



# The Heart Failure Policy Network

## Heart Failure Policy Network Terms of Reference

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The Heart Failure Policy Network is an independent, multidisciplinary platform made possible with financial support from AstraZeneca, Vifor Pharma and Novartis Pharma. The content produced by the Network is not biased to any specific treatment or therapy. All outputs are guided and endorsed by the Network's members. All members provide their time for free.



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# 1 Objectives

**The aim of the Heart Failure Policy Network is to drive a new generation of policies on heart failure (HF) in Europe.**

The Heart Failure Policy Network ('the Network') is a unique group consisting of patient advocates, healthcare professionals, policymakers and other key stakeholders in Europe who work together to raise awareness of unmet needs surrounding heart failure (HF).

The overarching objectives of the Network are:

- to define what governments can do to help turn existing policy recommendations into concrete, sustainable action for the prevention, management and care of HF
- to champion the adoption of these recommendations at the European, national and local level, including the provision of support to national HF advocates.



## 2 History of the Network

The Network was established in 2015 following a process of key stakeholder consultation as to the aims, objectives, working methods and governance of a multidisciplinary group on HF. In the same year, the Network's inaugural policy position paper, the [Heart Failure Policy Toolkit](#), was launched in the European Parliament, providing an evidence-based and comprehensive overview of key challenges in HF and a proposal for the way forward.

In 2016, the Network led the largest European political campaign on HF to date to develop and launch the European Parliament [Written Declaration on Heart Failure](#) (110/2016). The declaration gained 234 signatures from MEPs across 26 European countries, as well as support from organisations in HF, cardiovascular disease and other sectors. This was followed by the [State of play summaries](#), launched in 2017 to analyse the diagnosis and clinical management of HF in Europe.

In 2018, the Network launched its second landmark policy report: [The handbook of multidisciplinary and integrated heart failure care](#). The handbook outlined the importance of multidisciplinary and integrated care for HF, presented a comprehensive evidence-based overview of effectiveness, described the 'state of play' in Europe in terms of performance and barriers, identified five key areas where care typically fails people with heart failure and outlined a clear progressive consensus for change. It was accompanied by short 'pressure point' reports, which went into greater depth on key issues along the patient care journey, including best-practice case studies and reproducible tools for change.

In 2019, the Network published [Understanding heart failure guidelines](#), a collection of lay summaries of key principles in leading European HF guidelines. This work aimed to increase the uptake of leading guidelines in HF care, and empower patient advocates and health policy commentators to scrutinise local and national HF policy, guidance and care arrangements.

In 2020, the Network launched the [Spotlight series](#), which features evidence-based reports on topics at the forefront of debates and challenges in the future of HF care. So far, the series includes reports on HF with preserved ejection fraction (HFpEF), iron deficiency in HF, telemedicine in ongoing HF care, quality assessment in HF care and hyperkalaemia in HF. Each report highlights clinical challenges, policy issues, patient needs and best-practice case studies to support meaningful and sustainable improvements in policy, care provision and research.

The Network's latest landmark project, [Heart failure policy and practice in Europe](#), was launched in November 2020. It aimed to support advocates with a comprehensive overview of policy issues and best practice in HF in 11 European countries. This work, which was the natural successor to the 2018 handbook, was developed based on the literature and input from more than 50 HF experts from across Europe. It includes a pan-European report and 11 standalone country profiles, each with five urgent actions needed to improve the lives of people living with HF.



### 3 Proposed work for 2021

As of 1 January 2021, the Heart Failure Policy Network Secretariat proposes a programme of work (outlined below), with other work anticipated to arise over the course of the year. The Network's target over 2021–23 is to ensure that concrete, high-level policy commitments to HF come into being, particularly in Belgium, France, Germany, Greece, Ireland, Italy, Poland, Portugal and Spain.

In 2021, the Network will focus on mobilising HF advocates to communicate with decision-makers by building a sophisticated online policy advocacy and learning hub in HF, catering to the clear opportunities to advance HF policy today. Proposed activities include the following:

- **Guided representation to national decision-makers** with a new cadre of national HF leaders, ideally with national translations of the country profiles from Heart failure policy and practice in Europe
- **Heart Failure Policy Trailblazers hub** and integrated communications campaign to elevate policy successes in HF and upskill HF advocacy
- **Direct political representation within European Union (EU) institutions** building on a virtual policy round table held in December 2020, generating supportive pressure and resources for national efforts
- **Annual heart failure leadership and policy summit** to grow and inspire a cohort of national leadership and link national, European and global influencers
- **Engagement of the World Economic Forum** to showcase HF as a global sustainability case study, via the Partnership for Health System Sustainability and Resilience (PHSSR)
- **Reorganisation and growth** of the Network membership and other core functions (see *Roles within the Network*), to maximise the public leverage and visibility of the Network.

