

# Ethically sharing qualitative data

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Sebastian Karcher, Qualitative Data Repository  
McGill University Data Anonymization Workshop Series  
October 17, 2023

**QDR**  
The Qualitative  
Data Repository

# Shared Qualitative Data: Some Examples

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# Interviews, Focus Groups, and Ecological Data

 [README\\_Jones.txt \(39.1 KB\)](#)

## ▸ Documentation

## ▾ Qualitative Data

### ▾ Farmer interview transcripts

#### ▸ Burkina Faso

#### ▸ Mali

#### ▸ Niger

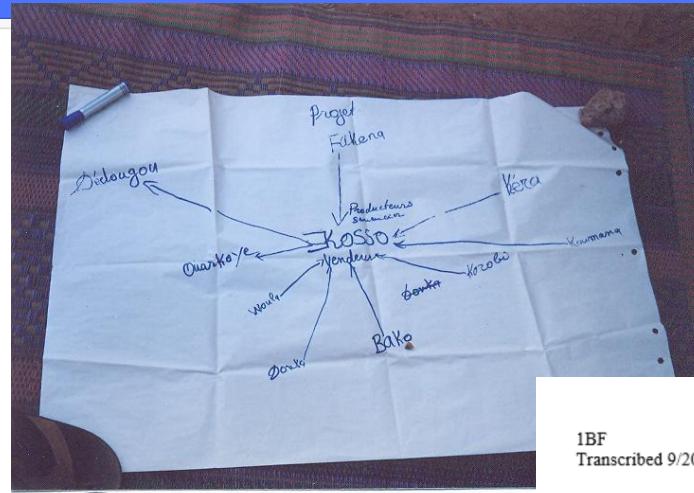
### ▸ Village focus group seed maps

### ▸ Village focus group transcripts

## ▾ Tabular data

 [Jones\\_Tabular\\_FarmerCharacteristics.csv \(75.1 KB\)](#)

 [Jones\\_Tabular\\_RainfallByRegion.tab \(15.0 KB\)](#)



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	Sibv

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.

B: 55 years old.

I: And you speak Bomu, French?

Jones, Kristal. 2020. "Seed systems in West Africa".  
Qualitative Data Repository.  
<https://doi.org/10.5064/F6URYY11>. QDR Main Collection.

# Context for Ethnographic Research Videos and Online Sources

QDR

Video Preview

Filename: Wedeen\_A Forgotten Village\_Air Raid Siren.mov

In Data for: *Authoritarian apprehensions: Ideology, judgment, and mourning in Syria* (version 1.0), by Wedeen, Lisa

Download File Close Preview

File uploaded on 2019-02-11



Wedeen, Lisa. 2019. "Data for: Authoritarian apprehensions: Ideology, judgment, and mourning in Syria". Qualitative Data Repository. <https://doi.org/10.5064/F63776W4>

