

The Power of Data and Storytelling: Let's Change Minds and Systems to Advance Social Justice

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Addressing Health Disparities: A Framework and Quantitative Data

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Police Brutality and the Black Community



The COVID-19 pandemic increased discussions about differences in health, health behavior, and health care-related outcomes by demographic groups such as race/ethnicity and income.

Death rate for Latino people is **8% higher** than the rate for all Californians

Deaths per 100K people:

272 Latino
251 all ethnicities

Case rate for Pacific Islander people is **82% higher** than the rate for all Californians

Cases per 100K people:

50,571 NHPI
27,813 all ethnicities

Death rate for Black people is **19% higher** than the rate for all Californians

Deaths per 100K people:

299 Black
251 all ethnicities

Case rate for communities with median income <\$40K is **14% higher** than the rate for all Californians

Cases per 100K people:

31,692 income <\$40K
27,813 all income brackets

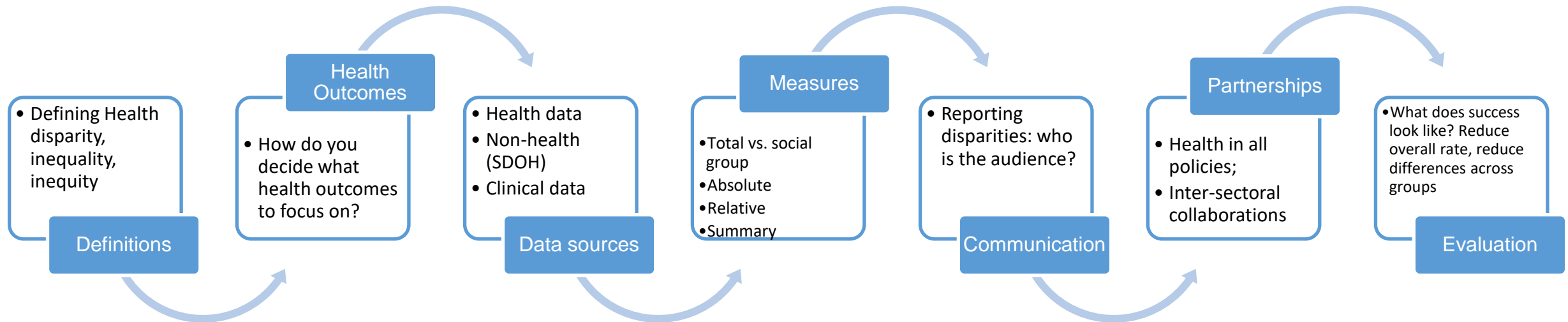
What does “equality” mean?

“There is not even a common language when the term ‘equality’ is used. Negro and white have a fundamentally different definition. Negroes have preceded from a premise that equality means what it says, and have taken white America at its word when they talked of it as an objective. But most whites in America in 1967, including many persons of goodwill, proceed from a premise that equality is a loose expression for improvement.” (*Martin Luther King, Jr, 1967*)

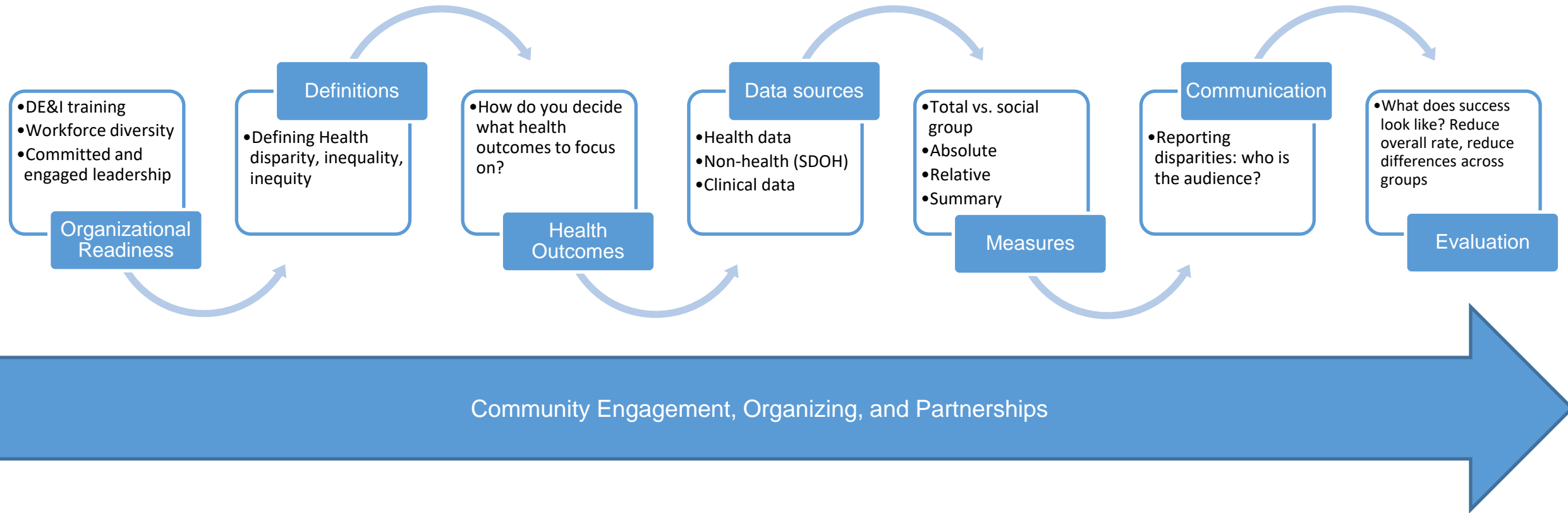
King Jr, M.L., 1967. Where do we go from here: Community or chaos. A Testament of Hope: The essential writings and speeches of Martin Luther King Jr. San Francisco, CA: Harper Collins.