The Network is uniquely placed to lead a combined national and European strategy over 2021–23. At the national level, we aim to engage with elected politicians in a scrutiny role, national officials within health authorities and ministries of health, and senior clinicians and academics in a strong position to communicate with decision-makers. At the European level, we hope to contribute to ongoing policy efforts in cardiovascular disease, build an effective scrutiny group on HF in the European Parliament, ensure that the EU4Health programme and other EU funding streams consider HF, and map a path to a dedicated session on HF with high-level health officials (Council of Ministers).



## 4 Project-based approach

From 2017, the Network adopted a project-based approach whereby the Secretariat has the option to run multiple projects concurrently, with different or otherwise separate funders. This allows for sponsors with different but complementary policy interests within HF to form component parts of a broader and more comprehensive campaign. Projects may focus on specific policy themes, policy activities and/or geographical locations. Projects (in both conduct and scope) must adhere to the Terms of Reference set out herein and the values of the Network, and must include a 15% contribution to core Secretariat costs that may arise, proportional to the funding.

Within reason, there is no limit to the number of projects that could be run by the Network, provided that they are compatible with the Terms of Reference. The Secretariat (The Health Policy Partnership Ltd) will lead discussions with potential sponsors and will submit all major proposals to the Steering Committee for approval (see *Steering Committee*). Steering Committee members have the right of comment and veto on any proposed project.

The Secretariat will independently approve and action small work programmes and inform the Steering Committee at the next suitable juncture. Examples of small work programmes include the continuation or extension of existing programmes and events, and minor supporting budgets for expenses.



## **5 Roles within the Network**

### **5.1 Members**

**Role: to participate and support the Network and its outputs**

Membership is open to any stakeholder who shares the aims and mission of the Network and/or is interested and able to take an active and constructive role in projects. Membership in the first instance is for individuals, but relevant organisations will also be considered.

Stakeholders shall become Members at such time as they agree in writing to observe the Terms of Reference, to recognise the Secretariat as the executive and external representation of the Network and to permit the Secretariat to feature the Member's name on the Network website and core materials.

Membership shall be confirmed by the Secretariat through appropriate correspondence (e.g. via email). Consistent with the mission statement and core activities, the Secretariat will strive to have multidisciplinary societal representation in its membership.

While no Member is obliged to accept or respond, the Secretariat may approach Members for the development of research (e.g. as a member of a Project Advisory Group), public dissemination of work and consultations of the HFPN membership on the future strategy of the Network. As and when appropriate, the Secretariat will send Members personal correspondence with regard to attendance at events, research and any other activities that may be relevant to Members. For example, an expert on specialist nursing may be consulted on research findings and document drafts on the topic of integrated person-centred care.

Membership survives the entirety of the existence of the Network; there is no limit to the number of Members. If a Member no longer wishes to be considered part of the Network, they are free to leave at any time by notifying the Secretariat of the decision in writing.

### **5.2 Steering Committee**

**Role: to act as a senior advisory committee with whom the Secretariat discusses key strategic and project decisions relating to the future of the Network and its goals**

The Steering Committee comprises a group of six to eight highly active or founding members of the Network. Participation in the Steering Committee is by invitation from the Secretariat, who will ensure that the composition of the Steering Committee is representative of all stakeholder groups with an interest in HF and clinical disciplines relevant to HF.



The Steering Committee shall be advisory. Beyond their individual conduct, members of the Steering Committee shall accept no liability for the broader conduct of the Network in public life, responsibility for which shall rest fully with the Secretariat.

Activities of the Steering Committee:

- **Approval of major Network projects:** in line with the project-based approach, the Secretariat will provide the Steering Committee with a proposal for any new major project, for its approval or rejection.
- **Consultation on breadth of Steering Committee membership:** when provided with details of new membership, the existing Steering Committee shall approve or reject proposed members against the Terms of Reference.
- **Editorial scrutiny over all significant Network outputs:** the Secretariat will present major outputs to the Steering Committee for scrutiny and consultation to ensure that all work represents an objective consensus consistent with the Terms of Reference.
- **Participation in annual policy forum with sponsors:** once a year, the Secretariat will organise a Strategic Steering Committee Forum. This meeting is not mandatory but will offer a discussion of the HF policy landscape and strategic priorities of the Heart Failure Policy Network programme. **To note:** project-specific information, such as proposals, development of outputs or composition of Project Advisory Groups, will not be discussed.

