Improving race and ethnicity completeness in reportable disease surveillance data by matching to external data sources

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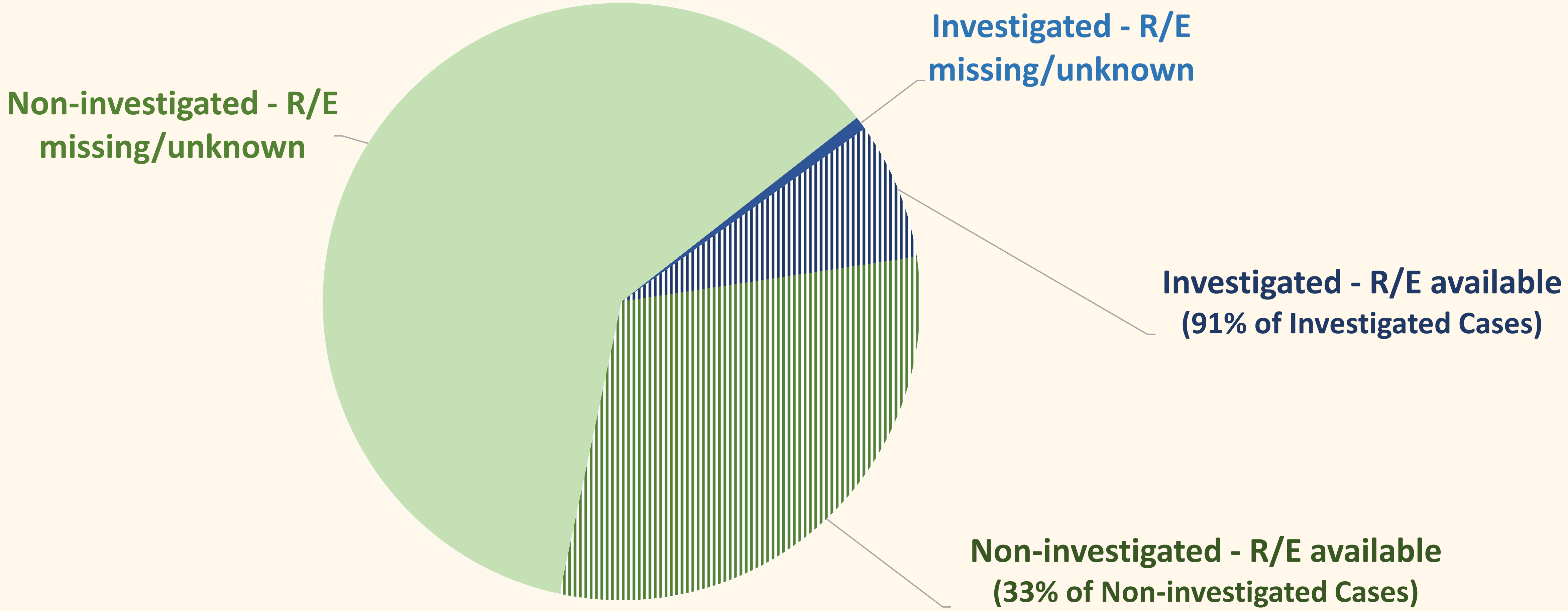
Background

The availability of race and ethnicity (R/E) data for cases of reportable disease is critical for

- understanding disparities in disease incidence and outcomes
- developing and evaluating the success of strategies to address these disparities

Availability of race & ethnicity data in the NYC Communicable Disease Surveillance System (Maven)

Race Ethnicity is Complete for 38% of Total Cases*



Confirmed and probable cases N=63,777

Purpose

- Determine the quality of R/E data found in the external sources
- Inform the decision on which external source can be used to improve the completeness of R/E data in Maven

Data sources

NYC Communicable disease (Maven - CD)

Confirmed, probable, suspect

Diagnosis years 2000 - 2016

External Sources

Combined surveillance database

- HIV, TB, STD, >30 communicable diseases, death records, A1C
- Diagnosis years 2000 – 2013

Hospitalization/Healthcare database (SPARCS)

- Inpatient, outpatient, emergency room visits
- Discharge years 2000 – 2015

Health Information Exchange (HIE)

- Any patient with a Hepatitis C ICD 9/10, lab result, or medication reported to HIE between July and December 2016

Methods - Record matching and QA

- SPARCS dataset
  - Matching done on keys: parts of first name, last name, SSN, DOB, sex
  - QA – random sample manually reviewed

