

# Time To Get It Right: Improving Accuracy Of Demographic Data In Maternal Health Records To Identify And Address Maternal Health Disparities

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NH AIM/ERASE Monthly Webinar  
March 10, 2022



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## Agenda

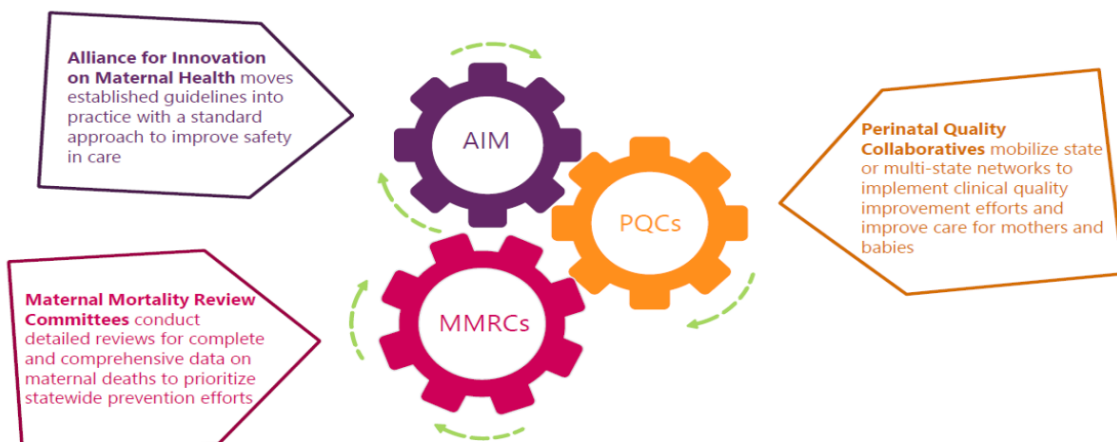
- I. Why this matters
- II. Data: Disaggregation & Standards
- III. How does your EHR align with the standards?
- IV. Comparing EHR and birth certificate records
- V. How can we get this right?
- VI. Improvements can be made!

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# I. Why This Matters

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## Critical Collaborations: NNEPQIN, ERASE and AIM



Created from a Centers for Disease Control, Division of Reproductive Health source

