

## **Sexual health research for and with urban youth: The Toronto Teen Survey story**

Sarah Flicker<sup>1</sup>, Robb Travers<sup>2,3</sup>, Susan Flynn<sup>4</sup>, June Larkin<sup>5</sup>, Adrian Guta<sup>3</sup>, Roxana Salehi<sup>1</sup>, Jason D. Pole<sup>3,6</sup>, and Crystal Layne<sup>4</sup>

<sup>1</sup> Faculty of Environmental Studies, York University, Toronto, ON

<sup>2</sup> Department of Psychology, Wilfrid Laurier University, Waterloo, ON

<sup>3</sup> Dalla Lana School of Public Health, University of Toronto, ON

<sup>4</sup> Planned Parenthood Toronto, Toronto, ON

<sup>5</sup> Women and Gender Studies/Equity Studies, University of Toronto, Toronto, ON

<sup>6</sup> Pediatric Oncology Group of Ontario; Hospital for Sick Children Research Institute, Toronto, ON

**Abstract:** This article provides an overview of the development and implementation of the Toronto Teen Survey (TTS). The TTS was a partnership between Planned Parenthood Toronto and a network of academic researchers. The primary objective of the TTS was to assess the sexual health education needs and service access barriers among youth living in one of the most ethno-racially diverse cities in the world. The TTS used a community-based research approach that involved youth as full partners in the project.

---

### **Introduction**

The Toronto Teen Survey (TTS) sought to explore assets, gaps, and barriers that currently exist in sexual health education and related services for urban youth. The large study sample was diverse in terms of ethno-cultural background, immigration history, religion, and sexual self-identification and was thus characteristic of urban youth in Toronto. The focus of TTS is on diversity, equity and adolescent sexual health. This article reflects these themes and documents the story of the Toronto Teen Survey.

#### ***The city***

Toronto is one of the world's most ethno-racially diverse cities, home to more than 80 ethnic groups speaking over 100 languages. For many years, Ontario has been the destination for over half of all immigrants to Canada; Toronto has received a sizeable portion of that influx. Changes in immigration policy concerning source countries contributed to the growth of youth communities that were varied in terms of race, culture, and language. As this trend unfolded, community-based organizations across the city recognized gaps in their capacity to offer culturally-effective sexual health education and promotion services. Planned Parenthood Toronto (PPT), a

community health centre offering a variety of clinical and health promotion services to individuals in the Toronto area, found itself increasingly called upon by sister organizations to help them build capacity and to develop effective sexual health services for their particular youth populations.

Since its inception in 1961, PPT has evolved by developing programs and services that kept pace with complex and changing community needs in the area of sexual and reproductive health. The changing face of those needs prompted PPT's strategic plan (2003-2005) which sought to increase positive sexual health outcomes for youth and to decrease the barriers to sexual health programs and services encountered in youth communities. To this end, PPT reached out to build partnerships with a network of academic researchers with expertise in youth sexual health research. Our goal as a community-university research team was to explore how best to use research to assess the sexual health needs of diverse groups of youth, to identify the service access barriers they might experience, and to suggest recommendations for best practices for ensuring their overall sexual health. The eventual result of this collaboration was the Toronto Teen Survey.

**Initial discussions**

In our preliminary discussions, we quickly noted that there is no shortage of research documenting teen sexual behaviour, but the focus of this research is limited. As Michelle Fine has aptly written, “Today we can “Google” for information about the average young woman’s age of “sexual debut,” if she used a condom, got pregnant, the number of partners she had, if she aborted or gave birth and what the baby weighed. However, we don’t know if she enjoyed it, wanted it, or if she was violently coerced” (Fine & McClelland, 2006, p. 300). We think this perception also applies in the Canadian context and would add that we also probably would not know, particularly for diverse populations of urban youth, whether a young woman had support, adequate sexual health information about options to protect herself, or other information or resources to deal with the complex and important sexual milestones that young people encounter. Furthermore, behavioural studies of youth have tended to under-represent some populations of youth (e.g. racialized or sexually diverse youth) with the result that some marginalized young people’s sexualities are more likely to get erased or pathologized. These issues concerned and shaped the novel approach to research adopted by the TTS.

**The social context**

The actions youth take related to sexuality, sexual activity, and their sexual health are profoundly influenced by larger socio-cultural and political contexts. Factors such as racism, newcomer status, religion, cultural heritage, socio-economic status, access to services and social support must be considered in assessing sexual health outcomes and in developing effective program interventions. Many youth find it difficult to access appropriate sexual health resources and may encounter unwanted sexual outcomes as a result. For example, rates of STIs (including HIV) are higher among street-involved youth, youth in care (criminal justice system and state wards) (Joeseof, Kahn, & Weinstock, 2006; Rothon, Strathdee, Cook, et al., 1997), young men who have sex with men, (Remis, Alary, Otis, et al., & the OMEGA Study Group, 2004; Weber, Craib, Chan et al., 2003), Aboriginal youth (O’Brien Teengs & Travers, 2006; Ontario Federation of Indian Friendship Centres (OFIFC), 2002; Prentice, 2004), and young injection drug users (Miller,

Spittal, Frankish et al, 2005; Public Health Agency of Canada, 2006). Absent or insufficient access to information and services is likely due to a combination of systemic factors that shape individual risk and increase barriers to service. Newcomer youth, racialized youth, and young people with disabilities (DiGiulio, 2003; Grabois, 2001; Nosek, Howland, & Hughes, 2001; Tepper, 2001) also report barriers to accessing appropriate medical care and sexual health advice.