- Health Equity: Does your notion include the elimination of the difference between group(s) OR a reduction in the difference?
- What is the difference between “diversity, equity, and inclusion” efforts and efforts to reduce health disparities/create health equity?

Tucker-Seeley Model of Measuring and Reporting Health Disparities (*original*)

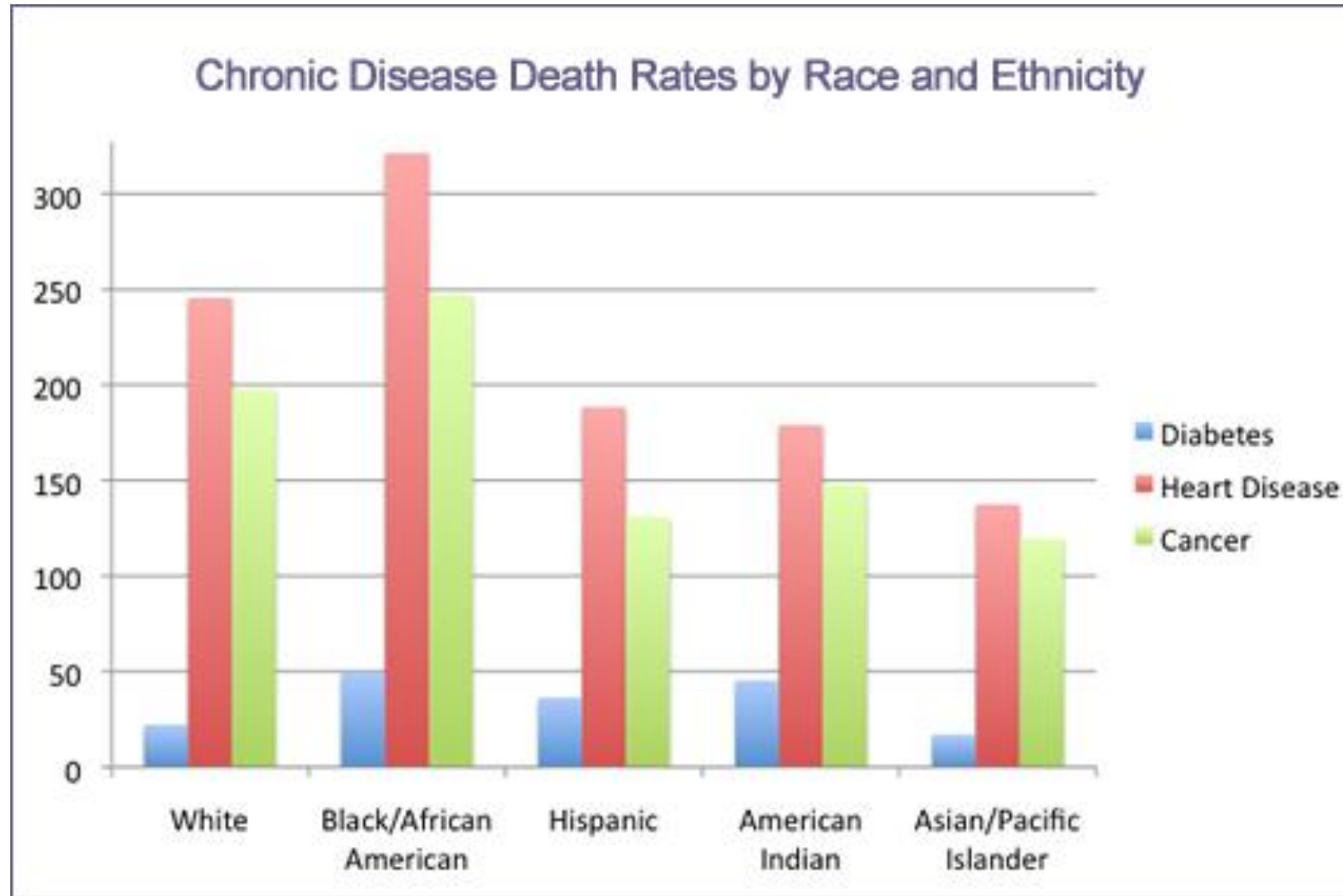


Tucker-Seeley Framework for Efforts to Address Health Disparities (*updated*)



Source: Tucker-Seeley RD, Wallington SF, Canin B, Tang W, McKoy JM. Health Equity for Older Adults With Cancer. J Clin Oncol. 2021 Jul 1;39(19):2205-2216.

