Organizing and Sharing Qualitative Data via the Qualitative Data Repository (QDR)

Dessi Kirilova
Johns Hopkins Love Data Week
February 14, 2024

JOHNS HOPKINS
UNIVERSITY

QDR
The Qualitative
Data Repository

What Is QDR?

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- ...other t...
- ...d inter...
- Currently over 180 data projects published
- Over 30 institutional members
- Continuously CoreTrustSeal-certified

Special Collections

The Trachtenberg Papers

QDR Main Collection >

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This data collection - The Trachtenberg Papers - broadly concerns Cold War policy from the end of WWII to 1964. The data was accumulated in order to write several books and articles relating to Cold War relations during this pivotal period, most notably *A Constructed Peace: The Making of the European Settlement, 1945-1963* (Princeton: Princeton University Press, February 1999).

It includes five data projects. The three Cold War Documents projects contain archival data, whereas the remainder contain the appendices to *A Constructed Peace* and a broader collect pedagogical materials.

Search this collection... 🔍

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Filters   1 to 5 of 5 Results

Northern Ireland Research Initiative

QDR Main Collection >

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The Northern Ireland Research Initiative (hereafter NIRI) was created in 2008 to address the current lack of: 1) disaggregated, 2) systematically collected, 3) publicly available data on the Northern Ireland conflict, 4) across source and type of violation. The goal of this effort is to advance our ability to assess important theoretical explanations for what took place, such as explorations of the importance of political, economic, cultural, and social factors commonly believed to influence conflict activity. NIRI has engaged in an ambitious research effort composed of numerous elements including a unique, systematic, and comprehensive data collection of events with information about perpetrators and victims at different levels of analysis (i.e., street, neighborhood, city, region and country) as well as multi-level theorization and examination about the determinants and processes of political conflict/violence. Additional information on the project can be found at niresearch.org.

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Filters

☑ 👤 Collections (0)
☑ 📄 Data Projects (1)
☐ 📄 Files (1,913)

Publication Year

1 to 1 of 1 Result   Sort ▾

Association for Legal Justice (ALJ) Human Rights Testimony, Northern Ireland
Dec 3, 2018

Loyle, Cyanne E.; Davenport, Christian; Sullivan, Christopher. 2018. "Association for Legal Justice (ALJ) Human Rights Testimony, Northern Ireland". Qualitative Data Repository. https://doi.org/10.5064/F6LHMHJR. Northern Ireland Research Initiative. V1

SECURITY STUDIES

Security Studies

(Security Studies Journal)
QDR Main Collection >

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Collection for supplementary data for the *Security Studies* journal. By agreement between *Security Studies* and the Qualitative Data Repository, data deposited to supplement articles accepted for publication in *Security Studies* do not incur deposit fees.

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⊕
New Project

A Changing Landscape: Funder Expectations for Sharing Data

- NSF: 2023 update to [Open Access & Data Sharing policy](#)
  - 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
  - DMP reviewed by grant panel
  - Anecdotally, program officers increasingly insistent to address data sharing
  - Little accountability for DMP content, but new policy suggests change

- NIH: [New DMSP requirement](#) for *all* funded research data began in 2023
  - Strong data sharing requirements
  - Updating of DMSP possible with interim and final grant reports
  - Implementation of DMSP – a consideration for future support applications

Uses of Shared Data – the "why"

- Secondary analysis and collaboration
- Transparency for specific publications
  - Replication
  - Reproducibility
  - Verification
  - Traceability of methodological choices
- Giving back to participants / communities
  - Direct sharing back to individuals
  - Not over-researching same communities
- Methodological innovation
- Teaching and training

"Sharing scientific data accelerates biomedical research discovery, enhances research rigor and reproducibility, provides accessibility to high-value datasets, and promotes data reuse for future research studies.

Ultimately, the sharing of scientific data expedites the translation of research results into knowledge, products, and procedures to improve human health."

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

Re-use in practice: Graduate Thesis

Graduate Theses, Dissertations, and Problem Reports

2022

Barriers and Opportunities to Exiting Prostitution: An Analysis of Prostitution Diversion Programs

Marina Binti Mohd Hamdan
West Virginia University, mbm0031@mix.wvu.edu

https://researchrepository.wvu.edu/etd/11238

"This study is a critical program evaluation of two court-affiliated diversion programs with data collected by Corey Shdaimah from the University of Maryland School of Social Work. Shdaimah conducted a longitudinal study examining the perspectives of women exiting prostitution (…) through open-ended interviews with the participants as well as significant stakeholders (Shdaimah 2020).

