Community Science
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# Tips for Using Data to End Health Disparities and Strengthen Communities

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## Understanding Health Disparities and Health Equity

When we look across the country, it's clear that certain groups have more health problems than others. Sometimes, it seems like they're more severe. Why does this happen to some groups of people and not to others? Some of it has to do with differences in social experiences and economic conditions, which can cause some people to have different access to resources and opportunities. These differences are the health disparities we see and read about. Everyone, regardless of their social, economic, or other characteristics, should have the right to the resources and opportunities that can positively affect their health. When they do, health equity becomes possible.

Low-income families; racial and ethnic minorities; lesbian, gay, bisexual, and transgender (LGBT) people; people with disabilities; elderly people, and people who live in rural or geographically isolated places — these groups often experience social and economic disadvantages. For example, low-income working families frequently cannot have regular preventive check-ups because they don't have health insurance. People with disabilities and LGBT people sometimes face discrimination when they visit the doctor; the same happens with racial and ethnic minorities. Rural residents may live in areas that don't have the infrastructure to ensure clean water. There are many reasons why disparities occur, and many populations that experience disparities. The tips provided here can be applied to any population.

## How Data Can Be Used to Tell Different Stories About Health Disparities

Data or "facts" can be a powerful tool for communities fighting for fairness in health and mobilizing around other key issues that matter to residents. By harnessing the power of data, community groups, and residents can more effectively "fight back" against policies and practices that create health disparities and advocate and push for new ways of doing business in our communities.

*Data = plural of datum. Data refer to the text or numerical information collected and organized into a format suitable for analysis in order to make a point, tell a story, inform decisions, or shed light on a situation. Data have the power to divide communities or unite them.*

But many of us don't have the tools or background to crack the "data code" — the sometimes complex universe of understanding, accessing, analyzing, interpreting, and using all of the text, numbers, and statistics that make up the world of data. The concern with data is that they can seem, at first glance, to be "neutral" — just groups of numbers or words or statistics that can only tell one story. **Even more important, all of the data can be collected, "spun," or used in many different ways to create very different stories — to divide various groups in communities or potentially to unite them; to make the case for doing more of something or less; and to argue for some groups getting "this," while other groups get "that."** The headlines of these stories then appear in the news on TV, in the newspaper, and on the Internet, and more frequently than not, people don't have the time or ability to question the interpretation and use of the data that support the stories or put another way, to understand who's telling the story and how are they telling it.

*We ask you to look more deeply and think critically about how data can give many different "messages" depending on how the data are analyzed, interpreted, and presented. We encourage you to become not just good data collectors and analysts but strong critical thinkers about the data you uncover, how it can be interpreted, and how it can be used to create positive outcomes for the many groups that make up your community rather than a source for division, perpetuation of stereotypes and myths, and unequal distribution of resources.*

Below, we offer you six key questions about using data to understand health disparities and tips for answering those questions with data. We also provide a glossary of key terms related to data and data analysis.

**Caution! It's Not Always a Straight Line!** The steps you take to answer questions 1 through 6 do not occur in a direct or straight-away fashion. In fact, it is usually more of a process where you might be asking more questions after you have studied the data and have to find more data to answer those questions. Sometimes, you might not find the data you need and may have to collect your own data. The key is to dig more deeply into the data (not assuming that the interpretation and presentation of data are neutral or objective) to get a complete picture of the situation.

## Six Key Questions for Understanding Health Disparities

For any issue or opportunity you want to tackle, here are questions to help you at each stage of the process to understand the situation and the data that exist and use the data for strategy development and improvement:

### 1. What's the starting point?

You can start by looking at the data for a specific population (e.g., African American, low-income women, Latino immigrants, etc.), a particular health issue (e.g., diabetes, suicide, lead poisoning, etc.), a specific time frame (e.g., last decade, last year, last month), a specific place (e.g., state, county, or city), or all of the above. At this stage, you begin to form a simple research question. Don't worry about getting it perfect. You will have a chance to refine it later.

#### Tips ✓

- *Start with the population, health issue, place, and/or time period of interest, such as the people who live in your community.*
- *Examine health data to find out leading health problems, rates of health conditions, and causes of death in a particular place (such as your community), and during a particular period.*
- *Form an initial research question.*

## 2. What's the disparity (inequality or difference) compared to other populations?

It is important to know what the disparity is and compare it to which groups.

