

# BMJ Open Arts-based HIV and STI prevention intervention with Northern and Indigenous youth in the Northwest Territories: study protocol for a non-randomised cohort pilot study

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## ABSTRACT

**Introduction:** Indigenous youth are disproportionately represented in new HIV infection rates in Canada. Current and historical contexts of colonisation and racism, disconnection from culture and land, as well as intergenerational trauma resulting from the legacy of residential schools are social drivers that elevate exposure to HIV among Indigenous peoples. Peer-education and arts-based interventions are increasingly used for HIV prevention with youth. Yet limited studies have evaluated longitudinal effects of arts-based approaches to HIV prevention with youth. The authors present a rationale and study protocol for an arts-based HIV prevention intervention with Northern and Indigenous youth in the Northwest Territories (NWT), Canada.

**Methods and analysis:** This is a multicentre non-randomised cohort pilot study using a pretest/post-test design with a 12-month follow-up. The target population is Northern and Indigenous youth in 18 communities in the NWT. The aim is to recruit 150 youth using venue-based sampling at secondary schools. Participants will be involved in an arts-based intervention, Fostering Open eXpression among Youth (FOXY). Participants will complete a pretest, post-test survey directly following the intervention, and a 12-month follow-up. The primary outcome is new or enhanced HIV knowledge, and secondary outcomes to include: new or enhanced sexually transmitted infections knowledge, and increased self-esteem, resilience, empowerment, safer sex self-efficacy and cultural connectedness. Mixed effects regression analyses will be conducted to evaluate pretest and post-test differences in outcome measurement scores.

**Ethics and dissemination:** This study has received approval from the HIV Research Ethics Board at the University of Toronto (REB: 31602). In addition, the project is currently registered in the NWT with the Aurora Research Institute (Licence: 15741). Trial results will be published according to the Transparent Reporting of Evaluations with Nonrandomised Designs statement.

**Trial registration number:** NCT02743026; Pre-results.

## Strengths and limitations of this study

- First trial to evaluate an arts-based HIV and sexually transmitted infection (STI) intervention in Northern Canada with Indigenous and Northern youth.
- This study integrates a 12-month follow-up which will expand on knowledge regarding the long-term efficacy of arts-based HIV and STI prevention.
- The non-randomised design of the study and lack of a control group could impact external validity.

## INTRODUCTION

In Canada, Indigenous peoples are disproportionately impacted by HIV, with estimated new infection rates 3.6 times higher than among non-Indigenous persons.<sup>1</sup> First Nations, Métis and Inuit comprise about 4.3% of the Canadian population but represent ~12.2% of new HIV infections in Canada<sup>2</sup> and new HIV cases tend to be among younger Indigenous peoples in comparison with non-Indigenous populations.<sup>2</sup> Rates among Indigenous youth are concerning, with individuals 15–29 years of age accounting for 31.6% of positive HIV test results among Indigenous people.<sup>2</sup> HIV also disproportionately impacts Indigenous women in Canada: from 1998 to 2012 women represented 47.3% of all positive HIV test reports among Indigenous peoples compared to 20.1% of reports among non-Indigenous persons.<sup>2</sup> These statistics underscore the importance of addressing HIV vulnerabilities among young Indigenous people, in particular young women.

There are staggering sexual health disparities in Canada's North in comparison with

the rest of Canada.<sup>3</sup> In 2010 the Northwest Territories (NWT) had the highest rates of chlamydia and gonorrhoea cases in Canada.<sup>4 5</sup> In addition, rates of sexually transmitted infections (STI) in the NWT are disproportionately high among youth,<sup>6</sup> with STI rates 10 times the national average.<sup>7</sup> Although having an STI is a known risk factor for HIV transmission<sup>8 9</sup> the recorded HIV rates in the NWT are consistent with the rest of Canada. This may be due to the convergence of geographic isolation, stigma and reduced sexual healthcare access that contribute to low HIV testing rates, and under-reporting.<sup>6</sup> Yet, elevated STI rates are predicted to result in future increased HIV infection rates in Canada's North.<sup>10</sup> Sexual health programmes and HIV/STI prevention interventions with Northern and Indigenous youth in the NWT are therefore important sites for prevention. There is limited rigorous evaluation of HIV prevention strategies tailored for Indigenous youth, in particular, in assessing long-term effects in reducing HIV exposure and promoting protective factors.<sup>11</sup>

