Understanding Disparities Through Race & Ethnicity Data

Considerations, Challenges, and Possibilities for Better Decision Making to Eliminate Disparities in Outcomes

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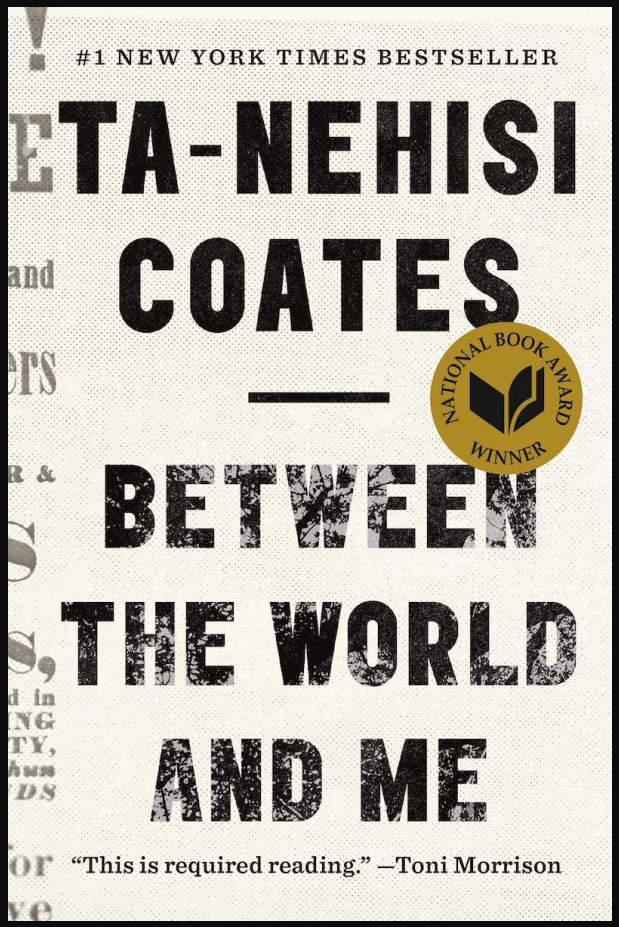
Definition of Race

"**Race is a social construct** used to group people. Race was constructed as a hierarchal human-grouping system, generating racial classifications to identify, distinguish and marginalize some groups across nations, regions and the world."

~ National Genome Research Institute

https://www.genome.gov/genetics-glossary/Race



https://ta-nehisicoates.com/books/between-the-world-and-me/

"But race is the child of racism, not the father. " ~Ta-Nehisi Coates

What is underneath the social construct of race that we can change?

racialize verb

ra·cial·ize ˈrā-shə-ˌlīz

racialized; racializing; racializes

transitive verb

: to give a racial character to : to categorize, marginalize , or regard according to race (see RACE entry 1 sense 1a)

> Just as racist power *racializes* people, racist power *racializes* space. The ghetto, The inner city. The third world.
> – Ibram X. Kendi

> *Racializing* poverty helps to distract from the systemic factors at the foundation of both racial and economic inequality.
> – Keeanga-Yamahtta Taylor

marginalize verb

mar·gin·al·ize ˈmärj-nə-ˌlīz ˈmär-jə-nᵊl-ˌīz

marginalized; marginalizing

transitive verb

: to relegate (see RELEGATE sense 2) to an unimportant or powerless position within a society or group

> We are protesting policies that *marginalize* women.

minoritize [mahy-**nawr**-i-tahyz, **-nor-**] SHOW IPA

verb (used with object)

1 to make (a person or group) subordinate in status to a more dominant group or its members:
Though women constitute a majority of employees, they are routinely minoritized, passed over for promotion, and poorly represented in upper management.

2 *Linguistics.* to devalue (a language), often by granting official status and thereby higher prestige to another, competing language in the same community:
French policies minoritized the Picard dialect until it was seriously endangered—today it has fewer than 500,000 native speakers.

subordinate 3 of 3 verb

sub·or·di·nate sə-ˈbȯr-də-ˌnāt

subordinated; subordinating

transitive verb

1 : to make subject or subservient

2 : to treat as of less value or importance

Need to Transition our Analytic Approach

Current State

- Using the socially constructed demographic variable of "race" in various forms of analysis as an **independent factor** or predictor to explain variation in outcomes

Approach implies race is biological and can be altered

Future State

- Understanding the **sources, structures, systems, and decision-making processes** that racialized & minoritized people encounter that help explain variation in outcomes including the ability to thrive

