

Communication of Disclosure Risk in the NHANES Survey

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What We'll be Talking About Today

- NHANES
- NHANES Disclosure Risks
- Communication of Disclosure Risks



NHANES – Overview

- NHANES: National Health and Nutrition Examination Survey
- Objective: To assess the health and nutritional status of adults and children in the United States
- Approach: Perform a national survey with interview and clinical measurements

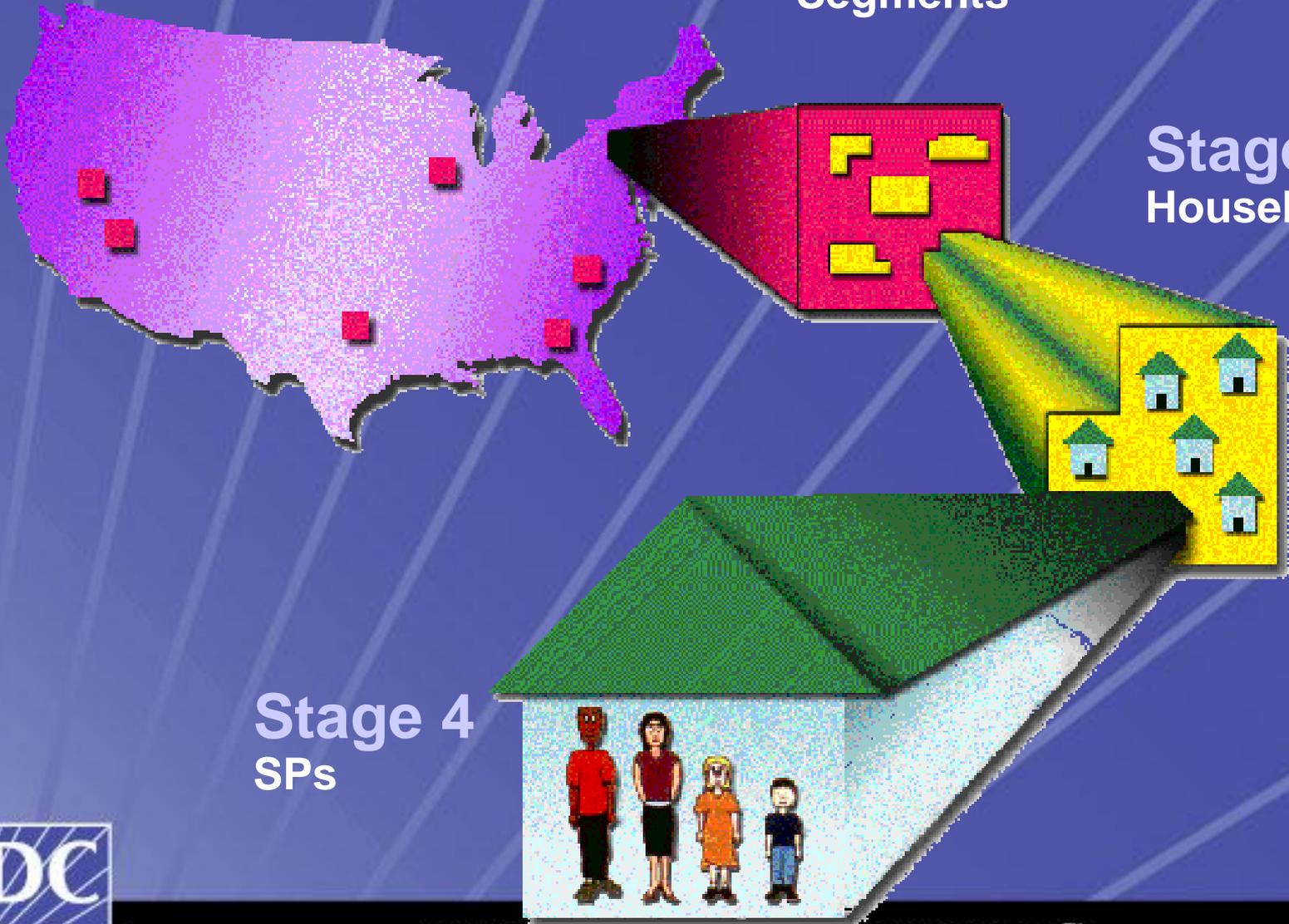


Stage 1
Counties

Stage 2
Segments

Stage 3
Households

Stage 4
SPs

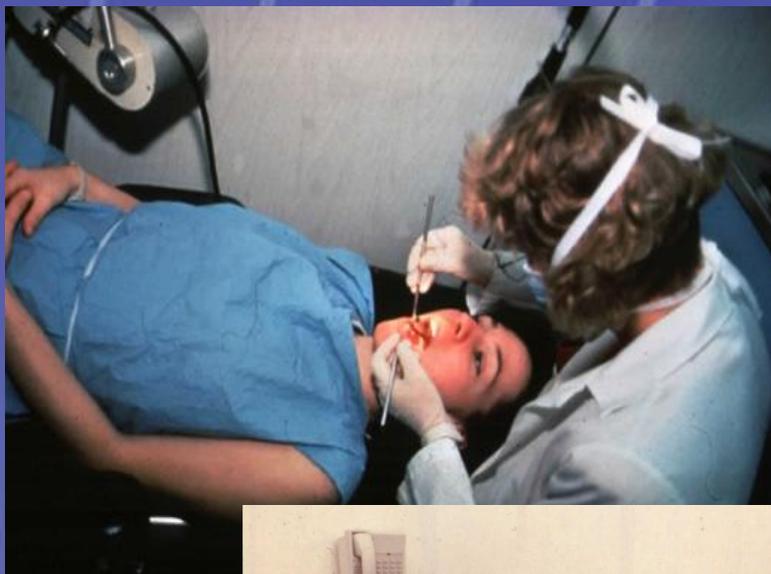


NHANES Overview – Picture

- Obtain national estimates of health conditions, 1999 – present

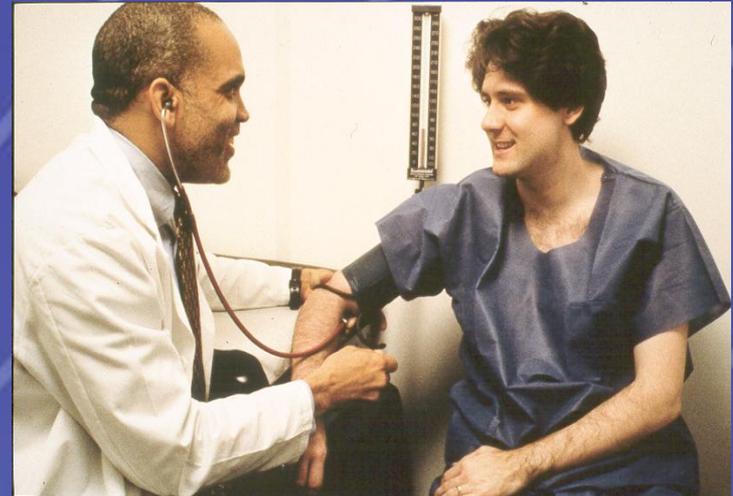


NHANES Overview – Picture



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NHANES Overview – Picture



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NHANES Response Rates by Survey Cycle

NHANES II	73%
Hispanic HANES	73%
NHANES III	78%
NHANES 1999–2004	77%
NHANES 2005–2006	77%
NHANES 2007–2008	76%
NHANES 2009–2010	77%
NHANES Completed 2011 Stands	74%



Response rates are indicated as percentages

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Questions so far?

- NHANES
 - 15 counties per year
 - Roughly 5,000 survey participants per year
 - Collects:
 - Personally identifiable information
 - Survey information
 - Clinical measurements
 - Around 75% response rate



Disclosure Risks on NHANES

- What could be disclosed:
 - Legal, e.g. Name, Address, SSN
 - Personal, e.g. Behavioral
 - Medical, e.g. Diabetes, STDs
- How it could be disclosed:
 - Conversation / presentation
 - Willful disclosure
 - IT Security Breach
 - Improper sending of Report of Findings
 - Incomplete disclosure review of public use dataset



Communicating Disclosure Risks

- Who we communicate to:
 - NCHS Research Ethics Review Board (ERB)
 - Confidentiality Officer
 - County Officials
 - Community Leaders
 - Media
 - Survey Participants
- Communication is through:
 - Internal documents (ERB)
 - “Advance Arrangements”
 - Field interviewers
 - Brochures
 - Website



Ethics Review Board (ERB)

- All protocols, consent forms, and important survey materials are reviewed by our ERB
- ERB ensures that materials are written such that survey participant understands protocol and confidentiality risks
- NCHS Confidentiality Officer reviews ERB submissions



Advance Arrangements

- Advance Arrangements are what NHANES calls its contacts with a community prior to coming
- This includes:
 - Local officials
 - Community leaders
 - Media
 - Survey participants
- All receive information regarding confidentiality
 - County officials do not receive data on survey participants



Advance Arrangements, cont'd

- Sample persons receive an advance letter containing the following text