**NNEPQIN**  
NORTHERN NEW ENGLAND  
PERINATAL QUALITY IMPROVEMENT NETWORK

**AIM**  
ALLIANCE FOR INNOVATION  
ON MATERNAL HEALTH

**NH DIVISION OF  
Public Health Services**  
Improving health, preventing disease, reducing costs for all

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# Why This Matters

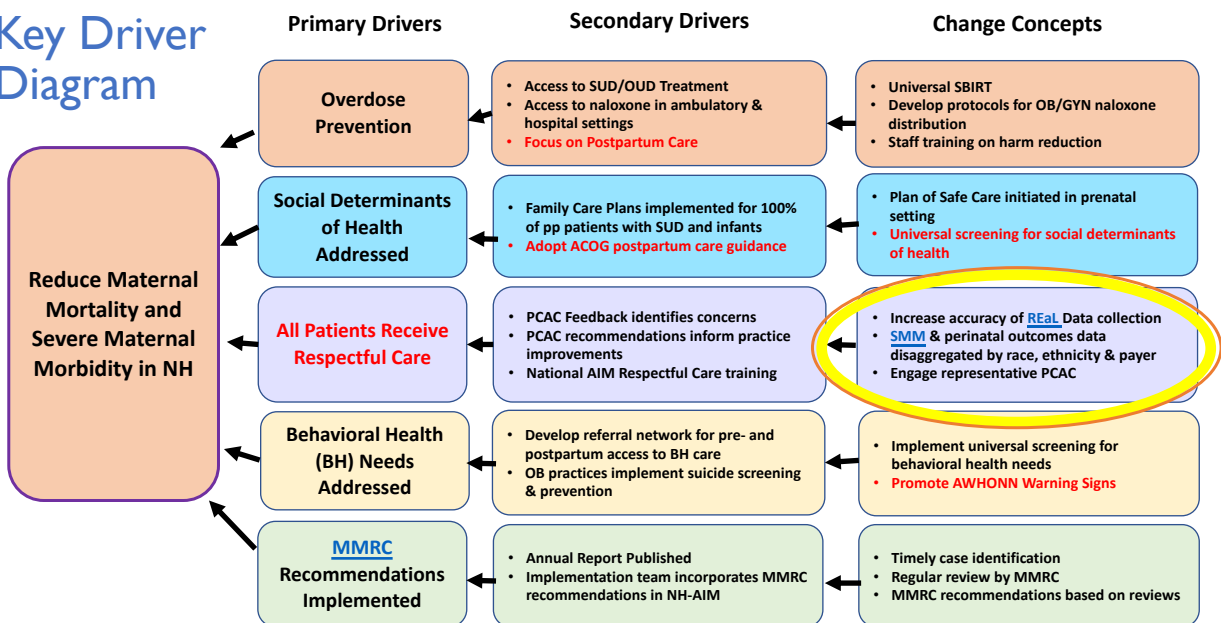
Maternal health disparities are real

CMS encourages us to collect demographic data

AIM asks us to report disaggregated outcomes

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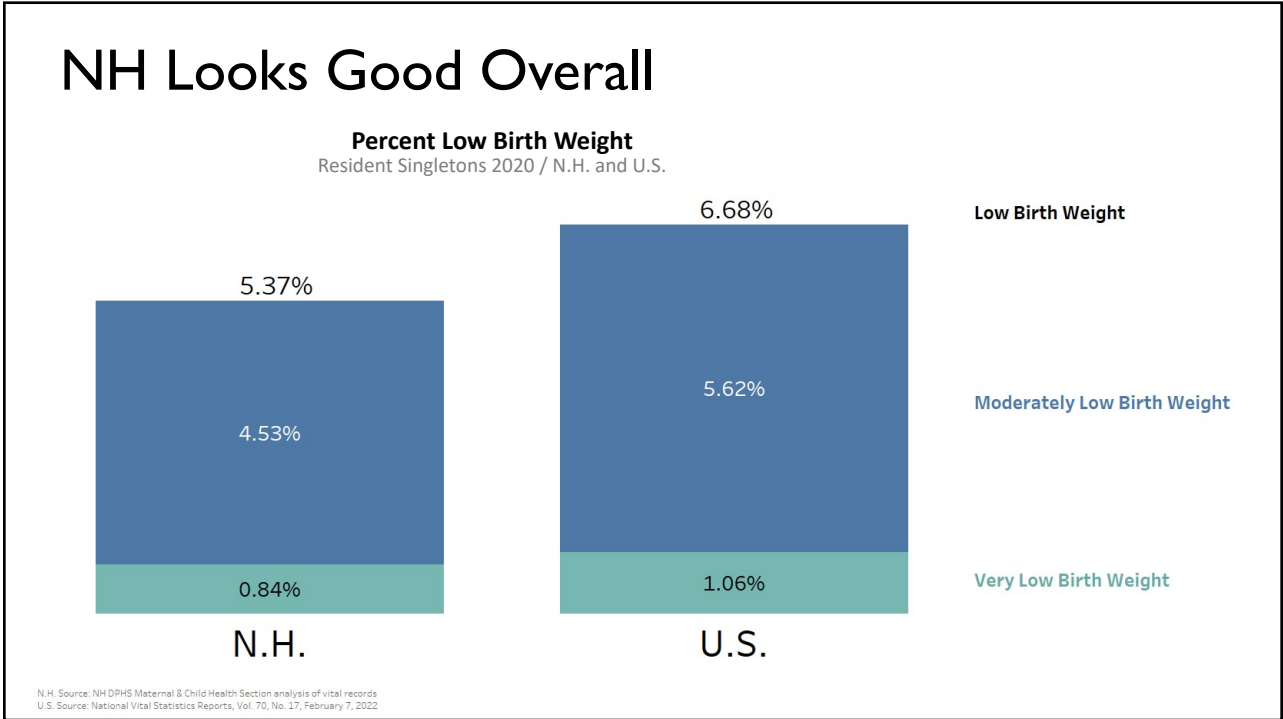
## NH-AIM Key Driver Diagram



