Race and Ethnicity Data Collection: Strategies, Challenges, & Opportunities

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Methods and Strategies for Data Collection

- **Indirect Methods:**
  - Geographic Assignment
    - Assign race/ethnicity based on most common value at given geographic unit (census tract)
  - Bayesian Indirect Surname and Geocoding (BISG)
    - Statistical imputation using surname and geographic data
- **Direct Data Collection Methods:**
  - Collection at Enrollment/Re-enrollment
  - Obtaining data from EHR (Electronic clinical data systems)
  - Obtaining data from providers as part of claim
  - Surveying members and other outreach methods (e.g., annual newsletter)
  - Revising Health Risk Assessment
  - Website, customer contact center, submit grievances, etc.
  - When a member utilizes LEP services (interpreter, translation)
  - Care managers or those participating in health education or chronic disease management programs

Direct Data Collection Methods, Challenges, & Opportunities

Direct Data Collection Method	Challenges	Opportunities
Enrollment	Legal barriers/state laws preventing collection at enrollment (CA, MD, NJ, NH)	Check with governing bodies of DC Exchange to see if any laws prohibiting collection of race/ethnicity as part of enrollment. If not, start including it but with explanations as to why and how data will be used and not used.
	Challenges to revising enrollment forms (state agencies, employers)	
	HIPAA 834 transaction does not require inclusion of demographic codes	
Claims Data	HIPAA 837 transaction does not require use of demographic codes	Educate provider networks on provision of race/ethnicity on claims
Survey Data	Negative member reaction to surveys—the perception of potential discrimination for benefit eligibility, distrust, lack of understanding of the purpose	Design surveys, HRAs, or outreach materials that would have strong relevance for members to increase response rate. Explain why asking for this information and how it will be used to inform and improve care. Work with employers to survey members.
	Difficult to have successful outreach due to churn, address changes, hesitancy to respond	
	Some employers prohibit health plans from surveying their employees	
EHR Data	Not routinely shared with plans unless attached to claim but important to inform/educate consumers on this	Can consider DC-specific bill to require data sharing between providers and plans (Look at CA SB 853 and CA SB 137 Provider Directory Law)
	Interoperability issues, included in USCDI v2 (July 2021)	

Issues with Data Collection Methods: Indirect Data

Challenge	Opportunity
Often inaccurate—could mask disparities	Review algorithms for biases and inaccuracies and update appropriately. Enhance data that algorithms are based on
Lack of trust with these methods	
If plans/organizations use different indirect methods, could produce different results so not apples to apples comparisons on disparities identification and reduction	Require software vendors who support the accreditation and measurement process to load a standardized methodology into their programs
Indirect data should not be used to inform direct member interventions. Do not populate this data into membership databases	Use for population health management and disparity identification

Sample Scripts and Forms for Collecting Race and Ethnicity

Importance of Introductory Script

Important to build trust with community when collecting this information. Introductory script should include:

- Why collecting this information
- Providing information is voluntary
- How it will be used and how it will NOT be used
- How it will be protected

Sample Script*: Why are we asking about your race and ethnicity?
All of our members deserve high quality healthcare. By sharing your race and ethnicity with us, you are helping us make sure everyone receives the best care possible. We ask every member the same questions. Your responses are private and will be securely stored. Your responses will not impact your benefits in any way but will only be used to inform how we provide health care to our communities. You do not have to answer these questions if you do not feel comfortable.

Definitions:
Race is one way our society groups people together. Categories of race have been made up over time. These categories are often based on things we can see, like a person's skin color. Our race is a combination of the races of our parents.

Ethnicity is based on how we identify with other people when we share certain experiences or backgrounds with them. This may include things like language, history, religion, or culture.

Adapted from Mount Sinai. http://images.healthcare.pressganey.com/Web/PressGaneyAssociatesInc/%7B6df15bb8-92aa-44b7-ac82-fcea3a00d5f0%7D_Press_Ganey_Equity_Partnership_Webinar__Jan_20_2021_Mount_Sinai.pdf

Example Form to Collect More Granular Race/Ethnicity & OMB*

1. Do you identify as LatinX/Hispanic/Spanish? (select one)

- I am LatinX/Hispanic/Spanish
- I am not LatinX/Hispanic/Spanish
- I decline to respond

Start by asking ethnicity first

[Allow organizations to choose which nationalities to include when asking more granular race/ethnicity questions based on most common nationalities in their areas.]

