Establishing Data Linkages for Targeted Immunization Data Analyses

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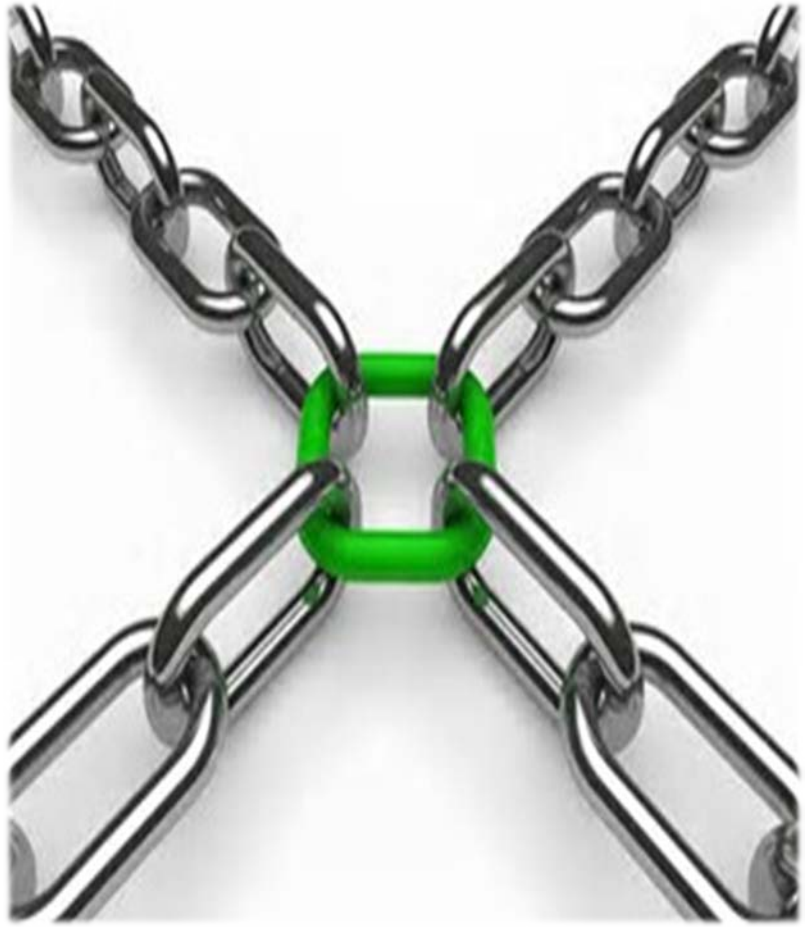
Why Explore Data Linkages?

- Increasing uptake of HPV vaccine is a national priority
- IIS have been essential for capturing vaccine coverage estimates
- Use the IIS to help understand vaccine effectiveness for reducing the incidence, severity of disease, or preclinical outcomes



Objectives

- Describe Sentinel Site experience establishing connection with external data registries
- Describe strategies to overcome technical and operational challenges
- Explore clinical outcomes that can be potentially linked to difference data sources
- Identify what the IIS community is doing

MICHIGAN'S IIS TO CANCER REGISTRY LINKAGE

Rachel C. Potter, DVM, MS

AIRA, 2017

BACKGROUND

Demographic records from the Michigan Care Improvement Registry (MCIR) were linked to the Michigan Cancer Surveillance Program via the Live Birth File

MCIR (our Immunization Information System) was established in 1998

- Opt-out
- Required reporting of all immunizations administered to children aged < 19 years
- Permissive reporting of immunizations administered to adults

The Michigan Cancer Surveillance Program was established in 1985

- Includes surveillance of pre-invasive cervical lesions

Centers for Disease Control and Prevention approached Michigan with an idea:

- Can your existing resources be leveraged to assess the early impact of HPV vaccinations?

