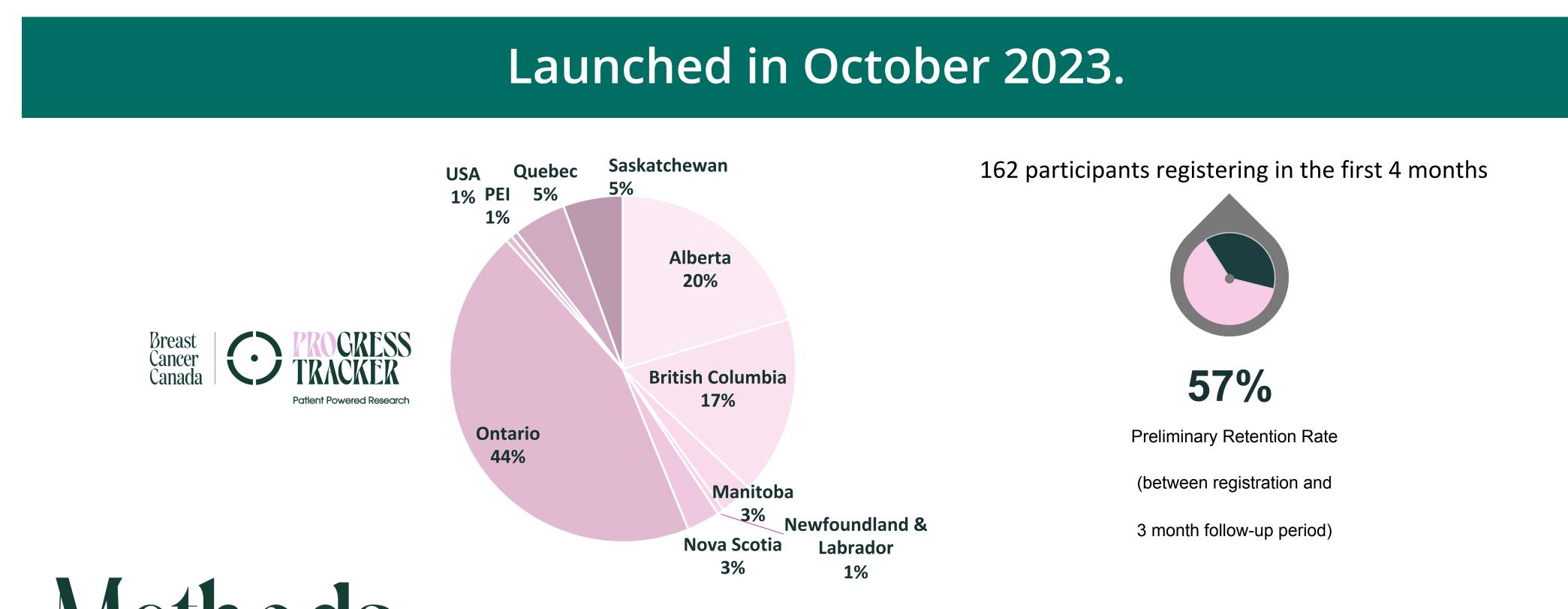


PROgress Tracker Breast Cancer Registry: feasibility of a longitudinal patient-led, patient-reported outcomes (PROM) registry.