Generic prevention programs targeted generally toward all youth and focussed solely on STI and HIV/AIDS prevention are often unsuccessful because youth in different communities approach their sexual health differently and have unique concerns based on other social and cultural characteristics (Franz & Poon, 2000). Also, while service providers and youth identify many of the same sexual health issues, they often have very different ideas on how best to address these concerns (Larkin et al., 2005; Raphael, 2008).

Given the foregoing observations, the TTS team was interested in the “story behind the story.” We wanted to understand how the social and environmental determinants of adolescent sexual health played out in diverse groups of youth in Toronto. As a guiding framework for the study, we adopted the World Health Organization’s broad definition of sexual health described here, in part, as:

....a state of physical, emotional, mental and social well-being in relation to sexuality, ....requiring that the sexual rights of all persons be respected, protected and fulfilled.

These rights, identified here in part, include:

...the right of all persons, free of coercion, discrimination and violence, to: the highest attainable standard of sexual health, including access to sexual and reproductive health care services; [to] seek, receive and impart information related to sexuality; and [to] pursue a satisfying, safe and pleasurable sexual life.

### ***Access to services and sexual health information***

Although the TTS did address the individual behaviours of youth, our key focus was on the institutions that are meant to promote better sexual health, namely youth-serving health and social services, community health centres, and sexual health clinics. We wanted to know what services were available for young people in Toronto, which services they were using and why, and what systemic barriers they had encountered in accessing these services and why. In the latter case, we wanted to know whether these services were meeting the needs of all of the diverse groups of young people in Toronto and particularly those that we know shoulder a disproportionate burden of poor sexual health outcomes. Finally, we wanted to understand how needs were being met and why some were not.

Similarly we asked where youth got their information about sex, what topics they learned, what they thought of it, and where and who they would like to get that information from in the future. We also wanted to know if there were key differences between groups in the types of information that they needed and wanted. With respect to behaviour, we wanted to know whether particular groups of youth were more or less likely to be engaging in behaviours associated with high levels of behavioural risk for STIs, pregnancy, and HIV/AIDS. Overall, our aim was to collect information and insights toward the goal of creating the most effective sexual health services for Toronto's increasingly diverse youth communities.

We knew that we needed to reach a large number of youth in order to have the statistical power to speak to issues of diversity in a city the size of Toronto. To get the full story, we knew that we had to fully engage youth in the process but that we also had to hear from the service providers working with those youth.

### ***Youth engagement and mentorship***

Both the research team and PPT promote the importance of engaging young people in decision-making to promote active citizenship, community mobilization, and social change. Globally, young people are networking, collaborating, and fostering change in exciting new ways (Juris & Pleyers, 2009). Participation in social activism can promote the

development of critical reflection, a more developed sense of self, and exposure to communitarian principles (Deuchar, 2008). Youth who participate in school and community programs often remain engaged in civic life as they move into adulthood and beyond (Borden & Serido, 2009). Yet, "today's youth are less likely to engage in meaningful civic activities and more likely to experience social exclusion because of disparities in educational settings, economic disadvantages, and health disparities" as a result of a breakdown in trust with adults and government (Kelly, 2009). When done well, participation can result in intergenerational collaboration and trust building (Lawrence-Jacobson, 2006).

We also recognized the importance of mentoring youth in a way that challenged them to think critically about themselves and about conditions in their communities. Specifically, we drew on the model of critical youth empowerment (Jennings, Parra-Medina, Messias, & McLoughlin, 2006) which attends to: (1) a welcoming, safe environment, (2) meaningful participation and engagement, (3) equitable power-sharing between youth and adults, (4) engagement in critical reflection on interpersonal and sociopolitical processes, (5) participation in sociopolitical processes to effect change, and (6) integrated individual-level and community-level empowerment. When provided with opportunities to participate and share their views, youth can be empowered to act on their own behalf and for their communities (Cargo, 2003). These opportunities can become invaluable learning experiences where young people actively learn and teach each other (Celio et al., 2009). However, the promotion of active citizenship also raises ethical and methodological issues that need to be addressed for successful partnerships to take place (Matthews & Limb, 2003).

We did not take on this partnership-with-youth approach lightly nor were we naive about the potential consequences of this approach. We understood that simply involving young people in research does not automatically equate to creating the conditions for social change (Crawshaw, Mitchell, Bunton, & Green, 2000). The promise of empowerment often assumes that youth are "powerless" and need to be empowered in ways that fit adult and organizational agendas (Villadsen, 2008, p. 102). This can obscure

the need for critical questions to be asked about the nature of empowerment. This is especially true in relation to young people and sexual health, since young people have often been mobilized to speak in certain ways about sexuality and risk (Shoveller & Johnson, 2006). The goal of the TTS was not to prescribe a certain version of what young people's sexuality should look like or how it would be discussed. Rather, we challenged the youth involved to think critically about their own environments, social circumstances, and values so that we could then find safe ways of welcoming other youth into the conversations.

