

EXPLORING THE RESULTS FROM THE PATIENTS LIVING WITH ELEVATED CHOLESTEROL (IPEC) STUDY

ISPOR | 5 May 2024 | Atlanta, GA, USA
Patient-Centered Research Summit



Steering Committee

REGULAR MEETINGS TO GUIDE INSIGHTS COLLECTION AND DATA GENERATION

- **Fernanda Carvalho**, Lado A Lado Pela Vida, Brazil
- **Celina Gorre**, CEO WomenHeart, USA
- **Tanya Hall**, CEO Hearts4heart, Australia
- **Susan Hennessy**, PhD, MHSc, BScN, RN, University of California, USA
- **Neil Johnson**, GHH
- **Dr. Dhruv S. Kazi**, MSc, MS, Richard A. and Susan F. Smith Centre for Outcomes Research, Cardiac Critical Care Unit, Beth Israel Deaconess Medical Centre, Associate Professor - Harvard Medical School
- **David Kelly**, GHH
- **Professor Kornelia Kotseva**, MD, PhD, FESC, National University of Ireland – Galway, Imperial College Healthcare NHS Trust, London, UK
- **Patsy Petrie**, HEART UK & FH Europe Ambassador & Global Heart Hub Affiliate & Member of ALLIANCE Scotland

Steering Committee Member Expectations & Acknowledgement

Roles & responsibilities

- Guide data collection
- Periodic review of the study progress
- Guide and contribute to dissemination efforts

Thinking ahead - Who Is an Author?

- The International Committee of Medical Journal Editors (ICMJE) recommends that authorship be based on the following 4 criteria:
 - Substantial contributions to the **conception or design of the work**; or the acquisition, analysis, or interpretation of data for the work; AND
 - Drafting the work or **reviewing it critically for important intellectual content**; AND
 - **Final approval** of the version to be published; AND
 - **Agreement to be accountable for all aspects of the work** in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

Patient Experience Mapping



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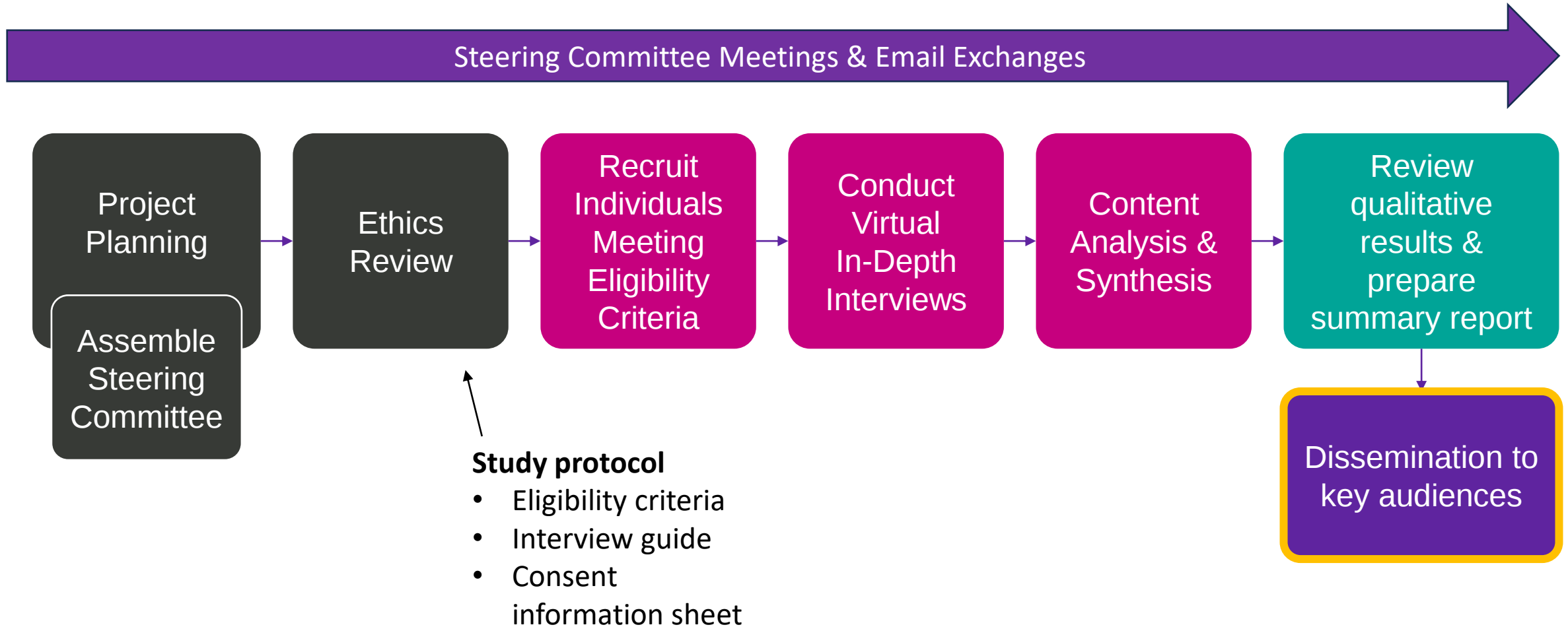
Research Objective

Describe people's experiences living with and treating high cholesterol and ASCVD in the United States, Brazil, and Australia

- Pathways and barriers to a high LDL-C diagnosis
- The burden of managing high LDL-C, including the impact on family members, work or student life, comorbidities, finances, and other life factors/social determinants of health.
- Patient awareness of the association between high LDL-C, and other risk factors, for heart disease and stroke
- Perspectives on current and future treatments for high LDL-C, including meaningful treatment benefits.