### Social and structural factors impacting exposure to HIV among Indigenous youth

The contexts that increase exposure to HIV acquisition and transmission among Indigenous peoples include, but are not limited to: geographic isolation, limited access to health services and information, poverty, drug use, sex work and gender-based violence.<sup>12–15</sup> Yet, exposure to HIV among Indigenous peoples, in Canada and globally, must be situated within larger structural drivers, which include social, political and economic inequities<sup>16 17</sup> such as colonisation; racism; disconnection from language, culture and land; and intergenerational trauma due to forced attendance at residential schools.<sup>18 19</sup>

Limited healthcare in rural, remote and small communities creates a unique and significant determinant of sexual health in Northern Canada.<sup>13 20</sup> In particular, a shortage of family doctors and sexual health clinics in remote Northern communities creates barriers to healthcare access.<sup>21</sup> Moreover, inadequate services and a real or perceived lack of confidentiality in small, tight-knit communities further limit STI testing and treatment access.<sup>6</sup> HIV-related stigma also continues to present an important barrier to accessing HIV prevention services.<sup>17 22–24</sup> Stigma and discrimination towards people living with HIV persist globally,<sup>23 25 26</sup> and this is also true in Northern Canada.<sup>12</sup> Initial research in the NWT with lesbian, gay, bisexual and transgender youth, including Indigenous youth, reports widespread stigma that devalues same sex sexuality, relationships and identities,<sup>27</sup> which is important to address in HIV/STI prevention strategies.

It is important that sexual health promotion and HIV prevention programmes in Northern communities take into account the unique social, structural and geographical factors that contribute to health inequities in the North.<sup>3</sup> HIV-related research and interventions in Northern communities must build on Indigenous

knowledge, contextual resources and strengths.<sup>19</sup> Contextually situated capacities include strengthening connection to, and awareness of, ethno-cultural identities,<sup>28 29</sup> incorporating traditional teachings and healing practices,<sup>30</sup> and embracing the wisdom and involvement of Elders.<sup>31–33</sup> Indigenous voices have often been marginalised in research and health practice—perpetuating colonisation in knowledge production.<sup>34–37</sup> Public health practices in Canada have not always integrated community knowledge and priorities<sup>38</sup> and have largely been developed for urban environments in Canada's South.<sup>39</sup> Stark geographic and cultural differences<sup>40</sup> and limited health resource access<sup>41</sup> in the North reduce the relevance of these approaches.

### Intervention: Fostering Open eXpression among Youth

This study will evaluate an arts-based HIV prevention programme, Fostering Open eXpression among Youth (FOXY) in the NWT, Canada that works with Northern and Indigenous youth to promote sexual health and reduce exposure to HIV/STI. FOXY explores sexual health, HIV/STIs, sexuality and healthy relationships with young women in the NWT. The programme's goal is to use arts-based methods and peers to facilitate education and foster more open expression and communication regarding sexual health and sexuality.<sup>42</sup> FOXY uses arts-based approaches in programme delivery; for example, drama techniques are used to facilitate discussion and learning about healthy relationships and making positive choices in realistic sexual scenarios.

Arts-based methodologies are rooted in social justice and control over the production and dissemination of knowledge, and have been associated with increases in the feeling of empowerment, especially around sexual health decision-making.<sup>43</sup> As an arts-based HIV prevention programme, FOXY has integrated local knowledge and contextual resources from its inception. Arts-based approaches to HIV prevention engage, and are enjoyed by, youth<sup>11 18</sup>—yet there is little known about the long-term efficacy of arts-based and other approaches to reducing exposure to HIV. Specifically, there are gaps in knowledge regarding efficacy of arts-based HIV prevention including: (1) studies with quantitative measures often have insufficient sample sizes to make statistically robust predictions;<sup>44 45</sup> (2) most studies have evaluated immediate effects of programme participation, resulting in a lack of knowledge regarding long-term effects of programme participation;<sup>44–46</sup> and (3) scant research has evaluated arts-based HIV prevention programmes in Canada. We aim to address these gaps by conducting a longitudinal evaluation of FOXY, among Northern and Indigenous youth in the NWT.

