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Survey Design From the Ground Up: Collaboratively Creating the Toronto Teen Survey

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The Toronto Teen Survey is a community-based participatory research study whose aim is to gather information on the accessibility and relevance of sexual health services for diverse groups of urban youth (13 to 17 years of age). This information will be used to develop a proactive, citywide strategy to improve sexual health outcomes for Toronto adolescents. In this article, the authors focus on the processes of collaboratively developing a survey tool with youth, academics, and community stakeholders. An overview of the project and examples from the design stage are provided. In addition, recommendations are given toward developing best practices when working with young people on research and survey design.

Keywords: youth; community-based participatory research; survey design; sexual health; HIV

The Toronto Teen Survey (TTS) is a community-based participatory research (CBPR) study. Our aim is to gather information on the accessibility and relevance of sexual health services for diverse groups of urban youth (13 to 17 years of age). This information will be used to develop a proactive citywide strategy to

improve sexual health outcomes for Toronto adolescents. In phase 1 of the project, seed funding¹ was secured to build Planned Parenthood of Toronto's research capacity, develop partnerships with researchers and policy makers, and engage a diverse group of Toronto youth in the development of a survey tool and research protocol. In this article, we focus on the processes of collaboratively developing a community-based survey tool with youth, academics, and community stakeholders. An overview of the project and examples from the design stage are provided. In addition, recommendations are given toward developing best practices when working with young people on research and survey design. Our intention in sharing this information is to assist other teams that want to work in partnership with teenagers on developing local public health evidence-based intervention strategies.

► BACKGROUND

Sexually transmitted infections (STI), including HIV/AIDS, pose a significant threat to the health and well-being of young people. Youth are disproportionately affected by STIs as a result of complex interactions between biological, social, developmental, and behavioral factors (Health Canada, 2000). They are biologically more vulnerable to infections, more susceptible to peer pressure, developmentally more disposed to risk taking, and behaviorally often lack the skills and confidence to negotiate safer sex practices. As a result, STI rates among Canadian youth are on the rise (Centre for Disease Prevention and Control, 2003).

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Population-based efforts to provide youth with sexual health information have resulted in limited improvements to their understanding of sexual health risk. A national youth survey showed that knowledge about HIV, and other STIs, has actually declined in the past decade (Boyce, Doherty, Fortin, & MacKinnon, 2003). It is unfortunate that youth report ongoing confusion in relation to sexual health information, in particular in the areas of STI prevention and treatment (Larkin et al., 2005).

Over the past decade, the international sexual and reproductive health movement has increased its efforts toward improving youth access to sexual health information and appropriate STI prevention strategies (UNAIDS, 1998, 2000; UNESCO, 2001; UNICEF, 2002). In Canada, these efforts, undertaken through the public school system, community health centers, and other venues, have had modest success (Barnes, Courtney, Pratt, & Walsh, 2004; Frauenknecht, Droog, & Minnear, 1999; Maticka-Tyndale, 2001). Despite high rates of reported sexual activity, youth are often uninformed about sexual health prevention issues (Boyce et al., 2003), with younger teenagers demonstrating an even greater lack of clarity around myths and facts relating to sexual health (Byers et al., 2003; Creatura, 1998; Hansen, Mann, Wong, & McMahon, 2003).

The limited effectiveness of these initiatives may be a consequence of the lack of youth involvement in the development and dissemination of sexual health information and resources intended for them (Walsh, Mitchell, & Smith, 2002). The benefits of involving communities in research and intervention development have been demonstrated in the growing body of research using a CBPR approach (Israel, Schulz, Parker, & Becker, 1998; Minkler & Wallerstein, 2003). Specifically, youth involvement in community-based projects contributes to their enhanced sense of control over their lives, while improving the relevance and appropriateness of programs and services developed (Checkoway & Gutierrez, 2006; Suleiman, Soleimanpour, & London, 2006; Wilson et al., 2006). Interventions are more likely to succeed if they involve youth in a manner that stimulates learning, makes best use of their knowledge and skills, and works to empower them (Advisory Committee on Population Health, 2000; Bettencourt, Hodgins, Huba, & Pickett, 1998; Blum, 1998; Checkoway, Dobbie, & Richards-Schuster, 2003; Flicker, 2006; Harper & Carver, 1999; Horsch, Little, Smith, Goodyear, & Harris, 2002; Skinner et al., 1997).

