



Journal of Adolescent Health 42 (2008) 3–10

JOURNAL OF  
ADOLESCENT  
HEALTH

Original article

## Ethical Approaches to Adolescent Participation in Sexual Health Research

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Manuscript received January 30, 2007; manuscript accepted July 18, 2007

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### Abstract

**Purpose:** In this paper we make the case for the importance of adolescent sexual health research, and argue that requiring parental consent for adolescent participation may (a) be unwarranted, (b) be inconsistent with the principles of justice and inclusiveness, (c) be confusing, and (d) serve to silence young people who most need to have a voice in sexual health research.

**Methods:** Through a case study of the Toronto Teen Survey, we offer concrete suggestions and alternatives for protecting adolescent health research participants in community-based settings and promoting ethical research approaches.

**Results:** Strategies suggested include: (1) adopting a community-based participatory research approach, (2) careful attention to youth-friendly protocols and consent procedures, (3) proper training of all research staff and peer researchers, (4) partnering with experienced community based youth-serving agencies, (5) paying maximum attention to issues of confidentiality and anonymity, and (6) valuing participation appropriately.

**Conclusions:** Institutional review boards and researchers should be encouraged to adopt localized context-dependent strategies that attend to the unique vulnerabilities of their particular study populations. Attention to flexibility, vulnerability, and community-specific needs is necessary to ensure appropriate ethical research practices that attend to the health and well-being of young people. © 2008 Society for Adolescent Medicine. All rights reserved.

### Keywords:

Adolescent health; Sexual health; Research; Ethics; Parental consent; Community-based participatory research; Ethical review

Owing to a number of biological, social, developmental, and behavioral factors, youth locally [1] and globally [2] are disproportionately affected by sexually transmitted infections (STI). STIs, including HIV/AIDS, pose a significant threat to the health and well-being of young people. In Canada, the highest rates and increases of STIs are in people between the ages of 15 and 24 [1]. Globally, half of all new HIV infections occur among those under the age of 25 [3].

In Canada, 2% of grade 7 students (ages 12–13) report sexual intercourse. These figures jump dramatically, by

grade 11 (ages 16–17): 40% of boys and 46% of girls report being sexually experienced [4]. American data show that by the 11th grade, 51.4% of teenagers are sexually active [5]. Despite engaging in sexual activity, youth are often uninformed about safer sex practices, with younger teenagers demonstrating an even greater lack of clarity around STI and pregnancy prevention information [6].

Adolescence is a time when youth are increasingly required to make complex choices affecting their health and wellness. Healthy development for this age group means learning how to make informed decisions, manage risk(s), and negotiate options [7]. Research has been instrumental in helping us learn more about both effective and ineffective strategies for supporting young people in minimizing risks associated with adolescent sexual development [8–10]. De-

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spite the need for further investigation in this area, researchers are often hesitant to include adolescents in their studies because of fears associated with navigating ethical review, and in turn, youth are hesitant to seek health service and participate in research when parental permission is required [11].

In this paper, we use the Toronto Teen Survey as a case study to explore ethical issues related to conducting adolescent sexual health research. We discuss why seeking parental consent would not have been appropriate in this particular context, and offer concrete alternatives for attending to youth vulnerability. The protocol underwent ethical review at the coinvestigators' home institutions, York University and the University of Toronto.

The Toronto Teen Survey is a collaborative research initiative undertaken by Planned Parenthood of Toronto, in partnership with academics housed in a number of research settings, Toronto Public Health, and youth (ages 13–17) [12]. We are currently surveying 1200 teenagers through community-based service settings. The goal is to identify access barriers and facilitators to community sexual health resources. This information will be used to inform the development of a municipal teen sexual health strategy. The strategy will consist of targeted recommendations that attend to the unique issues identified for working with different adolescent communities.

