Exploratory Study of Women's Experiences with Cardiomyopathy: Findings from IPEC 2

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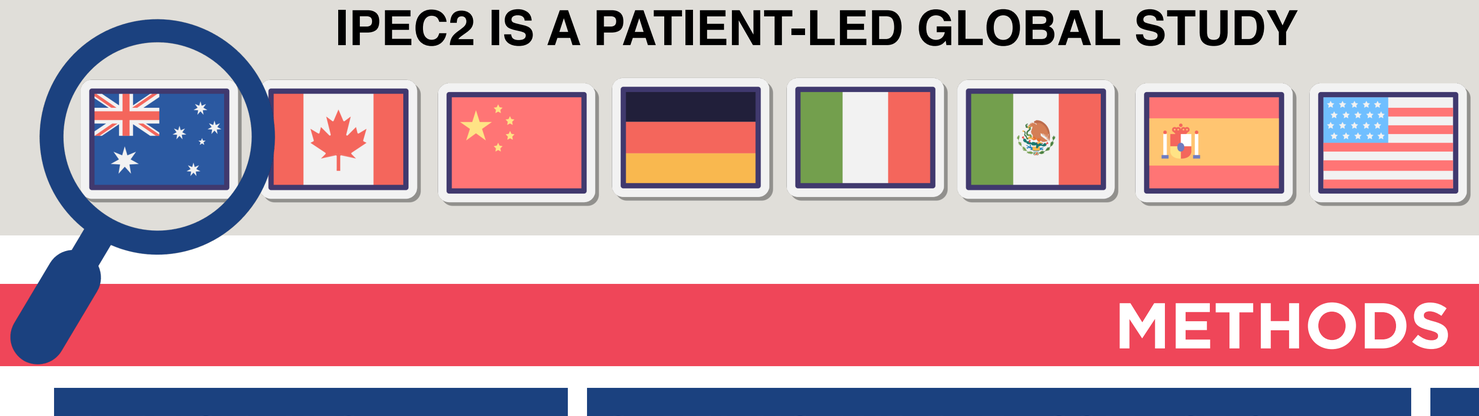
IPEC2 IS A PATIENT-LED GLOBAL STUDY



This patient-led study, conducted as an Australian sub-analysis of **Insights & Patient Experiences with Cardiovascular Disease** (**IPEC 2**), explored the experiences of women living with cardiomyopathy to identify opportunities for partnerships to improve care.

METHODS

PARTICIPANTS
Adult women living in Australia with physician-confirmed cardiomyopathy

SAMPLING AND DATA COLLECTION
- Purposive sampling
- Virtual focus group discussions (90-minute)
- Conducted by Australian moderator
- Semi-structured discussion guide

ETHICS
- Advarra advisory review
- Protocol: Pro00089336
- Exempt under 45 CFR 46.104(d)(2)

ANALYSIS
Iterative thematic analysis

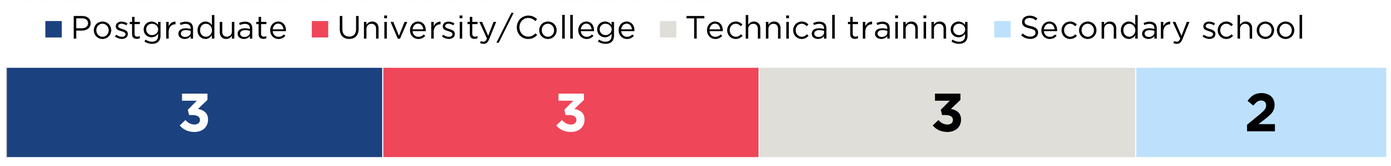
PARTICIPANT CHARACTERISTICS

13 PARTICIPANTS IN TWO FOCUS GROUPS

CARDIOMYOPATHY TYPE

ABBREVIATIONS: ACM: arrhythmogenic cardiomyopathy; HOCM: hypertrophic obstructive cardiomyopathy; HCM: hypertrophic cardiomyopathy; LVNC: left ventricular non-compaction

