (Spain)
- Sjogren Europe
- SOSTE – Finnish Federation for Social Affairs and Health (Finland)
- SUSTENTO – Latvian Umbrella Body for Disability Organisations (Latvia)
- Swedish Disability Rights Federation (Sweden)
- The ALLIANCE – Health and Social Care Alliance Scotland (Scotland)
- VPP – Flemish Patients' Platform (Flanders)
- ZOPS – Association of Patient Organisations of Slovenia (Slovenia)

Editorial by Marco Greco

President of the European Patients' Forum (EPF)

As patient advocates, we know first-hand what patient involvement means. It is when we are proactively asked for our views, listened to, and involved in the decisions – and their implementation – that affect our communities. It is when we are "part of the process". Patient organisations (POs) are at the heart of what we call "health democracy". They represent people and families who regularly interact with healthcare systems and professionals; who experience diseases and the benefits and side effects of treatments; who take part in clinical trials and share their data for the common good. They also provide essential support, from information and guidance for those navigating the system for the first time, to psychosocial support and community engagement. Above all, they give a voice to communities that might otherwise go unheard.

The economic and political crisis of the past few years caused an evident step back for what we define as "Health democracy". This is testing the foundations of our social contract. That is what happens when the role of civil society weakens: decisions risk becoming more unilateral and less grounded in people's needs. At the same time, expectations are rising, and patient organisations are increasingly asked to do more with fewer resources. As health slips down the political agenda and funding tightens, many organisations are forced to prioritise securing resources over fulfilling their core mission, creating a growing gap between expectations and capacity.

So why measure patient involvement in this context? Because we need data to understand what works, to identify common trends across countries, and to define what meaningful involvement should look like. At EU level, we know the reality well: patient organisations are present in many committees and expert groups, but our contribution is not always matched by adequate resources, and there is too often a strong and tangible sense that the real decisions are being made elsewhere. This Barometer builds on the experience of our national coalitions in shaping health policy at national level. The differences between countries reflect a diversity of approaches, but also offer opportunities to learn from one another and improve. Measuring these differences is a first step towards driving positive change.

This Barometer shows that better is possible. As demonstrated by the case studies, where patient organisations are meaningfully involved, policies are stronger, more relevant, and deliver real added value for public health. This report is not just a measurement tool; it is a call to strengthen institutional frameworks, invest in patient organisations, and ensure that patient voices are not only heard, but embedded in transparent, accountable and truly democratic decision-making.

Methodology

Scope and limitations

Most of the data on which the report is based were collected through an online questionnaire between March 2025 and June 2025. While the vast majority remain relevant, some recent developments in certain countries may not be reflected.

Reflecting the composition of EPF, the geographical scope of the Barometer extends beyond the countries of the European Union and covers Europe in a broader sense. The Barometer is based primarily on information provided by national coalitions representing countries. However, there are a few exceptions, such as constituent countries (e.g. Scotland in the United Kingdom) and regions (e.g. Flanders in Belgium).

Some of the questions required subjective responses from experts. As only one respondent per organisation completed the questionnaire (to limit the need for reconciliation), differences in the interpretation of questions may have led to variations in the answers provided, potentially affecting the comparability of results across countries.

In this context, the ranking of countries should not be interpreted as a definitive assessment of each national system, but rather as an indicative snapshot and a basis for identifying best practices and areas for improvement.

Phase 1:
Defining objectives and research questions
November 2024 – March 2025

- **Drafting of the concept note:** Building on the priorities identified through EPF's 2024 European election campaign. In particular, the EPF Manifesto on patient involvement served as a key reference to identify the main areas of focus for the Barometer;
- **Indicators and questionnaire development**: Desk research, complemented by consultations with EPF members, informed the development of indicators of patient involvement. These indicators underpin the eight thematic areas covered by the Barometer. They were translated into a questionnaire combining multiple-choice and open-ended questions, allowing both quantitative assessment and the collection of contextual information and case studies;
- **Weighting system development**: A scoring system was developed to support the aggregation of results across indicators and comparative analysis across countries. Points were allocated to responses to multiple-choice questions based on different dimensions of patient involvement: higher scores were assigned to answers indicating formalised, early and systematic involvement, while lower scores reflected more ad hoc or limited practices.

Phase 2:
Data collection
January 2025 – January 2026

- **Desk research**: A comprehensive desk-based review of publicly available sources, including reports, policy documents and relevant publications on patient involvement in health policymaking in Europe, was conducted to map existing knowledge and compare findings across sources;
- **Survey dissemination** (March 2025 – June 2025): The questionnaire was disseminated to patient organisations within the EPF membership across European countries. This phase aimed to gather insights into the current

state of patient involvement in health policymaking at national level. Each organisation identified one expert to complete the survey;

- Case studies and best practices (December 2025 – February 2026): Following an initial analysis of the survey results, EPF contacted members individually by email to clarify certain responses and collect additional information to develop case studies. These aim to highlight particularly relevant examples of successful patient involvement in health policy. The selection of case studies sought to ensure geographical balance. Where needed, follow-up interviews were conducted with national coalition experts to complement survey responses and support the development of these examples.

Phase 3:
Data analysis, drafting and review

September 2025 – May 2026

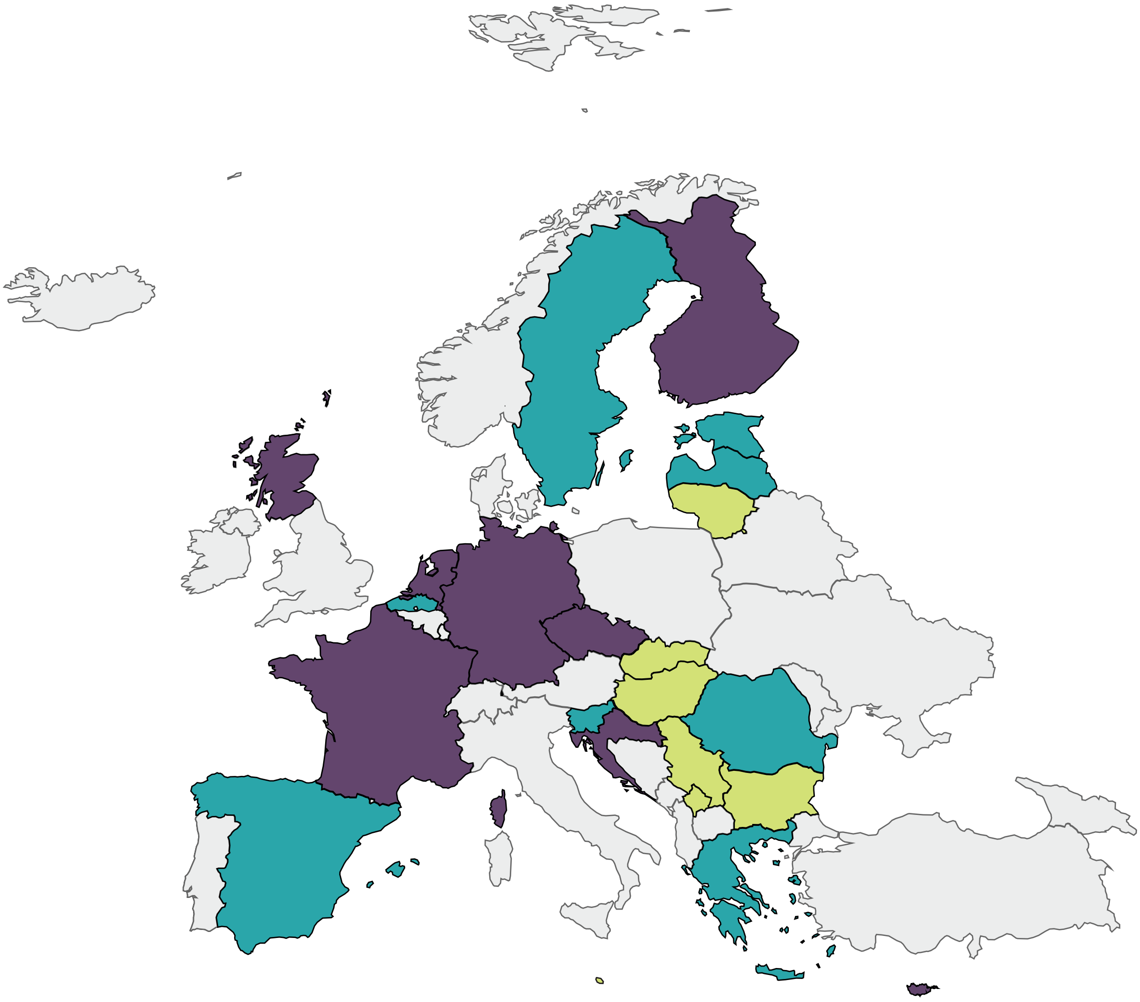
Data analysis:

- Survey results were analysed to:
  - » Provide an overview of the situation at national level in each country or region covered;
  - » Identify key trends, challenges, opportunities and recommendations across the different indicators of patient involvement.
- Reconciliation: In four cases, two national coalitions per country responded to the questionnaire (Spain, Latvia, Bulgaria, and Greece/Southern Europe). Where responses diverged significantly, dedicated calls were organised to better understand the differences and validate the inputs to be retained. In cases where no agreement was found, input from organisations with stronger experience in advocacy was prioritised;
- Ranking: Based on the weighting system developed during Phase 1, points were allocated to establish an initial ranking of countries per section. The overall ranking is determined based on each country's position in the eight rankings corresponding to the eight sections;
- Report drafting: Drafting of the report was carried out in two stages, starting with thematic chapters based on the indicators, followed by the development of short country profiles;
- Review: The draft report was shared with all contributing experts for review and comments. The country ranking was further refined during this phase, as experts compared and contextualised their responses, leading to minor adjustments where needed.

Use of AI

ChatGPT was used to support certain aspects of the data analysis and drafting process, including the identification of patterns and trends in the data under strict human oversight, as well as to review the final text for clarity and consistency. The data, core analysis, and conclusions remain under the full responsibility of the EPF team.

A map of Europe



1. Scotland – UK - 25 points
2. Netherlands - 28 points
3. Cyprus - 30 points
4. Czechia - 33 points
5. Germany - 36 points
6. Finland - 46 points
7. France - 50 points
8. Croatia - 58 points
9. Estonia - 59 points
10. Slovenia - 63 points
11. Sweden - 64 points
12. Flanders – Belgium - 66 points
13. Romania - 71 points
14. Greece - 72 points
15. Latvia - 81 points
16. Spain - 83 points
17. Kosovo - 84 points
18. Lithuania - 94 points
19. Slovakia - 100 points
20. Hungary - 112 points
21. Malta - 117 points
22. Serbia - 123 points
23. Bulgaria - 127 points

🟪 Highest Overall Performance
🟦 Mid-Level Overall Performance
🟨 Lower Overall Performance

Figure 1. *Overall Performance*

Geographical trends

The ranking reveals a geographical pattern, with Northern and North-Western European countries generally performing best. Scotland, the Netherlands, Germany, Finland, Sweden, Flanders and France all appear in the upper half of the table, with several occupying the top positions.

Central and Southern Europe display mixed results. Czechia ranks relatively high, while Slovenia, Slovakia and Hungary fall into the mid to lower range, reflecting variations within Central Europe.

Southern Europe is similarly heterogeneous: Cyprus performs strongly, whereas Greece, Spain and Malta are positioned in the lower part of the ranking.

By contrast, Eastern and South-Eastern European countries are generally lagging behind, with some variations. In the Baltic region, Estonia performs better than Latvia and Lithuania.

Introduction: setting the scene and overview of the literature

Patients are not only users of healthcare services: they have valuable experience in navigating the health system and a deep understanding of their condition based on lived experience. They experience first-hand the benefits and shortcomings of healthcare systems and have specific expertise that can inform all aspects of healthcare.

The Alma Ata declaration defined civic involvement in healthcare as both a right and a duty. "The people have the right and duty to participate individually and collectively in the planning and implementation of their healthcare."[1]

46 years later, the World Health Organization (WHO) Resolution on Social Participation in Health Decision-making[2] highlights the importance of implementing, strengthening and sustaining meaningful social participation to promote mutual respect and trust, while making health systems more responsive, equitable and resilient.

In addition to being a right, patient involvement is increasingly recognised as benefitting the research and development of therapies and the design and implementation of healthcare services that better address patients and societies' needs. This growing body of evidence has led to increased recognition of patient involvement across the healthcare continuum. For example, in the regulatory field, patients' contributions are reported as having "a tangible impact on the recommendations provided to developers and in over half of the cases". Similarly, in health technology assessment processes, studies show that "the patient perspective is essential for identifying preferences, estimating values and identifying unmet medical needs in the context of research and development"[3].

Defining patient involvement

The notion of **patient and public involvement** (PPI) is often used in research, defined as "*research being carried out 'with' or 'by' members of the public rather than 'to,' 'about' or 'for' them*"[4].

Patient involvement is defined in the PaSQ Joint Action[5] as:

- Individual: the extent to which patients and their families or caregivers, whenever appropriate, participate in decisions related to their condition (e.g. through shared decision-making, self-management) and contribute to organisational learning through their specific experience as patients.
- Collective: the extent to which patients, through their representative organisations, contribute to shaping the health care system through involvement in health care policy-making, organisation, design and delivery.

Involvement therefore has both an individual and a collective dimension and can take place at different levels. Patient involvement at individual (micro) level allows patients to participate in their care through shared decision-making and self-management. At organisation (meso) level, patients can participate in the development and implementation of specific initiatives, e.g. quality improvement initiatives at hospitals. At policy (macro) level, patient organisations are involved in policy-making processes.

Patient involvement is often used interchangeably with patient engagement, although there are important nuances.

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[1] WHO (1978). Declaration of Alma-Ata. https://www.who.int/publications/i/item/declaration-of-alma-ata

[2] WHO (2024). Resolution "Social participation for universal health coverage, health and well-being", 1 June.

[3] Dimitrova, M., Jakab, I., Mitkova, Z., Kamusheva, M., Tachkov, K., Nemeth, B., Zemplenyi, A., Dawoud, D., Delnoij, D., Houÿez, F. and Kalo, Z. (2022). Potential barriers of patient involvement in health technology assessment in Central and Eastern European countries. Frontiers in Public Health, 10:922708. https://www.frontiersin.org/journals/public-health/articles/10.3389/fpubh.2022.922708/full

[4] Arumugam A, Phillips LR, Moore A, Kumaran SD, Sampath KK, Migliorini F, Maffulli N, Ranganadhababu BN, Hegazy F, Botto-van Bemden A. Patient and public involvement in research: a review of practical resources for young investigators. BMC Rheumatol. 2023 Mar 9;7(1):2. doi: 10.1186/s41927-023-00327-w. PMID: 36895053; PMCID: PMC9996937.

[5] PaSQ, adapted from Luttrell et al. 2009 and the Duque project (www.duque.eu), as quoted in EPF Background Brief on Patient Empowerment, May 2015

Patient engagement is defined by the WHO as “*facilitating and strengthening the role of service users as co-producers of health, as well as of healthcare policies and practices*”[6]. Other sources define engagement as “raising awareness, sharing research knowledge and findings”, emphasising the role of patients in receiving and disseminating information provided by others, as opposed to involvement, meaning that research, policies, or decisions are “done with or by patients, not to, about or for them”.

Level of institutionalisation

In this report, “*patient involvement*” refers specifically to the involvement of patient organisations, unless otherwise stated. This reflects the focus on collective, representative participation in health policy-making.

Although there is no legal definition of a **patient organisation**, the European Medicines Agency (EMA) has developed a widely used definition: “patients’ organisations are defined as not-for-profit organisations which are patient-focused, and whereby patients and/or carers (the latter when patients are unable to represent themselves) represent a majority of members in governing bodies”[7].

The concept of a patient organisation differs from that of a patient expert, defined as a patient with experience of living with a disease who uses this experience to engage in healthcare decision-making processes. While patient experts only convey their own views, patient organisations provide collective input to decision-makers based on the aggregated experience of the community they represent.

Building on this distinction, the literature addresses not only whether patients are involved, but how this involvement is formally integrated, supported and sustained within health systems and policy-making processes.

A continuum of involvement is often illustrated by the “ladder” model first developed by Arnstein[8] in 1969, moving from research subject to info provider, advisor, reviewer, co-researcher and driving force. A study by Biddle *et al*. characterises the approaches to patient involvement in healthcare with three main types:

1. **Choice** (consumerist): patients acting as consumers who can choose between providers, treatments, or services;
2. **Voice** (deliberative): patients expressing views, preferences, and experiences to influence healthcare decisions;
3. **Co-production** (participative): patients and professionals working in partnership to design, deliver, and evaluate healthcare services or policies (Dent and Pahor, 2015)[9].

The same study concludes that the “choice” (consumerist) level is generally the most widely implemented approach to patient involvement in healthcare (Coulter & Magee, 2003), while co-production (participative) is less evident (Coulter & Collins, 2011)[10]. A European-wide study, based on 8 scientific databases and 40 articles, concludes that patient and public involvement (PPI) was “not yet firmly embedded or adequately formalised in European healthcare systems and research”[11], pointing to persistent gaps in institutionalisation.

In practical terms, a European study on cancer patient organisations found that participation was highest at the strategic (macro) level, such as in hospital boards, health policy reforms and clinical trial ethics committees, while involvement was lower at the institutional (meso) level, including Ministry of Health panels and other health-related organisations.[12] The study concluded that legislation supporting patient rights is the most decisive factor in strengthening participation, highlighting the importance of institutional support. While participation alone does not translate into impact, stronger structures, networks and skills support organisations’ ability to influence[13].

Diversity of approaches across Europe

Several studies suggest that differences between countries in terms of culture, political environment and healthcare systems contribute to the diversity of approaches to PPI. While these factors remain under explored, countries

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[6] World Health Organization Regional Office for Europe (2019). Patient engagement: technical series on safer primary care. Copenhagen: WHO Regional Office for Europe.

[7] European Medicines Agency. (Year). Assessment of patient, consumer and healthcare professional organisations’ compliance with EMA eligibility criteria. https://www.ema.europa.eu/en/documents/other/assessment-patient-consumer-and-healthcare-professional-organisations-compliance-ema-eligibility-criteria_en.pdf.

[8] Arnstein, Sherry R. “A Ladder of Citizen Participation,” JAIP, Vol. 35, No. 4, July 1969, pp. 216-224. Accessed at http://lithgow-schmidt.dk/sherry-arnstein/ladder-of-citizen-participation.html

[9, 10, 11] Biddle, M. S. Y., Gibson, A., & Evans, D. (2021). Attitudes and approaches to patient and public involvement across Europe: A systematic review. Health & Social Care in the Community, 29(1), 18–27. https://doi.org/10.1111/hsc.13111

[12] Souliotis, K., Peppou, L. E., Agapidaki, E., Tzavara, C., Debiais, D., Hasurdjiev, S., & Sarkozy, F. (2018). Health democracy in Europe: Cancer patient organization participation in health policy. Health Expectations, 21(2), 474–484. https://doi.org/10.1111/hex.12638

such as the UK, the Netherlands and several Scandinavian countries are often cited as more advanced. This is visible in the number of publications, with the UK, the U.S., and the Netherlands leading published work on PPI. More specifically, another study focused on health technology assessment examines whether factors such as administrative tradition (contractual/corporate or organic) and the structure of health systems (Bismarckian or Beveridgean) could influence patient involvement. The study suggests that contractual and corporate administrative traditions (e.g., in England), where governance emphasises negotiation and participation, tend to involve external stakeholders more actively[14].

The nature of participation also varies across cultures. One study explores patient and public involvement (PPI) in two Beveridge-type health systems, in England and Sweden, where healthcare is funded by general taxation and focused on equity and universality. The conclusion is that in England, patients are more inclined to want personal decision-making autonomy, while Swedish systems may offer more inclusive models of collective participation[15].

Barriers and enablers

The solutions for increased patient involvement recommended across studies are varied. They include addressing current barriers to patient involvement, '*including a lack of power, organisational support, guidelines, resources and examples of good practice*'[16]. Souliotis et al highlight three key measures: establishing or strengthening patient rights legislation in all countries; monitoring participation for impact; and investing in organisational development, including training, coalition building and advocacy skills among patient organisations[17]. Digital solutions (online portals / overview platforms, etc.) are also highlighted as means to facilitate participation[18,19].

Beyond structural changes, a Finnish study recalls that institutions alone are not enough: open procedures, active feedback and integration into decision-making are necessary to truly give patients a voice[20]. Similarly, a Hungarian study emphasises that cultural changes are needed to establish more patient-centred healthcare systems, citing health education programmes as a way to instil a patient-centred mindset in future healthcare professionals[21].

Tools to measure the involvement of patient organisations

Very few tools are designed to measure the involvement of patient organisations comprehensively, across the policy spectrum.

Under PPI, evaluation frameworks' measure how well PPI is implemented and its impact. For example the GRIPP2 checklist (Guidance for Reporting Involvement of Patients and the Public) evaluates quality and reporting of PPI. The Public and Patient Engagement Evaluation Tool (PPEET) is also widely used to assess engagement processes and outcomes.

The Health Democracy Index (HDI), developed by the National Academy of Medicine, is a validated, research assessment tool that measures the involvement of patient organisations in policy-making across 8 items. These include policy reforms, Ministry of Health workshops/panels, other health-related organisations, hospital boards, clinical trial

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[13] Souliotis, K., Peppou, L. E., Agapidaki, E., Tzavara, C., Debiais, D., Hasurdjiev, S., & Sarkozy, F. (2018). Health democracy in Europe: Cancer patient organization participation in health policy. Health Expectations, 21(2), 474–484. https://doi.org/10.1111/hex.12638

[14] Cavazza, M., & Jommi, C. (2012). Stakeholders involvement by HTA organisations: Why is so different? Health Policy, 105(2–3), 236–245. https://doi.org/10.1016/j.healthpol.2012.01.012

[15] Fredriksson, M., Eriksson, M., & Tritter, J. (2018). Who wants to be involved in health care decisions? Comparing preferences for individual and collective involvement in England and Sweden. BMC Public Health, 18, 18. https://doi.org/10.1186/s12889-017-4534-y

[16] Biddle, M. S. Y., Gibson, A., & Evans, D. (2021). Attitudes and approaches to patient and public involvement across Europe: A systematic review. Health & Social Care in the Community, 29(1), 18–27. https://doi.org/10.1111/hsc.13111

[17] Souliotis, K., Peppou, L. E., Agapidaki, E., Tzavara, C., Debiais, D., Hasurdjiev, S., & Sarkozy, F. (2018). Health democracy in Europe: Cancer patient organization participation in health policy. Health Expectations, 21(2), 474–484. https://doi.org/10.1111/hex.12638

[18] Gesundheit Österreich GmbH (GÖG). (2023). Partizipation im Gesundheitssystem [Report]. Vienna: Gesundheit Österreich GmbH. Retrieved from https://jasmin.goeg.at/id/eprint/3119/1/Bericht_Partizipation%20im%20GS_bf.pdf

[19] Rojatz, D., & Wahl, A. (2023). Bevölkerungs- und Patientinnen/Patientenbeteiligung im Gesundheitssystem – Status quo der Umsetzung und Entwicklungsperspektiven. Wien: Agenda Gesundheitsförderung. Retrieved from https://agenda-gesundheitsfoerderung.at/sites/agenda-gesundheitsfoerderung.at/files/inline-files/FS%20Partizpation.pdf

[20] Tran Minh, M., Airaksinen, M., & Lahti, T. (2024). Experiences of patient Organisations' involvement in medicine appraisal and reimbursement processes in Finland: A qualitative study. International Journal of Technology Assessment in Health Care, 40(1), e26. https://doi.org/10.1017/S0266462324000229

[21] Brito Fernandes, Ó., Hölgyesi, Á., & Péntek, M. (2022). Patient-centred care in Hungary: Contributions to foster a policy agenda. Zeitschrift für Evidenz, Fortbildung und Qualität im Gesundheitswesen, 171, 58–61. https://doi.org/10.1016/j.zefq.2022.04.015

ethics committees, health technology assessment (HTA) processes, and national parliament. It is a simple tool that requires patient organisations to answer whether or not they are involved in these settings. The HDI assesses both the degree of involvement (presence in different policy areas) and the perceived impact (perceived influence on policy outcomes)[22].

While the HDI measures the presence of participation, it does not explore the barriers that prevent more meaningful engagement[23]. It also lacks the granularity needed to fully assess the full breadth of patient involvement across the policy-making process, from agenda setting to evaluation of health policies. The HDI also doesn't measure the quality of the involvement (what degree of influence or decision-making is ceded).

The purpose of the Barometer

Taken together, the literature highlights both the recognised value of patient involvement and its uneven implementation across Europe. Differences in institutional frameworks, organisational capacity and cultural contexts all contribute to variations in how patient organisations are involved, and in how much influence they are able to exert.

However, despite this growing body of research, participation often remains fragmented, insufficiently institutionalised, and variable in its impact on decision-making. In addition, existing studies do not provide a comprehensive and comparable overview of patient organisations' involvement across the full health policy cycle.