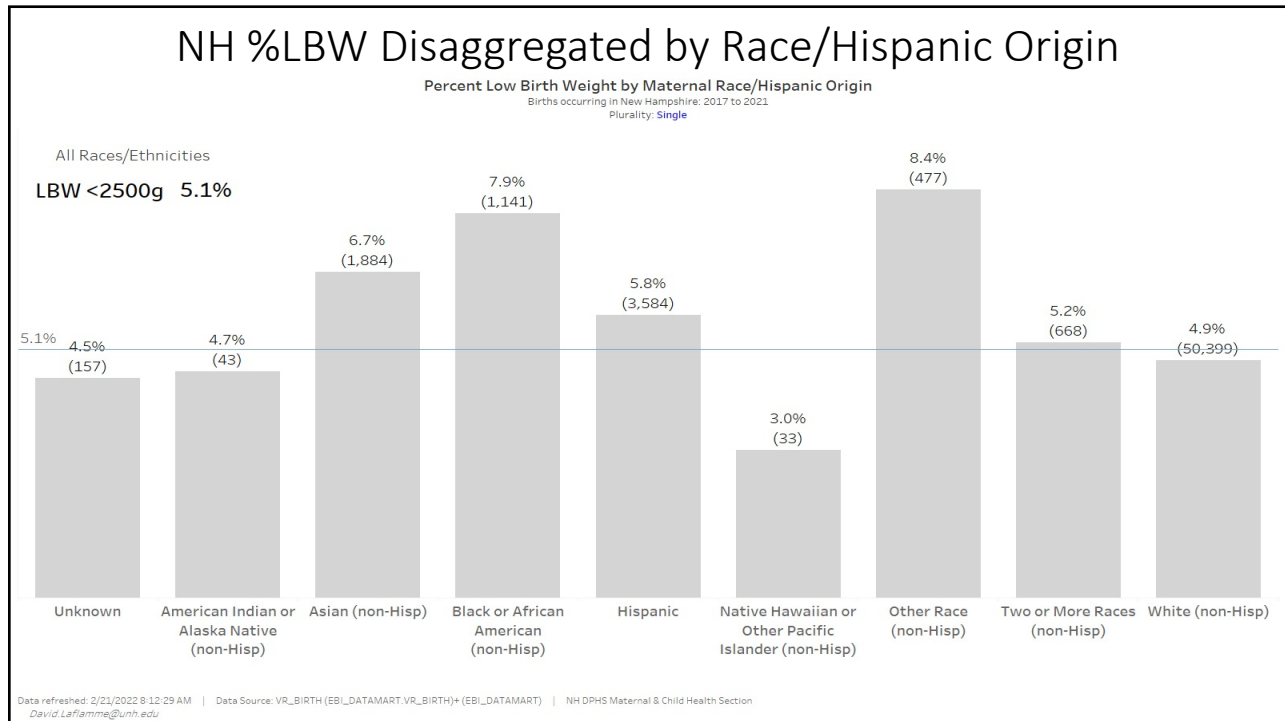
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## II. Data: Disaggregation & Standards