Focus on fixing the system and NOT the people

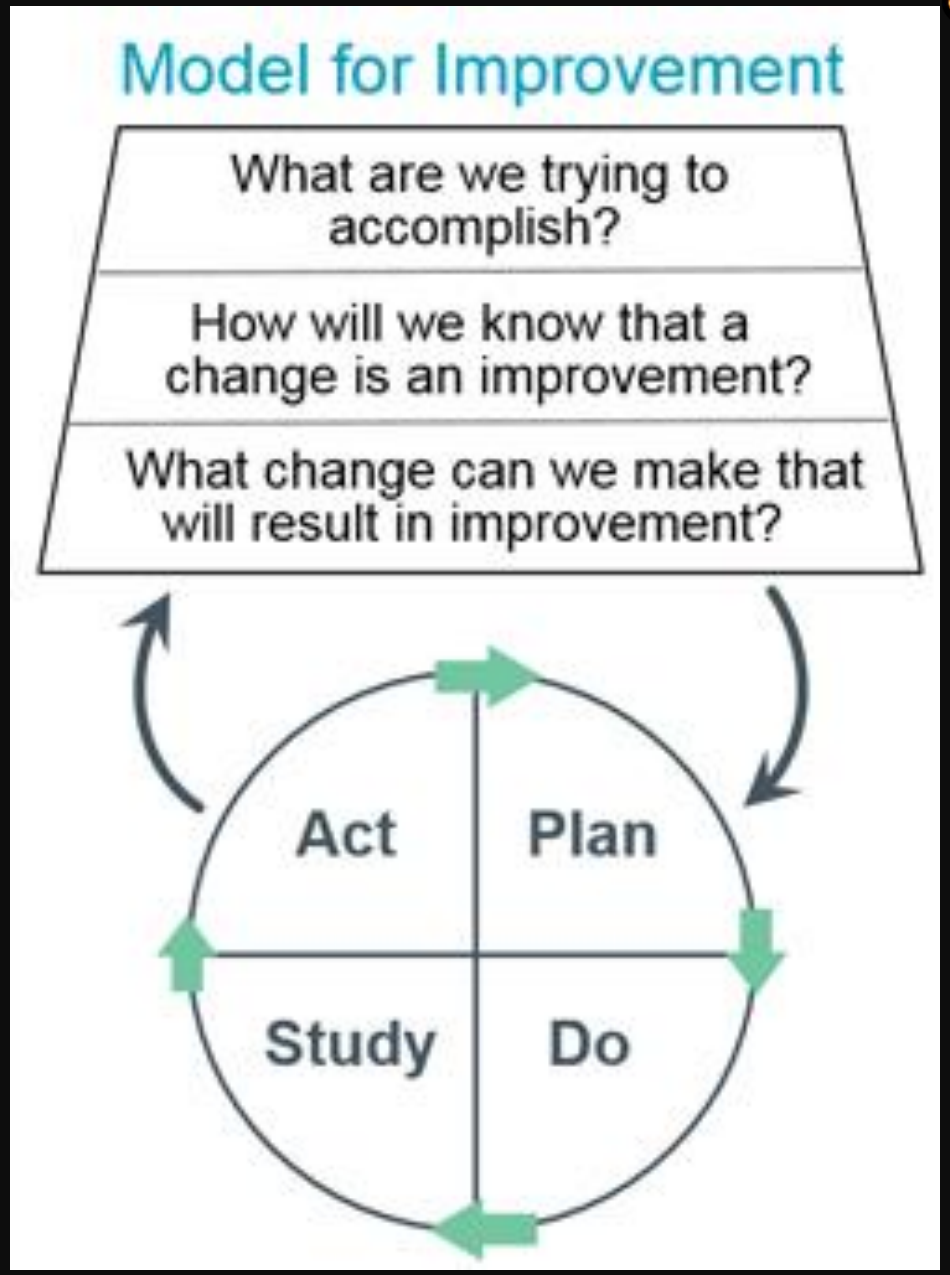
Critical QI Question to Answer

If outcomes differ by “race”, what are the **specific and intervenable** sources, structures, systems, operational processes & management choices that unfairly advantage and unfairly disadvantage racialized and minoritized populations in our health care system?

Use the 5 Whys to be curious about the system root causes NOT the people

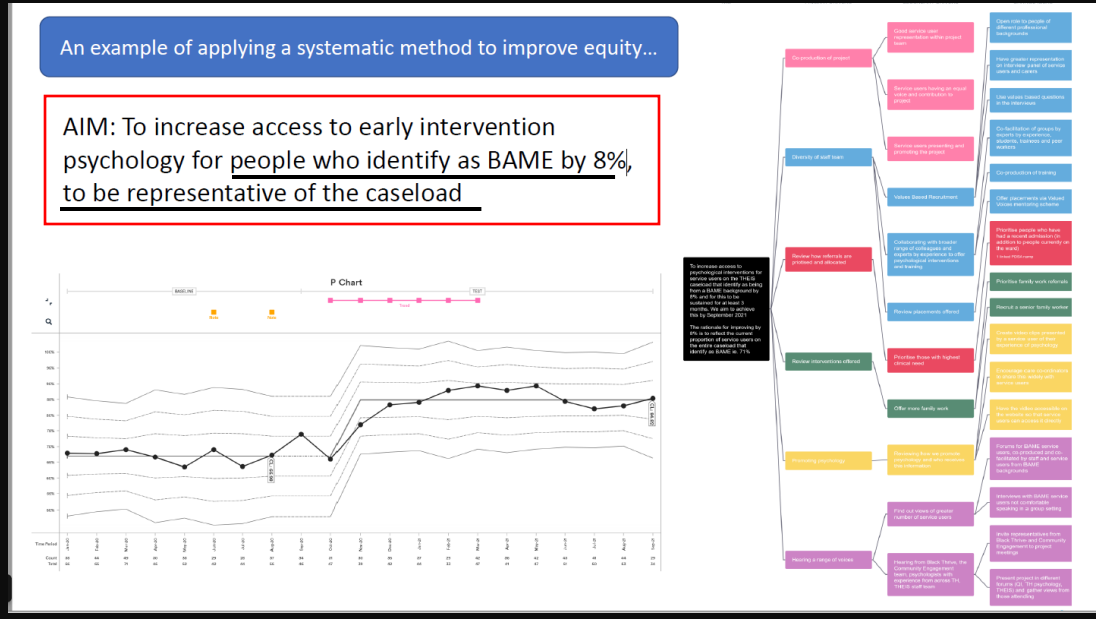
5 Considerations

1. What is our **framed intent** when using race/ethnicity data? (MFI #1)
2. How are **we disaggregating** the data? (MFI #2)
3. How can you **check for bias** in the analysis? (MFI #2)
4. How should you **validate** the interpretation of **results**? (MFI #3)
5. How do we communicate results to **restore dignity**? (MFI #3)



1. Framed Intent (Examples)

- Identifying health outcome disparities between racialized subgroups
- Investigating variation in reliability for common processes among racialized subgroups
- Assessing relationship between racialized patient/family experience & health outcomes
- Evaluating effectiveness of interventions within racialized subgroups
- Examining interactive effects of multiple factors on health outcomes among racialized subgroups (i.e. insurance status)
- Finding evidence of different forms of racism encountered by racialized subgroups