METHODS

Collaboration with Glenn Copeland, State Registrar and Director, Michigan Cancer Surveillance Program

- Institutional Review Board review and approval
- Execution of a Data Use Agreement between programs

Mei You, a statistician dedicated to the matching project, was hired

Establish a cohort of women *continuously resident in Michigan*, to assure complete capture of immunizations and cancer diagnoses

- Women in MCIR born between 1980 and 2004
- Link MCIR records and MCSP records to the Michigan live birth file
  - Assures Michigan birth
- Linkage variables were first name, middle name, last name, date of birth, and, after 1993, birth file ID number
- Used SAS and LinkPlus

LIMITATIONS

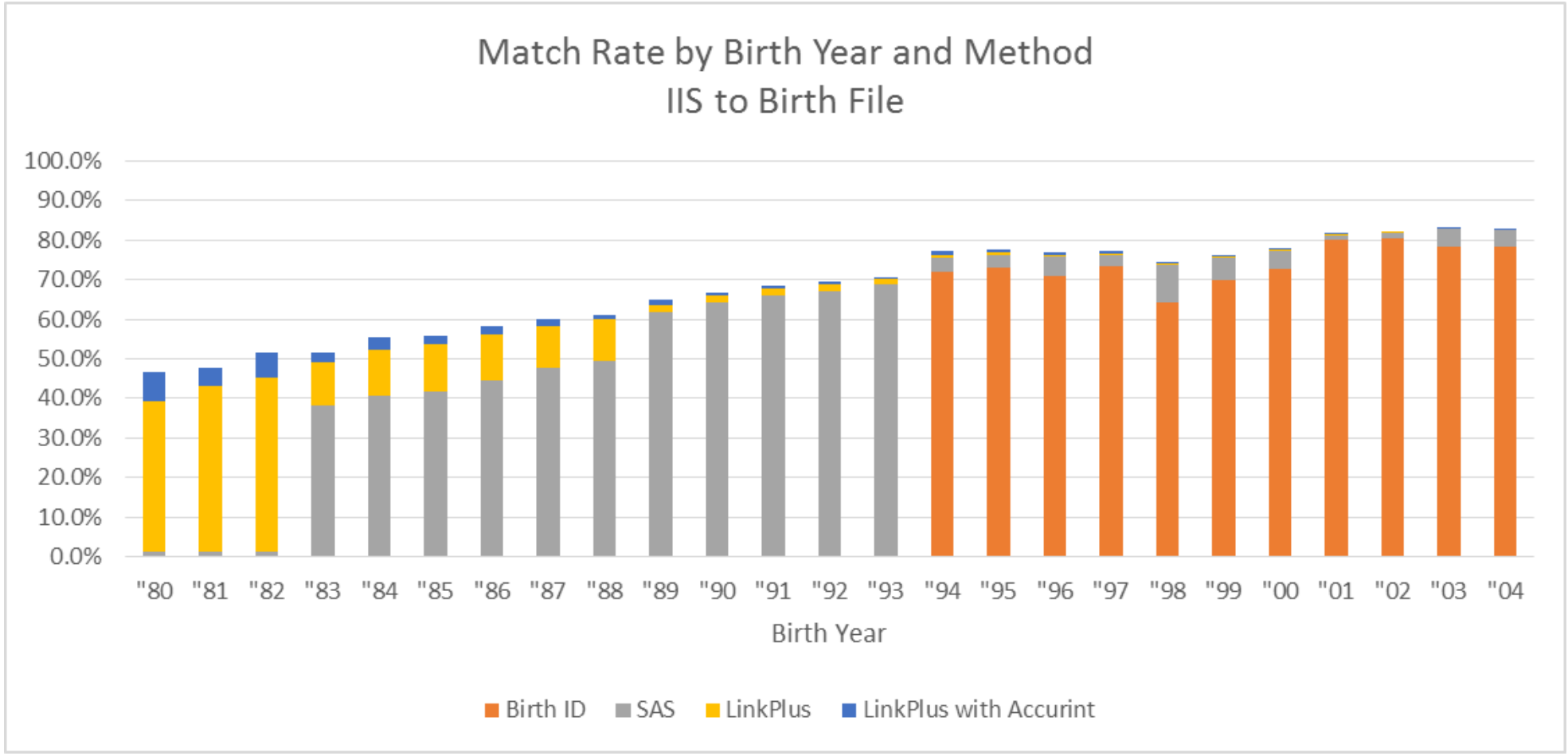
In general, the older the woman, the greater the effort and the lower the match rate between the IIS and the birth file

- Data quality in the birth file has improved over time
- Data quality in MCIR has improved over time
- Women's last names can change

