

Thinking About Research – Consent and Organizations

Patricia Katopol

Introduction

Well, it's the beginning of a new year; time to take a look over the previous twelve months and see how far we've come, what worked for our organization and our patrons, and what did not. So, grab a cup of your favorite caffeinated beverage and get out those survey reports and start reading. Uh oh, it looks like that project didn't work out the way you planned, which is confusing. You and your staff wrote up a nice survey and you got a lot of information to support the changes you wanted to make, but it didn't work out the way you thought it would. The staff loves the new service, but patrons can't be bothered. And there are the findings on interviews you did with kids who use the library after school. You had no idea parents would react the way they did when they found you had talked to their children. Come on, the kids you interviewed were old enough to get to the library on their own, they use the services on their own, so why would you need to talk to their parents before you interviewed them? It's not like you were taking a blood sample.

It always surprises me how many library students avoid a research methods course. Maybe they were traumatized by census statistics at some point in their lives, I don't know, but I do not understand why graduate students would think that research in their discipline was not part of a graduate education. Sadly, much of what passes for research in our field is what is often called 'how we done it good.'¹ By this, I mean articles by practicing librarians about projects or processes they've tried in their organizations. Some try to present what they perceive to be best practices; others don't even make that effort. Research methods rarely relate back to theories in library and information science. If surveys and interviews are used, there is no mention of a pilot to test the questions or of analysis informed by theory. Because almost everyone has taken part in some kind of survey, from political surveys during campaigns to being asked whether they prefer Coke or Pepsi in the mall, maybe they think it's easy – just ask a few questions and get some information. Well, no.

If you did not take research methods or who haven't seen a research methods book in some time, there are many good resources on doing research in LIS, so I will not review the research process here. Some of the books I've used over the years have been Pickard,² Creswell's Research Design,³ Qualitative Research & Evaluation Methods: Integrating Theory and Practice,⁴ the SAGE Dictionary of Qualitative Inquiry, and Yin⁵ on the case method. For a quick review of a broad cross section of LIS theories, see *Theories of Information Behavior*.⁶

In this issue, I want to focus on two important aspects of the research process - consent and doing research in organizations. It is necessary that you think first of your participants and their welfare first. In an academic environment, the Institutional Review Board (IRB) reviews applications for human subjects research - intervening with or collecting data from living people in a systemized process which includes identifiable private information.⁷ You may be in an environment which doesn't have or require research oversight, but don't think that the ethical considerations behind how you treat participants doesn't apply to you. In my opinion, lack of institutional oversight is all the more reason to be familiar with the ethical components of doing research with people.

Ethics and consent

The most important aspect of conducting research with people is to do no harm to the participant. An important way of 'doing no harm' is via the consent process. Researchers in social science (that's us) often think that since they aren't engaged in biomedical research such as a clinical drug trial, that they don't have to worry about ethics. They aren't going to hurt anybody by asking a few questions about how they store their files at work or watching how someone uses an OPAC, right? Wrong.

Let's start with protected populations that deserve our utmost protection when doing research with them – children, neonates, pregnant women, prisoners, and the cognitively impaired (45 CFR 46.101-409). These are people that need protection from research that might hurt or take advantage of them. Protecting children may seem obvious – they don't have the analytical or decision-making skills of adults and may not be capable of fully understanding the research project in which they are asked to participate. Prisoners may understand the project, but aren't fully able to make decisions for themselves because their freedom of movement and decision-making is constrained by their incarceration. It is a misapprehension to think that prisoners get

time deleted from their sentences if they participate in research. The opposite is true, because there can be no intimation that the prisoner was coerced into participating in the study. Prisoners, like everyone else, have the right not to be mistreated when they volunteer for research.

Why are we concerned about consent and how we treat participants? We need only recall the work of Nazi doctors and the Nuremberg Trials following World War II. In the United States, the Tuskegee Syphilis Study is a prime example of failure to protect the participant. In this study, black men were lied to and told that they had 'bad blood.' Those who had syphilis were left untreated, even after an effective treatment was developed. The study was supposed to last for six months, but continued for 40 years. The men did not give consent, nor were they told they could leave the study, but they did receive free medical exams, food, and burial insurance. It took until the Clinton Administration before the US government gave an apology for their mistreatment.⁸ This study has had a continuing impact on blacks. To this day, blacks are underrepresented in clinical trials⁹ and have been distrustful of government programs for HIV/AIDS and other diseases.¹⁰ Not as well-known are the radiation tests done on American service men and the use of radiation to treat children.¹¹ These incidents happened because researchers put science first and recognizing their participants' humanity second, if at all.

The Belmont Report¹² sets forth three primary elements that must be present when designing research using humans. First, there is Respect for Persons. People have a right to decide for themselves whether they will participate. Those unable to do so, for a variety of reasons, ranging from newborns to those with mental health issues, should be protected. Protections should remain in place, even if the proposed participant has a guardian or parent make the actual decision as to whether the protected person is in the study.