1A. If you are LatinX/Hispanic/Spanish, what is your background? If you are not LatinX/Hispanic/Spanish, please skip this question.
(Choose up to two or write down your response if your background is not listed)

- Argentinian
- Brazilian
- Cuban
- Dominican
- Honduran
- Puerto Rican
- Columbian
- Ecuadorian
- Mexican
- Mexican American Indian
- Salvadorian
- Other (please specify): _____

* Adapted from Mount Sinai

2. Please tell us which race(s) you identify with: *(select one or two)*

- American Indian or Alaska Native
- Black
- White
- Asian
- Native Hawaiian or Pacific Islander
- I decline to respond

2A. If you identify as Asian, Black, Native Hawaiian, Pacific Islander, White, or American Indian or Alaska Native, please tell us your background. *(If your background is not listed, please let us know by writing on the blank line.)*—(Organizations may choose which nationalities to include when asking more granular race/ethnicity questions based on most common nationalities in their areas)

Black
- African American
- Barbadian
- Cameroonian
- Congolese
- Ethiopian
- Ghananian
- Haitian
- Jamaican
- Kenyan
- Nigerian
- Sengalese
- Somalian
- South African
- _____

Asian
- Asian Indian
- Bangladeshi
- Burmese
- Cambodian
- Chinese
- Filipino
- Hmong
- Indonesian
- Japanese
- Korean
- Laotian
- Pakistani
- Thai
- Vietnamese

Native Hawaiian and Pacific Islander
- Chuukese
- Chamarro
- Guamanian
- Marshallese
- Native Hawaiian
- Papua New Guinean
- Samoan
- _____

White
- Arab
- European
- North African
- _____

American Indian or Alaska Native
- Athabascan
- Creek
- Sioux
- Wichita
- Yakima
- Wichita
- _____

Considerations

- Can take time to create data systems, collection points, coding systems, and technological infrastructure
- Involve IT Programmers as part of conception and design to provide expert advice on using codes (alpha, numeric, or combination)
    - Include other appropriate stakeholders, such as staff who would collect or use this information, data informatics staff, consumer members, providers, etc.
- Race/Ethnicity categories and codes selected
    - Center for Disease Control and Prevention (CDC) and Office of Management and Budget (OMB) categories for race and ethnicity used

