Incorporating Qualitative Transparency into Grant Proposals

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QDR
The Qualitative Data Repository

Recap: A Changing Data Landscape: Funder Expectations for Sharing Data

- NIH: new DMSP requirement for *all* funded research data began in 2023
  - Strong data sharing expectation
  - Updating of DMSP possible with interim and final grant reports
  - Implementation of DMSP – a consideration for future support applications

- NSF: new Open Access & Data Sharing policy published in early 2023
  - Existing Data Management Plan (DMP) requirement since 2011; renamed to Data Management and Sharing Plans (DMSP) to better align with intent and other funders' nomenclature
  - DMSP reviewed by grant panel
  - Anecdotally, program officers increasingly insistent for PIs to address data sharing
  - Little accountability for DMP content / implementation, but new policy suggests change

What Do Funders Say They Expect?

NIH

- [PIs to include in proposals] "…Data Management and Sharing plan outlining how scientific data and any accompanying metadata will be managed and shared, taking into account any potential restrictions or limitations."
- [PIs to] "comply with the Data Management and Sharing plan approved by the funding Institute or Center (IC)."

https://sharing.nih.gov/data-management-and-sharing-policy/about-data-management-sharing-policy/data-management-and-sharing-policy-overview

NSF

- "Recipients are required to share all data supporting NSF funded publications at the time of publication. Exceptions to this sharing requirement should be described and justified within the DMSP."
- "A valid Data Management and Sharing Plan may include only the statement that no detailed plan is needed, as long as the statement is accompanied by a clear justification."

What Do They Really Have in Mind?
Motivations and Substantive Approach

- “Gold Standard” open science (public access)
- Research transparency
- Magnifying the return of public investment

Sharing Data from Human Research Participants

The rights and privacy of human research participants who participate in NIH-sponsored research must be protected at all times. It is the responsibility of the investigators, their institution and reviewing Institutional Review Board (IRB) to protect the rights of research participants and the confidentiality of the data.

Note

If research participants are promised that their data will not be shared with other researchers, the application should explain the reasons for such promises. Such promises should not be made routinely and without adequate justification. In general, it is inappropriate for the initial investigator to place limits on the research questions or methods other investigators might pursue with the data. It is also not appropriate for the investigator who produced the data to require authorship as a condition for sharing the data.

Investigators who are planning to share data obtained from research involving human participants should discuss the potential risks posed by data sharing, and the steps taken to address those risks with research participants as part of the informed consent process. Plans for protecting privacy can be discussed in the Human Subjects and Clinical Trials Information Form

https://grants.nih.gov/policy-and-compliance/policy-topics/sharing-policies/dms/data-sharing-approaches

- Expectations for FAIR data
- Repository use
- Explicit budgeting for data management and sharing
- Attention to appropriate human participant considerations

Fresh of the Press: A New NIH Format

1. Will there be maximum appropriate sharing of scientific data underlying peer-reviewed publications and other findings resulting from the work supported by this award (including preprints, refereed papers reported at conferences, and other findings)?
   Yes☐ No☐
2. Will the scientific data underlying peer-reviewed publications be shared by the time of publication, or for other findings, by the end of the period of performance, which includes no-cost extensions?
   Yes☐ No☐
3. Will shared scientific data be made available for at least as long as required by applicable data repository policies and/or journal policies?
   Yes☐ No☐
4. If you answered "no" to elements 1, 2, or 3, or if you anticipate that sharing will be limited in some other way, please describe these limitations and the ethical, legal, or technical factors for them. Your response should specify a particular reason(s) for limiting sharing. *[300 words maximum]*
5. If scientific data derived from human research participants will be shared, will privacy, rights, and confidentiality of participants be protected as outlined in NOT-OD-22-213?
   Yes☐ No☐ Not Applicable☐
6. In the table below, please list [100 words maximum]:

   a. **Key types of scientific data anticipated** to be generated during the project, including the species and modality, if known (e.g., "human genomic data," "rat functional magnetic resonance imaging data"). NIH recognizes that not all data types expected to be generated in the study will meet the definition of scientific data or can be anticipated in advance. If a data type does not appear on the list, it does not imply that that data type will not be shared if it is generated in the study.
   b. **The repository or an example of a repository where the scientific data may be managed and shared**, if the scientific data is known at time of application. NIH expects the use of established repositories for preserving and sharing scientific data when they are available.
7. For studies subject to the NIH Genomic Data Sharing Policy (GDS) (e.g., using NIH funds to generate large-scale human genomic data):
   a. Will you share all large-scale human genomic and associated data in a NIH-designated repository according to the accelerated timelines expected in the GDS Policy?
   Yes☐ No☐ Not Applicable☐i f "no," address in element 4.

