



## National Study of Long-Term Care Providers

# 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



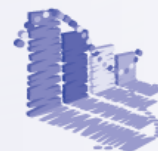
## Brief Literature & Justification

- 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 – brochure excerpt

## How the National Health Care Surveys Keep Your Information **Confidential**

National Ambulatory Medical Care Survey

National Hospital Ambulatory Medical  
Care Survey

National Hospital Care Survey

National Study of Long-Term Care Providers



Centers for Disease  
Control and Prevention  
National Center for  
Health Statistics

## 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.



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# 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.

	<u>Column 1</u> This center has. . .	<u>Column 2</u> I would be willing to provide . . .
a. Full names	<input type="checkbox"/> Yes → <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
b. Dates of birth	<input type="checkbox"/> Yes → <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
c. Last four digits of Social Security numbers	<input type="checkbox"/> Yes → <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No
d. Full Social Security numbers	<input type="checkbox"/> Yes → <input type="checkbox"/> No	<input type="checkbox"/> Yes <input type="checkbox"/> No



## Questionnaire items (2)

Is this adult day services center a Health Insurance Portability and Accountability Act (**HIPAA**)–**covered entity**?

Yes

No

Do not know





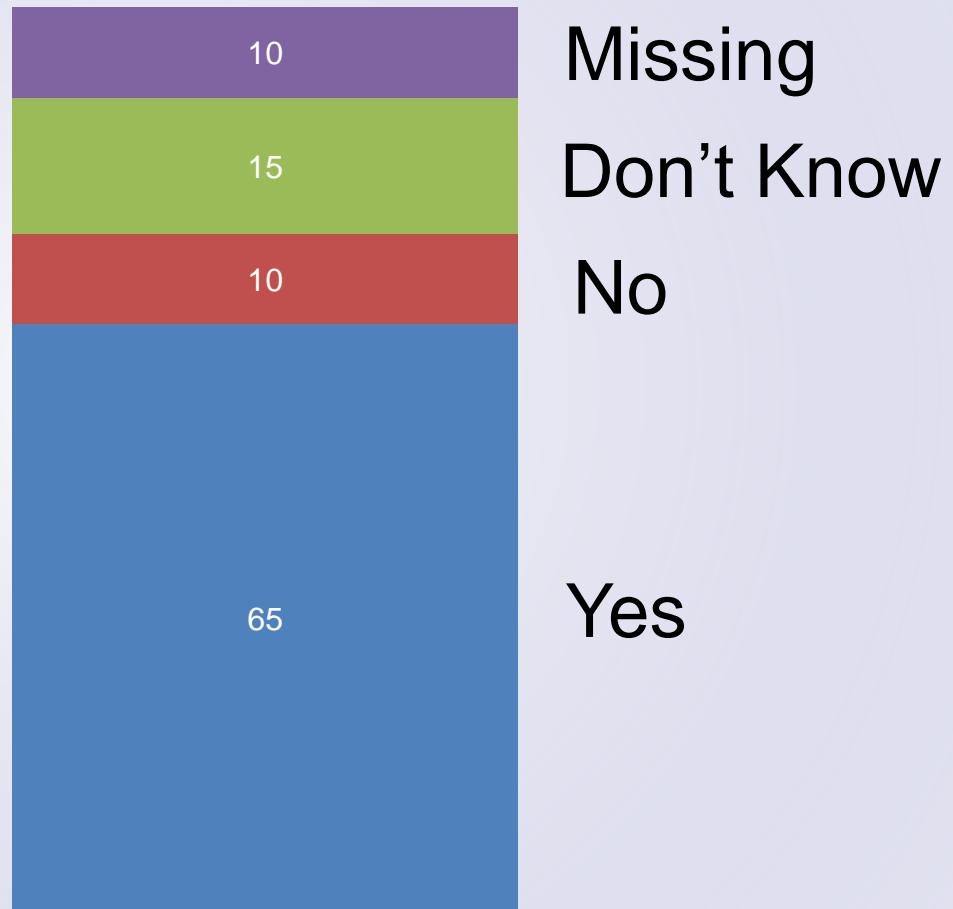
## Analyses

- 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

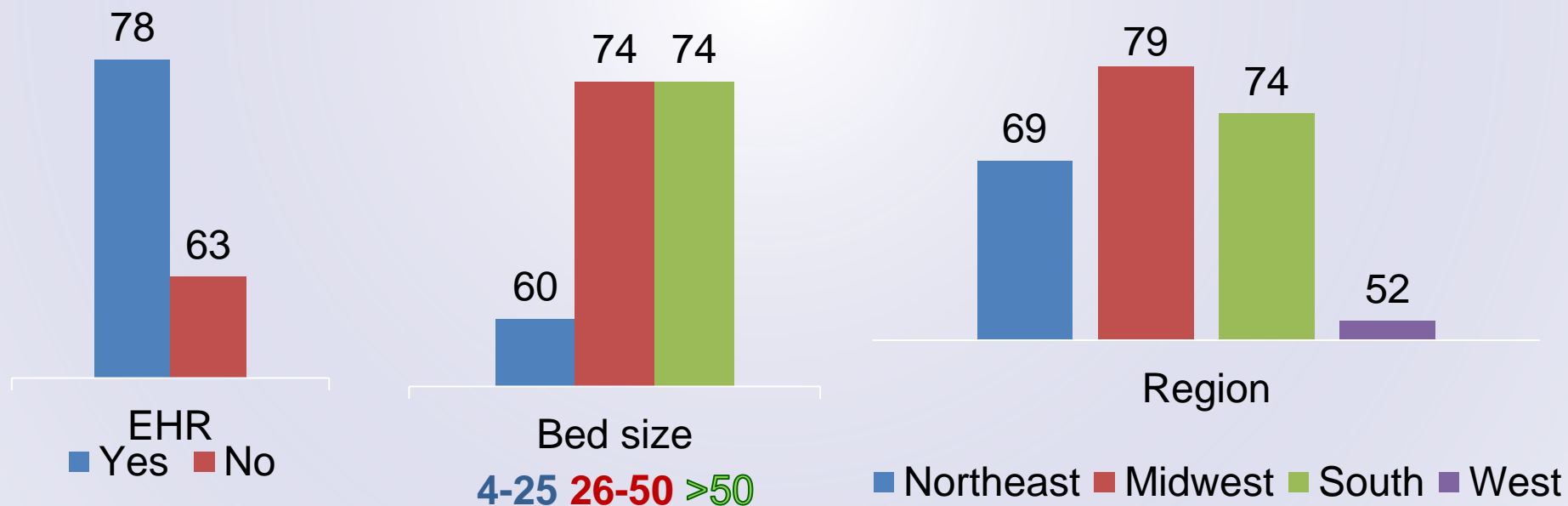
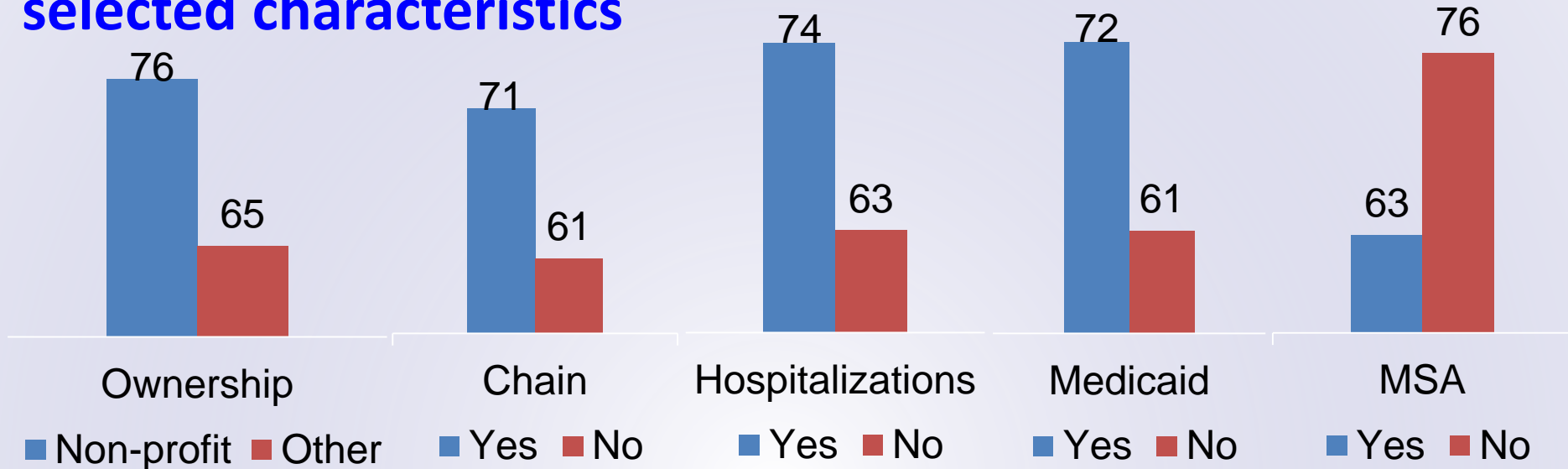