THE TORONTO TEEN SURVEY PARTNERSHIP

The TTS was born out of an understanding that as Toronto's population continues to diversify, new strategies and approaches are necessary to meet the specific sexual health needs of young people.

Planned Parenthood of Toronto (PPT) is a pro-choice community health center committed to the principles of equity and to providing accessible and inclusive services that promote healthy sexuality and informed decision making to the people of Toronto. PPT currently runs a sexual health clinic serving youth (ages 13-25), runs a variety of peer education programs (online, phone, and in-person), and regularly provides training to the community on a broad range of sexual health-related topics (see <http://www.ppt.on.ca/>).

PPT is situated in one of the most ethnically and racially diverse cities in the world. As a result of relatively liberal immigration policies and a booming economy, Toronto has become a central migration point and one of North America's fastest growing metropolitan regions. Fifty-four percent of Toronto's population was born outside of Canada, making it second only to Miami in numbers of foreign-born residents (see www.toronto.ca). Twenty-five percent of young people living in the city (ages 5-16) have been living in Canada less than 5 years. Forty-three percent of the population identify as a visible minority,² and more than 100 languages (other than English) are spoken in

Toronto homes (www.toronto.ca). Toronto is also regarded internationally as a principal migration center for lesbian, gay, bisexual, and transgender communities (Travers, Leaver, & McClelland, 2002). Stakeholder groups, including PPT staff, clients, and partner agencies, continue to seek innovative and culturally sensitive approaches for serving increasingly diverse groups of youth.

PPT felt the need to reach out to young people in a systematic way to understand how to better meet their needs. The agency approached investigators associated with the Gendering Adolescent AIDS Prevention (GAAP) Project to assist in designing a community survey that would begin to explore access barriers and facilitators to sexual health services for Toronto's diverse youth populations. GAAP is a collaborative research initiative that has conducted a series of studies with Canadian and South African youth who face various conditions of HIV risk (see www.utgaap.info). GAAP investigators are housed in a number of research settings, including the University of Toronto, York University, and the Ontario HIV Treatment Network. Academic investigators on the TTS team are an interdisciplinary group with expertise in adolescent health research, HIV prevention and support research, and gender and sexuality theory and have training in epidemiology, sociology, public health, and educational psychology. They work collaboratively with youth and youth-serving organizations on developing new approaches for engaging youth in sexual health promotion and HIV prevention. Although members of the team had substantial experience developing and modifying survey instruments, our commitment to a youth-driven model necessitated adapting our approach.

► COLLABORATIVE SURVEY DESIGN

Although there is no shortage of helpful textbooks and journal articles on survey design (Abramson & Abramson, 1999; Aday, 1996; Boynton, 2004; Boynton & Greenhalgh, 2004; Boynton, Wood, & Greenhalgh, 2004; Gillham, 2000; Jackson, 1999; Oppenheim, 1992; Salant & Dillman, 1994; Sapsford, 1999), few address the issue of collaborative community-based survey construction (Schulz et al., 2005). Face validity (Does the survey make sense?), content validity (Has the conceptual been appropriately operationalized?), construct validity (Do a group of questions appropriately measure a theoretical idea?), and consensual validity (Do experts think you have done it right?) are often cited as critical to survey design. Usually, experts are considered to be professional members of the academy rather than community residents. Community input into the design is often relegated to the pilot testing stage of nearly completed instruments. Whereas many texts stress the importance of pilot testing with target populations,

our project was committed to involving youth and service providers at every step along the way.