### Situating Parental Consent

North American guidelines for research involving human subjects make stipulations for the protection of vulnerable subjects, including children and youth [13,14]. The standard practice is to obtain assent from youth and consent from the parent(s) or guardian(s) of anyone under the age of 18 prior to engaging in health research. This practice is partially due to legal contexts that stipulate fiduciary duties; most states and provinces understand unemancipated children to be the responsibility of their parents or the state until their 18th birthday. Additionally, this safeguard recognizes the emerging capacity of youth to provide informed consent through this period. Here, capacity is understood to be limited both in terms of life experience and developing cognition [15]. Generally, adults are understood to have this capacity and children are not. As young people mature, this capacity is developed.

Much debate has been had over allowing youth to consent in health research. American Federal Regulation offers two special exemption clauses to waive parental consent requirements [14]. These exemptions can be sought if research risk is minimal, and the research could not be practically carried out without the waiver (45 CFR 46.116d) or when parental permission is not a reasonable requirement (e.g., neglected or abused children) (CFR 46.408c). In Canada, Tri-Council documents state that those who are able to understand the information presented and appreciate the

potential consequences, are eligible to participate in research and suggests that “in some situations adolescents can be regarded as competent and provide their own consent” [13]. (These situations are not specified.) In general, these decisions are left up to individual institutional review boards.

The Toronto Teen Survey team had a number of concerns around mandating parental consent in our study; these included that it was unwarranted, unjust, confusing, and may inadvertently silence those voices that most need to be heard.

#### *Mandating parental consent may be unwarranted*

A number of studies have demonstrated that adolescents as young as 14 are competent to make informed decisions. In their study comparing youth (ages 9, 14, 18, and 21), Wiethorn and Campbell [16] found 14-year-olds did not differ from adults in their decision making. Similarly, when Bruzzese [17] examined the capacity of 291 4th, 7th, 10th graders, and college students, he found that 10th graders understood their rights as well as adults following exposure to a Research Participants' Bill of Rights. Essentially, from “the age of 14 years, and clearly from 15 years, adolescents have the cognitive capacity for making informed decisions” ([18], p. 337).

#### *Mandating parental consent may be inconsistent with the principles of justice and inclusiveness*

Ethical guidelines generally promote “justice” as a touchstone principle for conducting an “ethical review” [13,19]. Operationally, this principle is used to ensure that research does not coercively target vulnerable groups (e.g., prisoners); or, without good reason, ban a whole groups (e.g., youth) from studies that might benefit them. There is evidence to suggest, however, that researchers are hesitant to involve adolescents in their research due to difficulties around navigating parental consent procedures [11]. The underlying assumption is that parents have the ability to understand research and assess harms, over and above that of their adolescent children [20]. However, parents and their children do not always agree on the need for consent; parents' opinions are often informed by their own experience of adolescence (rather than the realities of their children's experience), and their willingness to consent changes with topic matter and scope of research [21,22]. Sexuality and sexual health are often difficult topics for parents to discuss with their children, and there remains ongoing confusion about the role of formal and informal sex education strategies [23]. Consequently, young people are often excluded from participating in research and initiatives that may serve to improve their health.

#### *Mandating parental consent for research is often confusing*

A number of inconsistencies currently exist between youths' capacity to consent to medical consultation and

their capacity to consent to participate in related research and evaluation. Currently, the Ontario Child and Family Services Act (s.28), allows service providers to “provide a counselling service to a child who is twelve years of age or older with the child’s consent, and no other person’s consent is required, but if the child is less than sixteen years of age the service provider shall discuss with the child at the earliest appropriate opportunity the desirability of involving the child’s parent” [24]. However, other policies and institutions do not require a minimum age of consent for releasing health information [25], and/or seeking medical intervention [26]. A review of North American age-related policies demonstrates that there is a great deal of variation (14–21) across States and Provinces in terms of when a youth is eligible to drive, join the military, drink alcohol, vote, consent to sex, access health services, etc. [27]. It is unclear how, if at all, service providers reconcile competing policies and guidelines. In fact, recommendations that promote disclosure to parents and other authority figures may be antithetical to the mandates of organizations offering youth programming and services, especially those offering sexual health services and treatment.