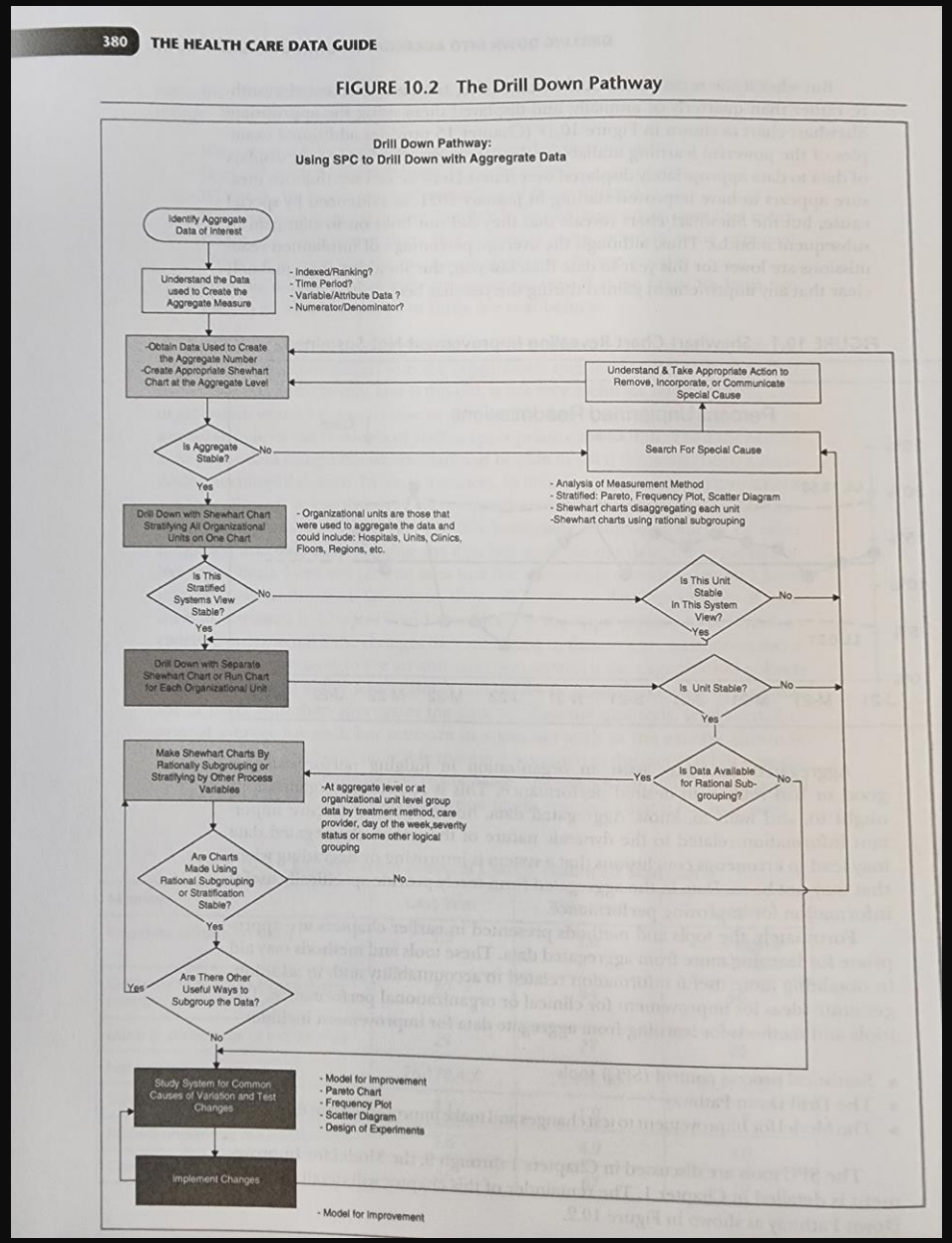


slide from Dr. Amar Shah's talk, *An Introduction to East London NHS Foundation Trust*

Provide the "why" or framed intent in the smart aim or problem statement

2. Pathway for Disaggregating & Segmenting Data

- Run descriptives on raw data for total & subgroup populations
- Use the drill down pathway/rational subgrouping techniques
- Quantify variability between groups & within groups
- Monitor the subgroup size & disease burden within the subgroup over time
  - Implement weighting based on size and health burden in subgroups, when appropriate
- **Consider using summary impact measures**
  - **relative (ratio) disparity between groups**
  - **absolute (arithmetic difference) disparity between groups**