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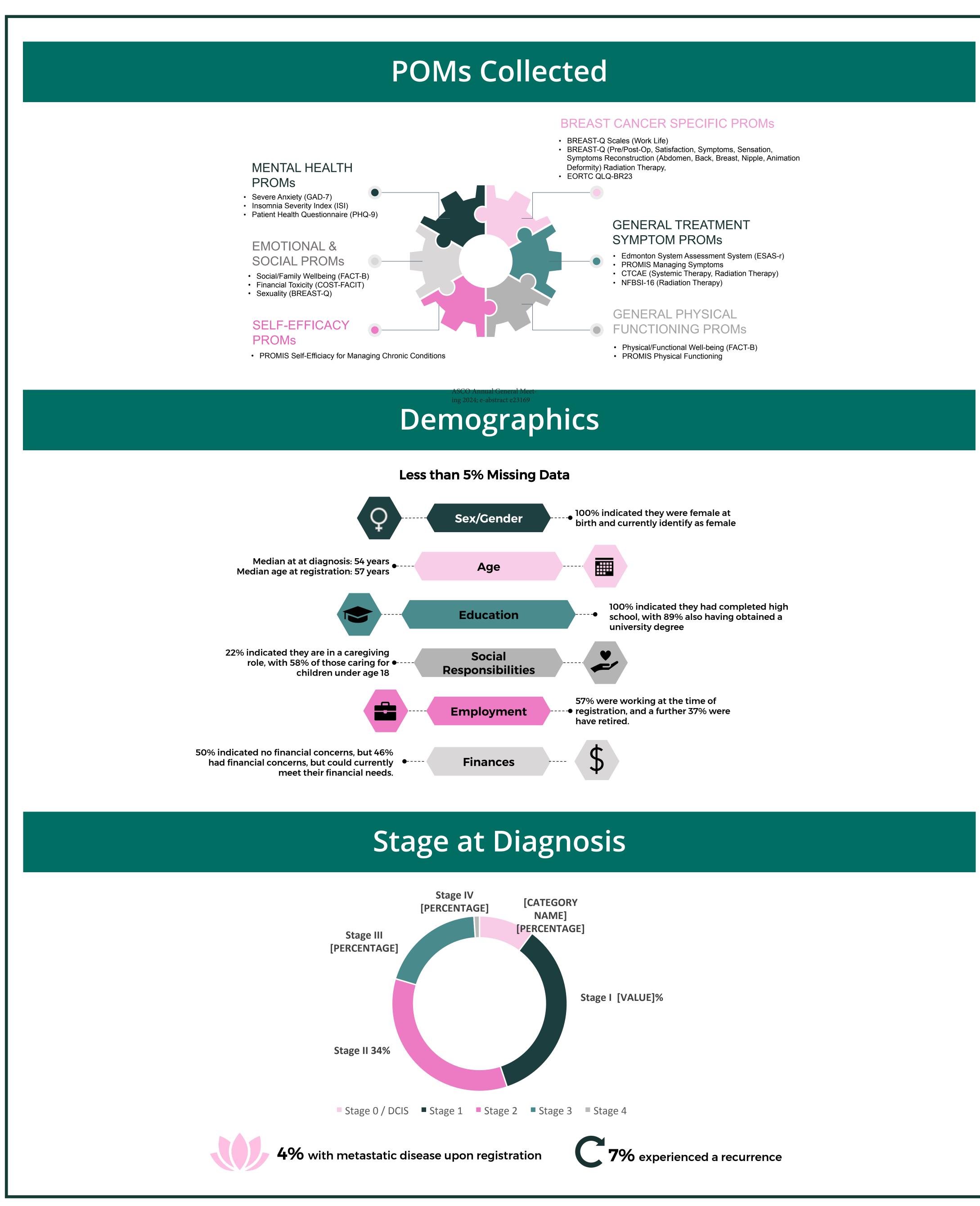
Background:

A breast cancer diagnosis has the greatest disability-adjusted life years lost of all cancers and significant impact on physical, psychoemotional, social and overall global functioning.1-3 Directed by Breast Cancer Canada, a registered non-profit patient-led organization and data managed by the University of Calgary's POET Program, PROgress Tracker uses a novel, peer-to-peer support model for recruitment, engagement and retention, and is the first national longitudinal and non-interventional PROMs registry. Our aim is to demonstrate the feasibility and potential of this registry in centering patient voice and lived experience to transform breast cancer management.



Methods

PROgress Tracker, with 10-year enrollment goal of 50,000 Canadians with Stage 0-IV breast cancer, extends a series of validated PROMS (PROMIS, BREAST-Q, FACT-B, GAD, PHQ-9, COST-FACIT, ISI and ESASr-CA) via a digital platform every 3 months for up to 10 years. 8,9 Dynamic customization of additional PROMs (PRO-CTCAE, BREAST-Q) based on patient and treatment-specific trigger questions assess evolving components of wellbeing, including financial stress, work life and adverse treatment effects.



Results:

Recruitment began in October 2023. 162 participants from all Canadian regions including remote/rural geographic areas have shared baseline demographic and clinical data including stage, genetic/molecular tumor markers, treatment type(s) and completed an initial series of PROMs. Comprehensive PROMs including sensitive topics (finances, sexuality, mental health) were completed with minimal missing data (< 5%); 3-month follow-up surveys show a current retention rate of 57%. Preliminary analysis: median age of participants 54 yrs, 95% identify as Caucasian, and 57% are currently working. 46% reported financial stress (99% response rate); 63% reported ongoing symptoms requiring follow-up. 6% were BRCA+ and 19% triple negative, 7% experienced recurrence, 3% Stage IV, 75% received systemic and/or radiation therapy, 38% received targeted therapy.

Conclusion:

The lived experience of breast cancer is integral to patient-centred change in the era of precision/personalized medicine and is captured by PROgress Tracker using a diverse set of periodic PROMs to understand the evolution of global measures of wellbeing over time. Initial data indicates that this novel peer to peer model via digital administration of comprehensive and longitudinal PROMs is feasible. This initiative demonstrates attaining this scope of data is achievable, has interest and participation from the national breast cancer community and growing capacity to accrue important, real-time data to inform best practice and identify additional supports required for breast cancer care. While early feasibility is evident, further outreach and recruitment initiatives will ensure diversity of participants.

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