I will be utilizing secondary data, her interview transcripts, of program participants from Specialized Prostitution Diversion program (SPD) in Baltimore City and Project Dawn Court program (PDC) in Philadelphia."

Re-use in practice: Developing & contrasting methodologies

Introduction to Special Issue: Diverse Approaches to Qualitative Data Analysis for Applied Research

Jessica N. Lester
Indiana University, jnlester@indiana.edu

Noah Goodman
EDC's Center for Children & Technology

Michelle O'Reilly
University of Leicester & Leicestershire Partnership NHS Trust, mjo14@leicester.ac.uk

https://doi.org/10.46743/2160-3715/2021.5015

"We suggest that the field can benefit from new and practical examples that allow researchers to compare different qualitative approaches, how they can be used in applied settings, and the unique lenses they bring. In order to achieve this goal, we have asked each author in this special issue to analyze one shared data set from a study exploring "postnatal care referral behavior by traditional birth attendants (TBAs) in Nigeria" (Chukwuma, Mbachu, Cohen, Bossert, et al., 2017). The shared data set, which was secured from Syracuse University's Qualitative Data Repository, consists of transcripts from three focus groups—one with hospital health care workers, another with traditional birth attendants, and a third with TBA delivery clients (Chukwuma, Mbachu, Cohen, McConnell, et al., 2017). Contributing authors—who work within in a range of disciplines—were encouraged to focus less on the substantive findings of factors affecting TBAs' postnatal referral behavior, and instead aim to unearth the analytical contributions and insights that their approach might contribute to a similar data set."

Re-use in Practice: Teaching

From Alastair Tomlinson, Cardiff Metropolitan University, UK:

"I teach a postgraduate research methods course for approximately 130 students per year, across a range of health-related degree subjects. We have used the QDR to enable students to develop their understanding of qualitative methods, and to demonstrate their qualitative data analysis skills. Students register with the QDR and access a specified research study. As part of their course assessment, students have to critique the qualitative design and methods used in the research study (relevance and appropriateness of design methodology to research question, evidence of rigour in sampling and data collection methods). They then access a subset of interview transcripts from the study and conduct a qualitative thematic analysis using the approach recommended by Braun & Clarke (2013). They produce a short research report summarising their evaluation and analysis, presenting the key themes that they have developed from their data analysis, and draw a brief conclusion. The QDR has been invaluable in enabling our students to work with real-world qualitative materials relevant to their subject area – and raising their awareness of the broader issues about making qualitative research data available to other researchers, and the appropriate access controls that need to be applied."

Why Share (Qualitative) Data?

- **Be a good colleague:** Allow others to scrutinize and build on your work

- **Be a good teacher:** Students benefit from working with "real" data

- **Be a good citizen:** Open science is more impactful science

- **Get funded and published:** Scientific funders and publishers increasingly expect data sharing and research transparency

- **Get cited:** Lots of empirical evidence across different disciplines that publications whose data are shared, do get more visibility and attention

Data Management and Planning – the "how"

Think about data sharing early on and holistically – fine-grained choices

Consider data security and access: Both during project and after

Plan & organize early: Folder names and structure, file names

Create documentation throughout the project

Benefits of Sharing Data in a Repository – the "where"

- Stable links (Digital Object Identifiers – DOIs)

- Long-term digital preservation (incl. keeping formats up to date)

- Meeting institutional requirements

- Data management planning and curation assistance
  - can help you with sharing data *well*

- Makes data more visible/easier for others to discover, access, cite

- Interoperability across disciplines

- Custom solutions for sensitive data (access controls, use agrements, embargoes, etc.)

→ FAIR Data

Shared Qualitative Data: Some Examples

Partial Sharing of Full Transcripts

Previous Next Page: 1/17

Date of Interview: 22Aug14 | Start Time: 12:10 pm | End Time: 12:50 pm
Interviewer's Name: TJ | Location: An NGO clinic, Darshana, Damurhuda (2)
Respondent's Name: Dr. Numinul Islam (Pseudonym)
Type of Respondent: Private (NGO) Sector | Number: 2
Gender of Respondent: Male | Year of Graduation: [1993-1998] | Position/Rank: MO- [Health Clinic]

