Quick Intro to the Qualitative Data Repository (QDR)

Dessi Kirilova, QDR Workshop on Open Data and Reuse in Social Science Weather Research April 11, 2023

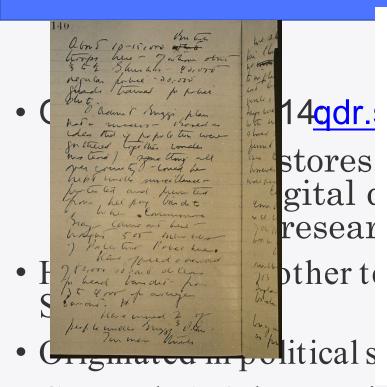








What Is QDR?



A FOCUS GROUP DISCUSSION WITH THE HEALTH WORKERS

DATE: 3rd August, 2016

LOCATION: Federal Teaching Hospital, Abakaliki

DURATION: 74 minutes

I = INTERVIEWER

P = PARTICIPANTS.

[Names of participants have been omitted. Study team member nam

I: Good morning.

ALL: Good morning.

I: Some of us were not here when we did the introduction. M Mbachu. Here with me are;

I2: Adanna Chukwuma

I3: Eze Nelson

I: What language do you prefer that we use in this discussic combination of both?

ALL: Combination of the two.

- Currently 154 data projects published
- Over 30 institutional members
- Continuously CoreTrustSeal crtified



es the



GERENCIA DE AGUA POTABLE HORARIOS DE SERVICIO DE AGUA POTABLE POR COLONIA EN NAUCALPAN

No.	POBLACION	TIEMPO DE SERVICIO	HORARIO DE SERVICIO (HORAS)		
J	PUEBLOS		[1] [1] [1] [1] [1] [1] [1] [1] [1] [1]		
1	LOS REMEDIOS	Diario	8 hrs.		
2	SAN ANTONIO ZOMEYUCAN	c/3er día	24 hrs.		
(3)	SAN BARTOLO NAUCALPAN (NAUCALPAN CENTRO)	Diario	ario 24 hrs.		
4	SAN ESTEBAN HUITZILACASCO	Diario	24 hrs.		
5	SAN FRANCISCO CHIMALPA	No existe infraestructura hidráulica operada por este Organismo			
(6)	SAN FRANCISCO CUAUTLALPAN	Diario	24 hrs		
7	SAN JOSÉ RÍO HONDO	Diario	24 hrs.		
8	SAN JUAN TOTOLTEPEC	Diario	24 hrs.		
9	SAN LORENZO TOTOLINGA	c/3er día	24 hrs.		
10	SAN LUIS TLATILCO	Diario	14:00 a 6:00 hrs		
11	SAN MIGUEL TECAMACHALCO	Diario	24 hrs.		
12	SAN RAFAEL CHAMAPA	Diario	6:00 a 13:00 y 19:00 a 6:00		
/13	SANTA CRUZ ACATLAN	Diario	24 hrs.		
14	SANTA CRUZ DEL MONTE	Diario	24 hrs.		
15	SANTA MARÍA NATIVITAS	Diario	24 hrs.		
16	SANTIAGO OCCIPACO	Diario	24 hrs.		
17	SANTIAGO TEPATLAXCO No existe infraestructura hidráulica operada po Organismo				

QDR-fills a niche based on existing best principles + innovates in that space

About QDR

Sharing data and its documentation for secondary analysis

Empowering qualitative and multi-method inquiry through guidance and consultation

Providing data and materials to enrich and enliven teaching

Developing innovative approaches for enriching publications with data and analysis

Our Mission

QDR curates, stores, preserves, publishes, and enables the download of digital data generated through qualitative and multi-method research in the social sciences. The repository develops and disseminates guidance for managing, sharing, citing, and reusing qualitative data, and contributes to the generation of common standards for doing so. QDR's overarching goals are to make sharing qualitative data customary in the social sciences, to broaden access to social science data, and to strengthen qualitative and multi-method research.

Learn more about us >

Uses of Shared Datathe "why"

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

"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/datamanagementand-sharing-policy/about-datamanagementsharing-policy/data-managementand-sharing-policy-overview

Why Share (Qualitative) Data?

- Be a good colleague llow others to scrutinize and build on your work
- Be a good teachestudents benefit from working with "real" data
- Be a good citizenOpen science is more impactful science
- Get funded and publishedScientific 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



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 Repositorythe "where"

- Stable links (Digital Object Identifiers DOIs)
- Long-term digital preservation
- Meeting institutional requirements
- Data management planning and curation assistance
 - can help you with sharing datavell
- Makes data more visible/easier for others to discover, access, cite
- Interoperability across disciplines
- Access controls, embargoes, etc.

