

Trans PULSE Canada: Plan for a National Survey of Trans Health

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ABSTRACT

Purpose: Trans PULSE Ontario (2005-2014) was the first and only population health study of trans adults in Canada. With the support of its data, Canada has seen policy advances for trans people on human rights, gender-affirming medical care, and identity documents. The study documented inequalities (e.g. suicide risk, unmet health care needs); the extent to which these persist following policy changes is unknown. The extent to which health outcomes may differ across Canada's 13 provinces and territories, and among population subgroups, remains largely unstudied. We present the plan and protocol for Trans PULSE Canada, a national study with data collection planned for 2019.

Materials and Methods: Study aims include: 1) describing the health and social determinants of health of trans people in Canada, and comparing with the general Canadian population to identify disparities; 2) Comparing health outcomes and health care access for trans people across provinces or regions, and across time (in Ontario); 3) Generating policy-relevant data for priority populations, including those who are Indigenous, sex workers, immigrants, youth, elders, racialized, rurally/remotely located, and those who identify as gender non-binary, or live with disabilities; 4) Identifying key factors that shape trans health equity, to guide intervention strategies; and 5) Using this data source to provide responsive analysis to meet emerging information needs of policy-makers and community organizations. Finally, the development of an Indigenous research study using decolonizing methodologies has its developmental phase embedded in this project, and will use survey data to identify potential participants.

Results: Trans PULSE Canada uses a community-based research approach, with a trans-majority team and National Steering Committee, an Indigenous Leadership Group, and Priority Population Consultation Teams. We are led by a pan-Canadian team of academic, community, service provider, and policy partners. The Trans PULSE Canada survey will be a large multi-mode convenience sample, promoted as a 'community census'. All Canadian residents aged 16 and older whose gender identity does not match their sex assigned at birth will be eligible to choose to complete the full questionnaire (approximately one hour) or a short version (approximately 15 minutes) containing key items. To account for participation bias, data from the combined sample will be used to produce sampling weights for analysis of the full survey data. The self-administered questionnaire will be available in English or French, to be completed online, by paper copy, or by telephone with language interpretation. In Canada's ten largest cities, peer workers will visit community organizations with survey tablets to collect data from trans people who face barriers to participation. Given that this will be a unique data resource, participants will be consented for recontact to allow for follow-up studies.

Conclusions: Building on our earlier success in translating evidence into policy and practice, Trans PULSE Canada will use an integrated and responsive knowledge translation strategy to produce information in ways that most directly support community

NINE PRIORITY POPULATIONS

- Indigenous gender-diverse people
- Trans refugees and immigrants to Canada
- Trans sex workers
- Racialized trans people
- Trans elders
- Trans youth
- Trans people living with disabilities
- Trans people living in rural and remote areas
- Those with non-binary identities

The project team will convene a Priority Population Consultation Team (PPCT) for each of the nine groups. Each PPCT will be responsible for:

1. identifying additional questions to be added to the survey for this group specifically
2. selecting key findings for the initial report for this population
3. in conjunction with the full team, designing a knowledge translation strategy

Figure 1. Time line

Development (2018-2019)

Core survey development
PPCT formation
Targeted survey questions
Survey translation
Promotion strategy developed
Developmental phase for Indigenous gender diversity project

Data Collection (2019)

Survey data collection
Survey promotion online and in communities
Data cleaning and coding concurrent with data collection

Knowledge Translation (2020-2022)

Initial rapid reports on data from provinces/territories
Rapid reports to priority populations
Grant application for separate Indigenous-led research project following up with selected participants
Targeted reports for community or government agencies with specific and immediate data needs
Brief reports to communities
Academic papers
Infographics
Website
French and English language results, plus additional languages as needed

BACKGROUND

The Trans PULSE Project conducted the first quantitative population survey of trans health in Canada, in the province of Ontario in 2009-2010. Publications and testimony from this project were instrumental in the passing of a bill to include protection of gender identity and expression under the Canadian Human Rights Act, the listing or re-listing of gender-affirming surgeries under provincial health plans, and the implementation of policy regarding sex designations on identity documents. Survey measures and methodologies from Trans PULSE have been replicated and adapted internationally.

Ten years later, much change in policy and practice has occurred in Ontario and updated data are needed. Moreover, no all-ages data exist for many provinces and territories in Canada, and a larger data set is needed to conduct subgroup-specific analysis to inform region- and community-specific information needs and policy.

Specific policy-related information needs have been identified for priority populations.

COMMUNITY-BASED RESEARCH STRATEGY

- Study combines community-intensive research process with rigorous methodology
- Large research team with depth and breadth of academic and community knowledge
- Priority Population Consultation Teams provide deeper knowledge on key issues of nine priority populations
- Indigenous Leadership Group within the study team serves to ensure appropriate survey questions, and develops a separate Indigenous-lead study using Indigenous and decolonizing methodology
- Peer Research Associates will be on the ground for recruitment and data collection in the ten largest cities: Toronto, Montreal, Vancouver, Calgary, Ottawa, Edmonton, Quebec City, Hamilton, Winnipeg, and Kitchener
- Key policy groups involved as project partners, including Canadian Aboriginal AIDS Network and the Canadian Human Rights Commission

DATA

- Data collection will take place summer of 2019
- Surveys will be available for completion in English or French online, on paper (by mail), on tablet with a Peer Research Associate in each of the 10 largest cities, or via telephone with a language interpreter
- Survey will be promoted as a voluntary community census
- Similar to the Canadian census, there will be a "long form" and a "short form"; participants will be encouraged to complete the long form, with the short form available for those who are unable or unwilling to complete a lengthy survey
- Survey weights will be constructed to weight for the demographic composition of the full sample (long and short forms) to reduce bias related to long form non-completion

BUILDING FUTURE RESEARCH

- At the end of the survey, participants will be asked if they are willing to be contacted by our research team with invitations to participate in additional research conducted by us or by other teams
- This enables:
 1. Follow-up data collection for future time points
 2. Use of survey data to select and recruit targeted samples for qualitative or quantitative data collection on new studies
 3. Potential for combining survey data with new data for greater efficiency and more targeted topics

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