The EPF Barometer on patient involvement in health policy aims to address existing information gaps on patient involvement across the policy continuum and provide a comprehensive overview of the situation across EU member states. The Barometer leverages the experience and knowledge of EPF's national coalitions across 23 countries to:

- Map the level of patient organisations' involvement in the development, implementation and evaluation of health policies in EU Member States in 8 key areas;
- Identify good practice in patient involvement in health policy and the mechanisms and structures in place to facilitate the involvement of patient organisations in policy-making processes;
- Examine the barriers and challenges that patient organisations face in participating effectively in health policy-making;
- Identify some impacts of patient involvement and patient advocacy on ensuring better, more equitable healthcare systems;

The Barometer will provide a roadmap for fostering meaningful involvement of patient organisations across Europe, ensuring a system where nothing is decided about patients without them, and where health policies are co-designed and co-created based on patients' unique expertise.

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[22] Souliotis, K., Peppou, L. E., Agapidaki, E., Tzavara, C., Debiais, D., Hasurdjiev, S., & Sarkozy, F. (2018). Health democracy in Europe: Cancer patient organization participation in health policy. Health Expectations, 21(2), 474–484. https://doi.org/10.1111/hex.12638

[23] Souliotis, K., Agapidaki, E., Peppou, L. E., Tzavara, C., Samoutis, G., & Theodorou, M. (2016). Assessing patient participation in health policy decision-making in Cyprus. International Journal of Health Policy and Management, 5(8), 461–466. https://doi.org/10.15171/ijhpm.2016.78

Section 1
An incomplete institutional framework for patient organisations' involvement

Definition

Institutional framework on patient organisations' involvement: (formal basis) whether legislation, strategic policy/guidelines, international conventions or civil society sources – that specifies how and when patient organisations should be involved in decision-making on national health policy.

Institutional frameworks for patient organisations' involvement across Europe

Does your country have legislation, guidelines, or a strategy in place for the involvement of patient organisations and/or other health civil society organisations in health policy at national level?

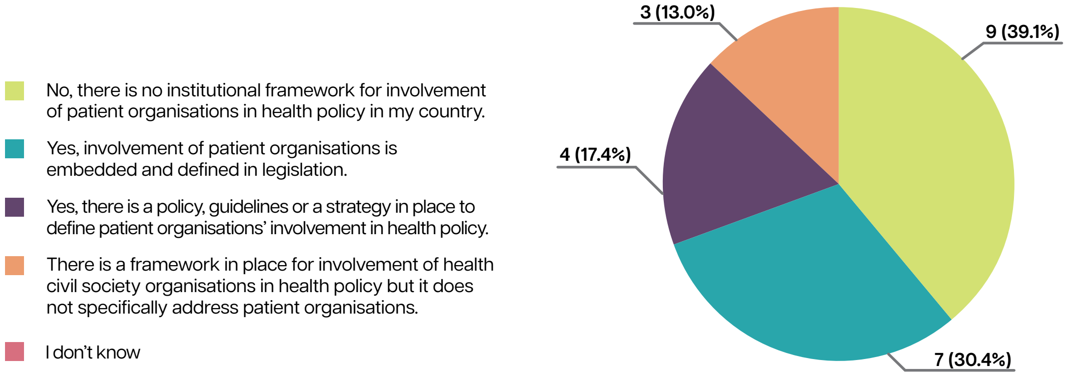


Figure 2. *Extent to which countries have legislation, policies, or frameworks for involving patient organisations in national health policy (n = 23).*

30% of the respondents answered that the involvement of POs is embedded in legislation. Policy/guidelines/strategies (not necessarily legislative) represent 19% of the cases. General civil society framework represents 17% of the cases. There is no institutional framework for the involvement of POs in health policy among 39% of the participants.

Takeaway #1

About 1 in 2 report some formal basis (law or policy guidelines), but more than 1 in 3 say no framework at all.

While non-profit, representative and participatory functions are recurring themes in most of the references cited by participants, countries differ mainly on the question of whether the participation of patient organisations is defined in hard law (binding, enforceable), in soft law/policy (strategic, flexible), or through civil society self-organisation.

🟩 **Embedded and defined in legislation**: Cyprus, Germany, Netherlands, Croatia, Finland, France, Greece

🟦 **A policy, guidelines or a strategy in place to define patient organisations' involvement in health policy**: Sweden, Czechia, Estonia, Scotland

🟧 **A framework in place for involvement of health civil society organisations in health policy but it does not specifically address patient organisations**: Kosovo, Hungary, Romania, Latvia

🟪 **No institutional framework for involvement of patient organisations in health policy in my country**: Bulgaria, Slovenia, Slovakia, Malta, Flanders, Lithuania, Serbia, Spain

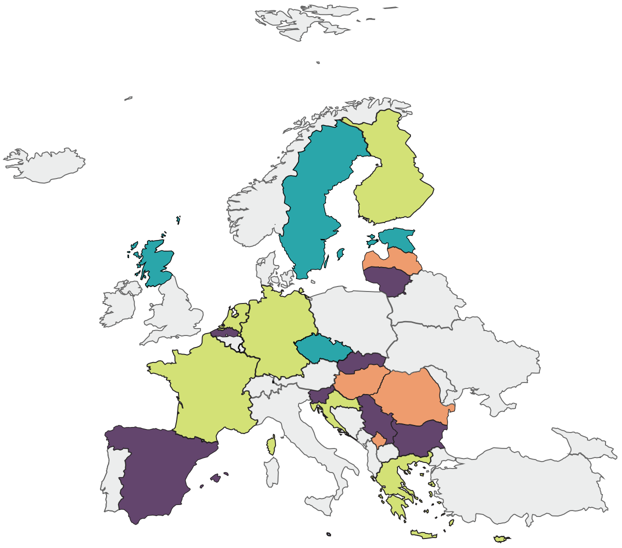


Figure 3. *Institutional frameworks for patient organisations' involvement across Europe.*

Of course, there are certain nuances to these distinctions. In Finland, for example, the involvement of patient organisations and public health organisations in health policy is not defined within a single, comprehensive legislative framework, but it is well established and firmly rooted in practice through consultation mechanisms and various decision-making processes. In Flanders, the national coalition of patient organisations is recognised by law and receives public funding. Patient organisations also fulfil certain advocacy roles, as required by law, but patient organisations focusing on specific conditions do not have a clearly defined institutional framework. Slovakia does not yet have a single, comprehensive law defining the involvement of patient organisations, but has partial guidelines as well as by ad hoc mechanisms.

Case study

In Spain, the legislative process to recognise patient organisations has been launched

What do you currently know about the forthcoming law on patient organisations in Spain?

Monica de Elio de Bengy, Executive Director & **Raquel Sánchez Sanz**, Representative; Spanish Patients' Forum (FEP)

"The aim of the new law is to formally strengthen state-level patient organisations as interlocutors with the State Administration, ensure their participation in public health policy, and define the rights and obligations that apply to them in carrying out their activities."

Pedro Carrascal, Executive Director, Spanish Patient Organisations Platform (POP)

"This is part of an ongoing legislative process, as the Law on Patient Organisations remains under negotiation. One of the key issues currently being discussed is the definition of what constitutes a "patient organisation". In this context, efforts are focused on ensuring that patient organisations are clearly recognised as private, non-profit associative entities with their own legal personality, whose governing bodies are mainly composed of people with chronic health needs, together with their relatives and non-professional caregivers, and which are established to defend their rights and interests.

The draft law also seeks to set out core principles such as good governance, transparency, democratic participation, autonomy, and the prevention of conflicts of interest; to establish formal participation mechanisms, including a structured dialogue forum and a public State Register of Patient Organisations; and to ensure the inclusion of representatives of patient organisations in relevant national bodies, such as the SNS Advisory Committee.

At the same time, there has been a notable development with the recent Ministerial Order establishing the Patient Participation Table. This constitutes an important first step towards structuring dialogue with the Ministry of Health. However, its actual scope will largely depend on how the future law defines patient organisations, their rights and obligations, as well as on the regulatory framework governing the State Register. In this regard, the Table should be seen as part of a broader normative development process aimed at building a coherent, meaningful, and effective system for patient participation.

What are your organisations' key asks?

Monica de Elio de Bengy, Executive Director & **Raquel Sánchez Sanz**, Representative; Spanish Patients' Forum (FEP)

"*Our presence in key decision-making bodies—such as the Health Advisory Council, the Advisory Committee of the Interterritorial Council of the National Health System, the Drug Pricing Committee, the Pharmacy and Therapeutics Committees, and the Spanish Agency for Medicines and Health Products—is urgently needed.*

Our voice must be heard in the development of public health plans and strategies, including the Antimicrobial Resistance Plan, the Global Health Strategy, and the Advanced Therapies Plan.

Formal recognition is essential to ensure our effective representation and equitable access—on the same footing as other non-profit organisations—to funding opportunities, training resources, and support for our professionalisation."

Pedro Carrascal, Executive Director, Spanish Patient Organisations Platform (POP)

Our key demands are to ensure that the law fulfils its intended purpose: recognising and protecting patient organisations as a distinct stakeholder within the health system. This requires a clear and precise legal definition that explicitly reflects their patient-led nature, ensuring that governing bodies are primarily composed of people with chronic health needs, their families and non-professional caregivers, and avoiding overly broad formulations that could dilute this specificity.

We consider it essential to maintain a strong focus on people with chronic health needs, as this reflects a differentiated reality within the health system and should not be replaced by more generic or ambiguous categories that fail to capture their specific circumstances.

In addition, we call for solid criteria on governance and representativeness, as well as for participation mechanisms that are genuine, enforceable, and embedded early in decision-making processes, rather than merely symbolic.

We also emphasise the importance of ensuring adequate resources and sustainable conditions so that organisations can participate on an equal footing. In this process, POP recognises the Ministry's openness to dialogue and its willingness to engage in a genuine and constructive manner, and remains committed to contributing to a regulatory framework that strengthens patient organisations across Spain.

How can the text be improved in order to strengthen the participation of patient organisations in health policy in Spain?

Monica de Elio de Bengy, Executive Director & **Raquel Sánchez Sanz**, Representative; Spanish Patients' Forum (FEP)

"*With regard to the definition of patient organisations, the text does not specify the criteria by which their representativeness will be recognised—whether by pathology, thematic remit, geographical scope, or other factors.*

It also does not explicitly establish formal mechanisms for securing stable public funding.

In addition, the published draft does not acknowledge our standing to defend patients' collective interests or claims before the courts, unlike the legal standing currently granted to consumer and user organisations.

Finally, the preliminary text neither provides nor anticipates the mechanisms or resources needed to ensure ongoing training and capacity-building for those who represent our organisations."

Pedro Carrascal, Executive Director, Spanish Patient Organisations Platform (POP)

The definition of "patient organisation" continues to be a key area requiring improvement. If it remains too broad or ambiguous, patient-led organisations—particularly those representing people with chronic health needs—may find themselves sharing institutional spaces with entities that are not governed by patients, thereby undermining legitimacy, clarity, and representativeness.

Moreover, ongoing discussions indicate that particular care must be taken in how the law recognises and protects the specific reality of people with chronic health needs, avoiding formulations that could dilute this group within broader categories that do not adequately reflect their lived experience.

The draft also primarily focuses on state-level organisations, which may result in a significant portion of the patient movement—especially regional and local organisations—being only indirectly covered, unless strong coordination and inclusion mechanisms are put in place.

Recent developments, such as the establishment of the Patient Participation Table through Ministerial Order, are positive steps. However, their effectiveness will depend on the broader regulatory framework, particularly the future law and the rules governing the State Register, which will determine who participates and under what conditions.

In the absence of clear, fair, and inclusive criteria, participation risks becoming procedural rather than genuinely influential. This concern is especially pertinent in the implementation phase of the law.

Finally, the "no increased spending" clause creates a structural risk: rights and participation mechanisms may exist formally, but without the necessary resources and capacity-building measures to ensure meaningful, sustained, and high-quality participation—particularly for smaller organisations.

Takeaway #2

Implementation overall is not viewed positively by patient organisations.

Another sign of the incompleteness of institutional frameworks for POs involvement is their implementation. Implementation is not viewed positively by participants overall; out of the 14 countries that have an institutional framework in place (either a law or a guideline), only 5 (Netherlands, France, Finland, Scotland, Romania) of them consider the framework to be "well implemented".

Case study

In Sweden, the Patient Parliament plays an important role in supporting the effective implementation of European or national regulations

Hanna Sejlitz, Policy Analyst, Swedish Disability Rights Federation

"In Sweden, the Patient Parliament plays an important role in supporting the effective implementation of European or national regulations. It serves as a multi-stakeholder forum where patient organisations, pharmaceutical companies, and policymakers come together to discuss how best to implement both national and EU legislation. This is particularly significant in the Swedish context, where the country's 21 regions hold primary responsibility for healthcare delivery.

This collaborative approach is especially relevant for major European initiatives such as the European Health Data Space. For instance, the Patient Parliament has developed a Manifesto emphasising key priorities, including patient control over health data, the need for interoperable and accessible systems, and the use of data to improve care and advance research. Beyond regulatory implementation, the Patient Parliament also promotes broader, cross-cutting discussions on issues such as equitable access to healthcare, patient-centred innovation, and health system preparedness in times of crisis, including war."

Patient organisations' in the law: are definitions the exception?

A final example of the incomplete nature of the institutional frameworks for the involvement of POs is the near absence of a definition of POs in the law.

Takeaway #3

The vast majority of European countries do not have a definition of POs in their national legislation; only 4 countries have a definition of patient organisation in their legislation (Germany, Netherlands, Bulgaria, Czechia).

Where a legal definition exists, patient organisations have generally been involved in its development. In Germany, the Netherlands, Czechia patient organisations were involved but not in Bulgaria.

Content-wise, all definitions of POs agree that patient organisations are non-profit, legally constituted entities. They all stress some combination of advocacy, representation, and/or patient support. The collective nature (representing groups of patients, not just individuals) is also consistent. The definitions differ in terms of their emphasis: legalistic vs mission-based.

For example, Germany stresses the representativeness and legitimacy of patient organisations. The Netherlands highlights their threefold role: (1) supporting patients (information & self-help), (2) advocating for rights and needs, (3) partnering in policy shaping. Czechia defines patient organisations as a legal person whose main activity is the defence of patients' rights or the support of patients with a specific illness. Finally, Bulgaria defines a patient organisation as a non-profit legal entity representing patients, registered under the Non-Profit Legal Entities Act.

Bulgarian definition of patient organisations

Art. 86b. (New - SG, issue 101 of 2009, effective 18.12.2009)

(1) Representative Organisations for the protection of patients' rights are Organisations that meet the following conditions:

1. to have as their goal the protection of the rights and interests of all patients regardless of specific diseases, diagnoses and suffering;

2. to be registered as non-profit associations for public benefit activity within the meaning of the Non-profit Legal Entities Act;

3. to be nationally represented, having established regional structures throughout the country.

Other countries, such as France, do not have a precise definition of patient organisations, but use the similar term "healthcare users".

Case study

Advantages and limitations of the Czech definition of patient organisations

Why the Czech definition?

The definition of patient organisations in Czechia was first incorporated into law in 2012 and patient organisations were involved in its drafting.

Definition of patient organisation: *A patient organisation is a registered association whose main activity is to assist patients and protect their rights and interests and whose members are usually persons with a specific illness or disability, their close ones (as defined by law) or their representatives. A patient organisation can also be an association, an institute or a charitable organisation.*[24] *Patients have demonstrably significant influence on the activities (initially a decisive share on the management of the organisation), members of the statutory and supreme body, if this body is not a general meeting, are elected by the members of the association.*[25]

The original proposal by the Ministry of Health was based on the European Medicines Agency (EMA) definition, with the primary requirement that eligible organisations must be membership-based organisations (in Czechia 'associations') in which patients, as members, hold a decisive share in the management of the organisation, i.e. they possess majority decision-making power[26].

This requirement was amended a first time during the legislative process, expanding the definition to include organisations where patients have "a decisive share in the management of the organisation" (Healthcare Services Act as amended in 2021, Sect. 113f). Two years later, this condition was further broadened, replacing the requirement for a majority vote in decision-making with the more flexible criterion of having "a major influence on the activities of the association" (Healthcare Services Act as amended in 2024, Sect. 113f). As a result, the criteria were diluted, allowing a broader range of organisations to qualify.[27]

[24, 25, 26, 27] Holtorf, AP., Dinböck, M., Moutet, A., Davies, E.H. (2026). Patient Involvement Throughout the Medicine Life Cycle: A Pharmaceutical Industries' Perspective. In: Facey, K.M., Holtorf, AP., Single, A.N. (eds) Patient Involvement in Health Technology Assessment. Health Informatics. Springer, Cham. https://doi.org/10.1007/978-3-032-11284-2_31

Members voice

Robert Hejzák, Chair, National Association of Patient Organisations (NAPO)

What is the main strength of the Czech legal definition of patient organisations?

“The main strength is that the definition is legally binding. It is not merely part of a methodology but is firmly enshrined in law. In terms of its content, its value lies in the fact that it is based on the EMA definition and is therefore linked to established standards that have proven effective across the European Union for more than 20 years. Another important strength is that the definition is not overly prescriptive: it provides sufficient clarity while still allowing the Ministry the necessary flexibility to carry out its role and assess candidate profiles without being rigidly constrained by the criteria.”

Since its introduction, the definition has evolved considerably. What do you think of these changes?

“Since its introduction, the definition has been gradually diluted. Under the original version, patients were required to play a decisive role in the governance of the organisation; today, it is sufficient for them to have a major influence on the organisation’s activities. We were not satisfied with this change and actively opposed it. As a result, the Czech definition has begun to diverge increasingly from the EMA definition. We now have organisations that are legally recognised as patient organisations despite having no patients or caregivers represented on their executive board Initially, the definition was applied exclusively within health technology assessment (HTA) procedures. It was only when its use was extended beyond HTA that the definition itself began to be questioned. In particular, during discussions on the sustainable funding of patient organisations—including the introduction of government core funding—there was clear pressure to broaden it. As a result, we estimate that more than 200 organisations could now be formally recognised as patient organisations.”.

As Czechia is a pioneer in this field, have you been actively involved in discussions on a European legal definition of patient organisations?

“In 2025, Czechia advocated for the inclusion of a legal definition of patient organisations in the revision of EU pharmaceutical legislation. This was a joint effort involving Czech patient organisations, the European Patients’ Forum, and the Czech Ministry of Health. Although the proposal was not accepted by the Council, I continue to believe that institutional recognition of patient organisations at the EU level is essential to strengthening the patient voice within individual EU Member States.”

Key recommendations

- Institutionalisation is essential to embed the role of patient organisations in health policy-making; while the absence of a legal basis is not, in itself, a barrier to meaningful participation, it risks making engagement ad hoc rather than structural and fails to recognise the legitimacy of patient organisations’ contributions;
- Legal frameworks are only effective if properly implemented and accompanied by adequate resources to support meaningful participation, including training and financial support;
- A clear definition of patient organisations is needed to distinguish organisations that genuinely represent patients and their interests from other types of organisations;
- Strong governance of patient organisations is critical to ensure trust, including transparency of funding, appropriate registration, democratically elected bodies, and robust accountability and consultation mechanisms with their membership.

Section 2
Formal mechanisms for participation in decision-making

Different countries, different models

How often are patient organisations consulted on health-related matters in your country?

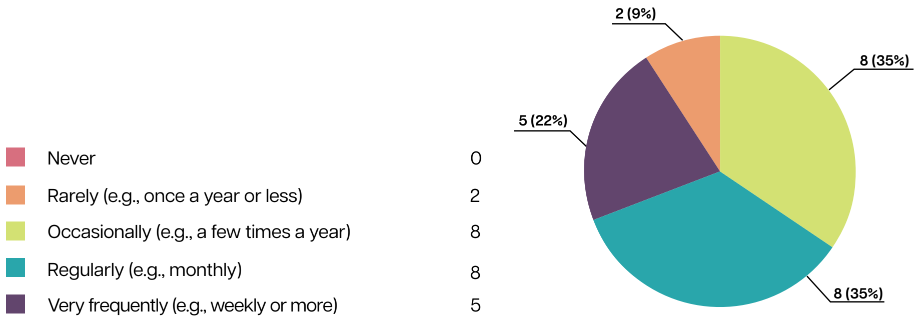


Figure 4. *Frequency of consultation with patient organisations on health-related matters across countries (n = 23).*

Takeaway #1

The responses reveal a highly uneven situation across Europe.

For example, 22% of patient organisations report being consulted very frequently, 35% regularly, 35% occasionally and 9% rarely.

None of the organisations in the surveyed countries responded having no involvement whatsoever in policy processes. Almost all patient organisations responded that they are involved in advisory committees, in expert and working groups, and consulted as part of targeted stakeholder consultations. Only 2 organisations responded that they are consulted "rarely (once a year or less)" - these are located in Malta and Bulgaria.

Three different models stand out:

1. **Structured, legally mandated involvement** (e.g.: Netherlands, Scotland)
   - Clear legal requirements for patient representation;
   - Institutionalised consultation systems;
   - Formal roles in parliamentary hearings and structured committees.
2. **Regular but partially structured engagement** (e.g.: Slovenia, Croatia, Finland)
   - Standing committees and working groups with inconsistent influence on final decisions;
   - Frequent consultations with limited impact.

3. **Ad-hoc, informal, or politically driven processes** (e.g.: Bulgaria, Serbia)
   - » Circumstantial involvement: consultations happen when a ministry is revising strategies or action plans;
   - » Dependence on informal relationships: patient organisations must rely on personal relationships to secure invitations to contribute;
   - » Patient organisations engage proactively on selected topics of interest to them, without consultation structures in place.

Members voice

Baiba Zeimele, LPOT - Latvian Network of Patient Organisations (Latvia)

> “*Volunteering is not very popular. Defending patients’ rights is not as prestigious here as it is in Western Europe, we do not all have the necessary experience and cooperation to do it properly, and many patient associations disband once they have achieved their goal, usually access to a particular treatment, and are unable to defend patients’ rights systematically.*”

How are patient organisations involved in health decision-making?

Takeaway #2

Advisory boards and committees, working groups and targeted stakeholder consultations appear to be the most common engagement mechanisms. Participation in parliamentary committees does exist, but is less common. Participation in regional/local health boards and hospital boards ranks last.

How are patient organisations involved in health decision-making in your country?

🟥	Participation in parliamentary committees	12
🟦	Participation in advisory councils/committees	19
🟩	Participation in working groups	22
🟪	Participation in hospital boards	12
🟧	Targeted stakeholder consultations	21
🟦	Participation in regional/local health councils	13
🟩	They are not involved	0
🟨	I'm not sure	0
🟪	Other	6

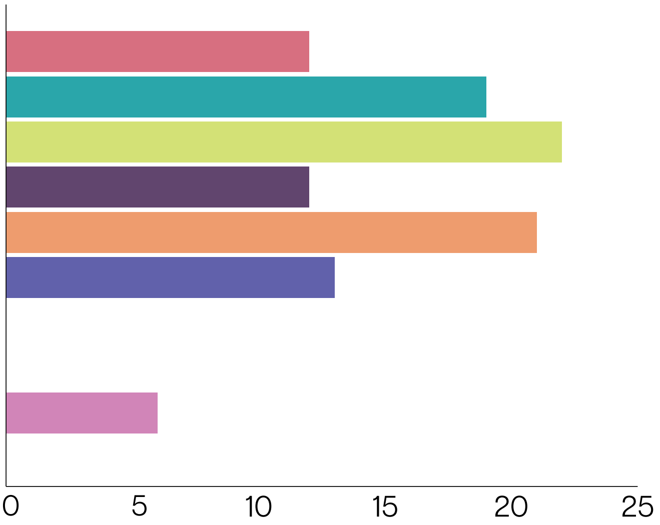


Figure 5. *Forms of involvement of patient organisations in health decision-making processes across countries.*

Analysis of the data also reveals that organisations have several channels to reach decision-makers. For example, nearly half of those surveyed say they participate in 6 types of healthcare decision-making channels (parliamentary committees, hospital boards, targeted stakeholder consultations, etc.).

Members voice

The diversity of situations

Cyprus CyFPA – Cyprus Federation of Patients' Associations

"*Any committee related to issues of relevance to patients must include a patient representative. We have monthly meetings with the Department of Health, the health insurance organisation, etc.*"

Latvia LPOT – Latvian Network of Patient Organisations

"*Anyone can submit opinion pieces and conduct advocacy activities on their own initiative, and patient engagement is highly chaotic, mainly due to personal relationships, attitudes, and misinterpretations of patient engagement at different levels.*"

France France Assos Santé

"*All legislative proposals relating to health are normally forwarded to France Assos Santé for its opinion.*"

Case study:

Estonian organisations representing patients and persons with disabilities are involved across different policy areas

In Estonia, patient organisations participate in committees within several ministries: the Ministry of Social Affairs (ex: Commission on preferential medicines, E-Health Strategy Council), the Ministry of Education and Research (e.g.: Youth Council), the Ministry of the Interior (e.g.: Monitoring Committee for the Operational Programmes of the European Union's Internal Security Policy Funds) and the Ministry of Culture (e.g.: Cultural Accessibility Steering Group).

The Estonian Chamber of People with Disabilities also has a seat at the National Health Insurance Fund advisory board. The purpose of health insurance in Estonia is to cover the costs of health services provided to insured persons, prevent and cure diseases, finance the purchase of medicinal products and partly certain medical technical aids, and provide temporary incapacity benefit and other benefits.