Second, *beneficence* brings an obligation to do no harm. Simply put, we treat people as we wish to be treated. And third, the requirement of *justice* means that we must treat people equally. We do not take advantage of marginalized populations – ethnic or religious minorities, prisoners, the mentally challenged or institutionalized children, for example - just because they may be easily obtained or manipulated. This is not to say that you cannot do research with these populations. You must, however, be mindful of why you've chosen them – is there a valid research reason to use them or are they just a convenient population? You don't put the weight of research on

populations already under economic, racial, and other burdens, For example, mostly black prisoners at Holmesburg Prison in Pennsylvania were used in dermatological studies that often had long lasting and devastating physical repercussions for the prisoners. The prisoners were paid for their participation, but were chosen for their easy availability to a doctor who saw them only as ‘acres of skin.’¹³

Stories of physical harm done to participants may be so shocking that we believe we would never do these things to another person. But we may well inflict other types of harm. People can be emotionally and financially damaged by participating in research. For example, if you are studying workers’ information behavior, a participant may be concerned about his supervisor’s reaction to his responses. Supervisors may not be happy about workers talking to outsiders and retaliate against them for doing so. Or, a participant may feel inadequate or embarrassed if you ask about their technology use and she thinks she doesn’t measure up to what the researcher expects. Even a topic such as literacy can cause distress to someone concerned about their reading ability. In social science research, there may be issues of social stigma, decreased self-confidence, changes in relationships, and loss of privacy that result in a risk to the participant. You may have a ‘minimal risk’ study, one whose risks are no greater than what people encounter in their day-to-day lives, but there is no risk-free study.

Be mindful of the individual who agrees to take their time to participate in your study. Be respectful. Respect for participants goes a long way toward creating ethical behavior. Imagine the difference in community acceptance of government sponsored research if the researchers in the Tuskegee Syphilis Study had respected their participants

Research in organizations

Most people function in an organization of some type. We work for the city or the state, in an academic institution (which may itself be a governmental entity), for a business or a nonprofit. We go to school, we are in prison, in hospitals, in church groups, and in assisted living facilities. For the researcher, this means that any study carried out without considering the organization in which the participants function is bound to have shortcomings. To design information systems and services for use in organizations, it is necessary to understand the organization in which your participants ‘live.’ One way of doing this is by understanding organization’s culture.

Organizational culture consists of shared basic assumptions, learned by the group as it solved problems of external adaptation and internal integration. These assumptions work so well that they are taught to new members as the correct way to perceive, think, and feel in relation to those problems. For example, most of us have been in work situations where we've brought in our previous methods of performing a task, only to be told that 'we don't do things that way.'¹⁴ That's organizational culture talking to you. You can pick up on an organization's culture just by looking around. Is everyone wearing formal business attire? Campus casual? Do staff have offices, artwork, and plants or do they work in cube farms? Are the cubes decorated with family pictures and tchotchkes or are they soulless grey spaces? Do people use first or last names when they talk to each other? Do they gather in the hallways to chat or are they too busy to talk to each other? If you are working with students, what is the campus environment like? Is it a residential or commuter school? Are professors approachable or not?

With a little effort, you will be able to develop questions about your participants' organization. For short (1-3 pages) LIS interviews and surveys, you only need a few questions about the organization to get a feel for the participant's information environment. You want to ask questions about communications lines – who talks to whom and why; do they avoid talking to certain people in the organization? Do they have work-arounds because the systems they must use are poorly designed for the task to be performed? Do coworkers socialize inside and outside of work? How would they describe their section, their department, their organization? What is it like to work there?

One research method that I employ and which I believe brings particularly rich and thick data is 'critical incident.'¹⁵ This technique is employed in fields including management, nursing and other health sciences, and information science. Using critical incident technique, we ask the participant to recall a particular incident that includes the actions, processes, or problems that are the topic of your study. What caused the incident? What happened? What did you do in this situation? How did you feel when it happened? What tools did you use or what people did you talk to that helped you deal with the issue? Where and how did you get the information you needed? What would you change about what you did? What information did you wish you had? As you can see, with some modification, you can use critical incident technique for many situations and with participants of all ages. Another benefit of letting the participant talk about critical incidents is that it puts brakes on the librarian's domination of the research process. Remember, you are there to learn from the participant, not the other way around. You know a

lot, but you don't know everything. Let your participants speak to you about the research topic in their own words, not in the words you prefer. Even when you do mailed or online surveys, make sure you have some questions that are open-ended (no responses are provided) so that the participant has an opportunity to respond in her own way. For example, in interviewing graduate students about the information technology they used, I had several technologies in mind. So I was surprised when the students mentioned several tools with which I was not familiar. If I had only created a checklist of the technologies I knew about, I would not have found out about some popular new tools. This isn't complicated - if you are using a written survey, it is a simple thing to add the choice of 'other' and a comment box.