### ***The Toronto Teen Survey approach***

The TTS employed a community-based research (CBR) approach which elevates the status of community members as partners in research toward the goal of providing the most accurate information possible using the most community-sensitive methods available. To that end, Planned Parenthood Toronto housed the project and TTS was presented publically as a project of PPT. CBR has gained increasing popularity in the Canadian context as a strategy to improve health and to reduce health inequities (Flicker, Savan, McGrath, Kolenda, & Mildenberger, 2008; Flicker, Savan, Mildenberger, & Kolenda, 2008). The benefits of involving communities in research and intervention development have been demonstrated in the growing body of CBR projects and publications (Minkler & Wallerstein, 2003; Seifer, Shore, & Holmes, 2003; Viswanathan et al., 2004). CBR encourages teams to draw on the special strengths that partners bring to the table in order to foster equitable collaboration, to ensure that research questions are relevant to the community, to utilize the most community sensitive methods possible, and to produce data that policy-makers and other knowledge users will attend to (Flicker, 2008; Flicker, Larkin et al., 2008; Flicker, Maley et al., 2008; Travers et al., 2008).

One of the unique aspects of the TTS was our determination to involve youth in all stages of the TTS project, from its original design, to its implementation, and finally in its dissemination strategies. CBR has been shown to be a particularly successful approach to research for engaging youth (Checkoway & Gutierrez, 2006; Suleiman, Soleimanpour, & London, 2006; Wilson et al., 2006).

Specifically, youth involvement in CBR projects give youth an enhanced sense of control over their lives, while improving the relevance and appropriateness of the programs and services developed (Checkoway, Dobbie, & Richards-Schuster, 2003; Checkoway, Richards-Schuster et al., 2003; Flicker & Guta, 2008; Flicker et al., 2010; Harper & Carver, 1999). Interventions are more likely to succeed if they: involve youth in a manner that stimulates learning; make the best use of their knowledge and skills; and are designed with the intention of empowering them.

The effectiveness of peer researchers has been established in sexual health research and prevention strategies (Barker, 2000; Trussler, Perchal, & Barker, 2000; Wilson et al., 2006). Peer-based researcher models provide sensitive and culturally appropriate inroads into "hard to reach" communities (Barker, 2000). Young people are often most aware of the realities of issues facing their communities and are most directly affected as they have limited economic and social capital (Driskell, Fox, & Kudva, 2008; M. Miller, 2008). As youth are often the primary source of sexual health information for their peers (Beitz, 1998), they should be involved in the planning and development of sexual health initiatives and education strategies (DiClemente, 2001). This approach to research has been proven to be particularly effective for health research with adolescents and youth (American Academy Of Pediatrics, 2004; Boutilier, Mason, & Rootman, 1997; Mason, 1997; Mason & Boutilier, 1996; National Research Council and Institute of Medicine, 2005; Smyth, 2001). When given the chance, young people co-researching can take the research agenda in exciting new directions that reflect the realities of their unique social location and life circumstances (Campbell & Trotter, 2007).

Some researchers have shown that despite good intent, the involvement of community members in research is not always evident (Flicker, Savan, Kolenda, & Mildenberger, 2008; Travers et al., 2008). For the TTS, it was particularly important to devise and implement a model of youth engagement that would provide meaningful experiences for the youth involved. In addition to the inclusion of youth in the research process, a collaborative partnership was formed with Toronto Public Health early on in the project to ensure policy expertise during the

project and a greater likelihood of data uptake at the dissemination stages. We were committed to ensuring from the outset that both our processes and outcomes would lead to change.

## Methods

### *Phase I: Developing a survey tool*

In November 2004, research development funds were secured from the Toronto-based Wellesley Institute to form a research team, create a youth advisory committee, develop research goals and objectives, undertake a literature review, conduct consultations with youth, and develop a full research proposal.

Twelve diverse teens (aged 13-17 years) were recruited to form a Youth Advisory Committee (YAC) from PPT partner agencies across Toronto, including community and recreation centres, supportive housing organizations, and child protection services. The teens (two males and ten females) represented great diversity in terms of neighbourhood geography, racial and ethnic background, newcomer status, and socio-economic status.

The role of the YAC was to assist in the development of a survey tool to assess the current state of sexual health services and identify the ideal attributes of such services for diverse communities of youth in Toronto. In addition, they provided considerable advice on how to develop a survey protocol that was youth-friendly and accessible (Flicker et al., 2010).

YAC members received extensive training to prepare them to develop a research protocol and survey tool. Training sessions covered a range of topics related to qualitative and quantitative research, survey design, relevant and pertinent youth sexual health issues, anti-oppression frameworks, and the social determinants of health. The goal of these training sessions was to ensure that YAC members were sufficiently prepared to provide guidance on the conception and implementation of the project. During the survey design workshops, the YAC explored how a survey tool might measure key sexual health issues, including behavioural risks and service access barriers. They then proceeded to operationalize concepts through drafting, adapting, and refining survey drafts. They also made recommendations for

implementation related to survey length and layout, order of questions, and strategies for administration. For instance, YAC members maintained that the survey could not be “too long,” it should look “fun” and be “easy” to read and fill out. They were also very clear about how they felt their peers would respond to the survey. The YAC felt that the survey would be better received if it were administered by a youth peer researcher. Furthermore, the YAC were adamant about their desire to have an educational component for youth who completed the survey to answer any immediate sexual health questions they may have. They did not feel it was adequate to simply administer the survey, but rather that the researchers had a responsibility to make the experience educational and informative for respondents (Flicker & Guta, 2008). Accordingly, after each survey collection session, youth were provided with an opportunity to ask questions about any pertinent sexual health issue. It is worth noting that all of the YAC members indicated an interest in being involved in this phase of the research.

