

# Improving the Patient Pathway:

The value of patient experience data -  
Insights from Patients living with Elevated Cholesterol  
(IPEC) case study

Unite Summit  
*November 4, 2024*



# What are patient experience data (PED)?

*Patient experience data (PED) is an umbrella term that describes patients' experiences, perspectives, needs, and priorities related to a disease or condition.*

Data collected are intended to provide information about patients' experiences with a disease or condition.



# The Value of Patient Experience Data

PED are a valuable asset that can be used to improve healthcare delivery and enhance patient-centered care.

PED can offer a better understanding:

- Physical and psychosocial impact of a disease
- Ways to improve quality of care
- Unmet patient needs
- Evolving informed decision making
- Ways to enhance patient education and engagement



# A first of its kind EXAMPLE led by the cardiovascular community



**RESEARCH OBJECTIVE:** to collect and deliver insights regarding the lived experiences of individuals whose LDL-C levels are not at target

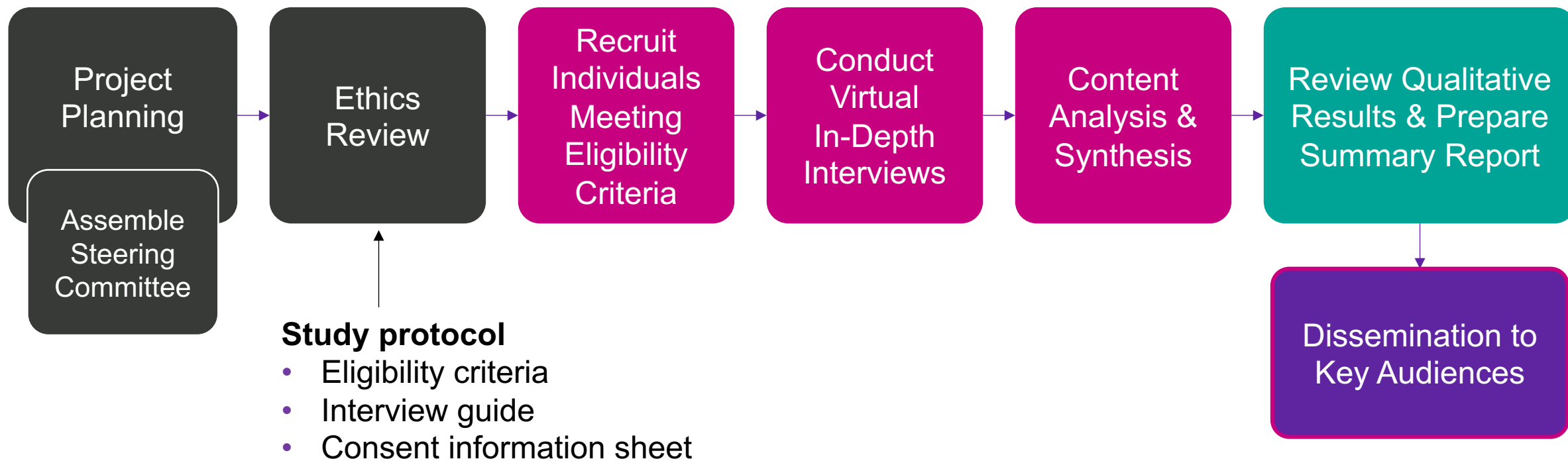
- Countries involved: **United States, Brazil, and Australia**
- **Led by an independent specialist multidisciplinary steering committee** comprised of patient community representatives, clinicians and academics
- Data collected through interviews based on the National Health Council's Patient Experience Mapping Toolbox; aligned with **FDA patient-focused drug development methodology**
- Study protocol approved by an independent Institutional Review Board registered with the FDA

Insights from Patients living with Elevated Cholesterol



# A thorough process

Steering Committee Meetings & Email Exchanges



# What we looked for

**IPEC set out to better understand the experiences, opinions, and needs of individuals whose cholesterol levels are not at target.**

Recognizing that lowering LDL-C levels plays a crucial role in reducing the risk of ASCVD events, all participants who took part in IPEC:

- Were diagnosed with high LDL-C by a physician at least two years prior to the start of data collection
- Approximately half of participants were individuals who had been hospitalised for an ASCVD event at least one year after their high LDL-C diagnosis

