Pursuing Consent for Record Linkage in an Establishment Survey: Results from a National Survey

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Overview of 2016 surveys

- On average 30-minute questionnaire
- Multi-mode sequential protocol
- Advance letter, 3 mailings (web & mail), CATI follow-up with non-respondents
- 4,578/11,688 residential care communities participated—51% weighted AAPOR Response Rate 4
- 2,836/5,348 adult day services centers participated—62% weighted AAPOR Response Rate 4
Brief Literature & Justification

• Linking survey data & administrative records increasingly common
• Data protection legislation typically requires informed consent for record linkage.
• Linkage consent refusal can result in...
  ▪ smaller samples than the original survey and
  ▪ potentially bias, if those who consent differ from those who refuse to consent on characteristics key to the study (Eisnecker & Krow, 2017; Shakshaug & Bender, 2014; Weissman et al., 2016).
• Most research on linkage consent has been in population surveys.
• We explore establishment respondents’ willingness to share record linkage information about the people they serve.
Practical challenge

- Is it worthwhile to pursue administrative data linkage for the NSLTCP survey data?
  - Resulting sample size?
  - Potential for bias?
    - HIPAA-covered establishments not consenting
    - In non-HIPAA covered establishments, cost to get resident or family consent prohibitive
  - What will the linked sample represent?
Research questions—feasibility, data quality (bias), cost

1. What proportion of establishments are HIPAA-covered entities?
2. Does whether or not an establishment is a HIPAA-covered entity vary by certain characteristics?
3. What proportion of HIPAA-covered establishments have & will share PII elements? PII bundles?
4. Do HIPAA-covered establishments with certain characteristics vary in having & being willing to share PII elements or bundles that could potentially result in bias?
HIPAA Privacy Rule on individual patient information and survey participation

The Health Insurance Portability and Accountability Act (HIPAA) Privacy Rule permits you to make disclosures of protected health information without patient authorization for public health purposes and for research that has been approved by an institutional review board (IRB) with a waiver of patient authorization. The National Health Care Survey (NHCS) meets both of these criteria.

National Ambulatory Medical Care Survey
National Hospital Ambulatory Medical Care Survey
National Hospital Care Survey
National Study of Long-Term Care Providers
**Questionnaire items**

The National Center for Health Statistics (NCHS) links person-level survey data with health records from other data sources, such as Medicare or Medicaid data. Linking allows NCHS to better understand the services participants of centers use. In order to link data in future surveys, we would need the information below about your current participants. We would use this information for research purposes only. Federal laws authorize NCHS to ask for this information and require us to keep it strictly private.

To help NCHS plan for future surveys, please answer the following questions: For each item below, in **Column 1**, indicate **whether or not this center has this information about its current participants**. For each “yes” in Column 1, in **Column 2**, indicate **whether or not this center is willing to provide this information about participants**.

<table>
<thead>
<tr>
<th>Column 1</th>
<th>Column 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Full names</td>
<td>□ Yes □ No</td>
</tr>
<tr>
<td>b. Dates of birth</td>
<td>□ Yes □ No</td>
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<tr>
<td>c. Last four digits of Social Security numbers</td>
<td>□ Yes □ No</td>
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<tr>
<td>d. Full Social Security numbers</td>
<td>□ Yes □ No</td>
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</tbody>
</table>
Is this adult day services center a Health Insurance Portability and Accountability Act (HIPAA)–covered entity?

☐ Yes
☐ No
☐ Do not know
Analyses

• Univariate and bivariate distributions
• Chi square tests
• We examined both sectors—residential care communities and adult day services centers
  ▪ Because results were similar in both sectors, in the interest of time, we present on residential care today
  ▪ Exception—there were a higher percentage of HIPAA-covered entities in adult day than in residential care
One-third of establishments are not HIPAA-covered, don’t know if they are, or left the item missing

Is establishment a HIPAA-covered entity?