Listed URL	Full URL	Archived URL
<a href="https://tinyurl.com/y7rlby93">https://tinyurl.com/y7rlby93</a>	<a href="https://www.rt.com/news/39984">https://www.rt.com/news/39984</a>	<a href="https://perma.cc/BC2C-SVEV">https://perma.cc/BC2C-SVEV</a>
<a href="http://syriauntold.com/2018/06/">http://syriauntold.com/2018/06/</a>	<a href="http://syriauntold.com/2018/06/1">http://syriauntold.com/2018/06/1</a>	<a href="https://perma.cc/R8CV-6EL5">https://perma.cc/R8CV-6EL5</a>
<a href="http://www.arabnews.com/news">http://www.arabnews.com/news</a>	<a href="http://www.arabnews.com/news">http://www.arabnews.com/news</a>	<a href="https://perma.cc/VVD6-27TH">https://perma.cc/VVD6-27TH</a>
<a href="https://tinyurl.com/yabcnmt8">https://tinyurl.com/yabcnmt8</a>	<a href="https://view.publitas.com/the-int">https://view.publitas.com/the-int</a>	<a href="https://perma.cc/7EFA-RDA9">https://perma.cc/7EFA-RDA9</a>
<a href="https://tinyurl.com/lfnjcuw">https://tinyurl.com/lfnjcuw</a>	<a href="https://www.nytimes.com/2013/">https://www.nytimes.com/2013/</a>	<a href="https://perma.cc/SGE3-AVWQ">https://perma.cc/SGE3-AVWQ</a>
<a href="https://tinyurl.com/y87dhbym">https://tinyurl.com/y87dhbym</a>	<a href="http://brown-moses.blogspot.co">http://brown-moses.blogspot.co</a>	<a href="https://perma.cc/LK6N-NC7L">https://perma.cc/LK6N-NC7L</a>
<a href="https://tinyurl.com/ybbarngd">https://tinyurl.com/ybbarngd</a>	<a href="http://brown-moses.blogspot.co">http://brown-moses.blogspot.co</a>	<a href="https://perma.cc/TRF3-QFSQ">https://perma.cc/TRF3-QFSQ</a>
<a href="http://gawker.com/asma-al-assa">http://gawker.com/asma-al-assa</a>	<a href="https://gawker.com/asma-al-assa">https://gawker.com/asma-al-assa</a>	<a href="https://perma.cc/9MSA-VRCG">https://perma.cc/9MSA-VRCG</a>
<a href="https://tinyurl.com/noh3fm9">https://tinyurl.com/noh3fm9</a>	<a href="https://www.nytimes.com/2013/">https://www.nytimes.com/2013/</a>	<a href="https://perma.cc/MEQ2-M7DZ">https://perma.cc/MEQ2-M7DZ</a>
<a href="https://tinyurl.com/m9lh8q8">https://tinyurl.com/m9lh8q8</a>	<a href="https://www.theguardian.com/w">https://www.theguardian.com/w</a>	<a href="https://perma.cc/764P-ZZXW">https://perma.cc/764P-ZZXW</a>
<a href="https://tinyurl.com/y8dxdswh">https://tinyurl.com/y8dxdswh</a>	<a href="https://now.mmedia.me/lb/en/re">https://now.mmedia.me/lb/en/re</a>	<a href="https://perma.cc/7R7M-X58T">https://perma.cc/7R7M-X58T</a>
<a href="https://tinyurl.com/nbrykrr">https://tinyurl.com/nbrykrr</a>	<a href="https://www.mintpressnews.com">https://www.mintpressnews.com</a>	<a href="https://perma.cc/BFW4-22VV">https://perma.cc/BFW4-22VV</a>
<a href="https://tinyurl.com/l835ygp">https://tinyurl.com/l835ygp</a>	<a href="https://21stcenturywire.com/wp">https://21stcenturywire.com/wp</a>	<a href="https://perma.cc/WWK7-ZSC4">https://perma.cc/WWK7-ZSC4</a>
<a href="https://tinyurl.com/ycyer6f4">https://tinyurl.com/ycyer6f4</a>	<a href="https://www.gq-magazine.co.uk">https://www.gq-magazine.co.uk</a>	<a href="https://perma.cc/V6DY-PEC5">https://perma.cc/V6DY-PEC5</a>
<a href="https://tinyurl.com/y94gadfc">https://tinyurl.com/y94gadfc</a>	<a href="https://www.bellingcat.com/new">https://www.bellingcat.com/new</a>	<a href="https://perma.cc/9HFX-EP44">https://perma.cc/9HFX-EP44</a>
<a href="https://tinyurl.com/ybaxukm2">https://tinyurl.com/ybaxukm2</a>	<a href="https://www.bellingcat.com/new">https://www.bellingcat.com/new</a>	<a href="https://perma.cc/KRP9-66R8">https://perma.cc/KRP9-66R8</a>
<a href="https://tinyurl.com/y7rld8ud">https://tinyurl.com/y7rld8ud</a>	<a href="https://syriadirect.org/news/hts">https://syriadirect.org/news/hts</a>	<a href="https://perma.cc/P9VN-BH8D">https://perma.cc/P9VN-BH8D</a>