# One-third of establishments are not HIPAA-covered, don't know if they are, or left the item missing

Is establishment a HIPAA-covered entity?

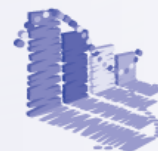
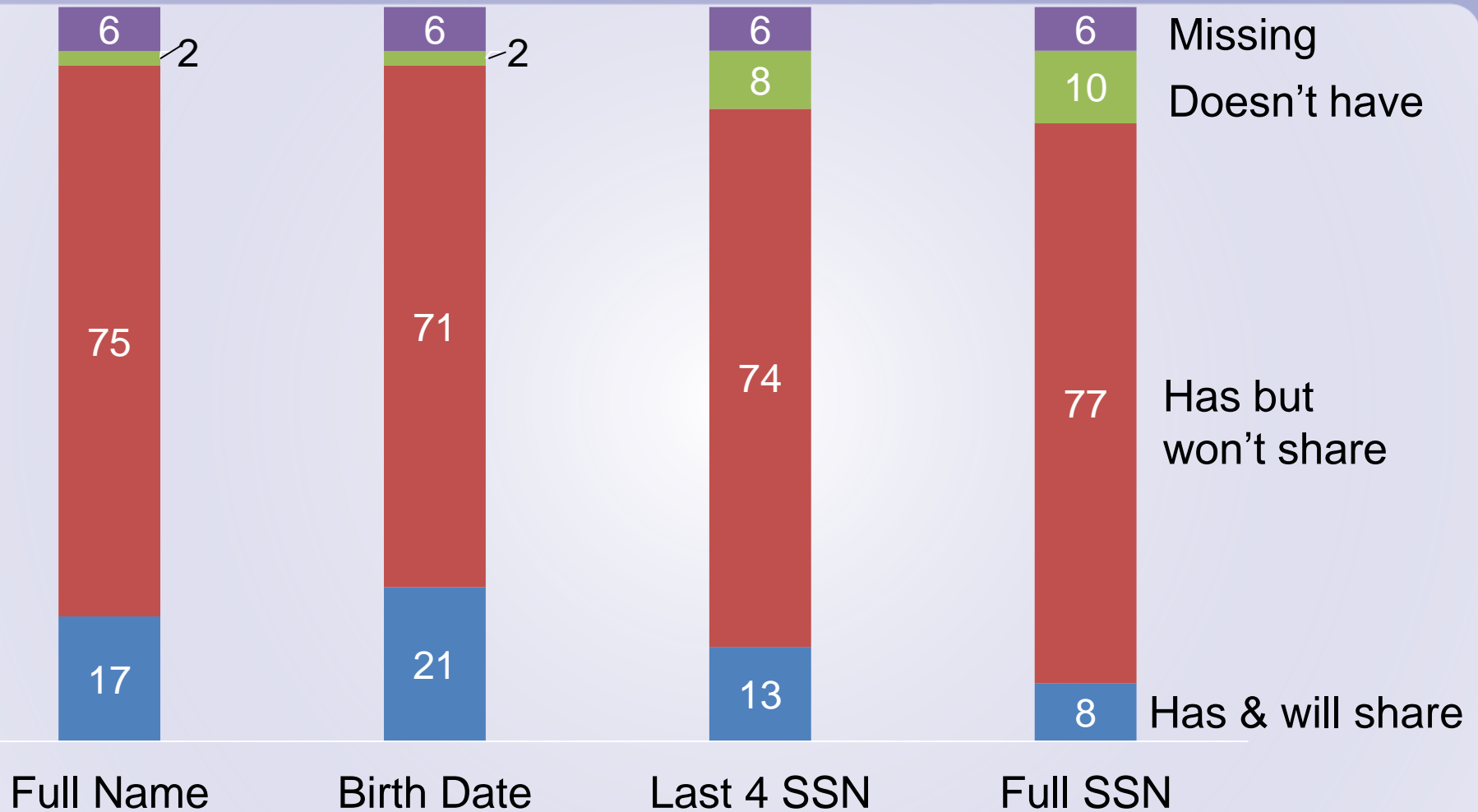