Study Overview



Patient Experience Mapping Toolbox



Project Planning

- Introductory video
- Project Coordinator Guide
- Interviewer Training Guide

Data Collection Tools

- Plain language consent form
- Interview Guide Template
- “Map My Experience” visual

Developing the draft interview guide(s)

Life Before Getting a Diagnosis

- Symptoms
- Questions and information gathering
- Emotional health and personal goals
- Life factors
- Transition to seeking a diagnosis
- Awareness of LDL-C & of ASCVD
- Comorbidities prior to diagnosis

Getting a Diagnosis

- Seeking care
- Follow-up care
- Changed diagnosis/ misdiagnosis
- Treatments
- Symptoms
- Questions and information gathering
- Emotional health and personal goals
- Life factors
- Transition to living with a diagnosis
- Diagnosis prior to or at birth, or as a young child
- Understanding if the rationale for treatment was explained (to prevent an event)
- Adherence to lifestyle changes & treatment
- Understanding if living with cholesterol is lifelong (connecting this to adherence)

Living with a Diagnosis / Post-event

- Impacts on daily life
- Care routine & satisfaction with care
- Treatment they are currently getting
- Treatment they have tried but stopped
- Ideal treatment
- Surgeries and procedures
- Hospitalizations/ urgent care visits
- Clinical trials
- Life factors
- Care coordination & multiple chronic conditions
- Quality measurement
- Genetic testing
- Emotional health and personal goals
- Desired outcomes and life aspirations
- Understanding what it would take to permanently alter their lifestyle

For individuals who have had an event

- Level of understanding of risk factors for heart disease and stroke prior to their cv event
- Level of understanding of the role LDL-C plays in cardiovascular disease
- Change in lifestyle habits & adherence to the changes
- Level of concern about having a second event
- Understanding if being on treatment provides enough confidence to not look back at the event

Awareness of heart disease before event	What did you know about your heart disease risk before your [cardiac event]? • Did your doctor explain your overall heart disease risk to you before your [cardiac event]? How? • Do you have a family history of heart conditions?
LDL-C: awareness before event	• Were you aware that you had high cholesterol before [event or symptoms]? Could you tell me more about what you knew?
LDL-C: medicine before event	• Were you taking medication for high cholesterol before [event or symptoms]? • What medicines were you taking? Were you aware at that time that the medicines were for high cholesterol?

Target Population & Eligibility Criteria

Inclusion Criteria

Adult (“Age of majority”) in their state or country

Diagnosed with high cholesterol (high-LDL-C) by a physician at least two years ago

Able to participate in an interview lasting approximately 60 minutes

Able to read and communicate in:

- AUS English (Australia)
- Portuguese (Brazil)
- US English (US)

Resident of Australia (n=15); Brazil (n=15) / the United States (n=15)?

Has an internet connection with a laptop, desktop, or tablet

Exclusion Criteria

Currently incarcerated

Sampling priorities among those meeting eligibility criteria

Approximately half from each country must have one of the following:

At least **one year ago**, experienced a hospitalization for any of the events below:

- ☐ Heart attack (myocardial infarction or MI)
- ☐ Unstable Angina
- ☐ Ischemic Stroke
- ☐ Peripheral Artery Disease

Diagnosed with high LDL-C at least one year before the cardiac event.

