

EHN Patient Advocacy Handbook

Volume II

*Shaping Policy with Patients:
A Practical Guide for National
Heart Organisations*

2026



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Introduction

Policies with and for Patients: Why It Matters.

Across Europe and globally, the involvement of patients in policy and research has become increasingly recognised as essential for shaping effective health policies and practices. Integrating patients' perspectives into these processes not only values their lived experiences but significantly enhances the legitimacy, relevance, and impact of policy change efforts. Patient engagement ensures that health policies and research agendas are grounded in real-world needs and priorities, ultimately leading to better health outcomes and more sustainable health systems.

In the EU, this principle is well reflected in the European Medicines Agency's¹ institutionalised involvement of patients through the Patients' and Consumers' Working Party (PCWP) and other mechanisms that ensure patients are

consulted on matters related to their conditions, ranging from supporting scientific advice to contributing as advisors to medicine approvals and pharmacovigilance activities.² Initiatives such as the European Patients' Academy on Therapeutic Innovation (EUPATI)³ have also played a valuable role at European level by equipping patients with the knowledge and confidence to contribute meaningfully to medicines development and regulatory discussions. Together, these experiences illustrate the direction of travel towards a more participatory health policy and research environment.

Building on the foundations set out in the EHN Handbook Vol. 1, this handbook focuses on how patient organisations can translate those principles into effective policy and advocacy practice.

The evolving role of patients: from beneficiaries to co-advocates

The days when patients were seen solely as passive recipients of care are gradually giving way to a more inclusive approach. While the transition is still unfolding, there is growing recognition that “nothing for patients without the patients” should be the guiding principle in both policy and research. However, it is not enough to invite patients merely to participate in isolated activities or

to speak at events. For patient engagement to be meaningful and effective, patients should be involved at every stage of policy and research processes—from the earliest planning phases to execution and evaluation. This co-production approach ensures that advocacy efforts reflect patients' priorities and insights, ultimately leading to better outcomes for all.

¹ The European Medicines Agency is a regulatory body responsible for evaluating and supervising medicines in the European Union. It ensures that medicines are safe, effective, and of high quality before they can be marketed and used across EU member states. Read more at <https://www.ema.europa.eu/en/homepage>

² <https://www.ema.europa.eu/en/partners-networks/patients-consumers>

³ <https://eupati.eu/>

Why national heart organisations are well-placed to lead this shift

Many patients are ready and willing to share their stories and take action. Yet storytelling alone, while powerful, is insufficient. For patient-led engagement to drive real policy change, it requires structured channels through which patient voices can be organised, amplified, and connected to decision-making processes. National heart organisations are ideally positioned to lead this shift. They can:

- ✓ Provide platforms for patients to share their experiences with one another, fostering peer support and collective strength.
- ✓ Create strategic opportunities for patients to communicate their experiences to policymakers and the public.

- ✓ Help patients navigate complex national legislative landscapes.
- ✓ Identify key stakeholders and policy opportunities where patient voices can have the most impact.
- ✓ Train patient advocates and equip them with the tools and knowledge to convey powerful, actionable messages.

In short, national heart organisations can act as bridges between patients and policymakers, ensuring that patient-led engagement becomes an integral and influential part of the policy ecosystem.



EHN members at the European Heart Network Annual Workshop, Amsterdam, 2024.

Building on Handbook Vol. I

This handbook builds on the foundations laid out in the EHN Handbook Vol. I, which introduces the role of the patient advocate and encourages patients to share their stories as an entry point into engagement. The first volume is primarily directed at patients themselves. By contrast, the present volume shifts the focus to EHN member organisations, providing them with practical tools and frameworks to structure, sustain, and scale patient-centred policy. Its purpose is to help national heart organisations take the next step: moving from individual patient voices to collective, organised engagement strategies that can influence health policy and research agendas at both national and European levels.



Policy trends at the EU and global levels

At the time of writing, several key trends are shaping the policy landscape, particularly in areas such as research, artificial intelligence (AI), and data governance. While the specific policy environment will inevitably evolve, sustained engagement is expected around digitalisation and the ethical, practical use of AI in healthcare. The EU4Health Programme 2021–2027⁴, the EU's flagship health funding programme, includes support for initiatives in these areas. For example, one initiative supports leveraging AI and health data for cardiovascular health and related non-communicable diseases (NCDs) to improve risk prediction, personalised prevention, treatment and rehabilitation.

This represents a significant opportunity for national heart organisations to connect patient expertise with cutting-edge innovation and help ensure that data-driven health solutions are shaped by real-life patient priorities.



⁴ https://health.ec.europa.eu/funding/eu4health-programme-2021-2027-vision-healthier-european-union_en

These developments are critical not only because patients are the ultimate beneficiaries of technological progress, but also because data and digital tools are increasingly central to how health systems and research operate.

At the EU level, the publication of the **European Cardiovascular Health Plan** (*Safe Hearts Plan*) marks an important milestone for cardiovascular health policy across Europe. The Plan is expected to drive a range of programmes, initiatives and funding opportunities in the coming years, many of which will have significant implications at national level - particularly in supporting the development, implementation and updating of national cardiovascular health plans.

Patients must sit at the planning table, where priorities are set, safeguards are discussed, and outcomes are shaped.



EU Health Commissioner Olivér Várhegyi at the EACH Cardiovascular Health Summit, Brussels, 16 December 2025.

For national heart organisations, it is more important than ever to be strategically positioned and ready to engage with this evolving policy landscape. Proactive involvement will help ensure that patient perspectives are embedded throughout implementation and that national actions effectively address real-world needs.

More broadly, for national heart organisations to achieve lasting influence, patient engagement should not be seen merely as a reaction to individual policy windows.

Instead, it should be proactively and structurally integrated into engagement strategies, regardless of the immediate legislative agenda. Consistently involving patients in this way enhances credibility, builds relationships with policymakers, and ensures that when new opportunities arise, patient voices are already established as a trusted and indispensable part of the conversation.

Part 1: Laying the Groundwork

– Internal Roles, Structures & Resources

Before embarking on engagement activities that truly integrate patient voices, national organisations must first build a robust internal foundation. This begins with defining clear staff roles and responsibilities, continues through adapting those roles to the organisation's size and capacity, and is underpinned by a realistic budget and resource plan. By attending to these elements up front, organisations can shift from sporadic, ad-hoc campaigns to sustainable, strategic programmes that deliver measurable impact—even when operating with limited staff or financial resources.

1.1. RACI matrix: assigning responsibilities for engagement

A RACI matrix⁵ is an ideal tool for clarifying who does what and to what degree for each critical task in a patient-led engagement programme. The acronym stands for Responsible, Accountable, Consulted, and Informed, four categories that help prevent confusion and duplication of work.

The following page presents an illustrative RACI matrix. While each organisation will tailor roles and activities to its own context, this example demonstrates how tasks such as patient identification, training, campaign planning and delivery can be assigned across key staff and advisors to ensure clear responsibilities and effective coordination.