- Combined surveillance database
  - Common person ID exists in matched dataset and Maven-CD

- HIE
  - Matching done on key: parts of first name, last name, DOB

Methods - Race & ethnicity value cleaning

Collapsed race & ethnicity values
Hispanic
American Indian/Alaska Native, non-Hispanic
Asian, non-Hispanic
Black/African American, non-Hispanic
Native Hawaiian/Pacific Islander, non-Hispanic
White, non-Hispanic
Multiracial (>1 race), non-Hispanic
Other, non-Hispanic
Missing/Unknown

Methods - Race & ethnicity value matching

- The “gold standard” was used to evaluate concordance
  - Investigated cases from Maven used as a proxy “gold standard”
  - R/E values that were Missing/Unknown were not used

Type of R/E value or match	Maven	External data source
Exact informative	Asian	Asian
Exact non-informative	Other	Other
Mismatch	Asian	Black/African American

Methods - Measures

- Concordance: Exact informative only

	Maven - CD			
External source		Match	Mismatch	Concordance
	Match	A	B	(A/A+B)*100

- Concordance of R/E: Number of persons categorized as a specific R/E category in the external source that matched to the same R/E category in Maven over the total number of persons categorized as that same R/E in Maven

- Improvement: Replacing Maven R/E values that were Missing/Unknown with external source values that were not missing/unknown, multiracial or other
  - If post-match completeness is greater than pre-match completeness, we consider this an improvement

$$\textbf{R/E Completeness} = \left(\frac{\text{No. known R/E}}{\text{Total N Maven}}\right) * 100$$

Results – Person record match with Maven

Data source	Percent
Combined surveillance (2000 – 2013)	16%
SPARCS (2000 – 2015)	81%
HIE (July – December 2016)	73%

Results - Race & ethnicity value match

Data source	N	Concordance	R/E completeness	
			Pre-match (Maven only)	Post-match (Maven + Data source)
Combined surveillance	401,360	91%	44%	51%
SPARCS	579,124	91%	46%	76%
HIE*	7,005	NA	71%	89%

* Concordance not calculated because Hepatitis C cases are not investigated

Results - Concordance in the combined surveillance dataset

Combined surveillance database	Race & ethnicity categories	Concordance
	Hispanic	95%
	Black/African American, non-Hispanic	94%
	White, non-Hispanic	91%
	Asian, non-Hispanic	87%
	Other, non-Hispanic	19%
	American Indian/Alaska Native , non-Hispanic	17%
	Multiracial, non-Hispanic	7%
	Native Hawaiian/Pacific Islander, non-Hispanic	6%

Results - Concordance in the SPARCS match

	Race & ethnicity categories	Concordance
SPARCS	Black/African American, non-Hispanic	89%
	White, non-Hispanic	85%
	Asian, non-Hispanic	65%
	Hispanic	64%
	Other, non-Hispanic	33%
	American Indian/Alaska Native , non-Hispanic	13%
	Multiracial, non-Hispanic	0%
	Native Hawaiian/Pacific Islander, non-Hispanic	0%

Conclusions

- These preliminary results suggest we can improve our R/E data through importation of data from external sources
  - High person record match rate
    - 81% Maven to SPARCS
    - 73% HIE to Maven
  - High concordance
    - 91% SPARCS and combined surveillance database
  - > 10% improvement in R/E completeness
    - 13% combined surveillance database
    - 65% SPARCS
    - 25% HIE

Limitations

- R/E data from SPARCS and HIE sourced from electronic medical records (EMRs) which may not be accurate [1,2]
    - Perceived R/E by provider → Misclassification of R/E
- "Gold standard"
    - Approximately 11% of the cases that are investigated are by medical chart review, sourced from EMRs
    - Approximately 80% of investigated cases are by phone interview – quality of R/E data may vary across staff that collect these data

[1] West CN, Geiger AM, Greene SM, et al. Race and ethnicity: comparing medical records to self-reports. J Natl Cancer Inst Monographs. 2005;(35):72-4.

[2] Klinger EV, Carlini SV, Gonzalez I, et al. Accuracy of race, ethnicity, and language preference in an electronic health record. J Gen Intern Med. 2015;30(6):719-23.

Next steps

- Additional matches
    - Enhanced QA on matches
- HIE will conduct a person match to BCD’s reportable diseases for 2016
- Evaluate Multiracial category – Can it be more informative?
- Multivariable analysis to evaluate factors associated with missingness or mismatches

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Questions?

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