Although there exists a profound difference between accessing needed medical interventions and participating in research and evaluation, the inconsistencies between the two creates a situation where youth accessing sexual health services are excluded from participating in the process of research and evaluation. For example, in Ontario, a 13 year old (without parental consent) may obtain information about abortion from any number of sources, and subsequently terminate a pregnancy. However, this same youth might require parental consent to participate in a formal study providing her with opportunities to make recommendations on the process and potentially improve conditions for other youth. As a consequence of this disjuncture, young people’s agency is ignored, this may have resulted in the poor returns on previous sexual health strategies and the rising rates of STIs in youth populations [28].

*Mandating parental consent may cause inadvertent harm and/or silence those voices that most need to be heard*

The act of presenting a consent form to their guardian(s) may be problematic for some youth. In respect to sexual health research, their desire to participate in a study may be interpreted as admitting to being sexually active and/or having accessed sexual health services. In instances where this is true, it puts those youth at risk of losing access through increased parental supervision or monitoring. Unfortunately, those youth unable to obtain parental consent to participate are often the ones most in need of sexual health information and resources. When denied opportunities to participate, their experiences and needs are unlikely to be reflected in research findings. For many adolescents, parental notification of their use of sexual health services or

contraceptives impedes their continuation of use of these services and may have adverse effects on the youths’ sexual health [29,30]. This process serves to continuously silence those youth most in need of voice and access.

### **Safeguarding Youth: Alternatives for Protecting Adolescent Participants**

It is important to maintain the highest ethical standards when engaged in research with young people. Although we have flagged concerns around mandating parental consent as a precursor to youth involvement in adolescent sexual health research, this puts an even greater onus on researchers and institutional review boards to ensure that the vulnerabilities of young people are especially attended to in the research process.

Community-Based Participatory Research (CBPR) is increasingly recognized as an effective strategy for addressing complex health disparities [31]. CBPR is an approach to research that involves working in equitable partnership with those most affected by a problem toward developing actionable solutions. Giving marginalized communities an opportunity to shape research agendas has been identified as a key strategy for redressing systemic barriers to research participation and increasing the likelihood of locally acceptable ethical research practices [32]. This strategy has been highlighted as particularly effective for health research with adolescents [15].

Adopting a CBPR approach can foster youth leadership while at the same time support more meaningful research results [33]. Partnering with youth on research projects and community initiatives has been shown to improve the youth’s social capital and provide opportunities to develop skills and empower themselves [34]. Furthermore, it builds communal social capital so that skills and resources remain in the community to address future health issues long after the project is completed [35]. However, there are very few published examples of how CBPR approaches are enacted to ensure ethical integrity [27].

In the following section, we describe how CBPR principles were operationalized toward achieving effective and ethical outcomes. We offer concrete, creative, and practical approaches adopted by the Toronto Teen Survey research team to ensure ethical integrity in the absence of parental consent practices.

#### *Situating the research in a community context*

Although no “magic formula” exists for assembling an interdisciplinary research team, a number of considerations are helpful in creating an effective team to work with youth. In this case, the research team had considerable experience and a proven record of working collaboratively with marginalized and vulnerable youth populations, including innovative work with HIV+ youth [36]. Although individual experience varied, partners were expected to share the

project's vision of working equitably with youth and share the hosting organization's values. Planned Parenthood Toronto (PPT; see <http://www.ppt.on.ca/>) has almost 40 years of experience working in the area of sexual health and provided additional guidance on legal and ethical issues.

PPT is a local trusted youth-serving community health center that is a leader in sexual health advocacy, community programming, and youth primary health care. To leverage the resources, skills, assets, and community contacts of the agency, PPT acts as the project host. This way, research and referrals to appropriate clinical care are a part of a seamless integrated approach. It also meant that the research team could build internally on the agency's rich experience of developing appropriate risk management policies and procedures, and externally on the credibility PPT had established as a trustworthy service provider. Finally, we are confident that results will be integrated into practice: PPT as a responsive agency is committed to acting on the results.

