

# PROgress Tracker Breast Cancer Registry: A Breast Cancer Canada initiative.

**Authors & Affiliations:** Doris Howell, Scientific Advisory Committee Breast Cancer Canada, Senior Scientist, Princess Margaret Hospital Cancer Centre Research Institute; Amanda Gibson, Precision Oncology and Experimental Therapeutics (POET) Program, Faculty Of Medicine, Department Of Oncology, University of Calgary; Shaniah Leduc, Board Chair, Breast Cancer Canada; Kimberly Carson, CEO Breast Cancer Canada; Clinical Associate Professor, Department of Oncology, University of Calgary.

## Background:

Significant gaps exist in the collection of real-world evidence and validated patient-reported outcome measures (PROMs) data from Individuals with breast cancer. Variations in treatment and surveillance care across regional jurisdictions present knowledge gaps across diverse populations which remain difficult to study. The PROgress Tracker Breast Cancer Registry, a large, prospective Canadian patient-reported outcomes cohort study aims to identify care gaps through the lived patient experience to inform patient-centered care and new research directions.

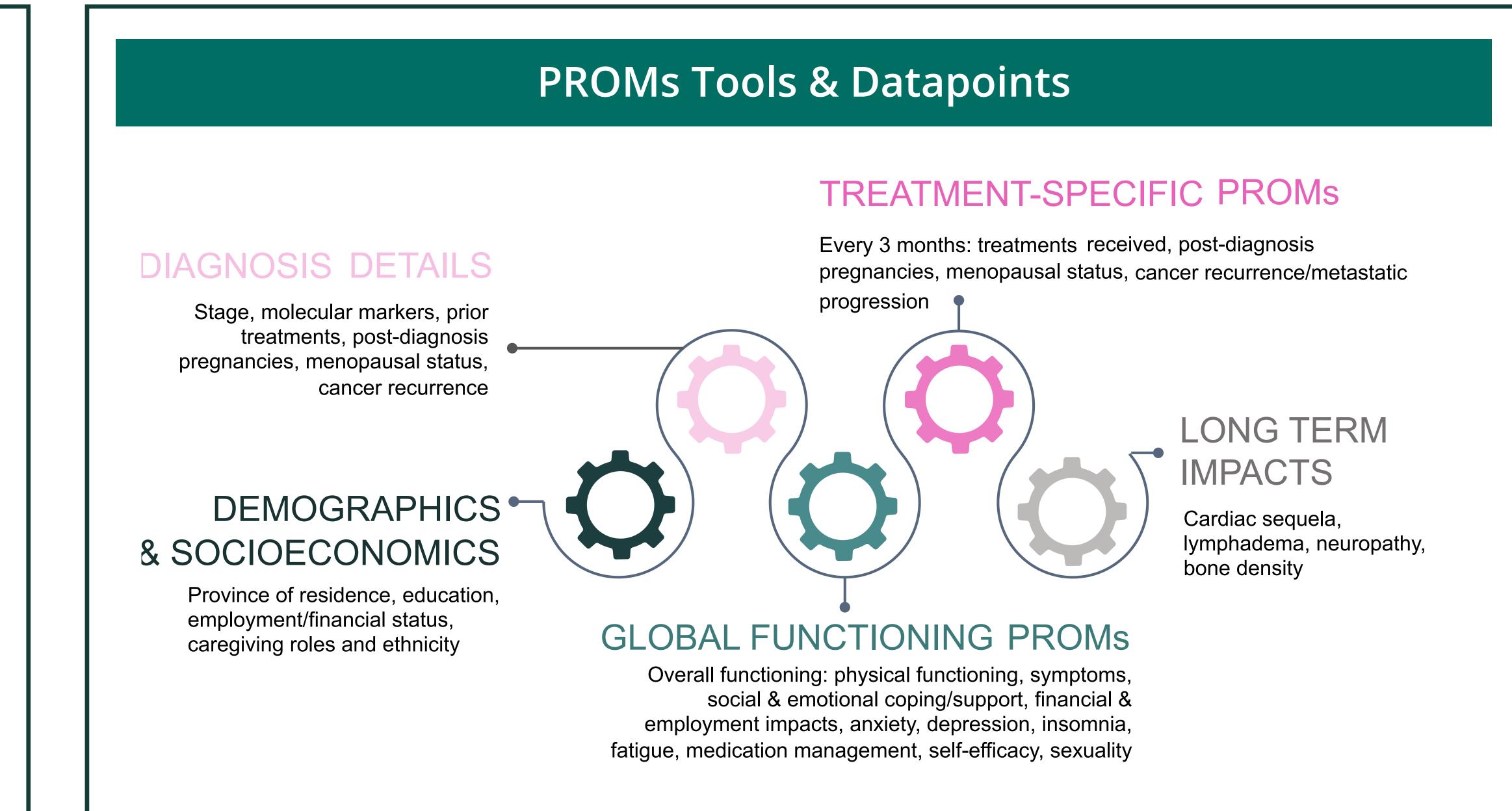
#### Conceptual Framework **Personal Factors** (Perceived severity, burden, self-efficacy, resilience) Immediate Treatment Health, Wellbeing Impacts of Cancer Demographics Clinical & and Disease-Specific Diagnosis on Global **Treatment Specifics** Long-Term Impacts Socioeconomics Functioning **Impacts Environmental Factors** (Healthcare treatment & utilization) Life Course: Longitudinal PROMs every 3 months, for up to 10 years