## Objectives

- Explore the pathways to diagnosis for high LDL-C
- Understand the burden of managing high cholesterol and gauge patient awareness of associated risks
- Evaluate perspectives on current and future treatments



# What we uncovered: **Key findings**

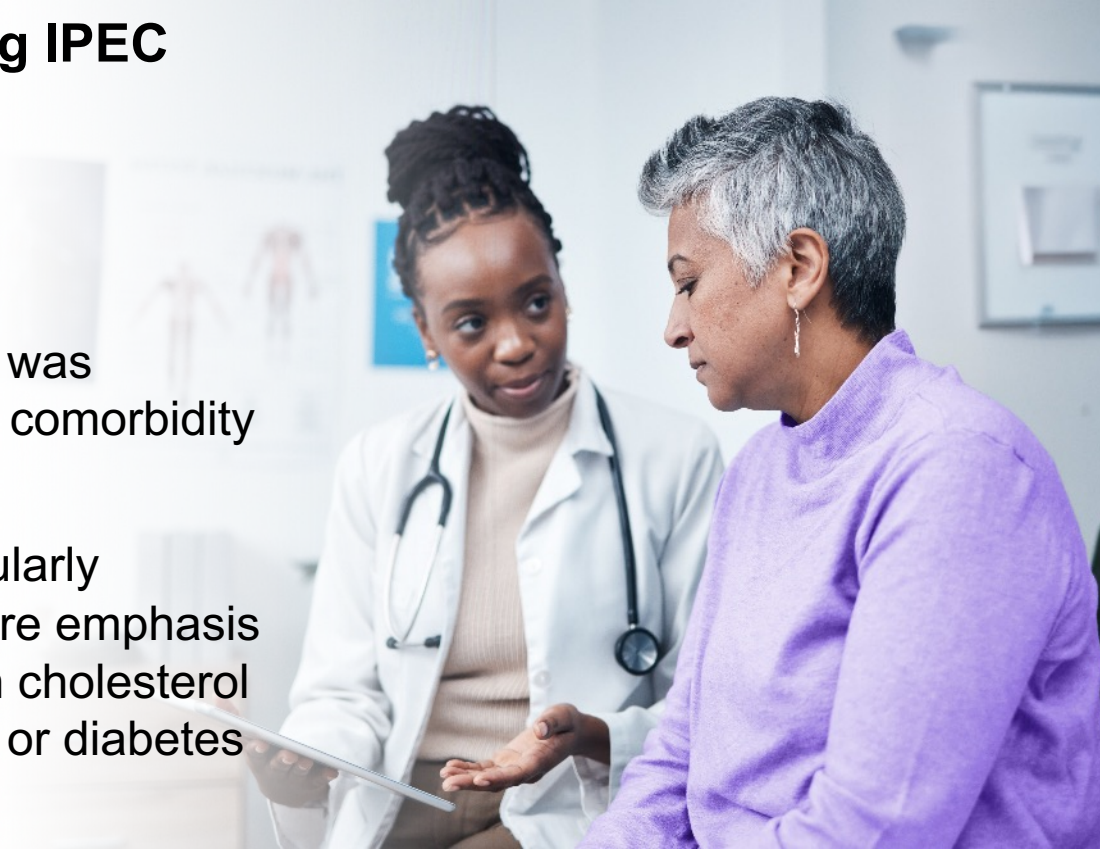
- The most common path to diagnosis ( 50%) was a diagnosis **by a primary care physician during an annual physical exam.**
- One-quarter ( 26%) **experienced symptoms** such as shortness of breath, nausea, dizziness, or general discomfort **before diagnosis.**
- **Challenges** among participants in managing high cholesterol following diagnosis:
  - Making and sustaining lifestyle changes and adhering to medication regimes.
  - Life factors, including career and family obligations, often hinder sustained lifestyle changes.