### Tips ✓

- *Compare the rates for the health condition of interest across three to five years or at least three data points.*
- *Compare your local results to state or national results for the same population, to another racial/ethnic group, or to the group with the best rates.*

**Caution! Sometimes, the research to understand the "big picture" can get bigger and bigger without you realizing it and before you know it, you have spent too much time on it! You might find yourself drowning in data!**

**To prevent this, make sure you:**

- *First think about what the end product will be — will it be an "internal document" for your organization or will it be an "external" document for wider distribution and if so, to whom (e.g., policymakers, residents)?*
- *Consider your capacity to gather and make sense of all the data and who can help you; for instance, someone from the university or college.*
- *Take the time to stop before you decide to go and get more data; the additional data can help you refine your research question. Remember, a good research question can help you focus your effort.*

## 3. What are the social determinants of health that affect the disparity?

It is important to know about the conditions and environments in which people live so that you can address issues that may cause or contribute to poor health and achieve long-term improvements for everyone. At this stage, you will stop to refine your research question.

### Tips ✓

- *Visit Healthy People 2030 Social Determinants of Health.*
- *Visit Social Determinants of Health at the Centers for Disease Control and Prevention.*
- *Find out if there is a Center for Excellence in health, healthcare, or public health. near you and contact an expert there.*
- *Find out who the State Office of Minority Health director or liaison is and contact that person.*
- *Check to see if your state or county has a health equity report card, score card, or assessment report. Usually these documents already contain data that might be relevant to you.*

## 4. Where are the data gaps, and what do you do to fill the gaps?

If there are gaps, consider what you can do to collect this data and whom you should engage in your data-gathering work.

### Tips ✓

- *Check to see if you have all the data you need to understand the complete and accurate story about the health disparity of interest. Two ways to check:*
    - *Can you answer the research question with the data you have*
    - *Could you tell someone else the full story and answer their questions?*
- *Determine if there are any additional data you might need and how best to get the data. You can identify a proxy measure or partner with an institution or individual with the capacity to do primary data collection.*
- *For an accurate picture of the data, both qualitative and quantitative data are important. Numbers only tell half the story, especially when comparing social groups.*
- *There are three levels of data that can be used — national, state, and local. Local could be a county, city, or smaller geographic area. Local data are usually harder to get, depending on where you live or the place you want to change.*
- *Don't just focus on the risk factors, challenges, and negative aspects of a community. Also, identify and build on existing community assets (e.g., community pride, healthy traditions, social networks) and engage the community to determine how to use these assets to overcome a health challenge.*

## 5. What is the story you can tell to describe the situation?

You will need to combine the numerical and text information to tell an accurate story about the disparities in your community.

### Tips ✓

- *Look for a pattern such as when one rate increases for a* ***variable****, so does another, or if the reverse is true.*
- *Use qualitative data to support the quantitative data you find, and vice versa.*
- *Check the reliability of the data and also compare the data to what you know about the community.*
- *Identify your audience for the story.*
- *Decide the best format for your story for that audience.*

**When presenting the results, consider:**

- *Who the audience is*
- *Balancing text with visual information*
- *Describing differences and disparities in ways that do not "pit" one group against another*
- *Providing information about both the challenges and the assets of each population or group.*

## 6. How can you use the data to build a healthier community?

Decisions about the next steps must be made with serious consideration for what the data tells you.

### Tips ✓

- *Strengthening the sense of community, building coalitions and advocating for policy change all increase the potential for long-term sustainability for change.*
- *Coalitions bring new partners to the table.*
- *Advocacy can create a new friendlier playing field in terms of laws and policies and a more unified and aware community.*

**Program development will be most successful when you follow these four "Cs":**

- *Do you have the* ***capacity*** *to make it happen?*
- *Are you being* ***concrete*** *(or specific) about what you want to address?*
- *Are you being* ***creative*** *about what will work?*
- *Is the program* ***culturally*** *appropriate for the population you are targeting?*

*NOTE: Data about certain populations, including rural residents and communities, LGBT people, and people with disabilities are usually harder to get for many reasons; this is one of the challenges we face in health and human services. Consequently, data-driven strategies to improve the health of these populations are more difficult to develop. Further research and evaluation of programs targeted at these groups of people are necessary for knowledge development and knowledge transfer. This also means that you may have to collect your own data if you are interested in these populations, which can be costly and labor-intensive, but sometimes necessary.*

## A Few Thoughts About How Data Can Be Friend or Foe

Data — text or numerical information — can be a powerful tool for effecting change through action and advocacy. When you are armed with "the facts," what you say can have much greater weight and power. While you may feel that genuine and heartfelt stories from our communities should outweigh numerical information, you also know that others don't often see it that way. People may infer that the stories you hear from the community are just anecdotes with no "scientific" backing. Still, even stories can be collected through a rigorous data collection and analysis process such as the one used in focus groups. Put them together, and you have a strong tool for getting increased funding, new programs, and the power for real change and collaboration with others in our communities.

