

Challenges to Informed Consent from Administrative Data Linkage and Secondary Usage

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Overview

- 1) Policy on informed consent – frameworks that apply to administrative data linkage and secondary use, and how they are changing
- 2) Research – from the general to the specific
- 3) Assertions about record linkage consent – decisions can be complex and context-specific
- 4) Questions for consideration – what might constitute meaningful and appropriate informed consent?

Concepts & Issues

1) Privacy

- Control over management/use/disclosure (confidentiality and security aspects)
- Intrusion of requests, what information should be collected at all

2) Secondary usage

- Re-use subsequent to or ongoing from the original use instance
- Usage for entirely different research or administrative purposes

Frameworks Related to Informed Consent in Linkage/Secondary Use

1) Common Rule revisions

- Increase **exemptions** for nonsensitive, federal survey practices (specific legal authorities take precedence)
- Focus on **data security** by original data producers, less on secondary users

2) CIPSEA and agency-specific Titles

Frameworks

3) OMB Memos

- M-11-02: Sharing Data While Protecting Privacy
- M-14-06: Guidance for Providing and Using Administrative Data for Statistical Purposes

Frameworks

4) Related and Developing

- Fair Information Practice Principles (FIPPs)
- GDPR
- Other national statistical system policies
- Professional association standards and ethical principles
- CNS/NAS Panels
- Commission on Evidence-Based Policymaking

Research – Fundamentals

- 1) Public awareness of and attitudes about privacy, confidentiality and disclosure issues
 - Thorough past work (e.g. Singer, Gerber, Mayer)
 - Continuing – Cybersecurity Act adaptations to CIPSEA language

Research – Admin Records Linkage

2) Public attitudes towards linkage

- Census' Center for Administrative Records Research and Applications
- Attitudes Towards the Use of Administrative Records
(Childs, King, Eggleston, 2016)

Research – Increasing Focus

3) Linkage consent rates and decision mechanisms

- Consent may be declining (Kreuter et al., 2016)
- Experimental evidence that privacy and trust influence linkage consent decisions (Sakshaug et al., 2012)

Research – Increasing Focus

4) Linkage consent decisions rates & nonconsent bias

- Consent rates – they vary, with at least some degree of nonrandomness
- Effects of nonconsent bias – varying impact

(Sakshaug & Vicari, 2018)

Research – Increasing Focus

5) How to maximize consent rates

- Framing and Wording the request
- Placement – 2 somewhat conflicting recent studies on effects on researcher goals

(Sakshaug & Vicari, 2018; Eckman & Haas, 2017)

State of Research – Observations

- 1) Important research, but focus is largely on maximizing consent, avoiding bias, and access/security practices under consent conditions
- 2) Research on context-specific informed consent decisions?
- 3) Can informed consent practices adhere to principles? (Barocas & Nissenbaum, 2014)

Assertions with some degree of experimental or empirical support

- 1) Prospective respondents' concerns and informed consent decisions are complex, and vary in at least some nonrandom ways under some conditions
- 2) Prospective respondents make research participation decisions to varying extent on predispositions, information received on sponsorship, purpose, data usage, and nature of information requested during the interview

Assertions - Continued

- 3) Once enrolled into a survey, respondents make linkage and secondary usage consent decisions on similar factors, but not only considering information they knowingly provide during the interview but also their beliefs about the nature and use of information to be linked.
- 4) During interviews, respondents make decisions on participation continuation, specific item response, and anonymity-maintenance decisions (if applicable) based on question content.

Example of “During Interview” Consent Behavior

- Anonymity-maintenance decisions in a web-based establishment survey:

Respondents given initial options to determine level of identification and potential followup on additional subjects (akin to linkage)

Example of “During Interview” Consent Behavior

- Consent Options:
 - At enrollment: choices of a) maximum anonymity, b) email only (for enhanced survey administration), c) additional personal identification
 - At interview end: consent request to followup (akin to linkage decision) and provision of full contact information

Example of “During Interview” Consent Behavior

Maximum anonymity throughout	19%
Email only at enrollment	7%
Partial identification at enrollment	48%
Maximum identification throughout	21%
Conversion: anonymous enrollment, maximum identification at end	5%

Question for Consideration

- How problematic, if at all, is broad, a priori linkage consent, given varying (but generally low) respondent knowledge of questionnaire content and subsequent linkage and usage conditions?
- How would participation and response behavior be affected by more specific knowledge of linkage and secondary use conditions?

Question for Consideration

- Does this argue for consent placement at end of the interview?
- Does this argue for increasing specificity, to the extent practical, in the consent request?
 - But bias. Analogy: sponsorship disclosure in market research and political polling
 - But may reduce linkage consent.

Big-Picture Issues

- Public trust and confidence in the federal statistical enterprise
- Operationalization of meaningful informed consent in an increasingly complex big data world
- What research participant “agency” means – what and how much do they need to know for informed consent

Some Informed Consent Messaging Examples

ACS brochure/FAQ material: (2015 Summer Mandatory Messaging Test Final Report)

How will the Census Bureau use the information I provide?

Your confidential response will be aggregated with information from other nearby households to produce a portrait of your community. This information is made freely accessible to government leaders, businesses, nonprofit organizations, and the public at large.

Based on the information you provide, you may be asked to participate in other Census Bureau surveys that are voluntary. We may combine your answers with information that you gave to other agencies to enhance the statistical uses of these data. This information will be given the same protection as your survey response.

Language from SIPP opt-out advance letter:

“To be efficient, the Census Bureau attempts to obtain information you may have given to other agencies if you have participated in other government programs. We do so because it helps to ensure your data are complete, and it reduces the number of questions you are asked on this survey. The same confidentiality laws that protect your survey answers also protect any additional information we collect (Title 13, U.S.C., Section 9). If you wish to request that your information not be combined with information from other agencies, we ask that you notify the field representative at the time of the interview.”

Language from EIA “Agreement for Official Use of Information” form

“On behalf of (*company name*), I hereby authorize EIA to share information reported on Form EIA-xxx with other components of the Federal government for official uses in planning for and/or responding to a major energy supply emergency as designated by the EIA Administrator. The information will be treated as confidential and will not be publicly released. The information shall not be used for any action against this company. Release of the information for any other purpose, or in any other manner, is neither given nor implied.”