HIGHEST EDUCATION LEVEL

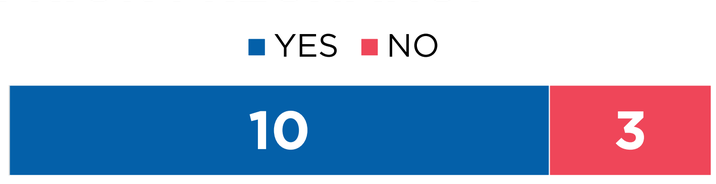


PROCEDURES AND DEVICES*

*Total exceeds 13 as participants could report multiple procedures and devices. **ABBREVIATIONS:** ICD: implantable cardioverter-defibrillator; CRT: cardiac resynchronization therapy

HOSPITALIZATION IN LAST YEAR

PRIOR PREGNANCY



PRIVATE HEALTH INSURANCE

KEY THEMES AND ILLUSTRATIVE PARTICIPANT QUOTES

Women with cardiomyopathy perceived substantial gaps in sex-specific cardiovascular care.

"I asked, 'How is this going to affect me moving into menopause?' And he dismissed the question." [FG01]

One thing, I haven't been pregnant since diagnosis. But I found it interesting that I'm in my late 30s and I have two young children and no one at all has broached the topic of whether I want to have more children and how that might be managed. It's interesting. It's like it's just completely not even something to talk about or a consideration. [FG02]

Women with cardiomyopathy described experiencing unmet educational, rehabilitation, and psychosocial support needs.

"I did have preeclampsia in one of my pregnancies, but heart issues down the track was never mentioned. I was very young, that pregnancy. I guess just a conversation about keeping on top of my heart health, perhaps having ECGs, monitoring things like that. 'Cause I've never had any testing on my heart until it all went right up in the air." [FG02]

Women with cardiomyopathy envisioned a coordinated, multidisciplinary, and person-centred model of care.

"I think there needs to be multidisciplinary support after diagnosis, just like cancer diagnoses get." [FG01]

Cardiomyopathy was unexpected and poorly understood before diagnosis

"Before I was diagnosed, I was 39, so it wasn't even a blip on the radar. It wasn't in my mind at all. [...] I guess because of my age I didn't think that it was something I had to worry about at all." [FG01]

Women experienced prolonged, complex, and often invalidating diagnostic journeys

"GP basically said asthma, pumped me full of steroids for months and months and months. And then I went back and he said, 'No, you're overweight. That's the issue.' [FG01]

Participants became the drivers of their own care

"It really pushes you to very quickly deep dive, so you're able to be your own advocate and to ask and push... What are the next steps?" [FG01]

Fragmented healthcare systems placed the burden of care coordination on patients

"I waited months and months for a genetic appointment... It was then six months before I got results." [FG02]

Living with cardiomyopathy created ongoing uncertainty and psychological burden

There's something inherently stressful about being diagnosed with a condition where you may die suddenly... I wish there was more attention given to the psychological support." [FG02]

Cardiomyopathy fundamentally altered identity and everyday life

"Suddenly, I was dependent on people and it was very hard." [FG02]

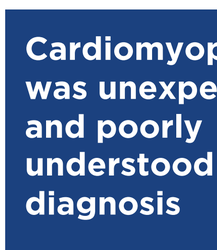
The invisible nature of cardiomyopathy created misunderstanding, isolation, and changing relationships

"I even find it within my family, that people don't realize how unwell I actually am." [FG02]

CONCLUSION

Opportunities exist to improve woman-centered cardiomyopathy care through earlier recognition, coordinated multidisciplinary care, proactive counseling, and improved patient support.

PRESENTER



Leigh Bell
President

CARDIOMYOPATHY Australia New Zealand
The Big-Hearted Community

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IPEC 2 Insights & Patient Experiences with CVD

Global Heart Hub

DISCLOSURES

Global Heart Hub's Insights and Patient Experiences with Cardiovascular Disease (IPEC) study is a patient-led initiative made possible with the support of Amgen Inc, Daiichi Sankyo Europe, and Novartis Pharmaceuticals Corporation.

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