⁵ The RACI matrix is a widely used tool in project management and organisational design, created to clarify roles and responsibilities across complex tasks. The method emerged in the 1970s in the field of project management, gaining traction with the rise of structured methodologies like PMI's [Project Management Body of Knowledge \(PMBOK\)](#) and frameworks used in large corporate and IT projects. It has since been widely adopted in diverse sectors, including healthcare, non-profits, and government, because of its simplicity and adaptability.

Table 1: Illustrative RACI matrix for patient advocacy activities

Activity	Policy Manager	Patient Liaison Officer	Campaign Coordinator	Comms Lead	Finance	Policy Advisor	External Trainer
Patient identification & outreach	A	R	I	C	I	C	–
Training & capacity building	A	R	I	I	C	–	R
Campaign planning with patients	A	C	R	C	I	C	–
Campaign delivery & stakeholder engagement	A	C	I	R	I	C	–
Monitoring & evaluation	A	I	R	I	C	C	–

RACI key

A = Accountable · **R** = Responsible · **C** = Consulted · **I** = Informed

This matrix should serve as a living document. As the project's/campaign's programme evolves, the organisation should revisit and revise assignments to reflect new activities, emerging partnerships or shifting priorities.

**Tip!**

Begin with a streamlined grid, covering the five core tasks shown above, and expand only as necessary to avoid over-complexity.

Not all organisations, however, possess the same scale or capacity, so internal structures must flex accordingly:

Small organisations

It is common for one or two staff members to wear multiple hats. For example, a Policy Manager may also act as the Patient Liaison Officer, managing both stakeholder outreach and patient support. In such contexts, processes must be lean yet well documented, and voluntary networks or allied NGOs should be engaged strategically to supplement staff capacity. A single, streamlined RACI matrix that covers all critical activities will help prevent role confusion.



Medium organisations

At this level, organisations often formalise cross functional teams and establish patient panels with clear terms of reference. Here, distinct roles, such as a Campaign Coordinator and a Communications Lead, allow for better division of labour, while the RACI matrix ensures smooth handoffs between teams. Regularly scheduled panel meetings, combined with written guidelines on patient involvement, help to institutionalise patient engagement as part of the organisation's DNA.



Large organisations

These often have the advantage of dedicated units staffed by specialists in policy analysis, communications, and patient engagement. Formal, long-term partnerships with patient groups, academic institutions and other stakeholders can be codified through memoranda of understanding, ensuring continuity and shared ownership over time.



1.2. Budgeting and resource allocation

A credible patient led engagement programme is ideally backed by a transparent, responsive budget. As a starting guideline, organisations might allocate approximately 40 % of their policy budget to staff time and capacity building, 30 % to patient engagement activities (such as workshops, panel meetings and travel), 20 % to communications and campaign materials, and the remaining 10 % to monitoring, evaluation and a contingency reserve.

When involving patients directly, remuneration and expense reimbursement become critical. At minimum, all out-of-pocket costs—travel, accommodation and meals—should be covered.

Two common models are:

- **Daily allowances (per diem)**, These are standardised amounts allocated to cover daily expenses. While they may not always reflect the exact costs incurred by patients, they provide greater cost control for organisations, ensure consistency, and enhance transparency and fairness. For example, the EMA's reimbursement rules⁶ provide a per diem rate covering these costs for delegates attending meetings; and
- **Invoice based reimbursement**, which reimburses real expenses against receipts but requires additional finance team capacity for document review. The European Patients' Forum (EPF) outlines such procedures in its travel and reimbursement policy⁷, emphasising reasonable costs and itemised receipts—with limits on expenses that exceed standard thresholds.

Quarterly budget reviews will ensure that allocations remain aligned with actual spending and evolving strategic priorities.

Beyond financial costs, organisations should actively seek in-kind contributions—for example, venues provided pro bono or assistance from interns and volunteers for logistics. Particularly in smaller organisations, volunteers can play an essential role in extending capacity and reducing costs. Volunteers may assist with administrative tasks such as preparing materials for meetings, maintaining databases of stakeholders and policymakers contacts, or managing event logistics. They can also contribute valuable skills in areas like graphic design, social media management, or translation, providing professional-level services that might otherwise be unaffordable for the organisation.

⁶ https://www.ema.europa.eu/en/documents/other/rules-reimbursement-expenses-delegates-attending-meetings-effect-17-march-2023_en.pdf

⁷ https://www.eu-patient.eu/globalassets/events/2019/epf_travel_and_reimbursement_policy_2019.pdf

Moreover, involving volunteers who have personal connections to cardiovascular health—whether as patients, carers, or family members—can bring additional authenticity and insight to policy work.

These individuals often possess strong motivation to contribute and may serve as powerful advocates themselves, helping to

amplify messages within local communities or online networks. For smaller organisations, strategically integrating volunteers into engagement activities allows staff to focus on core responsibilities, ensures continuity when resources are stretched, and helps build a committed network of supporters invested in the organisation's mission.



The German Heart Foundation's biennial volunteer meeting, Frankfurt, 2025.

© German Heart Foundation (DHS) / Andreas Malkmus

Investing in volunteers

helps build organisational capacity and sustain long-term advocacy efforts.

However, to fully benefit from volunteer support, it is important to provide clear guidance, appropriate training, and recognition for their contributions. Even informal volunteer roles should be accompanied by defined tasks, timelines, and supervision to maintain quality and consistency in engagement efforts.

Part 2: Meaningful Patient Engagement in Policy

2.1 Identifying, selecting, and preparing patient partners

An effective patient-led engagement programme begins with careful identification and selection of patient contributors. There is no single “ideal” patient partner; rather, a diversity of profiles can enrich policy work. One important group comprises patients who have lived experience with specific cardiovascular conditions or unique personal journeys—such as individuals affected by heart failure, stroke, or cases of misdiagnosis or mistreatment. These contributors bring authentic, firsthand insights into the challenges faced by people living with cardiovascular disease, grounding policy messages in reality.

Another valuable category includes so-called “community connectors”—individuals who are not only patients themselves but who are also integrated into broader networks, either as healthcare professionals, caregivers, or leaders of patient communities. Their dual perspective allows them to bridge individual experiences with wider community concerns, making them particularly effective in shaping policy recommendations that reflect broader patient needs.



Patient advocates and researchers at the EHN Patient Workshop in the European Parliament, Brussels, 2026.

Equally important are patients who possess policy-related skills, such as familiarity with legislative processes, public speaking, or experience working within organisations. While such skills are undoubtedly beneficial, they should not be viewed as fundamental prerequisites for participation. Communication and policy literacy are skills that can be nurtured and acquired over time. In fact, some individuals who initially appear highly confident may require greater guidance to align their contributions with organisational priorities, particularly if they arrive with strong pre-existing views or engagement styles that differ from the organisation's approach.

It is also essential to distinguish between good public speakers and those who can provide deep, substantive contributions. Storytelling is undeniably a crucial skill; however, it is equally important to ensure that patient stories go beyond personal narrative to deliver insights that are relevant and valuable to the policy objectives at hand. The aim is to balance compelling storytelling with contributions that help shape evidence-based policy messages.



Patient advocates at the EHN Patient Workshop in the European Parliament, Brussels, 2026.