### Methods:

PROgress Tracker is a real-world, longitudinal, non-interventioal PROMs registry directed by Breast Cancer Canada, a registered non-profit patient-led organization, and data managed by University of Calgary's POET program. Launched in October 2023, this registry aims to enroll up to 50,000 adult Canadian participants with a histologic diagnosis of in-situ or invasive breast cancer (stage 0 through IV) within 10 years. A volunteer-led peer-to-peer support model, based in regional and provincial hubs across Canada, facilitates participant recruitment, engagement, and retention. Individuals who self-identify for study inclusion provide informed consent, demographic and socioeconomic profile, and clinical inclusion provide informed consent, demographic and socioeconomic

profile, and clinical information on their breast cancer diagnosis. Every three months (and up to 10 years) a bilingual digital platform to reduce barriers to access is used to provide all PROgress Tracker participants 8 validated PROMs to capture evolving measures of self-efficacy for wellbeing, symptoms and overall global functioning. Based on treatment, up to 10 additional PROMs to assess the immediate adverse effects and long-term impacts of treatment are collected. PROgress Tracker has the additional capacity to link to external ethics-approved studies to investigate clinical outcome and healthcare utilization metrics for participants consenting to additional studies.

#### Registry Model **ORGANIZATION** ACTIVE **FACILITATION** PEER-TO-PEER CO-Pl's Dr.'s Doris Howell and Omar Khan OGISTICS Database Software: REDCap Data management by University of dinal PROS Every 3 Months Calgary's POET Progream Registry Pathway Global **Functioning Treatment-Specific PROMs** Cancer Gathering the life experience of a breast cancer diagnosis every 3 months For 10 years



### Conclusion:

PROgress Tracker represents Canada's first national PROMs breast cancer registry. Its unique design and implementation by a patient-led research organization helps fill gaps in current knowledge through longitudinal follow up of patients prior to, during, and after cancer care, and from the time from diagnosis through active treatment, long-term survivorship, and/or palliative care. The PROgress Tracker Registry will comprehensively gather the validated real-world data information rarely collected in in the traditional clinical or trial-based research setting using a novel self-enroll design and digital process. Such information is crucial to support evidence-based decision making to inform patient-centered healthcare change. This enables comparison across Canadian jurisdictions, is scalable to other jurisdictions around the world and additionally explores the utility of electronic PROMs data capture within a diverse patient population.

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