Across all working groups, the role is advisory rather than decision-making. Even in the advisory board of the Estonian Health Insurance Fund—where the role is formally defined as decision-making—it is not, in practice, possible to block decisions, as working parties prepare the proposals in advance and submit them for adoption.

The e-Health Strategy Council is closely connected to health policy and patient empowerment. Recently, it has addressed topics such as the use of AI in healthcare, the potential of gene technologies and personalised medicine, an innovation roadmap, and a technology sandbox for health-sector companies, among others. Much of its current work also focuses on issues related to the European Health Data Space.

Overall, in these working groups we see it as essential to have access to information and to be able to take part in discussions, even if they are not primarily decision-making bodies. Bringing patients' rights and lived experience into these conversations is crucial, as public sector staff and civil servants may not have first-hand insight into many of the issues under discussion.

Do patient organisations have a seat at the table?

Do patient organisations have the opportunity to provide feedback on impacts and outcomes of health policies?

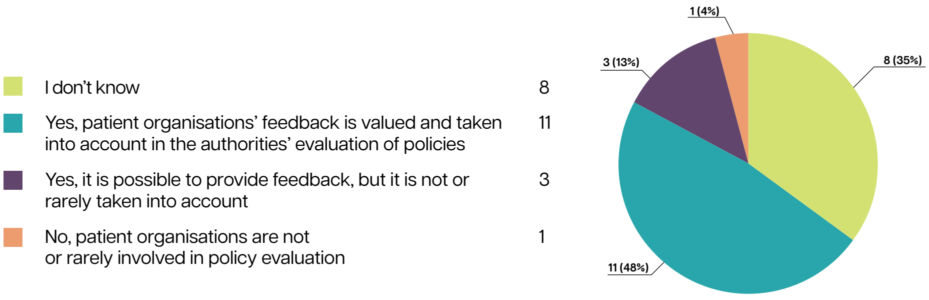


Figure 6. *Extent to which patient organisations can provide and influence feedback on health policy impacts and outcomes (n = 23).*

How often are patient organisations asked to provide feedback on the impacts of national health policies?

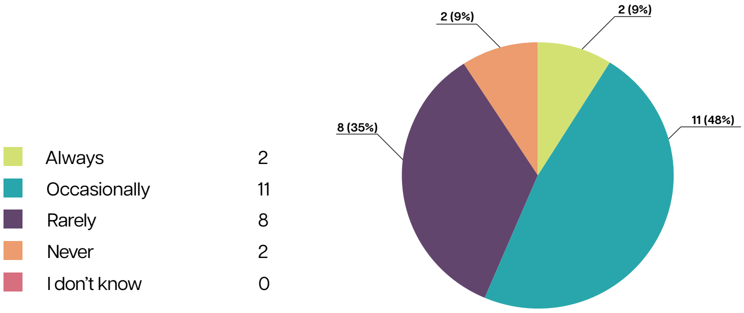


Figure 7. *Frequency of requests for patient organisation feedback on the impacts of national health policies (n = 23).*

Very few national coalitions reported that they are not consulted on the impacts and outcomes of health policies. More specifically, patient organisations' feedback is valued and taken into account in policy evaluation in Flanders, Cyprus, Finland, Germany, Greece, Netherlands, Scotland and Slovenia.

In contrast, while patient organisations are consulted in Croatia, Czechia, Estonia, Hungary, Kosovo, Latvia, Romania, Slovakia, Sweden, Spain and Lithuania, their input is rarely or not systematically reflected in final policy assessments. At the end of the spectrum, patient organisations are not or rarely involved in policy evaluation in Malta, Serbia and Bulgaria.

While patient organisations' feedback on the impacts of national health policies is "always" asked in the Netherlands and Scotland, it is "never" asked in Bulgaria and Serbia.

Case study:

Feedback on the impacts of national health policies: In Malta, the National Patient Safety Strategy 2025–2035 exposed gaps in how patient organisations' feedback is taken on board

In 2025, the Malta Health Network (MHN) strengthened its collaboration with the national Acute Hospital, Mater Dei Hospital. MHN was included to represent patients on an EU-funded initiative, Safest, where Mater Dei Hospital evaluate the current practices against the SAFEST standards across 13 different areas including areas such as patients' feedback before surgery and post-operative outcomes. While this work was under way, the National Patient Safety Strategy was published. Although it concerned the same subject, those involved in this project were not informed about the development of the strategy.

In Malta, responsibilities are often fragmented across multiple bodies, with overlapping remits. There was concern that the National Patient Safety Strategy 2025–2035 may have been largely finalised before the consultation process began.

The Malta Health Network did provide input to the consultation after it was launched and open to the public. It sought feedback from its members by email and received written contributions from two organisations. In addition, an in person consultation meeting was held. Around 30 people attended, representing no fewer than 15 member organisations of the Malta Health Network.

However, although the Network's contribution was acknowledged, it is not yet clear if its proposals will be reflected in the final document of the Patient Safety Strategy. In practice, the consultation appeared largely tokenistic.

Are patient organisations a "tick box exercise" at the end of the process?

At what stages of the decision-making process are patient organisations involved in your country?

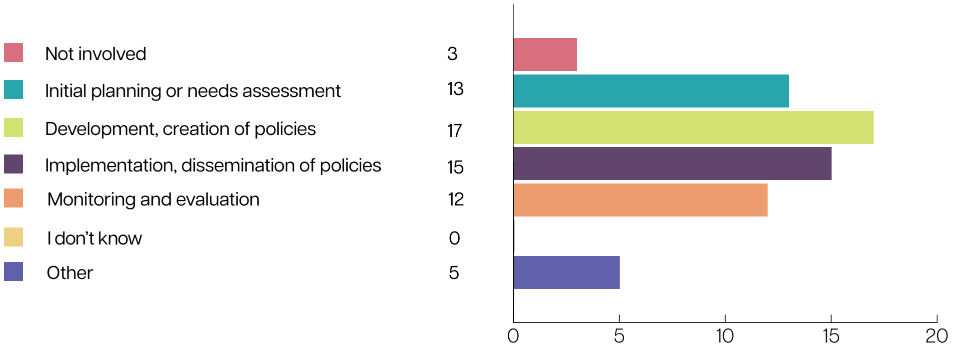


Figure 8. *Participation of patient organisations throughout the policy and decision-making cycle (n = 23).*

What decision-making power do patient organisations have in your country?

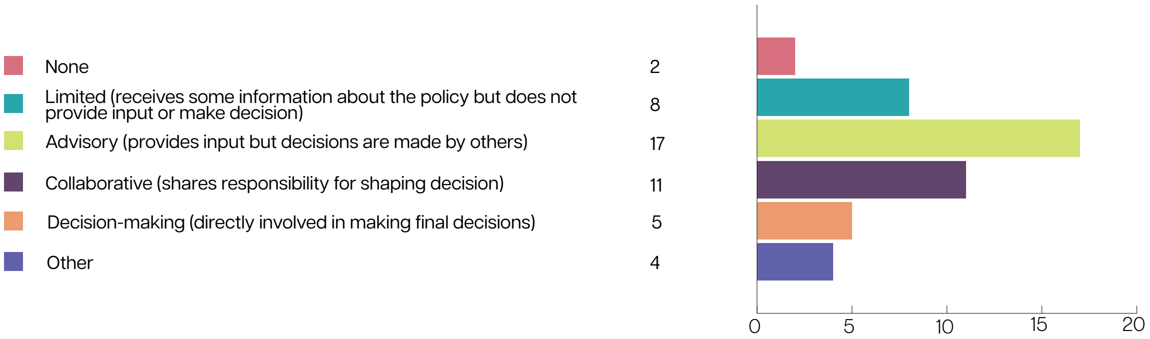


Figure 9. *Levels of authority and influence exercised by patient organisations in health-related decision-making*

Takeaway #3

Patient organisations are involved in a relatively consistent manner throughout the decision-making process, but their decision-making power remains limited.

Contrary to assumptions that patient involvement is a tick box exercise at the end of the process, patient organisations report being as involved, if not more so, in the early stages of the process (e.g. "Initial planning and needs assessment" and "Policy development and creation") as they are in the later stages of the process (e.g. "Policy implementation and dissemination" and "monitoring and evaluation").

While consistent involvement throughout the decision-making process is positive, it does not guarantee decision-making power. 15 countries report having some form of decision-making power – e.g. "Collaborative (shares responsibility for shaping decision)" or "Decision-making (directly involved in making final decisions)".

However, the boxes relating to decisions made by others were ticked more often – e.g. "Advisory (provides input but decisions are made by others)" or "Limited (receives some information about the policy but does not provide input or make decision)".

Only 4 countries (Cyprus, Kosovo, Czechia, Netherlands) feel that they are truly directly involved in the decision-making process on policies that affect patients.

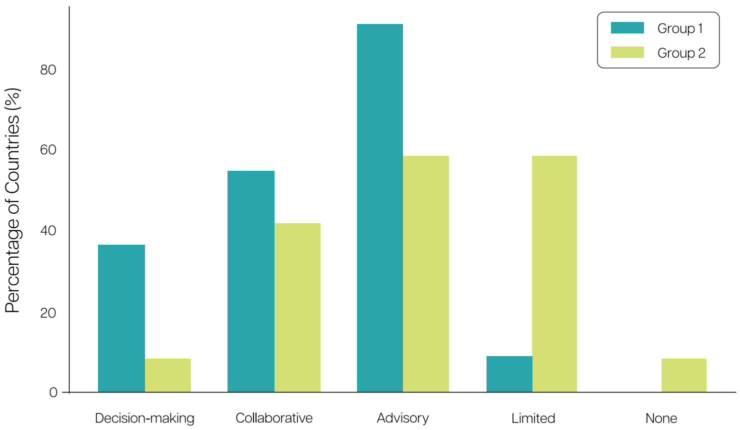
Do institutional frameworks efficiently support patient organisations' involvement in decision-making processes on the ground?

Takeaway #4

Countries that reported having an institutional framework for patient organisation participation (group 1, in blue) were also more likely to report playing an active role (decision-making, collaboration, advisory role) in the health system than countries that did not report having an institutional framework (group 2, in green).[28]

For example, the Netherlands stated that it had an institutional framework for the involvement of patient organisations and noted its organisations sometimes played a role in decision-making. By contrast, Bulgaria and Malta did not indicate that they had an institutional framework and acknowledged that their role was more "limited".

Figure 10.
Decision-Making Power By Country Group



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[28] While this likelihood does not imply causality, it suggests that institutional frameworks may contribute significantly to patient organisations having a greater role in healthcare systems.

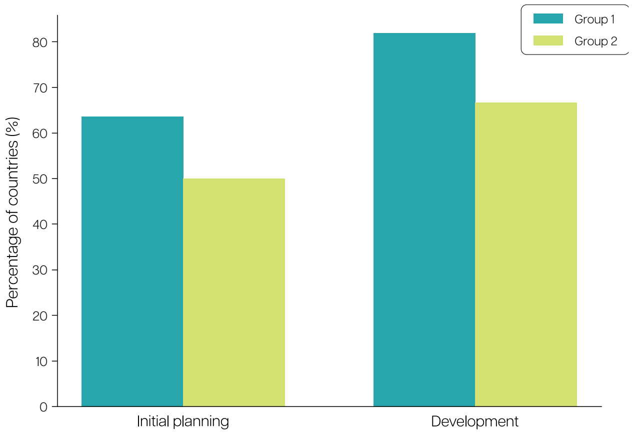
Takeaway #5

Countries that reported having an institutional framework for patient organisation participation (group 1, in blue) generally appeared to involve patient organisations at an early stage of the decision-making process (e.g. “Initial planning and needs assessment” and “Policy development and creation”). This was less the case for countries that did not report having an institutional framework (group 2, in green).[29]

For example, patient organisations in Czechia and Scotland reported having an institutional framework that facilitates their participation and being involved in the health policy decision-making process from the outset, whereas countries or regions such as Lithuania and Flanders, which did not report having such an institutional framework, were involved in this process at a slightly later stage.

Figure 11.

Stages of Policy Involvement by Group



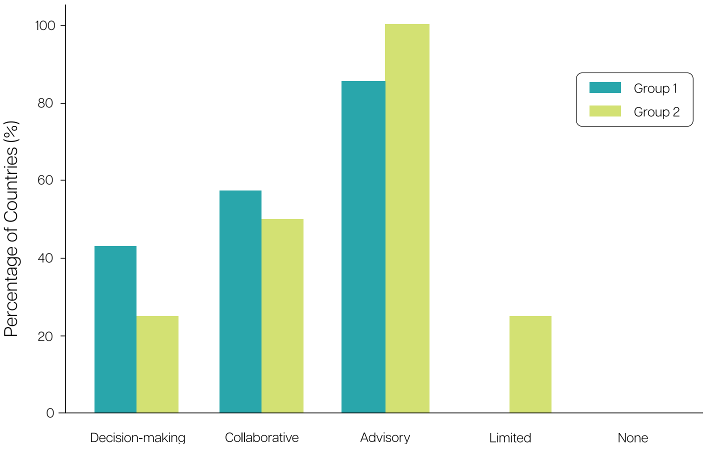
Takeaway #6

The kind of institutional framework – meaning legislation versus policy guidelines – seems to matter, too. Countries that reported having a legal basis for patient organisation participation (group 1, in blue) were also slightly more likely to report playing an active role (decision-making, collaboration) in the health system than countries that reported having policy guidelines (group 2, green).[30]

For example, Cyprus, Kosovo and France, which stated that they had a legal basis for the involvement of patient organisations, also reported that these organisations played an active role (decision-making, collaboration). Conversely, Sweden, Estonia and Slovakia, which indicated that they had an institutional framework based on policy guidelines, reported that their organisations played a slightly less active role.

Figure 12.

Decision-Making Power by Country Group (Revised Group



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[29] While this likelihood does not imply causality, it suggests that institutional frameworks may contribute significantly to involving earlier patient organisations in the decision-making process.

[30] While this likelihood does not imply causality, it suggests that a legal basis may contribute significantly to patient organisations having a greater role in healthcare systems.

How do patient organisations advocate?

At what stages of the decision-making process are patient organisations involved in your country?

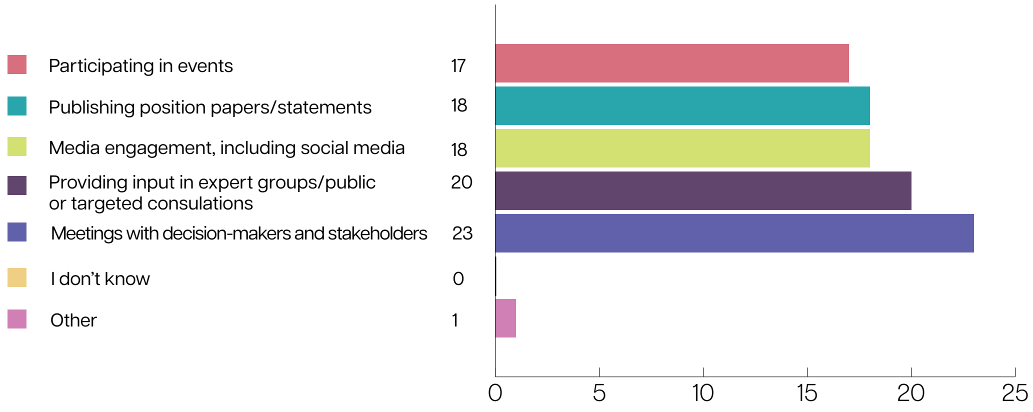


Figure 13. *Extent of patient organisation involvement throughout the decision-making process in each country*

73.9% of organisations use at least 5 different advocacy methods, whether it be participating in events, publishing position papers/statements, media engagement – including social media, providing input in expert groups/public or targeted consultations and meetings with decision-makers and stakeholders.

Best Practice:

Successful advocacy: In Finland, patient and public health organisations have played a central role in bringing the concept of the "wellbeing economy" onto the national agenda

Innovations often emerge in civil society organisations and later gain national—and even international—visibility. One such innovation is the wellbeing economy concept, coined by SOSTE (the Finnish Federation for Social Affairs and Health) and Finnish social and health NGOs in 2012 as a tool to encourage stakeholders to discuss the future of social and health policy, the welfare state, and the relationship between well-being and the economy. Initially, it served mainly as a conversation-starter, aimed at rethinking and renewing the welfare state.

The concept has then been further developed through publications, including SOSTE's Hyvinvointitalous (WellBeing Economy, 2014), which explores the early evolution of the idea and its relevance. Finland's Ministry of Social Affairs and Health has also promoted well-being economy thinking in international settings, including at the UN Social Summit in 2025. The concept gained prominence during Finland's 2019 EU Council Presidency and has since featured in national and international policy debates, including OECD analyses and national action plans that seek to integrate well-being dimensions into core policymaking.

SOSTE and its member associations have continued to play a key role in advancing the concept by publishing further materials, engaging policymakers, and promoting it nationally and internationally through advocacy, seminars, and practical guidance.

Key recommendations

- Early and consistent involvement of patient organisations across the policy process, from ideation to monitoring and evaluation, is essential to ensure that decisions truly meet patients' needs;
- Diverse consultation channels, ranging from advisory boards to expert group meetings, help broaden the scope of patient participation. Within these channels, patients should be empowered to co-create decisions that affect their communities.

A dedicated legal framework is necessary for meaningful engagement, as structured participation through clear and institutionalised consultation mechanisms ensures consistency and continuity.

Section 3

Transparency: the blind spot in patient organisations' involvement?

Definition:
In this context, *transparency* refers to the clear, accessible and timely disclosure of the processes, criteria, roles and decision-making mechanisms governing the involvement of patient organisations in policy-making processes. This includes the transparent identification and management of potential conflicts of interest among all actors involved.

Takeaway #1

A majority of the responding countries (13/23) state that there are "no specific and transparent criteria" for patient organisations' involvement in "policy and regulatory processes in their country".
This is generally linked to the lack of an institutional framework for patient organisations' involvement.

These countries include: Spain, Latvia, Kosovo, Greece, Bulgaria, Slovenia, Sweden, Slovakia, Malta, Hungary, Flanders, Serbia and Lithuania. Three other countries (Estonia, Finland and Malta) have not taken a position on this issue.

Of the 13 countries that report that there are "no specific and transparent criteria" in "their country's political and regulatory processes", only 2 have an institutional framework (Greece, Sweden) – and 11 have no institutional framework in place.

Does limited transparency call into question the quality of diversity in representation?

Takeaway #2

In some cases, a diverse representation seems to be the result of ad hoc or random selection rather than of a transparent, representative and well-defined process.

When asked to reflect on the diversity of patient organisations' representation in national health policy decision-making processes, a significant proportion of national coalitions report a certain degree of diversity. For example, the two most frequent responses mention that "other representatives of patient organisations are part of the bodies to which my organisation contributes" and that there is "a clear effort to involve all relevant patient organisations and ensure diversity of views". At the same time, "unequal representation of certain groups" is reported as one of the main barriers to POs ability to influence policy.

This apparent contradiction suggests that, in some cases, diversity in representation is not the result of a structured and transparent approach, but rather of ad hoc or informal selection processes. The situation in Southern Europe illustrates this broader European trend.

Members voice

Diversity of representation and transparent criteria do not always go hand in hand

Katy Antonopoulou, President, Sjogren Europe

> "*While authorities do include several well-established patient organisations in certain bodies or consultations, the process is usually ad hoc and lacks consistency. As a result, some groups may be overrepresented, while others – especially smaller or less visible ones – are left out. Additionally, the roles and expectations of patient participants are not always clearly defined. Overall, there is some diversity of representation, but it is not systematically ensured, and involvement remains uneven and dependent on informal practices or advocacy pressure.*"

What are the most common transparency practices?

🟥	4	Existence of clear, defined, and publicly available eligibility criteria for patient representatives involved in official processes, ensuring candidates are suitable for the role (e.g. health condition, knowledge, etc.)
🟦	4	Organisation of regular public calls for applications
🟩	8	Existence of conflict of interest policies (e.g. disclosure requirements, targeted and proportionate limitations based on interests declared)
🟪	1	Existence of transparent evaluation processes (e.g. applicants are evaluated using standardised criteria, public disclosure of methodology)
🟧	2	Availability of a transparency register or registry of experts, and/or publication of lists of selected representatives (e.g. names, roles, and affiliations of selected patient representatives are published to ensure accountability)
🟦	2	Availability of feedback and appeals mechanisms (e.g. unsuccessful applicants can request feedback on their applications, mechanisms for candidates to contest decisions if they perceive unfair treatment)
🟨	13	There are no specific and transparent criteria
🟪	3	I don't know
🟩	4	Other

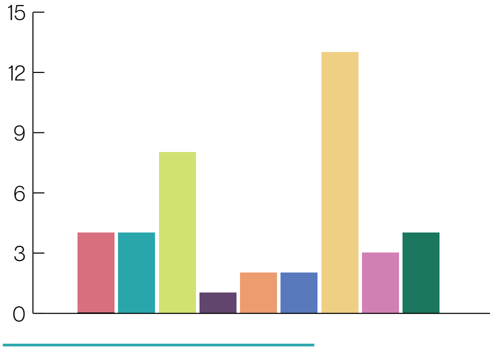


Figure 14. Most common transparency practices reported across countries.

- The existence of clear, defined, and publicly available eligibility criteria for patient representatives involved in official processes, ensuring representative candidates are suitable for the role (e.g. health condition, knowledge, etc.): in 4 countries – Croatia, Cyprus, Germany, Scotland
- The organisation of regular public calls for applications to take part in policy processes: in 4 countries – France, Germany, Netherlands, Scotland
- The existence of conflict of interest policies (e.g. disclosure requirements, targeted and proportionate limitations based on interests declared): in 8 countries – Croatia, Czechia, France, Germany, Greece, Netherlands, Romania, Scotland
- The existence of transparent evaluation processes (e.g. applicants are evaluated using standardised criteria, public disclosure of methodology): in 1 country – Cyprus
- The availability of a transparency register or registry of experts, and/or publication of lists of selected representatives (e.g. names, roles, and affiliations of selected patient representatives are published to ensure accountability): in 2 countries – Croatia, Czechia
- The availability of feedback and appeal mechanisms (e.g. unsuccessful applicants can request feedback on their applications, mechanisms for candidates to contest decisions if they perceive unfair treatment): in 2 countries – Germany, Netherlands

The over-reliance on patient experts, another example of a lack of transparency regarding patient involvement

Recent trends highlighted by EPF national coalitions point to an increasing reliance on individual experts, generally as a complement to, but at times at the expense of, the structured involvement of patient organisations in healthcare decision-making across Europe. While individual contributions can play an important role in raising awareness and bringing personal experiences into policy discussions, patient organisations are uniquely positioned to aggregate these experiences, reflect a collective voice in all its diversity, and translate them into constructive policy proposals.

The "shrinking civic space" identified in many countries and across policy processes further reflects a tendency to prioritise individual inputs, with a clear risk of bias, rather than recognising civil society organisations as essential bridges between people and policy-makers. While patient organisations should continue to strive to strengthen their representativeness, especially by better including young patients and underserved and underrepresented communities, policy frameworks should recognise the value of their system-level perspective, which supports more balanced and sustainable decision-making by reflecting the interests of the community as a whole rather than individual needs.

Takeaway #3

Excessive reliance on patient experts remains a cause for concern.

With regard to over-reliance on patient experts, the situation is uneven across Europe, with different models at work: clear, organisation-led involvement; mixed models with a growing imbalance; over-reliance on individual patient experts; and systemic confusion and a lack of clear definitions. On this last point, authorities sometimes have a vague understanding of what constitutes a "patient organisation" or a "patient expert", leading to fragmented or politicised engagement.

Members voice

Latvia LPOT - Latvian Network of Patient Organisations

"There is no definition of the term 'patient expert' in our country. Many policy-makers and civil servants consider that everyone is a patient and that every patient can defend the interests of patients."

Kosovo PRAK - Patients' Rights Association in Kosovo

"In Kosovo, patient representation remains a challenge, as authorities often rely on individual patient experts rather than systematically involving patient organisations. This approach limits the diversity of viewpoints and does not fully address the broader needs of the patient community"

Sweden Swedish Disability Rights Federation

"It varies, but this challenge also exists in Sweden. We have worked to strengthen the patient movement by developing digital educational programmes, serving as a contact base that authorities can turn to in order to reach representatives of patient organisations, and through projects launched by EUPATI Sweden, which works to increase patient participation in research and development of medicines, medical technologies and clinical studies."

Takeaway #4

The division of roles between POs and patient experts seems to follow various and sometimes informal rules.

Members voice

Cyprus CyFPA – Cyprus Federation of Patients' Associations
Despite increased involvement of individual patient experts, national bodies remain strictly reserved for patient organisations.

Latvia SUSTENTO – The Latvian Umbrella Body for Disability Organisation
Patient experts are consulted on targeted areas specific to certain diseases, while POs are consulted on cross-cutting issues.

Croatia KUZ – Coalition of Associations in Healthcare
The health authorities include patient organisations in discussions, while patient experts have a greater presence in the media and the public sphere.

Estonia EPIK – Estonian Chamber of Disabled People
It is "*those who shout the loudest and cause political unrest that are heard, but in a very irregular manner*".