**Every patient
brings a unique
perspective.**

**Together,
those perspectives
shape stronger policy.**

To identify suitable patient partners, organisations can employ several practical recruitment methods. These include:

- Outreach through patient associations or support groups, who may be able to recommend individuals already active or interested in policy;
- Invitations on organisational websites and social media channels, describing opportunities for involvement and how patients can express interest;
- Referrals from healthcare professionals, who may know patients willing and able to share their experiences constructively;
- Targeted calls for participation issued during events, webinars, or newsletters; and
- Snowball recruitment, whereby existing patient partners recommend others who might be interested.

Once potential contributors are identified, it is helpful to apply a few simple selection criteria to ensure a good fit for engagement roles. Suitable candidates should ideally:

- Feel comfortable sharing aspects of their personal health journey publicly, while recognising that they retain the right to set boundaries;
- Demonstrate an ability to listen and engage respectfully with different perspectives;
- Show interest in learning about policy processes and the broader issues affecting cardiovascular health;
- Be reliable and able to commit time as agreed for preparation and participation in engagement activities;
- Be willing to collaborate as part of a team and align their contributions with organisational objectives; and
- Ideally, have at least a basic working knowledge of the English language, which can be a significant advantage for participating in cross-country discussions, EU-level activities, and collaborations with European institutions and networks.

These criteria should be communicated clearly during the recruitment process, so patients can self-assess their readiness and interest. Openness and transparency help manage expectations and lay the groundwork for positive, long-term partnerships.

Conflict of interest

In addition to alignment of values and capacity, organisations may wish to perform basic background checks to identify potential conflicts of interest that could undermine the credibility or independence of patient representatives. For example, patients who hold shares in pharmaceutical companies or have ongoing consultancy agreements with industry actors may have competing interests that should be transparently managed or may disqualify them from certain roles.

The EMA, for instance, applies a strict policy for managing conflicts of interest among scientific committee members and experts. Under its Policy 0044,⁸ the EMA may restrict or exclude participation in specific activities based on declared ties to the pharmaceutical or medical device industry.

The World Health Organization (WHO) has also taken a leading role in setting expectations for conflict-of-interest management, particularly through its Framework for Engagement with Non-State Actors (FENSA).⁹ FENSA emphasises transparency, due diligence, and proportional risk assessment—mandating that any engagement with external actors, including patient representatives, be preceded by a clear understanding of their interests, affiliations, and potential risks.

While national or civil society organisations may choose to apply more flexible standards in their own work, it is important to be aware that patients selected to engage in EMA-related processes must comply fully with this policy and that, wherever possible, WHO-aligned principles of due diligence and risk management should guide decision-making even in broader contexts.

Beyond regulatory compliance, reputational considerations are also relevant. Inviting a patient to speak at a public event or represent the organisation in a high-profile setting while having undeclared financial ties to industry may raise concerns about bias and compromise the perceived legitimacy of their input. To protect both the patient and the organisation, establishing a simple but robust disclosure process and offering guidance on transparency expectations is an advisable step in formalising patient engagement.

⁸ https://www.ema.europa.eu/en/documents/other/policy-44-european-medicines-agency-policy-handling-competing-interests-scientific-committees-members-experts_en.pdf

⁹ <https://www.who.int/about/collaboration/non-state-actors>

2.2 Training, briefing, and supporting patient contributors

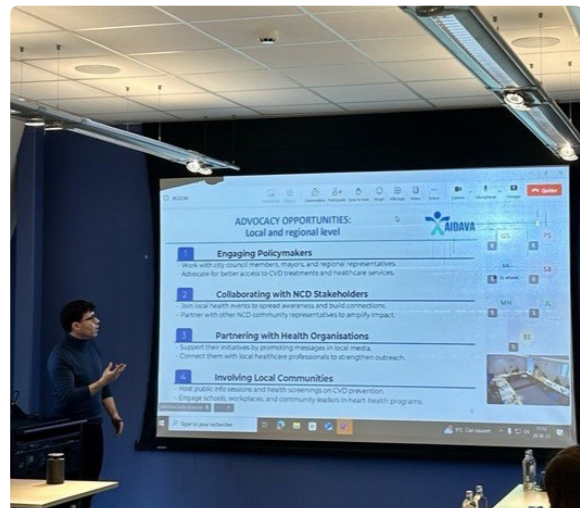
Empowering patients to participate meaningfully in policy shaping requires well-structured training and sustained support. Patient contributors must understand not only the health issues affecting cardiovascular care but also how policymaking works at the national level, and how their personal experiences can be channelled effectively into engagement efforts.

For most national heart organisations, engagement begins first and foremost within their own countries or even regions/communities. It is important that patient partners develop a basic understanding of how national and regional politics and policy processes work—including how laws are proposed and passed, the roles of government ministries and parliamentary committees, and where opportunities arise for public consultation or input.

Beyond national processes, many issues relevant to cardiovascular health are increasingly shaped at the EU level. Regulations, directives, research funding, and digital health initiatives often originate in EU institutions but ultimately require implementation and adaptation at national level. Therefore, training should help patients appreciate the nexus between national and EU policymaking—how decisions and priorities flow between these levels, and how engagement at one level can influence or reinforce efforts at the other. Without this understanding, patient advocates may struggle to identify the most strategic moments or venues to voice their concerns or ideas.

Patient advocates do not need to be experts in politics or law, but they should aim to grasp the main steps of the policy-making process and, most importantly, be able to recognise the key moments when patient voices can be invited or included—such as public hearings, stakeholder consultations, or comment periods on new legislation and other non-binding EU instruments.

Understanding who the key stakeholders are—such as health ministries, regulatory agencies, or patient ombudspersons—also helps advocates identify where their involvement can have the greatest impact.



Gregorio Sambataro, EHN Project Manager, leading a session at the EHN co-hosted patient workshop as part of the AIDAVA project, Brussels, 2025.

To equip patient contributors for these complex environments, organisations should combine written materials with interactive learning opportunities. Some foundational knowledge can be provided through ready-made training materials shared with newly recruited patient partners. These resources might include:

- **Visual overviews of national/regional policymaking**, explaining legislative processes, the roles of ministries and parliaments, and the ways civil society can engage;
- **Introductions to EU-level policymaking**, highlighting relevant institutions such as the European Commission, the European Parliament, the European Council and the Council of the European Union, as well as agencies like the European Medicines Agency, while explaining how EU decisions impact national policies.
- **Introduction to WHO-Europe**, where health ministries in Europe join for common projects, initiatives and where patient input from national/regional level can be filtered in through the above-mentioned link to ministries and policymakers.
- **Glossaries of key terms and acronyms**, to help patients navigate technical language and policy documents; and
- **Guiding principles of the organisation's policy work**, which should be firmly grounded in EHN's core values, including equity, transparency, independence, integrity, solidarity, sustainability, and accountability. These principles establish clear boundaries and expectations for collaboration and ensure that patient contributors understand the framework within which their input will be used. Confidentiality, respect for internal processes, and responsible sharing of information are essential. These guiding principles should always be documented in writing and countersigned by the patient contributor, to ensure mutual understanding and to protect both the organisation and the patient from potential conflicts or reputational risks.

