

Terms of Engagement with the Global Heart Hub

Global Heart Hub Overview

The Global Heart Hub is the first global non-profit organisation established to provide a voice for those affected by cardiovascular disease. We are an alliance of heart patient organisations and advocates, aiming to create a unified global voice for those living with or affected by heart diseases. Our aim is to unite patient groups and advocates from every country in the world under the umbrella of the Global Heart Hub. Our combined mission is to raise awareness of heart diseases and the challenges it presents in everyday life. The Global Heart Hub is a platform for heart patient organisations to share their views, learn from each other's best practice, collaborate on common advocacy goals, and share resources. We aim to increase awareness and understanding of the many heart conditions that exist, improve patient outcomes, enhance quality of life, and optimise longevity and healthy ageing.

All cardiovascular disease patient groups / organisations; individual patient advocates; and organisations / groups who are predominantly focused on the needs and issues relating to heart patients and their carers across the world are welcome to be part of the Global Heart Hub. Affiliation is free of charge. There are three ways of affiliating with the Global Heart Hub:

1. **Patient Organisation**

*Any group of individuals who have come together to highlight the needs of heart patients and their carers. Organisations must be **patient-led** with leadership and membership predominantly comprised of those living with a cardiovascular condition, carers or patient advocates.*

2. **Individual Patient Advocate**

*Heart patients or carers motivated to advocate for the needs of those living with, or affected by, heart disease. Individual Patient Advocates are viewed as **general affiliates** and do not participate on any of our patient councils. However, there are opportunities for engagement with patient councils as well as being kept informed of all Global Heart Hub Activities.*

3. **Associate Organisation**

*An organisation or group who are predominantly focused on the needs and issues relating to heart patients and their carers. Associate Organisations are viewed as **general affiliates** and do not participate on any of our patient councils. However, there are opportunities for engagement with patient councils as well as being kept informed of all Global Heart Hub Activities.*

The Global Heart Hub is made up of a number of patient councils and each council is an alliance of patient organisations. Currently, our established patient councils include the Global Heart Failure Patient Council and the Global Heart Valve Disease Patient Council. Other patient organisation working groups are currently being formed with the aim of establishing additional patient councils as the Global Heart Hub continues to grow.

Once a Patient Organisation registers with the Global Heart Hub and aligns with, and accepts, the criteria for engagement, they are invited to join a Patient Council or Councils working in an area relevant to their interests. Patient Organisations can join the Global Heart Hub as a general affiliate without being attached to a patient council.

Global Heart Hub Limited by Guarantee



Global Heart Hub Governance and Transparency

The Global Heart Hub is a registered Charity with its offices based in Ireland. The charity is governed by a board of directors who offer their service and expertise in a voluntary capacity. They do not receive any remuneration for fulfilling this role.

Patient Organisations / Individual Patient Advocates / Associate Organisations who affiliate to the Global Heart Hub do so without any cost or legal obligation to themselves or their organisations. They affiliate on the basis of common interest and in the spirit of collaboration.

Each Patient Council is led by an agreed Council Chair who volunteers to be the liaison link between the Patient Council and the Executive Director/Secretariat of the Global Heart Hub. The Chair of each Council is agreed for a two year period. Neither the Chair nor any affiliate of a Patient Council receives any remuneration for their activities with the Global Heart Hub.

Each Patient Council agrees its own work agenda/activities and is responsible for securing the necessary funding. The Chair of each Patient Council agrees its work programme/activities with the Executive Director/Secretariat who in turn lead the approach to funders and take responsibility for project management.

The work of the Global Heart Hub is largely funded through grants from industry, which are either unrestricted or by way of sponsorship of specific activity initiated by the Global Heart Hub. The Global Heart Hub believes that ethical and transparent collaboration between industry and patient organisations contributes to valuable and important healthcare discussions, which ultimately lead to improved outcomes for patients. We undertake to, at all times, disclose the names of all our industry funders; seek support from multiple funders (to avoid real or perceived exclusive relationships); and only work with those companies who abide by our [code of conduct](#) on working with industry.

Global Heart Hub Engagement Operating Standards

Patient Organisations - Criteria to [join a Global Heart Hub Patient Council](#):

1. Organisations must be a charity, social enterprise or not-for-profit operating in the area of cardiovascular disease.
2. Organisation leadership and membership of the patient group must predominantly comprise of those living with a cardiovascular condition, carers or patient advocates.
3. Organisations must be patient-led with ideally at least two patients on its Board of Directors.
4. Organisations who affiliate to the Global Heart Hub should be in a position to demonstrate that they have independent governance structures and transparent operating procedures in place. For start-ups, this is required within two years of affiliation.
5. Organisations must adopt/abide by the Patient Council Industry Charter.
6. If industry funded, organisations must be multi-industry funded (after 2 years for start-ups) and do not engage in the promotion of any medical product or device. Organisations must be free of any influence from any Med-Tech, Pharma industry or other enterprise which could present a real or perceived conflict of interest.

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Commitments to Engagement on a Patient Council

The work of each council is based on collective action by council members on a voluntary basis aligned with an agreed strategy (with Executive Director/Secretariat) for the sole purpose of responding to patient and carer needs, disease awareness and education, detection, diagnosis, treatment and recovery.

- Organisations must participate in the agreed council programme of engagement which includes regular virtual and/or face-to-face meetings.
- Organisations must actively engage, support and promote agreed patient council activities and projects such as awareness and social media campaigns or other agreed initiatives.

Individual Patient Advocates / Associate Organisations – Criteria to affiliate with the Global Heart Hub

1. Organisations must be a charity, social enterprise or not-for-profit operating in the area of cardiovascular disease.
2. Organisations must be patient-centric and have as part of its core mission and values the advancement of patient care, improved patient health outcomes or patient advocacy.
3. Organisations must be able to demonstrate involvement of patients or carers in its leadership or membership.
4. If industry funded, organisations must be multi-industry funded (after 2 years for start-ups) and do not engage in the promotion of any medical product or device. Organisations must be free of any influence from any Med-Tech, Pharma industry or other enterprise which could present a real or perceived conflict of interest.
5. Organisations should be in a position to demonstrate that they have independent governance structures and transparent operating procedures in place. For start-ups, this is required within two years of affiliation.
6. Individual Patient Advocates who affiliate with the Global Heart Hub cannot be an employee of, or be influenced by, any Med-Tech, Pharma industry or other enterprise which could present a real or perceived conflict of interest.