Hiring appropriate project staff with the right balance of research, community, and clinical experience helped to ensure professional ethical standards were met at all times. Research staff that work closely with diverse youth often need to attend to emerging issues that come up in youths' lives in a sensitive and responsive manner. A trained social worker was hired as the project coordinator, with graduate training in professional ethical conduct and previous experience working with youth in a vulnerable setting. All staff associated with the project underwent PPT staff training. As such, we were confident that the staff had the training to handle complicated dilemmas as they arose and make appropriate clinical referrals as needed under the direction of the investigator team.

Risk to participants can be minimized by conducting survey sessions through community networks of youth-serving agencies. Toronto Teen Survey (TTS) sessions all take place in safe, youth-friendly spaces with experienced staff available that already have a working relationship with participants. This sampling strategy ensures that we reach a diversity of youth who are often excluded from this sort of research (including youth in care, youth with mobility disabilities, youth involved in the criminal justice system, youth from specific ethnoracial or sexual minority communities, etc.) in their normal community-based settings. The diverse youth frequenting selected agencies will likely be familiar with each other, the setting, and the topics being covered on the survey. Many of these agencies already host occasional sexual health workshops, and can integrate the study into existing schedules. Although this approach builds on community networks, one limitation is that youth not accessing services are excluded de facto.

By partnering with agencies that have a prior relationship with the youth involved, staff familiar with participants are on hand to follow up/intervene should a youth become upset during a survey session and/or disclose sexual violence or other reportable issues. Finally, the research team took an

additional precautionary measure: requesting permission forms be signed by the executive directors and agency management. This proxy fiduciary consent outlines the project, host agencies roles and responsibilities, and confidentiality procedures. It goes further than a traditional memorandum of understanding (which often focus on administrative duties and authorship) and mandates that hosting agencies take on the legal "duty to report" to Children's Aid should youth disclose abuse.

For many of the youth frequenting these settings, the organization serves as a stable, trusted fixture in their lives. We wanted to be sure that youth (and the host agencies) were clear that decisions around participation should in no way jeopardize service use.

#### *Ensuring youth-friendly processes, protocols and consent procedures: creating a youth advisory committee*

Youth Advisory Committees (YAC) can be an effective way of incorporating youth into the planning and development of programs meant to serve them. Other research teams found YACs to be helpful in exploring and attending to ethical issues [27]. Our YAC advised on all aspects of protocol development and implementation. They were recruited from community-based partner agencies and mirrored the diversity of the city in terms of ethnicity, socioeconomic status, and neighborhood residence. They applied for the position, were interviewed, brought on as volunteers, and paid a small stipend for their participation [12]. The survey content, length, format, structure of the questions, and administration process was heavily influenced by the opinions and suggestions of the youth involved [12]. Although YAC never spoke of "ethics," they were quick to point out what was acceptable within their peer group and what "felt wrong."

YAC members were adamant that mandating parental consent would severely limit youth participation. Despite reporting high rates of sexual activity, most YAC members did not want to discuss issues of sexuality with their parents, and some told us that they might purposefully "forget" a consent form to avoid a conversation about research participation. Furthermore, because we were collecting surveys in community settings that routinely invite Planned Parenthood to conduct sexual health education programming, our ethics review board(s) approved a protocol that enabled all youth availing themselves of sexual/health-related clinics/drop-ins/programs, the opportunity to consent for themselves.

Informed consent was sought in accordance with the Canadian Tri-Council guidelines [13], which understands it as a "dialogue, information sharing, and general process through which prospective subjects choose to participate in research involving themselves." Article 2.4 of the TCPS states:

Researchers shall provide, to prospective subjects or authorized third parties, full and frank disclosure of all information relevant to free and informed consent.

Throughout the process of free and informed consent, the researcher must ensure that prospective subjects are given adequate opportunities to discuss and contemplate their participation.