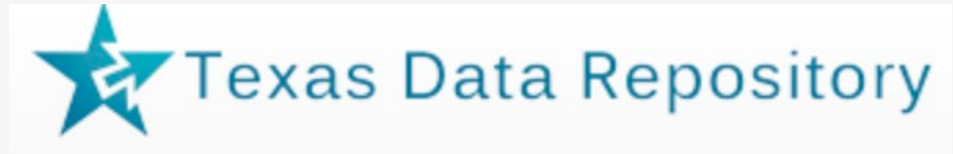
   b. Do you anticipate that when sharing you will be able to meet the expectations of the Institutional Certification in the GDS Policy?
   Yes☐ No☐ Not Applicable☐

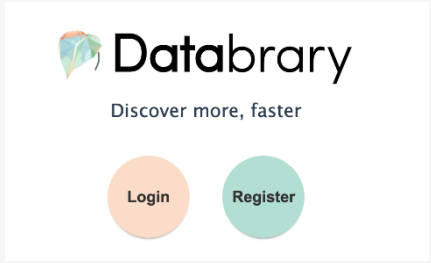
https://grants.nih.gov/policy-and-compliance/policy-topics/sharing-policies/dms/writing-dms-plan

Myriad Repositories, Multiple Types

- Self-deposit generalist repositories
- Institutional repositories (affiliated with a university / system)
- Domain / disciplinary repositories
- Hybrid (e.g., Dryad)
- Funder-supported specialized repositories
  - E.g., over 100 NIH-supported ones

QDR
The Qualitative Data Repository





Examples of Shared Qualitative Data Possibilities

De-identified, Restricted Interviews & Documentation

CShdaimah Keisha Interview 1, Copy 2 12-4-12

INTERVIEWER: ....cause it would be sad for both of us. Okay. I'm gonna put this just a little closer.

RESPONDENT: Okay.

INTERVIEWER: But you don't have to worry about speaking in it, it takes a...

RESPONDENT: Okay.

INTERVIEWER: So thank you again.

RESPONDENT: You're welcome.

INTERVIEWER: And I'm just gonna start off, I have just like a few demographic questions, and then it'll be more like a conversation.

RESPONDENT: Okay.

INTERVIEWER: Okay. So how old are you?

RESPONDENT: I'm [30-40].

Shdaimah, Corey. 2020. "Problem-Solving Courts, Street Level Bureaucrats, and Clients as Policy Agents in a Prostitution Diversion Program". Qualitative Data Repository. https://doi.org/10.5064/F6C8VUHP

Filename: Shdaimah_Guide_Interview-1.pdf

Description: First Interview with Program Participants

In *Problem-Solving Courts, Street Level Bureaucrats, and Clients as Policy Agents in a Prostitution Diversion Program* (version 1.0), by Shdaimah, Corey

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First Interview for Program Participants

A member of the research team will conduct the interview within first week of program acceptance. She will thank the participant for taking time to speak with her and review the letter of explanation. If the participant agrees to continue, the interviewer will stress that there are no right or wrong answers, and that she is interested in the participant's experiences with the Specialized Diversion Program/Project Dawn Court. The interviewer will remind the participant that she should not provide any identifying information in the course of the interview

Background

I am going to start with a few demographic questions:

- What is your age?
- What grade did you go to in school?
- What do you consider to be your race or ethnicity?
- What neighborhood or community do you come from in Baltimore?

Motivations

Researchers say that we don't really know enough about why women engage in prostitution. We think one of the reasons is that not many researchers talk to women. We hope it is okay to ask you these questions, but please feel free to refuse to answer them.

- What was the major reason that you started to engage in prostitution? How old were you?
- Are there any other reasons?
- Do you still engage in prostitution sometimes? If so, is this for the same reasons or other reasons?

Data Sharing Added to Informed Consent during Data Collection

Data for: What Extraordinary Times Tell Us about Ordinary Ones: A Multiple Case Study of Precariously Employed Food Retail and Service Workers in Two U.S. State Contexts during the COVID-19 Pandemic

Version 1.0

Vignola, Emilia F.; Ahonen, Emily Q.; Hajat, Anjum. 2024. "Data for: What Extraordinary Times Tell Us about Ordinary Ones: A Multiple Case Study of Precariously Employed Food Retail and Service Workers in Two U.S. State Contexts during the COVID-19 Pandemic". Qualitative Data Repository. https://doi.org/10.5064/F6Z82KER. QDR Main Collection. V1

Cite Data Project ▾ Learn about Data Citation Standards.