(2. continued)
Key Questions Disaggregation Should Help Answer

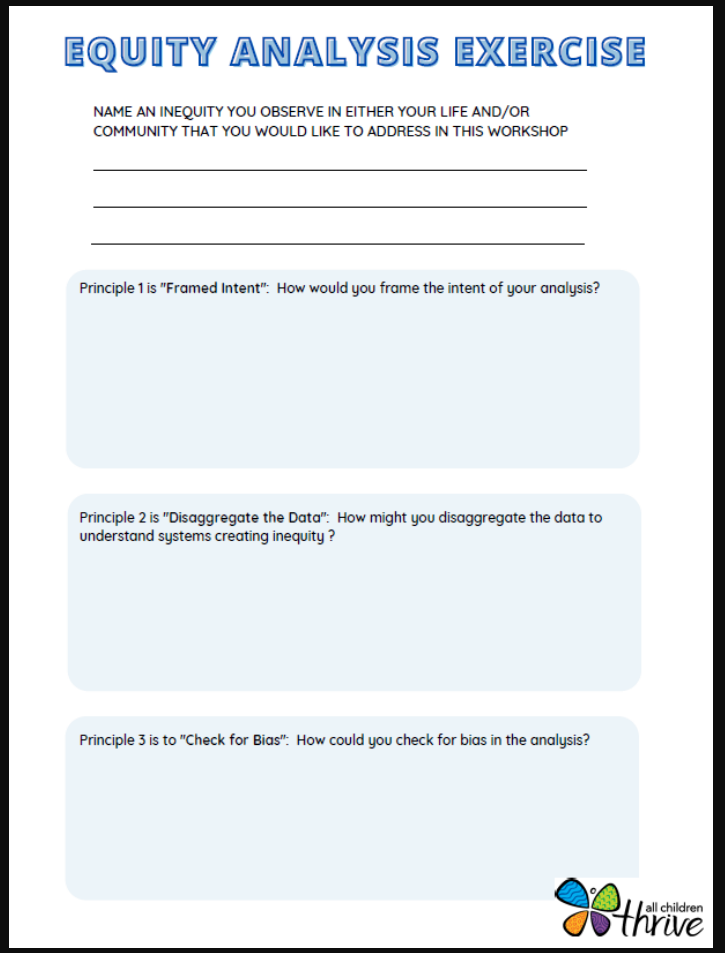
- **How would an intervention eliminating this disparity impact the population burden of the disease outcome?**
- What processes are related to subgroup variation in outcomes?
- What part(s) of the system fail(s) racialized patients?
- When is a disparity eliminated?
- When has parity been reached?
- When has health care equity been achieved?

These questions are not interchangeable

Pair FMEA with disaggregation insights

Exercise Prep: Let's apply what we learn!

- What is an area of inequity in your work that you could apply these guidelines?
- Let's walk you through an Asthma example first...



EQUITY ANALYSIS EXERCISE

NAME AN INEQUITY YOU OBSERVE IN EITHER YOUR LIFE AND/OR COMMUNITY THAT YOU WOULD LIKE TO ADDRESS IN THIS WORKSHOP

Principle 1 is "Framed Intent": How would you frame the intent of your analysis?

Principle 2 is "Disaggregate the Data": How might you disaggregate the data to understand systems creating inequity ?

Principle 3 is to "Check for Bias": How could you check for bias in the analysis?

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Asthma HEN Team


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April York

Teaching Example - Asthma Admission Disparities

Framing our Intent: To investigate variation in asthma care processes that produce inequitable outcomes between racialized subgroups.

Why Asthma?

- This is one of the largest disease sub-populations driving hospitalizations [at CCHMC]
- CCHMC has many resources and QI efforts prepared to support optimizing Asthma care

Why SW Ohio?

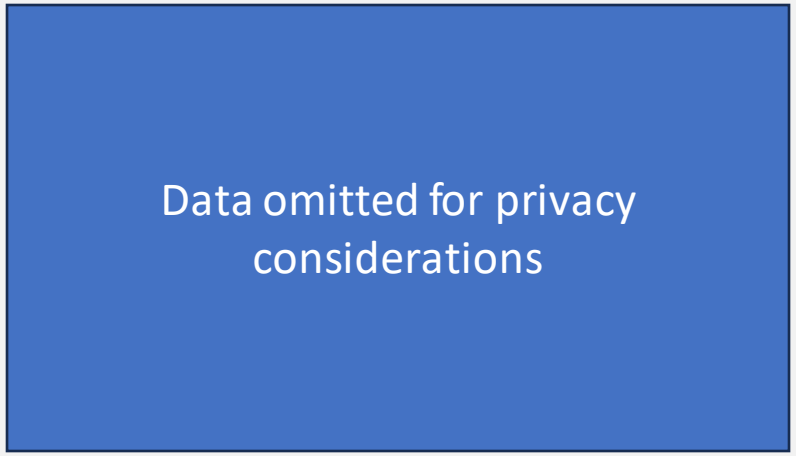
- We want to improve care for kids in the community beyond our Gen Peds population
- This particular geography allows us to leverage and share with Health Vine more readily

Why compare subgroups that identify as Black and NonBlack?

- This is often where we see the largest disparities in the region
- This way of dividing the population gives us the best chance of getting enough observations when we look at sub-populations by condition

Asthma Hospital Admissions

- To improve asthma care in the community we looked at Asthma Hospital admissions relative to the population in SW Ohio
- At first glance we see a fairly stable system that foreshadows a possible increase, via upward trend, towards the end of 2022
- If we only focus on the "overall" picture then we might not take action to improve the system, potentially ignoring processes that need to change for subgroups experiencing underlying inequities of care



Asthma Hospital Admissions Inequity

In a given month, children who identify as Black in SW Ohio experience approximately X hospitalizations per 100,000 while children who identify as non-Black experience X per 100,000.