The survey tool went through several iterations between the research team and the YAC members. In addition to youth input, we also conducted a “diversity check” of the survey tool by soliciting feedback from several service providers who worked with specific populations of Toronto youth (e.g., newcomers, LGBT youth, youth with drug and alcohol problems, and racialized youth). In sum, we feel that the research team worked as hard as possible to create a tool that was youth-friendly and sensitive to equity concerns, and yet easy to navigate.

### *Survey implementation*

Funding for survey administration and analyses was secured in 2006 from The Ontario HIV Treatment Network. While only four of the original YAC members were able to re-commit to this stage of the project, the overall positive experiences of the group made it easier to recruit new members. This second stage of YAC recruitment generated an enthusiastic response and 20 youth aged 13-17 signed on in just under a month. This group worked to finalize the survey, and further refine the strategy for survey administration conceived by the original YAC. In September and October 2006, the YAC participated in ten weeks of comprehensive sexual health and

**Table 1 Training modules for Youth Advisory Committee group facilitators**

Module	Workshop topic	Hours	Achieved learning objectives
1.	<b>Introduction</b>	3	- Introduction to Planned Parenthood Toronto (including mission, values, programs, and services) and TTS project, icebreakers to build group cohesion.
2.	<b>Anti-oppression practice</b>	3	- Understanding of anti-oppression practice in research and how it relates to accessibility barriers.
3.	<b>Survey &amp; survey administration</b>	3	- Familiarity with survey methodology and thorough understanding of TTS questions and purposes. Understanding of ethics protocol, informed consent procedures, and confidentiality.
4.	<b>Reproductive systems</b>	3	- Knowledge of male and female reproductive systems, puberty, menstruation; common questions.
5.	<b>Being sex-positive</b>	3	- Sex positivity as a Planned Parenthood Toronto value and how it translates into sexual health education practice. Exploration of personal and alternative values and the appropriate expression or communication.
6.	<b>Birth control methods Pregnancy options</b>	3	- Review of common hormonal and non-hormonal birth control methods, myths, and common questions relating to pregnancy.
7.	<b>Trans 101</b>	3	- Understanding difference between gender and sex, gender roles, gender identity and transgenderism, and transphobia.
8.	<b>Anti-homophobia education</b>	3	- Encourage critical thinking about heterosexism and homophobia in various communities and how it creates barriers to sexual health care access.
9.	<b>STIs &amp; HIV/AIDS</b>	3	- Understand common STIs and HIV/AIDS, disease symptoms, modes of transmission, safer sex practices (including condom demonstration), common myths about sex, sexuality and sexual health.
10.	<b>Healthy relationships</b>	3	- Knowledge of various components of healthy and unhealthy relationships (sexual and non-sexual), including "sexual readiness." Defining sexual assault and harassment, as well as appropriate responses.
11.	<b>Information &amp; referrals</b>	3	- Thorough understanding of sexual health care resources in Toronto (e.g., clinics, Community Health Centres, etc.), and ability to locate key providers by neighbourhood. Knowledge of patient rights, confidentiality, and complaint procedures.

group facilitation training (over 30 hours!) designed to prepare them to facilitate survey workshop sessions with their peers (see Table 1). These training sessions were interactive and YAC members were encouraged to identify additional topics of interest and areas where they needed additional training. Training was ongoing in debriefing sessions, where challenging issues were raised and discussions were held about possible improvements to protocols and practices.

All YAC members completed a post-training evaluation survey. Overall, 95% indicated that they felt adequately prepared for the responsibilities set out for them in this survey administration phase; 80% felt they were more aware of themselves as sexual beings as a result of the training; 90% said they were very knowledgeable of the sexual health service system in Toronto; and 75% indicated that participation in the YAC training made them more likely to engage in safer sex practices in the future.

*Survey procedures and educational intervention*

Between December 2006 and August 2007, the YAC conducted 90 survey collection workshops in community-based settings across neighbourhoods in Toronto that are considered high risk and underserved. We purposely targeted these neighbourhoods knowing that these were areas where youth were at significant risk for adverse sexual health outcomes. We visited after-school drop-in programs, shelters, summer camps, community centres, group homes, and other community spaces where youth congregate. We collected over 1,200 surveys from a diverse cross-section of youth. In each of these youth-led sessions, the YAC members reviewed informed-consent procedures, explained what the survey was about, noted the instructions for completing it, and then distributed the survey to the youth in attendance.

Confidentiality was extremely important for the youth who participated in the survey workshops. YAC members were trained to explain to survey respondents that they were not obligated to complete the survey and that the process was entirely voluntary. Respondents were also informed that the information they provided would be confidential and anonymous and that all results would be provided in aggregate form so that no individual responses would be identifiable. Respondents were informed that since the surveys were anonymous, they could not be withdrawn once completed and submitted. Youth respondents' completion and submission of the survey was considered as consent to participate. The TTS Research Coordinator or a Research Assistant was also present throughout the duration of the survey administration sessions to ensure that survey respondents received all the information necessary to give informed consent and to provide support to YAC members during the sexual health question period that followed the completion of the survey.

