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.

Source: https://covid19.ca.gov/equity/
“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)
Equality to Equity

• 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)

- **Definitions**
  - Defining Health disparity, inequality, inequity

- **Health Outcomes**
  - How do you decide what health outcomes to focus on?

- **Data sources**
  - Health data
    - Non-health (SDOH)
    - Clinical data
  - Health data

- **Measures**
  - Total vs. social group
  - Absolute
  - Relative
  - Summary
  - Reporting disparities: who is the audience?

- **Communication**
  - Health in all policies;
  - Inter-sectoral collaborations

- **Partnerships**
  - What does success look like? Reduce overall rate, reduce differences across groups

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

Organizational Readiness
- DE&I training
- Workforce diversity
- Committed and engaged leadership

Definitions
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Data sources
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Communication
- Reporting disparities: who is the audience?
- What does success look like? Reduce overall rate, reduce differences across groups

Measures
- Reporting disparities: who is the audience?

Evaluation

Community Engagement, Organizing, and Partnerships

Is this a health disparity/health inequality?

Chronic Disease Death Rates by Race and Ethnicity

- White
- Black/African American
- Hispanic
- American Indian
- Asian/Pacific Islander

- Diabetes
- Heart Disease
- Cancer
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

\[ RD = R_{NHB} - R_{NHW} \]
Rate Ratio

$$RR = \frac{R_{NHB}}{R_{NHW}}$$
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

\[
ID = \sum_{j=1}^{J} \left( \frac{|y_j - y_{ref}|}{n} \right) / y_{ref}
\]

Source: Harper, 2011
Policy and Measurement Implications

- 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?

• 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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I, Sherrie Flynt Wallington, PhD, have no disclosures to report
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)
Structures

Policies
Economic systems
Social Hierarchies (e.g., racism)

Poverty/Inequality (i.e., housing, transportation, jobs, education)

Health Outcomes (i.e., maternal mortality, chronic conditions)

Social Determinants of Health

Health Disparities

Structural Competency

“Structural determinants of the social determinants of health”

https://outreach-partners.org/2019/06/27/structures-starter-kit/
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

<table>
<thead>
<tr>
<th>Qualitative Research</th>
<th>RESEARCH ASPECT</th>
<th>Quantitative Research</th>
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<tbody>
<tr>
<td>Discover ideas, with general research objects</td>
<td>COMMON PURPOSE</td>
<td>Test hypotheses or specific research questions</td>
</tr>
<tr>
<td>Observe and Interpret</td>
<td>APPROACH</td>
<td>Measure and Test</td>
</tr>
<tr>
<td>Unstructured, Free Form</td>
<td>DATA COLLECTION APPROACH</td>
<td>Structured Response Categories Provided</td>
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<tr>
<td>Research intimately involved, Results are subjective</td>
<td>RESEARCHER INDEPENDENCE</td>
<td>Researcher uninvolved observer, Results are objective</td>
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<tr>
<td>Small samples — Often in natural setting</td>
<td>SAMPLES</td>
<td>Large samples to produce generalizable results (Results that apply to other situations)</td>
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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)
<table>
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<tr>
<th>Ask Questions That Yield Powerful Information</th>
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<tbody>
<tr>
<td>Use open-ended questions</td>
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<td>Avoid dichotomous questions</td>
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<tr>
<td>&quot;Why?&quot; is rarely asked</td>
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<td>Use &quot;think back&quot; questions</td>
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<tr>
<td>Carefully prepare focus questions</td>
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<td>Ask uncued questions first, cued questions second</td>
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<td>Consider standardized questions</td>
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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 provide 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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