### Study purpose

The proposed study will evaluate whether, in comparison to preintervention, participants in the FOXY programme demonstrate capacities that reduce exposure to HIV and STI. We hypothesise that participants of the FOXY

programme will report higher primary outcome (HIV knowledge) measurement scores, and higher secondary outcome (STI knowledge, self-esteem, empowerment, safer sex self-efficacy and cultural connectedness) measurement scores in a pre-post intervention comparison.

## STUDY DESIGN AND METHODS

### Design

This is a multicentre non-randomised pragmatic cohort pilot study using a pretest/post-test design with a 12-month follow-up. Venue-based sampling will be implemented in grade 7 through 12 classes at secondary schools in 18 communities of the NWT (Yellowknife, Hay River, Inuvik, Fort Smith, N'Dilo, Norman Wells, Fort Providence, Behchoko, Tuktoyaktuk, Wha Ti, Fort Resolution, Aklavik, K'atodeeche First Nation, Ulukhaktok, Fort Liard, Fort Simpson, Lutselk'e, Fort McPherson).

### Randomisation, allocation and blinding

Owing to the pilot study design, randomisation, allocation and blinding are not relevant.

### Participants

We aim to recruit a sample size of 150 young women. Inclusion criteria for this study sample includes youth who: are participating in FOXY; self-identify as a woman; live in the NWT; are between the ages of 13 and 17 years; are capable of providing informed consent.

### Sample size determination

Hypotheses informed sample size calculations will be conducted using G\*Power V.3.1. To conduct mixed-effects regression with six measurements, effect size: 0.15, power: 0.95, correlation among repeated measures: 0.45, the sample size required is 87. We will over-sample to account for a 20% attrition rate.

### Recruitment

Prior to the beginning of the study, FOXY staff will have communicated with each school and the students will be notified that there will be a series of workshops in which they can voluntarily participate. Reverse consent forms will be sent out to parents or guardians at least 1-week in advance of the workshop. Reverse consent forms work by assuming parental or guardian consent unless parents or guardians complete and submit the form indicating they do not want their child to participate. Only those workshop participants whose parents or guardians have not returned the reverse consent form will be asked to participate in the research component of this programme. On the initial day of the workshop, these programme participants will be asked if they would like to participate in the survey. At this point, prospective participants will be informed of all stages of data collection: baseline, postintervention and 12-month follow-up. If they indicate interest in participating, they will be presented with assent forms.

Our research team opted to use a reverse consent process rather than mandating parental consent in order to reduce barriers to young women participating in the FOXY intervention and research process. Mandating parental consent might mean that youth who experience less parental engagement might be unable to participate in a programme that aims to facilitate important skills around sexual health communication and healthy relationships. Several studies have concluded that youth as young as 14 years of age are capable of making informed decisions about their participation in research.<sup>47–50</sup> Along with receiving approval from our research ethics board, the reverse consent process was also approved through our research licensing process, which consulted community organisations, schools and Aboriginal governments in all communities that FOXY reaches before the NWT Research License is issued.

## INTERVENTION

### Pretest and post-test evaluations

Participants in FOXY (n=150) will complete a structured survey on tablet-based computers directly before participating in the intervention at baseline (t0), directly following the completion of the intervention (t1), and at 12-month follow-up (t2). We will pilot test the survey with peer research assistants (PRAs) and integrate feedback to enhance validity, cultural relevance and clarity. PRAs are young individuals who identify as women and are from the NWT. PRA also have previous experience and involvement with research (eg, research training, prior engagement as a PRA). Data will be collected at the school sites where the FOXY interventions take place.

### FOXY group-based programme

The FOXY intervention was developed through an iterative and intensive revision process that took place over a 2-year period. The first stage entailed the FOXY team working with youth peer leaders from various communities in the NWT to develop an initial intervention. The intervention was then focus tested across the NWT with youth who chose to participate. Following every workshop, the FOXY team considered and integrated feedback from youth who participated in the intervention which included multiple revisions of workshops.

