

DO NO HARM GUIDE
CRAFTING EQUITABLE
DATA NARRATIVES

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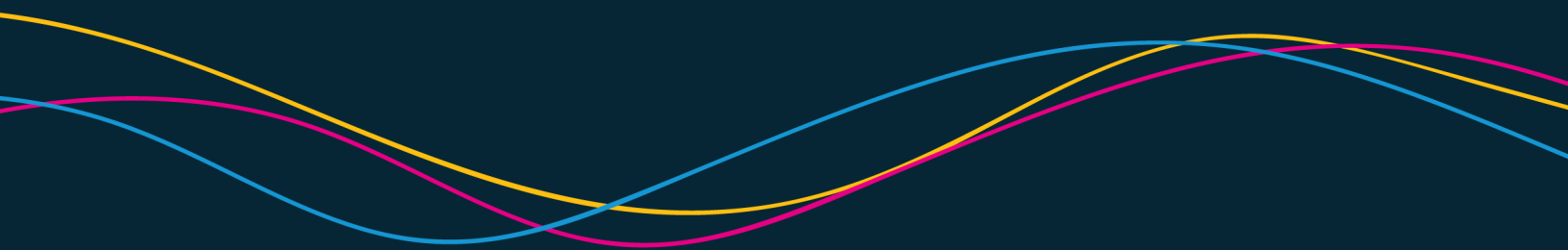
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Introduction

Introduction

So much of our world derives from framing. The narratives we lift up or suppress, the words we use or not use, the images we show, the data we highlight, the context we leave out—all these framing decisions embolden and enrich some people while demonizing or minimizing others.

Data practitioners, specifically, often frame their work as definitive: if the data say so, it must be true. But so many assumptions and decisions shape every part of the data collection, analysis, and communication process, leaving some groups of people lumped together and others left out entirely. Interrogating this framing—who is included, how the work is conducted, and what the work portrays—at every point in the process is crucial to promoting data equity.

Throughout the Urban Institute's *Do No Harm Guide* project, we have sought to inform data practitioners about data equity and resetting their framing to prioritize intention and empathy. We have worked to show that data represent real people and to demonstrate that when practitioners fail to use data with care or consideration, they can cause harm.

The first guide, *Applying Equity Awareness in Data Visualization*, stressed the importance of avoiding stereotypes, biases, and other kinds of harm when working with and communicating data. It offered actionable lessons around engaging with communities, building diverse teams, creating visualizations with intentional color palettes and words, and much more. The second guide, *Additional Perspectives on Data Equity*, sought to expand this purview by asking people in various fields how they prioritize equity in their work, with a focus on reaching out and supporting specific communities. The other three guides—*Centering Accessibility in Data Visualization*, *Applying Equity Awareness in Data Privacy Methods*, and *Collecting, Analyzing, and Reporting Gender and Sexual Orientation Data*—focused more narrowly on accessibility, data privacy, and sexual orientation and gender identity data.

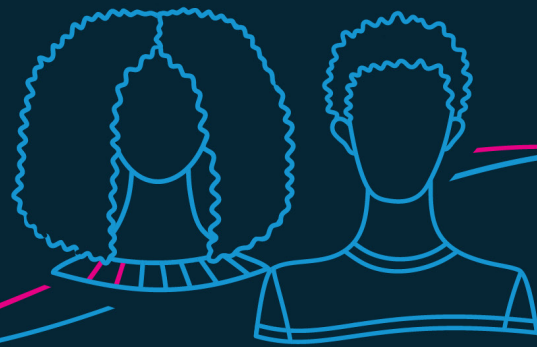
In this *Do No Harm Guide: Crafting Equitable Data Narratives*, we discuss how data practitioners can reframe their work at every stage of data collection. After soliciting essays in early 2023, we worked with authors to refine their ideas and create a cohesive final product. This guide contains 12 essays divided into three parts.

The first part deals with the framing decisions data practitioners must make. The authors tackle how to define rural areas, what kinds of studies are considered rigorous, who is given the opportunity to lead studies, and which groups avoid detection and analysis altogether.