In some cases, where a participant's ability to speak English was limited, YAC members were also supported by professional interpreters. In other cases, where youth in the workshops faced literacy challenges, YAC members would read the questions out loud or work with an individual youth to complete the survey, or both. In all instances, they made themselves available to answer questions and facilitate survey completion.

Once all surveys were collected, the YAC members then facilitated a question-and-answer "education session" with the youth on sexual health related topics and distributed information about local community resources. An adult member of the research team (usually the TTS Research Coordinator) always accompanied the YAC members. Monthly meetings and ongoing training sessions were scheduled as needed to support their ongoing work and to provide them with opportunities to celebrate and socialize. Through their involvement in this phase of the project, the YAC members reported that they had gained invaluable skills and knowledge in research, public speaking, group facilitation, peer education, and sexual health. Their experience as youth researchers is featured in *Sexpress: The Toronto Teen Survey Movie* (see: <http://vimeo.com/4953806>).

Throughout the research process, evaluation measures such as regular informal check-ins among the YAC, the Research Coordinator, and the Investigators were integrated to ensure that outcomes were being achieved in a timely manner, and that project partners, community members, and YAC were satisfied with the process.

Over and over again we heard from our community partners that hosted the survey workshops that the peer-approach we adopted was highly successful in opening up honest dialogue between youth about sexual health issues and concerns. A year after we stopped collecting survey data, we were still being invited back to facilitate workshops. We also heard from our YAC that they had become sexual health "knowledge brokers" at schools and in their communities. Many have expressed interest in continuing in the area(s) of research and health promotion in the future.

As a result of our community-based and peer-driven approach to research, we gathered one of the largest and most diverse samples in Canada that investigates sexual health issues. For example, 85% of our sample are visible minorities; 33% were born outside of Canada; 17% reported a disability such as a mobility impairment, depression, or problematic alcohol and drug use, and 7% identified as lesbian, gay, bisexual, queer, or "questioning" their sexual orientation.

### *Survey data analysis*

Given that the aim of the TTS was to identify gaps in sexual health education and service access barriers for various diverse groups of youth across Toronto, the majority of analyses were an examination of percentages. Surveys were “cleaned” and entered into an SPSS database by the York Centre for Social Research at York University. The next step was to share crude totals with the YAC and to gather their observations on the data. Then, each investigator took the lead on a sub-sample of the data (e.g., LGBTQ youth), prepping summary tables for the team. Although simple in approach, these descriptive statistics were intended to assist PPT and other community organizations in their assessment of basic health service utilization. In addition, more advanced statistical modeling or analysis was carried out by Investigators Jason Pole and Sarah Flicker with the involvement of students for various reports arising from the survey findings.

### ***Phase II: Service provider focus groups***

One of the most significant concerns of the TTS was to affect change by ensuring that our data met the needs, issues, and concerns of people serving youth on the frontlines. In order to do this, we shared our survey findings in focus groups with service providers, including clinicians, social workers, shelter and group home staff, public health nurses, and community outreach workers. In these focus groups, population-specific (e.g., Black youth) survey findings were presented to service providers as a means of developing further insights into the data and to assist in developing a knowledge transfer strategy that would ensure the uptake of TTS data.

During recruitment, service providers were provided with an introductory letter outlining the general purpose of the TTS and of the focus groups. They were also given an executive summary of survey findings. Service providers were recruited from those agencies that hosted youth focus groups and other networks of both PPT and the City of Toronto. Thirteen focus groups were held with 90 service providers from across the Greater Toronto Area. Each focus group lasted between two and three hours. The focus groups were facilitated by the Research Coordinator with the assistance of a note taker and often a TTS Investigator, and were audio-taped and

transcribed verbatim. Participants provided their informed consent indicating that they understood the purpose and goals of the focus groups and how the information they were providing would be used.

Each focus group followed the same process, with the TTS Research Coordinator providing a project overview, followed by group introductions. Participants also shared the particular sexual health issues that were most pertinent in the context of their work with youth. This provided a shared context for the group from which to proceed. Targeted findings from the survey were presented to the group through a power point presentation and participants were then asked to comment on the findings, what the findings meant to them, and how they could work more effectively to create a coordinated strategy for change.

### ***Phase III: Youth focus groups***

In Phase III of TTS, we undertook a series of focus groups with youth to share population-specific findings and to provide them with opportunities to identify and address their community sexual health issues and concerns. Youth were recruited purposively from community groups that bear an increased burden of sexually transmitted infections and/or experience greater barriers to accessing sexual health services (e.g. LGBT youth, racialized youth, newcomers). Thirteen focus groups, comprising 100 youth participants, were held between October 2008 and August 2009. During these focus groups, participants were asked to comment on the survey findings relevant to their community and to explore in-depth the emergent themes, trends, and complexities in the data. This process also provided youth with an opportunity to make key program and policy recommendations for change.