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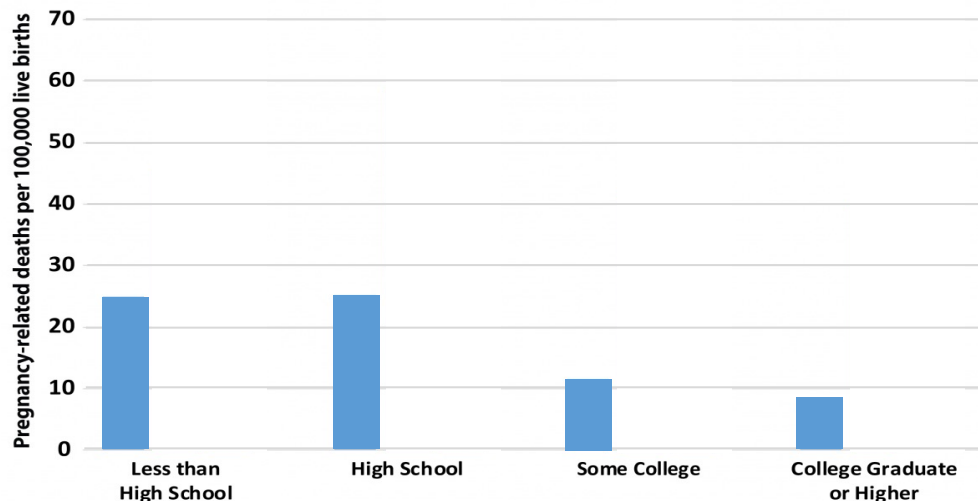
**Capacity to disaggregate data to identify disparities depends on our *collection* of those demographic/SES/SDOH identifiers!**

...by age	...by disability status
...by geography	...by migrant status
...by insurance status	...by access to housing
...by sexual orientation	...by income
...by gender identity	...by employment status
<b>...by race/ethnicity</b>	...by education level
...by language	...by incarceration history
...by veteran status	...by distance to service

**And those identifiers need to be collected *correctly* and *consistently*!**

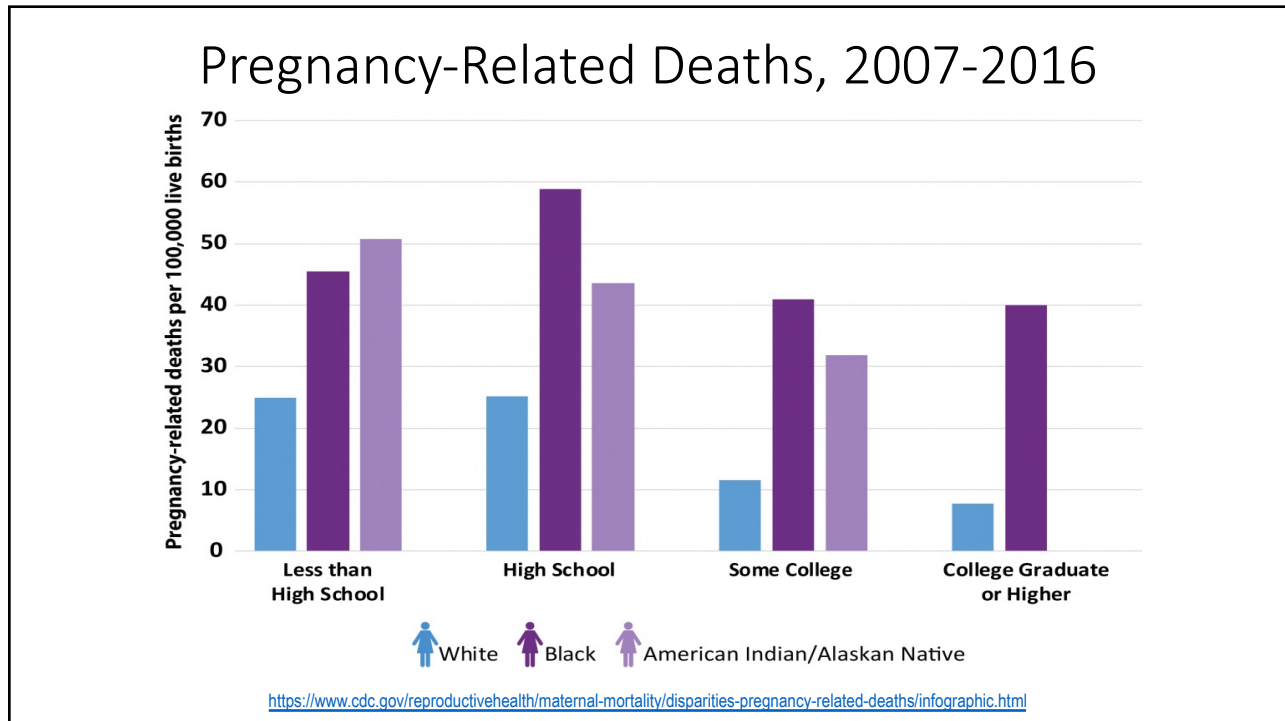
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## Pregnancy-Related Deaths, 2007-2016