Download Data Project ▾

Contact Owner | Share

Make Data Count (MDC) Metrics
since 2019-10-01

547 Views

240 Downloads

0 Citations

Description

Project Overview

This project consists of a multiple case study of older, precariously employed food workers in two U.S. states (Indiana and Washington) during the COVID-19 pandemic, designed to explore the links between employment quality and social context as drivers of disease prevention. This deposit is of individual semi-structured qualitative data in the form of de-identified and generalized transcripts of the interviews conducted.

Data and Data Collection Overview

We conducted data compilation, document review, and 26 in-depth interviews using a multiple case study design with two states, Indiana and Washington, constituting the cases (Stake, 2005). For each case, sources consisted of secondary data regarding state context (e.g., policy landscape and health measures) and semi-structured individual interviews with food retail or service workers. Details on the

"We conducted 26 total interviews but three of those are not included in the shared data because the question about consent to share their data had not yet been added to the consent script or the interview guide when those first interviews were conducted."

Vignola, Emilia F.; Ahonen, Emily Q.; Hajat, Anjum. 2024. "Data for: What Extraordinary Times Tell Us about Ordinary Ones: A Multiple Case Study of Precariously Employed Food Retail and Service Workers in Two U.S. State Contexts during the COVID-19 Pandemic". Qualitative Data Repository. https://doi.org/10.5064/F6Z82KER. QDR Main Collection. V1

Abridged Data: Fieldnotes (interview summaries)

Participant 13
Qualitative Interview
Date of Interview: 1/3/2020
Length of Interview: Approximately 40 minutes, including time for consent

Q1:

- She is the interim medical director of clinic since 8/2019 so don't have good context with clinic
- She had a handful of pts on PrEP before PC at another clinic
- Found it extremely difficult to f/u with pts
- No good system of f/u
- So for the 2-3 people she had on PrEP, she would lose track, they'd resurface, go on-off PrEP
- She wasn't screening everyone and only really talk to pts who weren't super complex (younger men, IDU) about PrEP
- Screening: hard to take bigger picture into account and look at pt population

Q2:

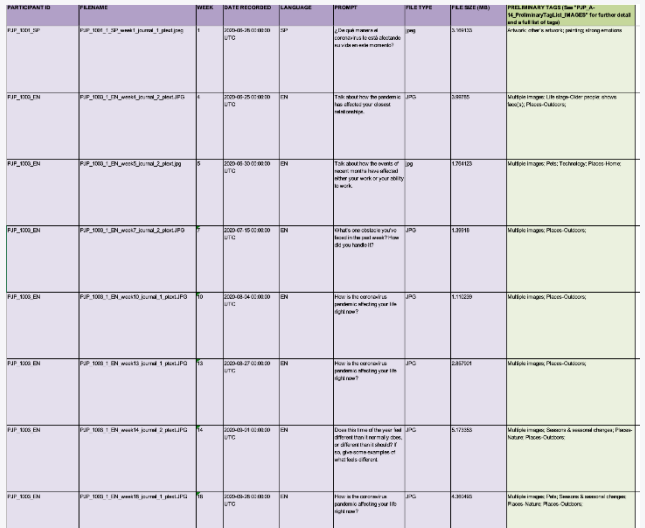
- Main change: conversation about PrEP and reconnect with PC to f/u on labs
- Ensure pt is appropriate for PrEP
- HCP has more time for education
- Detailed risk-benefit
- f/u with people has been good
- when competing priorities though, it is still difficult to have discussion
- PrEP is still rarely brought up by HCP; it's usually the pt who brings it up
- At clinic: PC involved from initiation phase and continued to f/u of labs; b/c she's newer there and the pts are new to her
- At other clinic: PC mainly involved with f/u and connection back to care; b/c she's been there much longer and has more established connection with pts

Saberi, Parya. 2020. "PrEP Optimization Intervention: qualitative interviews with healthcare providers". Qualitative Data Repository. https://doi.org/10.5064/F6SHNJUG. QDR Main Collection. V2