### *Focus group analysis*

Copious summary notes were taken by volunteers at each focus group. Focus group discussions were also audio-taped and then transcribed verbatim, and the accuracy of transcription verified against summary notes. A data analysis team of youth, students, and TTS Investigators worked collaboratively to develop a coding scheme based on emerging themes from the transcripts. Each transcript was coded using Nud\*ist 6 Qualitative Data Management Software by at least two Research Assistants and the Research

Coordinator. Coded data were then returned to the Investigators team to discuss themes, gaps, and issues of concern. Minutes and summary notes of those discussions became the basis for final analysis (Jackson, 2009).

## Discussion

### *Mobilizing knowledge*

We know that publishing in peer-reviewed journals is important. It helps to ensure that results remain in the academic domain, that they are searchable and retrievable, and that we continue to push our respective fields forward, especially with the next generation of students studying and preparing to work in this area. We also recognize that there are ways of sharing information that have more relevance for communities (see, for example, [www.torontoteensurvey.ca](http://www.torontoteensurvey.ca)).

Sexual health resources both in the Greater Toronto Areas and across Ontario represent a patchwork of competing policy interests and priorities. There is no singular policy we intend to challenge or alter, but instead propose a broad strategy for improving access to sexual health services for youth. In keeping with our *university-community-policy partnership* approach and reflective of the complex ways in which sexual health policy is formed, we are taking a “bottom-up” approach to disseminating our research with the intent of affecting sexual health policy.

In June of 2009, we launched a significant community report highlighting key TTS findings, a series of recommendations for improving the landscape of youth sexual health promotion in Toronto, and a youth sexual health “Bill of Rights”. Two hundred community service providers, policy-makers, and other knowledge users attended that event. Media coverage was extensive and reached news outlets across Canada, the United States, and even Australia. Clearly, there was significant interest in these data as service providers struggle to provide quality programming for ever-changing populations of youth

At the same time, we launched a youth-friendly poster that also highlighted some of the key findings, and then conducted presentations to nearly 100 youth serving organizations across Toronto. With

funding from the TELUS Community Foundation, PPT worked with youth to create videos that address some of their issues regarding access to sexual health services and information.

We have also currently launched a number of “Community Bulletins” that address the unique sexual health concerns, issues, and considerations of some of the sub-populations of young people in the TTS. Funded by a knowledge translation grant from the Canadian Institutes of Health Research, each bulletin contains in-depth community-specific data (e.g., newcomer youth, LGBTQ youth) as well as key recommendations for improving sexual health outcomes for these populations of youth. Each bulletin was undertaken with key partners to shape programs and policies for different sub-populations of youth in Toronto (e.g., African and Caribbean Council on HIV, Rainbow Health Ontario, and the June Callwood Centre for Women and Families). Each bulletin was launched in a manner that partners believed would best ensure the uptake of data.

Finally, we have been engaged in policy discussions with various levels of government to see what can be done to improve the landscape of youth sexual health in Toronto. These discussions have been very encouraging and prove to us that a community-based approach to research can produce policy relevant data. The TTS story continues!

## References

- American Academy Of Pediatrics. (2004). *Ethical Considerations in Research With Socially Identifiable Populations*.
- Barker, A. (2000). *Building gay men's health: A peer-based approach to creating community change*. Vancouver, BC: AIDS Vancouver.
- Beitz, J. M. (1998). Sexual health promotion in adolescents and young adults: primary prevention strategies. *Holistic Nursing Practice*, 12, 27-37.
- Borden, L., & Serido, J. (2009). From program participant to engaged citizen: A developmental journey. *Journal of Community Psychology*, 37, 423-438.

