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BACKGROUND

- Research on trans persons age 16+ in Ontario (Trans PULSE) has documented health concerns, including high levels of depression^{1,2} and suicide ideation/attempts,³ difficulties in accessing primary and emergency health care,^{4,5} and experiences of discrimination.⁶
- New national non-clinical data on trans youth age 14-25 (Canadian Trans Youth Health Study) reinforce many of these findings.⁷
- We do not know if these health concerns can be averted through gender-affirming hormone therapy.
- Family outcomes have rarely been studied, despite the potentially moderating role of having supportive parents,⁸ and the emotional challenges of parenting a trans child.⁹⁻¹¹
- This study will be the largest prospective cohort of trans youth undergoing medical care internationally, and the first in Canada.

OBJECTIVES

- To inform cultural competence within health care and social services, and provide an evidence base for the provision of high-quality care appropriate to the needs of trans youth and families.
- To provide accessible information to trans youth and their families to aid in self-understanding and in navigating the process of seeking care and interfacing with services.

DESIGN

- A 9-clinic, 2-year cohort study that will document sociodemographic and health-related characteristics of 300 pediatric trans youth and their parents/caregivers.
- We will recruit pubertal youth less than 16 years of age referred for hormone suppressant and/or cross-sex hormones, and their parents/caregivers.
- We will study pathways to care, hormone regimens, medical outcomes, psychosocial outcomes, stressors on the family, family functioning, and parent/caregiver well-being.
- The study will assess whether differences in hormone regimen, pathways to care, age, gender spectrum, and parental gender support impact youth outcomes.
- The study will assess needs and well-being of parents/caregivers.

DATA SOURCES

- Youth surveys (English, French) – baseline, 12 months, 24 months - administered by research assistant
- Brief online checklists for youth every 3 months – changes and side effects of hormone therapy, mental health
- Clinical case report forms – clinical measures, bloodwork
- Parent/caregiver surveys (English, French) – baseline, 12 months, 24 months

COMMUNITY ENGAGEMENT

- Youth Feedback Groups in English and French. Recruitment was by simple application. They workshopped survey measures that needed development (e.g., gender euphoria, stressors on families), and provided overall feedback on the youth baseline survey's "feel", flow and language.
- Parent Feedback Groups provided feedback on the parent baseline survey, with regard to measures, flow, and the overall impression the survey left.
- All Feedback Group participants received an honorarium.

MEASURES

Youth

- Sociodemographics
- Gender identity
- Hormone levels
- Pathways to care
- Current clinical care
- Gender dysphoria
- Gender euphoria
- Disordered eating behaviours
- Social support **
- Support for gender
- School safety **
- School connectedness **