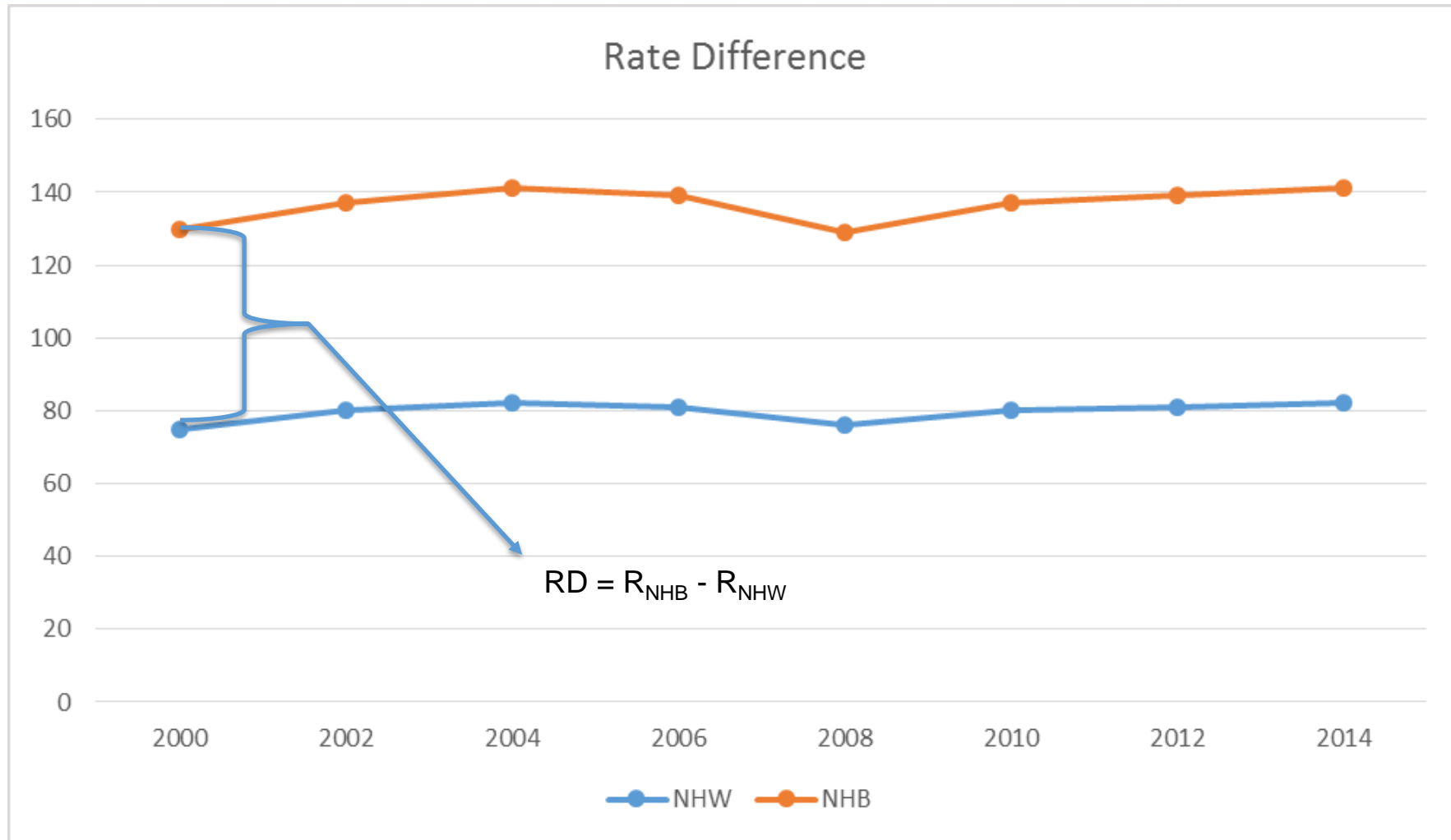
Is this a health disparity/health inequality?



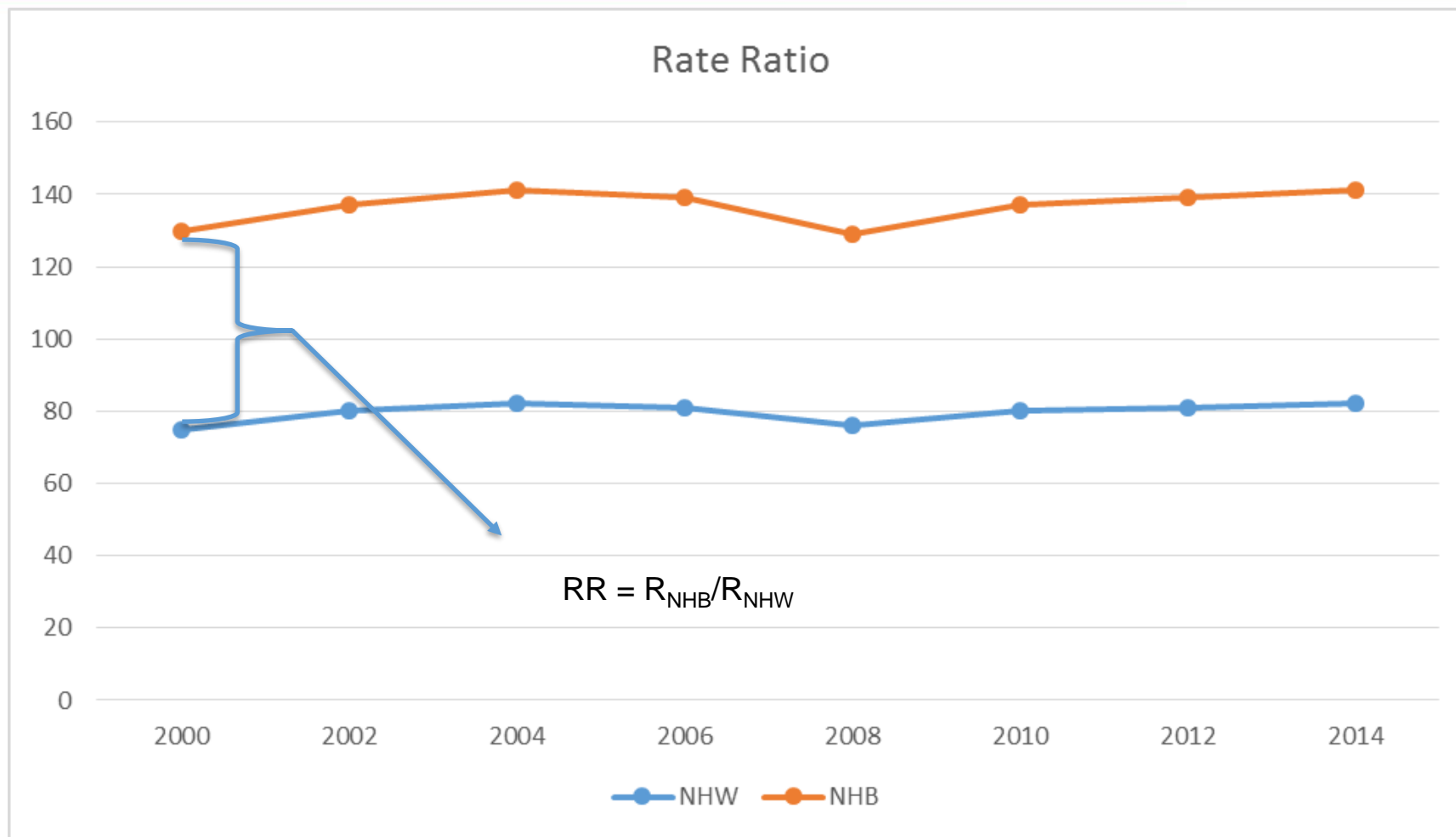
Questions to Ask Prior to Selecting Measures