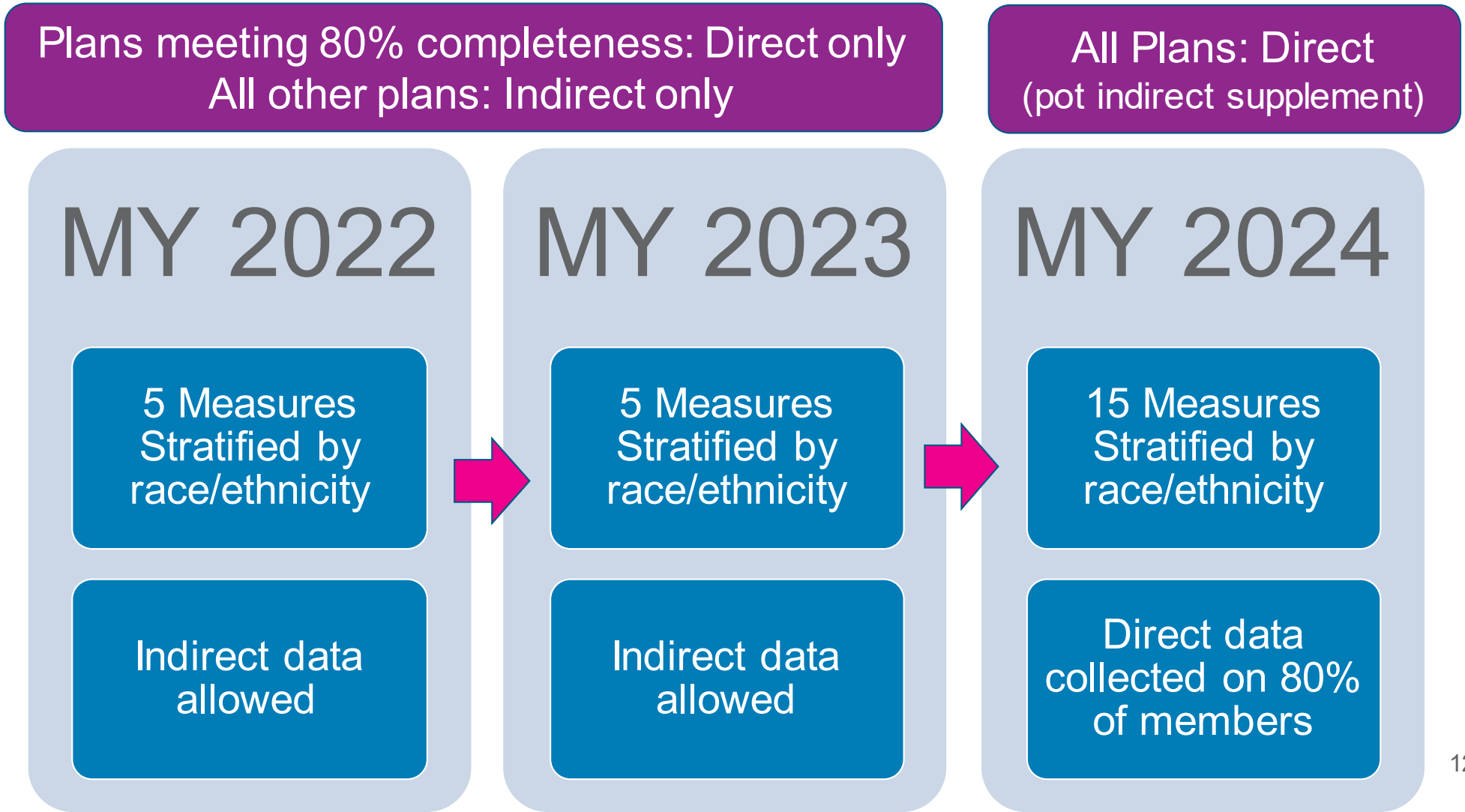
NCQA Proposal on Stratifying HEDIS Measures by Race & Ethnicity

Overview of NCQA Proposal to Stratify Select HEDIS Measures by Race/Ethnicity

- Purpose: advance health equity by leveraging HEDIS to hold health plans accountable for disparities in care among their patient populations
  - NCQA seeks to implement a required stratification by race/ethnicity to select HEDIS measures in order to encourage health plans to integrate equity into quality measurement efforts.
  - This approach will help identify plans that are successful in eliminating disparities in performance
- Overview:
  - 3-year phased approach for implementing the stratifications
  - Goal: require plans to report measure performance by race and ethnicity using directly collected member data by MY 2024
  - In MY 2022 and MY 2023, plans that meet a direct data completeness threshold of 80% for race and 80% for ethnicity will be allowed to report the stratification using their own directly collected member data for race and ethnicity. Others can use indirect methods.
  - Direct data is the gold standard