The YAC was integral in advising the research team on how to effectively translate the projects goals and methods into understandable language that was accessible to potential survey respondents. For instance, they asked us to put the consent form in a Q & A format. Additionally, rather than use terms such as confidential or anonymous; they encouraged us to use words more common to youth vernacular (e.g., “private”). Respondents are advised orally (to accommodate young people with literacy issues) and in writing on the first page of the survey, about the purpose of the survey and their roles and responsibilities (Figure 1). They are told that they are not obligated to complete the survey, it is entirely voluntary, and “no one will be mad or

upset with you if you don’t” [choose to fill out the survey]. In addition, YAC members remain on hand to answer any questions that arise and encourage dialogue and discussion around rights and responsibilities of participants.

YAC members told us that they would be more likely to respond honestly to surveys given out and explained by their peers in community settings (rather than in school or at home). As such, the entire YAC was hired to facilitate survey sessions. Having the sessions introduced and facilitated by YAC members minimizes the risk that youth feel coerced into participating to please agency staff.

*Paying maximum attention to issues of confidentiality and anonymity*

As is common in social science and health research, participants were anonymous to the research team, and no names were collected in the research process. Respondents

Toronto Teen Survey  
Planned Parenthood of Toronto

SID # \_\_\_\_\_

## The Toronto Teen Survey

**What is this project about?**  
It is about making sexual health services better for youth in Toronto. We want to hear from 1,500 different youth between the ages of 13-17 living in Toronto.

**Who is running this project?**  
A research team consisting of people from Planned Parenthood of Toronto, the University of Toronto, York University, Toronto Public Health, and the Ontario HIV Treatment Network.

**What do I have to do?**  
We are asking you to fill out a survey. The survey has 29 questions and takes about 15 minutes to fill out. It asks questions about how you get info about sex and where you go when you need help. We hope you will also stay for the part of the session where we can try to answer your questions about sexual health.

**What will happen to the info?**  
This info will be used to plan sexual health programs for youth in Toronto. We will also share the results by writing reports and developing creative ways to share our findings with various groups, organizations, and communities.

**Will it be private?**  
Yes. You will not be asked to give your name. There will be no way of connecting you with the info you write down. Only the research team will be able to see your finished survey – but they won’t know it is you who filled it out!

**Do I have to fill out the survey?**  
No. You can choose not to fill out the survey. No one will be mad or upset with you if you don’t. You will still be able to come to all the same programs here. You can stop at any time.

**Will I get anything if I fill out the survey?**  
Yes. You will get a movie pass to thank you for your time.

**Who can I call if I have questions about the Toronto Teen Survey?**  
If you have any questions about the survey, the project, or your ethical rights you can contact the appropriate people listed on the separate sheet that was handed out to you. We will also give you a list of places to call if you have more questions about your sexual health.

**Ready?**  
You can start filling out the survey if:  
 (1) you understand why the study is being done;  
 (2) you decide you want to participate;  
 (3) you know that you don’t have to;  
 (4) you know that we are here to help if you have any questions;

*Remember you can be honest...no one will know it is you. Thanks for your help!*

Figure 1. A youth-friendly consent form.

were informed that the information they provide will be confidential, and all results will be provided in aggregate form, with no individual responses made identifiable. YAC members are trained to preempt questions around confidentiality, anonymity, and privacy. For example, YAC reminded participants not to use identifying information in either the survey or following discussion. In our experience, many youth automatically write their name on the top of a paper handed to them. It was important to remind them not to do so.

In addition, some other unconventional precautions were taken to provide participants with more privacy. These included producing the survey as a booklet so that youth could shield their answers from friends with greater ease (especially relevant for youth who answered in the affirmative to having accessed a spectrum of sexual health resources, and for those youth who chose not to fill out the survey but may have been equally embarrassed to get up and leave), providing everyone with the same writing materials, and providing a drop box for youth to return the completed survey in.

#### *Valuing participation appropriately*

YAC members were clear that they felt it was “wrong” to administer a survey about access to sexual health information in community settings without seizing the opportunity to provide an educational component. As a result, a participatory education activity follows each survey session. During this component, youth anonymously write down questions they have about sexual health and they are put into a hat. YAC members draw questions from the hat and respond or provide an appropriate referral. An adult member of the TTS team is always on hand to assist.