- What is the goal?
 - Compare a few groups?
 - Summary measure across many groups?
 - Compare all groups to the “best” group or the “average”?
- Is there a natural ordering of the social group (e.g. education/income categories)?
- Summary measures
 - Who is included/excluded?
 - “Is this important?”
 - “What does it mean?”
 - “What should we do about it?” (Friedman, et al, 2005)

Rate Difference

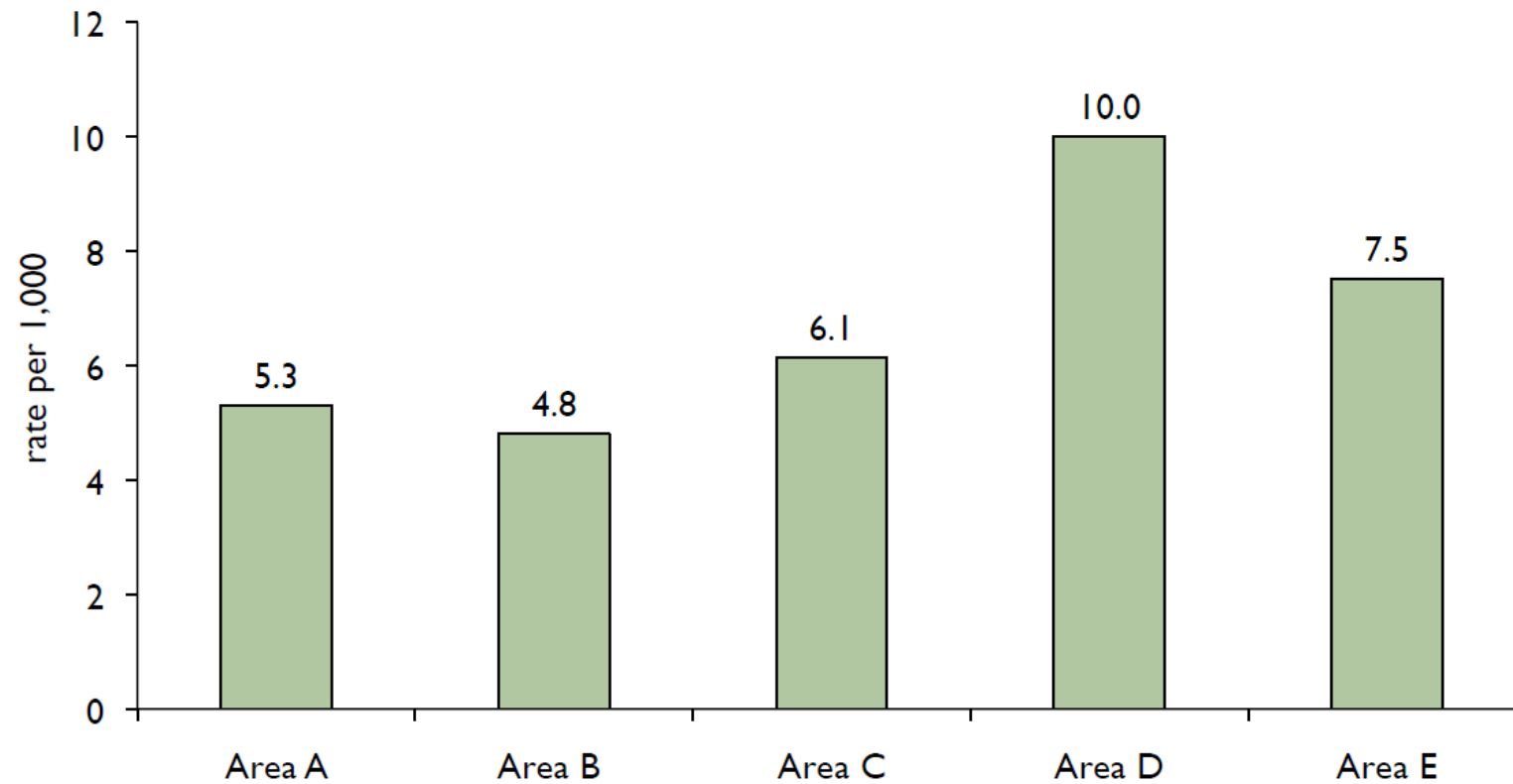


Rate Ratio



- Advantages of absolute and relative difference measures?
 - Easy to implement when interested in only comparing two groups
- Disadvantages of absolute and relative difference measures?
 - “there may be situations where large relative disparities may be viewed as grossly unjust, despite the fact that they reflect small absolute differences.”
 - So, important to know both!