Case study:

The Netherlands, a country in a transition phase, moving towards structured engagement of patient organisations

The Netherlands is an interesting example because the country is in a transition phase, moving towards systematic and structured engagement of patient organisations, but still facing challenges due to ongoing dependence on individual experts.

Klaartje Spijkers, Senior Advisor, Netherlands' Patients' Federation

"*Over the past ten years, it could be said that the Netherlands has shifted from an excessive reliance on 'expert patients' towards greater involvement of patient organisations. However, authorities still tend to favour the participation of individual expert patients and are now also seeking to involve citizens more broadly in healthcare decision-making.*

The move from one model to another has not been a formal transition; rather, it has been a cultural shift supported by financial incentives. In 2014, patient organisations began receiving funding from the national health insurance system to develop projects focused on the quality of care. This enabled organisations to strengthen their position, build capacity and begin conducting research. That same year, government subsidies also supported efforts to improve the information provided to patients and to ensure that research agendas better reflect patients' needs. During this period, patient organisations gained a seat at the table.

Although this shift was not, unfortunately, underpinned by legislation, it was clearly intentional. The government appears to have made a deliberate long-term investment, enabling patient organisations to develop their capacity over a decade.

This trend became visible across all levels of health policymaking in the Netherlands—at ministry level, in regulatory procedures, and in health technology assessment processes.

That said, financial incentives alone are not sufficient to complete the transition. Legal provisions are also needed, and that should be the next step."

Key recommendations

- Recognise and leverage the added value of patient organisations' collective, system-level perspective, ensuring that policy processes capture aggregated patient input in a consistent way;
- Establish clear and transparent criteria for the involvement of patient organisations in policy-making. These eligibility criteria should be publicly available and consistently applied, and should include:
  - » Governance criteria, including composition of the membership and governing bodies, not-for-profit status, representativeness, existence of accountability and consultation mechanisms;
  - » Relevance to the policy area and demonstrated expertise;
  - » Transparency of funding sources.
- Put in place robust conflict of interest (CoI) frameworks and disclosure requirements, as well as proportionate mitigation measures that ensure the integrity of policy processes without discarding relevant input;
- Establish transparent and publicly accessible registries of patient organisations and representatives involved in policy processes;
- Introduce regular, well-publicised and transparent calls for applications for patient organisations to participate in consultative or decision-making bodies. These should be accompanied by clear evaluation criteria, transparent selection procedures, and feedback mechanisms;
- Invest in capacity-building and support mechanisms for patient organisations, enabling them to meet transparency and governance requirements, strengthen internal structures, and enhance representativeness, particularly through the inclusion of underserved or underrepresented communities.

Section 4

Core activities of national patient organisations in Europe

A strong focus on healthcare systems and disease-specific policies

On which specific topic areas are patient organisations involved in decision-making processes in your country?

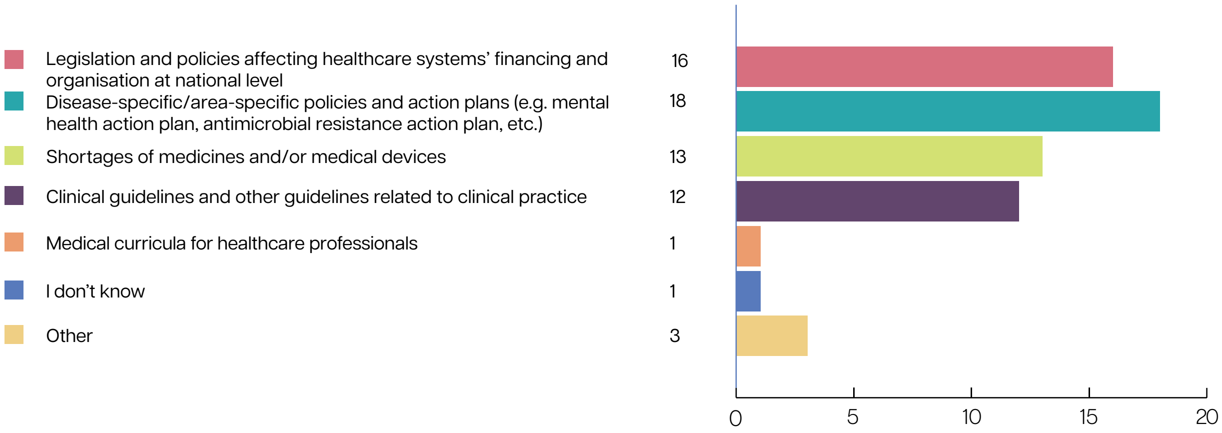


Figure 15. *Scope of patient organisation involvement across health-related decision-making areas*

Respectively, 78.3% and 69.6% of national coalitions surveyed deal primarily with disease-specific policies and policies affecting health systems.

Only seven countries (Bulgaria, Czechia, Greece, Malta, Hungary, Estonia, Serbia) didn't report explicitly working on "Legislation and policies affecting healthcare systems' financing and organisation at national level". However, this issue is cited even more frequently than shortages of medicines and/or medical devices (56.5%), clinical recommendations and other guidelines relating to clinical practice (52.2%), and medical training programmes for healthcare professionals (4.3%).

With regard to shortages of medicines and/or medical devices, the countries of Central and Eastern Europe were under-represented. For example, Bulgaria, Czechia, Hungary, Estonia, Slovakia, Latvia, Serbia and Kosovo did not tick the box "Shortages of medicines and/or medical devices".

Best Practice

Disease-specific action plans: In Finland, patient and public health organisations help to shape disease-specific strategies such as the “National Cancer Strategy 2026-2035”

Patient and public health organisations contribute to national health policy through legislative consultation processes, participation in expert groups and advisory bodies, involvement in strategic policy development, and the production of patient-led and experiential evidence to inform decision-making. By bringing patient and citizen perspectives, lived experience and specialist expertise into policymaking, these organisations help shape priorities and approaches – for example, during the development of the National Cancer Strategy 2026-2035.

Clinical guidelines: In Croatia, the Coalition of Associations in Healthcare (KUZ) has helped improve the lives of people with chronic conditions by supporting changes to clinical guidelines and the establishment of medical reference centres.

In the case of multiple sclerosis (MS), patients often waited around two years from diagnosis before starting treatment. MS patients had to experience two relapses, putting themselves at risk of permanent disability, before they could begin treatment. The National Alliance for Multiple Sclerosis raised this concern with its umbrella organisation, KUZ, along with the Croatian Neurological Society. They also conducted a public campaign entitled “Is treating MS a lottery?”. With the support of KUZ, patient organisations highlighted the issue and brought it to the attention of the Ministry of Health and the Croatian Health Insurance Fund.

As a result, treatment is now initiated after the first relapse, leading to better outcomes and helping to preserve quality of life. Earlier access to diagnosis and treatment can change the course of the disease, and new clinical guidelines have enabled timely access to treatment and innovative medicines. All this has changed the picture of living with MS, especially for younger patients who remain active participants in the treatment process and in social life.

Patient organisations have also contributed to establishing medical reference centres, especially for rare diseases, where patients can be diagnosed, examined and treated within a single setting, streamlining access to care. Such reference centers also hold added value in collecting relevant data and forming disease registries.

Involvement in regulatory processes varies from country to country

At European level, patient organisations have been interacting with the European Medicines Agency (EMA) since its creation in 1995. Two patient representatives are members of the EMA Management Board. In addition, EMA established the Patient and Consumer Working Party (PCWP) in 2006 as a platform for exchange of information and discussion on all aspects of medicines regulation. Members of the PCWP, along with patient representatives across EMA expert groups and committees, disseminate EMA information to their communities and provide input on all relevant Agency activities, from the management of drug shortages to the development and implementation of EMA’s data strategy.

Patients are also involved in scientific advice procedures, where they contribute their real-life perspectives in specific disease areas to help regulators and developers understand what matters most to patients, including relevant endpoints and acceptable benefit/risk trade-offs. With the revision of the pharmaceutical legislation, patients will continue to be represented in key EMA Committees, including through two members and two alternate members at the Pharmacovigilance Risk Assessment Committee (PRAC), and two members and two alternate members with one voting right at the Committee for Medicinal Products for Human Use (CHMP), which is responsible for the authorisation of medicines.

At national level however, patient engagement with regulatory authorities for medicines and/or medical devices is still lacking.

Members voice

Romania COPAC – Coalition of Patients' Organisations with Chronic Diseases

There is no systematic involvement, and patient representatives have no place at the discussion table.

Estonia EPIK – Estonian Chamber of Disabled People

There is some cooperation, but neither of the two health agencies has representatives from patient organisations on its board.

Slovenia ZOPS – Association of Patient Organisations of Slovenia; **Slovakia** AOPP – Association for the Protection of Patients' Rights; **Malta** MHN – Malta Health Network

The role of POs in their interactions with national medicines and/or medical devices regulatory authorities is limited to "*dissemination*", "*needs assessment*" and "*communication and education initiatives*" respectively, but they have no decision-making power.

France France Assos Santé; **Czechia** NAPO – National Association of Patients' Organisations; **Germany** BAG Selbsthilfe

Some countries such as France, Czechia and Germany have permanent representatives in several committees with at least an advisory role, if not a decision-making power.

Case study

Patient organisations' inclusion in regulatory processes in France

Yann Mazens, Health Products and Technologies Project Manager, France Assos Santé

1. Have you concluded a Memorandum of Understanding (MoU) with the medicines regulatory authorities?

"The mission of France Assos Santé is set out in law; therefore, we do not have any memorandum with the authorities.

Regarding pricing and reimbursement, we do have a framework agreement with the Economic Committee for Healthcare Products, which is tasked by law with setting the prices of medicines and the tariffs for individual-use medical devices covered by the mandatory health insurance scheme.

This framework agreement—which has just been renewed—establishes in particular an Interface Committee. In the context of this Interface Committee, associations are notably provided with: ministerial orientation letters, the doctrine on pricing and tariff-setting for reimbursable products, and legislative, regulatory, and contractual developments."

2. Do you have a committee equivalent to, or inspired by, the European Medicines Agency's Patients' and Consumers' Working Party (PCWP) [The PCWP provides a platform for information exchange and discussion on issues of common interest between the EMA and patients and consumers]?

"There is an Interface Committee between the French National Agency for Medicines and Health Products Safety (ANSM) and associations (see above). These interface committees exist for all stakeholder groups. They are established under the mandate of the Ministry of Health, through the framework agreement between the Ministry and the ANSM.

The interface committee with patient organisations meets four times a year for half-day sessions. In principle, the agenda is jointly set by the ANSM and the patient organisations. In practice, however, it is largely developed by France Assos Santé. The committee's purpose is to facilitate and strengthen the participation of patient organisations. Its main areas of focus are medicine and medical device shortages, safety issues, and patient information."

3. Are patients/patient organisations included in decision-making committees, whether specific (e.g., paediatric) or central?

"Associations participate within ANSM in the 15 Permanent Scientific Committees covering one or more medical specialties (cardiovascular therapy, dermatology, oncology, paediatrics, etc.) or an area of activity (haemovigilance, dermatology medicines, medicines quality and safety, etc.).

Associations also participate within ANSM in temporary scientific committees, expressly set up to address an issue that does not fall within the remit or missions of a permanent committee."

4. How do patient associations participate—for example, are they consulted when guidelines are drafted or in communications (e.g., on medicine shortages)?

"Regarding general guidelines established by ANSM: consultation is carried out mainly via France Assos Santé, for example on shortage management plans or guidelines on how financial penalties are determined.

Regarding the involvement of associations in communication actions: this consultation is not established as a general rule, but only to respond to specific issues encountered with medicines and medical devices (shortages, pharmacovigilance, materiovigilance). This communication generally involves France Assos Santé and the relevant associations."

5. For authorities responsible for both medicines and medical devices (such as ANSM in France), is the approach to patient inclusion different?

"There are no notable differences. However, advocacy/association mobilisation is 'weaker' around medical devices: in the area of health products, associations have historically mobilised around issues relating to medicines; the medical devices field is more complex, and the legislation and regulation require more limited national competent authority involvement."

What is the added value of patient engagement in regulatory decision-making?

Regulatory decisions informed by the patient's perspective are crucial:

- To enhance the quality of opinions provided by the committees and foster greater transparency and trust in the regulatory process;
- To gain a deeper understanding of the patient's perspective as patient representatives provide expertise based on their knowledge of specific disease areas, on patients' lived experience, and a practical understanding of new medicines' research and development. Patients have a thorough and often unique understanding of their disease or condition, the benefits and side effects of treatment, and its impact on their daily lives;
- Ultimately, to strengthen the public health system and lead to better health outcomes for all. Only through consistent patient engagement throughout products' lifecycle can we ensure that the voice of the patient community is heard and embedded in decisions that will directly impact their health, quality of life, and needs;
- Patient organisations also play a vital role in communication, as they help disseminate information about medicines within their communities and among carers, ensuring that patients receive clear, accessible, and accurate information about their treatment options.

Health literacy and education activities remain central to patient organisations' activities

Are patient organisations in your country involved in health literacy/patient education activities?

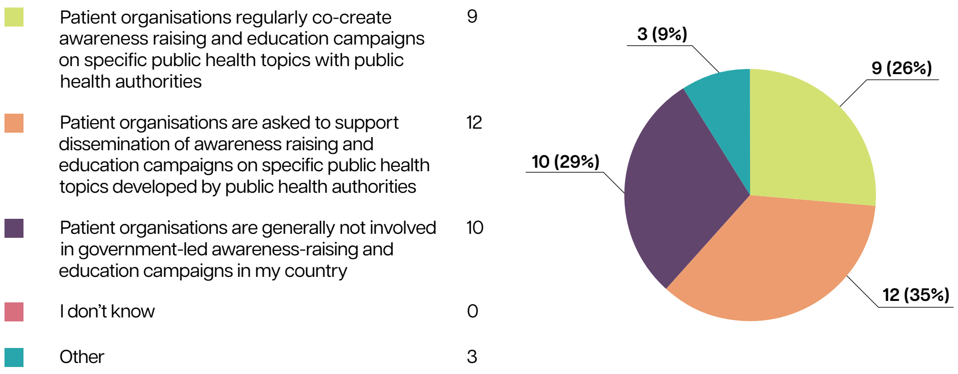


Figure 16. *Involvement of patient organisations in health literacy and patient education activities across countries.*

26% of POs report that they "co-create awareness raising and education campaigns on specific public health topics with public health authorities" (Cyprus, Kosovo, Netherlands, Croatia, Finland, Sweden, Scotland, Romania, Spain).

35% that they support the "dissemination of awareness raising and education campaigns" (Cyprus, Germany, Kosovo, Netherlands, Slovenia, Croatia, Sweden, Czechia, Greece, Estonia, Romania, Spain).

29% state that they are "generally not involved in government-led awareness-raising and education campaigns" (Germany, Bulgaria, Slovakia, Greece, Malta, Hungary, Flanders, Serbia, Lithuania, Latvia).

Best Practice

Education activities: In Finland, patient and public health organisations complement ministry-led health and wellbeing programmes on physical activity and broader lifestyle factors through practical, on-the-ground action

The Get Finland Moving programme promotes physical activity across the population through a coordinated, cross-cutting approach involving measures delivered by several government ministries. Its aims include fostering a culture of physical activity, expanding counselling services, improving the conditions and expertise that enable people to be active, and using fiscal incentives to encourage movement in everyday life.

Terveydeksi, - To your Health'- the national health and well-being programme coordinated by the Ministry of Social Affairs and Health, is delivered in partnership with the state, wellbeing regions, municipalities, NGOs and other stakeholders. The programme improves health and wellbeing through prevention, education, and structural actions such as better institutional meals, reducing obesity stigma, preventing loneliness, and strengthening health literacy and social-emotional skills for young people. It also strengthens preventive services via lifestyle counselling, self-care support, IPS employment models, and oral health promotion. The two programmes are closely aligned, including through the funding of regional pilot projects to promote public health.

Some of SOSTE's (the Finnish Federation for Social Affairs and Health) and its member organisations activities in this context include organising low-threshold exercise initiatives, offering counselling and peer support, sharing good practice, and advocating for equitable opportunities to be active—including for people whose functional capacity is limited by illness, injury, age or disability. Through these efforts, organisations aim to support citizens in adopting more active lifestyles and increasing everyday physical activity. Some SOSTE members also contribute to the coordination and delivery of sub-projects within the Terveydeksi programme, as noted above.

Beyond health: where do patients have a voice?

In which health complementary policies are patient organisations taking part in, in your country?

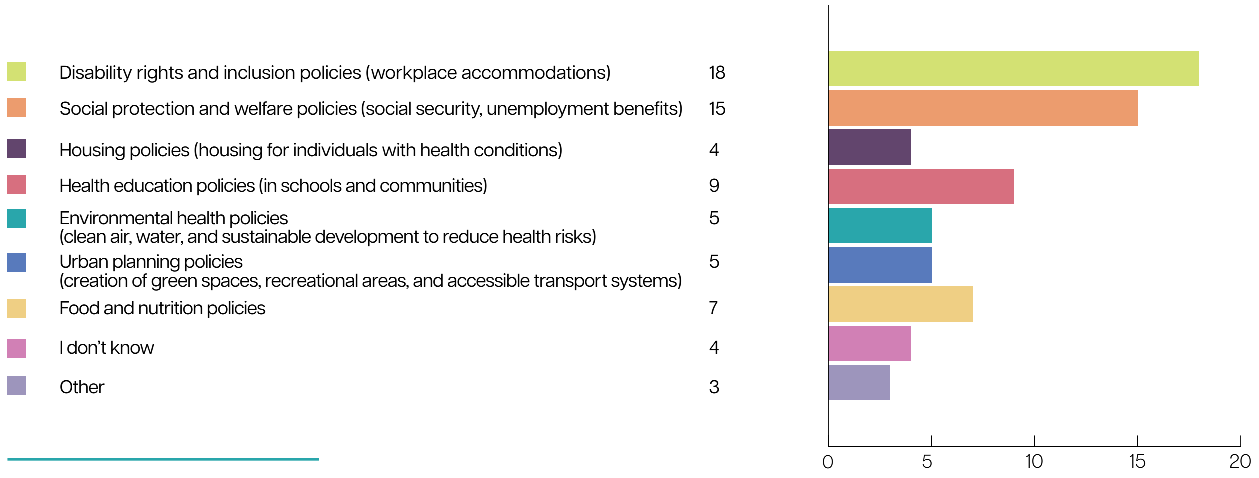


Figure 17. *Areas of complementary health policy involving patient organisations in each country.*

87% of participating POs reported being involved in some way in other policy areas (strong, moderate or limited involvement). In particular, 78.3% of POs are involved in policies relating to disability rights and inclusion, and 65.2% in social protection and social assistance policies.

However, one participant pointed out that this involvement is not always institutionalised, but may be occasional (e.g. during international days or public consultations) or linked to specific issues (e.g. pension reforms or disability certifications), and that there are no formal seats or mechanisms guaranteeing the participation of patient organisations across all ministries (e.g. labour, education or environment).

Despite the attention given in recent decades to the links between food and health, and between the environment and health, it seems that the necessary resources have not yet reached all patient associations, to completly adapt to these new realities. The complexity of the topic and lack of resources to invest in building the necessary expertise remain the main barriers. Only 30.4% of them are involved in food policies, including nutrition, and 21.7% in environmental health policies.

Best Practice

Social protection: The “right to be forgotten” and the “right to work” – patient organisations in Croatia have mobilised a number of institutional entities around the issue of access to employment and a return to “normal” life for people suffering from chronic diseases.

KUZ advocates, in cooperation with other cancer patient organisations, for the adoption of a national “right to be forgotten” law. Its advocacy focuses on engaging key stakeholders and drawing attention to discrimination faced by people with cancer and other chronic conditions, particularly in access to financial services and other aspects of everyday life. The organisations involved have agreed that the law should extend beyond the financial rights of cancer survivors to include parental rights. They also agreed that it should address not only the needs of people affected by cancer, but also those living with other chronic diseases.

Regarding the “right to work”, Croatia’s legal framework contains relevant provisions but patient organisations report that implementation remains uneven. Patient organisations working across different disease areas—including oncology, multiple sclerosis, rare diseases and mental health—have brought together the Ministry of Health, Ministry of Labor and Social Services, Croatian Health Insurance Fund, Croatian Employment Institute and Croatian Association of Employers to address barriers to work. In parallel, and together with the Croatian Association of Employers, patient organisations are exploring a series of training and awareness materials for employers to support workplace adjustments and enable people with chronic conditions to participate fully in working life.

Environmental health policies: In Germany, the Federal Association of Self-Help Organisations for people with disabilities and chronic diseases and their relatives (BAG Selbsthilfe) has conducted extensive work on environmental health issues

The German national coalition developed a guide on heat and health. It explains how heat affects the body and mind, describes heat-related illnesses, and includes thematic 'side notes' such as heat and cancer, mental health impacts, the spread of infectious diseases, and links between heat and air quality or urban living. A major section is dedicated to risk groups, with detailed chapters on people living with chronic conditions (e.g., cardiovascular disease, diabetes/adiposity, respiratory, skin, kidney, neurological and cognitive impairments) and on risks for people with disabilities. The guide then shifts to practical protection measures during hot days and heatwaves and the development of heat action plans.

BAG Selbsthilfe also developed a guide on climate action, especially in organisational and self-help contexts. One document covers change management and climate-conscious work routines (office organisation, home office, technology/digitalisation). It also addresses adaptation to climate impacts, psychological coping with climate change, structural adaptations to buildings/communities, and disaster protection.

The last guide centres on nutrition, health, and sustainability, introducing the links between diet, gut health, and the environment. It then applies nutrition knowledge to a wide range of conditions (e.g., migraine, obesity, cardiovascular disease, hypertension including DASH, gastrointestinal, liver and kidney diseases, allergies, rheumatism, metabolic disorders, osteoporosis, cancer, endometriosis).

Key recommendations

- Ensure systematic and early involvement of patient organisations across all core health policy areas, including the development of clinical guidelines and care pathways, as well as disease-specific strategies and design, management, and evaluation of healthcare systems;
- Strengthen the structured involvement of patient organisations in regulatory processes to ensure regulatory decisions meet patients' needs and improve trust;
- Support the meaningful engagement of patient organisations in health literacy and awareness-raising activities, including co-creation of public health campaigns and communications strategies;
- Institutionalise the involvement of patient organisations across sectors of relevance, such as social protection, employment, disability rights, environmental and food policies.

Section 5

Patient organisations' added value in national health technology assessment (HTA) processes

HTA in Europe: slow progress in more systematic involvement, boosted by the EU HTA Regulation?

While the implementation of the EU HTA Regulation is still in its initial phase and foresees the involvement of patient experts throughout the process, with further progress still needed, the situation at the national level remains uneven.

Awareness of HTA procedures among patient organisations, as well as their actual participation, varies considerably across countries. Although a few Member States have established stronger foundations for patient involvement, this remains the exception rather than the norm. Significant efforts will be required to strengthen and harmonise patient involvement across all EU Member States, particularly given the direct impact that HTA decisions have on patients.

This is particularly important as national HTA systems can feed into the forthcoming EU-level framework. Sharing of best practices, as well as a stronger and more coordinated approach are therefore needed to ensure that national HTA structures operate transparently and inclusively, and that patient involvement mechanisms at both national and European levels are aligned, consistent, and mutually reinforcing.

Is patient involvement the norm in national HTA processes?

Takeaway #1

More than half of responding countries report that patient organisations are involved in national HTA processes; however, direct participation by individual patients is less frequent

14 countries out of 23 (Cyprus, Czechia, Estonia, Finland, France, Germany, Latvia, Lithuania, Netherlands, Scotland, Slovakia, Slovenia, Spain and Sweden,) indicated that patient organisations are involved in their country's HTA process. However, when asked about the involvement of individual patient experts, only 7 respondents (Czechia, France, Germany, Scotland, Slovakia, Slovenia and Sweden) confirmed such participation, compared with 11 of them who said no and 5 who were unsure. Patient participation in national HTA process is therefore far from being universal.

Takeaway #2

Where patient organisations are involved, participation is mostly ad hoc rather than institutionalised

In the evaluation phase (i.e., collection, analysis, and synthesis of evidence to answer key questions about the technology's effectiveness, safety, economic value, and broader societal impact), 7 countries out of 23 mentioned that patients are involved on an ad hoc basis while only 2 respondents (Germany and Sweden) reported having a permanent seat in the relevant body.

The situation appears even less favourable in the appraisal phase (i.e., process of evaluating and interpreting the evidence collected during the assessment phase to formulate recommendations or decisions about the use of a health technology). In this situation, 5 respondents reported ad hoc involvement and 2 countries (France and Germany) reported having a permanent seat on the relevant body.

Only in Germany do patient organisations have a permanent seat for both the evaluation phase and the appraisal phase.

Are patient organisations able to bring added value to the decision-making process?

Takeaway #3

Written input dominates, with few opportunities for in-person meetings in the evaluation phase.

During the evaluation phase, the most common form of patient participation is through written submissions, as reported by 9 countries. Only 5 of the 23 countries (Cyprus, Germany, Estonia, the Netherlands, and Scotland) reported using mixed modes of engagement in addition to written input, such as participating in meetings or providing verbal contributions.

