Data Ethics

Data Analysis for Journalism and Political Communication
(Spring 2026)

Prof. Bell

Tuskegee Syphilis Study

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- Codified into law as the “Common Rule”, which covers all federally-funded research

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Justice

Groups who bear the burden of research should also be the beneficiaries of that research.

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vs. randomized drug trials

Expanding Principles for Equity (Urban Institute)

- Seek and include communities' interests in research design
- Seek out and incorporate communities' interpretation of the data
- Return data and research results to community members in a form they can use
- Be aware of how sensitive topics can affect people and communities
- Minimize the amount of personally identifiable information (PII) collected
- Avoid undue burden
- Share data to reduce the burden of duplicate data collection

Example: Project Nightingale

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- There are financial benefits that accrue to the companies, not the research subjects

Case Studies

1. Home DNA Testing
2. Crisis Text Line
3. Diversity in Faces (DiF) dataset

Case Studies

1. What are the relevant ethical principles and practices?
2. What concerns are there about violations of ethical principles?
3. How could the research have been conducted more ethically?

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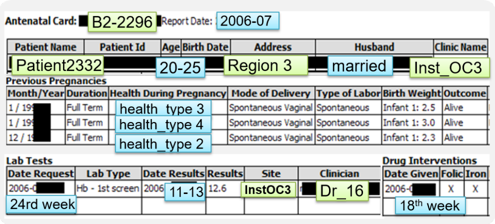
  2. **Indirect identifiers**: information that *in combination* would be sufficient to disclose an identity
- De-identification is the process of removing direct and indirect identifiers

DE-IDENTIFICATION

1. Remove direct identifiers



Antenatal Card: [redacted] B2-2296 [redacted] Report Date: 2006-07

Patient Name	Patient Id	Age	Birth Date	Address	Husband	Clinic Name
Patient2332	[redacted]	20-25	[redacted]	Region 3	[redacted] married [redacted]	Inst_OC3

Previous Pregnancies

Month/Year	Duration	Health During Pregnancy	Mode of Delivery	Type of Labor	Birth Weight	Outcome
1 / 19[redacted]	Full Term	health_type 3	Spontaneous Vaginal	Spontaneous	Infant 1: 2.5	Alive
1 / 19[redacted]	Full Term	health_type 4	Spontaneous Vaginal	Spontaneous	Infant 1: 3.0	Alive
12 / 1[redacted]	Full Term	health_type 2	Spontaneous Vaginal	Spontaneous	Infant 1: 2.3	Alive

Lab Tests

Date Request	Lab Type	Date Results	Results	Site	Clinician
2006-0[redacted] 24rd week	Hb - 1st screen	2006 11-13	12.6	InstOC3	[redacted] Dr_16 [redacted]

Drug Interventions

Date Given	Folic	Iron
2006-0[redacted] 18th week	X	X

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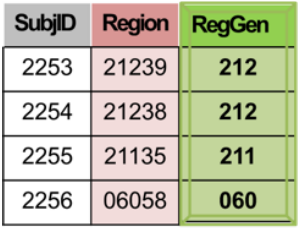
2. Aggregate or reduce the precision of a variable
   - Generalize the meaning of categories



SubjID	Region	RegGen
2253	21239	**212**
2254	21238	**212**
2255	21135	**211**
2256	06058	**060**

De-identification

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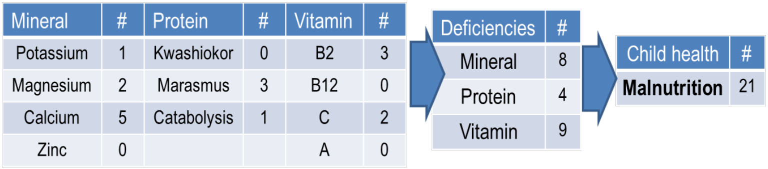
   - Collapse categories



Mineral	#	Protein	#	Vitamin	#
Potassium	1	Kwashiokor	0	B2	3
Magnesium	2	Marasmus	3	B12	0
Calcium	5	Catabolysis	1	C	2
Zinc	0			A	0

Deficiencies	#
Mineral	8
Protein	4
Vitamin	9

Child health	#
Malnutrition	21

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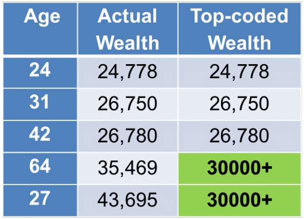
   - Restrict the upper or lower ranges



Age	Actual Wealth	Top-coded Wealth
24	24,778	24,778
31	26,750	26,750
42	26,780	26,780
64	35,469	**30000+**
27	43,695	**30000+**

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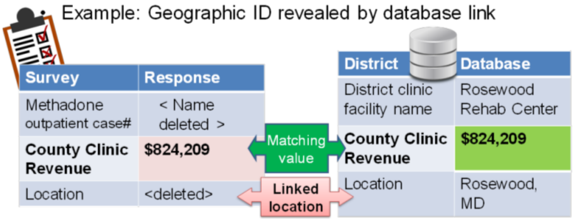
3. Anonymize keys that link to other datasets



Example: Geographic ID revealed by database link

Survey	Response
Methadone outpatient case#	< Name deleted >
County Clinic Revenue	**$824,209**
Location	<deleted>

District	Database
District clinic facility name	Rosewood Rehab Center
County Clinic Revenue	**$824,209**
Location	Rosewood, MD

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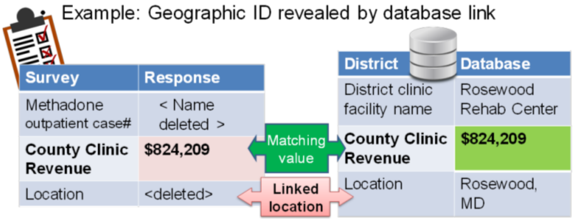
4. Maintain a master log of all replacements, aggregations, or removals and keep it in a secure location separate from the de-identified data files



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De-identification Exercise

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