- Boutilier, M., Mason, R., & Rootman, I. (1997). Community action and reflective practice in health promotion research. *Health Promotion International, 12*, 69-77.
- Campbell, C., & Trotter, J. (2007). Invisible young people: The paradox of participation in research. *Vulnerable Children and Youth Studies, 2*, 32-39.
- Cargo, M. (2003). Empowerment as fostering positive youth development and citizenship. *American Journal of Health Behavior, 27*, S66-S79.
- Celio, C.I., Durlak, J.A., Gullotta, T.P., Bloom, M., Gullotta, C.F., & Messina, J.C. (2009). Service-learning: Learning by doing for others. In Anonymous (Ed.), *A blueprint for promoting academic and social competence in after-school programs* (pp. 101-118). New York, NY: Springer Publishing Co.
- Checkoway, B., Dobbie, D., & Richards-Schuster, K. (2003). Involving young people in community evaluation research. *Community Youth Development, 4*, 7-11.
- Checkoway, B., & Gutierrez, L. (2006). Youth participation and community change: An introduction. *Journal of Community Practice, 14*, 1-9.
- Checkoway, B., Richards-Schuster, K., Abdullah, S., Aragon, M., Facio, E., Figuero, L., et al. (2003). Young people as competent citizens. *Community Development Journal, 38*, 298-309.
- Crawshaw, P., Mitchell, W., Bunton, R., & Green, E. (2000). Youth empowerment and youth research: Expertise, subjection and control. *Youth & Policy, 69*, 1-16.
- Deuchar, R. (2008). "All you need is an idea!": The impact of values-based participation on pupils' attitudes towards social activism and enterprise. *Improving Schools, 11*, 19-32.
- DiClemente, R.J. (2001). Development of programmes for enhancing sexual health. *Lancet 2001, 358* (9296), 1828-1829.
- DiGiulio, G. (2003). Sexuality and people living with physical or developmental disabilities: A review of key issues. *The Canadian Journal of Human Sexuality, 12*, 53-68.
- Driskell, D., Fox, C., & Kudva, N. (2008). Growing up in the new New York: Youth space, citizenship, and community change in a hyperglobal city. *Environment and Planning A, 40*, 2831-2844.
- Fine, M., & McClelland, S.I. (2006). Sexuality education and desire: Still missing after all these years. *Harvard Educational Review, 76*(3 Fall), 297-338.
- Flicker, S. (2008). Who benefits from community based participatory research? *Health Education & Behavior, 35*, 70-86.
- Flicker, S., & Guta, A. (2008). Ethical approaches to adolescent participation in sexual health research. *Journal of Adolescent Health, 42*, 3-10.
- Flicker, S., Guta, A., Larkin, J., Fridkin, A., Travers, R., Pole, J., et al. (2010). Survey design from the ground up: Collaboratively creating the Toronto Teen Survey. *Health Promotion Practice, 11*, 112-122.
- Flicker, S., Larkin, J., Smillie-Adjarkwa, C., Restoule, J.-P., Barlow, K., Dagnino, M., et al. (2008). "It's hard to change something when you don't know where to start": Unpacking HIV vulnerability with aboriginal youth in Canada. *PIMATISIWIN: A Journal of Indigenous and Aboriginal Community Health, 5*, 175-200.
- Flicker, S., Maley, O., Ridgley, A., Biscope, S., Lombardo, C., & Skinner, H. (2008). e-PAR: Using technology and participatory action research to engage youth in health promotion. *Journal of Action Research, 6*, 285-303.
- Flicker, S., Savan, B., Kolenda, B., & Mildenberger, M. (2008). A snapshot of community based research in Canada. *Canadian Journal of Public Health, 23*, 106-114.
- Flicker, S., Savan, B., McGrath, M., Kolenda, B., & Mildenberger, M. (2008). If you could change one thing...What Community-Based Researchers wish they could have done differently. *Journal of Community Development, 43*, 239-253.
- Flicker, S., Savan, B., Mildenberger, M., & Kolenda, B. (2008). A snapshot of community based research in Canada: Who? What? Why? How? *Health Education Research, 23*, 106-114.
- Franz, N., & Poon, C. (2000). *Making choices: Sex, ethnicity and BC youth*. Burnaby, BC: The McCreary Centre Society.

- Grabois, E. (2001). Guide to getting reproductive health care services for women with disabilities under the Americans with Disabilities Act of 1990. *Sexuality and Disability, 19*, 191-208.
- Harper, G., & Carver, L. (1999). "Out-of-the-mainstream" youth as partners in collaborative research: Exploring the benefits and challenges. *Health Education and Behavior, 26*, 250-265.
- Israel, B., Schulz, A., Parker, E., & Becker, A. (1998). Review of community-based research: Assessing partnership approaches to improve public health. *Annual Reviews Public Health, 19*, 173-194.
- Jennings, L.B., Parra-Medina, D.M., Messias, D.K. H., & McLoughlin, K. (2006). Toward a critical social theory of youth empowerment. *Journal of Community Practice, 14*, 31-55.
- Joesoef, M.R., Kahn, R.H., & Weinstock, H.S. (2006). Sexually transmitted diseases in incarcerated adolescents. *Current Opinion in Infectious Diseases, 19*, 44-48.
- Juris, J.S., & Pleyers, G.H. (2009). Alter-activism: Emerging cultures of participation among young global justice activists. *Journal of Youth Studies, 12*, 57-75.
- Kelly, D.C. (2009). In preparation for adulthood: Exploring civic participation and social trust among young minorities. *Youth & Society, 40*, 526-540.
- Larkin, J., Flicker, S., Mintz, S., Koleszar-Green, R., Dagnino, M., & Mitchell, C. (2005). *Youth, gender and HIV prevention: The CANFAR report*. Toronto, ON: Canadian Foundation for AIDS Research (CANFAR).
- Lawrence-Jacobson, A.R. (2006). Recreating the common good: intergenerational community action. *Dissertation Abstracts International, A: The Humanities and Social Sciences, 66*, 3094-A.
- Mason, R. (1997). "Total responsibility and absolutely no control": A case study of participatory research as a health promotion strategy. Toronto, ON: Ontario Institute for Studies in Education, University of Toronto.
- Mason, R., & Boutilier, M. (1996). The challenge of genuine power sharing in participatory research: The gap between theory and practice. *Canadian Journal of Community Mental Health, 15*, 145-152.
- Matthews, H., & Limb, M. (2003). Another white Elephant? Youth councils as democratic structures. *Space & Polity, 7*, 173-192.
- Miller, C., Spittal, P., Frankish, J. et al. (2005). HIV and hepatitis C outbreaks among high-risk youth in Vancouver demands a public health response. *Canadian Journal of Public Health, 96*, 107-108.
- Miller, M. (2008). Social capital; institutional agency; low-status, urban youth; and empowerment: An investigation of School on Wheels, Inc. *Dissertation Abstracts International, A: The Humanities and Social Sciences, 69*, 0052-0052.
- Minkler, M. (2005). Community-based research partnerships: Challenges and opportunities *Journal of Urban Health, 82*(Supplement 2), ii3-ii12.
- Minkler, M., & Wallerstein, N. (2003). *Community-based participatory research for health*. San Francisco, CA: Jossey-Bass.
- National Research Council and Institute of Medicine. (2005). *Ethical considerations for research on housing-related health hazards involving children. Report brief*. Retrieved from [www.iom.edu/Object.File/Master/32/245/Housing%20Ethics%20web.pdf](http://www.iom.edu/Object.File/Master/32/245/Housing%20Ethics%20web.pdf) on Nov 1, 2006: National Academy of Sciences.
- Nosek, M.A., Howland, C.A., & Hughes, R.B. (2001). Vulnerabilities for abuse among women with disabilities. *Sexuality and Disability, 19*, 177-189.
- O'Brien Teengs, D., & Travers, R. (2006). "River of Life, Rapids of Change": Understanding HIV Vulnerability among Two-Spirit Youth who Migrate to Toronto. *Canadian Journal of Aboriginal Community-Based HIV/AIDS Research, 1*, 17-28.
- Ontario Federation of Indian Friendship Centres (OFIFC). (2002). *Tenuous connections: Urban aboriginal youth, sexual health and pregnancy*. Toronto, ON: OFIFC.
- Prentice, T. (2004). *HIV Prevention Messages for Canadian Aboriginal Youth. Final Report. Last accessed: July 17, 2007*. [http://www.caan.ca/english/grfx/resources/publications/youth\\_prevent.pdf](http://www.caan.ca/english/grfx/resources/publications/youth_prevent.pdf). Ottawa, ON: Canadian Aboriginal AIDS Network.
- Public Health Agency of Canada. (2006). *I-Track (2003-2005)*. Ottawa, ON: Surveillance and Risk Assessment Division, Centre for Infectious Disease Prevention and Control.