While written contributions may be preferred for efficiency and practicality, offering additional formats, such as in-person or virtual discussions, and the possibility for patients to choose their preferred mode of engagement, can also allow patients to better articulate their perspectives and strengthen the overall quality and relevance of their input.

Takeaway #4

Limited clarity on voting rights and early-stage patient involvement activities.

Only 3 responding countries indicated that patient representatives have voting rights in appraisal committees (Czechia, France, Slovenia). However, most respondents were uncertain about how to answer this question.

Do patient organisations have voting rights in the appraisal phase?

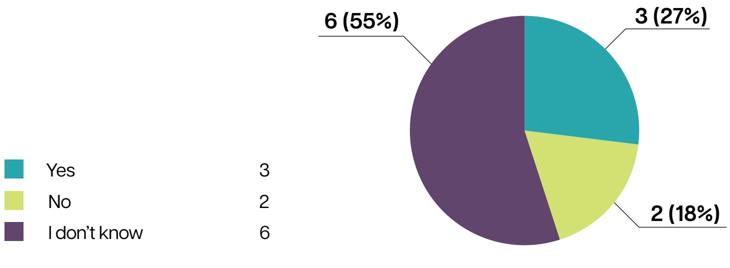


Figure 18. *Voting rights of patient organisations during the appraisal phase across countries (n = 11).*

A similarly high level of uncertainty was observed regarding patient organisations' involvement in horizon scanning activities. None of the respondents answered positively to this question.

Are patient organisations involved in horizon scanning activities (i.e. early identification of promising health technologies to help health systems prepare for them)?

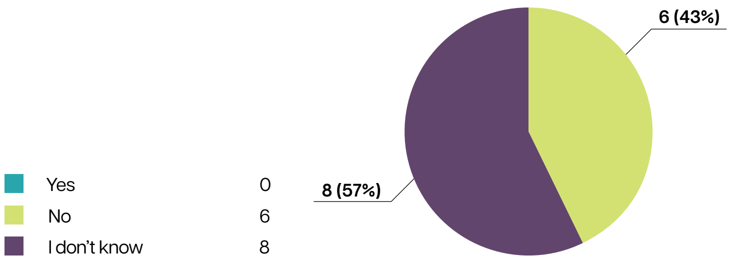


Figure 19. *Involvement of patient organisations in horizon scanning activities across countries (n = 14).*

Takeaway #5

When patient organisations play a more significant role in the national HTA process, they tend to benefit from more extensive rights in terms of reimbursement options and policy initiatives on access.

Countries with well-established patient participation frameworks, such as France and Germany, demonstrate that deeper engagement can go hand in hand with additional responsibilities.

In these national processes, when patients either have a permanent seat in the evaluation and assessment phases (Germany) or have voting rights (France), patient organisations actually take on additional responsibilities.

Members voice

Dr. Martin Danner, Federal Director, BAG Selbsthilfe

Germany

"*In Germany the so-called Federal Joint Committee (GBA) decides which medical treatment methods and which screening will be reimbursed for the patients by the health care funds. GBA conducts an HTA to prepare these decisions. Patient organisations are part of the GBA and have the right to submit an application to start an HTA process. GBA has the duty to start the assessment when our application is submitted, but our application will only be successful if we can identify studies that show the* *additional benefit of a method or a screening. For example, the introduction of skin cancer screening for all citizens, the reimbursement of balneophototherapy for psoriasis or the reimbursement of liposuction for lipoedema were made possible thanks to our applications."*

Charlotte Roffiaen, European Affairs Advisor, France Assos Santé

France

"*Early access authorisations are granted by the French National Authority for Health (HAS), following an assessment by the HAS Transparency Committee (CT). For early access, just as for assessments conducted with a view to routine reimbursement, patient organisations may submit a contribution to the CT, which is presented during the session by the patient representatives. They may also request to be heard by the CT.*"

Is there any sign of stronger patient participation in national HTA processes?

Takeaway #6

Some national HTA systems in transition offer a window of opportunity for stronger patient participation.

Several respondents noted that their national HTA systems are currently being reformed or newly established.

Slovenia

This is particularly the case in Slovenia, where respondents reported that, as the HTA system is still being implemented, patient organisations are expected to have a seat at the table.

Slovakia, Cyprus

A similar situation applies to Slovakia and Cyprus, which are also in the process of setting up their national HTA framework.

These reforms, taking place in the broader context of the implementation of the EU HTA Regulation, can represent a valuable opportunity to integrate best practices from other Member States.

Case study

Cyprus, a country reflecting the situation in Europe, where patient organisations' involvement in HTAs is still in its early (promising) stages

In Cyprus, the Ministry of Health and the Pharmaceutical Services [government body within the Ministry of Health] are still developing the national HTA framework, including finalising the specific processes and provisions related to patient involvement. This new development has been in particular driven by the adoption of the EU HTA Regulation and the broader push for greater harmonisation at EU level.

Within this still-evolving landscape, the Cyprus Federation of Patients' Associations (CyFPA), in collaboration with the Pharmaceutical Services of the Ministry of Health, has already developed a template questionnaire intended to feed into the EU-level process.

The purpose of this template questionnaire is to enable patient representatives to present their views and experiences regarding the disease/condition for which a health technology is being evaluated. This experience may relate to the patient's entire life cycle, including phases of the disease/condition and/or other situations that the patient no longer experiences and/or treatments that they may have received in the past. This questionnaire is also highlighting that "*the HTA process recognises that patients and/or their representatives have unique knowledge about what it is like to live with a particular disease or condition.*"

Assessment scope within the HTAR

The basis of a HTA is a set of defined research questions that are to be answered by the assessment and that together define the assessment scope. In the context of the HTA regulation with the Joint Clinical Assessment (JCA), the assessment scope reflects policy questions from the different healthcare systems in which the JCA will be used. The PICO framework provides a standard format for specifying research questions, detailing the following parameters: • P (population), • I (intervention), • C (comparator[s]), • O (outcomes). According to the Regulation and its Article 8(6), the overall assessment scope for the JCA "shall be inclusive and reflect Member States' needs". This means that the assessment should cover the PICO(s) requested by the Member States. Each member states can therefore submit contributions. This can be done by providing input gathered at a national level from patient representatives.

However, while involving patients at the national level in the development of PICO inputs for EU-level use is a step forward, CyFPA has identified several shortcomings that currently prevent meaningful patient involvement:

- **Limited timeframe to identify patient representatives and collect input:** Under the current procedure, CyFPA receives the questionnaire from the Pharmaceutical Services together with the proposed general indication, but is typically given a very short deadline to identify relevant patients via its member organisations and gather responses. At the outset, CyFPA was given only 1–2 working days to complete this task. After raising concerns about the feasibility of this timeline, CyFPA is now given one week;
- **Absence of compensation:** Neither patient representatives sharing their contributions nor CyFPA receive any form of compensation for participating in this process;
- **Lack of follow-up:** There is no follow-up or feedback on how patient input has been used, interpreted, or assessed at the EU level. However, implementing a robust feedback mechanism ensures that patients feel that their involvement is valued and meaningful, which increases their motivation to participate in future assessments and fosters a collaborative environment.

CyFPA is currently advocating for improvements to this framework. While consultation is a positive step, stronger transparency and genuinely meaningful involvement are needed, rather than patient involvement serving as a "tick-box" exercise. The sharing of best practices among Member States with more established experience in patient involvement in HTA is therefore strongly needed.

The next step in Cyprus is the establishment of a National Center for Clinical Evidence under Cypriot law. HTA procedures are expected to be transferred to this body within the next 6 to 12 months (at the time of drafting). CyFPA will continue to advocate for a stronger framework for meaningful patient involvement under the new system, and for improved national practices on HTA.

Key recommendations

- Involve patients and patient organisations as full partners in HTA processes: Patients and patient organisations must be systematically involved as partners throughout the process, not only on an ad hoc basis;
- Establish a predictable framework for patient involvement: A clear and public framework should define how patients and their representatives engage in HTA, including their roles, timelines, methods, and governance structures;
- Embed patient involvement throughout the HTA process, from scoping to appraisal: Patients should be involved as early as possible in the process and until the appraisal phase. Their contributions should not be limited to “late-stage consultation”;
- Provide accessible, plain-language information and summaries for patients: All materials shared with patients must be clear, timely, and easy to understand;
- Support and build capacity of patients and patient organisations: Patients and patient organisations involved in HTA need dedicated trainings to participate meaningfully;
- Ensure transparency about how patient input is used: Patients and patient organisations should be given clear, understandable feedback on how their contributions were incorporated (or why they may not have been) and what will happen next in the process to build trust;
- Integrate patient involvement into national HTA reforms and align with evolving EU frameworks: As EU and national HTA systems evolve under the implementation of the EU HTA Regulation, patient involvement must be strengthened and institutionalised. Ongoing national reforms provide a unique opportunity to embed best practices from the outset, ensuring that meaningful patient engagement becomes a core and permanent feature of all national HTA processes.

Section 6
The barriers and enablers to patient organisations' involvement

Lack of resources: the main barrier to patient organisations' involvement

How often are patient organisations asked to provide feedback on the impacts of national health policies?

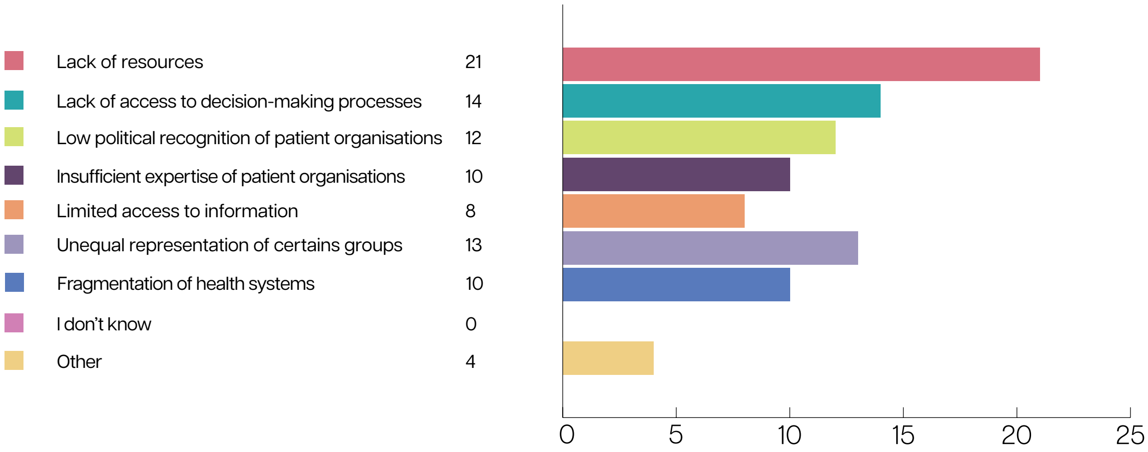


Figure 19. *Frequency of consultation of patient organisations on the impacts of national health policies across countries.*

Takeaway #1

Patient organisations face a multitude of barriers to meaningful involvement in policy-making, including low political recognition, fragmentation of health systems, and limited expertise, but an overwhelming majority of countries (91.3%) identify lack of resources as the main barrier.

The "lack of access to decision-making processes" emerges as a widespread pan-European issue, with particularly high prevalence in Central and Eastern Europe (CEE) and the Baltic countries (Estonia, Latvia, Lithuania). Similarly, both "low political recognition of patient organisations" and "limited access to information" show clear clustering in CEE and the Baltics, as well as in South-East Europe. By contrast, Western and Northern European countries—particularly Flanders, the Netherlands, and Sweden—appear to be less affected by these barriers compared to other parts of Europe.

Funding sources are diversified by necessity

What are the main sources of funding of your organisation?

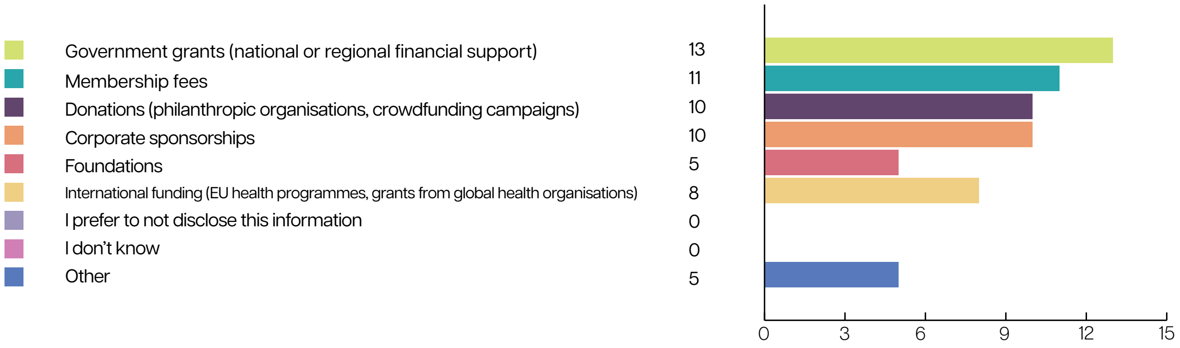


Figure 20. *Reported funding sources of patient organisations across countries.*

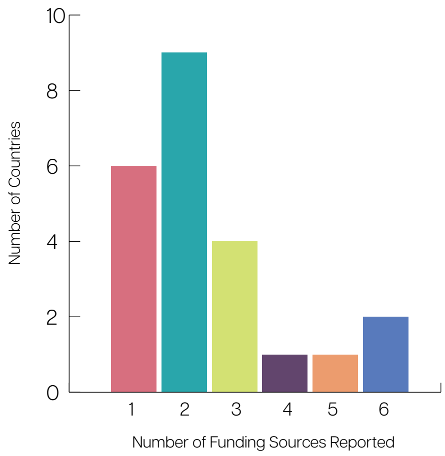
Takeaway #2

Most organisations combine multiple sources of funding, which supports increased sustainability but requires considerable effort in terms of fundraising and administration.

Most organisations typically combine a public grant component with own-resource income (fees/donations) and private support (corporate funders/foundations). Funding is diversified rather than single-source. Few organisations depend solely on one stream (6 countries out of 23).

The majority of organisations depend on 2 or 3 sources of funding. 17.4% of the organisations surveyed even depend on 4, 5 or 6 sources of funding.

Figure 20.
Distribution of Funding Sources Across Countries



Governmental grants: an insufficient but valuable source of funding

Takeaway #3

Government grants are the most common source of funding among all countries surveyed (13 countries out of 23), but still account for only a small proportion of organisations' financial resources.

The availability of government funding varies significantly across countries. Where it exists, it generally accounts for less than half of an organisation's budget (between 25–50%). In two countries, government grants represent up to 75% of financial resources (Czechia, Finland), while in three countries (Croatia, Estonia, Netherlands) they account for around 50%, and in another three, (Cyprus, Germany, Serbia) around 25%.

A sizeable number of countries – 12 in total (Flanders, Greece, Hungary, Kosovo, Latvia, Malta, Romania, Slovakia, Slovenia, Spain, Lithuania, Bulgaria) still report minimal or no public support. In three countries, the situation is particular: in Sweden and France, it varies from one organisation to another, and Scotland has not provided this information.

Government funding generally supports specific activities, such as project-based funding. In some cases, it is complemented by core funding, providing financial support for overall organisational objectives, including operational costs and programme development. In general, core funding is almost never provided on its own. Where public funding is accessible, organisations report that it is granted on an annual basis, requiring beneficiaries to reapply every year.

Members voice

What are the criteria for receiving public funding?

Germany, BAG Selbsthilfe

There is no systematic involvement, and patient representatives have no place at the discussion table.

Scotland, The ALLIANCE – Health and Social Care Alliance Scotland

The criteria are based on mutually agreed outcomes that are regularly assessed.

Netherlands, Netherlands Patients Federation

It is necessary to demonstrate a minimum threshold of donations/memberships (e.g., "at least 100 donations of ≥ £25") in order to prove that the organisation does not rely solely on public funds.

Serbia, UPS – Patients Association of Serbia

The criteria can be vague and grants are sometimes awarded at the last minute (e.g., funding received at the end of the year).

Sweden, Swedish Disability Rights Federation

Organisations must work towards change in several areas of society that are important to people with disabilities, be democratically structured, be independent of political parties and religions, have a national organisation with local or regional associations in at least ten counties, have been active for at least two years, and have at least 500 members.

Croatia, KUZ – Coalition of Associations in Healthcare

Co-funding is the norm, meaning that the patient organisation must contribute part of the financial resources needed for the project.

Czechia, NAPO – National Association of Patients' Organisations

Criteria generally include the organisation's history, financial and operational transparency, and co-funding.

Takeaway #4

Availability of public funding, and in particular of core funding alongside project-based funding, strengthens organisations' capacity to engage in policymaking.

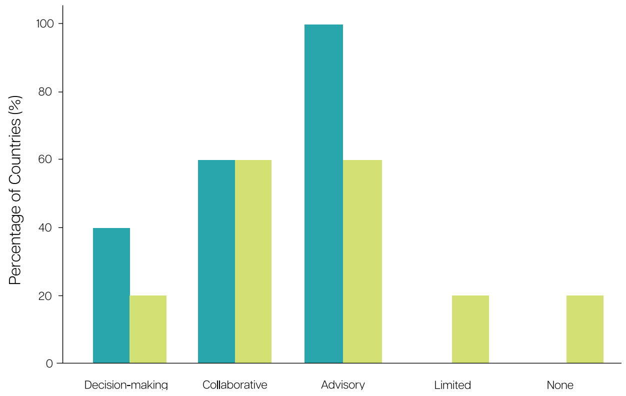
In our survey, patient organisations that reported receiving international funding (e.g. EU health programmes, grants from global health organisations) and government grants (national or regional financial support) were also more likely to report a stronger influence on health policy. In particular, they more frequently indicated having a "decision-making" or "collaborative" role within healthcare systems. While this likelihood does not imply causality, it suggests that access to public and international funding can strengthen organisations' capacity to engage in policymaking.

At EU level, EPF has consistently advocated for patient organisations' access to EU-funded operating grants. These grants enable patient organisations to set their own agenda based on the needs and priorities of their members and communities. When provided on a multi-annual basis, they provide stability, support long-term strategic planning, facilitate staff retention and strengthen organisational expertise. Crucially, they enable patient organisations to carry out their core advocacy role, namely representing the interests of their communities and addressing systemic gaps, rather than being limited to narrower, project-based activities.

The added value of unrestricted government funding

Our data suggest that countries that have received both unrestricted public funding and projects based funding (Group 1, in blue) are more likely to have a greater decision-making role in the healthcare system than countries relying solely on project based funding (Group 2, in green).[31]

Figure 22.
Decision-Making Power by Country Group (Revised Group)



Case study

In Germany, the limitations of a model that does not fund political and advocacy activities

Dr Martin Danner, Federal Director, BAG Selbsthilfe

"In Germany, government grants do not support political or advocacy activities, as authorities assume that civil society can raise funds through membership fees. In the past, the Ministry of Health supported

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[31] While this likelihood does not imply causality, it suggests that unrestricted public funding may contribute significantly to patient organisations having a greater decision-making role.

our political and advocacy work through a dedicated grant. Five years ago, however, it concluded that funding patient organisations for this purpose was no longer appropriate.

Likewise, health funds provide financial support to patient organisations only for the services they deliver to people with disabilities and those living with chronic diseases. Patient organisations and health funds sometimes hold different views on what should be reimbursed. As a result, health funds do not support the political work of patient organisations either. Financial support from health funds is generally limited to service provision by patient organisations.

This also raises an important question: how can patient organisations plan and sustain patient involvement in healthcare committees if this participation is not financially supported?

For us, this is also a barrier to working at the European level. There is no national funding for BAG SELBSTHILFE to collaborate with the European Patients' Forum at European level. This is not acceptable for the future development of the European integration process. The current structure of the German ministries does not help either. The Ministry of Health is focused on the national level and the Ministry of Foreign Affairs is rarely dealing with health issues. We collaborate at European level because we believe it is important—not because it is reimbursed. With appropriate support, we could do much more.

At national level as well, we could significantly expand our work, particularly in stakeholder engagement and in participating in complex negotiations within healthcare committees."

Capacity building programmes – key enablers to drive greater patient involvement

Takeaway #4

In only about one third of the countries surveyed do patient organisations have access to government-provided capacity-building or training programmes.

Capacity-building programmes are essential to enable patient organisations to meet the growing expertise required for meaningful participation in health policy and regulatory processes. As these processes become increasingly complex, training to build knowledge and expertise helps strengthen organisations' ability to engage effectively, represent their communities, and contribute to more informed decision-making. Capacity building also supports the development of strong governance structures, enhancing transparency, accountability and the credibility of patient organisations.

Do patient organisations have access to capacity building programmes (e.g. training) provided by national authorities to help their organisation grow and build its expertise?

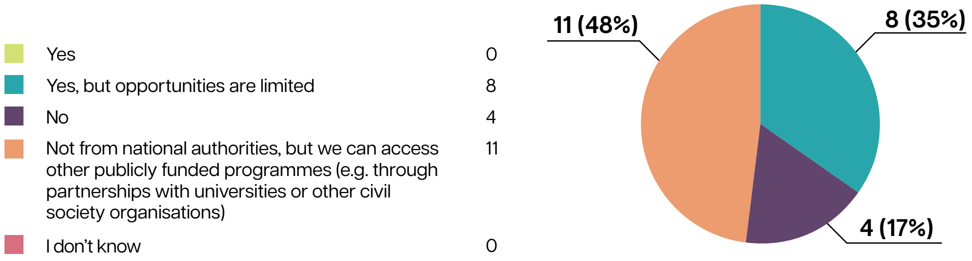


Figure 23. *Availability of capacity-building support for patient organisations from national authorities across countries (n=23).*

What types of capacity building programmes do patient organisations have access to in your country?

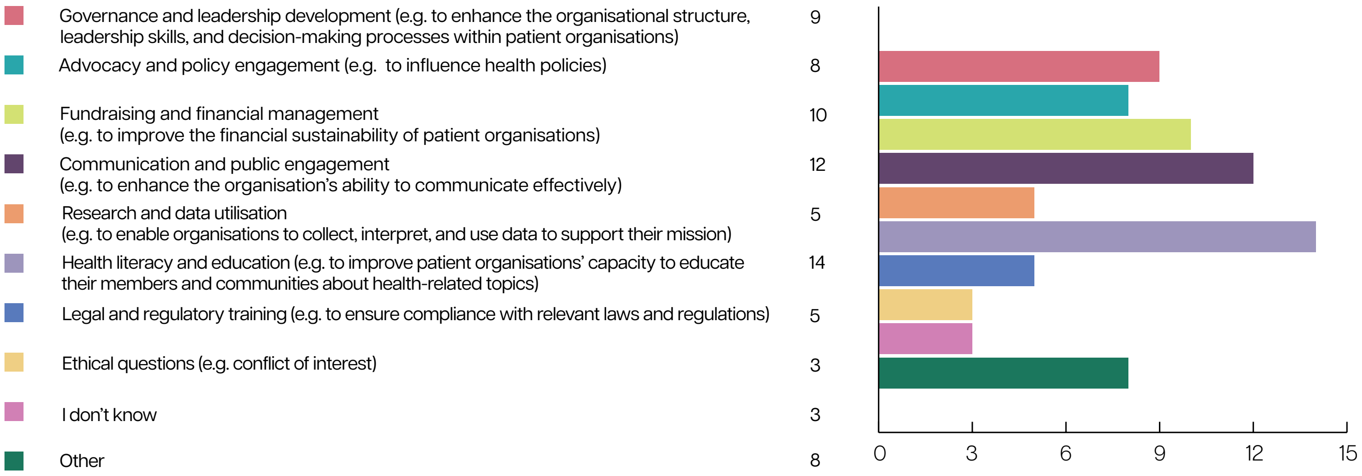


Figure 23. *Types of capacity-building programmes available to patient organisations across countries.*

Where such programmes exist, they most commonly cover areas such as health literacy and education, communication and public engagement, and fundraising and financial management. Czechia and the Netherlands, stand out as offering the most comprehensive and diversified range of capacity-building programmes.

However, opportunities remain limited overall. In countries such as Bulgaria, Romania, Hungary and Serbia, no capacity-building programmes are available, meaning that patient organisations lack access to the support and resources needed to develop the knowledge and expertise required to play a meaningful role in national processes. More generally, nearly 40% of the countries surveyed reported having access to two or fewer types of capacity-building programmes among the listed options.

Unlike the barriers to patient involvement, no clear geographical pattern emerges in the availability of capacity-building programmes. Differences between regions are relatively modest in terms of content. In Central and Eastern Europe (CEE), the Baltics and the Balkans, programmes tend to be broader and focus on structural capacity needs—such as advocacy, fundraising, governance, and communication. In contrast, in Western and Nordic Europe, programmes appear somewhat more specialised and geared towards targeted improvements. For example, capacity-building initiatives related to research and data utilisation are only reported in the Netherlands, Czechia, Estonia, Flanders, and Scotland.

Best Practice

Health literacy and patient education: In Kosovo, the Patients' Rights Association in Kosovo (PRAK) helped develop a Patients' Rights Charter, which has since served as the foundation for subsequent discussions on patient involvement

Historically, the involvement of patient organisations in Kosovo has been weak and fragmented. Although patient rights are enshrined in legislation—under a law adopted in 2004—implementation has been inconsistent. Mechanisms for feedback and accountability were not institutionalised, particularly at local level and in primary care.