With scant publicly available resources on collaborative survey design, the research team had few examples to draw from in developing the TTS. Using the partners' respective experience with standard survey design methods and previous work with youth, the team merged their understanding toward a participatory youth-driven survey design model. Consequently, the survey developed iteratively from the "ground up." By iterative, we mean that through multiple sessions, consultations, and conversations, we made adjustments and improvements along the way until we came up with a final product. The following provides an overview and timeline of events, with discussion of key findings and recommendations (see Figure 1).

► THE FIRST STEP: RECRUITING AND TRAINING AN APPROPRIATE RESEARCH COORDINATOR AND YOUTH ADVISORY COMMITTEE

Youth Advisory Committees (YACs) are becoming increasingly popular as effective means to incorporate youth into the planning and development of programs meant to serve them (Hohenemser & Marshall, 2002). In keeping with the principles of CBPR, our goal was to partner closely with young people in the development of our survey tools and research protocols. When partnering with young people, there is often a tendency to find the "professionalized" youth: strong students used to taking on leadership roles. Our goal, however, was to attract youth with a diversity of backgrounds and experiences.

As such, it was important to hire a research assistant who was pro-choice, skilled in research methods, and had substantial youth facilitation expertise and experience working with diverse communities. Agency management and an academic partner were present at each interview. We knew that finding the right mix would be crucial to our success, as CBPR staff and scholars often play multiple roles in a project (Minkler, 1997; Minkler & Wallerstein, 2003; Stoecker, 1999). To find the right person, we went through two rounds of posting the position and interviewing before choosing a master's student in a health promotion program.

The goal of the YAC was to take the lead in developing a youth-friendly survey and study protocol. YAC members were recruited from partner agencies within the city, including community and recreation centers, supportive housing organizations, and child protection services. Youth were asked to apply by completing an application form. Twelve teens (2 males and 10 females) between the ages of 13 and 17, representing great diversity

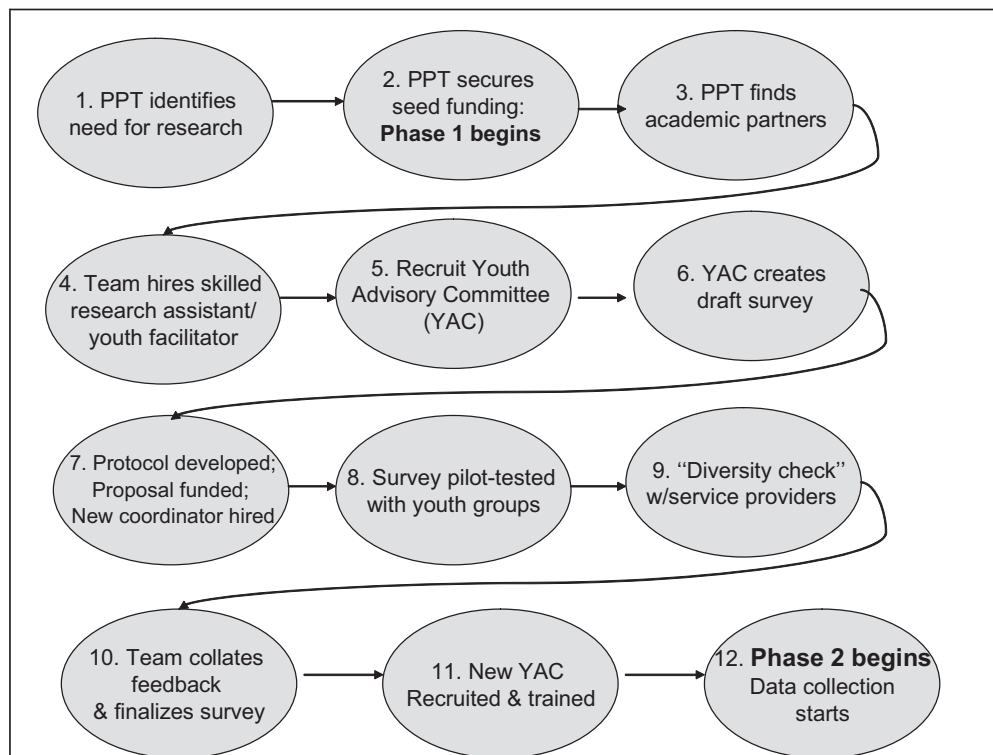


FIGURE 1 Toronto Teen Survey Timeline

NOTE: PPT = Planned Parenthood of Toronto.

in terms of neighborhood geography, racial and ethnic background, and socioeconomic status, participated. Despite strategic efforts to regularly recruit and engage young men in sexual health promotion, PPT often faces challenges in getting them to take on leadership roles. Inclusive and accessible recruitment strategies were employed, but young men in this age range have not been as receptive as their female peers.