ও– আমি ডাঃ তৌফিক জোয়াদার আমার পরিচয় আগেও একবার
বলছি আমি ড নহপকিন্স বিশ্ববিদ্যলয়ে চঞ্চেউ করছি। আর ঢ়যফ র
অংশ হিসেবে ড ক্তারদের সাক্ষ ৎসায় নিচ্ছি দের সংবেদনশীল
অর্থ ৎ রোগীর প্রতি রা কত টুকু সংবেদনশীল বা সংবেদশীল
বলতে রা কি বুঝেন এই বিষয়গুলে নিয়ে আমরা আলোচন করব।
এটার কিছু সংগ আছে এগুলে আমি একটু পরে বলে দিবো এটা
বলতে আমি কি বুঝাচ্ছি সংবেদনশীল বলতে কি বুঝাচ্ছি এটা নিয়ে
আলে চন হবে। কিন্তু আলে চন য় টুকু তল র আগে আমি আপন র
কাছে একটু নতে চাই যে আপন র নিজের সম্পর্কে যদি একটু
বলেন। যে আপনি কোন মেডিকেল থেকে পাস করলেন আপন র
এডুকেশন ল ব্যাক গ্রেডেট, ফ্য মিলি সম্পর্কে নিজের কা সম্পর্কে

QDR Project 10086_Joarder
- 0_README_Joarder.txt (3.3 KB)
- Joarder_Ali_Informal Sector.pdf (1.2 MB)
- Joarder_Dhand_Public Sector.pdf (569.0 KB)
- Joarder_Gaisal_Public Sector.pdf (1.3 MB)
- Joarder_Khontu_Informal Sector.pdf (688.8 KB)
- Joarder_Kohurul_Public Sector.pdf (1.1 MB)
- Joarder_Lhalid_Public Sector.pdf (492.4 KB)
- Joarder_Miakat_Private Sector.pdf (912.3 KB)
- Joarder_Nostofa_Private Sector.pdf (522.8 KB)
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- Joarder_Sowshon_Public Sector.pdf (1.0 MB)
- Joarder_Thuvo_Public Sector.pdf (1.4 MB)
- Joarder_Uarikul_Private Sector.pdf (919.0 KB)

Documentation
- Joarder_Ethical Review Board_ Approval Letter_DOCUMENTATION.pdf (357.0 KB)
- Joarder_Written consent form for IDI of providers_Bengali_21Jun14_DOCUMENTATION.pdf (486.8 KB)
- Joarder_Written consent form for IDI of providers_English_17Jun14_DOCUMENTATION.pdf (351.2 KB)
- Joarder_Written consent form for PO of provider_Bengali_21Jun14_DOCUMENTATION.pdf (477.5 KB)
- Joarder_Written consent form for PO of provider_English_17Jun14_DOCUMENTATION.pdf (353.0 KB)

Joarder, Taufique. 2017. "Understanding and measuring responsiveness of physicians in rural Bangladesh". Qualitative Data Repository. https://doi.org/10.5064/F6P55KNC. QDR Main Collection. V2

Mixed Method Data: Archival and Surveys

README_Hitt.txt (10.1 KB)
Hitt_Extracted Newspaper Excerpts.tab (1
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  ▶ 📁 Bullock