# Mixed Method Data: Archival and Surveys

- ▶ README\_Hitt.txt (10.1 KB)
- ▶ Hitt\_Extracted Newspaper Excerpts.tab (1.1 MB)
- ▶ Book
  - ▶ Hitt\_Ch1\_Burson\_Blackmun\_1.pdf (12.1 MB)
  - ▶ Hitt\_Ch1\_Burson\_Blackmun\_2.pdf (38.1 MB)
  - ▶ Hitt\_Ch1\_Burson\_Blackmun\_3.pdf (3.8 MB)
  - ▶ Hitt\_Ch1\_Burson\_Blackmun\_4.pdf (9.3 MB)
  - ▶ Hitt\_Ch2\_Lockett\_Blackmun.pdf (6.5 MB)
  - ▶ Hitt\_Ch4\_Resweber\_Jackson.pdf (6.1 MB)
  - ▶ Hitt\_Ch5\_Tidewater\_Jackson.pdf (8.6 MB)
  - ▶ Hitt\_Ch7\_Watts\_Jackson.pdf (3.9 MB)
- ▶ Replication
- ▶ Supplementary
  - ▶ 37Photographs
  - ▶ Adams
  - ▶ API
  - ▶ Apodaca
  - ▶ Bailey
  - ▶ Baird
  - ▶ Bakke
  - ▶ Banco
  - ▶ Barr
  - ▶ Beam
  - ▶ Bellotti
  - ▶ Books
  - ▶ Bowen
  - ▶ Braunfeld
  - ▶ Brock
  - ▶ Brown
  - ▶ Bullock

Supreme Court of the United States  
Washington, D. C. 20543

May 4, 1992

CHAMBERS OF  
JUSTICE ANTONIN SCALIA

Re: No. 90-1056 - Burson v. Freeman

Dear Harry:

I withdrew my concurrence in this case (though I still considered that the preferable approach) in order to give you the fifth vote for a court. Since then (and indeed after the case was tentatively scheduled for release) you elevated footnote 11 to text, and altered it in a manner that I cannot accept. The new statement that the "First Amendment does not require States to regulate for problems that do not exist, simply because that have historically produced violence cannot go along with the new version's exclusive reliance upon the absence of or commercial solicitation has been used

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

	distributionchannel	openingconsent	education	income	race	female	age_1	partiid	lean	strongdem	strongrep	ideology	politeres	lawyer	sck1	sck2	sck3	scideo	pk1	pk2	pk3	pk4	
anonymous	1	4	4	1	1	28	3	2				5	3	6	0	0	1	3	secretary	50		1	8 years
anonymous	1	2	2	7	1	69	3	2				4	2	6	1	0	0	3	don't know	don't know		0	4 years
anonymous	1	4	4	1	1	63	1			1		6	3	6	0	0	1	3	don't know	51			6 yrs
anonymous	1	2	2	7	1	52	3	3				1	2	6	0	0		4	Don't know	48		1	4 yearz
anonymous	1	3	2	1	1	46	2			1		3	3	6	0	0	1	4	Prime minister	100		1	8
anonymous	1	2	2	5	0	24	2			1		3	2	6	0	9	0	3	I don't know	200		0	2 years
anonymous	1	2	3	3	1	46	3	3				4	1	6	1	9	0	2	sectarian	12			6 years
anonymous	1	4	2	1	1	46	3	3				3	1	6	0	9	3	Don't know	Don't know			six years	
anonymous	1	3	3	1	0	46	3	3				7	2	6	0	1	0	4	leeward	50		1	2
anonymous	1	3	2	1	1	39	3	3				4	1	6	0	9	2		Don't know	Don't know			Don't know
anonymous	1	2	4	3	1	32	3	3				4	3	6	1	9	1	2	UK Prime Minister	435		0	2 years
anonymous	1	4	3	1	1	24	2			2		4	1	6	0	0		3	?	435		1	2
anonymous	1	2	5	8	1	53	1				2	7	1	6	0	9	3	don't know	don't know			don't know	
anonymous	1	2	3	1	0	26	2			1		1	2	6	1	9	0	3	British Prime Minister	435		1	6 Years
anonymous	1	2	4	1	1	67	3	3				4	2	6	0	0	1	2	Don't know	Don't Know		1	I think 6 - not sur
anonymous	1	4	5	1	1	27	1				1	7	3	6	1	1	0	2	International Relations.	125		0	8 years
anonymous	1	4	1	1	0	32	3	3				4	1	6	0	9	3	I don't know.	I don't know.			1	I don't know.
anonymous	1	2	5	1	0	69	2			2		4	2	6	0	0	1	2	unknown	100			6
anonymous	1	3	2	1	1	61	1				2	3	3	6	1	1	1	3	prime minister - england	435		1	6 yr terms - unlit
anonymous	1	3	3	1	0	26	1				2	4	3	6	1	0	0	2	conservative	535		1	6 years
anonymous	1	2	2	1	1	36	3	3				4	1	6	0	9	2		Prime minister	435			6 years
anonymous	1	4	5	1	0	34	1				1	3	2	6	1	1	1	2	dunno	300		1	10
anonymous	1	2	1	7	1	56	2			1		6	2	6	0	0	1		Member of Parliament.	435		1	6 years
anonymous	1	1	2	7	1	22	2				2	2	1	6	0	9	2		Don't know	Don't know			Don't know
anonymous	1	4	5	5	1	28	3	3				1	1	6	1	1	0	1	Prime Minister of the United Kingdom	435		0	6 years
anonymous	1	2	4	1	1	51	3	2				4	2	6	1	0	3		Member of Parliament.	435		1	6 years