The second part deals with the data collection process, specifically how the framing of survey questions, research designs, and community-engaged methods can potentially harm people and communities. The authors tackle how to support high school students experiencing homelessness, collect data on transgender people, work with immigrant communities in trauma-informed ways, and engage collaboratively with women experiencing homelessness.

The third part deals with the presentation of data, specifically how researchers can thoughtfully showcase their findings in ways that do not perpetuate harm or render groups invisible. The authors tackle using inclusive language when writing about gender data, framing community-based data analysis with positive language, adding contextual language to convey the full nuance of data analysis, and designing diverse anthropographics for visualizations.

With this sixth guide, we hope to provide a better understanding of all the narrative decisions that go into even the smallest piece of data work. Definitions, scopes, questions, methods, icons, and word choices—they all affect how people understand data and who benefits as a result. There is still much more work to be done in the field of data equity as many questions remain unanswered. As the field undertakes these new frontiers, data practitioners, researchers, policymakers, and advocates should keep front of mind who they include, how they work, and what they choose to show.



Part One

Who Defines Data Equity?

Modernizing Data Collection to Improve Rigor in Research Involving Human Participants



ERIN BRADLEY

Data scientists possess an undeniable power to help people better understand themselves, others, and the world. Unfortunately, current data practices in research involving human participants fail to offer proper representation or to adequately consider intersectionality, which can lead to only a partial understanding of the causes and solutions to some of society's most pressing concerns. Although researchers aim to produce results that are accurate and precise—or rigorous—far too often, data collection methods adhere to another meaning of rigor: unyielding or inflexible.¹ When researchers regard the accepted standards of rigor in data collection methods as inflexible, they produce less rigorous results by failing to collect information that sufficiently captures the perspectives or experiences of certain people or groups.

The prevailing view of methodological rigor has its origins in traditional laboratory science that focuses on conducting experiments in highly controlled settings, thus prioritizing procedural uniformity. This view is pervasive, and it is often reflected in funders' standards for evaluating a proposal's scientific merit. The National Institutes of Health, for example, has its origins in laboratory science,² and it defines rigor as "the strict application of the scientific method to ensure a robust and unbiased experimental design, methodology, analysis, interpretation and reporting of results."³ As a result, social and behavioral research studies using designs and methods that closely align with laboratory science tend to be considered the most rigorous, which increases the likelihood of being funded (Bourgeault 2012; Carey and Swanson 2003). Other research gatekeepers, such as scientific journal and book editors, manuscript reviewers, and publishers, also largely employ the same standards of rigor and are regarded as less credible if they do not. Yet, this myopic view of rigor can undermine the validity of research findings when it is inappropriately applied to social and behavioral research, or any research that relies on self-reported data.

The Best Practice Is the One That Yields the Most Accurate Data

Social and behavioral scientists have shown through a robust body of evidence that people and groups respond to data collection differently. Psychologists, for example, have explored the many ways people process information (Miller and Willis 2016) and their varying levels of openness to disclosing information (Petronio and Child 2020). And beyond individual differences, sociologists, anthropologists, and psychologists have demonstrated how culture shapes people's values, worldviews, interactions, and expressions (Miller 2019).

Because of the diversity across and within groups of people, using the same data collection measures and methods likely will not produce the desired outcomes. Most accurate data are collected by employing measures and methods that are best suited for the population of interest. Some individuals, for example, will more accurately express themselves verbally based on personal preferences or cultural norms.

Expanding data collection methods to include multiple response methods, such as an oral response and a written format, allows more participants to provide the most accurate data. In certain instances, having a person administer the survey could encourage participation and yield higher-quality data, particularly in socially and economically marginalized communities. For some people, sharing information with another person creates a human connection and demonstrates an investment from the researcher, whereas simply being given a survey to complete alone may feel extractive. People whose thoughts, feelings, and experiences are frequently ignored or undervalued would not want to share information with a researcher they perceive is collecting data for self-serving purposes.