Additional data sources were needed to improve match rates

- Accurint was used to review cases that matched on first name, middle name, and date of birth to determine if mismatched last names could be associated with the same person
- Additional cost

RESULTS


Match Rate by Birth Year and Method
IIS to Birth File
100.0%
90.0%
80.0%
70.0%
60.0%
50.0%
40.0%
30.0%
20.0%
10.0%
0.0%
"80
"81
"82
"83
"84
"85
"86
"87
"88
"89
"90
"91
"92
"93
"94
"95
"96
"97
"98
"99
"00
"01
"02
"03
"04
Birth Year
Birth ID
SAS
LinkPlus
LinkPlus with Accurint

CONCLUSIONS

Demonstrated ability to link demographic records from an IIS to a cancer registry

Will be able to compare immunization status of women with and without pre-invasive cervical lesions

Matching process can be tedious, but improves with increasing birth year

Leverage existing relationships

FUTURE IMPLICATIONS

Having identified a cohort of women born in Michigan, now should assess for continuous residence

With a cohort of continuously resident women, we can assess the impact of the HPV vaccine on pre-invasive cervical cancer rates in Michigan

NORTH DAKOTA DEPARTMENT of HEALTH

Establishing Data Linkages for Targeted Immunization Data Analyses

A Data Match Project between the North Dakota Immunization Information System (NDIIS) and the North Dakota State Cancer Registry (NDSCR)

Dominick Fitzsimmons, NDIIS Coordinator

NDIIS
NORTH DAKOTA IMMUNIZATION INFORMATION SYSTEM

NDSCR
NORTH DAKOTA STATEWIDE CANCER REGISTRY

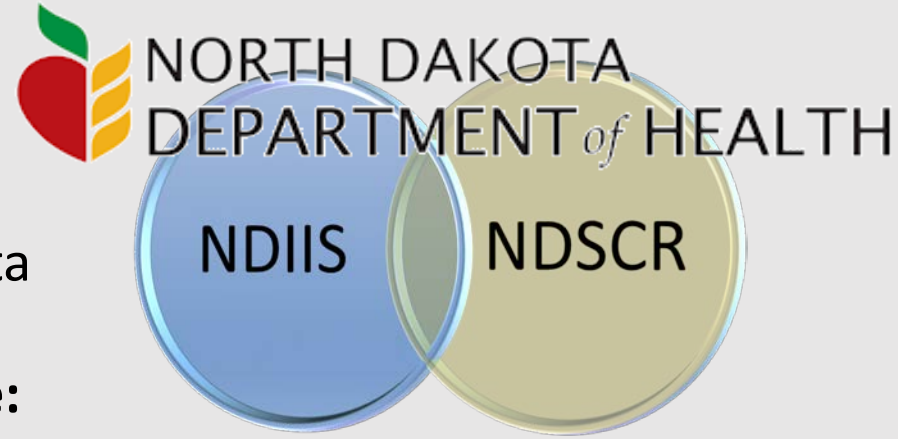
Background

Starting Point

Prior to this study, no data linkage or analysis of shared information had been completed between the two registries' datasets.

Within the North Dakota Department of Health

- NDIIS is housed in the Disease Control Division
- NDSCR is housed at the University of North Dakota



This project was designed with a two-fold purpose:

- To assess baseline shared information between the registries' datasets
- To assess baseline HPV-related cancer case vaccination data
- To understand HPV vaccination patterns among individuals diagnosed with a HPV-related cancer
  - For informing possible future tracking of HPV-related disease outcomes and vaccine efficacy in North Dakota's population