YAC sessions were a mix of training and survey-design workshops. YAC members received training on topics related to qualitative and quantitative methodologies, sexual health, anti-oppression analysis, and the social determinants of health (see Table 1). Although no short training program can be expected to create expert survey developers, our intention was to provide the YAC members with enough of an introduction to critically engage with these issues and draw on their own expertise. It was surprising to the rest of the research team that these young people had participated as respondents in a variety of formal (school) and informal (magazines or online) surveys and were able to draw on these experiences to

provide sophisticated analyses about the kinds of questions that would be effective for their peers.

During the survey design workshops, youth explored sexual health accessibility issues for survey inclusion. Our goal here was to draw on youth's local knowledge, theory, and experience to develop key concepts for survey inclusion. YAC members were provided a variety of similar surveys to serve as examples and draw from in developing their own tool. They then proceeded to operationalize concepts through drafting, adapting, refining, and amalgamating questions and approaches. They also made recommendations for implementation in relation to length, order, layout, and administration.

Each session was structured with concrete goals and objectives. Activities were designed to give youth the skills to meaningfully participate and then followed up with opportunities to contribute in various capacities. For example, the youth might individually complete a series of draft survey questions developed in the previous session and then discuss how respondents might interpret them as a group. Alternatively, they might

TABLE 1
Youth Advisory Committee Meeting Schedules

Meeting 1	Introduction Setting ground rules Human Knot (trust game) Flower Power (trust game) Research presentation (co-principal investigator) Feedback
Meeting 2	Introduction Sexy Bingo (game) Sex Language (game) Introduction to research What is sexual health? (brainstorm) What are sexual health services? (brainstorm) Developing survey sessions Feedback
Meeting 3	Introduction "What would you do?" scenarios (brainstorm) Assumptions in research questions Survey development Present questions Feedback
Meeting 4	Introduction Pilot survey (S1) (filling out a mock survey) Discussing individual questions (areas for improvement) Review of survey formats Feedback
Meeting 5	Introduction Pilot survey (S2) (modified based on discussion in last session) Discussing individual questions (areas for improvement) Feedback
Meeting 6	Introduction Pilot survey (timed) Discussing individual questions (areas for improvement) Discussing appearance of survey Where to distribute the survey (format of sessions) Incentives (discussing honoraria for respondents) Where to pilot the survey Feedback

break into smaller groups to discuss a case study on a relevant scenario involving a young person attempting to access sexual health services and then present their

analysis to the other groups, so as to brainstorm important dimensions for inclusion on the tool. This basic format was consistent for all six sessions.

Ground rules for participation were established at the first session to ensure a space in which all respondents were free to exchange their ideas without fear of reprisal. There was a general consensus from the youth concerning the importance of respect, both in terms of respecting others' ideas as well as personal freedom. YAC members cited the need for letting people finish their statements and not personalizing rebuttals. At the same time, they understood the importance of communication and open dialogue. In response to whether fighting was acceptable, a female respondent explained, "Not *no* fighting—some fighting is good to get ideas out." A male respondent added, "Attack the idea, not the person," and suggested saying, "I don't agree with your opinion, but this is what I believe." With respect to confidentiality, a male respondent said, "What is said in the group stays in the group." There seemed to be consensus around privacy and the need for confidentiality, because subject matter relevant to the group may be inappropriate if brought up elsewhere.