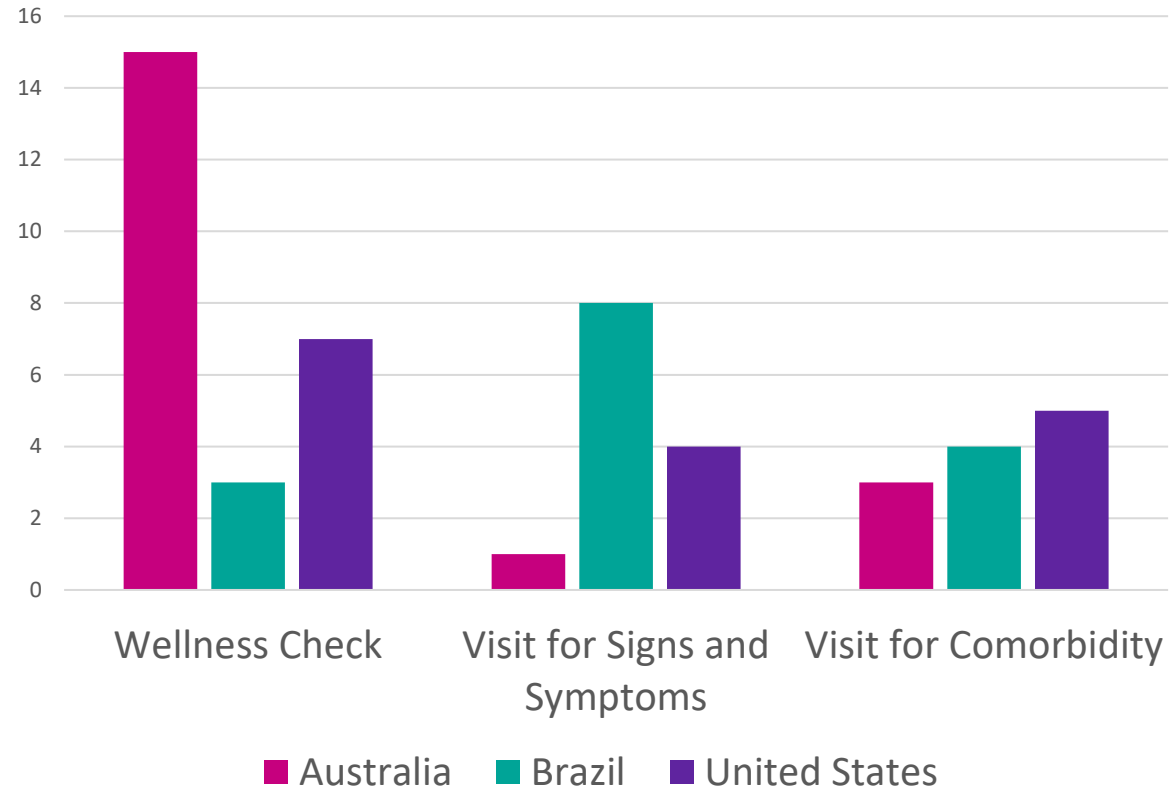
- ☐ Yes
- ☐ No (not eligible)

Example Results & Dissemination Plan



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In the IPEC study, only half of the participants received their initial high cholesterol diagnosis from a primary care physician during an annual physical examination.



Participants at diagnosis often felt:

- Overwhelmed by multiple concurrent diagnoses and unfamiliar medical terms
- That the risks of high cholesterol were not adequately conveyed
- Reassured when HCPs recommended lifestyle changes without a medicine

Factors impacting care plan adherence

HEALTH SECTOR

Provider availability, engagement, and time
Seriousness conveyed by provider
Bias (Age, Race, Gender, Weight)
Specificity of treatment plan or target goals
Adequacy of insurance coverage
Out-of-pocket costs

NON-HEALTH SECTOR

Seriousness understood by individual
Time to build into routine
Cost and availability of food
Work obligations
Family support

Dissemination Plan

ISPOR 2024 – ACCEPTED

5 – 8 May // Atlanta, GA, USA

UNDERSTANDING THE PATIENT EXPERIENCE WITH HIGH CHOLESTEROL IN THE UNITED STATES: A PATIENT-COMMUNITY-LED QUALITATIVE STUDY

EUROPEAN ATHEROSCLEROSIS SOCIETY (EAS) 92ND CONGRESS – ACCEPTED

26 – 29 May // Lyon, France

INTERNATIONAL HYPERLIPIDEMIA PATIENT UNDERSTANDING OF CARDIOVASCULAR DISEASE RISK FACTORS AND THERAPEUTIC OPTIONS: RESULTS FROM A PATIENT-LED STUDY

72nd CARDIAC SOCIETY OF AUSTRALIA AND NEW ZEALAND (CSANZ) ANNUAL SCIENTIFIC MEETING – SUBMITTED

01 – 04 August // Perth, Australia

Notified End of May 2024

POLICY TARGETS TO IMPROVE DIAGNOSIS AND TREATMENT OF HYPERLIPIDEMIA IDENTIFIED BY PEOPLE LIVING WITH HYPERLIPIDEMIA: RESULTS FROM A PATIENT-LED STUDY

79th CONGRESSO BRASILEIRO DE CARDIOLOGIA – SUBMITTED

20 – 22 September // Brasília, Brazil

Notified June 2024

BRAZILIAN PATIENT EXPERIENCES FROM THE INSIGHTS FROM PATIENTS LIVING WITH ELEVATED CHOLESTEROL (IPEC) STUDY: A PATIENT-LED INITIATIVE

EUROPEAN SOCIETY OF CARDIOLOGY (ESC) CONGRESS 2024 – SUBMITTED

30 August – 02 September // London, England

Notified Early May 2024

PERSONALIZING CARDIOVASCULAR CARE BY TAILORING SHARED DECISION-MAKING TOWARD PATIENT PRIORITIES & NEEDS: RESULTS FROM A PATIENT-LED STUDY

AMERICAN HEART ASSOCIATION SCIENTIFIC SESSIONS

16 – 18 November // Chicago, IL, USA

Deadline: 06 June 2024 // Notified TBD

TBD