However, some skills and knowledge are best developed through dedicated workshops and practical exercises. Storytelling particularly is a skill that benefits from interactive training, where patients can practice shaping their personal narratives into impactful policy messages. Workshops can help patient contributors move beyond simply telling their stories, teaching them to connect personal experiences with broader policy gaps or reforms.

Organisations may choose to hire external trainers to develop and deliver these sessions, especially when staff capacity is limited or when specific expertise is required. External trainers can bring professional facilitation skills and fresh perspectives, but outsourcing also comes with challenges. It can be costly, and if not carefully managed, it may limit the organisation's oversight over the content and approach used in the training.

To mitigate this, organisations should provide clear instructions and collaborate closely with external trainers to ensure training aligns with their strategic goals and values.



Participants at the European Heart Network's (EHN) inaugural Patient Advocacy Workshop in Brussels, December 2024.

Beyond initial training, ongoing support for patient contributors is crucial. Organisations should offer:

- **Regular briefing sessions** ahead of key meetings, consultations, or events, to ensure patients feel prepared and clear about their roles and messages;
- **Technical support**, such as assistance in reading complex documents, understanding meeting agendas, or crafting public statements;
- **Peer support networks**, giving patients opportunities to connect, share challenges, and offer mutual encouragement; and
- **Recognition and appreciation for patients' contributions**, whether through formal acknowledgements, certificates, or public thanks, which helps sustain engagement and motivation.

2.3 Formalise Collaborations: a Few Resources

Memoranda of Understanding (MoUs) and Terms of Reference (ToR)

Involving patients meaningfully requires not only goodwill but also clarity and transparency. To this end, written agreements such as MoUs and ToR are valuable tools.

- **Terms of Reference (ToR)** are useful for short-term collaborations or advisory roles (e.g. participation in a task force, working group, or single event). They set out the purpose, scope, roles, expected time commitment, and deliverables in simple terms.
- **Memoranda of Understanding (MoUs)** are more suitable for longer-term or project-based collaborations. They outline the background, aims, outcomes sought, mutual responsibilities, compensation arrangements, and procedures for amendments or termination.

Practical guidance

- Keep documents short, clear, and accessible.
- Use plain language rather than legal jargon.
- Include placeholders that can be tailored to the activity, project, or partnership.
- Annexes can provide simple forms for consent, payment requests, or data protection.

Examples: Templates of both a ToR and an MoU are provided in **Annex IV** and **Annex V** respectively. These can be adapted by national heart organisations and patient groups to fit their own contexts.

Data Protection and Consent Forms

Involving patients in policy and research inevitably requires the collection and use of personal information, ranging from contact details to sensitive health data. To ensure compliance with legal obligations (such as the EU General Data Protection Regulation, GDPR)¹⁰ and to protect the trust and dignity of patient partners, organisations should establish clear protocols for data protection and informed consent.



A consent form, either integrated into the patient involvement questionnaire or kept as a standalone document for easier archiving, should cover the following elements:

- **Purpose of data collection:** Clearly explain why information is being collected (e.g. to identify suitable opportunities for involvement, facilitate communication, support organisational policy goals, or contribute to EU-funded research projects). The purpose must be explicit, legitimate, and transparent to the patient.
- **Types of activities:** Offer patients the possibility to indicate which kinds of activities they wish to be considered for (e.g. research projects, policy consultations, policy campaigns, EMA-related work). This supports autonomy and prevents overreach.
- **Personal details and minimisation:** Collect only what is strictly necessary (e.g. name, email, country of residence, relevant cardiovascular condition, affiliation with a national member organisation). Avoid collecting sensitive data unless indispensable for the activity.
- **Confidentiality and security:** Assure patients that their personal and health data will be treated confidentially. Information will be stored securely (e.g. password-protected databases, restricted access for authorised staff only) and shared externally only with explicit, case-by-case consent.
- **Data storage and retention:** Specify how long data will be stored (e.g. reviewed every three years, deleted if no longer needed) and how it will be securely disposed of. Consider documenting retention and deletion schedules.

¹⁰ <https://eur-lex.europa.eu/eli/reg/2016/679/oj/eng>

- **Patient rights: Inform patients of their GDPR rights, including the right to:**
 - access their data,
 - request correction or deletion,
 - restrict or object to processing,
 - request portability of their data.
- **A clear contact person** (e.g. EHN Patients & Research Manager) should be identified for exercising these rights.
- **Conflict of interest:** Include a simple disclosure mechanism for financial or institutional ties that may be relevant, in line with EMA Policy 0044 and EHN's internal rules.
- **Signatures:** Include a section where both the patient consultant and a representative of the organisation sign and date the form, ensuring mutual understanding and accountability.

Using a structured form like **EHN's Patient Network Consent Form** (see **Annex III**) provides both patients and organisations with clarity and accountability. It also strengthens the organisation's ability to manage data responsibly while safeguarding against reputational or legal risks.

Recommendation

To streamline practice, organisations may choose to keep the consent form separate from the involvement questionnaire for easier archiving and auditing. However, integrating the two can reduce paperwork if the volume of data is low. The key principle is transparency: patients should always understand what they are consenting to and have an easy mechanism in place to withdraw their consent at any time.



2.4 Levels of involvement: inform, consult, co-create, co-lead

In order to match each patient contributor's commitment to the demands of engagement activities, it is essential first to ask prospective partners to declare their expected time availability. By doing so, organisations can tailor roles that respect participants' schedules and ensure that each person's contribution is both feasible and fulfilling.

Below is an overview of how declared availability maps onto levels of engagement. Use this matrix to guide discussions with prospective patient partners and ensure roles align with both their capacity and your programme's needs.

Table 2: Illustrative framework linking patient availability to levels of involvement

Availability Bracket	Time Commitment	Level of Involvement	Typical Activities
Occasional Contributors	Up to 2 hours per month	Inform	Receive monthly or quarterly policy updates; subscribe to brief e newsletters; join a messaging group to observe developments without active tasks.
Advisory Contributors	½–1 day per month	Consult	Provide targeted feedback on draft materials; participate in occasional focus groups or one-off online consultations; complete short surveys.
Collaborative Contributors	2–4 days per month	Co Create	Attend planning meetings; help draft sections of position papers or briefing notes; join workshop style sessions (e.g., storytelling exercises); review materials.
Leadership Contributors	≥2 days per week	Co Lead	Chair working groups or steering committees; share strategic decision making; represent the organisation at high level forums; mentor newer patient partners.

EHN recommends using this matrix as a starting point when recruiting and onboarding patient contributors. During initial conversations, ask candidates to select the bracket that best matches their expected availability, then outline the associated responsibilities. Revisit these commitments regularly, at least once per quarter, to adjust roles as patients' circumstances or interests evolve.

2.5 Ensuring diversity, equity, and accessibility

To create patient engagement that is truly representative and fair, organisations must prioritise diversity, equity, and accessibility in their recruitment and support of patient contributors. This includes actively seeking patient partners from different age groups, genders, socioeconomic backgrounds, ethnicities, and geographic regions, as well as individuals with varying degrees of digital health literacy and access.