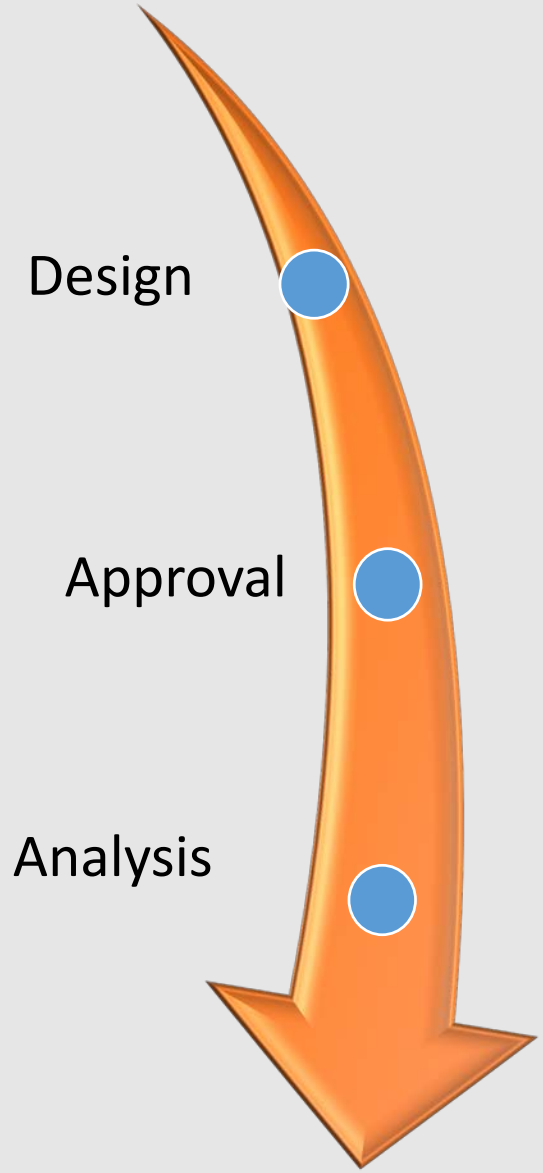
Methods

Project design – *a collaborative process*

- Identification of appropriate data fields for matching
- Identification of HPV-related cancer cases

IRB application- *key questions asked*

- Why do we need to analyze the entire dataset?
- How will the data be shared and presented?
- Security and confidentiality of data
  - As NDIIS and NDSCR are within the NDDoH no data use agreement is required
- North Dakota's process took several months from application to final decision
  - Providing full detail on each aspect of our proposal was beneficial in answering the IRB's concerns and instrumental in the project's approval.



Methods

Matching

- NDIIS/NDSCR staff collaborated to identify potential data fields for matching among demographics and vaccine records.
  - Fields with the most similarity and degree of population were chosen to use as matching parameters.
  - Active, non-MOGEd North Dakota records

LinkPlus®

- A probabilistic record linkage program developed at CDC's Division of Cancer Prevention and Control in support of CDC's National Program of Cancer Registries (NPCR).
  - Program favored by cancer registries for matching and consolidating data
  - Researchers may use SAS or similar programs to perform matching of delimited/fixed width data.
- LinkPlus was found to be very user friendly and ideal for manually reviewing uncertain matches

Both datasets were formatted for direct comparison

- Birthdates must be in the same format e.g. MMDDYYYY : MMDDYYYY
- Columns for comparison should be in text format, number format etc. for the best possible match rate.
- Character fields may be analyzed for match using Soundex or New York State Identification and Intelligence System (NYSIIS) phonetic algorithms depending on project needs and data suitability.

HPV-related cancer cases matched against NDIIS dataset for vaccination analysis

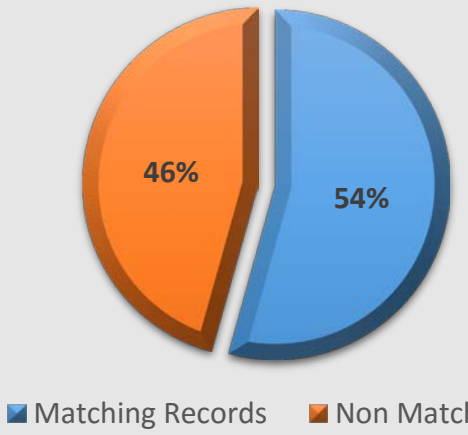
- Followed routine ACIP age indications, HPV licensure and the most recent year of consolidated NDSCR data.
  - For individuals ages 11-26 years during 2005-2013
  - HPV vaccination analysis was completed prior to the 2-dose ACIP recommendation, however no individuals receiving HPV vaccine were found to have initiated the series before their 15th birthday.