Mixed Methods Data:
Audio recordings; Photographs; Survey data; Web sources

- README_PJP.txt (182.5 KB)
- PJP_A_DescriptiveMaterials
- PJP_B_BackgroundMaterials
  - PJP_B-1_ResearchPersonnelAndAdvisors.pdf (89.3 KB)
  - PJP_B-2_Sponsors.pdf (119.5 KB)
  - PJP_B-3_SubsequentPJPProjectsAndSponsors.pdf (151.4 KB)
  - PJP_B-4_Websites
    - PJP_B-4a_MainWebsite
    - PJP_B-4b_MyJournal-FeaturedEntriesWebsite
    - PJP_B-4c_PicturingThePandemic_ExhibitionWebsite
  - PJP_B-5_SocialMediaSnapshots
    - PJP_B-5a_FacebookPage_PartialSnapshot.html (57.1 MB)
    - PJP_B-5b_InstagramPage_PartialSnapshot.html (4.0 MB)
    - PJP_B-5c_TwitterPage_PartialSnapshot.html (61.1 MB)
- PJP_C_DataFiles
  - PJP_C-1_Full Data.xlsx (63.4 MB)
  - PJP_C-2_Audio Catalog_RESTRICTED.xlsx (185.0 KB)
  - PJP_C-3a_ImageCatalog_RESTRICTED.xlsx (19.8 MB)
  - PJP_C-3b_Image Catalog_RESTRICTED_WithThumbnails.xlsx (214.5 MB)
  - PJP_C-4_AudioFiles
  - PJP_C-5_ImageFiles

pandemic JOURNALING project



Willen, Sarah S.; Mason, Katherine A.. 2024. "Data for: The Pandemic Journaling Project, Phase One (PJP-1)". Qualitative Data Repository. https://doi.org/10.5064/F6PXS9ZK. QDR Main Collection. V1

Responsible Sharing of Human Participant Data

DMSP-IRB Nexus

- IRB: required for human subject research based on federal regulations; typically based at an institution
- DMSP: a document required by funders; typically written by PI and not closely monitored by institution
- *Both require researchers to document data collection, sharing and security details*
  - *It is critical for PI to ensure that the two documents align*
  - *https://qdr.syr.edu/guidance/human-participants/informed-consent*

Data Sharing Considerations in the IC Process

- Balance: being transparent about data use, but remain intelligible
- Participants are often willing to help science broadly, not just individual researcher
- Opt-in consent for data sharing can be great; IRBs familiar with it as “tiered consent”
  - Careful with quantitative data & opt-in → partial data might be hard to analyze accurately

Data Sharing in Informed Consent: Example

Alicia VandeVusse and Jennifer Mueller, Guttmacher Institute

Potential for Data Sharing: If you agree, the transcript of your interview may be shared with researchers at other organizations in the future. We will take out or change any information that could identify you before sharing. You can be in the study whether you agree to data sharing or not (see *Optional Consent* below).

Then after the consent to participate, optional data-sharing consent included:

Do you agree to allow a written copy of your interview to be shared with other researchers in the future?

- Yes
- No

In a qualitative study on abortion using this consent script, 92% of respondents opted into data sharing.

VandeVusse A, Mueller J, Karcher S. "Qualitative Data Sharing: Participant Understanding, Motivation, and Consent." *Qual Health Res*. 2022 Jan;32(1):182-191. https://doi.org/10.1177/10497323211054058.

De-identifying Qualitative Data

- Removing / replacing information in text can distort data, make them unusable, unreliable or misleading: A balance to preserve context
- Remove direct identifiers, or replace with pseudonyms – often not essential research info
- Avoid blanking out; use pseudonyms or replacements [IDENTIFY REPLACEMENTS / REDACTIONS]
- Plan and apply de-identification at time of transcription
- Consistency within research team /project
  - Keep de-identification log of replacements or removals made; keep separate from the processed data files
- **Emerging semi-automated tools**

Controlling Access

"As open as possible, as closed as necessary" (European Union)

- Default to open data (license "CC0" or "CC-BY")
- Public-use data
- Timed embargo (in 1, 3, 10, 100 years) – NB: not a publication-based embargo
- Access by application
  - Identity and affiliation checks
  - Specific training requirements (e.g., CITI)
  - Signed DAUAs
  - Secondary IRB (appropriate for data that still has PII)
- Access using enclaves (not currently at QDR, but available for quantitative data at other repositories)

Not Sharing Data: NIH Rules

Examples of justifiable factors for limiting scientific data sharing include

- informed consent will not permit or will limit the scope or extent of sharing and future research use
- existing consent (e.g., for previously collected biospecimens) prohibits sharing or limits the scope or extent of sharing and future research use
- privacy or safety of research participants would be compromised or place them at greater risk of re-identification or suffering harm, and protective measures such as de-identification and Certificates of Confidentiality would be insufficient
- explicit federal, state, local, or Tribal law, regulation, or policy prohibits disclosure
- restrictions imposed by existing or anticipated agreements (e.g., with third party funders, with partners, with repositories, with Health Insurance Portability and Accountability Act (HIPAA) covered entities that provide Protected Health Information under a data use agreement, through licensing limitations attached to materials needed to conduct the research)
- datasets cannot practically be digitized with reasonable efforts