- Raphael, D. (Ed.). (2008). *Social determinants of health: Canadian perspectives* (2nd Ed.). Toronto, ON: Canadian Scholars' Press Inc.
- Remis, R., Alary, M., Otis, J., et al., & the OMEGA Study Group. (2004). Trends in HIV incidence and sexual behaviour in a cohort of men who have sex with men (MSM) in Montreal, 1996-2003. *Canadian Journal of Infectious Diseases, 15*(Suppl A), 54A (Abstract 318).
- Rothon, D., Strathdee, S., Cook, D. et al. (1997). Determinants of HIV-related high risk behaviours among young offenders: A window of opportunity. *Canadian Journal of Public Health, 88*, 14-17.
- Roy, E., Haley, N., Leclerc, P. et al. (2002). HIV incidence in the Montreal Street Youth Cohort (MSYC). *Canadian Journal of Infectious Diseases, 12*(Suppl A), 49A (Abstract 317).
- Roy, E., Hayley, N., Boivin, J., Frappier, J., Classenes, C., & Lemire, N. (1998). *Etude de cohort sur l'infection au VIH chez les jeunes de la rue de Montreal*. Montreal, PQ: Final Report to Health Canada.
- Seifer, S.D., Shore, N., & Holmes, S.L. (2003). *Developing and sustaining community-university partnerships for health research: Infrastructure requirements*. Seattle, WA: Community-Campus Partnerships for Health.
- Shoveller, J.A., & Johnson, J.L. (2006). Risky groups, risky behaviour, and risky persons: Dominating discourses on youth sexual health. *Critical Public Health, 16*, 47-60.
- Smyth, R. (2001). Research with children: Paediatric practice needs better evidence—gained in collaboration with parents and children. *British Medical Journal, 322*, 1378-1379.
- Suleiman, A.B., Soleimanpour, S., & London, J. (2006). Youth action for health through youth-led research. *Journal of Community Practice, 14*, 125-145.
- Tepper, M.S. (2001). Becoming sexually able: Education to help youth with disabilities. *SIECUS Report, 29*, 5-13.
- Travers, R., Wilson, M., Guta, A., Flicker, S., Bereket, T., McKay, C., et al. (2008). The greater involvement of people living with AIDS principle: Theory vs. practice in Ontario's HIV/AIDS community-based research sector. *AIDS Care, 20*, 615-624.
- Trussler, T., Perchal, P., & Barker, A. (2000). "Between what is said and what is done": Cultural constructs and young gay men's HIV vulnerability. *Psychology, Health & Medicine, 5*, 295-306.
- Villadsen, K. (2008). Freedom as self-transgression: Transformations in the "governmentality" of social work. *European Journal of Social Work, 11*, 93-104.
- Viswanathan, M., Ammerman, A., Eng, E., Gartlehner, G., Lohr, K., Griffith, D., et al. (2004). *Community-based participatory research: Assessing the evidence. Summary, evidence report/technology assessment, No 99* (No. AHRQ Publication 04-E022-1). Rockville, MD: RTI-University of North Carolina.
- Weber, A., Craib, K., Chan, K., et al. (2003). Determinants of HIV seroconversion in an era of increasing HIV infection among young gay and bisexual men. *AIDS, 17*, 774-777.
- Wilson, N., Minkler, M., Dasho, S., Carrillo, R., Wallerstein, N., & Garcia, D. (2006). Training students as facilitators in the youth empowerment strategies (YES!) project. *Journal of Community Practice, 14*, 201-217.
- World Health Organization (WHO). Sexual health working definitions. Retrieved from <http://who.int/reproductive-health/gender/sexualhealth.html>