Data omitted for privacy considerations

Asthma Hospital Admissions: Inequity and Opportunity

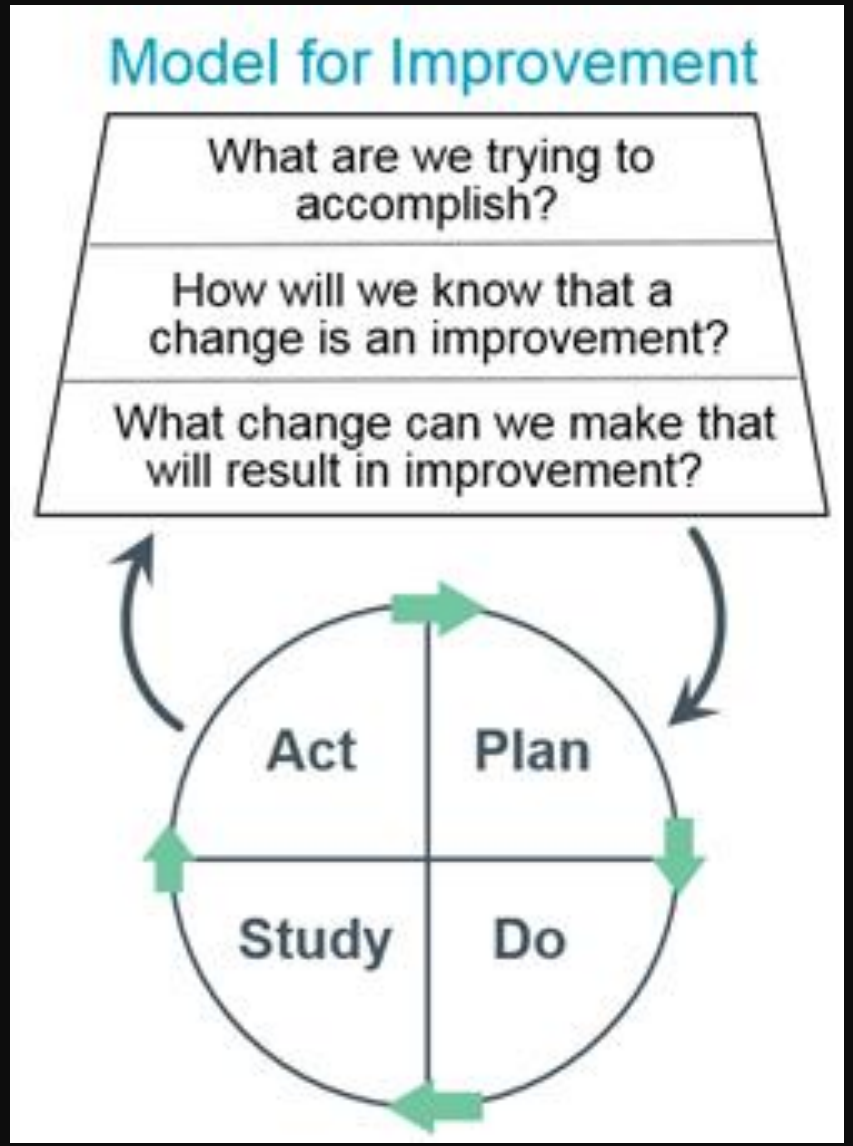
Data omitted for privacy considerations

- About X% of pediatric Asthma hospitalizations are experienced by patients that identify as Black while only 18% of the population in SW Ohio identifies as Black
- These data show a striking inequity and an opportunity for improvement
- A system that closed the Black-NonBlack equity gap would reduce “overall” admissions by X% relative to total population

Worksheet Questions 1 & 2

Keeping in mind our guidelines of framed intent and disaggregating the data think of an area where there is race and/or ethnic inequity

- How would you **frame your intent** for understanding and improving this inequity?
- How would **you disaggregate** the data to understand the systems creating and maintaining this inequity?

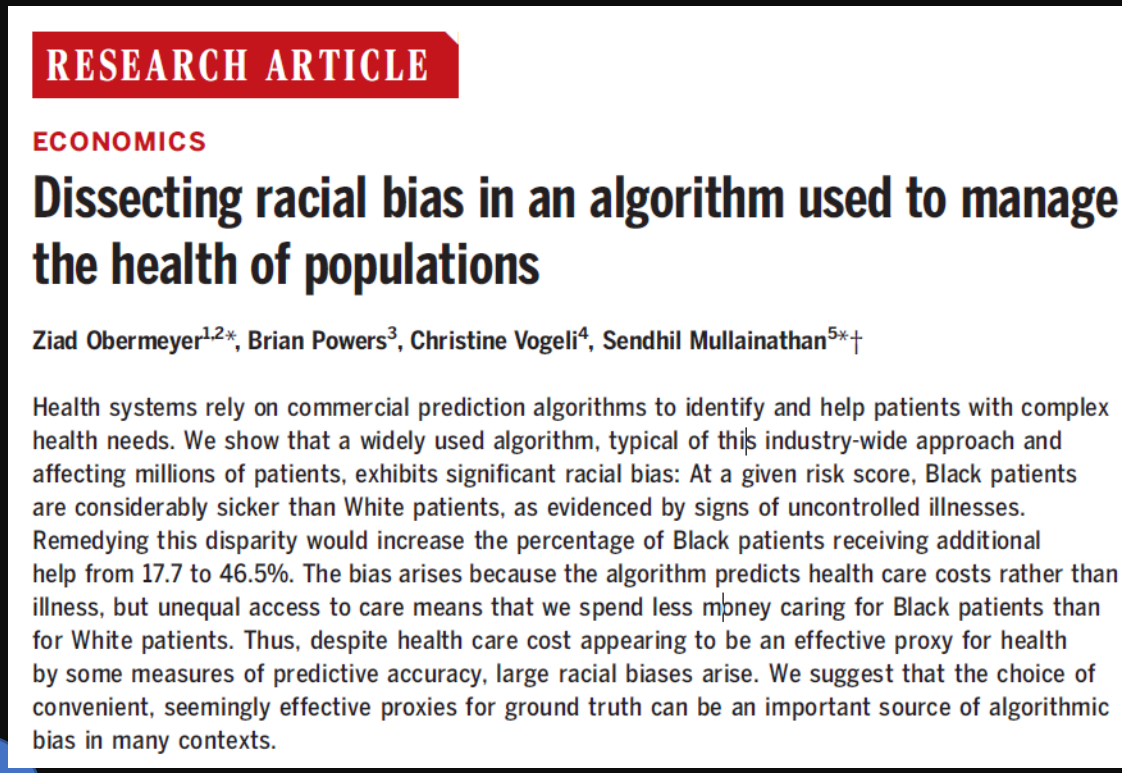


3. Checking for Bias

- Does your framed intent persist in the analytic methods chosen?
- What assumptions will the analyst use to perform the analysis?
  (i.e. missing data, multi-racial/ethnic identity selections)
- What patient experiences or voices informed the investigative path and selection of potential drivers/predictors?
- Have we vetted conventional assumptions about "ground truth" enough for this analysis?
- Are we using "deficit" language to describe the problem or outcomes?