Results

Overall Datasets Match

- 52.5% of records matched exactly using LinkPlus® and 1,080 additional matches were manually identified by the NDIIS coordinator.
- Total 54.3% of records were identified as matches.
- 72.0% of record matches belonged to individuals born before 1950.
- 2.1% of record matches belonged to individuals born after 1980.

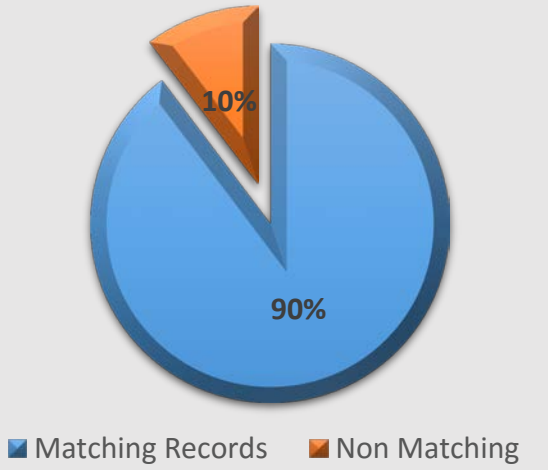
Overall NDIIS NDSCR Record Match



HPV-Related Cancer Cases Match

- 89.7% of records matched overall: 35 exact record matches with 8 manually matched
- Gender distribution - 15 female : 5 male
- Series completion - 10 females completed a 3 dose series, 5 had 1 or 2 doses
  - No males with a dose of an HPV vaccine
- Mean age of series initiation 21 years; age of series completion 22 years ; mean 3 dose series completion time was 18 months.

HPV-Related Cancer Cases NDIIS Match



Limitations

Matching process

- Based on variable text and date fields
- Not all uncertain matches could be included when manually reviewed due to small differences, precluding complete validation in these cases.

Understanding Variations

- Differences in provider-entered demographics e.g. name spellings, birthdates or addresses could result in a non-match.
- The majority of NDSCR records belong to adults, who typically receive fewer immunizations and have longer lengths of time between healthcare provider visits for demographic updates.
- North Dakota has no mandate for reporting of adult immunizations to the NDIIS.
- All diagnoses of cancer within the state are mandated for reporting to the NDSCR.
- Duplicate records may interfere with exact record matching.
- An individual who received immunizations outside of North Dakota will be unlikely to be represented in the NDIIS.

Conclusions

Match Rates

There was a high rate of overall match between the datasets

- Increasing numbers of interoperable providers will increase the number of client records in the NDIIS and the quality of their record data.
- Continued consolidation of duplicate records coming into NDIIS will increase data quality.

High number of HPV-related cancer cases found a match in NDIIS

- Future cases of HPV-related cancers may have their immunization status assessed
- Strategy for promoting immunization against HPV
- Improved diagnostic methods for HPV-related cancers (PCR) will identify more cases in the future.

Information Crossover

The registries have now established a baseline understanding of shared information and relative data structures.

The crossover of information verifies that similar data is being collected by these two state public health registries and that there would be value to future projects.

Relationships

We have established a collaborative relationship between the NDIIS and the NDSCR and now are familiar with a successful approval process.

- Having a collaborative relationship in place is the fundamental step to further projects.

Future Implications

Continued collaboration

- The registries are planning a new project assessing influenza vaccination data among cancer-diagnosed populations.
    - Collaborating to identify high-risk immunization recommendations and immunization statuses (NDIIS) among e.g. leukemia-diagnosed persons (NDSCR)

Areas of potential focus

- Analysis of disparities in vaccination amongst cancer patients
- Evaluation of vaccination rates amongst cancer patients
- State level vaccine efficacy studies e.g. HPV or Hep B
- The timing of this data match project may act as a primer for future disease outcomes studies.