# Whether an establishment is HIPAA-covered varies by selected characteristics

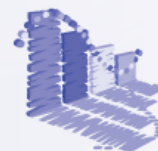
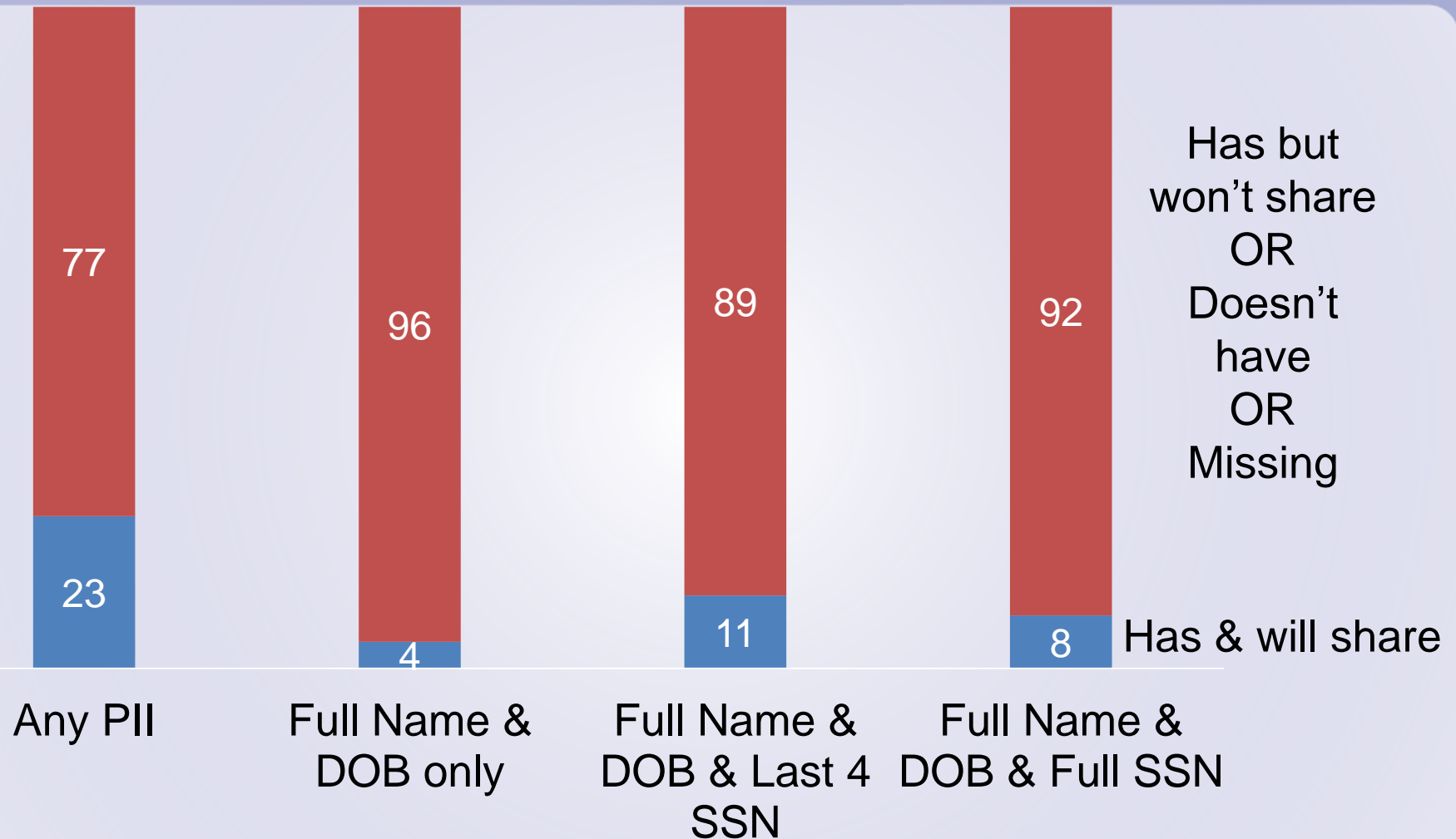