Bias shows up in data collection, use, and interpretation

Map out biases and mitigation choices in statistical analysis plan



RESEARCH ARTICLE

ECONOMICS

Dissecting racial bias in an algorithm used to manage the health of populations

Ziad Obermeyer[1,2]*, Brian Powers[3], Christine Vogeli[4], Sendhil Mullainathan[5]*†

Health systems rely on commercial prediction algorithms to identify and help patients with complex health needs. We show that a widely used algorithm, typical of this industry-wide approach and affecting millions of patients, exhibits significant racial bias: At a given risk score, Black patients are considerably sicker than White patients, as evidenced by signs of uncontrolled illnesses. Remedying this disparity would increase the percentage of Black patients receiving additional help from 17.7 to 46.5%. The bias arises because the algorithm predicts health care costs rather than illness, but unequal access to care means that we spend less money caring for Black patients than for White patients. Thus, despite health care cost appearing to be an effective proxy for health by some measures of predictive accuracy, large racial biases arise. We suggest that the choice of convenient, seemingly effective proxies for ground truth can be an important source of algorithmic bias in many contexts.

4. Validate Results

- When possible, **share results with stakeholders early**, especially in scope patient groups, SMEs, and process owners to help refine interpretation of results

- **Gemba - "go and see" - where the inequities are happening** based upon what the data tells you, especially if time between data collection and analysis is significant

- Site-specific or subgroup-specific **special cause investigation(s)** driven by data

Easy to skip this step because of pressure to go fast

Great learning can occur in the validation process…don't miss out!

"Dr. Tlaleng Mofokeng focuses on the impact of racism on human dignity, life, non-discrimination, equality, the right to control one's health and body, and the entitlement to a system of health protection."

https://www.ohchr.org/en/documents/thematic-reports/a77197-report-special-rapporteur-right-everyone-enjoyment-highest

5. Communicating Results

- **Center the voice and experience of the patient** as they've experienced the system and its processes
- **Describe the extent** of disparate outcomes and inequitable processes produced by the system
- Refine language to **not position race as biological**
- Ensure language **restores dignity** to racialized & minoritized people
- Highlight cultural or context specific aspects of safe, effective, & continuously reliable care to **integrate in common practice**
- **Promote** how examining and changing the system **generates opportunities** for racialized & minoritized people to thrive upstream and downstream

System insights can be invalidated if communication is misaligned

Create communication plans, ahead of time, for respectfully sharing insights

Exercise Prep: Questions 3,4,5

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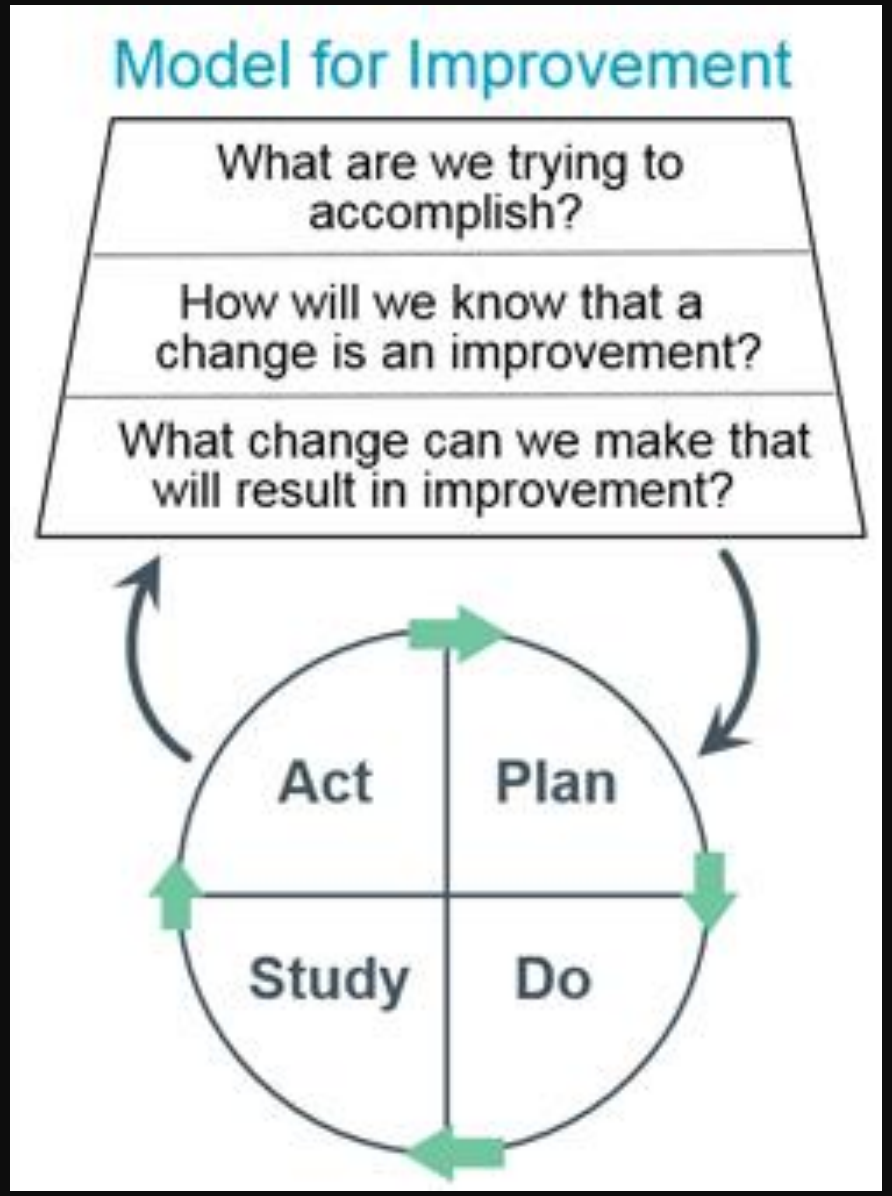


Asthma HEN: Current Progress In Aligning Intent with Approach

- ✓ Smart aim: Decrease monthly asthma rate of admissions among the shared (PPC and Pulmonary) population from XXX/month to XXX/month by June 30, 2023
- ✓ Active PDSAs using SME to guide
- ✓ Current KDD/theory in place
- ✓ Process measures created
- ✓ Decided how to track disparity
- ✓ Create dashboard to centralize learning

Team is learning rapidly and seeing inequities improve!