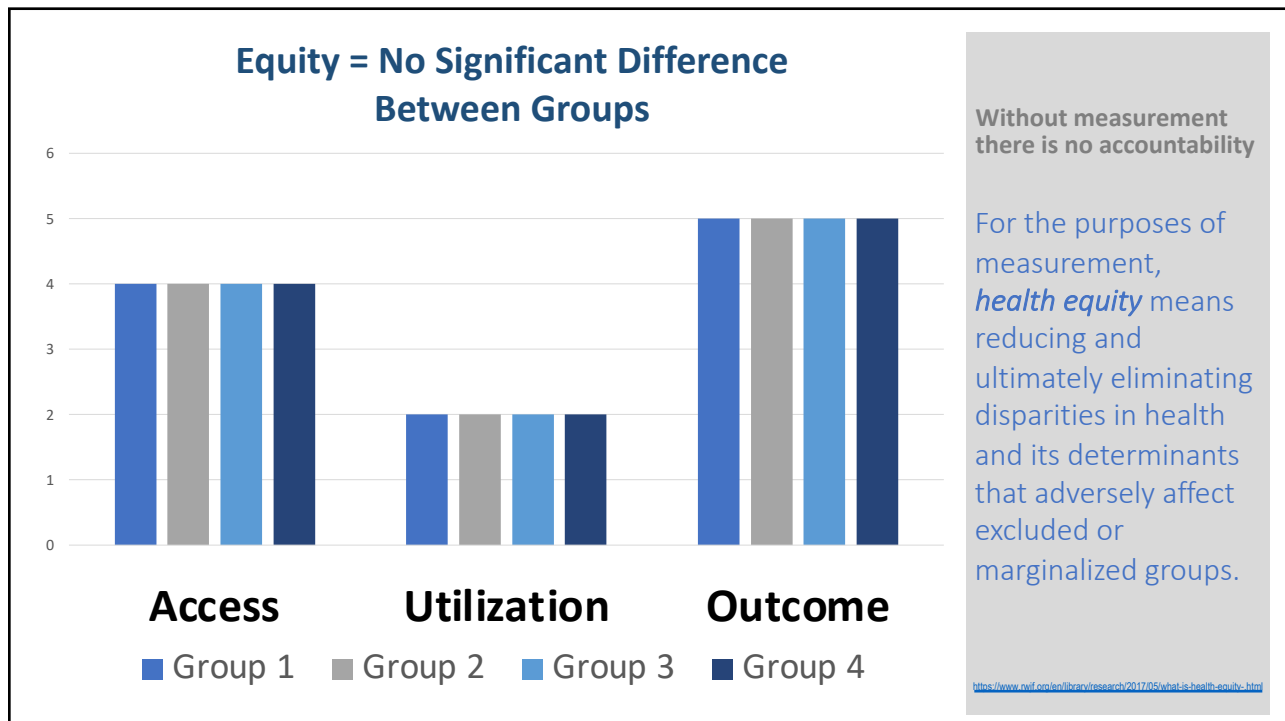


<https://www.cdc.gov/reproductivehealth/maternal-mortality/disparities-pregnancy-related-deaths/infographic.html>

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# Data Standards

U.S. Office of Management and Budget (OMB) Standards for the Classification of Federal Data on Race and Ethnicity, issued in 1997

