

Guiding Principles

For patient involvement and engagement in cardiomyopathy research



The Global Heart Hub (GHH) supports the principle of patient involvement and patient engagement in cardiomyopathy research. The GHH Cardiomyopathy Patient Council believe that the perspective of individuals with personal experience of cardiomyopathy and the impact it can have should inform all stages of the research process to lead to better outcomes for people affected by this condition.

The Cardiomyopathy Patient community will support research projects only where researchers agree to the following guiding principles:



1. INCLUSIVITY & EMPOWERMENT

Researchers must ensure that at all times patients are at the centre of their work and that the focus is on improving patient outcomes. Patients from all communities must be able to access opportunities to be involved in the research process, and the voice of patients must be respected.



2. ACCOUNTABILITY

Researchers must recognise the need for patient confidentiality and meet all the necessary legal and ethical requirements for conducting research in the country in which the research will take place.



3. TRANSPARENCY

Researchers must be clear and transparent in all communications pertaining to the research project and the research processes should be open to adjustments to meet the needs of patients.



4. COLLABORATION

Researchers must involve and engage patients in all stages of the research project, from concept through to dissemination.



5. COMMUNICATION

Researchers must ensure that all public-facing literature is patient friendly and excludes scientific speak and jargon, using lay summaries which have been reviewed by patients. Researchers must also respond to all requests for clarifications and provide feedback on comments and alterations.



6. IMPACT

Researchers must report the findings of their work to the patients with whom they have engaged and also disseminate findings to the wider cardiomyopathy community. Where applicable, researchers should provide a plan for the translation of their research into clinical practice.

Bringing the patient to the heart of cardiomyopathy research.

globalhearthub.org/patient-councils/cardiomyopathy

 **Cardiomyopathy**
Patient Council