→ FAIR Data

What Makes Data FAIR?

Findable Rich metadata, permanent identifiers

Accessible Data and metadata are machimeadable in standardized ways

Interoperable Metadata is described in standardized vocabulary

Reusable Metadata meet community standards and data have clear license

Shared Qualitative Data: Some Examples

Mixed Method Study: Interviews, Focus Groups, and Quantitative Ecological Data

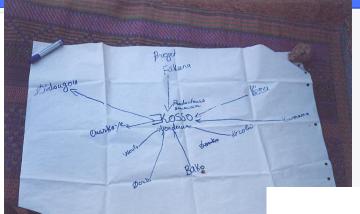


README_Jones.txt (39.1 KB)

- **▶ ■** Documentation
- **→ ©** Qualitative Data
 - Farmer interview transcripts
 - ▶ Burkina Faso
 - → **Mali**
 - ▶ Niger
 - **▶** ► Village focus group seed maps
 - **▶** Village focus group transcripts
- ▼ **©** Tabular data
 - **Jones_Tabular_FarmerCharacteristics.csv** (75.1 KB)
 - **■** Jones_Tabular_RainfallByRegion.tab (15.0 KB)

Jones, Kristal. 2020. "Seed systems in West Africa". Qualitative Data Repository.

https://doi.org/10.5064/F6URYY1IQDR Main Collection.



1BF Transcribed 9/20/11

Interviewer: Kristal

R: My French isn't very good.

I: No, no, it's fine, it's fine.

R: I didn't go to school. I only did three years.

Background: That's why his French isn't very good.

R: It's mixed up with Bomu. It's not good.

B:...if it's not good, we can translate again

R: That's already happened.

I: (laughs) Ok, and you are Bomu?

R: Yes. Bobo.

I: Bobo, ok. And you are how old?

R: I was born in 1956.

I: 56. Ah, that's just like my mom! That's 54, no, 55. This year

I: And you speak Bomu, French?

Filename: Jones_Tabular_RainfallByRegion.tab
In Seed systems in West Africa (version 1.0), by Jones, Kristal

Download File | Close Preview

	2010	2011	2012	Farmer ID	Region
1	1104	920	1196	1	Dioila
2	1104	920	1196	2	Dioila
3	1104	920	1196	3	Dioila
4	1104	920	1196	4	Dioila
5	1104	920	1196	5	Dioila
6	1104	920	1196	6	Dioila
7	1104	920	1196	7	Dioila
8	1104	920	1196	8	Dioila
9	1104	920	1196	9	Dioila
10	1104	920	1196	10	Dioila
11	1104	920	1196	11	Dioila
12	1104	920	1196	12	Dioila
13	1104	920	1196	13	Dioila
14	1104	920	1196	14	Dioila
15	1104	920	1196	15	Dioila
16	1012	828	1196	16	Siby
17	1012	828	1196	17	Siby
18	1012	828	1196	18	Siby
19	1012	828	1196	19	Sihv

Archival Materials: grey literature, governmental & NGO policy documents, media report



Mildenberger, Matto. 2020. "Data for: Carbon captured: How business and labor control climate politics". Qualitative Data Repository. https://doi.org/10.5064/F6GYLSON. QDR Main Collection.

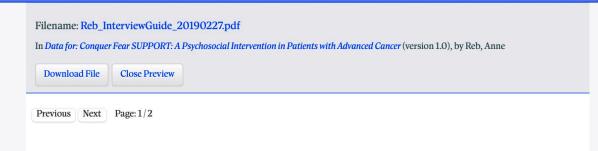
Previous | Next | Page: 1/312



De-identified, Restricted Interviews & Documentation

		GPG 20.10
1		CFS- 20:19
2	Interviewer:	Well this one's easy. This is the um, exit interview where I get an opportunity to
3		kinda ask you about, um, our sessions and to get ideas from you so that it helps
4		us with our writing of our next grant.
5	Patient:	Oh okay.
6	Interviewer:	So we wanna make sure and see what worked, what didn't work. You know,
7		remember I told you this was a pilot so we're trying it out to see if it worked.
8	Patient:	Right.
9	Interviewer:	So um, in general did you- overall, how was your experience of this Conquer
10		Fear program? Did ya, did it- did it help? Did you like it?
11	Patient:	Yes. It was a positive experience, because I learned things that um, I didn't- I
12		didn't know beforehand. It- it taught me how to um, focus on what I was doing
13		at the time and it taught me like not to um, read into stuff you know, like don't
14		panic right away when I would feel a symptom.
15	Interviewer:	Mhm.
16	Patient:	Uh, you know, and I remember that my last symptom, remember when I went to
17		the hospital?
18	Interviewer:	Yes.
19	Patient:	I didn't panic about that even though it hurt a lot, um, because it happened to me