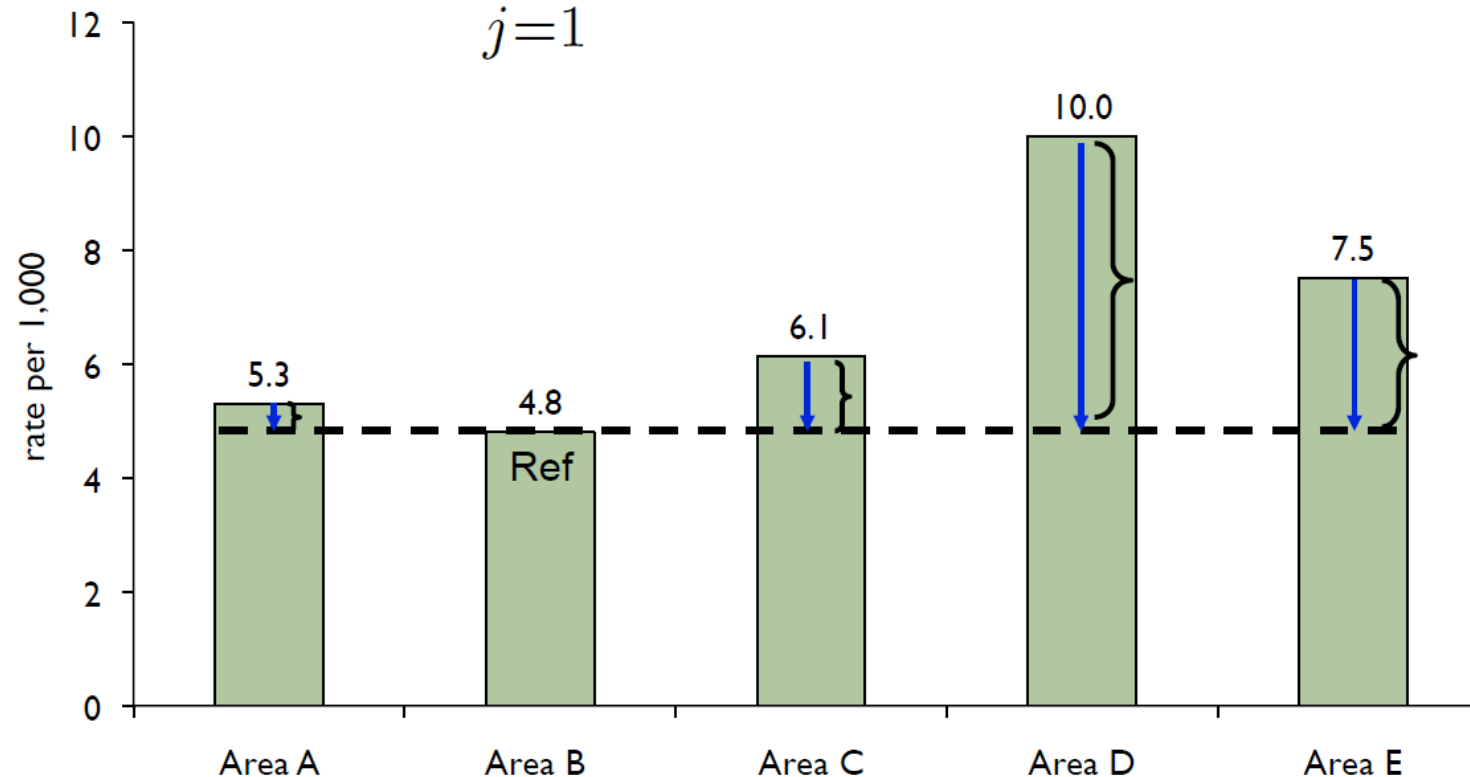
Measuring Disparity Across Multiple Nominal Groups