Re: No. 90-1056, Burson v. Freeman

Dear Nino,

While I appreciate your having extended yourself to make a Court in Burson, I am unwilling to remove the two sentences you object to on p. 15 of the 5th draft. ("States adopt laws to address the problems that confront them. The First Amendment does not require States to regulate for problems that do not exist.") I believe that these sentences are necessary to respond to the dissents contention that we have not "inquir[ed] into whether the content discrimination itself is related to the purported state interest" (p. 9 of 6th draft of JPS' dissent).



# 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].

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?

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>

# **Why Share Qualitative Data?**

# 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



# 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



The Qualitative Report

Volume 26 | Number 6

Special Section 17

6-22-2021

## 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:

“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.”

# **Ethically Sharing Human Participant Qualitative Data**

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# Ethics of Qualitative Research

- Qualitative research is often *relational*: The relationship between researcher & participant can be complex and multi-layered
- Often includes multiple interactions with varying levels of formality
- *Epistemological* commitments – how we get to knowledge – play an important role

# Planning for Ethical Data Sharing

- Consider what and how to collect
- Consent for data sharing
- Manage securely
- De-identify as promised
- Control access as necessary
- Additional considerations depending on participant groups



# Consider what and how to collect

- Don't collect identifying information if you don't need to
  - Example: Focus groups
- Careful with signed study information/informed consent
  - REBs/IRBs allow for oral consent when appropriate, but procedure needs to be documented
- Store identifying information separately from recordings/transcripts
- Plan for security, especially during fieldwork

# Informed Consent

- Explicitly ask consent for data sharing
- Think about & ideally test appropriate language
- Don't assume a particular view by participants
- Opt-in (sometimes called 'tiered') consent can be helpful
- In some cases (e.g., First Nations/Indigenous groups), additional community consent is appropriate (more on that later)

# 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 include after the consent to participate:*

**Optional consent to data-sharing:**

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](https://doi.org/10.1177/10497323211054058)

# De-identifying Qualitative Research

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# De-identifying Qualitative Data: Between pointless and useless

#### 4. Cohen's Illegal Campaign Contributions

On approximately June 16, 2015, Individual-1, for whom Cohen worked at the time, began an ultimately successful campaign for President of the United States. Cohen had no formal title

<https://www.politico.com/f/?id=00000167-a496-df35-adeb-fdf76fa30001>

U.S. Department of Justice  
Criminal Division

Washington, D.C. 20530

February 27, 2012

MEMORANDUM

TO: All Federal Prosecutors

FROM: Patty Merkamp Stemler /s PMS  
Chief, Criminal Appellate Section

SUBJECT: Guidance Regarding the Application of *United States v. Jones*,  
132 S. Ct. 945 (2012), to GPS Tracking Devices

THE MATERIAL IN THIS DOCUMENT CONSISTS OF  
ATTORNEY WORK PRODUCT AND SHOULD NOT BE  
DISSEMINATED OUTSIDE THE DEPARTMENT OF  
JUSTICE.

In *United States v. Jones*, 132 S. Ct. 945 (2012), the Supreme Court affirmed the suppression of location data generated by a GPS tracking device surreptitiously affixed to a car without court authorization and monitored continuously over a 28-day period.

