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# Ethical Considerations in Recruiting Online and Implementing a Text Messaging–Based HIV Prevention Program With Gay, Bisexual, and Queer Adolescent Males

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A B S T R A C T

**Purpose:** There is a dearth of HIV prevention/healthy sexuality programs developed for adolescent gay and bisexual males (AGBM) as young as 14 years old, in part because of the myriad ethical concerns. To address this gap, we present our ethics-related experiences implementing Guy2Guy, a text messaging-based HIV prevention/healthy sexuality program, in a randomized controlled trial of 302 14- to 18-year-old sexual minority males.
**Methods:** Potential risks and efforts to reduce these risks are discussed within the framework of the Belmont Report: Respect for persons, beneficence (e.g., risks and benefits), and justice (e.g., fair distribution of benefits and burdens).
**Results:** To ensure "respect for persons," online enrollment was coupled with telephone assent, which included assessing decisional capacity to assent. Beneficence was promoted by obtaining a waiver of parental permission and using a self-safety assessment to help youth evaluate their risk in taking part. Justice was supported through efforts to develop and test the program among those who would be most likely to use it if it were publicly available (e.g., youth who own a cell phone and are enrolled in an unlimited text messaging plan), along with the use of recruitment targets to ensure a racially, ethnically, and regionally diverse sample.
**Conclusions:** It is possible to safely implement a sensitive and HIV prevention/healthy sexuality program with sexual minority youth as young as 14 years old when a rigorous ethical protocol is in place.

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**IMPLICATIONS AND CONTRIBUTION**

Youth-inclusive research is less common than adult research because of ethical concerns (e.g., parental permission). When a rigorous ethical protocol is in place, our experiences demonstrate that it is possible to safely implement a sensitive and sexual identity-explicit intervention with sexual minority youth as young as 14 years of age.

Technology is infused in youths' everyday lives [1], leading researchers to integrate technology into their work [2–5]. This presents unique ethical challenges, particularly in terms of equity (e.g., the "digital divide"), privacy, and confidentiality (e.g., ensuring privacy in participants' study interactions) and ensuring truly informed assent [6]. Because youth are a group deemed by the Belmont Report to face diminished autonomy [7], attention to these issues is crucial.

**Conflicts of Interest:** The authors do not have any conflicts of interest to declare.
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Ethical issues also arise when conducting research with sexual minority youth. Their inclusion in sexual health research is critical given disparate HIV prevalence and incidence rates among sexual minority male teens [8,9]. Indeed, adolescent gay and bisexual males (AGBM) have the highest incidence rate of HIV among all people at risk for HIV [8]. At the same time, because of stigma and discrimination, sexual minority youth may be harmed if research protocols create situations where they must disclose their sexual identity to their parents to gain permission to participate in research [10–16]. Potential harm also exists if youths' identities as participants in a study for sexual minority youth became public [11].

This study builds on the growing literature examining ethical issues of youth-inclusive research by presenting ethics-related lessons learned in the implementation of Guy2Guy, a text messaging–based HIV prevention/healthy sexuality program for AGBM. To our knowledge, this is the only HIV prevention/healthy sexuality program developed for AGBM as young as 14 years of age and is among the first comprehensive HIV prevention programs delivered via text messaging. As such, lessons learned can inform future efforts using text messaging to deliver sensitive topics to youth and for HIV prevention research including sexual minority adolescents.

## Intervention Description

Guy2Guy is a text messaging–based HIV prevention and healthy sexuality program tailored to address unique concerns and considerations facing AGBM [17]. Based on the Information-Motivation-Behavior model of HIV preventive behavior, content areas included: HIV information (e.g., what it is and how to prevent it), motivation (e.g., reasons why AGBM may choose to use condoms), and behavioral skills (e.g., how to put on a condom correctly) [18,19]. Content also covered healthy and unhealthy relationships, coming out to parents and friends, and peer victimization. Participants were sent an average of eight messages daily for about 7.5 weeks.

The study was reviewed and approved by the Chesapeake Institutional Review Board and the Northwestern University Institutional Review Board. A Certificate of Confidentiality was obtained from the National Institutes of Health. Youth provided informed assent (for those under 18 years old) or consent (for 18-year-olds).

The protocol and intervention components were tested for acceptability and feasibility using an iterative formative approach [17]. First, focus groups were conducted to understand how youth make sexual decisions and to obtain feedback about study components (e.g., the Text Buddy concept, which has been used in previous text messaging programs [20,21]). Next, content advisory teams reviewed messages for salience. A β test was then implemented to test the randomized controlled trial (RCT) protocol and technology, followed by an RCT to pilot test the intervention against an attention-matched control group.

We discuss here our experiences implementing the finalized protocol in the RCT. Participants were recruited from all four regions of the United States (Table 1). Eligibility criteria included being aged between 14 and 18 years; male sex at birth and male gender identity; gay, bisexual, and/or queer sexual identity; and being English literate. Because Guy2Guy was a text messaging–based intervention, participants were required to: be exclusive owners of a cell phone, be enrolled in an unlimited text messaging plan, intend to keep the same phone number for the next 6 months, and have used text messaging in the past 6 months. Exclusion criteria included knowing another person enrolled in the program and participating in another study development activity. Participants received up to $45 in Amazon.com gift cards as incentives: $15 to complete the intervention-end survey and $20 to complete the 3-month post-intervention end survey (with an additional $10 to those who completed the survey within 48 hours of receiving the survey invitation). The gift cards were e-mailed to participants.

## Ethical Considerations

To guide the discussion, ethical considerations will be discussed within the context of the three key ethical components of the Belmont Report [7]: (1) respect for persons (i.e., respect for people's autonomy and voluntariness and the need for added protections for people with reduced autonomy); (2) beneficence (i.e., "do not harm and maximize possible benefits and minimize possible harms"); and (3) justice (e.g., communities should not be excluded from the benefits of research) [7,23,24]. Alongside potential risks, we highlight how the protocol was designed to reduce these risks, similar to the structure presented in the article by Bull et al. [25].

All study materials described herein are available online: http://innovativepublichealth.org/projects/guy-to-guy.

### *Respect for persons*

*Obtaining informed assent with an online protocol.* We chose to enroll youth via telephone to facilitate discussion of assent between potential participants and research staff. Youth were primarily recruited through Facebook advertisements containing links to the project Web site that described the RCT and included an online screener form. If responses to the screener determined ineligibility, candidates received an e-mail to the Centers for Disease Control and Prevention Web site about sexual minority health (http://www.cdc.gov/lgbthealth/). Candidates who appeared eligible or potentially eligible were sent a text by study staff to schedule an enrollment telephone call. Candidates who declined to speak on the phone were not eligible to participate in the study. Research staff spoke with 342 youth, of whom 328 individuals were eligible and were read the consent/assent form.

*Obtaining informed assent from a group with diminished autonomy (i.e., children).* We followed procedures described by Mustanski [11]. Specifically, decisional capacity was demonstrated by the correct and clear response to four questions [10,26–28]: (1) Name things you will be expected to do during the study; (2) Explain what you would do if you no longer wished to participate in the study; (3) Explain what you would do if you feel uncomfortable answering one of the questions; and (4) What are the possible risks for participating in the study? Youth were allowed to ask research staff to reread the assent/consent form if needed.

All youth passed the capacity to assent. Nonetheless, six youth declined participation: One discussed the study with his boyfriend and decided that participation was not in his best interest. Two declined participation at the self-safety assessment, described in the following sections. Two others did not have sufficient time, and the sixth decided he was not interested. That some youth actively chose not to participate during the assent process suggested the protocol to recruit online, and

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