We also learned about other barriers, including:

- A general **lack of awareness** of the seriousness of high LDL-C and the role of treatment at diagnosis.
  - One-third (36%) didn't understand the risks of high cholesterol, and only half ( 46%) knew lipid-lowering therapies are lifelong.
- **Meaningful treatment benefits** include improving laboratory values, avoiding heart-related events and living longer to spend more time with family.
- Most of the 22 people who had ASCVD event **did not immediately recognize their symptoms** as heart-related (68%), delaying care (Sometimes waiting hours or days before seeking care).
- **Healthcare providers** (54%) and **internet resources** (40%) were the most frequently mentioned **trusted information sources.**

# What we uncovered: Comorbidity findings

- **Prevalence of most reported comorbidities among IPEC participants:**
  - Diabetes: **40%**
  - High blood pressure: **66%**
- For one quarter of participants (24%), elevated cholesterol was discovered through a healthcare interaction related to their comorbidity (e.g., seeing an endocrinologist for diabetes care)
- Some participants perceived that their HCP was not particularly worried about their high cholesterol because there was more emphasis on some of their co-existing conditions instead of their high cholesterol care plan (e.g., received medicines to treat blood pressure or diabetes but no medicines for high cholesterol)





# International visibility

- **IPEC data is reaching clinicians, policy makers and decision makers at major international congresses**
- Abstract acceptance and 5 congress poster presentations to date



## Endorsement by the clinician community

“The EAS supports the key and important work done by the Global Heart Hub, which is bringing the voice of the patients living with cardiovascular disease and high cholesterol to the world stage. It is wonderful to see that their work is being presented in Scientific Arenas such as the EAS annual Congress 2024 in Lyon and elsewhere. There are three players, the **health system**, the **physicians** and the **patients** that need to come together to improve cardiovascular disease management. The EAS has long supported patient centered advocacy and look forward to seeing what we can achieve with the Global Heart Hub in 2024 and beyond.”

**Professor Kausik Ray**

*President, European Atherosclerosis Society*



# Value for patients

- **IPEC is creating a platform for patient organizations to actively engage in conversations with clinicians, policy makers and decision makers**
- Showcasing regional data at country-level congresses is creating powerful opportunities for local stakeholder engagement.



## Historical multi-stakeholder roundtable event the start of CVD policy change in Brazil

First-ever cholesterol-focused multi-stakeholder event held in Brazil triggered conversations around the country's first national strategy CVD

Audience of cardiologists, primary care representatives, nurses, policy makers, politicians and political advisors and representatives from the Pan American Health Organization (PAHO/WHO)

IPEC patient experience data presented by Lado a Lado

# IPEC congress highlights



## ISPOR 2024 – PRESENTED

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



## EAS 92<sup>nd</sup> CONGRESS – EUROPEAN ATHEROSCLEROSIS SOCIETY – PRESENTED

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



## ESC CONGRESS 2024 – EUROPEAN SOCIETY OF CARDIOLOGY – PRESENTED

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



## CARDIAC SOCIETY OF AUSTRALIA AND NEW ZEALAND 72<sup>nd</sup> CSANZ Annual Scientific Meeting – PRESENTED

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



## SOCIEDADE BRASILEIRA DE CARDIOLOGIA 79 Congresso Brasileiro de Cardiologia – PRESENTED

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

## AHA SCIENTIFIC SESSIONS – ACCEPTED

16 – 18 November // Chicago, IL, USA

TITLE: EFFECTIVELY COMMUNICATING THE SERIOUSNESS OF HIGH CHOLESTEROL AT DIAGNOSIS TO IMPROVE SHARED DECISION-MAKING AND ADHERENCE: FINDINGS FROM THE PATIENT-LED “INSIGHTS FROM PATIENTS LIVING WITH ELEVATED CHOLESTEROL” (IPEC) STUDY

## ACC.25 – SUBMITTED

TITLE: INTERNATIONAL PATIENT EXPERIENCE WITH LOW-DENSITY LIPOPROTEIN CHOLESTEROL (LDL-C) LABORATORY TESTING AND INTERPRETATION: FINDINGS FROM THE PATIENT-LED “INSIGHTS FROM PATIENTS LIVING WITH ELEVATED CHOLESTEROL” (IPEC) STUDY



# This is just the beginning...

## Continuity of IPEC & PED is vitally important

### Aim to add qualitative patient experiences from:

- Additional countries, documenting their experiences with high LDL-C & ASCVD
- Scale to quantitative study

### Explore additional topics:

- The differences in the experiences of men and women
- Underlying reasons for reinitiating treatment after discontinuing (without having an event)
- Understanding co-morbidities and the high LDL-C patient



Thank you.