To address this gap, PRAK initiated the drafting of a Patients' Rights Charter, drawing on the European model developed by the Active Citizenship Network. Building on this work, the Ministry of Health established a formal working group in which PRAK participated. The Charter was adopted in 2013 as a national reference document.

Today, it serves as a practical reference for citizens, healthcare professionals, and institutions, and has supported broader institutional reform. It is also a living document: PRAK has organised 250 citizen information sessions, delivered 200 accredited training sessions for healthcare staff, and distributed 11,000 brochures.

CHARTER OF PATIENTS' RIGHTS

1. Right to preventive measures
Every citizen has the right to proper health service with purpose of diseases prevention.

2. Right of access
Every citizen shall be warranted the right of equal access to health services without discrimination on racial, gender, ethnicity, place of residence and type of disease.

3. Right to information
Every citizen has the right to access all information about his state of health, health services and how to use them.

4. Right to consent
Every citizen has the right to give consent to decisions dealing with his health (family member or guardian if his condition does not allow), this information is a prerequisite for any procedure and treatment, including participation in scientific research.

5. Right to free choice
A citizen has the right to be consulted and be treated by a doctor of his choice with the consent of the health institution within the boundaries provided by law and operational rules of the institution.

6. Right to privacy and confidentiality
Every citizen has the right to confidentiality of personal information, including information concerning his health and potential diagnostic or therapeutic procedures.

7. Right to respect of patients' time
Every citizen has the right to receive necessary treatment within the shortest time period. This right applies at each stage of treatment.

8. Right to the observance of quality standards
Every citizen has the right to have access to high quality health services based on high quality standards.

9. Right to safety
Every citizen has the right not to be affected by the malfunction of health services, inadequate practices and medical mistakes. He also has the right of access to health services and treatments that are safe.

10. Right to innovation
Every citizen has the right to have access to new diagnostic procedures according to international standards.

11. Right to avoid unnecessary suffering and pain
Every citizen has the right to avoid as much as possible pain and suffering at every stage of his illness.

12. Right to personalized treatment
Every citizen has the right to diagnostic or therapeutic treatment adjusted to his personal needs.

13. Right to complain
Every citizen has the right to complain whenever he or she suffers physical, moral and psychological harm. He is also entitled to receive a response to his complaint.

14. Right to compensation
Every citizen is entitled to receive compensation in a timely manner whenever he suffered physical, moral or psychological harm caused during treatment, in accordance with the Law on Rights and Responsibilities of Citizens in Health Care.

CHARTER OF PATIENTS' RESPONSIBILITIES

1. If the citizen's state of health allows, depending on his skills and knowledge he should cooperate with health professionals involved in medical treatment in the following ways:

- **a.** information on all the details necessary for diagnosis determination, especially informing the health professionals, for any previous illness, medical treatment, use of drugs and his affinity against dangerous factors that may affect his health;
- **b.** information for every detail about his illness, which may endanger the safety of others' physical life, especially on an infectious disease or any condition that excludes it from the profession exercise;
- **c.** comply with the instructions received in connection with medical treatment;
- **d.** compliance with operating rules of the health institution;
- **e.** fulfillment of obligations (payments) for services received;
- **f.** presentation of reliable evidence to personal data.

2. In exercising the rights of the citizen, he or his relatives should respect the rights of other citizens.

3. In exercising the rights provided by this Administrative Instruction, the citizen or his relatives are prohibited to violate the rights of health personnel.

Image 1: *Charter of Patients' Rights & Responsibilities.*

Key recommendations

- Provide dedicated, predictable, and sustainable funding mechanisms for patient organisations, including public funding;
- Ensure the availability of multi-annual core grants, not only project-based funding, to support long-term strategic involvement and organisational stability, based on fair and transparent eligibility criteria;
- Formalise and institutionalise patient involvement in decision-making processes across all levels of governance, with a particular focus on equitable representation;
- Invest in capacity building for patient organisations across all countries, including training on health policy and regulatory processes, but also skills development, governance, and knowledge-sharing;
- Support cross-border collaboration and empower national coalitions to contribute to EU discussions through their representative organisations.

Section 7

From voices to impact – How patient organisations' are changing healthcare systems

Measuring the impact of patient organisations is essential to better understand their contribution to health systems and their ability to drive meaningful change in policies and practices. Beyond participation alone, assessing impact helps demonstrate whether and to what extent patient input influences decision-making, improves the relevance and quality of policies, and contributes to better healthcare systems.

Across Europe, this impact remains highly variable, reflecting differences in resources, recognition, and opportunities for involvement. From improved access to treatment and stronger inclusion of patient perspectives in healthcare systems, to disease-specific advocacy, enhanced patients' rights, and the design and implementation of large-scale prevention campaigns, the following section presents case studies from our members illustrating how their advocacy has contributed to improving patients' lives and strengthening healthcare systems.

Patient organisations' ability to change patients' lives

How would you describe the impact of patient organisations' involvement in shaping national policy?

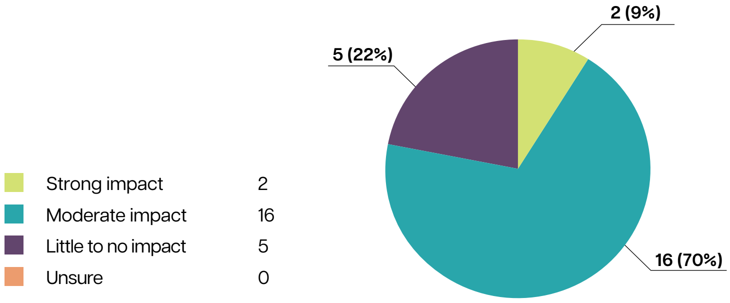


Figure 24. *Perceived impact of patient organisations' involvement in shaping national health policy across countries (n=23).*

Has patient organisations' involvement led to any changes in policy or legislation in your country?

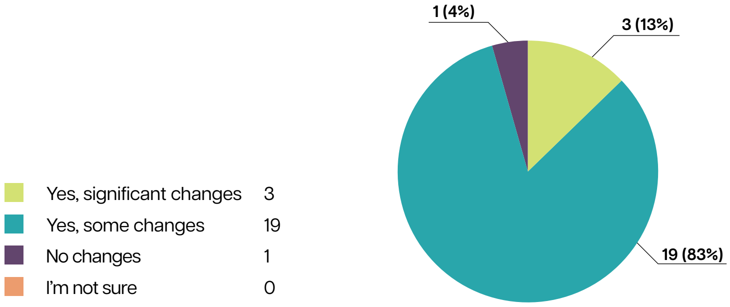


Figure 25. *Reported policy and legislative changes resulting from patient organisation involvement across countries (n=23).*

Cyprus and Slovenia report having a “Strong impact” on national policy, while Bulgaria, Hungary, Malta, Netherlands and Serbia report having “Little or no impact”. Cyprus, France and Slovenia also report having led to “significant changes” for patient communities in their country.

Best Practice Sharing

How patient organisations involvement are changing national health policies across Europe

Improving access to and affordability of treatments

In Germany, BAG SELBSTHILFE was instrumental in preventing the withdrawal of reimbursement for specialised wound care

There is a clear distinction between standard wound care (e.g. bandages, basic dressings, antiseptic solutions) and specialised wound care with a therapeutic effect. Specialised wound care includes, for example, the treatment of chronic or complex wounds (such as diabetic foot ulcers, pressure ulcers, and venous leg ulcers) and the use of advanced wound products (e.g. hydrocolloids, alginates, foam dressings, and antimicrobial dressings). Because specialised wound care is significantly more expensive, the government, through a guideline from the Federal Joint Committee, sought to exclude parts of it from reimbursement.

Patient organisations were among the very few stakeholders to anticipate the negative consequences of this measure on patients’ care. They engaged with Members of Parliament and highlighted the need to clarify the legal basis. Ultimately, BAG SELBSTHILFE succeeded in securing a clarification in the law to protect reimbursement for specialised wound care.

This experience demonstrates the real added value of patient organisations’ participation in committees and institutional decision-making processes to safeguard patients’ access to the care they need.

From an advocacy perspective, BAG SELBSTHILFE also relied on a strong network of wound-care scientific experts and companies active in the field—it was a genuine team effort.

The Netherlands’ Patients Federation’s has helped achieve a model in which highly complex treatments are centralised, while more routine care is delivered closer to home

Klaartje Spijkers, Senior Advisor, Netherlands’ Patients Federation

What are the benefits of organising complex oncological treatments in specialised centres?

“The Netherlands is a small country and, to deliver highly complex treatments safely and effectively, a certain degree of centralisation is necessary. This approach had already been established for rare diseases, but not for oncology. A similar model has since been developed for complex cardiac conditions.

Higher volume is a prerequisite for specialisation and achieving better therapeutic outcomes. Specialisation is necessary to keep up to date in the rapidly evolving field of oncology care and given the complexity of all the diagnostic and treatment options. Greater concentration of complex care is also necessary to sustain oncology as we move towards a shortage of staff and financial resources in the face of a significant increase in the number of cancer patients. This requires the efficient use of human resources and medical infrastructure.”

What was the role of patient organisations in this process?

"Patient organisations supported Patient Advisory Boards within hospitals. Their role is to advise the hospital's board and senior management, and—by law—they can formally agree or disagree with decisions taken by the hospital director.

Decisions about the need to concentrate care require a great deal of internal and contextual information from patient representatives. However, patient organisations have more of this information than local Patient Advisory Boards. In previous years, the cancer patient organisation has conducted numerous surveys of thousands of former cancer patients on all topics related to the concentration of cancer care. We compiled all this information into a summary report that we shared with all local Patient Advisory Boards, as well as local hospital boards and oncology teams. We also invited the local Patient Advisory Boards to several national meetings where we explained the context and need for oncology care concentration."

What was the result of this work?

"Some hospitals opposed the creation of centres for highly complex oncology treatments, partly because of the associated costs. Despite this, patient organisations succeeded in driving the centralisation of complex oncology care together with the Patient Advisory Boards. Establishing these centres took time: it required around five to ten years of sustained effort. We actively contributed by organising patient data and through our direct relationship with the responsible minister

According to the Patient Federation of patient organisations in Oncology, scientific evidence shows that there is a direct link between the provision of high-volume care and improved clinical outcomes. Thus, ensuring that a greater number of highly complex treatments are provided leads to better outcomes for patients."

In Belgium, patient organisations gain a formal role within the federal reimbursement authority

The National Institute for Health and Disability Insurance (RIZIV/INAMI) is Belgium's federal public body responsible for managing and regulating the compulsory health insurance system. It oversees reimbursement of healthcare services and medicines, disability benefits and sickness allowances, healthcare financing and provider payment systems and budget control within the health insurance system. It works through two key structures for engagement with patient organisations:

- The Patient Forum: This is a relatively new, disease-specific forum. A RIZIV/INAMI team meets with patient organisations every four months to give them a channel to raise needs and challenges linked to the reimbursement of specific treatments (for example, diabetes care). This provides a direct line between patient organisations and the institute. While the outcome does not always lead to reimbursement of a given treatment—given limited budgets—RIZIV/INAMI is generally willing to examine the issues, understand the underlying problem and identify possible solutions;
- Observatory for Chronic Diseases: This platform deals with cross-cutting issues that are not specific to any particular disease. The Minister of Public Health sometimes seeks its opinion on a particular subject. For other issues, the Observatory makes recommendations on its own initiative. Patient organisations and representatives of mutual insurance companies meet with RIZIV/INAMI to discuss topics such as patient rights, quality of care, financial accessibility of health care and digital health literacy;

Supporting patients in the transition to digital health

In Latvia, the Latvian Network of Patient Organisations (LPOT) brings the patient perspective in key national decision-making bodies, including the Strategic Council of Health Care, the Pharmaceutical Advisory Council, and the Digital Health Council

Across these platforms, LPOT's role has consistently been to ensure that patients and patient Organisations are recognised as distinct and essential stakeholders in health policy development. Participation in the Digital Health Council from the start has enabled LPOT to systematically integrate the patient voice into discussions and decision-making processes.

This engagement helped shape Latvia's 2024 Digital Health Strategy, with several patient-centred recommendations reflected in the final document. LPOT emphasised that digital services—such as telemedicine, e-prescriptions, and e-referrals—should be developed not only as technically efficient systems, but as solutions that are truly accessible and responsive to patients' needs.

In addition, LPOT has participated in working groups related to the national e-health portal – a large-scale system designed to centralise health data. The network has actively involved its member organisations and their members in testing processes to improve usability and ensure the system meets patients' real-world needs.

In a field where IT developers and government institutions often dominate discussions, consistently and constructively representing patients' perspectives remains essential to building inclusive and effective digital health solutions.

Ensuring the availability of innovative treatments in small countries

In Serbia, the Patients' Association of Serbia (UPS) has helped secure reimbursement for several innovative therapies—an important achievement in a country where access to such treatments is severely limited

Serbia currently has very low availability of innovative therapies. According to data, it ranks as the third worst country in Europe in this regard.

Despite these constraints, patient organisations succeeded in having multiple innovative therapies reimbursed in 2016, 2020, and 2023. Most notably, in December 2023, the Patients' Association of Serbia (UPS) advocated for expanded reimbursement, resulting in 16 additional therapies being covered—an exceptionally significant number by Serbian standards. These therapies span several disease areas, including lung cancer, breast cancer, melanoma, haematological conditions, ophthalmology, and head and neck cancers.

From an advocacy standpoint, media engagement has been one of the most effective advocacy channels. Through close collaboration with a public relations agency, the Patients' Association of Serbia (UPS) ensured strong public visibility and maintained consistent pressure on the issue.

The Patients' Association of Serbia (UPS) worked closely with both the Ministry of Health and the Health Insurance Fund. In recent years, these institutions have operated largely separately, which has required patient organisations to pursue advocacy efforts on two parallel tracks.

Regional cooperation is another key component of patient organisations' work in Serbia, particularly with Bosnia and Herzegovina, Croatia, Slovenia, and Montenegro. With Bosnia and Herzegovina especially, the Patients' Association of Serbia (UPS) has jointly advanced the topic of reimbursement for innovative therapies through regional meetings, shared statements, and the exchange of best practices.

Strengthening and formalising patients’ rights at national, local and hospital level

In Greece, the Greek Patients’ Association played an active role in policy dialogue aimed at strengthening and operationalising hospital-based “Offices for the Protection of Patients’ Rights”

Although these offices had long been provided for in legislation and each hospital had to formally establish one, their visibility and practical integration within hospital structures varied considerably. In many cases, patients were insufficiently informed about their existence, while the offices themselves were not always clearly embedded within administrative or managerial processes. Staffing arrangements also differed across institutions, with responsibilities often assigned to professionals whose primary training lays in other fields, such as nursing or social services.

Within this context, the Greek Patients’ Association focused on highlighting the importance of these offices as mechanisms for patient support, information, and feedback, rather than as complaint offices. A central element of its approach was to promote a constructive framework, emphasising collaboration with the people working at the Offices and the Ministry of Health.

The Association contributed to discussions regarding the clarification of the offices’ operational framework, including the development of more explicit terms governing their role, responsibilities, and procedures. The adoption of such guidance helped provide greater consistency in how the offices function across hospitals, supporting clearer mandates and more structured processes.

These developments have been accompanied by broader efforts at the Ministry of Health level, including initiatives to standardise complaint-handling procedures and to enhance transparency regarding patient feedback mechanisms, where the Greek Patients’ Association provided recommendations.

In February 2026, the Minister of Health also committed to further strengthening the offices and to increasing the involvement of patient organisations in their work.

In Kosovo, the Patients’ Rights Association in Kosovo (PRAK) has been instrumental in establishing Patient Councils, a key step in introducing patient representation at local level

In 2020, PRAK spearheaded the inclusion of Patient Councils within the administrative structures of primary healthcare. This initiative ensures that patient organisations have a clear role and mandate within the healthcare system, rather than relying on political will.

Patient Councils are designed to act as a bridge between citizens and health institutions:

- They co-represent patients’ interests in decision-making at medicines centres as part of the governing council of the main family medicine centre;
- They also gather and communicate patients’ needs to centre leadership. Councils have official email addresses and phone numbers, a presence in the media, and formal access to government structures;
- Patient Councils are also central to the regular collection of data on patients’ experiences and satisfaction with healthcare services across all levels of care.

Currently, there are nine Patient Councils operating in nine municipalities, and PRAK plans to establish a further ten. The long-term goal is to set up Patient Councils in every municipality in Kosovo. PRAK envisages exploring the creation of a national coordination or a central platform to link these local councils. The idea would be to strengthen coordination, exchange of experiences, and joint advocacy, while maintaining the autonomy of local councils. This could serve as a mechanism to aggregate patient voices and feed structured evidence and recommendations into national-level policy discussions.

Placing patients at the heart of healthcare system evaluation and improvement

In Greece, the Greek Patients' Association is working to place patients at the heart of the evaluation and improvement of hospital services

The establishment of a structured mechanism for capturing Patient Reported Experience Measures (PREMs) reflects a longstanding policy priority advanced by the Association, which has consistently emphasised the need for a reliable framework through which patients' experiences can be systematically integrated into quality improvement processes.

Within this context, the Greek Patients' Association engaged in sustained dialogue with the Ministry of Health, advocating for the development of a national patient experience measurement system. A key Ministry initiative has been the introduction of a digital questionnaire for users of public hospital inpatient services, distributed via email or SMS. The Association actively contributed to policy discussions and provided structured feedback during the design phase of the questionnaire, drawing on patients' lived experiences, international practices, and health literacy considerations.

The resulting tool captures multiple dimensions of hospital care, including accessibility, organisation and coordination of services, communication with healthcare professionals, patient involvement in decision-making, hospital environment, discharge processes, and awareness of patient rights structures.

Early implementation data indicate strong patient engagement. During the first evaluation period (July 2025 – October 2025), the tool was deployed across 111 public hospitals, generating 14,885 completed questionnaires. The results revealed a weighted average satisfaction score of 4.04 out of 5. Higher ratings were recorded in areas such as trust in healthcare professionals, adequacy of medical staff and equipment, and discharge information, while comparatively lower scores highlighted opportunities for improvement in domains including hospital food, patient involvement in decision-making, and perceived nursing staff shortages. Importantly, the findings provide a basis for targeted improvements.

At the core of this work is a simple principle: meaningful evaluation of the health system must be grounded in the experiences of those who use it.

Press conference link.

Co-creating disease-specific national plans with health authorities

In Greece, the Greek Association of People Living with HIV, in collaboration with the Greek Patients' Association, triggered the process for a National Human Immunodeficiency Viruses (HIV) Strategy Plan

Although the EU's Beating Cancer Plan exists, Greece still does not have a national cancer plan. This highlights how progress in specific disease areas can depend heavily on advocacy, in contrast to countries such as Australia, the United States and Switzerland, where strategies are regularly updated—often every four years—to track progress.

In the Association's view, this is a missed opportunity, as national strategies are valuable precisely because they create a structured process: they bring stakeholders together to take stock of the current situation, agree on a direction of travel, and set clear targets and indicators to measure outcomes. They also require the state to plan more systematically and to govern against defined objectives.

On HIV, the Greek Patients' Association took a leading role. It convened a meeting on the issue in the Greek Parliament, using both the 30th anniversary in 2021 of the HIV epidemic and the momentum created by the COVID-19 pandemic to push the topic up the political agenda. The Association made the adoption of a national HIV strategy a central ask in its engagement with government representatives—sustaining the effort across two or three successive Ministers of Health until it was achieved. People from the Greek Association of People Living with HIV, and the Greek Patients' Association also actively participated in the working groups that drafted the National Plan.

Media outreach, press releases and conferences were also used to build awareness and maintain political attention.

Bringing about patient-centred changes to clinical guidelines and improving hospitalisation conditions for patients

In Slovakia, the Association for the Protection of Patients' Rights (AOPP) advances patients' rights through legal reform on children's hospitalisation

The law now guarantees parents the right to stay in hospital with their children—something that, even a year ago, was still not assured. At that time, it depended on each hospital's willingness and capacity, including space, staffing, and the availability of basic equipment to enable a parent to remain in the room.

A new legal provision now requires every hospital to create the conditions for a parent to be offered the opportunity to stay with their child 24 hours a day. A transitional period is in place until 2028, during which hospitals must become properly equipped—for example, providing a chair suitable for sleeping and dedicated space next to the child's bed. This is particularly important for children, as the presence of a parent reassures them, they are not afraid of the hospital environment and are more accepting of procedures and treatments.

Parents and children's patient organisations—including the Association for the Protection of Patients' Rights (AOPP) which has been a leading organisation on this issue—raised this repeatedly with the Minister of Health. The Association for the Protection of Patients' Rights (AOPP) launched this effort a year ago, drawing attention to the distress experienced by parents. It was a highly sensitive and emotional issue—not only for families, but also for hospital doctors, many of whom recognised the importance of this need.

The Association for the Protection of Patients' Rights (AOPP) was actively involved throughout the legislative process: met with the Ministry, organised roundtables with hospital managers, and contributed to discussions leading up to the final text. Ultimately, Parliament adopted the law as a result of this sustained advocacy.

Preventing disease by reducing the determinants of chronic disease

In Romania, the Coalition of Patients' Organisations with Chronic Diseases (COPAC) was instrumental in catalysing a comprehensive adult vaccination programme

Radu Ganescu Costin, President, Coalition of Patients' Organisations with Chronic Diseases (COPAC)

How did vaccination emerge as a key area of focus for your organisation?

"*It began in 2018, when the European Patients' Forum and its VAC-PACT pilot project led to a series of meetings in Romania with health authorities. For the first time, we put on the table the question of protecting people living with chronic conditions—our organisation's core focus—through vaccination. However, there was a major financial barrier: these vaccines require substantial resources.*

We convened a forum bringing together a wide range of stakeholders, produced information materials setting out patients' needs, and contributed to economic analyses—for example, demonstrating the cost-effectiveness of broad influenza vaccination compared with the costs of treating patients who contract flu.

In 2020, the COVID-19 pandemic helped us—paradoxically—because it increased public understanding of the value of vaccines. It was also the first time that people with chronic conditions were prioritised for vaccination.

In 2022, together with the National Association of Epidemiology, we developed a vaccination protocol for people with immunosuppressive conditions. This marked the start of a clinical guideline designed to provide healthcare professionals with clear, practical information and age-specific recommendations for different patient groups (including people with diabetes, HIV, rare diseases, immune-mediated diseases, transplant recipients, and others). The Ministry of Health recognised the guideline and published it for the scientific community."

Did this guideline lead to other positive developments in vaccination?

"Yes. It helped lay the groundwork for reimbursement of Human Papillomavirus (HPV) vaccination for girls aged 11 to 18—recently extended to both girls and boys up to the age of 26. It was followed by the introduction of free influenza vaccination in pharmacies, particularly for older people. After two years, we can say that the programme is working well. Similar progress has been made on pneumococcal vaccination for people with chronic conditions, including those on dialysis or living with comorbidities, as well as on hepatitis B vaccination.

Vaccination coverage rates have improved in recent years, although they remain below optimal levels and continue to be influenced by broader systemic factors.

HPV vaccination coverage recorded a significant increase during the 2018–2024 period. While in 2018 vaccination was almost non-existent—estimated at approximately 2–3% among the eligible population—by 2024 coverage had risen to around 17%. This progress was driven in large part by the expansion of the national programme and the establishment of dedicated HPV vaccination centres, which improved access and visibility.

By contrast, influenza vaccination coverage remains low. In the 2023–2024 season, overall influenza vaccination coverage in Romania was estimated at approximately 6.1% in the general population. Among high-risk groups, such as older adults aged 65 years and over, coverage was higher but still limited, reaching only around 16–20%.

Although vaccination rates for both HPV and influenza have increased, they remain far from recommended targets. Beyond program availability, vaccination uptake is strongly influenced by factors such as medical education, the quality and consistency of public information, and the active promotion of vaccination by healthcare professionals."

How would you describe the role of patient organisations throughout this multi-year process?

"We translated the guideline into a public information guide on vaccination and chronic conditions to support informed decision-making among citizens. The guide provides accessible, evidence-based information on recommended vaccines for people living with chronic diseases.

More broadly, patient organisations played a convening and agenda-setting role: bringing stakeholders together, placing vaccination firmly on the policy agenda (including through a steering committee), and keeping it there through workshops, information materials and sustained engagement. We also helped ensure that the evidence and materials developed by clinicians and specialists reached health authorities. In that sense, patient organisations acted as a bridge between healthcare professionals and decision-makers."

With the pioneering North Karelia project, Finnish patient- and public health organisations have played a key role in changing behaviours and combating risk factors for chronic diseases

Kaarina Tamminiemi, SOSTE - Finnish Federation for Social Affairs and Health

What is the North Karelia project and what patient need does it strive to address?

"Launched in the early 1970s, the North Karelia Project emerged in response to an alarming health situation in Finland, particularly in North Karelia. Rates of heart disease among men were the highest in the world, claiming the lives of many young men and keeping male life expectancy under 65 years. The North Karelia Project was one of the world's first large-scale intervention projects aimed at addressing risk factors, including anti-smoking policy, dietary changes, smoking reduction, increased physical activity, blood sugar and blood pressure management, and addressing public health issues at the community and regional level. It was also significant internationally, as its results showed that actively supporting healthy behaviours could significantly reduce mortality from heart and cardiovascular disease. The successes and lessons learned from this project have played a key role in Finnish public health policy, and the North Karelia Project is often cited as an example of how regional and population-based health initiatives can have a positive impact on public health."