In another example, I enjoyed an article in which the librarians gave student-participants a camera to take photos of the places where they studied. They also went out to the student union to obtain some participants - going where the population was as opposed to waiting for them to come to the library. In what I interpret as a variation on the critical incident technique, they asked students to make a step-by-step drawing of the process they took for a writing assignment.¹⁶ I see the authors as being able to get past the 'I'm the librarian and I know best' mindset and get out into the participants' organization (school), see behavior in that environment, and obtain information about a specific activity (a writing assignment). Their efforts they took led to a great deal of unexpected, but useful, data and a deeper understanding of their patrons' information behavior which then informed the librarians' design of services - services which are more likely to be used because the design was based on participant behavior in the context of that particular university, and not only how the librarians thought services should be designed or what they assumed about their patrons' behavior and needs.

Conclusion

It seems easy to write up a survey or do interviews and think that you are doing research, but there is much more than that to the process. From the beginning, you must respect your participants. Even if you work in an organization where human subjects research does not need approval by an institutional review board, you should always act as if it does. You are asking people to use their time to participate in your study. You may be asking questions that seem innocuous to you, but are stressful or embarrassing for the participant. Do not take your interaction with participants for granted. As you design and carry out your study, keep in mind the organization in which your participants exist. Give them time and space to talk about their

organization and how it affects their actions in relation to the research question. You will be rewarded with open and cooperative participants and system and service redesigns that are more likely to be successful because they consider the organization in which they operate.

Patricia F. Katopol (pkatopol@uiowa.edu) is IRB Education & Compliance Specialist with the Human Subjects Office in the Harden Library for Health Science at the University of Iowa

Published: February 2015

-
1. Doucette, Lise, et al., et al. (2013). Reframing "How We Done It Good" Research Publications, Canadian Library Association Annual Conference: Ottawa, Ontario.
 2. Pickard, A. (2013). *Research Methods in Information*, (2nd ed.). Chicago: ALA Neal-Schuman.
 3. Creswell, J. (2013). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches*, (4th ed.). Thousand Oaks, CA : SAGE Publications, Inc.
 4. Patton, M. (2014). *Qualitative Research & Evaluation Methods: Integrating Theory and Practice*, (4th ed.). Thousand Oaks, CA : SAGE Publications, Inc.
 5. Yin, R. (2013). *Case Study Research: Design and Methods*, (5th ed.). Medford, NJ : SAGE Publications, Inc.
 6. Fisher, K., Erdelez, S. & Mckechnie, L. (2005). *Theories of Information Behavior*. Medford : Information Today Inc..
 7. US Department of Health & Human Services. (2009). 45 CFR 46.102 Definitions. *Human Subjects Research*:. <http://www.hhs.gov/ohrp/humansubjects/guidance/45cfr46.html>.
 8. White House, Office of the Secretary. (1997). Remarks by the President in Apology for Study Done in Tuskegee: <http://clinton4.nara.gov/textonly/New/Remarks/Fri/19970516-898.html>.
 9. Blackdoctor.org. (2012). *Are Clinical Trials Safe For Blacks? Part 1*: <http://blackdoctor.org/15374/clinical-trials-and-african-americans/>

10. Satcher, D. (2014, February 21). More African Americans need to participate in clinical trials. *The Washington Post*. Retrieved from http://www.washingtonpost.com/opinions/more-african-americans-need-to-participate-in-clinical-trials/2014/02/21/65c89742-9983-11e3-b931-0204122c514b_story.html
11. Welsome, E. (1999). *The Plutonium Files: America's secret medical experiments in the Cold War*. New York : Dial Press.
12. National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, Office of the Secretary, Department of Health, Education, and Welfare. (1979). *Ethical Principles and Guidelines for the Protection of Human Subjects of Research*: <http://www.hhs.gov/ohrp/humansubjects/guidance/belmont.html>
13. Hornblum, A. (1998). *Acres of Skin: Human Experiments at Holmesburg Prison*. New York : Routledge.
14. Katopol, P. (2006). We don't do that here: Using cognitive work analysis to learn about organizational culture, *Bulletin of the American Society for Information Science and Technology*, 33: 9-11.
15. Thorpe, R. & Holt, R. (Eds.) (2007). *The SAGE Dictionary of Qualitative Management Research*. Medford, NJ : SAGE Publications Ltd.
16. Biden, J., Burns, V., & Marshall, A. (2007). *Knowing our students: Undergraduates in context*. Presented at the Association of College and Research Libraries, 13th National Conference, March 29th-April 1, 2007, Baltimore, MD : Association of College and Research Libraries.