While a multimethod approach may be incorporated in some studies, it is not the standard for rigor. Current rigorous data collection typically includes written items with a set of fixed response options, which can reinforce an underlying perception

that quantitative research is more rigorous than qualitative. Additionally, existing surveys are often not developed with input from potential respondents. As a result, the measures may better represent how the researcher communicates about the topic than how the respondents express themselves. This disconnect is greater when researchers are not members of the population of interest.

Attention to cultural differences is also paramount. If in-depth interviews are identified as the best method to collect data, failing to adhere to cultural norms for engagement can harm rapport and data quality. Interview training from a traditional lens tends to emphasize the importance of establishing a "professional" tone and appearing "neutral" to guard against bias. But researchers and data collectors from more expressive cultures recognize this training as misguided, because seeming stoic or detached can be interpreted as being disrespectful or disinterested in what respondents have to say. Astute researchers and data collectors with marginalized identities are able to adjust elements of their training and respond appropriately (e.g., affirm or comfort) without undue influence on participants' responses.

When employing a more personal approach, it is essential to carefully select and train data collectors. Training in trauma-informed research methods may be especially useful to avoid unintended harm (Edelman 2023; Powell et al. 2022; SAMHSA 2014).⁴ If members of a community have personally or collectively been harmed by outsiders, they may be understandably hesitant or may refuse to provide information to a data collector who is not a member of their community. These communities are often inappropriately labeled as "hard to reach," although they are usually forthcoming when there is a transparent process outlining the purposes for collecting personal information, a community involvement in how members choose to engage based on their interest and ability, and a clearly established mutual benefit for both the people who commission and conduct the study and the participants who make the study possible by providing valuable data.

Methodological Flexibility Promotes Inclusivity

Modernizing data-collection best practices by creating more nuanced standards of rigor can allow researchers to capture the most accurate and complete data from increasingly diverse populations. Historically, research has been conducted with homogenous groups comprised of people who share similar demographic characteristics and social norms (e.g., white, educated, male). And many of the methods used today were established by and for this particular segment, which limits researchers' ability to gather the best data from a wider range of the population.

In recent years, there have been calls to ensure research participants better reflect the sociodemographics of the diverse US population. But doing so has its challenges (Bodicoat et al. 2021). African Americans, for example, have well-documented reasons for skepticism stemming from unethical research practices, including the denial of effective treatment for syphilis to African American men (Vonderlehr et al. 1936); widely used gynecological practices developed through experimentation on enslaved African women without anesthesia or consent (Washington 2006); and the unauthorized use of Henrietta Lacks's cancer cells (Skloot 2010), which were foundational for biomedical research discoveries that led to more than 100,000 scientific publications and several Nobel prizes and generated profit for at least one multibillion-dollar corporation.⁵

Furthermore, past experiences of being misrepresented, even by researchers with good intentions, can discourage people from participating in studies. For example, a study noting a higher rate of obesity among African Americans compared with their white counterparts without referencing the robust body of evidence that shows this gap arises from structural issues, such as suboptimal access to healthy foods or walkable neighborhoods (Newsome, Gravlee, and Cardel 2021), can incorrectly lead the public to conclude that African Americans simply do not care

about their health or are unwilling to adopt healthier lifestyles. These examples illustrate the exclusion or misrepresentation of racialized groups and the sociodemographic factors that commonly push people to the social and economic margins of society.

Because of the harm that has been done, expanding data collection to capture more segments of an increasingly diverse population will require establishing community-engaged methods as best practice (Harrison et al. 2021). Members of a community are best positioned to lead or direct data collection because they have the trust of other members and are intimately familiar with the barriers and facilitators to data collection within their community. They may advocate for multimethod strategies or adapt traditionally recognized best practices to create and administer measures that better align with the norms of their community. Although these strategies may be less rigid in implementation to account for heterogeneity or may rely heavily on long-standing community practices, they can produce high-quality data.