But there's a potential hidden trap when working with data that you must watch out for and understand. While data can be used for good, data can also be used to divide our communities in a number of subtle and not-so-subtle ways because of how data are interpreted and presented. At one time or another, you've probably all read some data or "fact" about a group you belong to — ethnic, racial, gender, or another form of social identity— that didn't quite sit right. Maybe it made you feel that you were being "labeled" or measured against another group unfairly. Maybe you felt like saying, "That is not my community!" or "It makes it sound like that group is better than mine!" Remember, just because data are presented as "facts" doesn't mean there isn't a deeper story. Here are some of the negative things data can be used to do, depending on how the information is gathered, packaged, and presented:

- *Use statistics to "label" certain groups as problems because they have higher rates of mental health issues, unemployment, or substance abuse, thereby perpetuating stereotypes without fully explaining the story behind the high rates;*
- *Fail to look across the causes of inequality for some groups by looking only at the symptoms of the health condition and not at the source of the problem;*
- *Assume a causal relationship between the problem and the result when the situation is more complex than that, and*
- *Group people so that what's presented does not reflect what's real "on the ground" in your communities.*

**Just remember: When working with data, be critical. Understand that the interpretation can be very subjective or one-sided, and don't assume that the person interpreting the data for you is not "taking sides"!**

## Tips✓

**Here's a way to remember how to determine if the data you find will be useful:**

- ***Relevant*** *— the dataset contains information about the population, geographic area, or health condition of interest*
- ***Representative*** *— the dataset contains information that contains a large enough sample to make generalizations about the larger population*
- ***Reliable*** *— the dataset comes from a credible source that adheres to scientific standards.*

## Final Words of Advice

As you move forward in your work in finding data that will help to support community realities, talking to community members about their experiences, and joining with others to forge new coalitions for health justice, remember:

**Be a "Critical Data Thinker"** — Always understand what's behind the data you find, and think deeply about how it can be used for community building, not community division.

**Combine Data with Your Knowledge** — Data are critical for understanding a situation; so is your knowledge as a community leader or member. Combining both and digging more deeply into discrepancies will give you a more accurate picture of what is happening in your community.

**Look for Common Ground** — Search for opportunities to build alliances to reduce community health disparities through partnerships and coalitions.

**Use a Strength-based Approach** — Don't focus only on the problems your community is experiencing; focus also on the assets in your community and how you can build on them to create the change you envision.

Community Science can assist your agency, organization, or project in numerous ways to achieve and support healthy, just, and equitable communities. Whether you need strategy development facilitation and support, evaluation, research, or capacity-building assistance, we can help. This includes coaching and training for organizations, coalitions, and grantees.

[Click here to contact Community Science]

# Definitions of Common Data Terms and Their Use

## Age-Adjusted Rate

Statistical adjustments that are made to ensure fair comparisons of mortality, hospitalization, and other health disease rates across different age groups because age is a factor that affects these rates.

> ***Example***
> The rate of hospitalization is highest among those ages 70 and older in County X, which is expected because of their age. However, the age-adjusted rate shows a different pattern. In fact, after adjusting for age, the rate of hospitalization for those between ages 25 and 40 is actually higher than those ages 70 and older. This requires further investigation to find out what is contributing to this higher rate of hospitalization (e.g., accidents, homicides).

## Bias

Systematic error in the design or conduct of a study or analysis of data that result in inaccurate findings.

> ***Example***
> The results of this study are not accurate because of a bias in the sampling strategy whereby only people with higher education were surveyed.

## Causal Relationship

This means that one thing happens as a direct result of the other.

> ***Example***
> There is a causal relationship between HIV and AIDS, meaning AIDS cannot occur unless an individual is HIV positive.

## Confidence Level

A confidence level refers to the estimated amount by which you expect your results to vary if a different sample were taken.

> ***Example***
> The confidence level for this study is 95%, meaning that we are 95% sure that the results represent the true population.

### Correlation

Means that one thing (A) is related to another other thing (B). It is possible that (A) causes (B), (B) causes (A) or the two are caused by a third thing (C). Positive correlation means that when one thing goes up, the other goes up too. A negative correlation is the opposite, when one goes up, the other goes down.

*Example*
There is a positive correlation between income and education, meaning that there is a relationship between the amount of education people have and their income; specifically, people with more years of education have higher incomes.

### Data

Data refers to the text or numerical information collected and organized into a format suitable for analysis to make a point, tell a story, inform decisions, or shed light on a situation.

