

Impacts of Patient-Centered Collaboration: Application of a Continuous Engagement Plan Across Multiple Phases of the Insights and Patient Experiences With Cardiovascular Disease (IPEC) Initiative

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OBJECTIVE

- As health systems face rising costs, evolving regulations, and rapid innovation, embedding patient-centered approaches in value and access decisions requires stronger partnerships across the healthcare ecosystem.
- This poster describes a real-world model for operationalizing such collaboration through Insights and Patient Experiences with Cardiovascular Disease (IPEC), a patient-led initiative launched in 2023 by Global Heart Hub (GHH), an international alliance of heart patient organisations aiming to create a unified global voice for those living with or affected by heart disease. [1]
- The initiative aims to systematically collect and amplify patient experience data to inform healthcare decision-making by diverse stakeholders, including clinicians, researchers, policymakers, payers, and regulators, and to guide healthcare quality improvement efforts. By integrating patients’ lived experiences with scientific and clinical insights, IPEC seeks to ensure that outcomes research, policy design, and access decisions reflect what truly matters to patients.
- The IPEC model integrates diverse stakeholder input to shape methods, interpretation, and dissemination, which is directly relevant to ISPOR stakeholders working to embed patient-centered approaches in outcomes research.

APPROACH

- GHH, an international alliance of heart patient organizations, hired researchers to implement a patient-centered qualitative study on their behalf.
- IPEC Phase 1 was a three-country qualitative study. GHH engaged patient advocate country leads in Australia, Brazil, and the United States alongside physicians, researchers, and other stakeholders as part of a Steering Committee.
- In Phase 2, the initiative expanded to eight countries and includes engagement from multi-stakeholder Steering and Review committees

PROJECT TEAM

The project team is directed by GHH leadership and includes the research team at AppliedPX as research consultants.

ADVISORS ENGAGED

ORGANIZATIONS AFFILIATED WITH GHH
An organization in the GHH alliance that provides a voice for those living with or affected by cardiovascular diseases

STEERING COMMITTEE
Constituted by people with lived experience, patient advocates, clinicians, and researchers who are engaged to provide expertise, collaborate to develop study materials, and provide input on dissemination

REVIEW COMMITTEE
An additional advisory group introduced due to the scope of Phase 2 to provide lived, clinical or research experience in a specific condition or geography

WOMEN & HEART DISEASE WORKING GROUP
Representatives from organizations affiliated with GHH exploring gender disparities in access to treatment and care

ENGAGEMENT ACTIVITIES



CONCLUSIONS

- IPEC offers a replicable approach to advancing equitable and meaningful patient involvement in research.
- The initiative enhances the value and relevance of patient-generated data through structured collaboration with diverse, regional stakeholders, aligning with ISPOR’s commitment to powering access via patient-centered collaboration.

REFERENCES

[1] Johnson N, Vandigo J, De Carvalho F, Gorre C, Hall T, Hennessy SE, Kazi DS, Kotseva K, Petrie P, Kelly D, Saxena A. Experiences of People Diagnosed with High Levels of LDL Cholesterol and Atherosclerotic Cardiovascular Disease: Results from a Multinational Qualitative Study. Global Heart. 2025 Jul 15;20(1):63.

DISCLOSURES

None