Examples of reasons that would generally not be justifiable factors limiting scientific data sharing include

- data are considered to be too small
- data that researchers anticipate will not be widely used
- data are not thought to have a suitable repository

https://grants.nih.gov/policy-and-compliance/policy-topics/sharing-policies/dms/writing-dms-plan#maximum-appropriate-sharing-of-scientific-data

Transparency Beyond Data Sharing

NIH Emphasizes Rigor and Transparency

- **Tips on Research Strategy Content**
  - A strong Research Strategy is the heart of your application. Describe your proposed project, its significance, and how you will conduct your research.
  - As you draft and finalize your Research Strategy content, we advise:
  - Learn what to include in your Significance, Innovation, and Approach sections and how they differ. The How to Apply – Application Guide provides extensive guidance on what to cover in each section.
  - Describe how your project reflects principles of scientific rigor, reproducibility, and transparency. Find application resources and guidance on Enhancing Reproducibility through Rigor and Transparency.
  - Consider including Tables, Charts, and Figures. They can help you summarize data, clarify key elements of your research, illustrate the flow of your planned experiments, and boost visual interest.

https://grants.nih.gov/grants-process/write-application/advice-on-application-sections#research-strategy

Sharing Data Collection Materials

- Recruitment materials
- Informed Consent
- Interview questionnaires
- Focus Group guidelines and materials

Preregistration

International Journal of Qualitative Methods

UNIVERSITY OF ALBERTA
INTERNATIONAL INSTITUTE
FOR QUALITATIVE METHODOLOGY

Impact Factor: **3.8** / 5-Year Impact Factor: **6.2**

Open access | Research article | First published online December 9, 2020

Preregistering Qualitative Research: A Delphi Study

Tamarinde L. Haven, Timothy M. Errington, [...], and Lidwine B. Mokkink +6 View all authors and affiliations

https://doi.org/10.1177/1609406920976417

Qualitative Preregistration

Anticipated Duration *
Please indicate the estimated project start date (mm/yyyy) and estimated project end date (mm/yyyy).

Design Plan
Study design *
Please provide a brief, overarching characterisation of the study design.

Your response might consist of a succinct label (e.g., "case study" or "ethnography") and/or a brief elaboration of that label's meaning.

A study may involve a combination of different designs, including a mix of quantitative and qualitative methods.

Sampling and case selection strategy *
Please describe your sampling or recruitment strategy (examples include, but are not limited to: purposive, snowball, theoretical, and maximum variation sampling) and/or your case selection strategy (examples include, but are not limited to: typical case, most similar case, most different case, diverse case, and deviant case).

Please provide a short rationale for why you selected this type of strategy.

Transparency Checklists

Lori Frohwirth[1], Sebastian Karcher[2], Tamrin Ann Lever[3]

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A Transparency Checklist for Qualitative Research

Abstract

Background: Transparency is increasingly recognized as an important goal for research. But while tools and guidance for transparency and reproducibility abound for scholars working quantitatively, relatively few such tools exist for qualitative researchers.

https://osf.io/preprints/socarxiv/wc35g_v1

Audit Trails

Structured audit trail for making the rigor in qualitative research explicit: a methodological tutorial

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10.31235/osf.io/9qekw_v1

Sharing Analysis Outputs

- Code reports
- Coding matrices
- Extended excerpts

Code	Illustrative Quotations
Policy: Epidemiological data could inform and evaluate changes in policy at local and larger levels	"When you do like those costs benefit analyses, not that I think those actually will change international policy, like international level, but just the fact that like the global burden of disease, mental health is such a huge part of the disability part of that....If you can get the research done sufficiently that you could add that in there, and therefore **quantify the benefits of halting like gas emissions and like, just different policies** that could something." "I think we have to see action at the lower level. Like we, we cannot rely on like major treaties, intergovernmental treaties, or national policies to move this. And we can work toward those. But so, I I say, to the extent possible that this could help inform it, help inform local action like, **could find scale resolution if possible in your results, as well as inform national or international policy.**"

Incorporating Transparency into Your Grant

- New DMSP format limits space, but: take advantage of listing data types – **qualitative research is rich**
  - List extended excerpts/coding reports
  - List data collection materials
- Consider adding flags signaling transparency to research strategy
  - Transparency checklist
  - Preregistration
  - Audit trails