Sharing Qualitative Research Data:
PSI Lab Receives Grant to Address Barriers

The Professional and Social Issues (PSI) Lab at Washington University School of Medicine in St. Louis has received a grant from The National Human Genome Research Institute (NHGRI). The PSI Lab focuses on social sciences research that improves understanding of ethics and professionalism in research and medicine.

The grant, awarded to PSI Lab Director James DuBois, DSc, PhD, supports research on barriers to sharing qualitative data in health sciences research.

Qualitative data, from recorded interviews, focus groups, or field notes, can provide information about human behavior, attitudes, and perceptions. Qualitative research is particularly useful when trying to understand behaviors that may be stigmatized or hidden.

Sharing research data is status quo when working with numbers. To ensure sound science and support continued research, scientists commonly upload raw quantitative data to large data repositories where other researchers can access it. It can then be used to verify the claims of the original study or conduct a new study by applying a different analytical lens to the pre-existing data.

Data sharing, however, remains rare among social sciences researchers.

Amy Pienta, PhD, Acquisitions Director of ICPSR, the leading social science data repository in the United States, is a collaborator on the project. She notes that the repository holds just 25 publicly available qualitative data sets—a strikingly small number considering how common qualitative data are.

The benefits of such sharing, says DuBois, could have a positive impact on the social sciences: “As a qualitative researcher, I know that the data I have are always much richer than the analyses we publish. Sharing data presents the opportunity for new analyses of existing data, for students to learn how to code data, and for increased transparency in research.”

The PSI Lab’s project tackles the unique challenges involved in sharing qualitative data. Not least among these challenges is concern for participant confidentiality in sensitive and identifiable data sets such as, for example, interviews of persons with alcohol addiction. Qualitative data are often provided in the context of a trusting relationship between researcher and participant that presumes anonymity.

For especially sensitive data, sharing may not be possible. “We do not assume that all data can be shared responsibly,” says DuBois, “nor that a one-size-fits-all approach will work for sharing diverse kinds of data.”
Data sharing requires that researchers “de-identify” the data, removing information that could lead to the identification of specific participants. Researchers worry about the time-burden and cost of de-identifying qualitative data, and whether the process would strip the data of essential significance.

As a solution and a key aspect of the project, the PSI Lab is collaborating with Washington University’s Institute for Informatics (I²) to develop software to support the anonymization of qualitative data.

Philip Payne, PhD, FACMI, Director of I², says the project demonstrates the power of alliances across disciplines to address “a complex and very timely problem.”

“This type of team science effort,” says Payne, “is emblematic of the great depth and breadth of expertise at Washington University, as well as the uniquely collaborative community-of-practice that exists in the School of Medicine.”

In collaboration with Washington University’s Dissemination and Implementation Research Core (DIRC), the PSI Lab plans to create a Qualitative Data Sharing Toolkit containing guidance and materials—including the new software—to disseminate to four stakeholder groups: data repositories, qualitative research journals, qualitative textbook authors, and research institutions.

NHGRI has been a leader within the National Institute of Health in the area of data sharing. Their interest in expanding to qualitative data sharing makes sense, says DuBois, when you consider that more than 60% of the grants they fund on the Ethical, Legal and Social Implications (ELSI) Research Program use some qualitative research methods.

As a culmination of the project, the Toolkit will be made freely and publicly available to support the ethical sharing of sensitive but valuable data from participants in health science research.