The youth were provided with general topic areas of interest to the hosting organization and investigator team but were also asked to supplement these general concepts with their own areas of interest. For example, the research team wanted to know what made for a positive clinic experience, but the youth were encouraged to brainstorm around this issue, and their numerous suggestions determined the final criteria used in this question:

18. What was *good* about your visits to clinics for sexual health stuff? (Please check all that apply.)
 - ☐ Nonjudgmental
 - ☐ Positive attitude towards youth
 - ☐ Free birth control or condoms
 - ☐ Confidential/private
 - ☐ I felt comfortable asking questions
 - ☐ Positive attitude towards sex
 - ☐ Sensitive to my ethnic or cultural background
 - ☐ Location was close by or easy to get to
 - ☐ Positive attitude towards teen pregnancy and parenting
 - ☐ Understood/spoke my language
 - ☐ The waiting room was really youth-friendly (e.g., had good music or magazines)
 - ☐ Sensitive to my religion
 - ☐ Positive attitude towards gay, lesbian, bisexual, and transgender people
 - ☐ Sensitive towards my gender
 - ☐ Physically accessible (e.g., wheelchair accessible)
 - ☐ Staff were available to see me
 - ☐ Provided good information
 - ☐ Provided all the services I needed

- ☐ Other (please specify) _____
- ☐ There was nothing good about it
- ☐ I have never received sexual health services

► EFFECT OF YOUTH COLLABORATION ON THE SURVEY

Collaborating with youth improved and challenged the research team's understanding of youth sexual health issues. They spent a lot of time debating the merits of how to word questions, where they should be located in the survey, and the possible meanings attached to questions and the examples within them. They were very vocal about how they wanted the content, length, format, and structure of the survey to look and feel. For instance, it could not be "too long" and 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 alternatives.

The research team was surprised by concerns around commonly asked demographic questions. For example, issues were raised over asking for respondents' postal codes. In filling out a trial survey, some of the youth admitted to having made up their postal code because they couldn't remember it. Several youth found the question unnecessary and threatening, wondering why it was relevant to a study on sexual health, and feared that other youth might interpret it as an attempt to locate them. As a team, we talked about the importance of understanding geography as an access barrier. In response, we decided to ask for the first three (out of six) digits of a postal code. This provided us with enough information to map variation by neighborhood, and it provided youth with an increased sense of anonymity (because the last three digits identify streets). In addition, another option was added, allowing youth to indicate that they do not know their postal code. In piloting the study with two youth groups, one an ethno-specific AIDS service organization, and the other providing a range of services to low-income youth and their families, the research team confirmed that this was indeed an issue for young people. Here, too, respondents questioned the need for this information and admitted to having answered incorrectly. Ultimately, the question was deemed to merit some explanation before being administered. On the YAC's recommendation, the protocol was amended so that when YAC members administer the survey in community settings, they now address this issue outright, explaining to respondents why researchers ask for this kind of information and how it will be used in this specific study—to identify parts of Toronto neighborhoods in need of improved or additional sexual health services for youth. This approach seems to be working and yielding more honest responses.

The question "To which ethnic or cultural group(s) do you belong, if any? (Please check all that apply)" incited much discussion about inclusion/exclusion criteria and showcased differences of opinion on ethnic/cultural boundaries among both the YAC and the research team. Consensus was not reached. After much (sometimes lively!) debate, the research team decided to take into account the YAC suggestions and adopted the categories that were being used by the Toronto District School Board in a study on equity issues, so as to provide a comparison group.

A question on immigration and newcomer status showed that youth are not always familiar with terms that professionals take for granted, and that terms familiar to them may not be acceptable. Although the terms *immigrant* and *refugee* were recognized and understood, YAC members felt that these terms are value laden and could be perceived as stigmatizing by respondents as well as service providers in potential hosting organizations. Ultimately, the question was presented as follows:

5. How long have you been living in Canada?
 - ☐ I was born in Canada and have lived here all or most of my life.
 - ☐ I was not born in Canada, but I have been living in Canada for 10 years or over.
 - ☐ I have been living in Canada between 4 and 9 years.
 - ☐ I have been living in Canada between 6 months and 3 years.
 - ☐ I have been living in Canada less than 6 months.