Unfortunately, community-engaged or community-led approaches that meaningfully involve community members in the development of data collection tools and processes are generally regarded as niche approaches and not valuable, credible, or methodologically sound. Even if researchers have been taught to adopt a researcher-participant relationship that positions participants as less capable, they should know that community members can be trained or might already possess the skills to develop measures or collect data; and community members may be able to do so more easily, efficiently, and accurately with fewer barriers to overcome than an outside researcher.

Avoiding Common Pitfalls

When engaging in dialogue or action to modernize standards for rigor in studies with human participants, researchers should be mindful of a few common pitfalls. Many interpret standardization as complete

uniformity in all procedures. However, when employing a range of data collection methods, standardization in methodology, generally, can be achieved while still leaving room for adjustments informed by social and behavioral science evidence or population “insider” knowledge to yield the most accurate data. Concerns that such flexibility may introduce bias are usually rooted in a traditional laboratory-science view of rigor that fails to distinguish the methodological uniformity required for the *implementation* of an experiment from the *assessment* in experimental studies, as well as studies that do not aim to establish causality. Varying the ways an intervention is delivered, for example, will hinder researchers’ ability to make causal statements about the intervention’s effect. However, the idea that varying the ways people self-report on key variables in an experimental study or in nonexperimental research poses an inherent risk of bias has not been substantiated.

Some researchers may discover that to incorporate community-engaged methods they need to make only a few small changes to their methodological approaches, while other researchers may need to make more extensive changes. Regardless, such changes will require an investment of time and resources. But there are experienced people, especially those who are members of the population of interest, and organizations with a proven record of community-engaged work that are well-positioned to lead or assist. They may be trusted, knowledgeable community members with valuable expertise in designing and implementing grassroots or homegrown initiatives, or researchers with a “dual citizenship” as members of marginalized communities with relevant lived experiences and of the scientific community

with formal training. As external consultants are hired or leaders are appointed, consider the depth of their expertise and look for experience working in true partnership with communities that extends beyond basic activities (e.g., hosting focus groups or listening sessions).

Reimagining Rigor

While the traditional view of rigor has created a foundation for better understanding the world, researchers should reconsider and refine data collection methods to more accurately capture missing or poorly represented segments of the population. It is not suitable to continue to embrace an outdated view of methodological rigor that prioritizes uniformity over data accuracy and completeness. But this change in data collection methods cannot fall on individuals and organizations alone; real systemic change will require a concerted effort among funders and gatekeepers at the highest levels.

It is possible and makes good sense to modernize standards of rigor for researchers to improve the accuracy and completeness of data collection, where people provide information about themselves and their experiences. Researchers are not subject to methodologies; methodologies exist for researchers’ benefit. When researchers recognize methods that do not adequately serve their needs, they should replace or enhance them. Similar to adjustments made in thinking and practice after a major medical or technological advancement, the catalog of rigorous methodological tools can and should evolve.

Let’s not miss the opportunity to improve the rigor of our results as we inch toward a better understanding of our increasingly diverse world.

NOTES

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3. National Institutes of Health, “Guidance: Rigor and Reproducibility in Grant Applications,” accessed November 1, 2023, <https://grants.nih.gov/policy/reproducibility/guidance.htm>.
4. Rebecca Wong, “Guidelines to Incorporate Trauma-Informed Care Strategies in Qualitative Research,” *Urban Wire* (blog), Urban Institute, August 30, 2021, <https://www.urban.org/urban-wire/guidelines-incorporate-trauma-informed-care-strategies-qualitative-research>.
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CHAPTER TWO

Elite Omitted Variable Bias: Missing Datasets and the Political Economy of Data Collection



TIMI KOYEJO

Data equity conversations often focus on how marginalized groups have been harmed by past and ongoing data collection practices. Extractive research methods, flawed and inaccurate databases, and omission of disadvantaged populations from important datasets have all been shown to disfavor marginalized groups (Chicago Beyond 2018; Consumer Financial Protection Bureau 2022; Maxim, Sanchez, and Huyser 2023). Although discussions of such harms are critical, the standard framing of data equity neglects to ask an important question: How have data collection practices been configured, consciously and unconsciously, to enable elites (advantaged groups) to evade public scrutiny and thwart progressive reforms?