2

*Handwritten notes:* RIP (b)5 7(e) and WIF (b)5 7(e)

[https://www.aclu.org/files/assets/doj\\_gps\\_tracking\\_memo1.pdf](https://www.aclu.org/files/assets/doj_gps_tracking_memo1.pdf)

# Basic Guideline for De-identification

- Remove direct identifiers, or replace with pseudonyms – often not essential research info
- Avoid blanking out; use pseudonyms or replacements (identify replacements)
- Consider broadening categories instead of redacting:
  - Born in 1937 → Born in [1930-1940]
  - Worked as a clerk in the zoning office → Worked [for the city]
- Consider indirect identifiers in context
  - Removing one piece of information will affect how identifying another one is
  - Who has access to the data also affects re-identification risk



# De-identification: Additional considerations

- Different disciplines/methods have different norms:
  - E.g., ethnography will almost always use pseudonyms and *may* accept “composite characters”. Clearly marking redactions is less common (though debated)
  - In other fields, placeholders like “Interviewee 1” or “City 1” are sufficient
- For groups, keep a log to standardize de-identification
- Plan or apply editing at time of transcription or coding
- De-identification typically for persons, but can also be appropriate to mask locations or communities

# De-identification exercise

- Go to: <https://managing-qualitative-data.org/files/de-identification-exercise.pdf>
- Take 15minutes to de-identify the text (assume/pretend it cannot be found online)
- We'll discuss together after

# De-identification: A Solution

I was born in Philadelphia. My parents were both born and raised in Philadelphia. My father, [Name], was Jewish and my mother, [Name], was Irish Catholic. They both lived in South Philadelphia [...], and there was no chance that they would meet each other. Back in those days, and even when I was growing up, Philadelphia was a city of great ethnic divides, where the Italian, the Jewish, the Irish, the Polish, the black community, and—to the extent there was a Hispanic community—the Hispanic community each lived in their own neighborhood(s) with very little interaction.

They both went to the University of Pennsylvania, but didn't meet there. They met later on. They were both working in public assistance as social workers when they got married. The biggest thing was that back in those days an Irish Catholic was not very welcome in a Jewish family, and a Jew was not very welcome in an Irish Catholic family, so it was interesting growing up with these two ethnic backgrounds.

At Penn, my mother was president of her sorority and was a big person on campus. Interesting point, at that point the Daily Pennsylvanian, even though women had been there for a number of years, never had a woman's name in the newspaper. Even though they were students there, they were never mentioned. My mother went to [a girls high school] in South Philadelphia.

My father went to [a co-ed high school in South Philadelphia], and then went to Penn on a [sports] scholarship. [description of his role on the team] He thought he may have been one of the first Jews to play in the Ivy League. He played and started his first year, but he hurt his knee and lost his scholarship—which is what they did back then. His picture with his team [from the 1930s] is on the wall [at Penn]. He went back and earned a degree in fine arts at Penn. He then taught art in the city schools, and then returned to Penn and earned a master's degree in social work. He spent his career in social work and especially helping children. He finished his career as [working] for the City of Philadelphia. My mother worked in a number of social work jobs and later was a teacher in the Philadelphia City Schools. In [the 1940s] my parents had the first of my [...] wonderful sisters, [Martha], who we called [by a short version of that name].

# Controlling Access

“As open as possible, as closed as necessary” (European Union)

- Default to open data (license “CC0” or “CC-BY”)
- Public-use & restricted data
- Timed Embargo (in 1, 3, 10, 100 years)
- Access by application
  - Simple identity checks
  - Signed DUAs
  - Secondary IRB/REB
  - Depositor approved
- Access using enclaves (physical/virtual)

# Additional considerations for research on:

- Groups with special status (prisoners, children, vulnerable groups)
- Indigenous groups
  - Legal requirements for research
  - Community consent
  - De-identification
  - CARE (**C**ollective benefit; **A**uthority to control; **R**esponsibility; **E**thics)/  
Indigenous Data Sovereignty

# Stay in Touch

- Email
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  - Sebastian: [skarcher@syr.edu](mailto:skarcher@syr.edu)
- Mastodon:
  - QDR: @qdrepository
  - Sebastian: @adam42smith
- Blog: <https://qdr.syr.edu/qdr-blog>