Several of the youth felt that if the question had been left as it was, respondents would reply based on their preference or perceived identity as opposed to where they "technically fit." For example, a female respondent explained that although her family has been here for multiple generations, she does not consider herself Canadian. In similar discussions, a number of respondents expressed a deeper sense of connection with their ancestral country of origin than with a Canadian identity.

Another question that proved problematic was one that involved disability and mental illness. The question was intended to gauge how youth living with disabilities or experiencing mental illness perceive barriers to access and service. Disability activists advised the research team to phrase the question, "Are you living with any of the following?" However, this phrasing was met with confusion. Several youth thought it was asking about their home life, and if any members of their family had these conditions. The YAC preferred to have the question written as, "Do you have any of the following disabilities . . .?" In consultation with members of the disability community, we

were told that this phrasing was not inclusive and might propagate increased stigma. Ultimately, we decided to frame the question in a way that was educational and remained sensitive to how it represented the community, but we added a bubble explanation for clarity. YAC members were also trained to specifically flag this issue in administration sessions. The bubble explanations were recommended by YAC members, and respondents have subsequently noted that they found them useful. Youth have shared with us that when the question itself is too long, they may simply stop reading; the bubbles, however, draw them in. The question now appears as follows:

This is another way of asking *do you have* any of the following?

9. Are *you* living with any of the following? (Please check all that apply.)
 - ☐ Learning disability
 - ☐ Mental illness
 - ☐ Mobility impairment
 - ☐ Hearing impairment (e.g., I have difficulty hearing even with hearing aid)
 - ☐ Visual impairment (e.g., I have difficulty seeing even with glasses)
 - ☐ I am not living with any of these

Examples of hearing and visual impairments were added so as to deter respondents who wear glasses, for example, from responding “yes” to having a visual impairment. In pilot testing the survey in settings where youth received mental health care, young people had no problems self-identifying. We considered adding depression as a separate item; however, when we consulted with adolescent health practitioners and the YAC, we were told that most youth “feel depressed” sometimes, regardless of a clinical diagnosis, and so that question might be confusing. Ultimately, we opted to go with a more general category that allowed youth to self-identify.

The YAC members were sensitive to the wording of questions, conscious of how they might be interpreted by respondents. In response to a question on the number of past sexual partners, a female respondent said she would be ashamed to answer six or more partners, which, although not a large number, was at the top end of the scale. In response to the question on sexual assault, a female respondent found the wording of the option “I have not had any of these experiences” problematic in that it implied that sexual assault is something worth experiencing. After evaluating their merits, the research

team ultimately took out these questions as they were not integral to the overall purpose of the study.

The TTS was designed to reach youth between the ages of 13 and 17, as this age range has not been heard from adequately in previous research. Because the surveys were being administered in community youth group settings with groups that did not necessarily match our age criteria, a number of older youth were often on site. YAC members felt it was important to let anyone present fill out the survey and then remove these before analysis. They argued that it was important to leave respondents in the community with a positive feeling and encourage them to participate again in another context if the opportunity should arise. Furthermore, we were conscious of not creating internal conflict between members of varying ages in established groups.

Furthermore, the YAC members were adamant about their desire to have an educational component for survey respondents to answer any immediate sexual health questions they may have following the survey. They did not feel it was adequate to simply administer the TTS but that the researchers had a responsibility to make the experience educational and informative for respondents. They also felt that the survey would be better received if it were administered by a youth peer researcher. The research team responded by adapting the protocol to encompass an information session to follow completion of the survey and to have the YAC member take the lead in the administration and education process in the second phase of the study—data collection.

► A CYCLICAL PROCESS

Once funding for phase 2 (survey administration) was secured, the research team engaged in another level of community consultation. Copies of the survey were sent to 12 key stakeholders at a variety of community organizations serving particular youth subpopulations (e.g., youth living with disabilities, transgender youth, gay and lesbian youth, new immigrant youth, etc.). Service providers were asked to comment on the survey and provide feedback on issues of diversity, inclusion, and equity. Simultaneously, the survey was piloted with youth groups in a variety of community settings (see Figure 1).