Data omitted for privacy considerations

Next Steps In Aligning Intent with Approach

Continue learning **from special cause investigation** and better understand the system

Additional drill-down analysis by subgroup to understand what processes are failing some but not others

Review KDD and update theory based on special cause/drill-down analyses with [new] intervenable sources of variation

Talking to families/SMEs and sharing early insights to verify next steps

Develop and refine language to describe changes in centerline (when they happen) by subgroup and by relative disparity

From Analysis to Action in Asthma Population

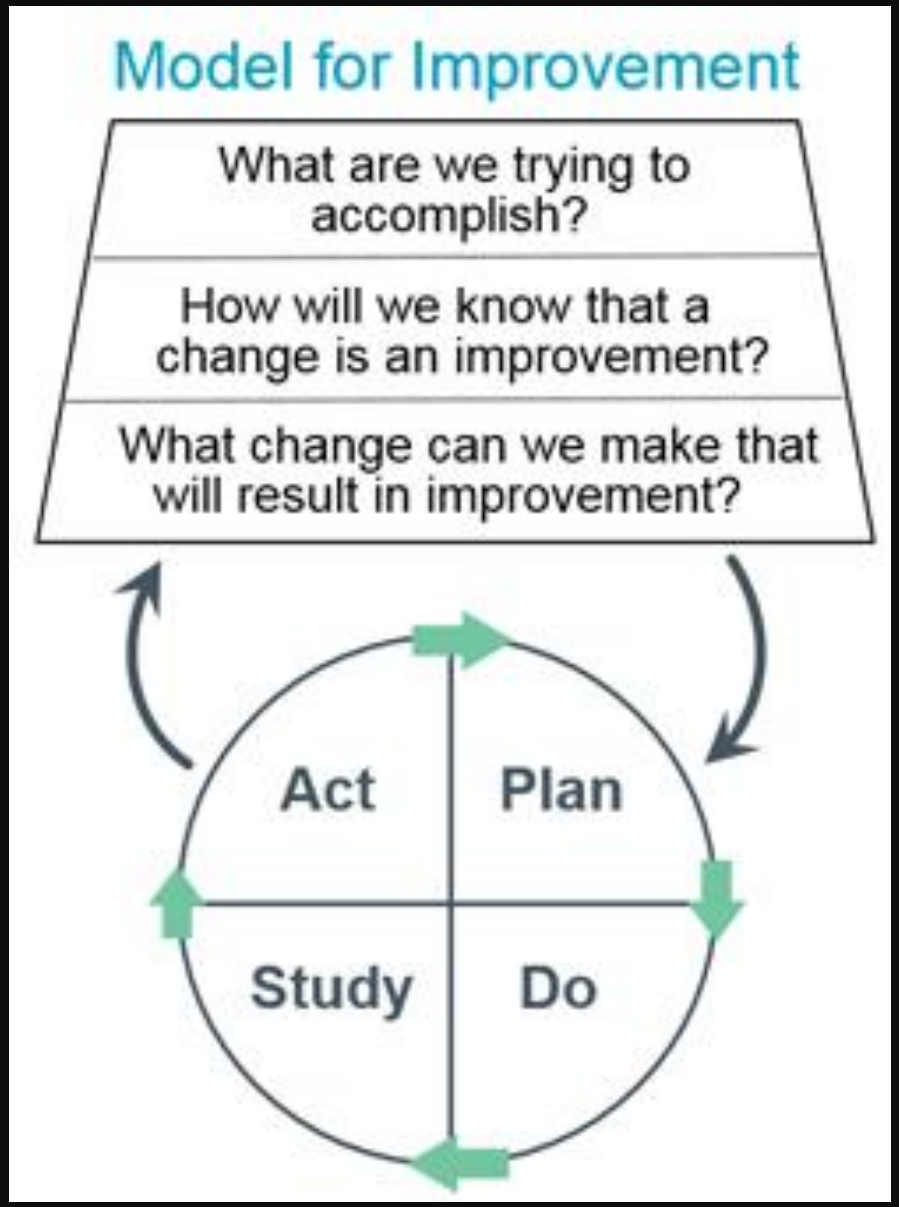
Equity Analysis for improving Asthma health has supported the following improvement efforts:

- Asthma HEN team begun with a focus on Gen Peds pulmonary patients to learn about ways to get Asthma under control
- Collaborating with legal aide to assist families and learn from their experiences
- Building partnership with CPS School Based health centers
- Building partnership with City Government to consider Asthma hospitalization data in actions to make housing safer
    - Identify "hot spots" of housing code violations and asthma hospitalizations to drive policies towards improvement
    - Provide context and support for city actions against criminal landlords

Worksheet Questions 3,4,5

Keeping in mind our 5 guidelines

- How can you **check for bias** in the analysis? (MFI #2)
- How should you **validate** the interpretation of **results**? (MFI #3)
- How do we communicate results to **restore dignity**? (MFI #3)