Organisations should create flexible roles to accommodate diverse forms of participation. Some patients may prefer to contribute via online feedback surveys, while others may wish to attend local in-person events or participate in small group meetings. Offering multiple engagement options reduces barriers and makes it easier for patients with different life circumstances, health statuses, or logistical constraints to contribute meaningfully.

Accessibility considerations should extend beyond physical access to venues. Materials should be written in clear, jargon-free language, and translated into relevant languages where possible. Digital engagement platforms should be user-friendly and, where necessary, supported by training or one-to-one assistance to ensure patients can participate fully.

2.6 Bridging patient engagement across policy and research

Patient voices are indispensable not only for shaping health policy but also for guiding the design, implementation and evaluation of research. The European Heart Network has collaborated for several years with its member organisations to ensure that Patient and Public Involvement (PPI) is embedded within EU-funded research projects. From the earliest stages of grant applications to the planning of study protocols, patients bring real-life experience that can refine research questions, highlight practical considerations and improve the relevance and uptake of study outcomes.

Importantly, this principle of meaningful involvement also extends to organisations that finance research directly—through scholarships, grant schemes or project funding. Even where members are not conducting the research themselves, they should ensure that the funding they provide supports projects that reflect patients' lived needs. For national heart organisations, this is particularly feasible, as they often design their own calls for projects, thereby having the power to shape the focus, criteria, and priorities from the outset. It is crucial that patient partners are involved in the design of the calls themselves. Patients can review applications or project proposals not only to assess their real-world relevance but also to offer critical insights into how projects could be improved. Too often, research priorities are driven by scientific trends or the development of novel molecules while overlooking pressing questions tied to day-to-day patient experiences.

**Meaningful
research
begins with
meaningful patient
involvement.**

Engaging patients early allows funders to avoid investing in projects that may be scientifically ambitious but disconnected from the community's most urgent concerns.

Integrating PPI into research begins with including patient representatives as co-applicants on grant proposals. When patients help draft the objectives and methods, they can ensure that projects focus on issues of greatest importance to those living with cardiovascular disease—whether that means prioritising quality-of-life metrics, real-world adherence challenges, or the acceptability of intervention designs. Once projects are underway, patient partners can serve on steering committees, review patient-facing materials for clarity and accessibility, and advise on recruitment strategies to reach under-represented groups. Their input helps researchers anticipate and overcome barriers that might otherwise delay or derail studies.



Project partners and patient consultants at the annual meeting of the EU-funded HYPERMARKER project, University of Birmingham, May 2025.

EHN's collaboration with the EMA further exemplifies the intersection of policy and research. Through EMA's Patients' and Consumers' Working Party (PCWP) and other consultation mechanisms, patient contributors provide scientific advice on medical products and participate in pharmacovigilance activities. Their familiarity with daily life under cardiovascular treatment enables them to spot safety signals or usability issues in medicine information that might escape the attention of experts whose perspective is primarily technical. By incorporating patient feedback into regulatory advice and safety monitoring, EHN helps to ensure that research outputs and regulatory decisions genuinely address patients' needs and concerns.



EUROPEAN MEDICINES AGENCY
SCIENCE MEDICINES HEALTH

The expertise required for these activities is not necessarily deep scientific training but rather an intimate understanding of living with cardiovascular disease. Patients' experiences of navigating complex treatment regimens, communicating with healthcare professionals and managing side effects offer unique insights into the practical implications of research protocols and regulatory guidance. Particularly, patient partners excel at reviewing lay-language summaries of trial results, consent forms and safety notices, ensuring that these documents are comprehensible and trustworthy. By bridging policy and research in this way, national heart organisations can foster a more patient-centred ecosystem—one in which policies, clinical studies and regulatory decisions all benefit from the vital perspective of those they are ultimately designed to serve.

Patients bring expertise that clinical data alone cannot provide.



Representatives of the EMA Patients' and Consumers' Working Party (PCWP) at its 20th anniversary celebration, Amsterdam, 2026.

Table 3: Examples of patient involvement across research activities

Activity	Type of Patient Involvement
Trialling medical apps & data repositories	Patients directly use the app or portal in a pilot phase and provide structured feedback on usability, functionality and relevance of data presentation.
Scientific advice procedure	Patients review draft briefing documents, flagging unclear language or missing real-world considerations.
Pharmacovigilance	Patients share firsthand experiences of side effects and treatment barriers, helping to identify emerging safety signals.
Research protocol design	Patient partners co-draft research questions, suggest outcome measures meaningful to daily life, and advise on recruitment strategies for diverse populations.
Reviewing funded project proposals	Patients assess applications for funding or scholarships to evaluate their relevance and propose improvements based on lived needs and overlooked priorities.

Note: The European Medicines Agency (EMA) offers training programmes for patient representatives, equipping them with the knowledge and skills needed to participate effectively in scientific advice procedures, pharmacovigilance activities and other research-related activities. If your organisation is interested in these opportunities, please contact the EHN Secretariat.

Practical Tips for Integrating PPI into Research Funding Calls

Integrating PPI into funding mechanisms is not only feasible—it adds significant value. Patient input strengthens project relevance, helps ensure public accountability, and increases the likelihood that research will translate into meaningful improvements in care and outcomes.

Here are key ways to embed PPI into the structure of your funding programmes:

1

Include PPI as a Formal Criterion in Evaluation

- Requirement: Make patient involvement a scored criterion in project evaluation forms.
- What to assess: Does the proposal include plans to involve patients in the design, implementation, and dissemination of research? Are these plans meaningful and well-integrated or tokenistic?
- Who evaluates: Consider including trained patient reviewers on funding panels alongside scientific assessors to evaluate this component.

2

Provide Clear Guidance for Applicants

- Include a dedicated section in the application template prompting applicants to describe:
 - How patients will be involved at different stages of the project;
 - Which patient group(s) they plan to work with and why;
 - How they will recruit and support those contributors (e.g. compensation, training);
- What impact they expect PPI to have.
- Offer a brief explainer or checklist in the application guidelines summarising best practices for PPI and common pitfalls.

3

Involve Patients in Pre-Award Processes

- Co-design the call: Involve patient partners in drafting the call text and setting funding priorities.
- Patient panel review: Invite patients to review shortlisted proposals or participate in consensus meetings.
- Needs assessment stage: For larger or long-term grants, request a preliminary community consultation report from applicants.

4

Support Applicants with PPI Resources

- Offer sample templates (e.g. patient contributor roles, consent forms, lay summaries).
- Provide a short “PPI 101” factsheet or link to EHN-curated resources.
- Where feasible, organise info sessions or webinars on “how to include PPI in your research proposal,” possibly co-led by researchers and experienced patient contributors.

5

Monitor and Follow Up

- Require successful applicants to report regularly on how PPI is being implemented, any challenges encountered, and resulting insights or changes to the project.
- Collect short testimonials or case examples from patients involved to document impact and build an evidence base for future calls.
- Consider a patient satisfaction survey post-project to gather reflections on how meaningful their involvement was.