Established social science literature demonstrates the challenges of researching elites. Household surveys regularly receive lower response rates from the very rich, introducing response bias; and qualitative researchers have difficulty researching political and economic elites, who often decline to sit down for interviews (Aberbach and Rockman 2002; Ravallion 2021). Investigative journalists have extensively detailed the lengths elites take to maintain their privacy. Examples include hiding campaign donations from public datasets by channeling them through “dark money groups,”¹ using untraceable shell companies and offshore tax havens to evade taxes,² and creating tax breaks like Opportunity Zones that offer minimal public benefit yet provide billions of dollars in tax relief to wealthy investors with barely any transparency measures.³ To borrow a phrase from cybersecurity, elites and their allies are quite adept at pursuing security through obscurity; if there is nothing to see, there is nothing for the public to be concerned about.

The Urban Institute's *Do No Harm Guide: Applying Equity Awareness in Data Visualization* points to the importance of acknowledging “who is and is not included in [the] data” and how the “groups whose data are and are not collected or shown often reflect who society deems as most important or valuable” (Schwabish and Feng 2021). The authors outline situations where marginalized groups are harmed by being excluded from datasets and visualizations. Of particular relevance to this essay is the following passage about missing data:

We can think about missing data even more broadly than data we have but do not include in our charts, graphs, and diagrams. Artist and researcher Mimi Ҡnұҫha's *The Library of Missing Datasets* project identifies “missing datasets,” or entire categories of data and information that do not exist but perhaps should. Ҡnұҫha (n.d.) writes, “That which we ignore reveals more than what we give our attention do ... Spots that we've left blank reveal our hidden social biases and indifferences.” (Schwabish and Feng 2021, 16)

Building off Mimi Ҡnұҫha's astute observations, a more comprehensive vision of data equity requires a grappling with the political economy of missing data—examining not only marginalized groups but the powerful and influential. In principle, society values data transparency as a universal public good. However, in practice, its requirements are disproportionately imposed on those with less power. While the wealthy, white, and advantaged are often able to enjoy the benefits of obscurity—and actively fight to maintain their anonymity—people living in poverty, people of color, and other marginalized groups are extensively tracked in various government datasets, especially if and when they interact with government services and benefit programs.

Drawing inspiration from a statistical concept, I have termed the relative absence of the powerful from public datasets as “elite omitted variable bias.” Although omitted variable bias (OVB) has a precise statistical meaning,⁴ quantitative social scientists broadly refer to it as the distorting effect of excluding

one or more variables with explanatory power from a statistical model. Consider, for example, a researcher studying whether there is a statistical correlation between class sizes and student literacy outcomes in a large, diverse school district. If the researcher fails to account for the differing share of English as a Second Language learners in each classroom, the resulting estimate would be biased. Similarly, the absence of data on elites can bias researchers' and the broader public's understanding of society and impose limits on how social problems are defined and discussed. To conduct a truly rigorous analysis of social inequities, it is necessary to look both up and down the social hierarchy.

The Political Economy of Elite Omitted Variable Bias

Data collection decisions shape policy action. These decisions range from the initial question of how to define and delimit phenomena to the many methodological and analytic data collection choices made throughout the research process. The way data are collected, parsed, and processed steers the questions data analysts can explore, sets research agendas down particular paths, and influences policy framings and social problem definitions. For example, divergent choices regarding how to define homelessness and count the number of people experiencing homelessness can lead to stark differences in how policymakers perceive the severity of housing insecurity in their cities and what resources should be brought to bear.⁵

Public-sector data collection is a costly endeavor. It can take a significant amount of planning, time, technical infrastructure, and money to create a new dataset or to simply ensure that an existing dataset is kept up to date. At their core, governmental data collection decisions are about prioritizing public resources and attention. And these decisions are influenced by political economy and interest group maneuvering. Data collection is often presented as a dry, technical matter best left to the experts, yet there are real ideological currents flowing beneath its placid waters. Even for sophisticated and critical data users,

elite OVB can float by undetected because of possible unconscious biases about who or what should be measured. As a result, elite OVB requires special attention to detect.