OMB 1997 (Minimum Categories)	
Select one or more	
<b>Are you Hispanic, Latino/a, or Spanish Origin</b> (One or more categories may be selected)	
Not Hispanic or Latino	
Hispanic or Latino	
<b>Race</b>	
White	
Black or African American	
American Indian or Alaska Native	
Asian	
Native Hawaiian or Other Pacific Islander	
More than one race	

- For census ("denominator"), household surveys, administrative forms and records, medical and other research, and other data collections.
- A **minimum** set of categories for data on race and ethnicity
- Self-identification is the preferred means
- Do not tell an individual who he or she is, or specify how an individual should classify himself or herself

*The categories represent a social-political construct designed for collecting data on the race and ethnicity of broad population groups in this country, and are not anthropologically or scientifically based.*

[https://obamawhitehouse.archives.gov/omb/fedreg\\_1997standards](https://obamawhitehouse.archives.gov/omb/fedreg_1997standards)

<https://www.govinfo.gov/content/pkg/FR-1997-10-30/pdf/97-28653.pdf>

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U.S. Office of Management and Budget	<b>OMB 1997</b> (Minimum Categories) Select one or more <b>Are you Hispanic, Latino/a, or Spanish Origin</b> (One or more categories may be selected) Not Hispanic or Latino Hispanic or Latino  <b>Race</b> White Black or African American American Indian or Alaska Native Asian  Native Hawaiian or Other Pacific Islander  More than one race	<b>2011 HHS Data Collection Standards</b> Select one or more <b>Are you Hispanic, Latino/a, or Spanish Origin</b> (One or more categories may be selected) No, not of Hispanic, Latino/a, or Spanish origin Yes, Mexican, Mexican American, Chicano/a Yes, Puerto Rican Yes, Cuban Yes, Another Hispanic, Latino/a or Spanish origin  <b>What is your race?</b> (One or more categories may be selected) White Black or African American American Indian or Alaska Native Asian Indian Chinese Filipino Japanese Korean Vietnamese Other Asian Native Hawaiian Guamanian or Chamorro Samoan Other Pacific Islander  More than one race	U.S. Department of Health and Human Services, October 30, 2011, issued as section 4302 of the Affordable Care Act: Data Collection Standards for Race, Ethnicity, Sex, Primary Language, and Disability Status
	<a href="https://aspe.hhs.gov/reports/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-disability-0">https://aspe.hhs.gov/reports/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-disability-0</a>	<a href="https://aspe.hhs.gov/reports/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-disability-0">https://aspe.hhs.gov/reports/hhs-implementation-guidance-data-collection-standards-race-ethnicity-sex-primary-language-disability-0</a>	

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### III. How does your EHR align with the standards?

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<ul style="list-style-type: none"> <li>• Which set of standards does your hospital EHR use?</li> <li>• Does your EHR have the right categories?</li> </ul>	<p><b>OMB 1997</b> (Minimum Categories)</p> <p>Select one or more</p> <p><b>Are you Hispanic, Latino/a, or Spanish Origin</b> (One or more categories may be selected)</p> <p>Not Hispanic or Latino</p> <p>Hispanic or Latino</p>	<p><b>2011 HHS Data Collection Standards</b></p> <p>Select one or more</p> <p><b>Are you Hispanic, Latino/a, or Spanish Origin</b> (One or more categories may be selected)</p> <p>No, not of Hispanic, Latino/a, or Spanish origin</p> <p>Yes, Mexican, Mexican American, Chicano/a</p> <p>Yes, Puerto Rican</p> <p>Yes, Cuban</p> <p>Yes, Another Hispanic, Latino/a or Spanish origin</p>	<ul style="list-style-type: none"> <li>• Can one select all that apply?</li> <li>• Is there an “other (specify)” or additional categories?</li> </ul>
	<p><b>Race</b></p> <p>White</p> <p>Black or African American</p> <p>American Indian or Alaska Native</p> <p>Asian</p> <p>Native Hawaiian or Other Pacific Islander</p> <p>More than one race</p>	<p><b>What is your race?</b> (One or more categories may be selected)</p> <p>White</p> <p>Black or African American</p> <p>American Indian or Alaska Native</p> <p>Asian Indian</p> <p>Chinese</p> <p>Filipino</p> <p>Japanese</p> <p>Korean</p> <p>Vietnamese</p> <p>Other Asian</p> <p>Native Hawaiian</p> <p>Guamanian or Chamorro</p> <p>Samoan</p> <p>Other Pacific Islander</p> <p>More than one race</p>	