- Yes: 65
- No: 10
- Don’t Know: 15
- Missing: 10

National Study of Long-Term Care Providers
Whether an establishment is HIPAA-covered varies by selected characteristics

- **Ownership**
  - Non-profit: 76%
  - Other: 65%

- **Chain**
  - Yes: 71%
  - No: 61%

- **Hospitalizations**
  - Yes: 74%
  - No: 63%

- **Medicaid**
  - Yes: 72%
  - No: 61%

- **MSA**
  - Yes: 63%
  - No: 63%

- **EHR**
  - Yes: 78%
  - No: 63%

- **Bed size**
  - 4-25: 60%
  - 26-50: 74%
  - >50: 74%

- **Region**
  - Northeast: 69%
  - Midwest: 79%
  - South: 74%
  - West: 52%

All differences significant at \( p < .05 \).
Percentage of HIPAA-covered establishments that have & are willing to share PII elements for research is low

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<th>Has but won’t share</th>
<th>Has &amp; will share</th>
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Percentage of HIPAA-covered establishments that have & are willing to share PII bundles for research is low.

<table>
<thead>
<tr>
<th>Any PII</th>
<th>Full Name &amp; DOB only</th>
<th>Full Name &amp; DOB &amp; Last 4 SSN</th>
<th>Full Name &amp; DOB &amp; Full SSN</th>
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Among the 23% of HIPAA-covered establishments that have & are willing to share PII, the majority are willing to share all elements.

- No PII: 77
- Full Name Only: 11
- DOB Only: 5
- Last 4 SSN or Full SSN Only: 4
- Full Name & DOB only: 2
- Full Name & DOB & Last 4 SSN or Full SSN: 2
Percentage of HIPAA-covered establishments that have & are willing to share PII elements varies by several characteristics

<table>
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<tr>
<th>Significant differences ( p &lt; .05 )</th>
<th>Non-profit</th>
<th>Other Chain</th>
<th>Non-chain</th>
<th>Any hospital stays in last 90 days</th>
<th>Northeast</th>
<th>Midwest</th>
<th>South</th>
<th>West</th>
<th>4-25 beds</th>
<th>26-50 beds</th>
<th>&gt; 50 beds</th>
<th>Participate in Medicaid</th>
<th>MSA</th>
<th>Non-MSA</th>
<th>Have EHR?</th>
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Percentage of HIPAA-covered establishments that have & are willing to share PII bundles varies by some characteristics

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Limitations

- Respondent fatigue may have influenced willingness to share
  - Consent questions at end of 8-page questionnaire
- Perhaps the “ask” could be better argued
  - Question text dense & neutral
  - Did not argue reduced respondent burden/time savings (Sakshaug & Kreuter, 2014)
  - Did not test language
  - Most completions were self- rather than interviewer-administered
- Questions were hypothetical
- About 3% of cases completed with a proxy
  - Proxies may have been more cautious about willingness to share PII
Take home summary—research questions

1. What proportion of establishments are HIPAA-covered entities? 65%

2. Does whether or not an establishment is a HIPAA-covered entity vary by certain characteristics? Yes.

3. What proportion of HIPAA-covered establishments have & will share PII elements? (6%-19%) PII bundles? (4%-11%)

4. Do HIPAA-covered establishments with certain characteristics vary in having & being willing to share PII elements or bundles that could potentially result in bias? Yes.
Take home summary—practical implications

• Should we pursue linkage for NSLTCP surveys? **Perhaps not.**
• Small sample size—Potential for bias—Unknown generalizability
  • Majority of HIPAA-covered establishments **not** share
    – 4%-11% of 65% = 7% of initial sample at best
  • The small % of establishments willing to share 1 PII element are willing to share others; but even when limit PII elements, willingness to share does not improve
• Willingness to share varies by key characteristics
• In non-HIPAA covered establishments, getting resident or family consent likely cost-prohibitive
• What would the linked sample represent? To what population is sample generalizable, if any, and with what probability?