Source: Harper, 2011

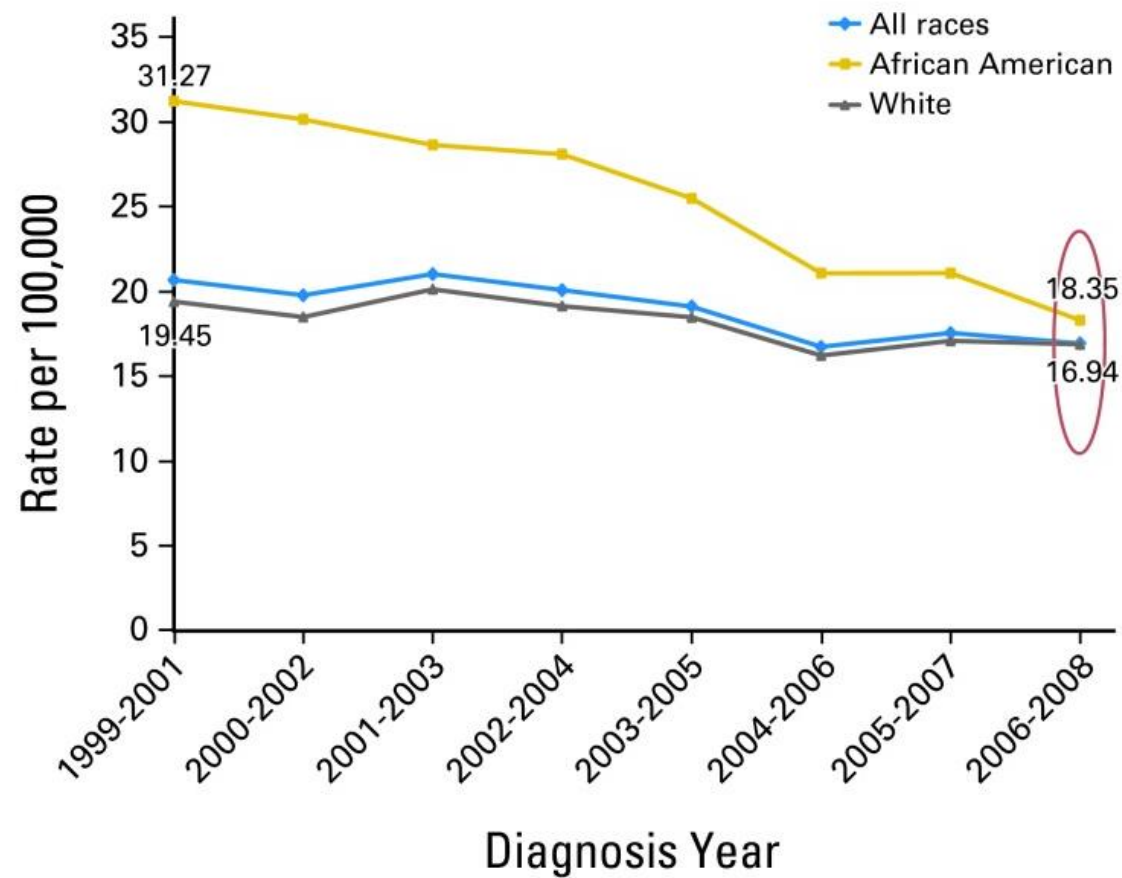
Index of Disparity

$$ID = \sum_{j=1}^J (|y_j - y_{ref}| / n) / y_{ref}$$



- When is a difference a “disparity”?
- When is a “difference” actionable?
 - Should efforts focus on the “difference” OR improving the outcome for the worse off group?
- When can the “difference” be ignored?
- What role does historical discrimination/marginalization play in determining when to act and what the action should be?
 - Who should right historical wrongs?

Has health equity been achieved in this example?



Source: Grubbs, S. S., Polite, B. N., Carney, J., Jr, Bowser, W., Rogers, J., Katurakes, N., Hess, P., & Paskett, E. D. (2013). Eliminating racial disparities in colorectal cancer in the real world: it took a village. *Journal of clinical oncology : official journal of the American Society of Clinical Oncology*, 31(16), 1928–1930.

- Ask/look for an explicit definition of the term “disparities” when you hear/read it;
- Ask/look for an explicit measurement (even though you know it will likely usually only mean difference) when you hear/read the term “disparities”;
- Recognize and appreciate the challenge of moving from conceptualization (definition) to operationalization (measurement) in research and practice; and
- Recognize and appreciate the challenge for policymakers/program developers in prioritizing the differences in health outcomes to address (e.g., chronic disease continuum).

The Importance of Qualitative Data and Storytelling to Address Health Equity and Social Justice:

Community Engagement Strategies

July 19, 2023

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Disclosure

I, Sherrie Flynt Wallington, PhD, have no disclosures to report

Achieving Health Equity

HEALTH DISPARITY

The disproportionate difference in health between groups of people.

HEALTH INEQUITY

The differences in population health status and mortality rates that are systematic, patterned, unfair, unjust, and actionable, as opposed to random or caused by those who become ill.

HEALTH EQUITY

A fair, just distribution of the social resources and social opportunities needed to achieve well-being.

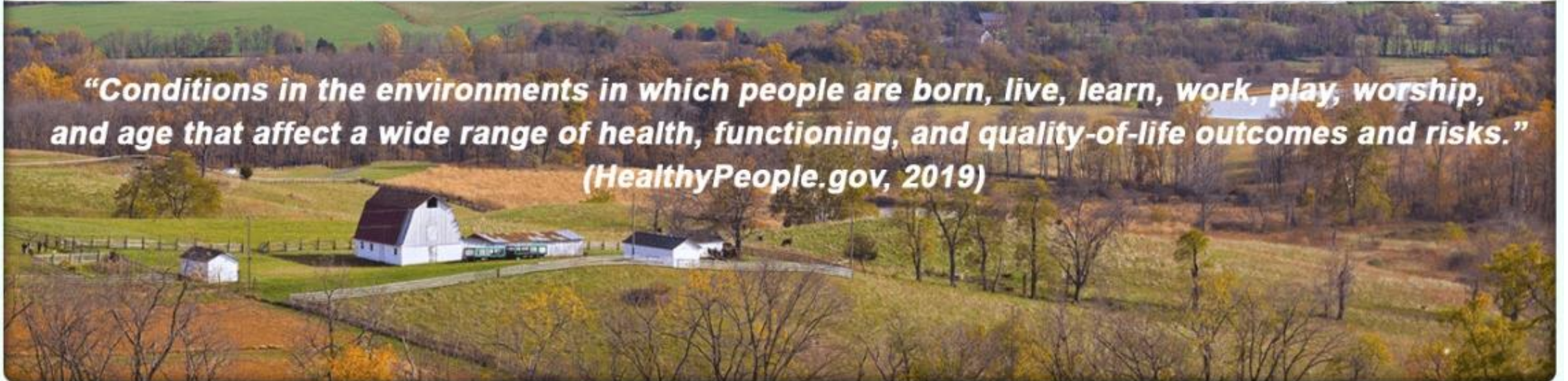
“Achieving health equity requires valuing everyone equally with focused and ongoing societal efforts to address avoidable inequalities, historical and contemporary injustices, and the elimination of health and health care disparities.”