This survey is a Federal program authorized by the Public Health Service Act. All of your answers will be kept in strict confidence. We will use this information only for statistical research and reports. Your answers will be added to others, so no one can identify which are yours.



Field Interviewers

- Field interviewers make contact with survey participants (SPs) at the household and obtain consent.
- Field interviewers are retrained in confidentiality annually.
- Field interviewers explain the following in the consent form:

Assurance of Confidentiality – All information which would permit identification of an individual, a practice, or an establishment will be held confidential, will be used only by NCHS staff, contractors, and other agents authorized by NCHS to perform statistical activities, only when required and with necessary controls, and will not be disclosed or released to other persons without the consent of the individual or establishment in accordance with section 308(d) of the Public Health Service Act (42 USC 242m) and the Confidential Information Protection and Statistical Efficiency Act (PL-107-347). By law, every employee as well as every agent has taken an oath and is subject to a jail term of up to five years, a fine of up to \$250,000, or both if he or she willfully discloses ANY identifiable information about you.



Brochures

- Survey participants receive a Consent Brochure which has the text below. In addition, we have a “Strictly Confidential” brochure.

We respect your privacy. Public laws keep all information you give private. These laws do not allow us to give out data that identifies you or your family without your permission. This means that we cannot give out any facts about you, even if a court of law asks for them. However, if we find signs of child abuse during an exam, we will report it to the local department of social services or the police. We will keep all survey data safe and secure. When we share data with our partners, we do so in a way that protects your privacy as required and guaranteed by law. Our interviewer can provide you a list of our partners if you wish to learn more.



Web Site

- Survey participants are encouraged to go to:
www.cdc.gov/nchs/nhanes/participant.htm

Welcome NHANES Participants

You, or a member of your family, may have a chance to take part in an important national health survey. The National Center for Health Statistics, a part of the Centers for Disease Control and Prevention, is responsible for this survey - The National Health and Nutrition Examination Survey (NHANES). This survey teaches us about the health and diet of people in the United States. Over the years, this survey has led to improvements in the food we eat and the health care we receive.



Conclusion

- NHANES takes every opportunity to point out we take the confidentiality pledge seriously.
- We do so in a way that we feel is best understood by the audience.
- In sum, we try to identify every disclosure risk, minimize it, and communicate it in the appropriate way to the appropriate people.