Reb, Anne. 2023. "Data for: Conquer Fear SUPPORT: A Psychosocial Intervention in Patients with Advanced Cancer". Qualitative Data Repository. https://doi.org/10.5064/F6FTJ1HUPalliative Care Research Cooperative QDREOLPC . V1



Exit Interview Guide-CFS

We want to understand your thoughts about your experience with the Conquer Fear SUPPORT (CFS) program. We want to know what helped and what didn't help you. We appreciate your honest opinions as they will help us improve the program for future patients.

- In general, can you tell us about your overall experience with the Conquer Fear SUPPORT program?
 - a. What did you find helpful?
 - b. What did you find challenging or less helpful?
- 2. Can you describe any concerns, worries, or needs you had related to your cancer experience before you participated in the program?
 - a. Can you describe any changes in how you feel since participating in the program? (symptoms, feelings, concerns etc.) Have you felt better, worse, or the same since participating in the program? Can you think of any specific examples?

Do you feel that you have gained anything of value?

- 3. We would like to get feedback on the individual sessions. Do you have any suggestions regarding the content of the sessions? (e.g. discussion of fear of recurrence model, discussion of goals and values, discussion on how to respond to symptoms and avoid excessive monitoring, healthy lifestyle guidelines, and new plans for dealing with fear of cancer recurrence)
 - a. What sessions did you find most helpful? What sessions if any did you find less helpful or challenging and why?

Do you think any of the sessions could be self-study versus in person?

4. Can you describe your experience with the home practice exercises and assignments? (e.g. values clarification; attention training exercises, detached mindfulness practices,

Annotation for Transparent Inquiry (ATI)

MATI-QDR V "Ninguém Me Chama" - "Nobody Asked Me": Gendered Patterns of Participation in sea Turtle Conservation in Northeast Brazia Annotation for Transparent Inquiry (ATI) in the area for a few years, noted that there were not many opportunities, while at the same time commenting that they were not aware of many groups and did not know many people in Sections P2: É um pouco de machismo. the community. Conversely, participants of the soccer club had been invited to participate in a P1: É. P2: Tem um pouco de. beach clean-up and other conservation-related activities by conservation staff members that Abstract P3: É orgullo were also members of the group. Because of men's social and professional networks they may Introduction be more likely to be invited to participate or belong to a group, and, in this case, conservation Gendered Participa activities. Women can also be motivated by their social networks to participate, as were the P2: o machismo women in the artisan association who were nearly all friends, neighbors or relatives. However, **Gendered Aspects** Source Excerpt Translation social ties can also restrict the variety of activities and groups they may be invited to Gender, Agency, an participate in or are exposed to. All focus group participants indicated that they had friends or Methodology family members that also participated in the community group. Although men may face less P1 · Ven P2: They have a little... **Discussion** structural and agency-related barriers to participation than women, women from the artisans'

Women's motivations for participation in this study focused more on learning and supporting their families (providing education and opportunity for their children or learning a skill that could help them earn extra money), and social interaction (getting out of the house, meeting new people, or spending time with family and friends). However, social interaction was an important motivator for both men and women, as much of their community participation serves the dual purpose of providing leisure and recreation alongside personal, familial, or community benefit. Despite the belief that community members were not interested in participating or individualistic, the men and women in the focus groups were motivated to participate as a way to foster unity within the community. Participants felt that they benefited from the unity of the group, or "união," stating that "united they achieved what they could not alone" and "unity provides strength." The theme of unity and collaboration was also mentioned when discussing the types of conservation activities or programs that could or should be carried out in the community. While a number of activities were listed (such as

group and the parent group for the youth association felt that men's participation in those

groups was inhibited by 'machismo,' or societal pressure to conform to male stereotypes.