The omission of data on elites is partially a result of the different ways advantaged and disadvantaged groups access government resources. A significant portion of the American welfare state that serves middle- and high-income households is invisible and operates as a so-called submerged state. For example, the billions of dollars of government benefits that are delivered indirectly through the tax code—such as the home mortgage interest deduction, employer-provided health insurance tax breaks, and tax-advantaged retirement investment accounts—do not leave a noticeable paper trail (Mettler 2011). In contrast, social programs that serve low-income households, such as rental assistance or the Supplemental Nutrition Assistance Program, require direct application to a government agency and are highly visible. To access these programs, applicants must submit a detailed accounting of household composition, number of hours worked, and a variety of personal demographic details—data that are often closely monitored and analyzed.

Still, it is unlikely that the obscurity of advantaged groups in public datasets is simply an incidental outcome of technical, policy design decisions. Governmental data collection practices have been shaped, consciously and unconsciously, to privilege powerful interests for the following reasons:

- 1. Elites are savvy and well-informed.** Advantaged groups have the expertise, time, and resources to understand (or pay others to understand) how to avoid visibility. Lobbyists, for example, can be tasked with keeping abreast of new policies by tracking notices for public comments, budget proposals, or public remarks. Additional data collection is often the first step government agencies take toward developing new or stronger regulations on private actors, so staging early interventions to block or weaken such data collection proposals is an effective maneuver.
- 2. Elites are highly organized.** When elites are alerted to new policy changes, such as additional public disclosure requirements not to their liking, they can tap into their networks to mount a collective response. They can take actions through both formal channels (e.g., public comments) and informal channels (e.g., directly contacting sympathetic elected officials). Furthermore, by using proxies, elites can distance themselves from the results of their self-advocacy and muddle responsibility.
- 3. Policymakers are more sympathetic to the administrative burdens and privacy concerns of elites.** Data collection imposes time and resource costs on the individuals and organizations subjected to it. Scholars have explored how these costs affect policy outcomes through the concept of “administrative burden,” which refers to the hurdles the public must overcome to receive benefits or services (Herd and Moynihan 2018). Research has shown that administrative burden is disproportionately borne by marginalized groups that have limited resources and time to navigate bureaucratic red tape. Additionally, some policymakers may believe elites are conscientious citizens who require less data oversight than members of “less deserving” marginalized groups who require close monitoring.
- 4. Public bureaucracies are resource constrained and responsive to elite pushback.** Many public-sector agencies are continually understaffed and often lack the capacity to execute their current responsibilities, let alone take on new ones. Furthermore, elected officials or senior agency staff rarely devote substantial resources to promoting new data collection policies. If a new data collection proposal were to generate organized backlash from elites, agency leadership likely would not expend significant political capital to protect it, especially if there were no vocal outside constituency advocating in favor of the proposal. Public agencies may also preemptively limit the scope of new data collection proposals that affect elites to avoid a drawn-out conflict.

Examples of Elite Omitted Variable Bias

The following two cases regarding housing and real estate policy in Chicago show how data collection power dynamics play out in more concrete terms and how to combat elite OVB.