Providing appropriate honoraria can be an ethical issue, especially if it is deemed coercive. In this case, honoraria were chosen that reflected the goal of the project and were desirable to youth. Participants are offered a “condom wallet,” containing condoms, local sexual health information resources, and a movie pass gift certificate for their time. They are informed of this honorarium in advance, and are advised that the compensation is not conditional on their level of participation. A movie pass was advised by our YAC as a valued token of appreciation that was not large enough to be seen as coercive.

In addition to direct honoraria, participants also benefit in other ways. They are thanked for their participation, not as respondents, but as stakeholders in designing a new citywide sexual health strategy. This strategy will ultimately improve access to service and health outcomes for Toronto youth. Furthermore, host agencies will become partners in the development of the strategy and may therefore host more relevant sexual health programming. Thus, the benefits are immediate, ongoing, serve to benefit their immediate community, as well as “society as a whole.”

## **Discussion**

In this paper we have argued that mandating parental consent for community based sexual health research may (1) be unwarranted, (2) be unjust, (3) serve to silence young people who most need to have a voice in sexual health research, and (4) cause inadvertent harm. Nevertheless, careful attention must be paid to ensuring that research involving adolescents be conducted with the utmost sensitivity to ethical issues. Strategies that were used in the Toronto Teen Survey included adopting a community-based participatory research approach, careful attention to youth friendly protocols and consent procedures, proper hiring and training of research staff, partnering with experienced youth-serving organizations, maximum attention to confidentiality and anonymity, and valuing participation appropriately.

Where research involves more than minimal risk, greater community consultation and debate may be necessary. However, the assumption that parents are always in the best position to assist with decision making belies the complex realities of many young people’s lives.

The detail provided herein may not be new to some readers; for others, it may affirm ongoing challenges related to reconciling the theory and practice of research ethics pertaining to adolescent health. In presenting the Toronto Teen Survey model at conferences [37–39], the first question we are often asked is how we negotiated ethical review. Despite federal policies in both the United States and Canada which offer special exemptions, barriers to conducting adolescent sexual health research without parental consent exist, even if the risk is minimal and the survey is anonymous. Other groups are keen to do similar work in a variety of urban centers across North America, and many do not believe it is possible in their local contexts.

A review of institutional review boards across the United States showed multiple interpretations of the same federal guidelines related to youth as subjects in research, with over half supporting changes to regulations allowing minors to provide informed self-consent for 7 of 10 general research categories [40]. A variety of inconsistencies exist within and between review boards. Ethics review boards are diverse in terms of culture (which may shift based on member rotation), board composition (which is not necessarily representative of the research reviewed), and context (geographic, political, and legal). It is not within the scope of this paper to address the complexity of these variances. Nevertheless, it is important to acknowledge that adolescent sexual health researchers need to be cognizant of sociopolitical and regulatory realities that shape local decisions around ethical review.

Another strategy that we adopted was to view our institutional review boards as partners. We consulted with them as we were developing our protocol, arranged face-to-face meetings during the review process, and were ultimately

applauded for our thorough and thoughtful approach for considering and contemplating ethical aspects of our research.

As “ethical” adolescent health researchers it is important to be thoughtful about our research practices. Institutional review boards and researchers should be encouraged to adopt localized context-dependent strategies that attend to the unique vulnerabilities of their particular study populations. Ongoing, open, and honest, dialogue and debate throughout the research process on potential harms and benefits can mean that sometimes protocols need to be adapted and changed [27]. This attention to flexibility, vulnerability, and community-specific needs is key to ensuring that we continue to do all that we can to attend to the health and well-being on young people.

### Acknowledgments

We thank our team of investigators, June Larkin, Jason Pole, Robb Travers, and Hazelle Palmer, as well as Susan Flynn, Crystal Layne, our Youth Advisory Committee, and the entire TTS team, for their dedication, hard work, and contributions to this project. In addition, we appreciate the ongoing support of the Research Ethics Boards at York University and the University of Toronto. This research was supported by funding from the Wellesley Institute and is currently supported by the Ontario HIV Treatment Network.

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