Sharing Health Sciences Data @QDR

Qualitative
Data Repository

You invest extraordinary time and energy collecting and generating research data. You spend countless hours in clinics, medical archives, interviewing health-care providers, conducting patient focus groups, and engaging in observational research. Why should you share your valuable data? Because doing so is good for you, for other scholars, and for the health sciences and clinical practice more broadly.

Sharing your research data helps you by:

- demonstrating the rigor and power of your analysis
- assisting readers to understand how you conducted your research, increasing confidence in your findings
- facilitating compliance with journal and funder mandates for data sharing, including the new NIH Data Management and Sharing Policy
- drawing attention to your work increasing, citations and real-world impact.

Sharing allows other scholars to re-use your data to:

- address new important questions in related topics
- conduct research when a lack of resources for data collection might otherwise prevent them from doing so
- teach qualitative methods to the next generation of health sciences researchers.

Sharing improves health research and practice by:

- ensuring qualitative findings are included in evidence synthesis
- preventing research waste and over-studying of vulnerable populations
- producing more transparent and reliable research to inform practice.

Why Share Data @ QDR?

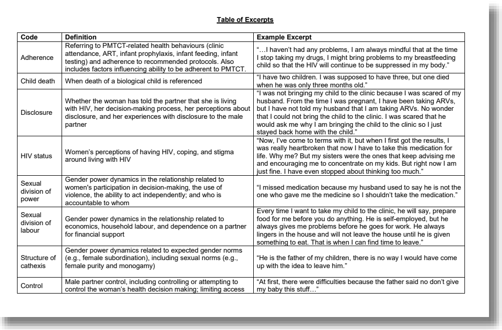
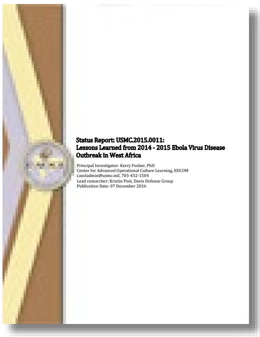


Table of Excerpts

Code	Definition	Example Excerpt
Adherence	Referring to PMTCT-related health behaviours (clinic attendance, ART, infant prophylaxis, infant feeding, infant testing) and adherence to recommended protocols. Also includes factors influencing ability to be adherent to PMTCT.	"…I haven't had any problems, I am always mindful that at the time I stop taking my drugs, I might bring problems to my breastfeeding child so that the HIV will continue to be suppressed in my body."
Child death	When death of a biological child is referenced	"I have two children. I was supposed to have three, but one died when he was only three months old."
Disclosure	Whether the woman has told the partner that she is living with HIV, her decision-making process, her perceptions about disclosure, and her experiences with disclosure to the male partner	"I was not bringing my child to the clinic because I was scared of my husband. From the time I was pregnant, I have been taking ARVs, but I have not told my husband that I am taking ARVs. No wonder that I could not bring the child to the clinic. I was scared that he would ask me why I am bringing the child to the clinic so I just stayed back home with the child."
HIV status	Women's perceptions of having HIV, coping, and stigma around living with HIV	"Now, I've come to terms with it, but when I first got the results, I was really heartbroken that now I have to take this medication for life. Why me? But my sisters were the ones that keep advising me and encouraging me to concentrate on my kids. But right now I am just fine. I have even stopped about thinking too much."
Sexual division of power	Gender power dynamics in the relationship related to women's participation in decision-making, the use of violence, the ability to act independently; and who is accountable to whom	"I missed medication because my husband used to say he is not the one who gave me the medicine so I shouldn't take the medication."
Sexual division of labour	Gender power dynamics in the relationship related to economics, household labour, and dependence on a partner for financial support	Every time I want to take my child to the clinic, he will say, prepare food for me before you do anything. He is self-employed, but he always gives me problems before he goes for work. He always lingers in the house and will not leave the house until he is given something to eat. That is when I can find time to leave."
Structure of cathexis	Gender power dynamics related to expected gender norms (e.g., female subordination), including sexual norms (e.g., female purity and monogamy)	"He is the father of my children, there is no way I would have come up with the idea to leave him."
Control	Male partner control, including controlling or attempting to control the woman's health decision making; limiting access	"At first, there were difficulties because the father said no don't give my baby this stuff…"



Status Report: USMC.2015.0011:
Lessons Learned from 2014 - 2015 Ebola Virus Disease Outbreak in West Africa

Principal Investigator: Kerry Fosher, PhD
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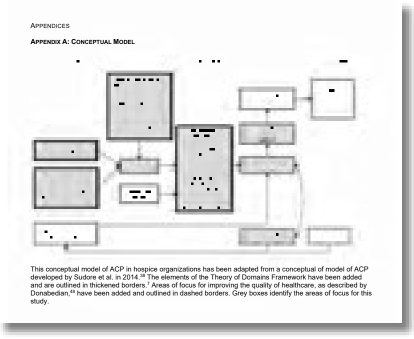
Publication Date: 07 December 2016



APPENDICES

APPENDIX A: CONCEPTUAL MODEL

This conceptual model of ACP in hospice organizations has been adapted from a conceptual of model of ACP developed by Sudore et al. in 2014.[38] The elements of the Theory of Domains Framework have been added and are outlined in thickened borders.[7] Areas of focus for improving the quality of healthcare, as described by Donabedian,[48] have been added and outlined in dashed borders. Grey boxes identify the areas of focus for this study.