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## How Does Your Process Work?

Do staff explain why the data is being collected?

Standard language/statement?

- Data is confidential
- Data is used for improving services for all

Are patients able to self-identify?

Are staff comfortable...?

asking the questions?

responding to patient's inquiries/responses?

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## IV. Comparing Data Sources: Birth Certificate & EHR Linkage

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NH Birth Certificate Select one or more	Hospital A Select only one race and one ethnicity	Hospital B Select one or more
<b>Mother of Hispanic Origin?</b> (Check the box that best describes whether the mother is Spanish/Hispanic/Latina or check the "No" box if the mother is not Spanish/Hispanic/Latina)	<b>Ethnicity</b>	<b>Ethnicity</b>
No, not Spanish/Hispanic/Latina	Non-Hispanic or Latino	Not Hispanic nor Latino
Yes, Mexican, Mexican American, Chicana	Hispanic or Latino	Hispanic or Latino
Yes, Puerto Rican		
Yes, Cuban		
Yes, other Spanish/Hispanic/Latina (Specify): _____		
Unknown	Unknown	Unknown or Unavailable
	Refused to Answer	Declines to List
<b>Mother's Race</b> (Check one or more races to indicate what the mother considers herself to be)	<b>Race</b>	<b>Race</b>
White	White	White
Black or African American	Black/African American	Black or African American
American Indian or Alaska Native (Name of the enrolled or principal tribe): _____	Indian/Alaskan Native	American Indian/Alaska Native
Asian Indian	Asian	Asian
Chinese		
Filipino		
Japanese		
Korean		
Vietnamese		
Other Asian (Specify): _____		
Native Hawaiian	Hawaiian/Pacific Islander	Native Hawaiian/Other Pacific Islander
Guamanian or Chamorro		
Samoan		
Other Pacific Islander (Specify): _____		
Other (Specify): _____	Other	
Unknown	Unknown	Unknown/Unavailable
	Refused/Declined to Provide	Declines to List
More than one race	Not possible since not select one or more	More than one race

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## Once you compare your EHR format with the HHS 2011/Birth Certificate format...

- Let's do the linkage in every birth hospital and see what we find
- The BC appears to be higher quality race and ethnicity data
  - Possibly due to best practice of self-identification
  - Still potential for inconsistency between and within birth hospitals
    - Possible literacy challenges
- Birth Certificate reflects "better" HHS standards

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## Example finding from one hospital

The birth certificate identified nearly 50% more racial diversity<sup>†</sup> compared to EHR alone

46%

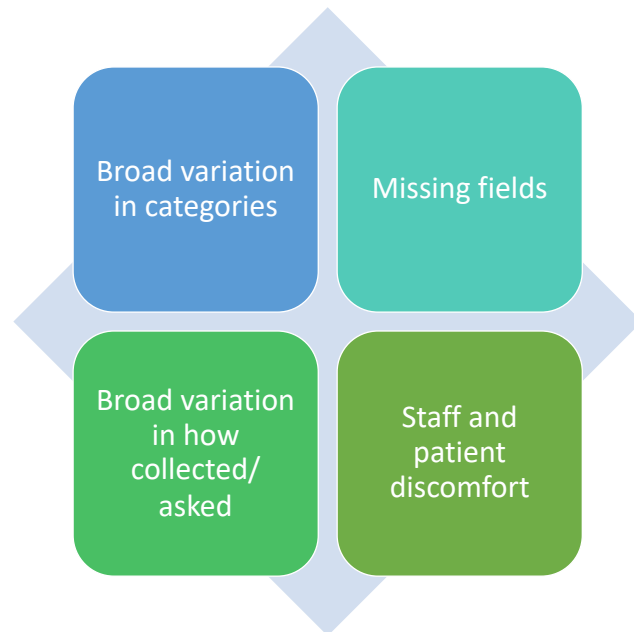
The EHR captured only about three-quarters of mothers of Hispanic origin compared to the birth certificate