Hitt, Matthew. 2019. "Replication Data for: Inconsistency and Indecision in the United States Supreme Court". Qualitative Data Repository. https://doi.org/10.5064/F6W7QRSX
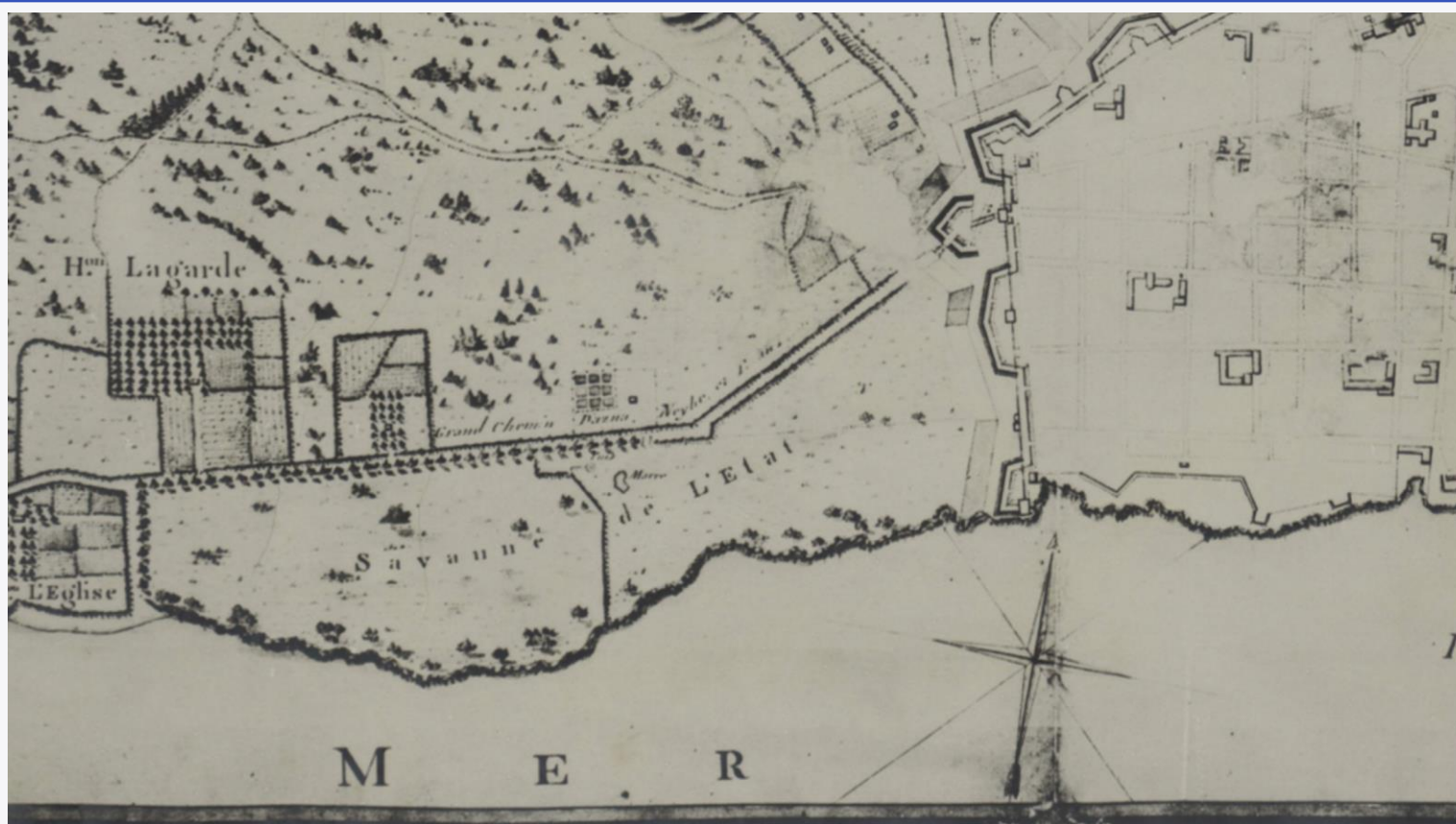
Rich Archival Materials

Leonard, Don. 2019. "Data for: Exposure to trade and postcolonial divergence on the island of Hispaniola". Qualitative Data Repository. https://doi.org/10.5064/F6MFN8D4. QDR Main Collection. V1

Change View | Table | Tree |

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  - ▸ 📁 **Reports**

De-identified, Restricted Interviews & Documentation

1	CShdaimah Keisha Interview 1, Copy 2 12-4-12
2	INTERVIEWER: ....cause it would be sad for both of us. Okay. I'm gonna put this
3	just a little closer.
4	RESPONDENT: Okay.
5	INTERVIEWER: But you don't have to worry about speaking in it, it takes a...
6	RESPONDENT: Okay.
7	INTERVIEWER: So thank you again.
8	RESPONDENT: You're welcome.
9	INTERVIEWER: And I'm just gonna start off, I have just like a few demographic
10	questions, and then it'll be more like a conversation.
11	RESPONDENT: Okay.
12	INTERVIEWER: Okay. So how old are you?
13	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.

Download File   Close Preview

Previous   Next   Page: 1 / 2

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?

QDR's Take on Responsible Sharing of Human Participant Data

Data Sharing and Ethical Concerns

- Research must be designed, reviewed, and undertaken to ensure integrity, quality, and transparency

- Any promises for confidentiality and/or anonymity of respondents must be respected

- Harm to participants must be avoided in all instances

- Any conflicts of interest must be explicit

- Participation is voluntarily, free of any coercion, and *informed*

DMP-IRB Nexus

- IRB: required for human subject research based on federal regulations; typically based at an institution
- DMP: 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 PIs to ensure that the two documents align*

Informed Consent Considerations

- 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

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. doi: 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 [FLAG REPLACEMENTS]

- 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

De-identification Protocol: Example

Some Guidelines on Making the Transcriptions Anonymous:

We change the names of many particular details (places, people, jobs, etc...) to more general categories. In an interview, the name of a of a particular detail will be assigned the general category in all caps and a number ##. The number will be consistently assigned to this particular detail throughout the transcribed interview. For example, if a broker named Jorge Martinez is mentioned, we will change his name to REFERENTE ##, where ## is a number that is assigned to Jorge throughout the transcribed interview.