What role did Finnish patient and public health organisations play?

"Patient and public health organisations, including the Heart Association and local health associations, supported the North Karelia Project through awareness campaigns, community engagement, and practical measures that contributed greatly to its success.

The methods and principles of the North Karelia Project spread widely and later served as a model for other programmes. Building on these principles, the Ministry of Social Affairs and Health and the Finnish Heart Association convened a national consensus conference in 1997, which led to the Action Programme for the Promotion of Cardiovascular Health in Finland. The programme set out more than one hundred recommendations and, among other outcomes, prompted the development of the Heart Symbol system. Still in use today, the Heart Symbol helps guide consumers towards healthier choices. The Finnish Heart Association and the Finnish Diabetes Association developed the Heart Symbol, *which was launched in 2000. It is now used by more than 100 companies and appears on over 2,000 products in Finland. Over 92% of consumers recognise the symbol, and 2/3 use it as a basis for their purchasing decisions.*

At the end of 2025, the North Karelia Project 2.0 initiative was launched to reduce the risks of non-communicable diseases and promote the health of the working-age population, in the spirit of the original North Karelia Project that began in 1970. The initiative builds on the earlier project's best practices while developing new, effective ways to support health-promoting lifestyles in the 2020s. It is coordinated by the North Karelia Centre for Public Health, and the development work is delivered through a project consortium that brings together public, private, and third-sector actors. The initiative is part of the implementation of the national Terveydeksi 'To your Health' programme on health and wellbeing (2024–2027)."

Section 8

Changing the narrative around patient organisations from “nice-to-have” to strategic partners in social services and research & development (R&D)

At European and national level, there is an increasing focus on “competitiveness” and “simplification”. In a broader context of resource shortages for health systems facing both an ageing population and increasingly expensive innovative personalised treatments, patient organisations are under growing pressure to demonstrate their role and prove their added value. In line with the EPF Barometer, national coalitions of patient organisations, such as those in Czechia and Slovenia, have produced comprehensive, data-driven reports to demonstrate their added value.

Members voice

Nikos Dedes, Chair of the Greek Patients Association

“Patient organisations more than most stakeholders are interested in the sustainability of the health system. Patient organisations are the first who are interested in optimising the allocation of scarce resources, the first to avoid wasting money, simply because if this happens, patient organisations are the first to suffer the consequences”

In Slovenia, a report shows the extent of health services provided by patient organisations at a much lower cost than comparable public services.

In Slovenia, chronic underfunding has forced patient organisations to refocus some of their advocacy activities in order to better highlight their added value to the economy. The Association of Patient and User Organisations of Health and Social Care Services of Slovenia (ZOPS) has produced a remarkable report entitled ‘The value of NGO services in the Slovenian health and social care system’, the main takeaways of which can be found here:

Main areas covered by patient organisations:

- Health and social care services, such as rehabilitation, counselling and patient support;
- Patient and public awareness and empowerment (publications, conferences, consultations);
- Prevention (primary prevention to reduce the incidence of disease);

- Secondary prevention (prevention of complications and improvement of patients' quality of life);
- Advocacy (participation in health policy development);
- Research activities, which contribute to understanding patients' needs and designing better quality care.

The most frequently performed services include:

- Individual counseling (in person or remotely) - over 30,000 counseling sessions;
- Rehabilitation exercise (guided and independent) - over 260,000 exercise units;
- Vital function measurements (blood pressure, sugar, etc.) - over 225,000 measurements;
- Conducting lectures, workshops and seminars - almost 15,000 performances with more than 25,000 participants;
- Psychosocial support (counselling, therapy, self-help groups) - more than 10,000 activities;
- And home visits, nursing assistance and palliative care - almost 8,000 visits.

A recap in figures:

- Total number of health services performed: 617,920;
- Number of individuals reached: 136,364;
- Estimated total cost of these activities: €3,889,739;
- Estimated value of services provided: €63,335,000.

Examples of good practices in Slovenia:

- Disability associations also provide training in the use of medical devices, which patients receive at the expense of the Health Insurance Institute of Slovenia (ZZZS), but often without proper introduction. Mental health Organisations provide regular telephone advice lines to alleviate long waiting times in the public system. Associations of patients with rare diseases provide access to specialist advice and information that the system does not provide as official services;
- Examples of research impact: NGOs recorded the inaccessibility of certain services for individual groups (e.g. patients with chronic pain, people with very rare diseases), conducted research on the social exclusion of patients and the challenges of long-term care, participated in the development of quality of life indicators in Slovenia, and introduced user experiences into the design of pilot health services.

Main conclusions:

- Many services provided by NGOs remain invisible and without systemic support, as they are mostly not included in the ZZZS code list or their public funding is deficient, discontinuous and incomplete;
- NGOs complement public services and increasing the accessibility and humanisation of the health system. Their cost-effectiveness has been proven, with some interventions being three to ten times cheaper than comparable public services;
- The report proposes systemic solutions, such as formally recognising NGOs as providers of health services, establishing a financing model through a regranting scheme managed by the ZOPS, and including NGOs in national health programmes.

In Czechia, patient organisations save public funds by reducing the costs incurred by the state for social services and healthcare professionals.

These conclusions are the result of an analysis conducted by the consulting firm EY in collaboration with the National Association of Patient Organisations (NAPO), in which seven selected patient organisations were subjected to in-depth analysis. The results are summarised in a report entitled "Quantified analysis of the contribution of patient organisations to the Czech economy"

Main areas covered by patient organisations:

- Pre-disease / "non-treatment" stage: health literacy, awareness, self-prevention, community outreach and screening support;
- Pre-treatment and diagnostic stage: information gathering, decision support, appointment navigation, and connecting to peer communities;
- Treatment stage: consultation, guidance on options, adherence support, psychosocial/community support, and ongoing navigation;
- Post-treatment / long-term living: rehabilitation support, adapting to a "new normal," return-to-work support, and (where relevant) long-term/palliative pathway support.

Performed services include:

- Breast cancer: peer-run support lines; informational campaigns; practical-life guidance around living with disease; community events; and prevention/education activities;
- Diabetes: peer support; signposting to other services; education projects; prevention and screening activities (e.g., awareness and measurements); educational stays and campaigns;
- Parkinson's disease: peer counselling centres; organised exercise/rehabilitative activities; educational magazines; community meetups and activity programs;
- Mental illness: peer support; partial return-to-work support; volunteer "confidant" systems; basic social/legal consultation; destigmatisation and prevention-of-deterioration activities.

A recap in figures:

- The analysis estimates that services delivered by seven selected patient organisations correspond to an equivalent annual value of up to 7,767,750.44 Euro, presented also as up to ~CZK 11,000 per patient (as defined/used in the study's calculations).
- The equivalent of the salary and corresponding social security contributions for social workers who would have to provide these counselling services in the absence of patient associations amounted to 803,560.39 Euro per year in the given sample of seven selected patient associations.
- The data on the financial benefit to the state is based on only a sample of seven organisations. Given that there are 140 patient organisations in Czechia, we can estimate that the entire sector generates value for the state in the order of 410,930,758.17 Euro.

Examples of good practices in Czechia:

- Patient organisations are described as conducting information and educational prevention campaigns and organising events that include preventive examinations—contributing to disease prevention, early detection, and preventing deterioration, thereby reducing the need for more expensive treatment.

Two quantified examples in the report:

- Breast cancer: equivalent value up to 2,013,560.72 Euro, framed around avoided costs when cancer is caught earlier through prevention activities (treatment cost differences plus disability/levy effects as used in the model);
- Diabetes: equivalent value up to 2,383,398.40 Euro, framed as avoided long-run costs of severe complications (the report references examples such as dialysis and lower-limb amputations in its narrative) and associated healthcare costs over the patient lifetime.

Main conclusions:

- Patient organisations help to save public funds by eliminating the costs incurred by the state for social services and healthcare professionals, but also by reducing expenditure on treatment and disability pensions through preventive measures;
- The report positions patient organisations as a structural component of the health ecosystem, often acting as a first point of contact for people seeking non-clinical guidance, psychosocial support, and navigation.

Call to action

Embedding patient involvement in policy structures across Europe

The Barometer has highlighted a wide diversity of practices related to patient involvement across Europe. While patient participation as a "tick-box exercise" is a widespread assumption, the findings of this report also demonstrate that meaningful involvement is possible and that best practices exist. Across several countries, patient organisations contribute to shaping more responsive and patient-centred health policies. Even in countries where significant room for progress remains, opportunities for engagement do exist – albeit often in a limited, inconsistent, or insufficiently influential manner.

Overall, one of the Barometer's key findings is the persistent missed opportunity to fully empower patient organisations to fulfil their public health mission. Structured and meaningful patient involvement from the earliest stages of policymaking can draw on the unique expertise and lived experience of patients and their communities to improve alignment with real patient needs, strengthen patient information and adherence, build awareness and trust, and ultimately contribute to more sustainable healthcare systems.

However, meaningful involvement cannot happen without adequate support. Patient organisations cannot be expected to contribute to increasingly complex policy and regulatory discussions while operating with unstable funding, volunteer-only structures, and limited institutional recognition. To fully play their role, patient organisations must have access to the financial resources, expertise, training, and organisational capacity necessary to represent their communities effectively and independently.

The EPF Manifesto for the European elections outlined key principles for a truly participatory, democratic, and impactful involvement of patient organisations – in other words, what a "perfect score" on patient involvement could look like. Building on the findings of this Barometer, EPF calls on European, national, and regional policymakers to strengthen the framework for engagement, institutionalise patient participation across policy structures, and operationalise sustainable mechanisms for involvement based on the following priorities:

1. Recognise patient involvement as a democratic principle by actively involving patient organisations in the design, implementation, monitoring, and evaluation of health policies at European, national, and regional level, as part of a broader commitment to transparency, accountability, and participatory democracy;
2. Embed patient organisations structurally in decision-making processes through clear legal definitions, transparent and predictable consultation mechanisms, conflict-of-interest rules that ensure independence and encourage disclosure without excluding valuable expertise, formal participation rights, and clear criteria for representation and accountability;
3. Ensure meaningful and early participation in policy and regulatory processes, including through representation in expert forums, parliamentary committees, advisory councils, HTA bodies, regulatory processes, and specialised working groups, with a genuine ability to influence and co-create policy decisions;
4. Strengthen the role of patient organisations beyond the health sector, recognising their contribution to policies affecting quality of life and the broader determinants of health, including social affairs, disability rights, employment, digitalisation, the environment, and education;
5. Recognise patient organisations as trusted public health partners, particularly in the fields of health literacy, digital health literacy, patient education, and public health communication. This is especially important in an era increasingly shaped by misinformation and disinformation;

6. Provide sustainable and independent support for patient organisations, including predictable and multiannual funding mechanisms, core operating grants to support policy participation and strong governance, and accessible capacity-building and training opportunities.

Achieving these objectives requires a long-term commitment from all stakeholders, but the benefits are clear: health policies that meaningfully involve patients are more transparent, accountable, inclusive, and ultimately more effective. At the same time, the Barometer also shows that progress can never be taken for granted. Patient involvement and civic participation require continuous protection and investment to ensure that people directly affected remain meaningfully represented.

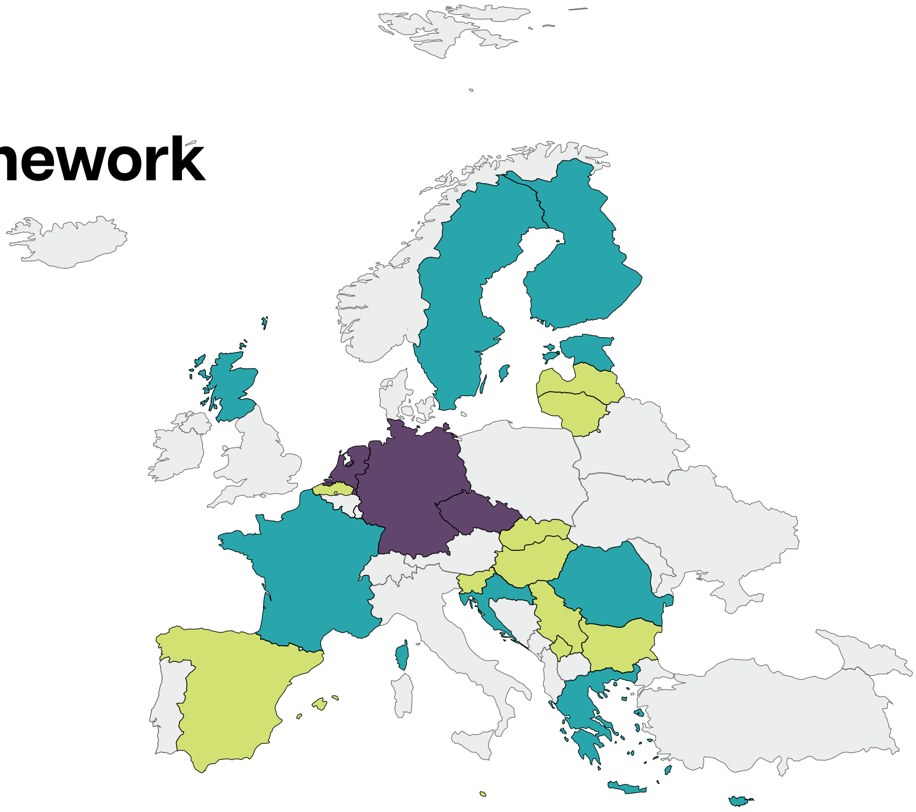
EPF looks forward to working with policymakers, healthcare professionals, researchers, regulators, and civil society partners to build a Europe that fully recognises the value of patient organisations and translates the principle of "nothing about us without us" into concrete and lasting policy action.

European countries: performance overview

Ranking per section

Section 2

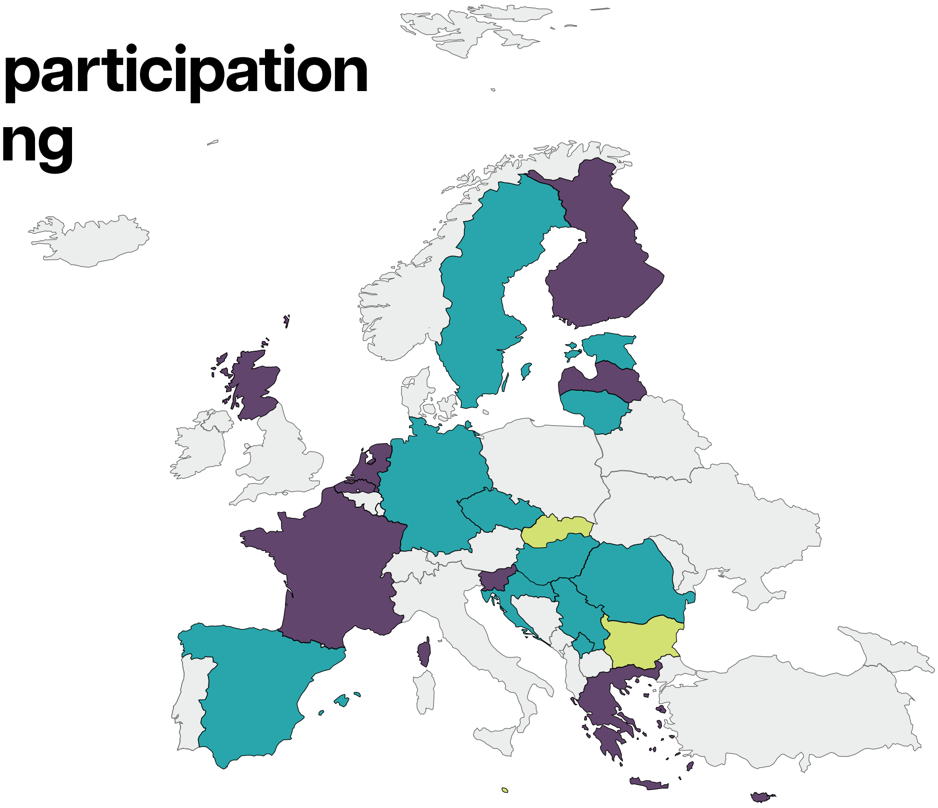
Institutional framework



🟪 Highest Overall Performance
🟦 Mid-Level Performance
🟨 Lower Overall Performance

Section 3

Mechanisms for participation in decision-making



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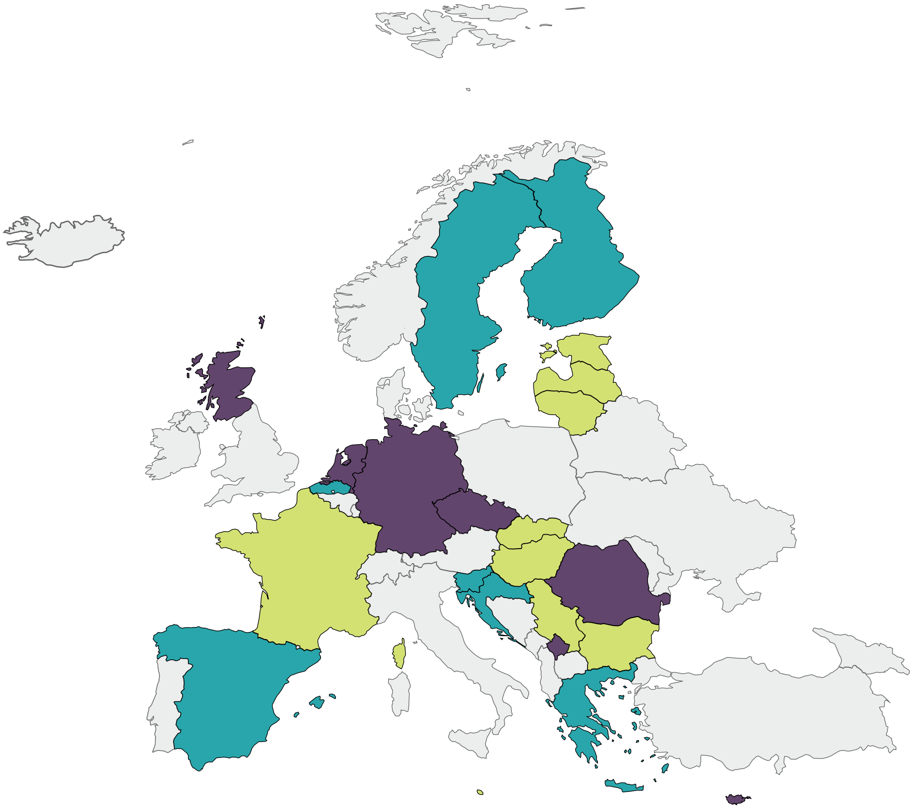
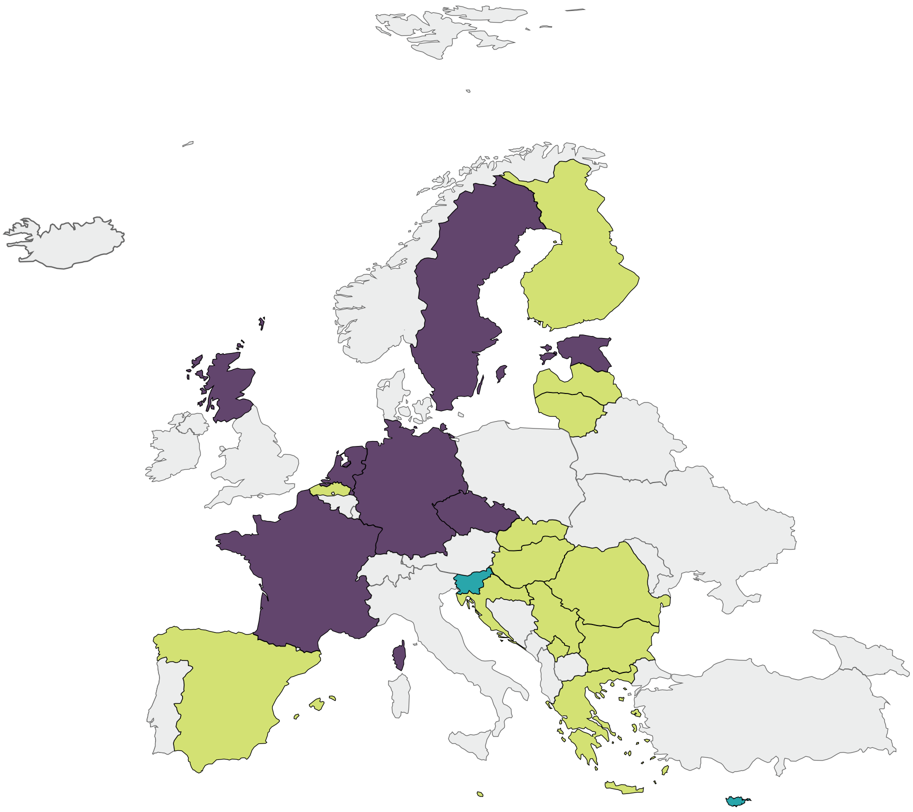
🟦 Mid-Level Performance
🟨 Lower Overall Performance

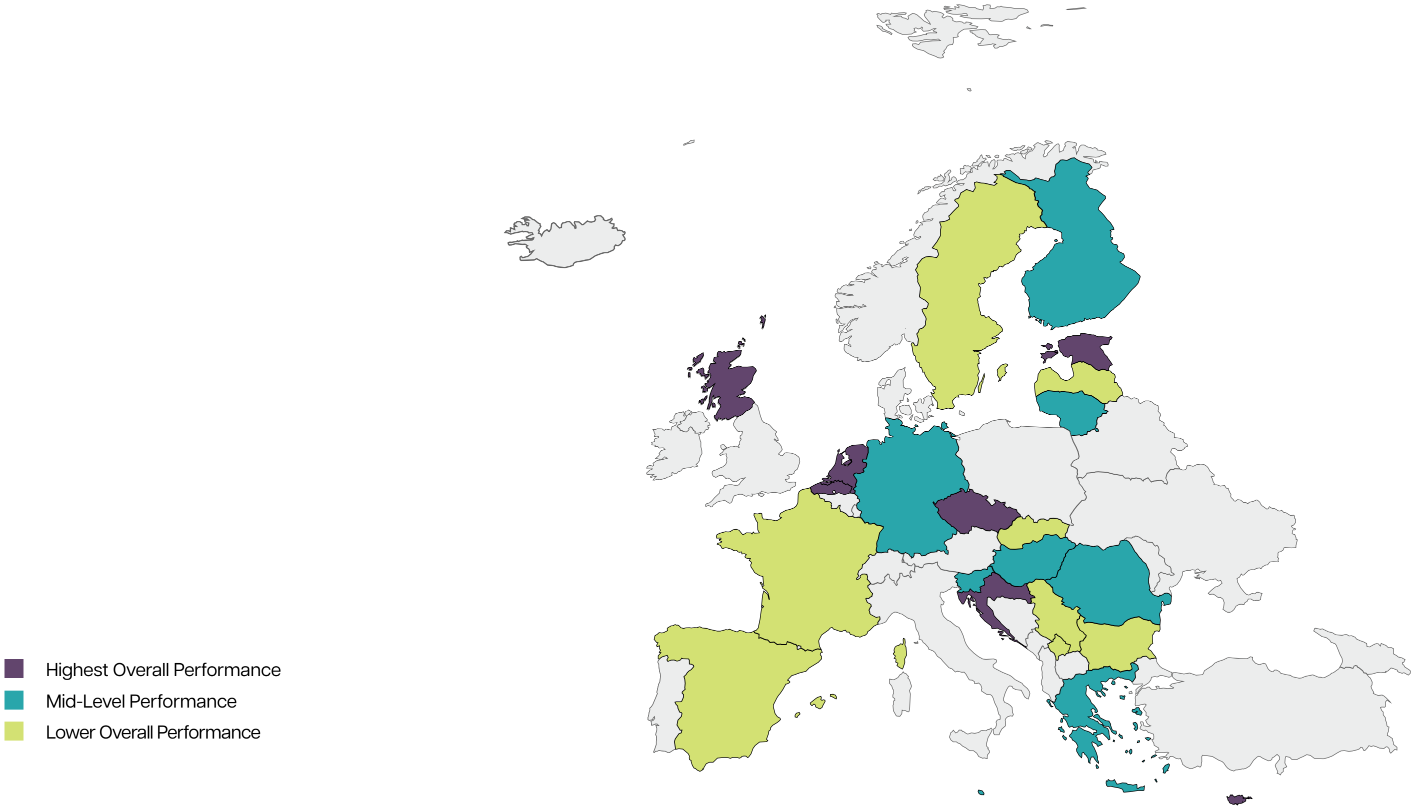
Section 4
Level of inclusion in decision-making