The FOXY intervention involves seven workshops that are 1–2 hours each. The complete intervention is conducted over 1–2 days in communities across the NWT. Each workshop will include ~8–15 youth participants. FOXY Executive Director (Lys C), as well as other facilitators and adolescent peer leaders on staff at FOXY will conduct the intervention in schools where FOXY has been invited. All facilitators and peer leaders have expertise in sexual health education and arts-based HIV prevention. The content will be delivered using a variety of methods including small and large group discussions,



theatre techniques such as, role playing and charades and other arts-based methods including body-mapping. Participants will receive gifts such as FOXY-branded materials for participating in the intervention and surveys.

The content areas for each 1–2 hour session include:

1. Birds and the bees: Participants will work together in groups to create visual word maps related to sexual health topics. These word maps engage participants in creative brainstorming in order to facilitate initial group conversations on the topics of HIV, STIs, healthy relationships, sexual health, safer sex, negotiating safer sex, safer self-efficacy, gender and healthy communication.
2. Question box: Group discussion is facilitated by having participants submit questions to a box and working together as a group to provide answers to the questions. Topics covered include HIV, STIs, healthy relationships, sexual health, safer sex, negotiating safer sex, safer self-efficacy, stigma, sexuality, gender, healthy communication and sexual orientation.
3. Student-led sex education: Participants will assess and enhance their knowledge of HIV, STIs, healthy relationships, sexual health, safer sex, negotiating safer sex, safer self-efficacy, stigma, sexuality, gender and healthy communication by developing a lesson and teaching it to the group.
4. Myth versus truth: This session explores participant's knowledge and understanding of HIV, STIs, healthy relationships, sexual health, safer sex, negotiating safer sex, safer self-efficacy, sexuality and gender. Participants are presented with statements and a group discussion is facilitated on whether the statements are true or false.
5. Body mapping: Using arts-based techniques, such as drawing and painting, participants will create a life-size image of the body. Body-mapping is a way for participants to tell stories about their experiences of the world, their lives and their bodies through visual representation.<sup>51</sup> Prompts will be offered to facilitate visual representation and storytelling related to the topics of relationships, sexuality, sexual orientation, personal goals, resilient coping, self-esteem, self-acceptance, barriers and opportunities for self-care, social supports, emotional and mental health.
6. Healthy relationship charades: Participants will engage in non-verbal role playing to promote dialogue and facilitate understanding on topics of healthy relationships, communication and social supports.
7. Role playing: Participants will be presented with scenarios and will perform skits on the topics of healthy relationships, communication and social supports.

## FEASIBILITY CRITERIA

As a pilot study we are measuring feasibility and initial indicators of efficacy of FOXY. We will use criteria for

pilot studies developed by Thabane *et al* including:<sup>52</sup> (1) process, such as retention rates for the 12-month follow-up, understanding of survey items, relevance of session content, length of sessions; (2) resources, including length of survey completion, collaboration with community-based agencies and facilitators, assessing information and resources to strengthen the programme; (3) management, such as challenges in study management, data collection, participant follow-up for data collection; (4) changes in outcome variables after participating in the programme, and the estimated effect. The next step after pilot study will involve a more rigorous design, such as stepped wedge.

## OUTCOMES

### Primary outcome

HIV knowledge will be measured using the Brief HIV Knowledge Questionnaire.<sup>53</sup>

### Secondary outcomes

STI knowledge will be measured using the Sexually Transmitted Disease Knowledge Questionnaire.<sup>54</sup> Self-esteem will be assessed using the Rosenberg Self-Esteem Scale.<sup>55</sup> Empowerment will be measured using the Empowerment Measure<sup>56</sup> that assesses power within (eg, confidence), power to (eg, relationship dynamics) and power with (eg, social membership). Safer-sex self-efficacy will be measured using the Safer Sex Self-Efficacy Scale.<sup>57</sup> Cultural connectedness will be assessed using the Awareness of Connectedness Scale<sup>58</sup> developed to assess culture-specific factors with Alaska Native Youth.

