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Assessing the Accuracy of Parent Recall of the Hepatitis A Immunization Status of Their Children: Data Collection Issues in a Telephone Survey Combined with Provider Record Check

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Presentation Overview

- Introduction
- Study Overview
- Data Collection Challenges and Solutions
- Conclusions
- Recommendations for Future Studies

Introduction

- Provider reports, while not perfect and very expensive, are considered the “gold standard” in obtaining vaccination coverage estimates.
- Goal of the project was to determine whether a relatively inexpensive RDD telephone study without a provider record check could provide accurate estimates of immunization coverage for hepatitis A.
- Success of the study dependent upon getting a sufficient number of cases with both parent and provider data.
- Faced multiple data collection challenges along the way, including some as a consequence of 2003 HIPAA regulations.

Introduction (cont'd)

- This project was made possible through a Cooperative Agreement between the Centers for Disease Control and Prevention (CDC) and the Association of Teachers of Preventive Medicine (ATPM), award number U50/CCU300860 TS-1225; its contents are the responsibility of the authors and do not necessarily reflect the official views of CDC or ATPM.

Study Overview

- Accuracy of Parental Reports of Hepatitis A Vaccination of Children (HAV PEP)
- Random-digit-dial (RDD) survey conducted in Oregon and Arizona
 - States with high incidence of hepatitis A at time of selection
- Interviewed parents (or guardians) of children aged 2.5 to 15 years of age
- Completed interviews with approximately 650 households, representing nearly 1,200 children
- Parent data collection conducted from September to November 2004
- Provider data collection conducted from September 2004 to March 2005

Study Overview (cont'd)

- Parents asked for:
 - Reports of childhood vaccinations (hepatitis A, hepatitis B, and varicella)
 - Permission to contact medical providers to obtain data on these vaccinations
 - Demographic characteristics of the household
- If parent verbally agreed to consent, mailed written consent form to complete and return to RTI.
- If written parent permission obtained, contacted medical providers to obtain vaccination records for the children.

Data Collection Challenges

Challenge #1: Creating the survey instrument

Challenge #2: Obtaining written parental consent to contact providers for the shot record for the child

Challenge #3: Obtaining provider reports

Challenge #4: Protecting the confidentiality of obtained medical records

Challenge #1: Creating Survey Instrument

- Adapted instrument from National Immunization Survey (NIS)
 - Challenge #1a: Older children (19-35 months in the NIS vs. 2.5–15 years in HAV PEP)
 - Solution #1a: Accommodated diverse family scenarios including up to 20 children, contacting additional family members for consent, and allowed recording of up to 6 providers per child.

 - Challenge #1b: Different immunizations (11 immunizations in the NIS vs. 3 immunizations in HAV PEP)
 - Solution #1b: Simplified instrument to ask about only 3 vaccinations. Cases were also randomly assigned to receive questions about hepatitis B vaccination.

Challenge #1: Creating Survey Instrument (cont'd)

- Challenge #1c: More complete information on hepatitis A coverage
 - Children up to 35 months in the NIS versus children up to age 15 in HAV PEP. Therefore the NIS only provides a very small subset of hepatitis A vaccination coverage information.
 - HAV PEP interested in hepatitis A vaccination (which can only be completed once a child reaches 2.5 years of age – or 30 months).
 - Hepatitis A vaccine was licensed in the United States in 1995. The vaccine was not available to older children when infants, and it may be harder for parents to recall whether their child received the vaccine because they may not have the shot card in hand. Also, parent reports may be subject to more recall and potential misclassification problems for older children.
- Solution #1c: To allow for more complete information on hepatitis A coverage, interviewed parents of children up to 15 years of age.

Challenge #2: Obtaining Written Parental Consent to Contact Medical Providers

- In pre-HIPAA era, verbal consent alone would have been sufficient for contacting medical providers.
- HIPAA Privacy Rule allows medical providers to disclose protected health information (PHI) without consent for public health purposes; allows for release of PHI for research studies with oral consent only.
 - Since our study was a grant from ATPM and CDC to investigate the accuracy of parental reports of childhood vaccinations, it could have been interpreted as not falling under the public health exception to the Privacy Rule.
 - Obtaining written consent helped to ensure that we would obtain a sufficient number of parent-provider matches for analysis. Written consent also help combat the potential misinterpretation of the HIPAA Privacy Rule by providers or using the Privacy Rule as an excuse to not send back the shot record.

Challenge #2: Obtaining Written Parental Consent to Contact Medical Providers (cont'd)

- Challenge #2: Obtaining written parent consent
 - 82% of parents verbally agreed: 532 cases (families) representing 1,027 children
 - However, after initial consent mailings to parents, very low return rate: 32% as of 12/20/2004
- Solution #2: Multiple follow-ups with parents using multiple modes
 - Initial mailing with consent form for each child, reminder postcard, replacement mailing
 - Added: telephone reminder calls, FedEx mailing with additional incentive offer
 - Resulted in 58% returned written consent forms: 306 cases (families) representing 560 children

Challenge #3: Obtaining Provider Reports

- Challenge #3: Obtaining shot records from providers
- Solution #3: Implemented multiple follow-ups with providers including:
 - Initial request mailing, multiple follow-up telephone calls
 - Customized response to providers as necessary to obtain completed shot records (e.g., fax, re-mail of questionnaire)
 - Resulted in 90% returned IHQ/shot record: 274 cases (families) representing 493 children

Challenge #4: Protecting Confidentiality of Medical Records

- Challenge #4: Protection of confidentiality for obtained medical records.
- Solution #4:
 - Records returned to one project staff member
 - Project specific fax machine located in locked staff member's office
 - Signed confidentiality agreements from all project staff, as well as officemate of staff member with fax machine

Conclusions

- Faced multiple data collection challenges and successfully overcame all of them.
- HIPAA contributed to the 2 most significant challenges: obtaining parent consent and provider records.
 - Were able to utilize multiple contact approaches for both parents and providers to obtain a sufficient number of parent-provider matches for analysis.
 - Implementing these additional steps used additional project resources including time (extending data collection period), project staff labor, and money.

Recommendations for Future Studies

1. Follow-up with parents as quickly as possible.
2. Plan for longer data collection period to obtain written parental consent.
3. Plan for increased and more in-depth interaction with some health care providers to obtain medical records.
4. Consider using interviewer signature to indicate respondent verbal consent and as proxy for respondent written consent.

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