All differences significant at  $p < .05$ .

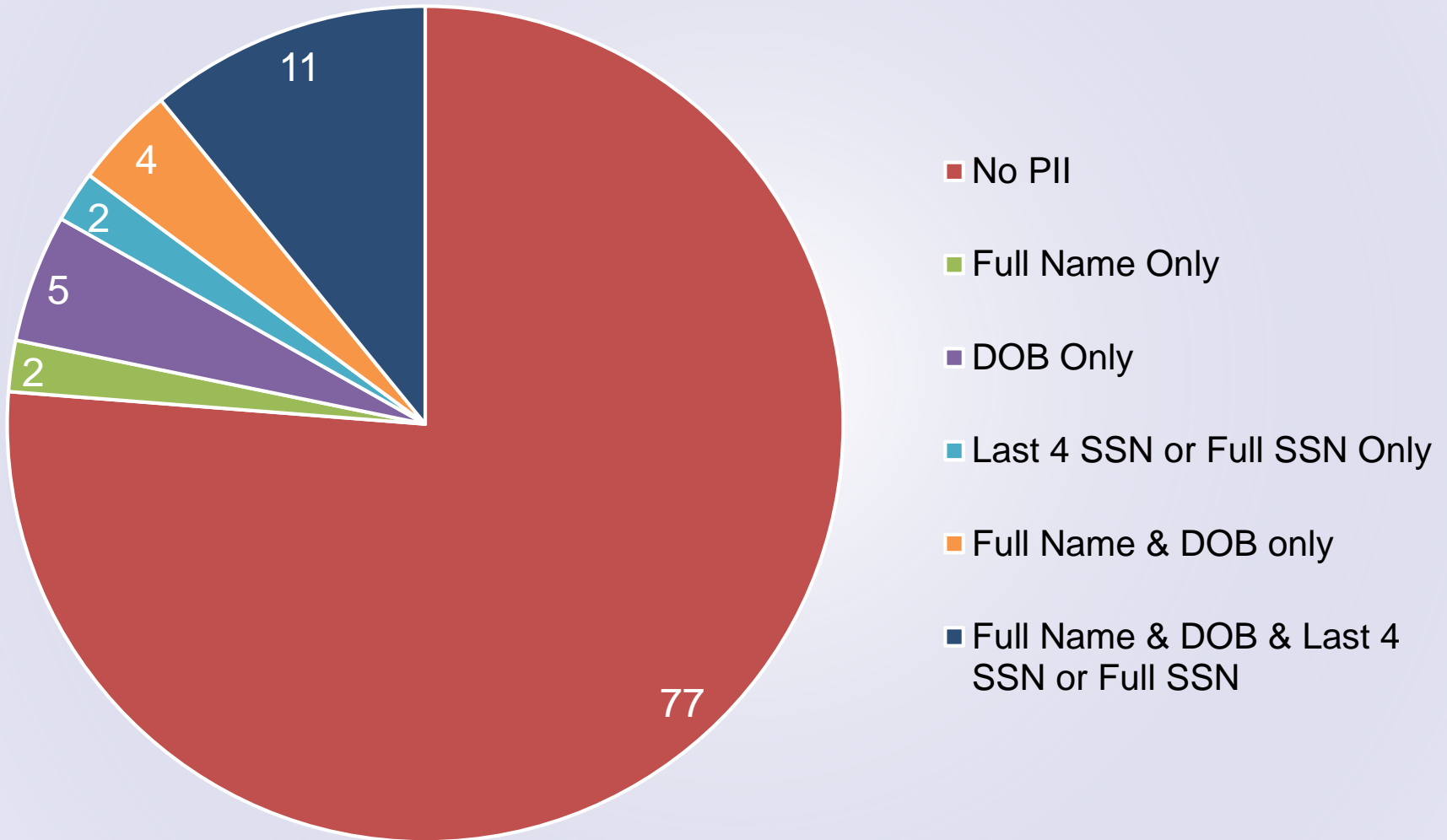
# Percentage of HIPAA-covered establishments that have & are willing to share PII elements for research is low