6

Prioritise Equity and Inclusion

- Encourage projects to work with diverse communities, especially underrepresented patient populations.
- Ask applicants how they plan to address barriers to participation, such as language, literacy, time constraints, or digital access.
- Offer guidance on fair compensation and recognition for patient contributors

Part 3: Sustaining Engagement and Measuring Success

Maintaining meaningful patient engagement over time requires deliberate efforts to build trust, manage expectations and demonstrate the tangible impact of involvement. Equally important is the establishment of metrics and feedback loops that allow organisations and patient partners to measure progress, celebrate early wins, and continuously refine their approach.

3.1 Managing expectations and building trust

Establishing and sustaining trust with patient contributors requires transparent, realistic communication from the outset. Organisations must clearly articulate not only what they aim to achieve, but also the practical constraints—whether political, regulatory or resource-based—that lie beyond their control. Although discussing barriers may feel like negative framing, it is essential for setting accurate expectations: patients need to understand which outcomes are realistically within reach and which will require creative workarounds when the political context is unfavourable.



Young patient advocate contributing to EHN's "Young Hearts, Healthy Futures" session at the European Parliament during European Youth Week, Brussels, 2026.

By outlining potential scenarios—both best-case and constrained—and describing strategies for navigating or circumventing obstacles, organisations help patient partners invest their energy in meaningful actions rather than chasing unattainable goals. Big promises may be appealing, but if left unmet they erode credibility and diminish motivation. Instead, highlighting achievable milestones and the mechanisms for adapting when barriers arise builds a shared understanding of what “success” looks like in practice.

This honest approach demonstrates respect for patients’ time and expertise, reinforcing the organisation’s commitment to reciprocity and continuity. When patient contributors see that their input is channelled into realistic, well-planned initiatives—and that the organisation has considered and prepared for external challenges—they are more likely to remain engaged, confident that their efforts will yield genuine impact even in a complex policy ecosystem.

Reciprocity is also critical to sustaining motivation: patient contributors should routinely see how their input influences policy or research outputs.

Whether it is a quote in a position paper, a modification in campaign materials or changes to a research protocol, organisations must close the feedback loop by acknowledging contributions and explaining how they shaped outcomes.

Continuity of engagement is equally vital. Rather than one off consultations, organisations should offer a structured progression of roles—inform, consult, co-create and, where appropriate, co-lead—so that patient partners can deepen their involvement over time in line with their interests and availability.

Recognition and shared learning further reinforce trust. Formal acknowledgements—such as certificates of contribution or public thanks at events—validate patients’ efforts. Equally important are structured feedback sessions and debriefs, where staff and patient partners come together to review what worked well, identify challenges and exchange lessons learned. These practices not only add value to patients’ commitment but also build collective capacity for future policy and research initiatives.

**Trust is
built
when patients know
their voices matter.**

3.2 Measuring impact: engagement, reach, and policy influence

If sustained enthusiasm depends on early visibility of progress, low-hanging fruits—small, achievable actions—can prove valuable allies in building momentum and delivering quick wins that energise both patient contributors and staff. Approaching ambitions in a step-by-step manner allows organisations to demonstrate initial successes, reducing the frustration that can arise from long-lead policy campaigns.

Clear key performance indicators (KPIs) should be established at the outset to track progress and celebrate milestones. Examples of relevant KPIs include the number of policymakers engaged in meetings or consultations, the volume of petition or campaign signatures gathered, and concrete policy outcomes such as amendments tabled in parliamentary questions or changes in guideline language. Regularly communicating these metrics—whether through email updates, a shared online dashboard, or brief “state of play” presentations during meetings—ensures that all collaborators remain informed and motivated by the project’s trajectory.

Table 4 presents an illustrative KPI tracker that can be shared with patient contributors and staff via a shared online dashboard or regular email update. It compares targets with actual progress, highlights achievements, and flags items requiring attention.

Table 4: Illustrative KPI tracker for monitoring patient engagement and policy impact

KPI	Target (Q3 2025)	Actual to Date	Status	Notes
Policymaker meetings held	6	4	● On track	Two meetings scheduled for August.
Petition signatures gathered	5,000	3,200	● Behind	Running a social media boost campaign in July to reach target.
Parliamentary questions or amendments tabled	3	1	● At risk	Drafting Q2 amendment; awaiting sponsor MP's sign off.
Patient reviewed briefing documents	10	8	● On track	Two more reviews scheduled in next month.
Storytelling workshops delivered	4	2	● On track	External trainer booked for September sessions.
Media mentions including patient quotes	5	3	● On track	Positive coverage in two regionals; pitching to national outlets in July.

How to use this tracker:

- 4. Update regularly** (e.g. monthly) to reflect progress against targets.
- 4. Share broadly** with all patient contributors—via email, a simple intranet page or a live dashboard—to maintain visibility.
- 4. Highlight low-hanging fruits** (e.g. the next quick win action) in accompanying commentary, so everyone sees immediate, achievable milestones.
- 4. Flag “At risk” items early**, so that staff and patient partners can brainstorm workarounds or reprioritise resources before frustration sets in.

When flagging “At risk” items, it’s important to acknowledge that unforeseen events and challenges are always around the corner—be it shifts in political priorities, sudden stakeholder changes, or logistical hiccups. The key is not to view these risks as failures but as signals to monitor the situation closely and act proactively. By surfacing potential roadblocks early, staff and patient partners can quickly brainstorm alternative approaches, reallocate resources, or adjust timelines, turning what might have become a bottleneck into an opportunity for creative problem-solving.



Managing “At Risk” KPIs

At-risk indicators are not failures. They are early warning signs that help organisations:

- ✓ Adjust timelines
- ✓ Reallocate resources
- ✓ Engage additional stakeholders
- ✓ Identify alternative advocacy opportunities
- ✓ Celebrate smaller interim successes

3.3 Learning from experience: adapting your model

Even the most carefully planned programmes benefit from periodic reflection and adaptation. By analysing engagement data, feedback from patient partners and outcome metrics, organisations can identify which strategies yield the greatest impact and which require recalibration. For example, if co-creation workshops consistently lead to richer policy proposals than one-off consultations, resources can be reallocated to expand workshop capacity. Conversely, if certain KPIs are persistently missed, it may signal a need to revisit assumptions about feasibility or to provide additional support and training.

Embedding a culture of continuous improvement involves scheduling regular review cycles—quarterly or biannually—during which staff and patient partners jointly assess successes, challenges and opportunities for innovation. Lessons learned should be documented and integrated into revised guidelines, training materials and RACI matrices. In this way, the engagement model remains dynamic, responsive to real-world experience and ever more effective in harnessing patient insight to drive lasting change.

3.4 Engagement in Times of Crisis: Ensuring Continuity of Cardiovascular Care

Conflict and humanitarian crises pose unique challenges to sustaining cardiovascular policies and patient care. During wartime or large-scale displacement, access to essential medicines, diagnostic services, and follow-up care may be severely disrupted. For national heart foundations, preparing for such scenarios is not optional but an essential dimension of patient engagement.