77%

<sup>†</sup> Other than single white race

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## EHR Issues



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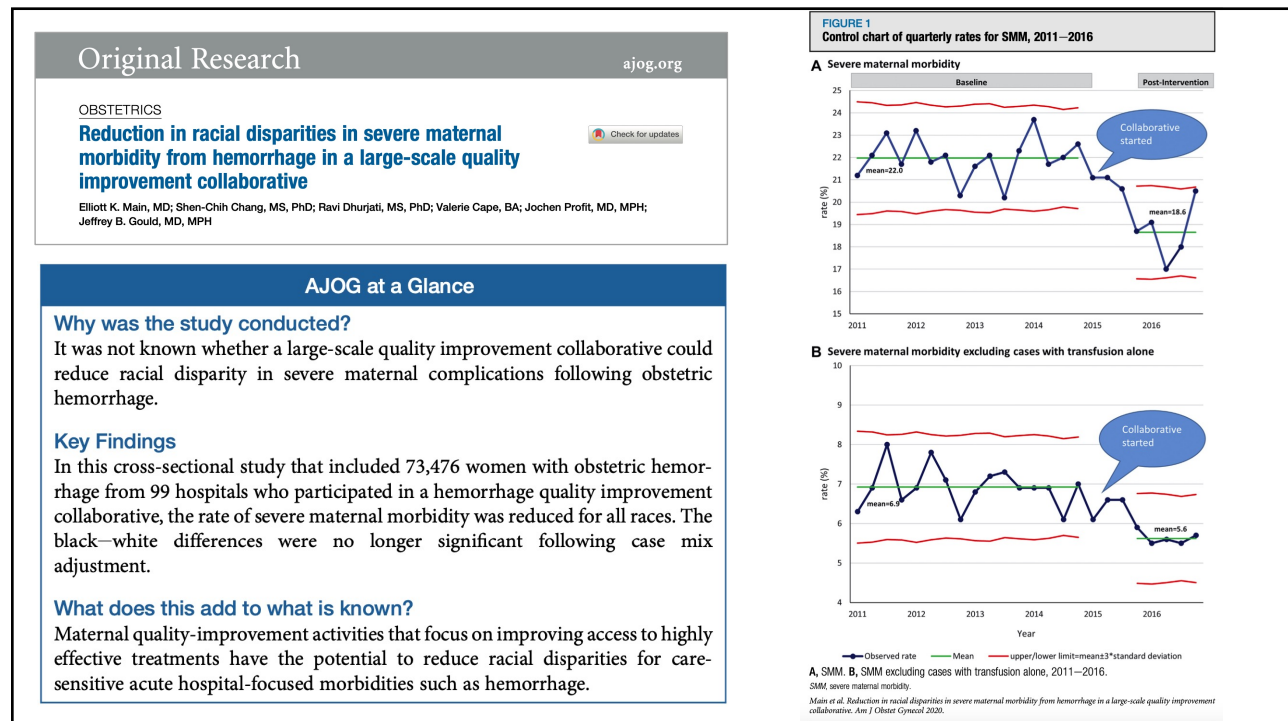
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## VI. Improvements can be made!

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Improvements  
can be made!

- Stratify your data and look at outcomes to uncover hidden variation and identify disparities
- National guidelines exist
- Vital records provide a useful comparison for demographic data contained in EHRs, and can be used to track improvement over time

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## Questions?

THANK YOU!

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