

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

N. Johnson¹, J. Vandigo², F. De Carvalho³, C. Gorre⁴, T. Hall⁵, S. Hennessy⁶, DS. Kazi⁷, K. Kotseva⁸, P. Petrie⁹, **D. Kelly**¹, E. Oehrlein²

(1) Global Heart Hub; (2) Applied Patient Experience; (3) Instituto Lado a Lado pela Vida; (4) WomenHeart, (5) hearts4heart; (6) University of California, San Francisco; (7) Beth Israel Deaconess Medical Center & Harvard Medical School; (8) National University of Ireland; (9) HEART UK & FH Europe Foundation Ambassador

Abstract: MDP1166



Scientific
Sessions



November 16-18, 2024
Chicago, IL

FINANCIAL DISCLOSURE

LIST ALL DISCLOSURES FROM PAST 12 MONTHS

Presenter: David Kelly

None

Co-author: N Johnson

None

Co-author: J Vandigo

Employed by Applied Patient Experience, LLC, which has contracts with a variety of nonprofit organizations, pharmaceutical companies, and academic institutions

Co-author: F De Carvalho

None

Co-author: C Gorre

None

Co-authors: T Hall

None

Co-author: S Hennessy

None

Co-author: DS Kazi

None

Co-author: K Kotseva

None

Co-author: P Petrie

None

Co-author: E Oehrlein

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Global Heart Hub's
Insights from Patients living with Elevated Cholesterol (IPEC)
study is a patient-led initiative made possible with the support
of Novartis Pharma AG.



BACKGROUND AND AIM OF IPEC

IPEC AIM: To learn from people with high cholesterol about their experiences, decisions, and perspectives on being diagnosed and living with high LDL-C

- Shared decision-making aims to improve health outcomes by empowering patients to make informed decisions with their healthcare providers.
- While decision aids guide treatment choices, they may not help providers effectively communicate the importance of treatment and the risks of non-adherence.
- We explored patient perspectives on shared decision-making and communication of CVD risks upon diagnosis with elevated LDL-C, a significant risk factor for CVD.

METHODS AND MATERIALS

- Seven-member multidisciplinary **Steering Committee** provided feedback on the study protocol, interview guide, and screening criteria and reviewed the findings
- Study protocol (Pro00074986) was submitted to Advarra and deemed to have met the criteria for exemption from IRB oversight under 45 CFR 46.104(d)(2)
- Interviews with 50 adults from Australia, Brazil, and the US diagnosed with high LDL-C **by a physician** at least two years ago
- Targeted half to have experienced ASCVD hospitalization
- Interview guide adapted from the National Health Council's Patient Experience Mapping Toolbox (PEMT) interview guide **[1]**

[1] National Health Council. Patient Experience Mapping Toolbox. Available at: <https://nhcstag.wpengine.com/additional-resources/patient-experience-map/>

RESULTS: PARTICIPANT EXPERIENCES

Diagnosis Encounter

Overwhelmed

Concerned

Information Sources

Health care provider
(#1)

The Internet
(#2)

Impact of Comorbidities

Relationship with
diagnosis

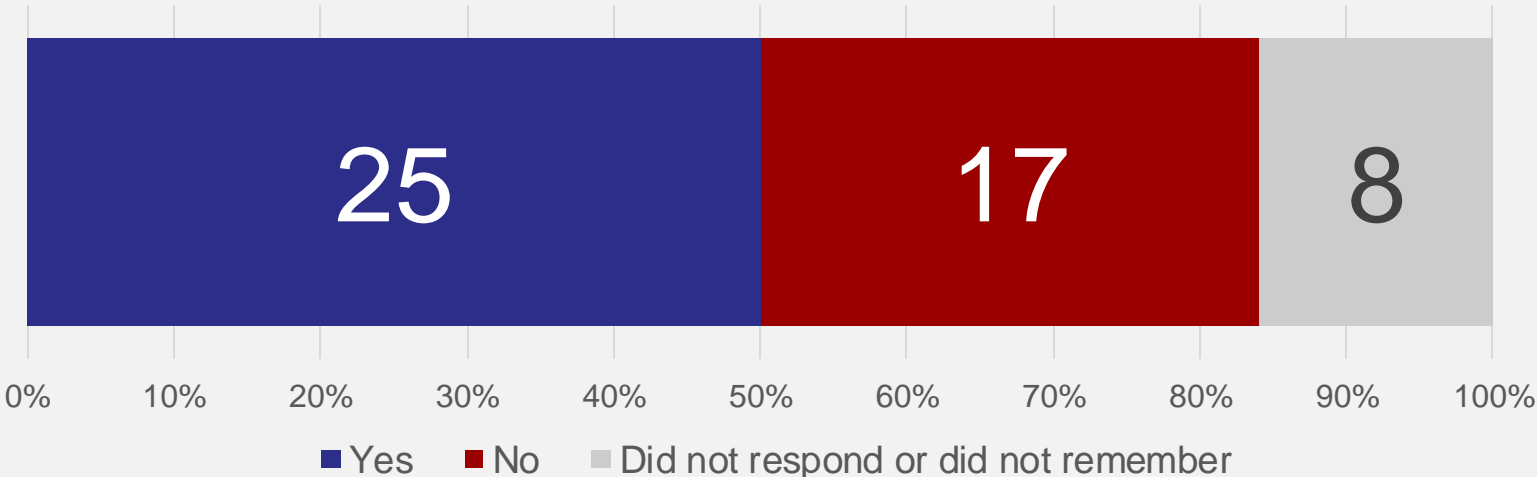
Potential for
deprioritization

Table 1. Characteristics of people participating in the Insights from Patients living with Elevated Cholesterol (IPEC) Study

Characteristic	Total	%
ASCVD event (n, %)		
Yes	22	44%
Country		
Australia	19	38%
Brazil	15	30%
United States	16	32%
Age (mean, SD)	54.7	10.7
Sex (n, %)		
Female	25	50%
Comorbidity (n, %)		
Diabetes	20	40%
High Blood Pressure	33	66%

RESULTS: LINKING HIGH CHOLESTEROL AND HEART DISEASE

Was the link between high cholesterol and heart disease made at diagnosis?



RESULTS: PARTICIPANT SUGGESTIONS

Share examples from real people living with high cholesterol

*I would start off with the education part of lowering your cholesterol could significantly lower your chances for heart disease, heart attack. **I would try to give examples of things that I have done myself**, and show little snippets of – or videos of me actually doing these things [. . .]*

IPEC participant from the United States who had experienced an ASCVD event

Build in repetition for key clinical messages

Probably in my case, it's effective just to hear it all the time. I can be stubborn and tend to do things at my own pace. So, I'm the kind of individual that constantly needs to hear it, probably, for it to be most effective.

IPEC participant from the United States who had experienced an ASCVD event

Be blunt about the risk of cardiac events

Put it very strongly so that the person understands because sometimes we don't take it as seriously as I didn't take it.

IPEC participant from Brazil who had experienced an ASCVD event

CONCLUSION

- Overcoming indifference towards high LDL-C presents an opportunity to improve cardiovascular care.
- Effective communication between people with high cholesterol and healthcare providers at diagnosis and beyond, such as around the emphasis on the severity of high cholesterol and care plan, is crucial.