The research team then met repeatedly to incorporate the suggestions of stakeholders and refine the survey. This was difficult and slow-going work. Sometimes feedback was contradictory; sometimes it did not make sense. At other times, the team struggled with balancing political correctness, youth friendliness, clarity, and the importance of having relevant comparison groups. Ironically, the

seemingly easy demographic-related questions gave the team the most trouble. In particular, the team repeatedly debated how to frame questions about racial and ethnic identities. In addition, we went in circles around how to ask adolescents about socioeconomic status. Ultimately, it was decided to ask about parental education to allow for a comparison of results with a concurrent initiative by the local school board.

We simultaneously had to recruit a new research coordinator and YAC to administer the survey. Our original research assistant had graduated and we now needed to hire a full-time staff member. Using similar criteria, we hired someone with a background in social work as well as research, equity values, and youth facilitation skills. This background in clinical group work proved to be a major asset. Next, we contacted the YAC members from phase 1. Four rejoined the project, providing some continuity. The remaining nine, although still supportive of the project, were unable to sustain their earlier commitment. Initially, all of the original YAC members said that they wanted to be involved in phase 2; however, the lives of young people change drastically in 12 months and their priorities change as they move from middle school to high school. Although only four of the original YAC members returned, the positive experiences of the group overall made it easier to recruit new members. Youth had heard about the project's merits and the hosting organization through word-of-mouth. This second recruitment generated an enthusiastic response, and 20 youth signed on in less than a month. This second YAC worked to finalize the survey and further develop the conceived survey administration sessions planned by the original YAC. They underwent extensive training and are currently "in the field" administering survey sessions.

► LESSONS LEARNED: RECOMMENDATIONS FOR PRACTICE

Several issues arose that may be of importance to future teams incorporating the use of a YAC model into their research process. First, a facilitator who is skilled in (a) research and (b) youth work is essential for successful youth engagement. As might be expected in any group process, there were a number of issues that arose related to group dynamics. Although youth were recruited from across the city, several already knew each other. This sometimes created situations in which outside tensions were brought into the sessions, such as altercations involving group members and other youth not affiliated with the project. Cliques inevitably formed; sometimes they only wanted to work with their friends. Having a facilitator who was skilled in group process helped to address these issues head-on.

Lateness was a persistent issue. In an effort to address issues of attendance and punctuality, prior to each meeting, the coordinator called youth individually to remind them of sessions and start times. Those seeking to work with diverse groups of youth may wish to build this into their scheduling and planning and consider the order in which they plan certain activities, perhaps moving more important ones toward the end of sessions.

The research team also struggled with tensions related to how much training the youth should be provided with prior to engaging in survey construction. Although we were committed to empowering our YAC to become knowledgeable in the area of adolescent sexual health, we wanted our survey tool to be youth friendly and accessible to those who had not had any special training on these issues. Ultimately, the youth asked for and received more in-depth training. Although this informed the process and improved the quality of subsequent sessions, significant time had to be devoted to being responsive. Specifically, timelines had to be adjusted, and new activities and learning opportunities included. This sometimes meant unexpected extra work for the facilitator and additional expectations of the hosting organizations' staff and resources. For example, a PPT staff member trained in sexual health education stayed late one day to provide a workshop for the YAC.

Another important concern when working with youth is acknowledging their contribution and limiting any potential barriers to their participation. Youth were provided \$20 honoraria at the end of each session, regardless of their level of participation, and were reimbursed for transit and child care expenses when necessary. The setting for sessions was informal, youth friendly, and located near a major subway line. The 4:30 p.m. start gave youth enough time to arrive after the end of the school day. Dinner was always provided.

Careful attention must be paid to ensuring that research involving adolescents be conducted with the utmost sensitivity to ethical issues, including minimizing harm, maximizing benefits, and ensuring youth-friendly research practices. We adopted a number of innovative strategies in our research to ensure ethical integrity. These included (a) adopting a CBPR approach; (b) careful attention to youth-friendly protocols and consent procedures; (c) proper training of all research staff and peer researchers; (d) partnering with experienced community-based youth-serving agencies; (e) paying careful attention to issues of confidentiality and anonymity; and (f) valuing participation appropriately (Flicker & Guta, in press).