Key priorities include:

Emergency Preparedness and Continuity of Care

- Support patients in developing personal emergency preparedness plans, including maintaining a reserve of essential medications and portable health records (digital or physical).
- Establish emergency communication channels (e.g., hotlines, text alerts, online portals) between patients and healthcare providers.
- Advocate for government recognition of uninterrupted cardiovascular care as a priority in crisis planning.

1

2

Engagement for Vulnerable Populations and Refugees

- Highlight the specific needs of refugees and internally displaced persons with CVD, who may face limited access to care.
- Call for dedicated resources such as mobile clinics, telemedicine services, and cardiovascular screening in refugee camps or war-affected regions.
- Work with humanitarian actors to ensure continuity of treatment for displaced patients on long-term therapies.

3

Collaboration with International and Humanitarian Partners

- Build partnerships with WHO, relevant EU institutions, and the appropriate components of the International Red Cross, in line with their respective mandates.
- Advocate for cardiovascular health to be explicitly integrated into humanitarian programmes, funding and medical supply arrangements.
- Strengthen international cooperation to support access to medicines, expertise and logistical assistance when national health systems are overwhelmed.

By integrating crisis preparedness into engagement strategies, national heart organisations can safeguard continuity of care for cardiovascular patients and ensure that even in times of disruption, patient voices remain at the centre of policy responses.

Conclusions: Capacity-building needs and how EHN can support

As patient-led engagement continues to evolve, one key takeaway is clear: capacity-building is not a one-off exercise but an ongoing necessity. National organisations—regardless of their size—require sustained support to build the structures, skills, and partnerships needed to meaningfully engage patients and embed their voices in both policy and research processes.

EHN stands ready to help its members rise to this challenge. At the patient level, EHN can offer targeted support by helping to train interested individuals through established EU-level curricula, with particular focus on policy literacy, research engagement, and storytelling for impact. For those with sufficient English-language proficiency, EHN can also act as a connector—linking national patient experts to relevant European initiatives, including opportunities for involvement with the European Medicines Agency (EMA), where patients contribute to scientific advice, pharmacovigilance, and medicine information reviews.

At the organisational level, EHN can assist in reviewing templates for training materials, advise on the structuring and allocation of human resources, and identify further best practices for managing patient engagement across policy and research. Whether by providing guidance on how to implement a RACI model, helping to define levels of patient involvement, or offering examples of briefing materials and consent protocols, EHN can help its members build more robust and sustainable frameworks.

Finally, in terms of outreach and visibility, EHN can support the amplification of patient recruitment efforts—sharing calls for involvement via Brussels-based networks, social media channels, and stakeholder mailing lists to help national organisations widen their reach and attract a more diverse pool of patient contributors.



EHN members at the EHN Annual Workshop, Stockholm, 2025.

Annexes

Annex I: Template Patient Advocates Recruitment Social Media Post

 Are You a Young Changemaker Living with a Heart Condition?

Join Our Youth Engagement Programme! 

Have you faced heart failure, stroke, misdiagnosis, or another cardiovascular challenge before the age of 35? Do you want to use your experience to shape real change in health policy and awareness in your country?

We're looking for young voices (16–35 years old) to become patient volunteers in a new policy initiative focused on improving the lives of those affected by CVD.

 Who we're looking for:

-  Young people living with cardiovascular disease (past or present)
-  Willing to share their story and contribute to policy work
-  Interested in learning about health policy and patient rights
-  Passionate about making healthcare more inclusive and responsive
-  No experience in policy? No problem.

We'll provide support, training, and guidance to help you share your story and make impact.

 Connect with fellow young advocates from across Europe.

 Have your voice heard in health policy conversations.

 Help shape messages that make a difference.

 Interested?

Apply now or tag a friend who might be interested!

 [Insert Link]

Deadline: [Insert Date]

 Questions? DM us or email [Insert Contact Info]

Let's make patient voices count. Starting with yours.  #CVDYouthVoice
#PatientEngagement

Annex II: Template Patient Advocate Recruitment Form

Thank you for your interest in becoming a patient partner. Please fill out the form below to help us understand your background, interests, and any support you may need. Your information will be treated confidentially and used solely for recruitment and coordination purposes.

Personal Information

Full Name: _____

Date of Birth (DD/MM/YYYY): _____

Country of Residence: _____

Email Address: _____

Phone Number (optional): _____

Health Experience

Please specify your heart condition/diagnosis _____

Current status of your condition:

- ☐ Ongoing
- ☐ In remission/cured
- ☐ Prefer not to say

Approximate year of diagnosis: _____

Are you comfortable sharing parts of your personal experience publicly?

- ☐ Yes
- ☐ No
- ☐ Unsure – I'd like to know more

Engagement & Communication Experience

Engagement involves speaking up, raising awareness, or taking action to improve the lives of people affected by a condition like cardiovascular disease. This might include sharing your story publicly, participating in campaigns, engaging with decision-makers, or supporting others in patient communities.

Your prior engagement experience:

- ☐ None
- ☐ Beginner
- ☐ Intermediate
- ☐ Advanced

Approximate year of diagnosis: _____

Briefly describe any relevant engagement or volunteer activities:

Comfort level with public speaking/presenting:

- ☐ Yes
- ☐ Somewhat
- ☐ No

Language & Accessibility

Your level of English proficiency:

- ☐ Fluent
- ☐ Conversational
- ☐ Basic
- ☐ None

Do you have any accessibility needs or travel limitations?

(e.g. reduced mobility, vision/hearing support, virtual-only)

Are you able to attend occasional in-person events in Europe?

- ☐ Yes
- ☐ No
- ☐ With notice only
- ☐ Prefer virtual-only

Time Availability

How much time can you dedicate to engagement per month?

- ☐ 1–2 hours/month
- ☐ 3–5 hours/month
- ☐ 6–10 hours/month
- ☐ More than 10 hours/month
- ☐ Unsure

Preferred days/times (optional): _____

If you foresee any periods in the next 6 or 12 months when you may be unable to attend advisory sessions due to treatment cycles or other commitments, please feel free to indicate them:

Preferred Level of Involvement

There are many ways to get involved in patient engagement. Please review the participation options below and tell us which one best fits your current availability and interest. Note: Time commitments are flexible and may vary month to month. You can change your level of involvement at any time.

Availability Bracket	Time Commitment	Level of Involvement	Typical Activities
Occasional Contributors	Up to 2 hours/month	Inform	Receive policy updates, newsletters; join messaging group to observe developments.
Advisory Contributors	½–1 day/month	Consult	Give feedback on materials; join focus groups or surveys; occasional online consultations.
Collaborative Contributors	2–4 days/month	Co-Create	Attend meetings; help draft materials; join workshops or storytelling sessions.
Leadership Contributors	≥2 days/week	Co-Lead	Chair working groups; represent the organisation; support strategic planning; mentor others.

Which level best describes how you'd like to participate (choose one or more if unsure)?