Summary of Essential Steps & Principles

Essential Steps

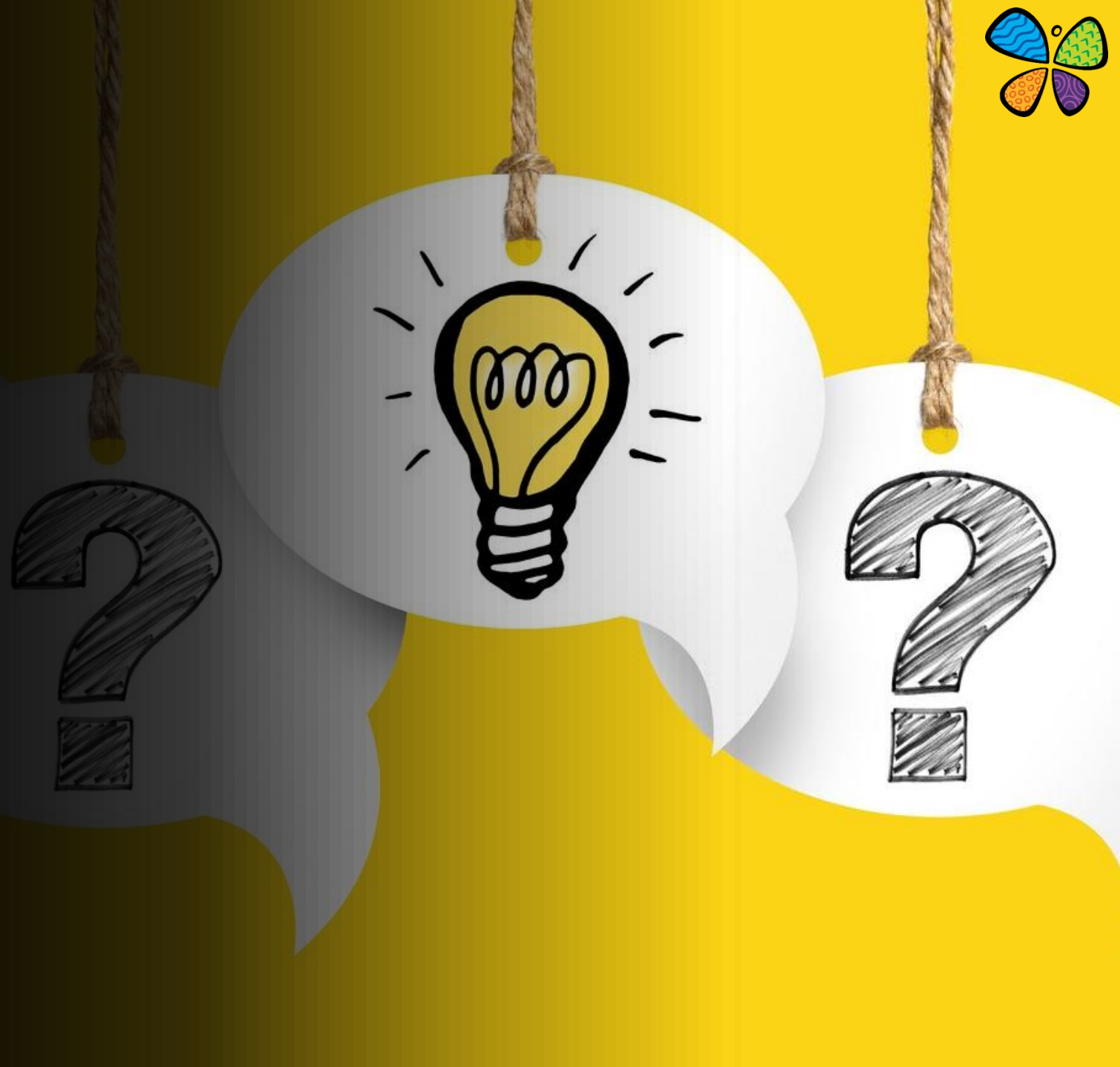
- ❑ Choose a framed intent for the analysis/improvement project
- ❑ Create explicit definitions of race/ethnicity variables that precede disaggregation/rational subgrouping
- ❑ Check the data collection process – garbage in, garbage out
- ❑ Decide on evaluation approach based upon quality of disaggregated data and framed intent
- ❑ Select reference group(s) informed by framed intent
- ❑ Validate results with primary stakeholders (including patient/family) first and incorporate their feedback into your QI plan – PDSA prioritization, KDD updates, sources of variation investigations

Principles

- ❑ Checking and mitigating bias in the approach at every step
- ❑ Disaggregation should inform where to interrupt patterns of inequity (factors over time)
  - Know distribution of disease burden within population
  - Know distribution of social/racialized groups within population
- ❑ Communicate results with compassion, empathy, and respect for the lived experience to restore dignity

Questions or Insights?

- Barriers you run into doing this work?
- Other support you need to do this well?
- How will this change your QI practice?
- What else is missing from the framework?



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- To Advance Racial Equity, Releasing Disaggregated Data while Protecting Privacy Will Be Key | Urban Institute
- Health Disparities & Determinants of Health - The Policy Circle

Glossary of Key Terms

Key Term	Definition
Equality	The effort to treat everyone the same or to ensure that everyone has access to the same opportunities. However, only working to achieve equality ignores historical and structural factors that benefit some social groups and disadvantages other social groups in ways that create differential starting points.
Equity	The effort to provide different levels of support based on an individual's or group's needs in order to achieve fairness in outcomes. Working to achieve equity acknowledges unequal starting places and the need to correct the imbalance.
Racial Disparity	An unequal outcome one racial group experiences as compared to the outcome for another racial group.
Racial Equity	Race is no longer a predictor of outcomes, leading to more just outcomes in policies, practices, attitudes, and cultural messages.

Selected entries from the Center for the Study of Social Policy (CSSP) (2019). "Key Equity Terms and Concepts: A Glossary for Shared Understanding." Washington, DC: Center for the Study of Social Policy. Available at: https://cssp.org/resource/key-equity-erms-concepts/.