QDR is the first repository in the United States dedicated to storing and publishing digital data generated through qualitative and multi-method research (e.g., text, images, audio, and video). QDR was built by scholars, for scholars, and serves a broad selection of disciplines, including population research, implementation science, social and preventive medicine, nursing and global public health.

As signaled by our CoreTrustSeal certification, QDR belongs to a select group of trusted data repositories. Our policies and technical infrastructure also **meet all criteria** for data repositories **set out by the NIH**. QDR's central focus on data underpinning qualitative and multi-method research distinguishes it from other domain repositories, from self-service repositories, and from university-based institutional repositories.

QDR helps scholars from across all health and social sciences to share data responsibly, ethically, and legally. We have the technical infrastructure and substantive expertise to store, preserve, and showcase all kinds of qualitative data, including sensitive human participant data. By following archival best practices, QDR ensures that data remain findable and accessible for the long-term.

QDR's collections include:

- **More than 30 published deposits on health-related topics** (funded, among others, by the National Institute of Nursing Research; the National Heart, Lung, and Blood Institute; the Eunice Kennedy Shriver National Institute of Child Health & Human Development and other agencies of the National Institutes of Health)
- **A dedicated repository collection**—The Palliative Care Research Cooperative Group (PCRC), which provides a model for other research-group-based partnerships
- **Transcripts of individual interviews and focus group discussions** with health care providers, patients and caregivers on a wide variety of topics and conditions
- **Data from global health studies** conducted in Bangladesh, Belgium, Canada, Ethiopia, France, Kenya, Liberia, Malawi, Nepal, Nigeria, South Africa, New Zealand

How to Share Data @ QDR?

QDR's experts offer tailored advice as you generate and share qualitative research data.

As you plan and carry out data collection, we can help you:

- draft a data management and sharing plan for grant proposals, including documents in compliance with the NIH's Data Management and Sharing Policy
- think about privacy and confidentiality, and craft informed consent protocols that anticipate the possibility of sharing human participants data.

When you are ready to share your data, QDR assists you with each step of the deposit process (described in more detail on the QDR website). In an initial conversation, you tell QDR about your research and communicate any concerns you have about sharing data, and we help you to consider:

- which data you might share
- how to organize your data and prepare them for sharing
- whether to de-identify or aggregate sensitive data (and how to do so)
- what documentation to generate to contextualize your deposit for secondary users.

Once you deposit your data, QDR checks the integrity, naming, and format of your files, and helps you to select appropriate access controls if your data are sensitive or need to be embargoed prior to the publication of an associated article.

QDR publishes your data project once you approve it. Lead time depends on data type and complexity; complete deposits can often be published in less than a week.

Our knowledgeable curators work with you to optimize how your data and documentation are displayed. We ensure that their presentation reflects the nature and the rigor of your scholarship, and allows other scholars to easily understand and re-use the data. Thanks to the standardized metadata QDR applies, data deposited in QDR are easy to find in our catalog, and in other catalogs such as DataCite or Google's Dataset Search.

Once it is published, we promote your data project by assigning it a digital object identifier (DOI) that makes it easy to cite, and we display metrics on how many times it was viewed and downloaded, highlighting your research impact.

Handling Sensitive Data

Qualitative health data can be particularly sensitive and at the same time contain rich information that could be used to breach the confidentiality of your participants. QDR's curation team specializes in helping researchers to handle sensitive qualitative data ethically and securely.

- As you plan your research, our staff helps you craft informed consent language to seek participants' permission for data sharing which allows them to make a truly informed decision without deterring them from participating in your study;
- QDR curators perform a disclosure risk review for all your deposited materials and advise you in how to address potential identifiable components of your data;
- QDR curators advise you on, and administer, access controls that determine who is able to access the data and under what conditions. Together with you, we arrive at optimal access conditions that maximize the possibility for re-use of the data while keeping them secure.

QDR Qualitative Data Repository

QDR provides resources and services for researchers who work with qualitative data:

- QDR advises on key issues such as data management, copyright, and working with sensitive research data.
- QDR personnel publish and teach broadly on best practices for managing, archiving, and sharing qualitative data.
- QDR convenes expert workshops on important topics such as sharing sensitive data
- QDR generates materials for teaching qualitative methods.

QDR working with the Palliative Care Research Cooperative (PCRC) and funding from the National Institute of Nursing Research, has compiled a first-of-its-kind collection of data projects centered around a shared research program in palliative care science. Data from the ten empirical studies in palliative care science that QDR has published in the three years since the collection's establishment have attracted more than 25,000 views.

> *“QDR has been a wonderful partner and provides such seamless guidance throughout the process of data deposits. Their team has curated a process that makes qualitative data deposits easy. The investigators receive help and guidance in every step from inspecting the consent for data sharing to guidance about data de-identification to avoid losing valuable qualitative context.”*
>
> —Salimah H. Meghani, PhD, MBE, RN, FAAN, Palliative Care Research Consortium

QDR's work has been generously supported by the National Science Foundation, the Robert Wood Johnson Foundation, the Institute of Museum and Library Services, the Mellon Foundation, and the Alfred P. Sloan Foundation. QDR also collects dues from institutional members and per-project fees from researchers not affiliated with a member institution. Visit our website for information on how charges are calculated and how you can apply for generous fee waivers and discounts.