- ☐ Occasional Contributor (Inform)
- ☐ Advisory Contributor (Consult)
- ☐ Collaborative Contributor (Co-Create)
- ☐ Leadership Contributor (Co-Lead)
- ☐ Not sure yet – I'd like to discuss it

Please describe anything else we should know about your availability (optional):

Conflict of Interest Declaration

Do you have any current or past affiliations with healthcare, pharmaceutical, or medical device companies? (e.g. shareholder, board member, employee, consultant, speaker)

- ☐ No
- ☐ Yes – please specify:

Additional Information (Optional)

Anything else you'd like us to know (e.g. motivations, support needs)?

Consent and Signature

☐ I confirm that the information provided is accurate.

☐ I understand this is a voluntary, unpaid opportunity.

☐ I agree to be contacted for follow-up.

For data protection purposes, the information you provide will be stored and processed by the European Heart Network (EHN) in accordance with the General Data Protection Regulation (GDPR) and used solely for the purposes of the agreed activities and related follow-up.

Signature: _____

Date: ____ / ____ / ____

Annex III: Template EHN Patient Network Consent Form (Example to be adapted for use at national level)

The data is collected to work on EHN's Strategic Goal (Strategic Plan 2023-2030), namely, to strengthen the patients' and public's voice and agency, within EHN and externally, through EHN's membership, enabling ongoing involvement of patients living with CVD in shaping policy and engagement efforts, and their meaningful engagement. Your information will be treated confidentially and used solely for recruitment and coordination purposes.

1. Please indicate the types of activities you would like to be considered for participation

☐ Research Projects (i.e. Patients can provide feedback on healthcare projects, receiving financial compensation for their contributions. These opportunities include both online and onsite workshops.)

☐ Engagement (i.e. Patients can play a key role in engagement efforts by reaching out to politicians to push for healthcare legislation or ensure patient interests are included in existing laws. These can also involve direct communication via email and in person/online meetings with politicians at the European Parliament)

☐ EMA related activities (i.e. patient advice on specific inquiries coming from EMA such as the language used in medication leaflets or the overall patient experience with a specific drug. These can involve participation in workshops organised by EMA)

2. Do you have previous experience in patient advisory roles?

☐ Yes

☐ No

3. If yes, please provide brief description of the type of involvement these entailed:

- 4. Please provide the name and email address of your main contact person from your patient organisation, so we can include them in our communications:**

- 5. Please provide your full name**

- 6. Please provide your email address**

- 7. Please specify your heart condition/diagnosis**

- 8. If you foresee any periods in the next 6 or 12 months when you may be unable to attend advisory sessions due to treatment cycles or other commitments, please feel free to indicate them:**

- 9. Data storage**

☐ I understand that my personal data will be stored and processed by the European Heart Network (EHN), in compliance with the General Data Protection Regulation (GDPR), solely for the purposes of patient consultant involvement in EHN activities. The data will be reviewed every three years and retained only for as long as necessary for these purposes.

- 10. Patient consultants' rights**

☐ I understand that patient consultants can: Access their data/Request corrections or deletions/Restrict processing or object to it

11. Signatures

Name of Patient Consultant [IN CAPITALS]

Date

Signature

I have accurately read out the above information sheet to the potential Patient Consultant and, to the best of my ability, ensured that they understand to what they are freely consenting.

Name of Patient Network Coordinator [IN CAPITALS]

Date

Signature

Annex IV: Terms of Reference Template

[Name of Task Force / Working Group]

Draft Terms of Reference

1. Background

Provide a short context on why the group is being set up.

(Example: “Young patients face unique challenges in cardiovascular health which are often underrepresented in policy.”)

2. Purpose

State the main aim.

(Example: “To bring together [target group] to identify challenges and co-create recommendations.”)

3. Objectives

- Map experiences
- Develop recommendations
- Raise awareness
- Empower patient voices

(Adapt as relevant)

4. Scope

- Geographic focus: [Insert region/countries]
- Focus areas: [Insert priority issues]

5. Deliverables & Timeline

Deliverable	Lead	Target Date
Task Force established	Secretariat	Month X
Kick-off meeting	Coordinator	Month X
Draft recommendations	Coordinator	Month X

6. Membership & Composition

- Coordinator: [Insert role]
- Members: [Number, criteria]
- Advisers: [If applicable]
- Secretariat: [Supporting staff]

7. Roles & Responsibilities

Role	Responsibilities
Coordinator	Lead meetings, ensure delivery
Members	Share experiences, review drafts
Advisers	Provide expertise
Secretariat	Administrative & communication support

8. Mode of Operation

- Meetings: [Frequency, format]
- Decision-making: [Consensus/simple majority]
- Reporting: [To Secretariat/Board/etc.]

9. Resources & Budget

Specify whether any honoraria, training, or support is provided.

10. Confidentiality & Data Protection

Refer to consent form (see Annex III).

11. Review & Amendment

Outline how the ToR can be revised.

Annex V: Memorandum of Understanding Template

MEMORANDUM OF UNDERSTANDING

Between

[Organisation name] (Party A)

and

[Patient Consultant / Patient Group name] (Party B)

For participation in the project entitled:

[Insert project title]

For the period:

[Insert start date] – [Insert end date]

Contents

- I. Parties to the MoU
- II. Background
- III. Terms
- IV. Project Scope
- V. Project Aim
- VI. Outcomes Sought
- VII. Responsibilities of Party A
- VIII. Responsibilities of Party B
- IX. Financial Agreement
- X. Data Protection
- XI. Amendments & Termination
- XII. Effective Date & Signature
- Annex I: Request for Payment Form (template)

I. Parties to the Memorandum

- Party A – [Insert organisation name]
- Party B – [Insert patient consultant / association]

II. Background

Short context about the project or collaboration.

III. Terms

Agreement duration: [Insert start/end dates].

IV. Project Scope

Describe the focus and scope in simple terms.

V. Project Aim

Define what the project or collaboration seeks to achieve.

VI. Outcomes Sought

List intended results from collaboration.

VII. Responsibilities of Party A

- Provide project information and feedback
- Facilitate meetings
- Ensure respectful engagement
- Share relevant results

VIII. Responsibilities of Party B

- Participate in meetings/workshops
- Provide input and feedback
- Respond to communications in a timely manner
- Right to withdraw participation at any time

IX. Financial Agreement

- Honorarium: [Insert rate/day or activity, if applicable]
- Reimbursement: [Travel/accommodation rules]
- Payment process: [How and when to submit requests]

X. Data Protection

The Parties shall process personal data in accordance with the GDPR and other applicable data protection legislation. Personal data, particularly health data, shall be used only where necessary for the project, kept confidential and secure, and retained no longer than necessary. Identifiable information, quotations, images or recordings shall not be shared or published without an appropriate legal basis and the prior permission of the person concerned.

XI. Amendments & Termination

Outline how the agreement may be changed or ended.

XII. Effective Date & Signature

Signatures from both parties with dates.

Annex I – Request for Payment (Template)

Request for Payment

Pursuant to our Memorandum of Understanding, please transfer EUR [XX.00] as honorarium for my participation in the following activity

Task	Description	Date	Hour	Cost

Bank details:

- Bank name:
- IBAN:
- BIC/SWIFT:
- Account holder:

Signature: _____

Name: [Insert]

Date: [Insert]

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