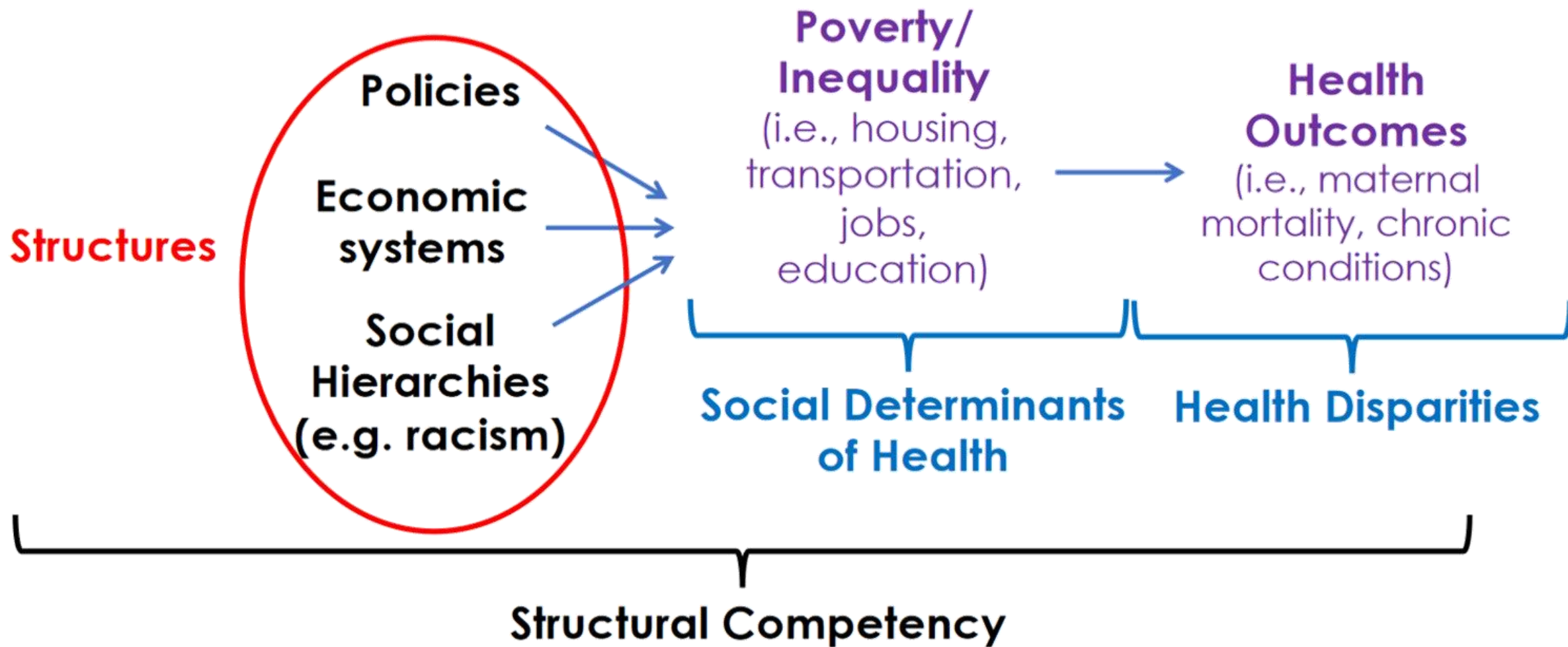
(HealthyPeople.gov, 2019)

Social Determinants of Health



“Conditions in the environments in which people are born, live, learn, work, play, worship, and age that affect a wide range of health, functioning, and quality-of-life outcomes and risks.”
(HealthyPeople.gov, 2019)





“Structural determinants of the social determinants of health”

Social Ecological Model



References:

Bronfenbrenner U. (1989);
CDC Division of Nutrition, Physical Activity, and Obesity (nd).



A Health Equity Lens

- **Question:** Who are the specific populations affected by a particular policy, practice, program, or decision? What are the potential impacts on these specific populations?
- **Question:** In what ways does a particular policy, practice, program or decision ignore or worsen existing disparities or produce other unintended consequences? What are the political, social, cultural, and human subjects' implication to be considered?
- **Question:** How have we intentionally involved the specific population affected through this policy, practice, program, or decision using input and feedback loops?

Defining Qualitative Research

Qualitative methods can be used to **understand complex social processes**, to **capture essential aspects of a phenomenon** from the perspective of study participants, to **uncover beliefs, values, and motivations** that underline health behaviors.

(Crabstree & Miller, 1999)



Comparing Qualitative & Quantitative Research

Qualitative Research	RESEARCH ASPECT	Quantitative Research
Discover ideas, with general research objects	COMMON PURPOSE	Test hypotheses or specific research questions
Observe and Interpret	APPROACH	Measure and Test
Unstructured, Free Form	DATA COLLECTION APPROACH	Structured Response Categories Provided
Research intimately involved, Results are subjective	RESEARCHER INDEPENDENCE	Researcher uninvolved observer, Results are objective
Small samples — Often in natural setting	SAMPLES	Large samples to produce generalizable results <i>(Results that apply to other situations)</i>

Narrative Analysis

- A qualitative research methodology that involves examining and interpreting the stories or narratives people tell to **gain insights into the meanings, experiences, and perspectives** that underlie them. Narrative analysis can be applied to various forms of communication, including written texts, oral interviews, and visual media.
- Researchers typically examine the **structure, content, and context of the narratives** they are studying, paying attention to the **language, themes, and symbols** used by the storytellers. They may also look for patterns or recurring motifs within the narratives and consider the cultural and social contexts in which they are situated.

Community-Level Research and Methodological Tools

- Community Assessments
- Focus Groups
- Key Informant Interviews
- Randomized Controlled Trials
- Assets Mapping
- Social Network Analyses
- Photo Voice
- Logic Models
- Mixed Methods
- Survey Research
- Story telling



Benefits of Storytelling in Health Equity Research

- **Digital storytelling is an emergent method in health promotion.** It addresses health inequities by combining technology with the voices of members of vulnerable, often underrepresented populations
- **Stories allow us to gain insights** into their cultures and locales, natural and social worlds.
- We ask for stories, broad or focused, in **interviews and focus groups.**
- The stories **bring quantitative finding to life** and understand that the numbers deal with real people and their experiences.