Area #1: Timeline

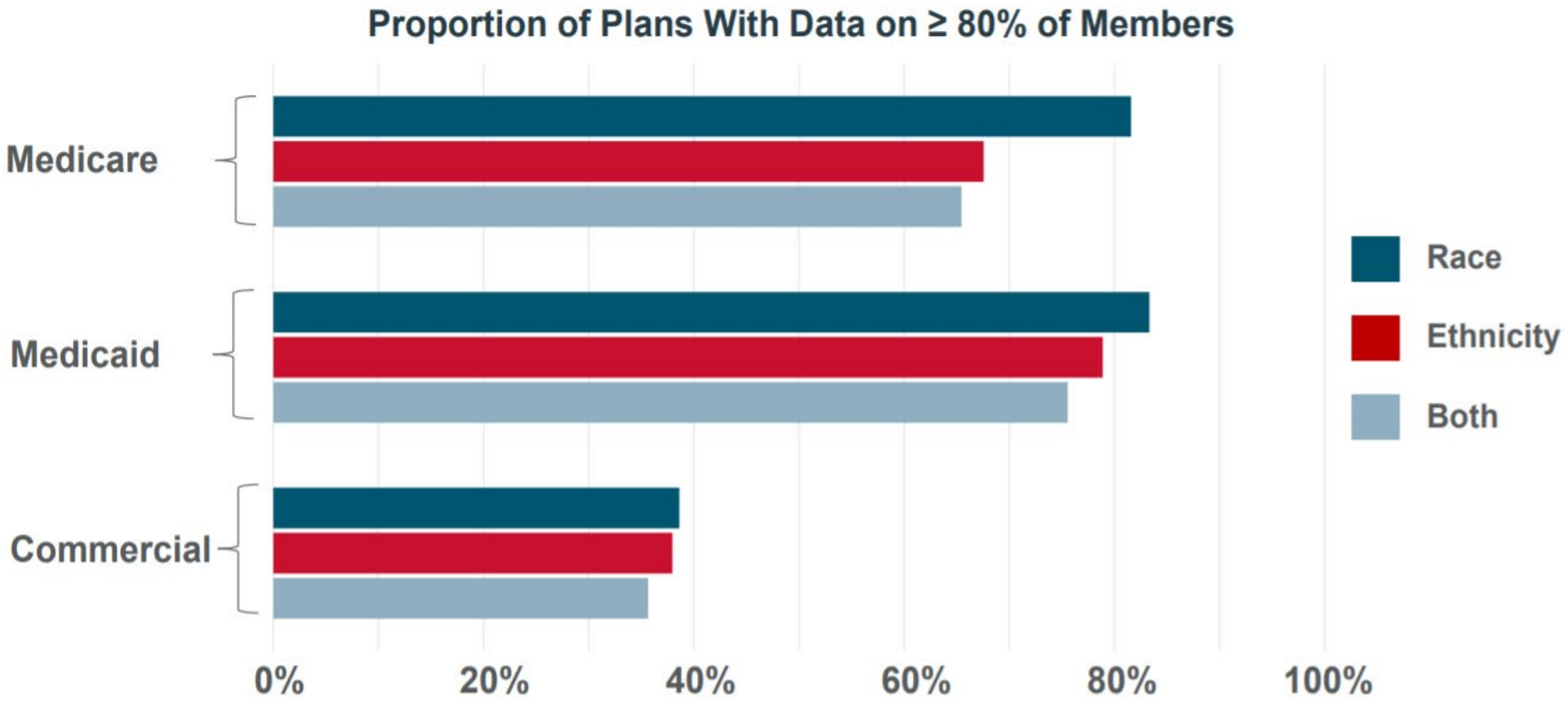
- NCQA will convene a Health Equity Expert Work Group throughout 2021 to gather ongoing feedback as they finalize the stratification specification



Area #3: Candidate Measures for Race/Ethnicity Stratification in MY 2022

Domain	Measure	Product Lines
Effectiveness of Care	Controlling High Blood Pressure	Commercial, Medicaid, Medicare
	Comprehensive Diabetes Care (HbA1c Control <8%)	Commercial, Medicaid, Medicare
	Comprehensive Diabetes Care (Eye Exam)	Commercial, Medicaid, Medicare
	Antidepressant Medication Management	Commercial, Medicaid, Medicare
	F/U after ED Visit for People with Multiple High-Risk Chronic Conditions	Medicare
Access and Availability of Care	Adults' Access to Preventive/Ambulatory Health Services	Commercial, Medicaid, Medicare
	Prenatal and Postpartum Care	Commercial, Medicaid
Utilization	Well-Child Visits in First 30 months of Life	Commercial, Medicaid
	Child and Adolescent Well-Care Visits	Commercial, Medicaid
	Mental Health Utilization	Commercial, Medicaid, Medicare

Proportion of Plans with Race/Ethnicity Data on >80% of Members



https://www.ncqa.org/wp-content/uploads/2021/02/Future-of-HEDIS_Digital-Measures-and-Equity_20210224.pdf?utm_source=sf&utm_medium=email&utm_campaign=ncqaevents&utm_content=20210225

We’re all on this journey together

https://www.forbesindia.com/article/stanford/redefining-success-adopt-the-journey-mindset-to-move-forward/56603/1

Questions or Comments?

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