

“PROTECTING PEOPLE, SHARING DATA”

DATA SHARING AND HUMAN PARTICIPANT CHALLENGES IN THE SOCIAL SCIENCES

A workshop organized by the Qualitative Data Repository (QDR) at Syracuse University, in collaboration with the Murray Research Archive at the Institute for Quantitative Social Science of Harvard University, the Inter-university Consortium for Political and Social Research (ICPSR) at the University of Michigan, and the Howard W. Odum Institute for Research in Social Science at the University of North Carolina-Chapel Hill

September 15, 2017
LUBIN HOUSE, NEW YORK CITY

8:30-9:00 **Check in / light breakfast**

9:00-9:55 **Introduction and Overview: The tensions between human participant protection and data sharing**

Presenter: Dessi Kirilova, QDR

QDR staff will briefly describe the motivation for and scope of the workshop: we will discuss how norms guiding the sharing of social science data are changing, what challenges data sharing presents for scholars who directly engage human participants (research subjects) in creating or collecting data, and consider how the social science community can meet these challenges. We will also clarify the workshop’s disciplinary, geographic, regulatory, and institutional parameters. Each workshop participant will be asked to give a two-minute self-introduction.

10:00-11:00 **Solutions I: The role of the consent process in conditioning data sharing**

Facilitator: Diana Kapiszewski, QDR

Presenter: Cornell IRB representative

The group will discuss two scenarios in which it can be easier to share data generated through interaction with human participants: when the data do not contain personal information because they were collected without it, and when the data lack personal information because the researcher sought to de-identify them before sharing. We consider the implications of each situation for how researchers interact with human participants (in particular how informed consent is secured), and how they share their data.

Recommended resources

- <https://www.irb.cornell.edu/documents/IRB%20consent%20template%20-%20social-behavioral.doc>
- <https://dataverse.org/best-practices/harvard-dataverse-general-terms-use> (section on User Uploads > Restrictions; esp. 6.)

- Please note both the Murray Archive and the Odum Institute use these
- <https://www.icpsr.umich.edu/icpsrweb/content/deposit/guide/chapter1.html> (section on Informed Consent under Ethics and Privacy)
- http://odum.unc.edu/files/2017/05/Policy_UNCDataverseTermsofUse_20170501.pdf
- http://odum.unc.edu/files/2017/05/Guidelines_DataSecurity_20170501.pdf
- <https://qdr.syr.edu/quidance/human-participants/informed-consent>
- Thorne, Barrie. (1980) "'You Still Taking' Notes?' Fieldwork and Problems of Informed Consent." *Social Problems* 27(3): Ethical Problems of Fieldwork: 284-297. DOI: 10.2307/80024; <http://www.jstor.org/stable/800247>

11:00-11:15 Coffee break

11:15-12:30 Solutions II: The role of technology and user agreements in data sharing

Presenters: Amy Pienta (ICPSR / National AIDS & HIV Data Archive Program), Lynette Hoelter (ICPSR / Population Studies Center), Thu-Mai Christian (Odum Institute), Sonia Barbosa (Murray Archive)

Participants from leading social science domain repositories will consider scenarios in which it can be more difficult to share data generated through interaction with human participants: when data include personal information and/or are sensitive, or when de-identification might not provide full anonymity. The discussion will highlight the technological, workflow and user-agreement based strategies that repositories offer to researchers for sharing such data. The group will discuss the utility of researchers carefully considering which strategies they might adopt as they are planning their research and the importance of building such solutions into their consent scripts. Finally, we will consider how researchers and IRBs can interact productively to generate scripts that allow for sharing such data while continuing to protect research subjects.

Recommended resources

- <https://www.icpsr.umich.edu/icpsrweb/content/ICPSR/access/restricted/index.html>
- Specific federally-sponsored collection example: <https://www.icpsr.umich.edu/icpsrweb/content/NACJD/restricted.html>
- <https://qdr.syr.edu/quidance/human-participants/access-controls>
- <https://qdr.syr.edu/termsandconditions> (Section 6. Responsible Use of Data and Data Confidentiality)
- Specific state-based census collection example: <https://community.isr.umich.edu/public/mcrdc/MCRDCOverview/DisclosurePrevention.aspx>

12:30-1:30 Lunch break

1:30-2:45 Considering data sharing when designing informed consent

Full-group discussion facilitator: Dessi Kirilova, QDR

The participants will break out into small groups, and assess brief portions of consent scripts relevant to data sharing just as they might consider such a text if a researcher had included it as part of their IRB application. They will consider the strengths and weaknesses of the script, whether it is sufficient to facilitate informed consent to data sharing, whether it complies with current regulations, and what the researcher might be asked to modify. The groups will then gather for a more general discussion to consider what elements of these examples and what lessons learned from their analysis could be incorporated into the guidance IRBs offer to researchers.

Recommended resources:

Four short real-world examples to be used in the activity will be shared in advance

2:45-3:00 Coffee break

3:00-4:00 Introducing lasting institutional change

Facilitator: Colin Elman, QDR

Presenter: Cornell IRB representative

Discussion with all attendees

In this discussion-based session, attendees will consider how the guidance and materials that their institutions provide to researchers can be modified to anticipate the possibility of, and include strategies for, data sharing (or using SBER data shared by others). Attendees will discuss what processes they would need to follow and personnel they would need to involve to introduce such changes at their institutions. We will consider how repositories can serve as a resource for IRBs and the researchers they serve. We will use as a starting point the changes that Cornell University's IRB recently introduced in the guidance it offers to researchers and the processes that led to those changes.

4:00-4:30 Debrief and plan for next steps

Facilitators: Colin Elman and Diana Kapiszewski

We will review the lessons our discussions have generated, consider the possibility of working together to develop model scripts or guidance materials, and discuss ideas for subsequent productive interaction between IRBs and data repositories more generally.