Qualitative Researcher's Toolbox

- Participant Observations
- Focus Groups
- Key Informant Interviews
- Mixed Methods
 - (Qualitative and Quantitative)



Ask Questions That Yield Powerful Information



Use open-ended questions

Avoid dichotomous questions

"Why?" is rarely asked

Use "think back" questions

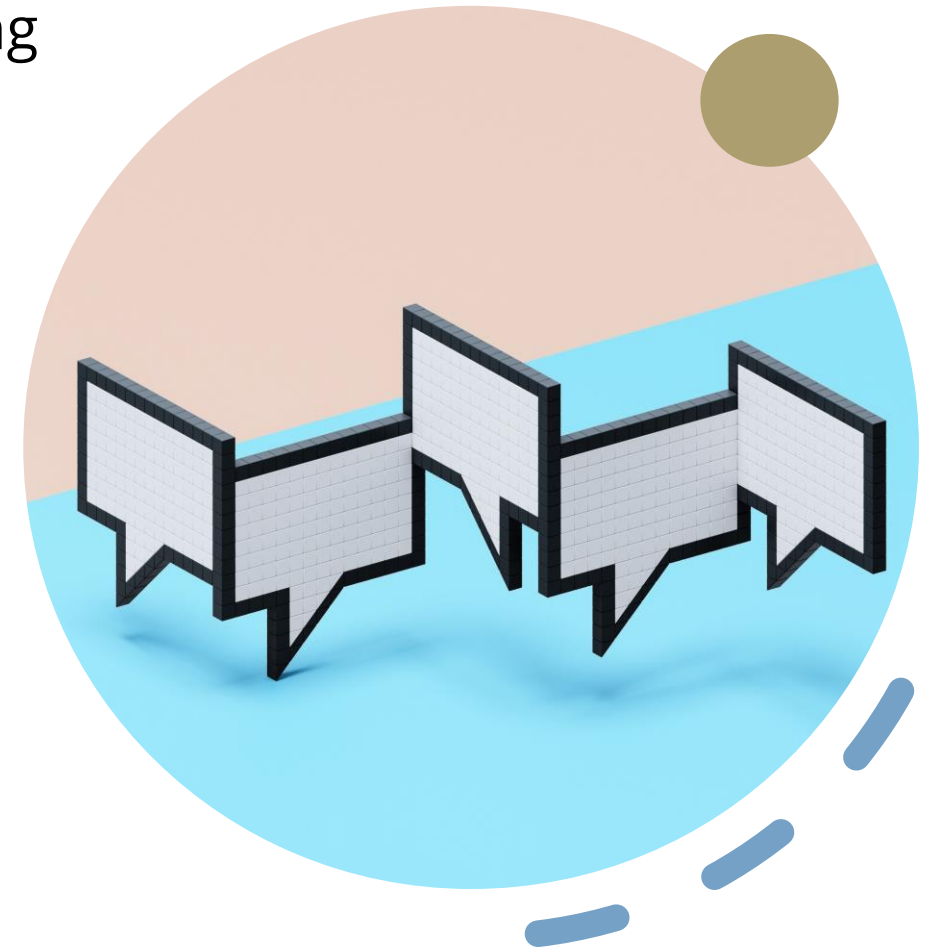
Carefully prepare focus questions

Ask uncued questions first, cued questions second

Consider standardized questions

Storytelling Is an Important Aspect of Community Engagement

- Storytelling cultivates a foundational understanding of **the importance of community engagement** around health or any topic
- Stories lead with emotion to make the **linking and connections** to your audience or community
- Stories provides parameters and criteria for community engagement and **call to action toward solutions**
- Sheds **inspiration for engagement**



Community-Engaged Research



- **Is** a framework or approach for conducting research
- **Is not** a methodology in and of itself
- **Requires partnership** development, cooperation, and negotiation
- **Requires commitment** to addressing various issues
- **Exists on a continuum**, with much variation in the strength and intensity of the community-academic collaboration
- **Depends on** the research objective, project, participants, community history, and local politics, among others

At the Core of all community-engaged research is the understanding that the community will be involved in a meaningful way

Telling a Story with Data

A Data Story

- A narrative constructed around a set of data that puts it into context and frames the broader implications
- Brings insights to better understand a relevant business goal or objective

Data Storytelling

- Crafting the narrative by leveraging the contextualized data to present to an audience
- Utilizes data analysis, statistics, data visualization, qualitative and contextual analysis

Importance of a Data Story

- Helps break down the results so that **any audience**, regardless of their background or expertise, **can understand them and the implications**
- Helps to explain data to people of different learning styles
 - Allows for communication methods to be **crafted to the specific audience**
- Includes combinations of various components to continue to **engage a diverse audience**



Data Stories vs. Data Visualizations

- **Data visualizations are actually just one piece of data stories and help deliver various points in a narrative**

- Used as an aid to tell a broader story



- **Data storytelling goes further than visualizations**

- Relies on industry/topic expertise and communication skills to help craft the analysis and visualizations into something that can explain the broader details



How to Tell a Story with Data

Find the story within the data

- Determine what the data is actually telling you. Provides a starting point into building a data story that can be conveyed to a diverse audience.

Consider your audience

- Determine who the story will be conveyed to and what their backgrounds are.
- Determines the complexity of the analysis and what components of the story the listeners will want to learn about.

Determine what data matters

- Start by identifying the data that informs the topics you want to explore instead of all available data.
- Ensures the key points do not get diluted and that audience does not get distracted.

Analyze data and find insights

- Perform data analysis to find insights that create meaning out of the data.
- Provides the general themes of the data story.

Identify the most effective data visualizations

- Pick a visualization that best represents your data and message.

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