The Secretariat will organise between two and four teleconference meetings and, ideally, one face-to-face meeting per year for the Steering Committee. An agenda and relevant materials will be distributed to all Steering Committee members via email. These will be timed to allow the Steering Committee adequate time to read or respond to the documents.

A member of the Steering Committee may resign and return to membership at any time, provided that the decision is made in writing.

### **5.3 Project Advisory Groups**

**Role: to enable the Secretariat to conduct in-depth consultation of selected, interested members in key project outputs**

During scoping discussions and upon confirmation of project work, the Secretariat will appoint a list of Network Members to constitute a multidisciplinary pan-national Project Advisory Group for that project.

Project Advisory Groups will be conducted in alignment with the Network Terms of Reference. They will meet (virtually or in person) at or around key project milestones

to assess and advise on the progress of the proposed activities against the agreed scope and any pre-specified key performance indicators.

Project Advisory Group members will be asked to read and provide in-depth comments on specific materials (e.g. document drafts, project plans, research briefs and/or final outputs) to ensure all outputs and activities reflect a broad, multidisciplinary and evidence-based consensus, and are justified, balanced and reflective of individual members' professional and personal experience. The Secretariat will, where required, pursue individual communication with Project Advisory Group members to acquire detailed feedback.

Prior to finalisation, or at the key stages of the project, the Secretariat will ask Project Advisory Group members for their approval of the final work product or the interim progress report. Upon finalisation, Project Advisory Group members are expected to publicly endorse the major public outputs for their respective projects and to give their consent for their involvement to be published.

## 5.4 Sponsors

**Role: to fund the activities of the Network, including core costs, and offer strategic insight at appropriate forums**

### 5.4.1 Strategic Steering Committee Forum

The Secretariat recognises the life sciences industry as an essential stakeholder in shaping the strategic policy environment in HF. Major sponsors are invited to send a suitable representative (from Medical, Patient or Government Affairs) to attend the Strategic Steering Committee Forum (see *Project Advisory Groups*). In this forum, the sponsor's representatives may contribute the strategic vision of the life sciences industry to group discussions of the HF policy landscape and are encouraged to comment on areas of mutual interest that may be the subject of future HFPN sponsorship.

However, sponsor representatives must:

- abide by and respect the Terms of Reference and the commitments made therein to independence, transparency and objectivity of the Network and its outputs
- not seek to override final editorial decisions by the Secretariat and Project Advisory Groups, nor demand adjustments to ongoing project work of the Heart Failure Policy Network.

For the avoidance of doubt, representatives of the sponsors will not be considered as members of the Steering Committee and have no right to claim reimbursement (see *Remuneration of members*)



### 5.4.2 Projects

Sponsors may be invited to comment on major outputs of projects for which they have provided funding. The Secretariat will share drafts of core project materials (e.g. reports) at pre-final stages, at such a time as the Project Advisory Group has been invited to comment in full.

Sponsors shall engage with any drafts from a whole-system perspective, as part of a shared stakeholder endeavour to enhance societal benefits, founded on objective analysis. Examples of appropriate comments from sponsors include those relating to the accuracy of any given analyses or findings, apparent omissions of relevant data or case studies from grey and scientific literature, or relevant environmental knowledge and learning (e.g. related to organisational and delivery barriers or effective engagement strategies with decision-makers).

Full editorial control of Network outputs and activities lies with the Secretariat, which retains the right to amend or reject any comments from sponsors (see *Independence, objectivity and transparency*). Ultimately, the Secretariat will assess the relevance and validity of sponsors' comments to the overarching Heart Failure Policy Network mission statement. For example, comments seen to promote the commercial interests of the sponsor in an unbalanced fashion, directly or indirectly, will be rejected. In addition, the Secretariat will not accept to be bound by any recommendation or veto resulting from legal or scientific review processes conducted by any sponsor. Comments from sponsors that are accepted (i.e. included) in the development of a Network report will always be independently validated by the Project Advisory Group in a subsequent draft.

Sponsors will have no contact with members of the Project Advisory Group in relation to Network matters, nor will they be included in any correspondence with the Project Advisory Group.

### 5.4.3 Communications between sponsors and Secretariat

At project initiation, the Secretariat will agree appropriate whole-programme key performance indicators with sponsors to ensure clear operational measures of success are agreed between all parties, towards which the Secretariat will endeavour in line with the Terms of Reference. The Secretariat will freely share such indicators (and any assessment of performance) with Members as it sees fit, or if requested by Members.

