

Informed Consent

A norm of voluntary participation is presumed in all sociological research projects. In other words, we cannot force anyone to participate in our research without that person's knowledge or consent (so much for that *Truman Show* experiment). Researchers must therefore design procedures to obtain subjects' **informed consent** to participate in their research. Informed consent is defined as a subject's voluntary agreement to participate in research based on a full understanding of the research and of the possible risks and benefits involved. Although it sounds simple, ensuring that one has actually obtained informed consent is a much more complex process than you might initially presume.

The first requirement is that, in giving their informed consent, subjects may neither waive nor even *appear* to waive any of their legal rights. Subjects also cannot release a researcher, his or her sponsor, or institution from any legal liability should something go wrong during the course of their participation in the research (US Department of Health and Human Services, 2009). US Department of Health and Human Services. (2009). Code of federal regulations (45 CFR 46). The full set of requirements for informed consent can be read at <http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.html#46.116>. Because sociological research does not typically involve asking subjects to place themselves at risk of physical harm by, for example, taking untested drugs or consenting to new medical procedures, sociological researchers do not often worry about potential liability associated with their research projects. However, their research may involve other types of risks. For example, what if a sociological researcher fails to sufficiently conceal the identity of a subject who admits to participating in a local swinger's club, enjoying a little sadomasochistic activity now and again or violating her marriage vows? While the law may not have been broken in any of these cases, the subject's social standing, marriage, custody rights, or employment could be jeopardized were any of these tidbits to become public. This example might seem rather extreme, but the point remains: even sociologists conduct research that could come with some very real legal ramifications.

Beyond the legal issues, most institutional review boards (IRBs) require researchers to share some details about the purpose of the research, possible benefits of participation, and, most importantly, possible risks associated with participating in that research with their subjects. In addition, researchers must describe how they will protect subjects' identities, how and for how long any data collected will be stored, and whom to contact for additional information about the study or about subjects' rights. All this information is typically shared in an informed consent form that researchers provide to subjects. In some cases, subjects are asked to sign the consent form indicating that they have read it and fully understand its contents. In other cases, subjects are simply provided a copy of the consent form and researchers are responsible for making sure that subjects have read and understand the form before proceeding with any kind of data collection. **Figure 3.6 "Sample Informed Consent Form"** contains a sample informed consent form taken from a research project on child-free adults. Note that this consent form describes a risk that may be unique to the particular method of data collection being employed: focus groups.

Figure 3.6 Sample Informed Consent Form

INFORMED CONSENT FORM: FOCUS GROUPS

You are invited to participate in a research project being conducted by Dr. Amy Blackstone, a faculty member in the Department of Sociology at the University of Maine. The purpose of the research is to understand the processes by which adults without children decide to not have children and the social responses to their choice.

What Will You Be Asked to Do?
If you decide to participate, you will be asked to respond to questions about your decision to not have children. Specific questions include the following: Why did you make the decision to remain childfree? What do you most enjoy about your childfree lifestyle? What are some of the drawbacks of your childfree lifestyle? How have others responded to your decision? What role does your status as married or single play in people's responses? What role does your identity as heterosexual or homosexual play in people's responses? What does the word "family" mean to you? It will take between 75 and 115 minutes to participate.

Risks
- In addition to your time and inconvenience, there is the possibility that you may become uncomfortable answering the questions.
- Due to the focus group format, it is possible the confidentiality of your responses will not be maintained by other focus group participants.

Benefits
- Except for the compensation you will receive (see below), there are no other benefits to you from participating in this study.
- While this study will have no direct benefit to you, this research will help us learn more about the processes by which some adults choose not to rear children. This population has been understudied in sociological research.

Compensation
You will receive \$20 for participating in a focus group.

Confidentiality
Your name will not be kept on any documents except a participant key (see below). A pseudonym will be used to protect your identity. The focus group will be tape recorded and then transcribed. Recordings will be stored in a locked file cabinet inside Dr. Blackstone's locked office and destroyed after data analysis is complete (by or before August 2010). Research assistant Alyssa Radmore will have access to the data in Dr. Blackstone's office when Dr. Blackstone is present. Your name or other identifying information will not be reported in any publications. The key linking your name to the data will be destroyed after data analysis is complete. Written focus group transcripts will be kept indefinitely in Dr. Blackstone's locked office. These transcripts will not contain any identifying information such as your name. Because individuals in addition to the researchers will be present during the focus group, your confidentiality cannot be guaranteed.

Voluntary
Participation is voluntary. If you choose to take part in this study, you may stop at any time during the study. Stopping the study will not alter the compensation you will receive. You may skip any questions you do not wish to answer. Skipping questions will not alter the compensation you will receive.