link.springer.com/article/10.1007/s10745-017-9914-5#annotations:group:2Nopp9mx

P1: Tem homens participando bastante porque hacen artesanato muito bonito, muito bem feito. Mas tambem sao um pouco de... P1: Mas tem eu sei que tem grandes talentos P1: É muito difícil para os homens... é bem difícil né? Collective -P1: There are men that participate a lot because they make very beautiful handicrafts and art, very well made. But also they are a P3: It's pride P1: But they have...I know that they have great talent. Conclusion P2: They make lamps... P1: It is very difficult for the men...it is really difficult, isn't it? Notes Collective - It is. P2: ..the machismo.. References Analytic Note: In this discussion among focus group participants from the local artisan's group, which was made up entirely of Author information women, the group discusses the lack of men in their group. It is common for men in the area to make different types of woodcarvings, paintings, and weavings. However, they felt that 'machismo' and pride kept them from participating in a group of all women. In another focus group of all women the issue of Sustainab machismo also arose when discussing men's participation with the youth group activities. Often the group hosts gatherings where food is served and asks families to volunteer to help cook and serve. This responsibility always falls to the women, as men don't see cooking and serving food as "men's work, reinforcing local gender roles. There are many men who own restaurants in the area and cook or serve food in this context, this adds an additional gender dimension between paid and un-paid work. This excerpt also illustrates how cultural norms lead to gender segregated networks. < .↑. □

Rinkus, Marisa A.. 2019. "Data for: "Ninguém me chama" - "Nobody asked me": Gendered patterns of participation in sea turtle conservation in Northeast Brazil". Qualitative Data Repository. https://doi.org/10.5064/F6SGXPOS. QDR Main Collection.



Sharing Human Participant Qualitative 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 formed

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 you to document data collection, sharing a security details
 - It is critical for PI to ensure that the two documents al

Informed Consent Considerations

- Balance: being transparent about data use, but remain intelligible
- Don't underestimate participants willingness to help science, not just you
- Opt-in consent for data sharing can be great; IRBs familiar with it as "tiered consent"
 - Careful with quantitative data & optin

De-identifying Qualitative Data

- Removing/ replacing information in text can distort data, make them unusable, unreliable or misleading balance to preserve context
- Remove direct identifiers, or replace with pseudonymsften not essential research info
- Avoid blanking out; use pseudonyms or replacements [IDENTIFY REPLACEMENTS]
- Plan and apply dedentification at time of transcription
- Consistency within research team /project
 - Keep deidentification 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

Applying Appropriate Access Controls

- "As open as possible, as closed as necessary" (European Union)
- Open data (license "CC0" or "CBY") often not appropriate for QUAL data
- Public-use data
- Timed Embargo (in 1, 3, 10, 100 years) B: not a publication based embargo
- Access by application
 - Identity and affiliation checks
 - Specific training requirements (e.g., CITI)
 - Signed DAUAs
 - Secondary IRB (typically for data that still has PII)
- Access using enclaves (not currently at QDR, but available for quantitative data at other repositories)

QDR for Weather / Climate / Environmental Social Scientists

Consultations at Different Points in the Project Lifecycle

When planning your research

- DMP / DMSP consultations and review for grant proposals
 - Including help with costing and budgeting
- Informed consent drafting advice and review
- Data management consultations

When depositing your data

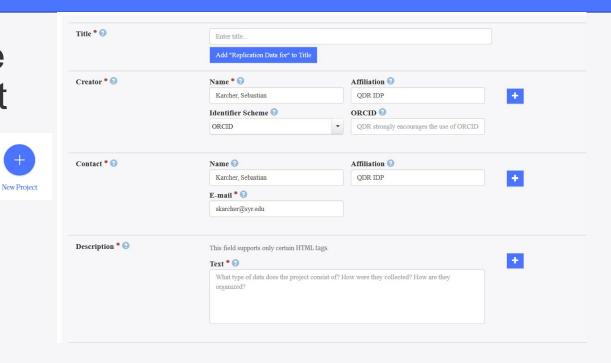
- Disclosure risk review
- Data organization and documentation consultation
- Data/file transformation

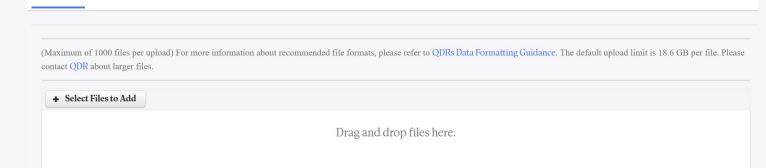


Depositing Your Data in QDR

Files

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





Questions? Comments? Please Stay in Touch!

7

Blog:

Web: https://qdr.syr.edu

@qdr@mstdn.science

@qdrepository

https://qdr.syr.edu/qdr-blog

QDR

The Qualitative

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