The Secretariat will coordinate dedicated monthly updates for sponsors, including a presentation of deliverables and timelines. If applicable, the Secretariat will share educational insights into HF policy and key findings. The Secretariat may also introduce national affiliates from different sponsors to one another and to stakeholders, where this assists in the development of separate, national-level alliances to advance HF policy.



Sponsors may submit interested and relevant stakeholders for consideration by the Secretariat for engagement in the Network. This is not contingent upon funding. The Secretariat will consider expressions of interest from any interested party, subject to vetting processes and final decision by the Secretariat.

#### 5.4.4 Major sponsor benefits

The Secretariat will judge whether a sponsor is a 'major sponsor' based on total contributions, and in recognition of this high level of support will offer the following benefits:

- Option for quarterly online educational sessions with major sponsors' internal affiliates to enable them to better consider the case for aligned policy activities in their fields/geographies. For example, the Secretariat may present key findings and updates on the Network's schedule of public events.
- Acceptance of speaker requests at events organised by sponsors, both public and internal, to share educational materials and insights from the Heart Failure Policy Network programme, where such events seek to further policy recognition of HF. The Secretariat will accept reasonable reimbursement of travel and other expenses for such engagements, should they arise.

It is important to note that in the interest of objectivity and independence, the Secretariat is not exclusively bound to any sponsors and may accept invitations to speak and/or serve in an advisory role for other life sciences stakeholders, judged on merit, and where such an event/role aligns with the Network's core objectives and Terms of Reference.

## 5.5 Secretariat

**Role: to provide overall coordination, delivery and strategic leadership for the Network; negotiate sponsorship and administer finances/resource allocation; act as chief editor of all outputs; and represent the Network in public life**

The Secretariat is provided by The Health Policy Partnership Ltd, which will be funded to provide support for the overall organisation and leadership of the Network. The Health Policy Partnership is responsible for allocating budgets for individual projects to cover any expenses or staff costs that may arise over the course of the project, including from document design, travel expenses, venue hire, organised catering and performance of the core Secretariat function.

The Secretariat's role will be in relation to the following:

- **Strategic leadership:** routinely optimising plans to deliver on the Heart Failure Policy Network core mission statement and consulting on such plans among Members, Steering Committee and sponsors etc. as outlined above
- **Nomination** of the Steering Committee and Project Advisory Groups



- **Recruitment and management of membership:** continuing to identify and recruit Members to the Network, overseeing the validation process and maintaining accurate records of membership
- **Administrative support:** providing comprehensive Secretariat support to the Network; running the Network as a cohesive and committed group consistent with the Terms of Reference; diarising and facilitating meetings; setting and amending work plans and staff allocations; engaging with sponsors' internal processes to secure release of funds; and providing any logistical support, processing of expenses and other administrative tasks, as required
- **Research and drafting:** developing all materials necessary for the smooth running of all Network activities and events, and facilitating co-development of all final outputs with Members, with the aim of reaching a consensus opinion
- **External representation:** actively supporting liaison with a growing circle of relevant external stakeholders to advance the goals of the Network and, where useful, playing standing roles in external advisory panels or working groups
- **Communication:** leading the dissemination of all outputs; developing social media campaigns; maintaining the Network website and quarterly newsletter; and engaging Members in the co-development of launch planning and delivery phases
- **Transparency:** providing any relevant information for transparency reporting as appropriate and required by funders or Members. This will include the maintenance of the Network's record within the European Transparency Register and other national registers, where applicable
- **Sponsor liaison:** updating sponsors at structured intervals, for the purposes of contracting (e.g. agreeing aligned and mutually compatible procurement and funding agreements, in line with the Terms of Reference), approaches to potential new funders and project-specific progress and achievements to date (e.g. current Members, notification of launch plans and group teleconferences, expected outputs).

## 6 Remuneration of Members

All Members participate in Network activities pro bono. Accordingly, no remuneration will be awarded.

The Secretariat will seek to fund and reimburse any reasonable expenses incurred by Members as a result of participating in Network events or face-to-face meetings. This includes standard-fare air or rail travel, business-standard accommodation, local use of taxis from or to airports and railway stations, meeting venues and accommodation, and reasonable refreshments and sustenance. The Secretariat reserves the right to impose an expense cap (e.g. €40 per day) on sustenance. In the interests of convenience and best use of funds, Members are asked to agree all travel arrangements or similar expenses with the Secretariat in advance.

Please note: any such reimbursement must be compliant with national laws or regulations regarding industry funding for this project.