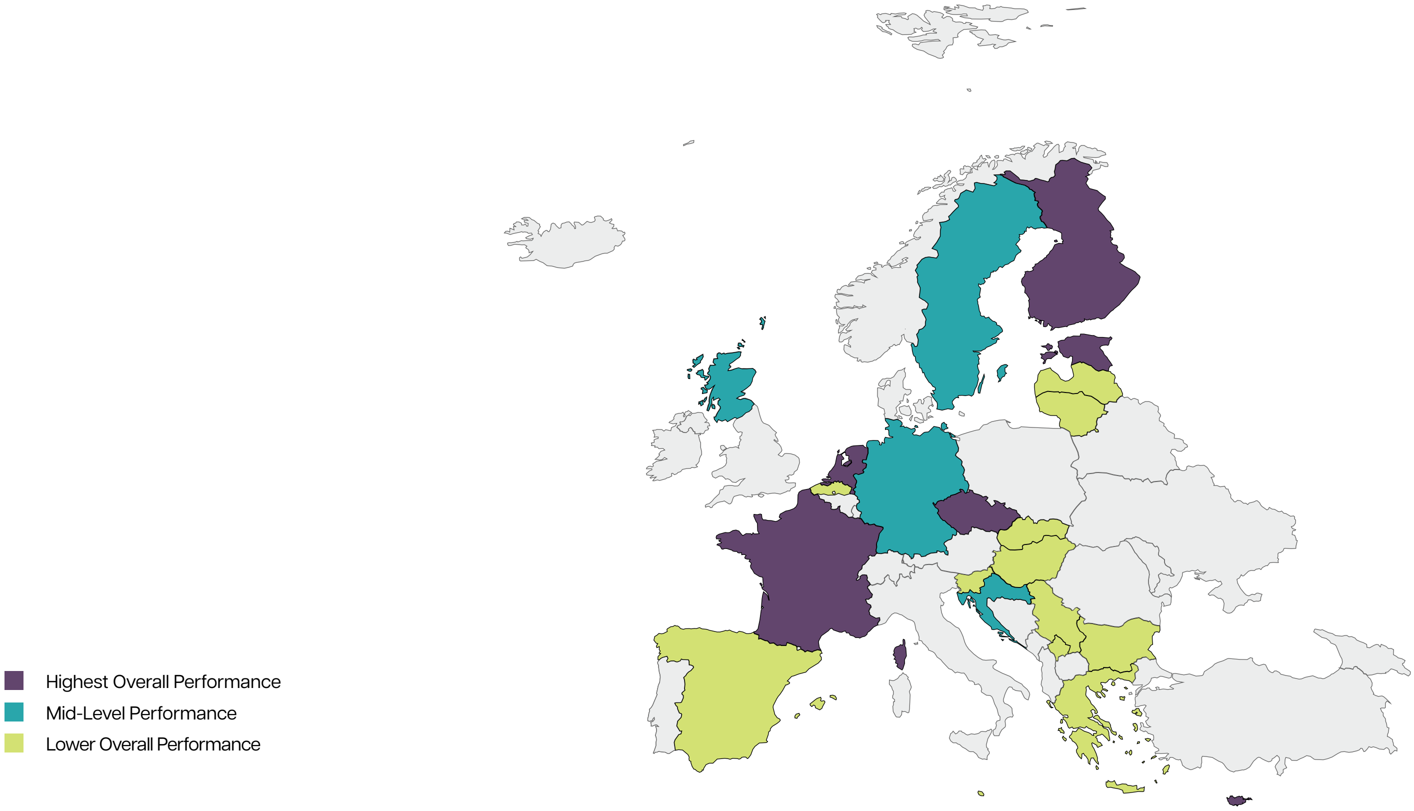
Section 5
Inclusion in health technology assessments (HTA) processes



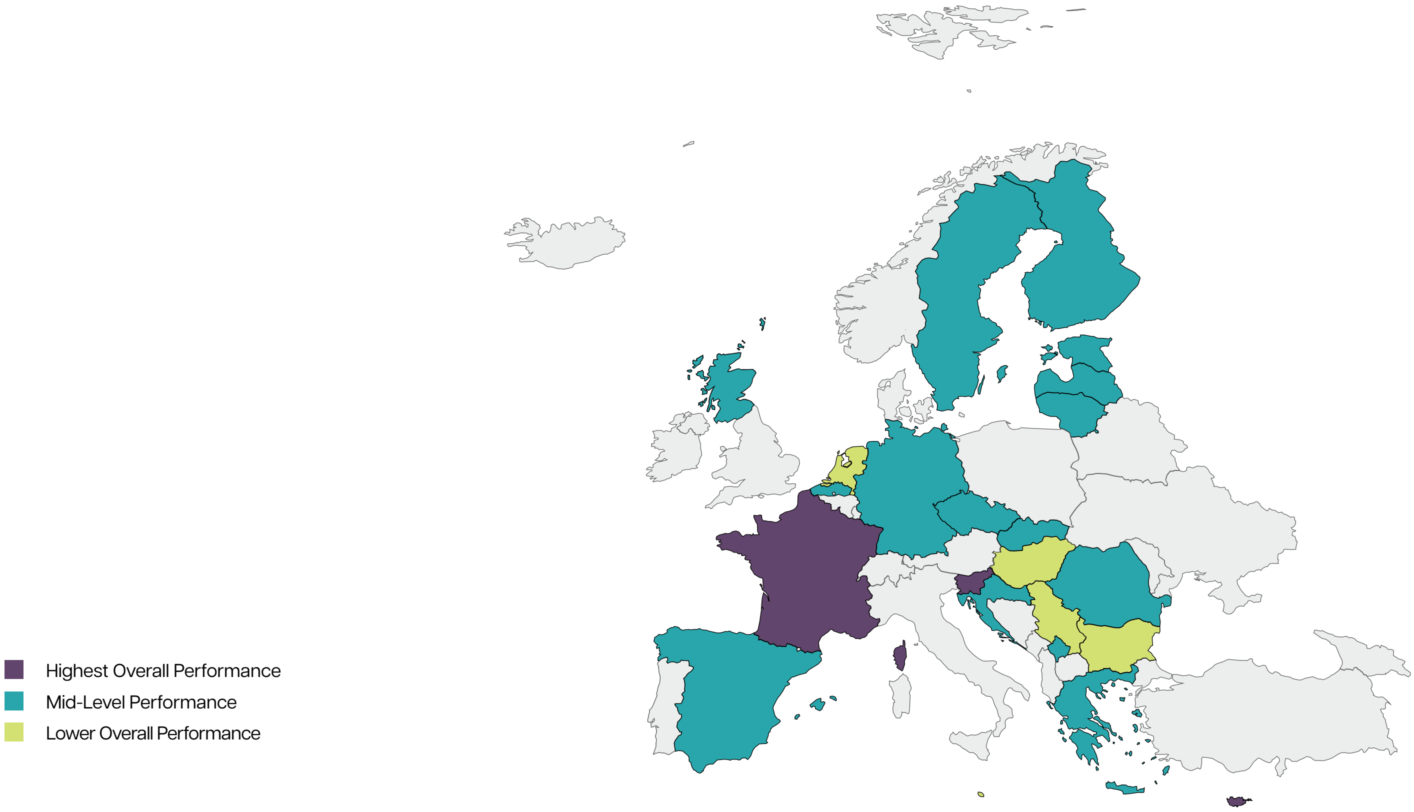
Section 7
Resources to support meaningful participation



Section 8
Financial support

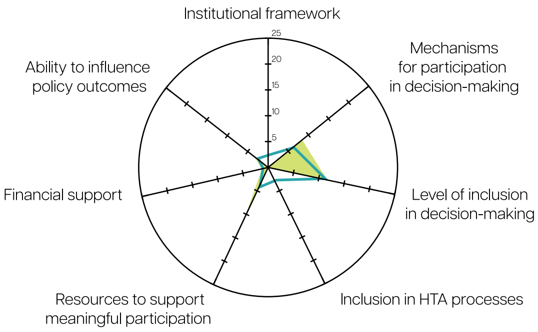


Section 9
Ability to influence policy outcomes



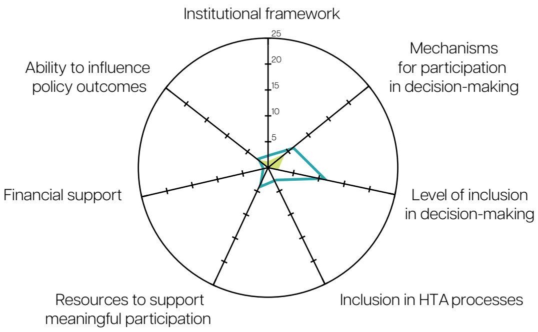
Radar chart per country

Flanders



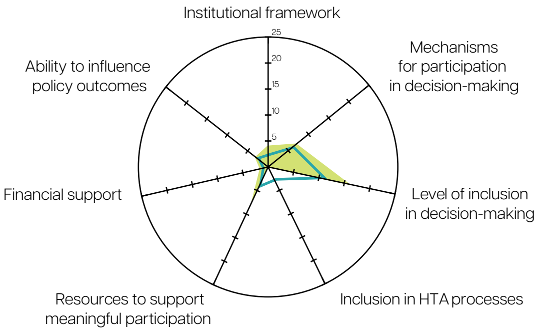
☐ Average
🟩 Flanders

Bulgaria



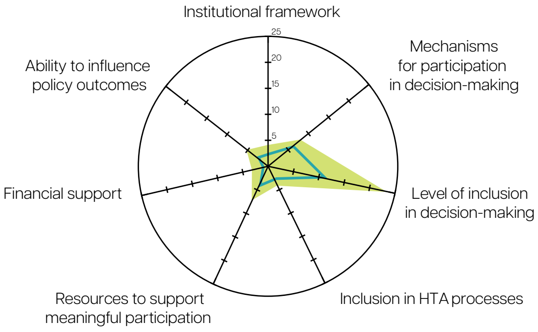
☐ Average
🟩 Bulgaria

Croatia



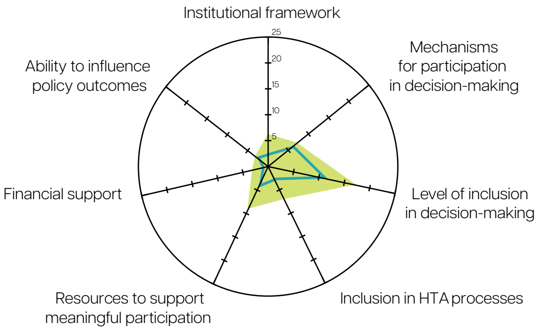
☐ Average
🟩 Croatia

Cyprus



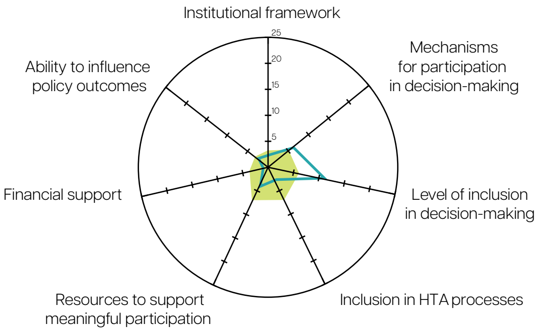
☐ Average
🟩 Cyprus

Czechia



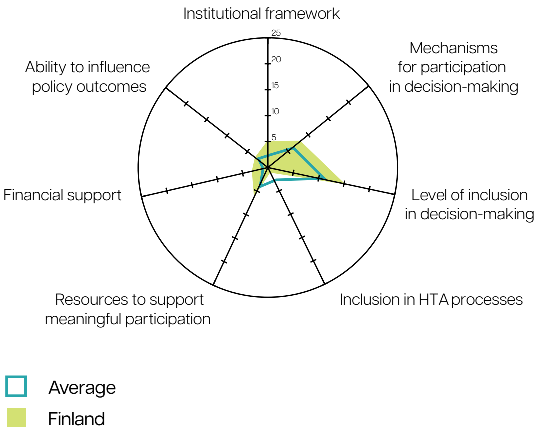
☐ Average
🟩 Czechia

Estonia

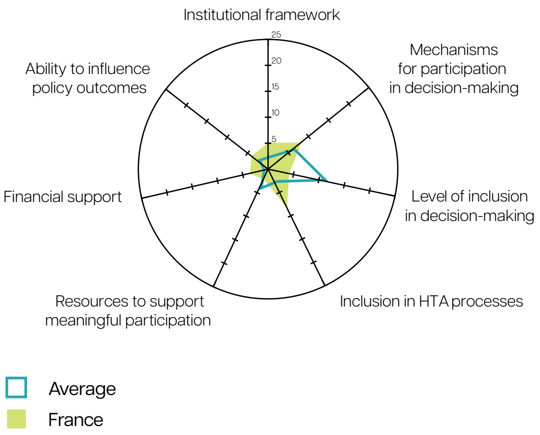


☐ Average
🟩 Estonia

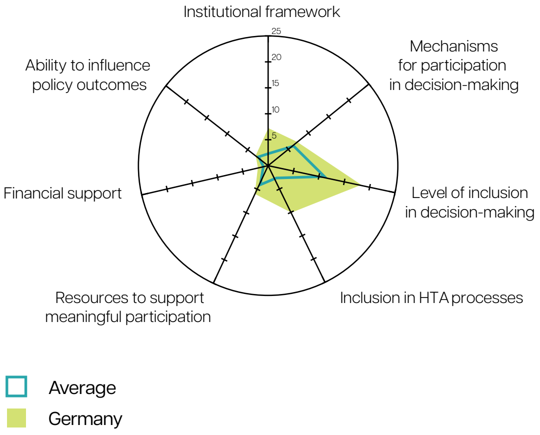
Finland



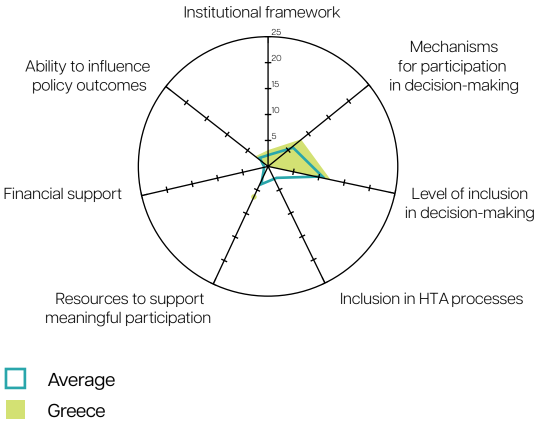
France



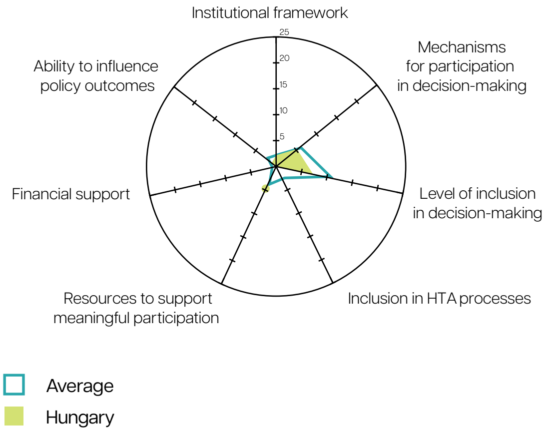
Germany



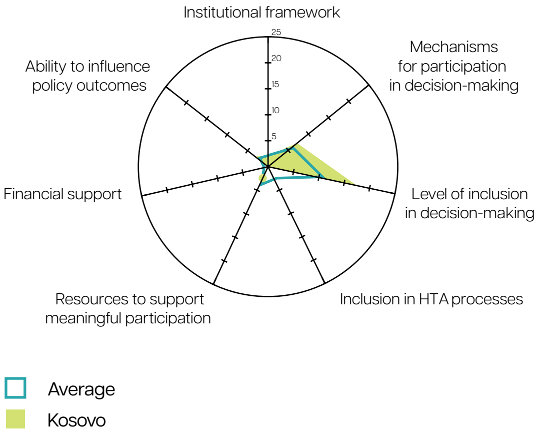
Greece



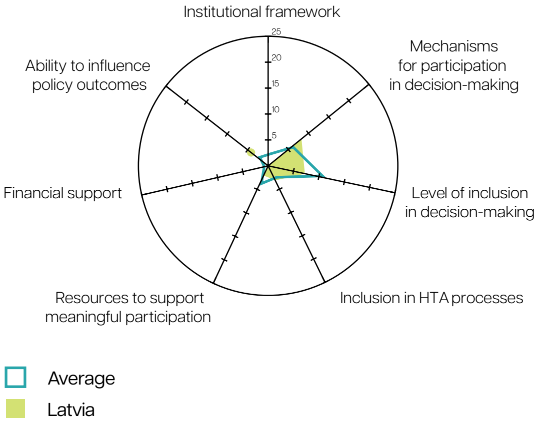
Hungary



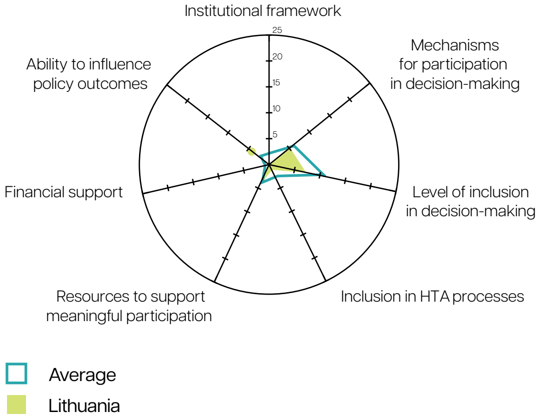
Kosovo



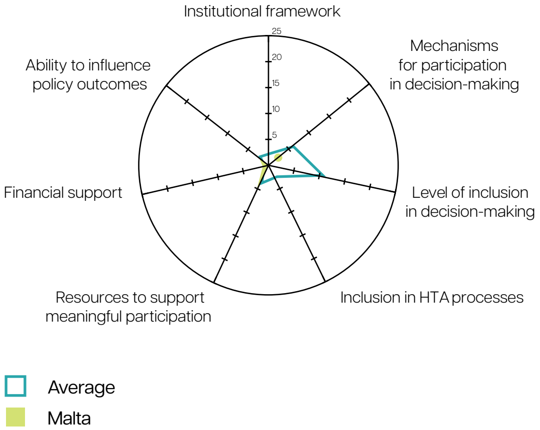
Latvia



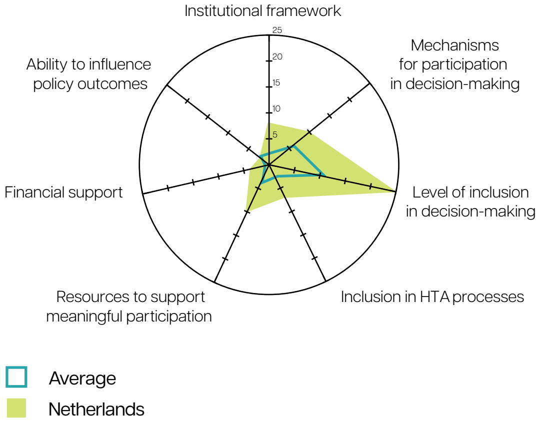
Lithuania



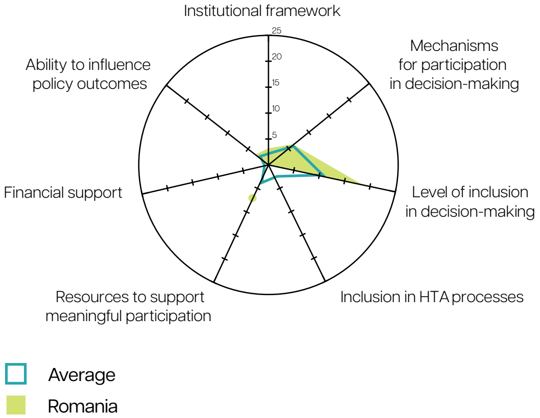
Malta



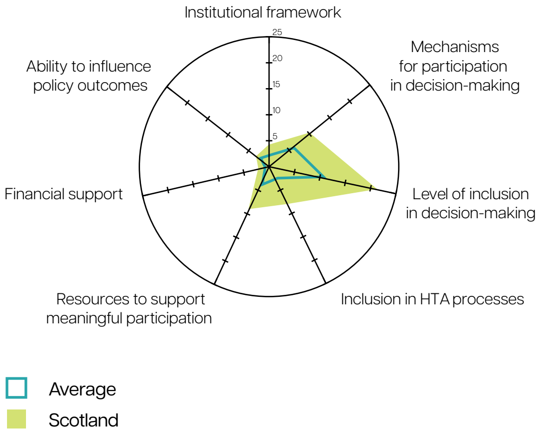
Netherlands



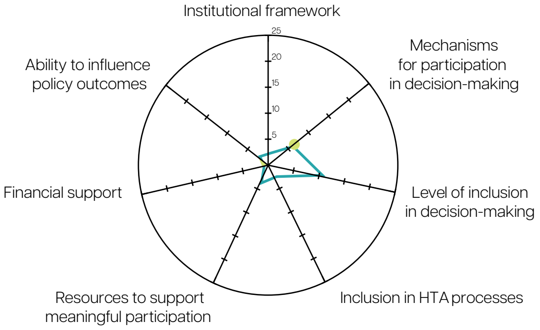
Romania



Scotland



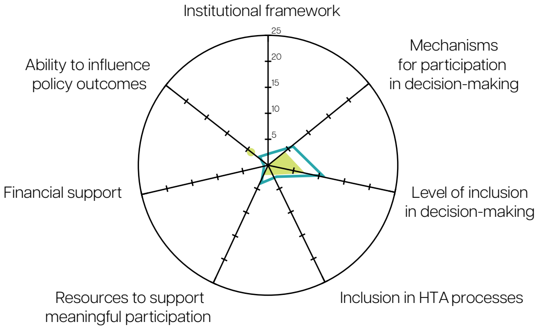
Serbia



☐ Average

🟩 Serbia

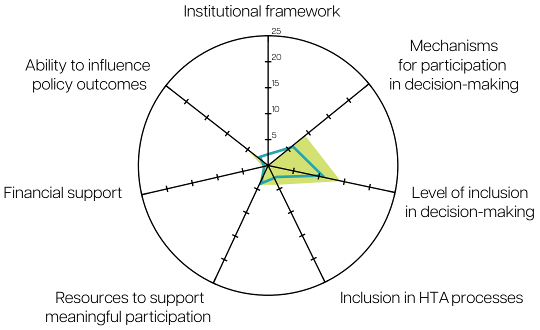
Slovakia



☐ Average

🟩 Slovakia

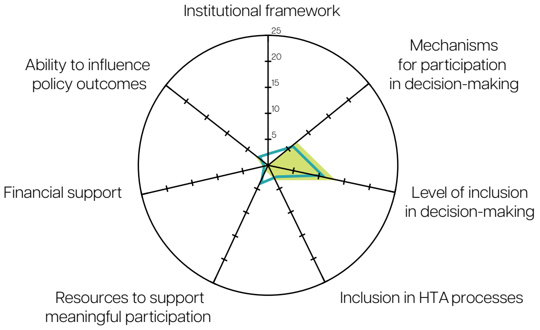
Slovenia



☐ Average

🟩 Slovenia

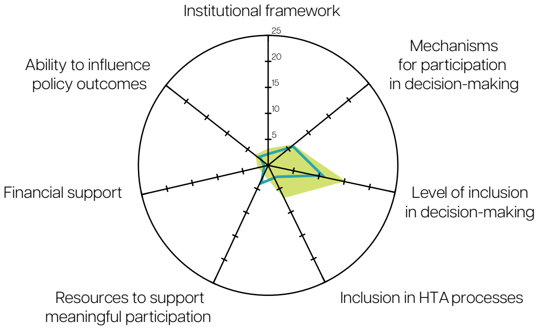
Spain



☐ Average

🟩 Spain

Sweden



☐ Average

🟩 Sweden

Thank you to all the 27 coalitions of patients organisations that contributed

AOPP – Association for the Protection of Patients' Rights (Slovakia)
BAG Selbsthilfe (Germany)
BAPD – Bulgarian Association for Patients' Defence (Bulgaria)
KZZ – Confederation of Heath Protection (Bulgaria)
COPAC – Coalition of Patients' Organisations with Chronic Diseases (Romania)
CyFPA – Cyprus Federation of Patients' Associations (Cyprus)
EPIK – Estonian Chamber of Disabled People (Estonia)
FEP – Spanish Patients' Forum (Spain)
France Assos Santé (France)
Greek Patients' Association (Greece)
HAPO (BEMOSZ) – Hungarian Alliance of Patient Organisations (Hungary)
KUZ – Coalition of Associations in Healthcare (Croatia)
LPOT – Latvian Network of Patient Organisations (Latvia)
LPOAT – Council of Representatives of Patients' Organisations of Lithuania (Lithuania)
MHN – Malta Health Network (Malta)
NAPO – National Association of Patients' Organisations (Czechia)
Netherlands Patients' Federation (Netherlands)
PRAK – Patients' Rights Association in Kosovo (Kosovo)
UPS – Patients' Association of Serbia (Serbia)
POP – Plataforma de Organizaciones de Pacientes (Spain)
Sjogren Europe
SOSTE – Finnish Federation for Social Affairs and Health (Finland)
SUSTENTO – Latvian Umbrella Body for Disability Organisations (Latvia)
Swedish Disability Rights Federation (Sweden)
The ALLIANCE – Health and Social Care Alliance Scotland (Scotland)
VPP – Flemish Patients' Platform (Flanders)
ZOPS – Association of Patient Organisations of Slovenia (Slovenia)