At the end of each session, youth were asked to reflect on how the session went and what lessons were learned about process that should be incorporated into future meetings. These informal and regular check-ins

TABLE 2
Key Lessons Learned on Partnering With Youth on Survey Design

1. Hire a skilled research coordinator with strong research and youth facilitation skills.
2. Set aside adequate resources to value youth commitments through honoraria, transit vouchers, meals, and celebrations.
3. Build in accommodating and flexible schedules to meet the complex needs of young people.
4. Don't be afraid to seek out diverse groups of youth for participation, but be sure to build in the resources/supports to accommodate the needs of youth from varied backgrounds.
5. Set clear ground rules for participation and provide adequate training and support.
6. Listen carefully and incorporate feedback.
7. Hearing from adult community experts is also important and can be very important for attending to equity issues.
8. It's OK to challenge youth input and work together to find optimal, innovative solutions.
9. The process may be iterative and more time-consuming than other approaches.
10. Be creative and have fun!

were valuable and provided important input about the way meetings were subsequently run. Responses ranged from recommendations about materials used in the sessions and seating arrangements to requests for more discussion and opportunities for participation. For example, when youth wanted to do more "fun" things, a game was created for them to play in the following session. Feedback from the youth at the end of phase 1 was extremely positive. A summary of helpful advice can be found in Table 2.

► DISCUSSION

Experts in the field of adolescent development have outlined the benefits to both youth and society when young people are provided with opportunities to contribute to policy development and community change (Blum, 1998; Nutbeam, 1997). Others have documented the important contributions of youth collaborators in research (Flicker, 2006; Harper & Carver, 1999; Smith, Monaghan, & Broad, 2002). These include valuable input in research design to ensure that processes are youth friendly and accessible, assistance in the recruitment of hard-to-reach youth through peer models, increased

accessibility, and community credibility. However, partnering with youth is not without its challenges. Including youth as coresearchers demands a higher investment of human and financial resources, creates new ethical challenges in relation to confidentiality, and requires the careful selection of appropriate adult mentors/collaborators (Harper & Carver, 1999; Smith et al., 2002). Greater care needs to be taken to sustain involvement and commitment and to appropriately match skills and interest levels to assigned work tasks (Hill, 1997; Poland, Tupker, & Breland, 2002; Smith et al., 2002).

As important as the youth's contributions were in designing the survey, equally important is how they benefited from the experience. The youth learned about sexual health and gained valuable experience applying survey design principles. This was, for many, an educational and personal achievement. The skills and experience gained throughout this process may be used toward securing entry into postsecondary education or becoming involved in different capacities in similar initiatives, a key issue in building community capacity (Hawe, Noort, King, & Jordens, 1997). Perhaps most important, they had an opportunity to work with youth who were sometimes very different from themselves and to learn how to negotiate and collaborate. Many spoke openly about building new friendships and networks across the city. Involvement was also a key opportunity to connect with adults working on issues of interest to them and their peers. Youth expressed appreciation for not only being heard but having their feedback and suggestions actively implemented.

Finally, this process also helped build the skills and capacities of PPT to conduct research. Capitalizing on these research skills in the future may help create the conditions for more responsive programming, advocacy, and services. Furthermore, the process of reaching out to service providers around the city and seeking their input in the design of the survey has created fertile ground for approaching them for survey administration sessions. Providers who saw their feedback taken seriously have become strong advocates for the project. We believe that the TTS is a stronger initiative and product as a result of engaging in this collaborative process and would encourage other teams to adopt this approach.

NOTES

1. Financial assistance was provided by the Wellesley Institute.

2. The term *visible minority* is used by Statistics Canada (the federal body that conducts Canada's national census) to describe groups that are not Caucasian or Aboriginal (see www.statcan.ca).

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