For the avoidance of doubt, the Secretariat will not reimburse the representatives of sponsors.

## 7 Independence, objectivity and transparency

In relation to the Network's operation and relevant standards in public life, the Terms of Reference assert the following:

### **Independence:**

- The Secretariat shall freely and continually develop strategies and plans to advance the Heart Failure Policy Network and its policy goals, consulting as it sees fit among stakeholders.
- The Secretariat shall freely enter into external partnerships as may be aligned to the Terms of Reference and will approach suitable sources of funding or other support as it judges useful to do so.
- Final editorial control rests wholly with The Health Policy Partnership, acting as the Secretariat of the Network. All outputs are guided and endorsed by Members of the Network involved in Project Advisory Groups, who shall comment freely.
- No sponsor (nor their nominated representative) will have any right of editorial control over the outputs of the Network. For the avoidance of doubt, this includes no right to veto or amend outputs as a result of legal or scientific review by any sponsor.
- Within the scope of each agreed project, including core funding, the Secretariat is solely responsible for the manner in which funding is disbursed.
- Although highly unlikely, in the event the Secretariat decides to terminate the Network, this decision will be communicated to all Members and the Network will be considered disbanded indefinitely with immediate effect.

### **Editorial objectivity and balance:**

- The Network is for educational purposes and will not promote the products of any sponsor, either directly or indirectly.
- The content produced by the Network is not biased to any specific treatment or therapy. Funding should not be conditional upon the prescription, supply, sale or consumption of therapeutic products being developed or marketed by sponsors.
- Outputs must be objective, balanced, accurate, and not misleading or deceptive.
- The Secretariat shall be responsible for an appropriate and comprehensive process of research and analysis to drive multidisciplinary consensus out into the public domain. Research and drafting processes will, at the discretion of the Secretariat, involve expert consultation relevant to the topic.



- All outputs of the Network should accurately represent the consensus position adopted by the Steering Committee, Project Advisory Groups and, to the greatest extent possible, the wider membership. The Secretariat commits to making all reasonable efforts to secure a consensus during the drafting and development process. Final judgement in this matter will be exercised by the Secretariat.
- In certain circumstances, Network outputs may encompass therapeutic areas or technologies in HF in which sponsors hold commercial or strategic interests. In such cases, final editorial decisions will be judged by the Secretariat in an evidence-based and consensus-driven process, in consultation with Members.
- Reference shall not be made to a single product, nor will any comparative assessments be made in relation to relative clinical effectiveness or safety as regards the choice of treatment for HF. In presenting any discussion of effectiveness of treatment, the Secretariat shall in the first instance be guided by scientific guidelines as to proven treatment models.
- All substantive outputs of the Network will acknowledge the Project Advisory Group as contributors, as well as any general Members or non-Member individuals participating in the work.

#### **Transparency:**

- The Secretariat is responsible for ensuring that the Network and its activities are compliant with all relevant laws, rules and regulations (including any codes of practice or other guidelines) generally followed by life sciences companies in each relevant country.
- The Secretariat will disclose publicly all financial support provided to the Network.
- For outputs related to specific projects, the Secretariat will publicly disclose which sponsor(s) have provided funding.
- The Secretariat shall maintain an accurate record of the Network activities and its financing, as per the requirements of the European Transparency Register and other transparency registers at the national level, as judged relevant by the Secretariat.
- All Members of the Network, as well as all those involved in any activity coordinated through the Network, are required to comply with any such laws, rules or guidelines for the duration of their membership and/or during the course of their participation. They must communicate immediately to the Secretariat any contraventions that may have occurred, or may reasonably be anticipated to occur, to the very best of their knowledge.



- Noting its responsibilities (and legal accountability) above, the Secretariat will retain final authority over all Network activities and outputs, and reserve the ultimate right to award or withdraw membership.
- While the Secretariat will provide all final Network materials free to the public domain, ownership and intellectual property generated by the Network will reside with the Secretariat, specifically The Health Policy Partnership (including electronic or hard-copy documents, logos, graphics, website URLs, social media feeds, logos and trademarks, and conference banners).
- The Secretariat places enormous value on the trust and goodwill offered by each Member as we work together. Accordingly, each Member agrees:
  - to abide by the declarations made above, to the best of their knowledge and ability
  - that all discussions within the Network (e.g. during development and drafting stages) are to be considered 'off the record', unless otherwise stated.

## 8 Contact

The Health Policy Partnership will act as the main point of contact for the Heart Failure Policy Network.

Managing Director Ed Harding and Senior Researcher Marissa Mes can be reached as per below.

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