Miriam Muscoplat, MPH

Minnesota Immunization Information Connection

Manager, MIIC

Background

- Minnesota Immunization Information Connection (MIIC)
  - Lifespan IIS established in 2002
  - Housed within infectious disease division at Minnesota Department of Health
- HPV/pre-cancerous cervical lesions not reportable in Minnesota
- Attempted linkage with cancer registry proved challenging

MDH

MIIC

Methods

- Linkage with Hepatitis B Disease Surveillance Database
  - MIIC and Hepatitis B in same division
    - Simplified data sharing
    - Hepatitis Unit data request form
  - Data Received
    - 798 individuals with new diagnoses in 2015
    - First, middle, and last name, and date of birth
- Matching Procedure
  - Used list matching algorithm in MIIC user interface
  - Matched by name and date of birth

MDH

MIIC

Results

- 606 (76%) individuals matched using MIIC algorithm
- Of unmatched, 69 (36%) had more than one possible match
- Several individuals had very common names

Limitations

- Limited information from surveillance database
  - Restricted matching potential
- Participation in MIIC not mandated
  - Individuals (especially adults) may not be in MIIC

Conclusions

- This was successful!
  - High match rate with minimal data
- Consider pursuing other collaborations with cancer registry
  - Continue to work on relationship going forward

Establishing Data Linkages for Targeted Immunization Data Analyses: New York City

Kathleen Blaney, MPH, RN
Bureau of Immunization
New York City Department of Health and Mental Hygiene

NYC Health

Background (1)

- Objective: Demonstrate the feasibility of linking two New York City (NYC) Department of Health and Mental Hygiene (DOHMH) systems for the purpose of evaluating effectiveness of the Human Papillomavirus (HPV) vaccine

Background (2)

- Possible linkage partners
  - New York State Cancer Registry
  - Callen-Lorde Community Health Center
  - Bureau of Sexually Transmitted Disease Control (BSTDC)
    - Relationship with Bureau of Immunization (BOI)

Background (3)

Citywide Immunization Registry (CIR)

- Established in 1997
- Reporting of all immunizations given to people younger than 19 years has been mandated since 2005
- Reporting of adult immunizations requires patient consent
- Contains approximately 6.5 million patient records and over 88 million immunizations

STD-Electronic Health Record (STD-EHR)

- Available since 2005
- Contains clinical information for patients seen at 8 Sexual Health clinics run by DOHMH

NYC Health

Methods (1)

BOTH	• Discussion on methodology
BOI	• IRB application and determination of exemption
BSTDC	• Identification of women who had a Pap smear from 2011–2015 in STD-EHR • First Pap smear data used in analysis
BOI	• BSTDC data match to immunization records in CIR using internal matching algorithm and manual review
BOI	• CIR data extraction of all immunizations given
BSTDC	• STD- EHR data extraction including Pap smear results and genital warts, followed by de-identification of records to create analytic dataset
BOI	• Final dataset refined to include only those who had immunizations after 9 years of age and women who were 24 years and younger at time of Pap

NYC Health

Methods (2)

- Variables
  - Matching variables: last name, first name, middle name, date of birth, gender, mother's maiden name, phone number, address
  - Independent variable: HPV vaccine status
  - Dependent variables: Pap smear test result, genital warts diagnosis

NYC Health

Results (1)

9,912

- Initial data pulled from STD-EHR
- Included number of unique women with Pap smear from 2011 to 2015

4,197

- 42.3% matched to CIR

2,975

- 70.9% found to have immunizations after 9 years

2,132 (Final analytic data set)

- 71.6% were 24 years and younger

Results (2)

- There was no significant relationship between HPV vaccination and Pap smear result
- Women vaccinated with HPV were less likely to be diagnosed with genital warts (OR=0.50, 95% CI 0.33-0.76)
  - A 47% reduction in genital warts diagnoses was found among those vaccinated

NYC Health

Limitations

- Possible underestimation of HPV vaccine coverage due to incomplete CIR capture
  - Under-reporting of HPV vaccine doses administered to adolescents
  - The reporting of adult immunizations to the CIR is not mandated and requires patient consent
  - Women receiving care at BSTDC clinics may receive care in adjacent counties or states

Conclusions

- Linkage of an immunization registry and an electronic health record is feasible and may be a valuable and cost-effective tool in conducting vaccine effectiveness analyses at the population level

NYC Health

Future Implications

- This type of linkage holds promise for future studies on HPV vaccine effectiveness

For more information, contact CDC
1-800-CDC-INFO (232-4636)
TTY: 1-888-232-6348 www.cdc.gov

The findings and conclusions in this report are those of the authors and do not necessarily represent the official position of the Centers for Disease Control and Prevention.

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