Parents/caregivers

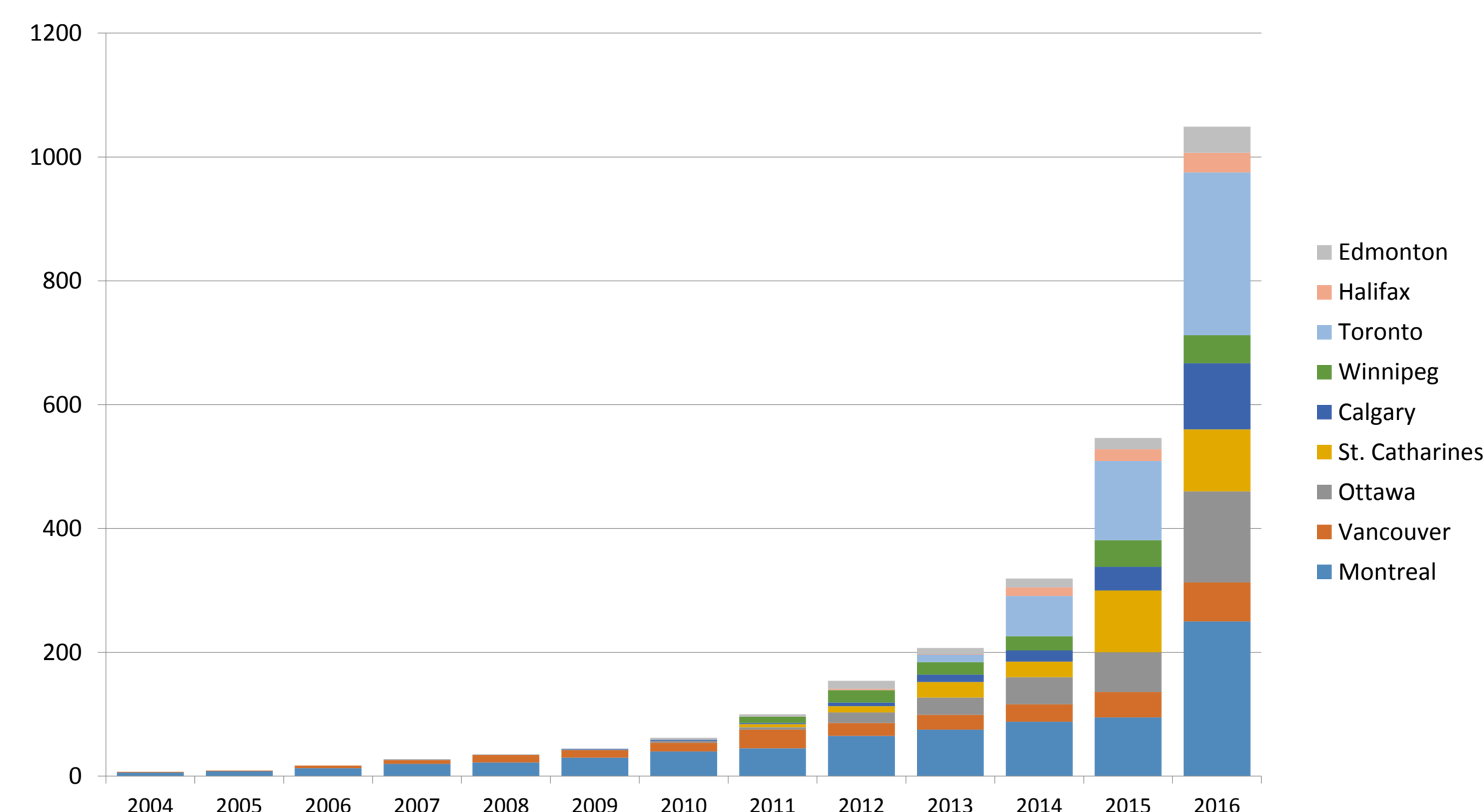
- Sociodemographics
- Family functioning **
- External stressors on family
- Psychological distress **
- Social support **

** Previously validated measures

CHALLENGES

- Increase in referrals presents a research opportunity, but also clinical challenges and increasing wait lists
- Increase in non-binary youth and necessary adjustments to clinical protocols to meet their needs
- Variation in clinical models and practices is a challenge but also a strength, as we can study this
- Absence of validated measures for youth and families (we had to create new methods and measures)
- High need for data versus difficulties with long surveys, especially for youth
- Age variation in youth at enrolment from puberty to 15 – some survey items are not necessarily appropriate for the youngest ages
- Clinics are usually not adequately supported with regard to clinical and staff person-time
- Gendered language and conceptualizations in English and French require careful navigation

Pediatric patient referrals* to specialist clinics for hormone treatment for gender identity issues: 9 Canadian clinics



* Some referral numbers estimated

Lawson ML, Bauer G, Bonifacio J, Couch B, Ducharme J, Ghosh S, Massarella C, Metzger D, Mokashi A, Pacaud D. Unpublished data, 2017.

PROGRESS AND NEXT STEPS

- Research Ethics Board approval obtained at Western and 4 clinical sites.
- Baseline data collection has begun, and will be complete in late 2018 or early 2019.
- There will be a call for youth, families, social service organizations, health care providers, and policy makers for applications for groups to work on knowledge translation and exchange (KTE), to help design our strategy for prioritizing information needs and to identify the best ways of putting research out to meet the needs of trans youth, health care providers, families, and policy-makers.

What do you most want us to find out from this study? (write below)

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