Contact Information
If you have any questions about this study, please contact me by phone (207-581-2392), e-mail (amy.blackstone@umit.maine.edu), or mail (University of Maine Department of Sociology, 5728 Fernald Hall, Orono, ME 04469). If you have any questions about your rights as a research participant, please contact Gayle Anderson, Assistant to the University of Maine's Protection of Human Subjects Review Board, at 207-581-1498 (or e-mail gayle.anderson@umit.maine.edu).

One last point to consider when preparing to obtain informed consent is that not all potential research subjects are considered equally competent or legally allowed to consent to participate in research. These subjects are sometimes referred to as members of **vulnerable populations**, people who may be at risk of experiencing undue influence or coercion. The US Department of Health and Human Services' guidelines on vulnerable populations can be read at <http://www.hhs.gov/ohrp/policy/populations>.

The rules for consent are more stringent for vulnerable populations. For example, minors must have the consent of a legal guardian in order to participate in research. In some cases, the minors themselves are also asked to participate in the consent process by signing special, age-appropriate consent forms designed specifically for them. Prisoners and parolees also qualify as vulnerable populations. Concern about the vulnerability of these subjects comes from the very real possibility that prisoners and parolees could perceive that they will receive some highly desired reward, such as early release, if they participate in research. Another potential concern regarding vulnerable populations is that they may be underrepresented in research, and even denied potential benefits of participation in research, specifically because of concerns about their ability to consent. So on the one hand, researchers must take extra care to ensure that their procedures for obtaining consent from vulnerable populations are not coercive. And the procedures for receiving approval to conduct research on these groups may be more rigorous than that for nonvulnerable populations. On the other hand, researchers must work to avoid excluding members of vulnerable populations from participation simply on the grounds that they are vulnerable or that obtaining their consent may be more complex. While there is no easy solution to this double-edged sword, an

awareness of the potential concerns associated with research on vulnerable populations is important for identifying whatever solution is most appropriate for a specific case.

Protection of Identities

As mentioned earlier, the informed consent process includes the requirement that researchers outline how they will protect the identities of subjects. This aspect of the process, however, is one of the most commonly misunderstood aspects of research.

In protecting subjects' identities, researchers typically promise to maintain either the anonymity or the confidentiality of their research subjects. Anonymity is the more stringent of the two. When a researcher promises anonymity to participants, not even the researcher is able to link participants' data with their identities. Anonymity may be impossible for some sociological researchers to promise because several of the modes of data collection that sociologists employ, such as participant observation and face-to-face interviewing, require that researchers know the identities of their research participants. In these cases, a researcher should be able to at least promise confidentiality to participants. Offering confidentiality means that some identifying information on one's subjects is known and may be kept, but only the researcher can link participants with their data and he or she promises not to do so publicly. As you can see under the "Risks" section of the consent form in Figure 3.6 "Sample Informed Consent Form", sometimes it is not even possible to promise that a subject's confidentiality will be maintained. This is the case if data are collected in public or in the presence of other research participants in the course of a group interview, for example.

Protecting research participants' identities is not always a simple prospect, especially for those conducting research on stigmatized groups or illegal behaviors. Sociologist Scott DeMuth learned that all too well when conducting his dissertation research on a group of animal rights activists. As a participant observer, DeMuth knew the identities of his research subjects. So when some of his research subjects vandalized facilities and removed animals from several research labs at the University of Iowa, a grand jury called on Mr. DeMuth to reveal the identities of the participants in the raid. When DeMuth refused to do so, he was jailed briefly and then charged with conspiracy to commit animal enterprise terrorism and cause damage to the animal enterprise (Jaschik, 2009). Jaschik, S. (2009, December 4). Protecting his sources. *Inside Higher Ed*. Retrieved from <http://www.insidehighered.com/news/2009/12/04/demuth>

Publicly, DeMuth's case raised many of the same questions as Laud Humphreys' work 40 years earlier. What do social scientists owe the public? Is DeMuth, by protecting his research subjects, harming those whose labs were vandalized? Is he harming the taxpayers who funded those labs? Or is it more important that DeMuth emphasize what he owes his research subjects, who were told their identities would be protected? DeMuth's case also sparked controversy among academics, some of whom thought that as an academic himself, DeMuth should have been more sympathetic to the plight of the faculty and students who lost years of research as a result of the attack on

their labs. Many others stood by DeMuth, arguing that the personal and academic freedom of scholars must be protected whether we support their research topics and subjects or not. DeMuth's academic adviser even created a new group, Scholars for Academic Justice (<http://sajumn.wordpress.com>), to support DeMuth and other academics who face persecution or prosecution as a result of the research they conduct. What do you think? Should DeMuth have revealed the identities of his research subjects? Why or why not?