## STATISTICAL METHODS

We will conduct descriptive analyses of sociodemographic variables, including means and SDs and proportions to provide an overview of participant characteristics. A sum of items will be completed for each scale to calculate total/subscale scores for each measure and calculate means (SD). Outcome measures for pre–post intervention differences will be tested by sociodemographic characteristics using Pearson product-moment correlation for continuous variables, Student's t-tests for dichotomous variables and analysis of variance for variables of three or more categories. A mixed-effects regression will be used to model each continuous outcome measure as a function of two time dummy variables, one for postintervention interview time point and one for 12-month follow-up. This method accounts for the correlated structure of three repeated measures (preintervention, postintervention, 12 month follow-up)<sup>59</sup> and uses maximum likelihood estimation for inference that allows inclusion of cases with missing data.<sup>60</sup> While accounting for within-subject and between-subject variability, regression-based models also allow the flexibility to adjust for sociodemographic covariates. The model coefficients for the model dummy variables

represent the change in outcome scores from preintervention to postintervention and from preintervention to 12-month follow-up. Statistical analyses will be conducted using IBM SPSS V.23.0.

## DISCUSSION

There is little known about the efficacy of arts-based interventions in reducing exposure to HIV, particularly with a long-term follow-up—yet research highlights how youth enjoy and engage with arts-based approaches to HIV prevention.<sup>21 23</sup> The current study aims to address this knowledge gap by conducting longitudinal evaluation of FOXY, an arts-based HIV prevention programme that works with youth in the NWT. The central goal is to assess the efficacy of FOXY for improving primary knowledge (ie, HIV knowledge) and secondary outcomes (ie, empowerment). A potential limitation of this study is its non-randomised cohort design and the lack of a control group. However, as a pilot study, the goal is to also assess and enhance FOXY's capacity to engage future research and programme evaluations. Post-pilot study research could include more rigorous design, such as stepped wedge, where it would then be more feasible to incorporate a control group into the study design. In addition, future research could explore whether FOXY is feasible from a community context rather than the intervention being implemented strictly within a school context. If efficacious, this study could be adapted and tested with other Northern and Indigenous populations of youth.

## ETHICAL CONSIDERATIONS AND DISSEMINATION

This study aims to evaluate an arts-based HIV prevention programme, and poses minimal risks to participants. The consent form will be read aloud to participants, and researchers will speak to each participant before the completion of surveys in order to ensure their understanding of the process. Participants will also be made aware of the purpose of the intervention and the measures in place to ensure their anonymity and confidentiality.

Psychological and emotional risks might include participants feeling uncomfortable or vulnerable discussing their experience(s) regarding some of the topics addressed through the prevention programme, such as sexual practices and sexuality. In order to minimise these psychological/emotional risks, the researcher will ensure the following: (1) participants are aware that they may skip any questions if they feel uncomfortable or do not wish to answer; (2) participants are aware that their participation is voluntary and that they may withdraw from the study at any time or stage of the study without any adverse consequences; (3) participants will be reminded that their participation in the study will not affect their access to current and future programmes, workshops and other services in the community; and, (4) participants will be provided with information about community resources, such as sexual/reproductive

health services, youth resource centres, mental health agencies and community health services. The team implementing this study have been trained in mental health first aid, have several years of experience conducting these workshops with young women across the NWT, have developed expertise in providing immediate emotional support and will refer participants who require it to support systems in their respective school.

Participants might perceive social risks regarding loss of privacy and breaches of confidentiality regarding self-disclosed personal information in the survey. This risk will be minimised by informing participants that no identifying information, such as their name or address, will be collected on the survey and that only numerical codes will be used to identify data. Participants will also be asked to mark X on the consent form to indicate their consent, and the X will ensure confidentiality. There will be no paper copies of the surveys, as survey responses will be collected online and surveys will be conducted with tablet-based computers. Codebooks that include the names/contacts of participants and their ID codes, to match participants for follow-up surveys, will be stored in a locked filing cabinet in the FOXY Executive Director's office and destroyed after the 12-month follow-up survey data are completely uploaded.

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**Competing interests** None declared.

**Ethics approval** Research ethics approval was obtained from the Office of Research Ethics (REB: 31602), University of Toronto. This research is also registered with the Aurora Research Institute (ARI) in the Northwest Territories (Licence: 15741).

**Provenance and peer review** Not commissioned; externally peer reviewed.

**Data sharing statement** Owing to the small population, and therefore the small sample size in some of the communities in the Northwest Territories, we do not wish to compromise participant confidentiality. We will limit data sharing to persons who are research team members.

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