Equitable People-centred Health Measurement (EPHM)

Novel methods for equitable people-centred health measurement

EXECUTIVE SUMMARY

It is widely recognized that health inequities are associated with poor health outcomes. Yet, current methods of measuring patient-reported outcomes (PROs) do not take individual differences in social determinants of health (SDOH) into account, resulting in potential measurement biases that reinforce these inequities by hiding or misrepresenting health outcomes of diverse people. In view of this systemic injustice, **our project seeks to develop and evaluate a novel methodology for equitable people-centred health measurement (EPHM).** We are conducting patient-oriented research to investigate this innovative methodology by applying it to the measurement of pain (i.e., symptoms of pain or discomfort and their impacts on activities) and emotional wellbeing (i.e., symptoms of depression and anxiety, and positive feelings) of adults living at home with chronic illnesses. Our EPHM methodology will be adaptable to other PROs and clinical contexts, serving as a foundational springboard for promoting equity-based health measurements to ultimately advance health equity and inform people-centred healthcare.

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SUMMARY

Health inequities are known to result in poor health outcomes. Current approaches to measuring patient-reported outcomes (PROs) do not consider individual differences in social determinants of health (SDOH) and assume that PRO scores mean the same thing for everyone. This assumption is not only false, but also inherently inequitable because our PRO measurements do not equally represent all people. As a result, health concerns of some people may go unrecognized and unattended. **We are addressing this problem by developing and evaluating a novel methodology for equitable people-centred health measurement (EPHM) that tailors PRO measurements by integrating information about SDOH in diverse populations.**

Our EPHM methodology builds on our team's expansive research and theoretical developments on measurement validity and biases. EPHM integrates modern psychometric methods (item response theory, latent variable mixture models and computerized adaptive testing) with social determinants and other health-related information into PRO measurement. Called "mixture computerized adaptive test" (*mixture*-CAT), our new method adaptively selects and scores PRO questions based on the respondents' socio-demographic context and other health-related information. It is specifically designed to administer the "right items to the right persons" in real time, thereby tailoring PRO measurements to each person, based on their socio-demographic context, in order to promote equitable health measurement.

We are conducting patient-oriented research to address the following **3 objectives** in the context of measuring pain and emotional wellbeing of people living with chronic illness: **1) Further develop *mixture*-CAT** using EPHM methods; **2) Evaluate *mixture*-CAT**; **3) Determine knowledge users' perspectives about the use of PRO results** using an integrated KT approach. Objective 1 further develops *mixture*- CAT in a mixed population of clinical and non-clinical participants. Informed by the Canada's Gender Based Analsyis Plus (GBA+) framework, we are integrating information about SDOH (e.g., age, sex, gender, race/ethnicity, language, sexual orientation, family income and housing) and health-related variables (co-morbidities, medication use and healthcare utilization) with established items banks for measuring pain and emotional wellbeing. Objective 2 evaluates predictive performance of pain and emotional wellbeing trajectories based on *mixture*-CAT compared to 3 conventional PRO measurement modalities: CAT, fixed-form PRO measures, and single-item PRO measures. Longitudinal data will be collected via a digital health platform, along with administrative health records, from 1500 adults to measure their PROs, healthcare experiences, clinical outcomes, healthcare use and SDOH. Objective 3 engages patient partners and knowledge users via a learning alliance. We are conducting in-depth qualitative research to create and refine knowledge translation (KT) resources to support understanding *mixture*-CAT as an approach to Equitable People Centred Measurement.

Our research will generate high-quality evidence to enhance equity in how we measure PROs in diverse populations. The results will provide a foundation for scaling up with application to other PROs and populations, with the ultimate goals to advance health equity and inform people-centred healthcare in diverse contexts.