*Example*
The data can be entered into a Microsoft Excel database to make it easier to organize and analyze.

### Hypothesis

An idea (even a guess) that would explain certain facts or things you see (you can then use data to prove or disprove this).

*Example*
Our hypothesis for this study is that people who exercise three times a week and eat at least two servings of vegetables daily have lower cholesterol than those who exercise once a week and eat one serving of vegetables daily.

### Incidence

Number of new cases of disease that develop in the population during a defined period (also called "occurrence").

*Example*
The incidence of infectious diseases has decreased in the United States since the institution of childhood vaccinations, meaning that the number of people who develop new cases of infectious diseases is fewer once vaccinations for polio, tuberculosis, and measles become a widespread practice.

### Interview

An interview is a conversation between two people – the interviewer and the interviewee – where the interviewer asks the interviewee questions using a questionnaire or an interview guide.

*Example*
The evaluator interviewed program participants about their perceptions of the program's benefits; each interview lasted about 30 minutes.

### Morbidity

The occurrence of ill health or disease in a population (frequency, rate, numbers, etc.).

*Example*
The morbidity rate of cholera in Haiti increased after the earthquake, meaning that the number of people who got sick with cholera, increased.

### Mortality

The occurrence of death in a population (frequency, rate, numbers, etc.).

*Example*
Mortality due to AIDS has decreased since antiretroviral therapy has become more widely available, meaning that the number of people in the population who died from AIDS has become smaller.

### Multivariate Analysis

Methods used to examine at the same time two or more factors contributing to the outcome you are studying and whether and how these factors are related.

*Example*
The multivariate analysis confirmed that adults with lower income who do not own a car and live at least one hour from a bus stop or train station have a higher sense of isolation.

### Prevalence

Number (frequency) of existing cases of disease in the population at any given time.

*Example*
The prevalence of obesity has become a major health concern, meaning that the number of people who classify as overweight and obese is increasing rapidly

### Primary Data

Primary data collection and analysis refers to any original data you collect and analyze.

> ***Example***
> Primary data collection will be necessary because no data exist about the health conditions of the recently arrived refugees; as such, you will have to design and implement a survey or conduct focus groups to get the data.

### Proxy Measure

A proxy is the next best way to measure the behavior or concept that you are interested in studying because it is too difficult to measure that behavior or concept directly, or the data for the behavior or concept you are interested in studying do not exist, and it is not possible to collect new data.

> ***Example***
> Social capital is a difficult concept to measure. Some people use the number of voluntary organizations as one of the proxy measures for social capital.

### Qualitative Data

Data that deal with descriptions in the form of words, pictures, and objects.

> ***Example***
> The qualitative data collected through focus groups are beneficial in understanding how people feel about their community. Words such as "pride," "unity," and "caring" were used by almost everyone in the focus group to describe their feelings about their community.

### Quantitative Data

Data that deal with numbers and amounts.

> ***Example***
> You can collect quantitative data about people's satisfaction with the training by asking them to respond to a series of questions using a scale where 1=very dissatisfied, 2=dissatisfied, 3=neither satisfied nor dissatisfied, 4=satisfied, and 5=very satisfied. This way, you can calculate the percentage of people who responded 1 (very dissatisfied), 2 (dissatisfied), etc.

### Reliability

The ability to get the same result when the test is repeated in the same conditions or context.

> ***Example***
> It is important to look at the reliability of a screening tool such as a mammogram to see if the tool produces the same result each time a test is given to an individual.

## Secondary data

Information collected by researchers but is available and accessible for use by other people.

> ***Example***
> Data from the U.S. Census are examples of secondary data, because the data have been collected by a source other than you and your organization, but are available for your use.

## Statistical Significance of Level of Significance

Indicates the probability that the result occurred by chance.

> ***Example***
> The difference in level of satisfaction between the participants in workshop A and workshop B is statistically significant ($p < 0.01$), which means that the likelihood that the difference occurred by chance is less than 1%.

## Survey

A process for systematically collecting information; a questionnaire is usually used to collect the information.

> ***Example***
> Residents in County Z were recently surveyed about their use of the recreational facilities in the county. The survey questionnaire was mailed to the residents' homes, along with a return envelope for them to mail their responses to the survey administrators.

## Validity

Refers to the accuracy of a test; the ability of a tool to measure what it is supposed to measure.

> ***Example***
> The validity of most public health tests is quite good, meaning that observations derived from these tests are in line with facts (i.e., they are accurate). One exception may be self-reported drug and alcohol use because people tend to report that they use less alcohol and drugs than they use.

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