# Percentage of HIPAA-covered establishments that have & are willing to share PII bundles for research is low



# Among the 23% of HIPAA-covered establishments that have & are willing to share PII, the majority are willing to share all elements



# Percentage of HIPAA-covered establishments that have & are willing to share PII elements varies by several characteristics

Significant differences $p < .05$	Non-profit	Other	Chain	Non-chain		Any hospital stays in last 90 days	Northeast	Midwest	South	West	4-25 beds	26-50 beds	> 50 beds	Participate in Medicaid		MSA	Non-MSA	Have EHR?	
				Yes	No									Yes	No			Yes	No
Birth Date	19	22	21	21	20	24	23	20	21	22	24	21	17	24	19	22	19	25	20
Full Name	13	17	16	17	15	19	16	13	19	18	20	13	13	19	14	17	13	18	16
Last 4 SSN	13	13	13	13	12	15	12	12	15	11	14	12	10	15	10	13	11	16	11
Full SSN	7	8	8	8	6	11	6	7	10	7	10	6	5	10	6	8	7	9	7

# Percentage of HIPAA-covered establishments that have & are willing to share PII bundles varies by some characteristics

Significant differences p < .05	Non-profit	Other		Chain	Non-chain		Any hospital stays in last 90 days	Northeast	Midwest	South	West	4-25 beds	26-50 beds	> 50 beds	Participate in Medicaid		MSA	Non-MSA	Have EHR?	
		Yes	No		Yes	No									Yes	No				
		Yes	No		Yes	No									Yes	No				
Any PII	22	24	23	24	22	26	24	20	24	25	26	22	18	26	20	24	20	26	22	
Full Name & DOB & Last 4 SSN	9	11	11	11	13	10	11	10	13	10	13	9	8	13	9	12	9	13	10	
Full name & DOB & Full SSN	6	8	8	7	6	10	6	7	9	6	9	6	5	9	6	8	6	9	7	
Full Name & DOB only	3	4	4	4	3	4	5	2	3	5	4	2	4	4	4	4	3	4	4	



## 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?

