IV. Ethical and Regulatory Issues

Working with the LGBT community brings up additional considerations when thinking about ethics and submitting proposals to the IRB. UIC IRB policies can be found at http://research.uic.edu/policies.

A. Sensitivity among the Research Team

Sensitivity is key for principal investigators, staff members, data collectors, and anyone else working on a study with sexual and gender minorities. Research team members should be knowledgeable about the group(s) with which they are working and the issues they face. This toolkit can help, but further reading and conversations will be necessary. Prejudice against the population being studied has no place in research. Many studies with LGBT populations can bring up very personal topics. Team members should have resources available to share with people who need support beyond what the study can provide. Additionally, the study purpose, methods, and materials should be respectful and inclusive. Making sensitivity a central aspect of the study, and continually checking in about it, will go a long way toward making the research more respectful and more likely to succeed.

For training materials and assessments to gauge research team members’ sensitivity, see Team Readiness to Work with Special Populations in Section XII.

B. Special Concerns about Confidentiality

Privacy and confidentiality are serious concerns for people in the LGBT community. A survey of 8,126 Canadian men having sex with men indicated that 30% would be unwilling to disclose their sexual orientation in a large government survey (such as a census). Thus, researchers should be cautious when using official estimates of the size of the LGBT community, for these estimates are likely to be lower than the actual proportion. Additionally, it demonstrates the reluctance that many in the LGBT community have for disclosing the orientation. Researchers should therefore be careful to preserve participants’ confidentiality. At the same time, in clinic settings, research suggests that most heterosexual and LGBT patients appreciate being asked questions about their sexual orientation and gender identity. Context is key in how to approach discussions of orientation and identity.

Though social attitudes have been shifting, sexual orientation stigma still manifests as both an external and internal pressure for many people. Moreover, sexual orientation is an identity that can be concealed. There are different ways people can be out, including publicly acknowledging their orientation and identity to all, being out with some people but not others, or not being out at all. As such, an individual’s right to maintain privacy about their identity must be respected. In addition to the normal safeguards of participants’ data, researchers should also consider privacy when developing participant communication materials, conducting outreach, and discussing the study with others. For instance, studies may use a codename when calling participants. This way, if someone other than the participant answers, the participant’s sexual or gender identity is not revealed through the name of the study. Additionally, focus group facilitators should take extra care to remind participants not to disclose others’ participation in the group. These are just some examples; privacy and confidentiality should be themes running throughout the study’s design and implementation.

C. Confidentiality and Parental Consent with Children and Youth Under Age 18
Confidentiality is especially relevant when conducting research with LGBT youth who are under the age of 18. Research on 16 and 17 year old LGBT youth in Chicago indicated that, among those in contact with a parent, only 36% had a positive attitude towards asking their mother to be involved in the research process, and just 29% had a positive attitude towards asking their father. Moreover, there were significant differences between the youth who had favorable and unfavorable attitudes towards researchers contacting their parents, suggesting that requiring parental permission may bias research results. Another study indicated that parental permission would be a significant barrier to youths’ participation in a PrEP trial, particularly if they were not out to their family. At the same time, youth understood the risks, benefits, and randomization they would experience. Additionally, a series of interviews with parents of LGBT youth found that most believed parental permission should not be required for minimal risk studies.

The UIC IRB offers the following guidance on waivers of parent/guardian permission for participation in research. See https://research.uic.edu/sites/default/files/0910.pdf for more information.

VII. Waiver of Parent or Guardian Permission. The IRB may waive the requirement for obtaining permission from parents or guardians when:

A. the research does not fall under FDA regulations, and

B. the research either:
   1. meets the provisions for waiver in 45 CFR 46.116(d)(1-4), [see below], or
   2. the IRB determines that the research is designed for conditions or a subject population for which parental or guardian permission is not a reasonable requirement to protect the subjects (for example, neglected or abused children).

3. When the requirement for parental or guardian permission is waived according to above, an appropriate mechanism for protecting the children who will participate as subjects in the research is substituted. Also, the waiver must not be inconsistent with federal, state or local law. Selection of an appropriate mechanism is guided by the nature and purpose of the research activities, the risk and anticipated benefit to the subjects, and their age, maturity, status, and condition.

…the conditions for which consent may be waived at 45 CFR 46.116(d)(1-4):

a. the research involves no more than minimal risk to the subject;

b. the waiver or alteration will not adversely affect the rights and welfare of the subjects;

c. the research could not practicably be carried out without the waiver or alteration; and

d. whenever appropriate, subjects will be provided with additional pertinent information after participation.

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3 Cahill, S., Singal, R., Grasso, C., King, D., Mayer, K., Baker, K., & Makadon, H. (2014 September 8). Do Ask, Do Tell: High Levels of Acceptability by Patients of Routine Collection of Sexual Orientation and Gender Identity Data in Four Diverse American Community Health Centers. PLOS One, 9(9). DOI: 0.1371/journal.pone.0107104


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