Eliminate names of municipalities. Anonymizing the names of the cities provides the best protection for the respondents. Of course, it is not possible to eliminate every detail about a municipality without losing much of the context in the interview. In all of the transcripts MUNICIPIO 1 will be the city, in which the respondent is a broker and/or city council member. Other cities that are named will be assigned a number so that the one city will have the same number throughout the individual transcript. The exception to this rule will be when a respondent refers to Capital or Buenos Aires. In this case, the risk of revealing the identity of the respondent's city or the identity of the respondent is low, and the distinction between Capital and the other cities is an important one. Similarly the names of streets will be termed CALLE and assigned a number. If a particular zone in a city is mentioned, it will be termed ZONA ##. If a neighborhood in a city is named it will be termed BARRIO ##.

All of the names of politicians will be changed to more abstract terms with the exception of the current and preceding presidents and governors. If possible the name of the politician will be changed to the politician's office. For example, if Javier Ramos is a concejal then we would change his name to CONCEJAL ##. If the position of the referenced politician cannot be identified then the name can be replaced with POLITICO ##. Each individual will be assigned a number and this number will be consistent throughout the transcript.

Entrevistador: ¿Y en qué barrio pensás, digamos, cuando, vos en qué barrio..?

Entrevistada: Bueno, yo soy BARRIO 1 y BARRIO 2. BARRIO 2 y BARRIO 1.

Entrevistador: Y, digamos, si tuvieras que, de esos referentes que conocés de diferentes partidos, dar un número, ¿te animás a dar un número, cuántos son?

Entrevistada: Y, son unos cuantos, son muchos eh, yo entiendo que son más de cincuenta

Entrevistador: Bueno, cincuenta me parece...

Entrevistada: Te digo, por ejemplo, en MUNICIPIO 1 hay [detalla el número] bibliotecas populares, reconocidas por la CONABIP, que es una institución nacional que las agrupa y ….

Dunning, Thad; Camp, Edwin. 2015. "Brokers, voters, and clientelism: The puzzle of distributive politics". Qualitative Data Repository. https://doi.org/10.5064/F6Z60KZB. QDR Main Collection. V1

Controlling Access

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

- Default to open data (license "CC0" or "CC-BY") for documentation
- 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)

QDR for JHU's Researchers and Students

Johns Hopkins University's Institutional Membership with QDR

QDR — The Qualitative Data Repository

Free curation & storage for typical qualitative and multi-method projects

Priority DMP consultations

Recommended by and compliant with federal and private funders

Strategies and tools for sensitive data

Virtual class visits (methods courses; graduate research seminars)

Johns Hopkins University's Local Data Service Resources

JHU's Dataverse instance (for open-access data): https://archive.data.jhu.edu/

JHU Libguide on "Protecting Human Subjects Identifiers": https://guides.library.jhu.edu/protecting_identifiers

Guidance on data sharing from 3 IRBs: General JHU IRB Expectations for Sharing of Individual Level Research Data

Trainings on de-identifying data with Dave Fearon (for JHU affiliates only)

- PROTECTING HUMAN SUBJECT DATA PRIVACY: AN INTRODUCTION: https://jhu.libcal.com/event/11787246
- PROTECTING HUMAN SUBJECT DATA PRIVACY PART II: DE-IDENTIFICATION: https://jhu.libcal.com/event/11787268

https://dataservices.library.jhu.edu/
dataservices@jhu.edu

Consultations at Different Points in a Project Lifecycle

When planning research

- DMP / DMSP consultations and review for grant proposal

- Informed consent review and advice

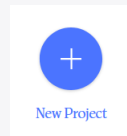- Data management consultations during project

When depositing data

- Disclosure risk review

- Data organization and documentation consultation

- Data/file transformation

Research Data Lifecycle by LMA Research Data Management Working Group

Depositing Data in QDR

- Initial Consultation: Possible anytime, best at project start
- Initial Deposit & Curation
- Final Review
- Publication & Promotion
- Can be qualitative only or mixed methods

Questions? Comments?
Please Stay in Touch!

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  @qdr@mstdn.science

  @qdrepository

QDR
The Qualitative
Data Repository

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Email: qdr@syr.edu   Dessi.Kirilova@syr.edu