Policy for Involvement in EU Projects

Preamble

As an umbrella patient organisation representing diverse patient groups across Europe and beyond, we recognise the importance of engaging in EU-funded projects to advance research, improve healthcare policies, and promote patient-centred care. This policy outlines our commitment to participating in such initiatives effectively and ethically, ensuring that the patient voice is central to all our activities.

Principles of Engagement

Our involvement in EU projects is guided by the following core principles:

- **Patient-Centricity**: Prioritising the needs, preferences, and experiences of patients in all aspects of the project.
- **Transparency**: Maintaining open and honest communication with all stakeholders, including patients, researchers, policymakers, and industry partners.
- **Equity**: Ensuring fair and equal access to project benefits and opportunities for all patient groups, particularly those in underserved communities.
- **Collaboration**: Fostering meaningful partnerships with diverse stakeholders, including patient organisations, researchers, healthcare professionals, and policymakers.
- **Impact**: Striving to achieve tangible and sustainable improvements in patient outcomes, healthcare practices, and policies.

Areas of Involvement

We actively seek opportunities to contribute to EU projects in the following areas:

- **Research & Development**:
    - Participating in the design, conduct, and dissemination of clinical research, ensuring patient perspectives are integrated throughout the process.
    - Supporting the development of innovative treatments, technologies, and healthcare models that address unmet patient needs.

    - Promoting the use of real-world data and patient-reported outcomes to inform research and improve patient care.
- **Policy Advocacy**:
    - Contributing to the development and implementation of EU health policies that promote patient empowerment, access to care, and quality of life.
    - Advocating for the inclusion of patient perspectives in decision-making processes related to healthcare funding, regulation, and innovation.
    - Monitoring the impact of EU policies on patient populations and advocating for necessary changes.
- **Capacity Building**:
    - Providing training and resources to empower patients and patient organisations to participate effectively in EU projects and healthcare decision-making.
    - Facilitating the exchange of best practices and knowledge among patient groups across Europe.
    - Supporting the development of patient-led research and advocacy initiatives.

Potential Roles for Global Heart Hub

Recognising the critical importance of the patient perspective, GHH brings invaluable experience and a broad network to joint initiatives. The following highlights the key contributions GHH can make, ensuring the patient voice is central to project activities:

- **Patient Engagement and Representation:** GHH provides a vital link to the patient community, ensuring that the lived experiences and perspectives of individuals affected by cardiovascular disease are at the forefront of project activities. GHH actively facilitates meaningful patient involvement throughout the entire project lifecycle, from initial design and planning to execution, evaluation, and dissemination. GHH prioritises diverse representation and seeks to include voices from across the CVD spectrum, encompassing varying demographics, geographic locations, and stages of disease progression.
- **Communication and Dissemination:** GHH leverages its extensive global network of patient organisations to effectively communicate and disseminate

project outcomes, key messages, and lessons learned. GHH utilizes well-developed communication tools, including its website and social media channels, to reach the wider CVD community and the general public, ensuring findings are accessible and understandable.

- **Advisory Role:** GHH can provide independent advice and guidance throughout project implementation through participation in advisory boards.

Patient Engagement Mechanisms

We employ a range of mechanisms to ensure meaningful patient engagement in EU projects:

- **Patient Advisory Boards**: Establishing advisory boards comprised of patients and caregivers to provide input on project design, implementation, and evaluation.
- **Patient Surveys and Focus Groups**: Conducting surveys and focus groups to gather patient perspectives on relevant issues and inform project activities.
- **Co-creation Workshops**: Organising workshops to co-create solutions and strategies with patients, researchers, and other stakeholders.
- **Dissemination Activities**: Involving patients in the dissemination of project results through presentations, publications, and social media.

Selection Criteria for Project Participation

To ensure effective use of resources and maximise impact, we prioritise projects that:

- Align with our organisation's mission and strategic priorities.
- Demonstrate a clear commitment to patient engagement and patient-centred outcomes.
- Involve a diverse and representative group of stakeholders.
- Have the potential to generate significant and sustainable benefits for patient populations.
- Provide adequate resources for patient involvement activities, including reimbursement for travel, accommodation, and time.

Ethical Considerations

We are committed to upholding the highest ethical standards in all our activities related to EU projects:

- Protecting the privacy and confidentiality of patient data.
- Obtaining informed consent from all patients involved in research or data collection.
- Managing conflicts of interest transparently and fairly.
- Ensuring that patient involvement is voluntary and free from coercion.
- Recognising and valuing the contributions of patients and compensating them appropriately for their time and expertise.

Review and Evaluation

This policy will be reviewed and updated regularly to ensure its effectiveness and relevance. We will also evaluate our involvement in EU projects to assess the impact of our contributions and identify areas for improvement.