Rental Registries

Although an estimated 44 million American households rent their homes, the underlying data on the rental sector are notably poor, fragmented, and incomplete compared with data on single-family homes (JCHS 2022).⁶ Often, the latest local median rent statistics are sourced from either flawed and unrepresentative private rental datasets or from more accurate but out-of-date census statistics.⁷ The lack of accurate, current data on landlords' rent-setting practices limits the ability of government officials, advocates, and community groups to monitor trends in housing affordability, gentrification, and disinvestment. In housing policy debates, which privilege data and statistics, flawed rental data present a barrier for tenant advocates seeking to make systematic critiques of the power imbalance between tenants and landlords. While advocates must work with limited access to sophisticated data on the rental sector, some landlords increasingly are using algorithms that leverage privately collected rent data to aggressively maximize rents.⁸

Local housing advocates in Chicago and elsewhere have pointed out the lack of comprehensive data on who owns multifamily rental housing in their cities. Having to go through significant hurdles to identify the true owner of an apartment building makes it difficult for tenants and tenant organizers to hold landlords accountable for poor maintenance or to negotiate over rent increases. Although some apartment ownership information is publicly available across disparate sources, most data are not readily accessible. In Chicago, for example, multiple data sources must be linked and assembled to attempt a more comprehensive analysis.⁹ Even innovative approaches to make rental ownership transparent

have limits, as some landlords may register each apartment building as a separate limited liability corporation with a generic, nonidentifiable name. As a result, it is challenging for researchers and public officials to understand new trends, such as the ownership concentration of corporate single-family rentals.¹⁰

To remedy this lack of rental ownership data, tenant advocates and some local elected officials in Chicago have called for the creation of a *rental registry* (also known as a landlord registry)—a database of rental units and their property owners.¹¹ In cities with established rental registries, they are usually administered by local government agencies and include a variety of data fields. At its most basic, a registry would include up-to-date landlord contact information and a 24-hour emergency contact. More expansively, a registry could include information on the number of units the landlord owns, vacancy status, date the unit was last inspected, and the current rent. Proponents argue that a rental registry could help combat housing scams by ensuring that potential tenants are interfacing with the true property owner. Housing scams are especially an issue in disinvested neighborhoods of color, where tenants are more likely to live in buildings that cycle through speculative landlords who change frequently with little notice.¹²

For many housing officials and advocates, the COVID-19 pandemic and associated eviction crisis showcased how little information local and state governments have on the rental sector, which made quickly establishing new rental assistance programs very challenging. Though the creation of a rental registry has been incorporated into broader housing legislation packages introduced in the Chicago City Council, there has been limited legislative progress thus far.¹³ Meanwhile, other cities have passed rental registry legislation in recent years, despite strong opposition from landlord interest groups; in Los Angeles, for example, these groups unsuccessfully sued to block the policy.¹⁴

Lending Equity Ordinance

Chicago has a long history of inequitable residential mortgage lending practices that continue to the present day. From 2012 to 2018, for every \$1 banks loaned in Chicago's white neighborhoods, just 12 cents were loaned in Black neighborhoods and 13 cents in Latino neighborhoods—even though there were similar numbers of majority white, Black, and Latino neighborhoods in the city.¹⁵

Chicago, like any large city, requires banks to manage the hundreds of millions of dollars it holds to operate city services, from payroll to procurement transactions. While local governments have limited tools to encourage greater bank lending in certain geographies, they can impose stronger public disclosure requirements for financial institutions that provide services to the city government. This approach has been adopted by various cities to spotlight inequitable lending practices. In fact, Chicago was one of the first cities to pass such legislation in 1970s, called Responsible Banking Ordinances—though analysis has shown that the policy up until recently had limited effect.¹⁶

Chicago annually issues a request for proposals to determine which banks will act as a municipal depository for the city. In 2021, a coalition of local housing advocates pushed for improvements to this proposal process to ensure greater lending accountability for the financial entities that partner with the city.¹⁷ Advocates ranged from groups with deep expertise in mortgage lending data to those working on neighborhood developments.¹⁸ Their efforts resulted in the drafting of the Lending Equity Ordinance, which passed with unanimous City Council approval. The ordinance requires the city's banking partners to provide additional data on who they are lending to, who they are hiring, and where they are making their biggest investments. The city then uploads the data to Chicago's public data portal in a machine-readable format to ensure they are accessible to the public.¹⁹ Additionally, the ordinance requires the City Council Finance Committee to hold an annual hearing to discuss trends in lending before approving the updated list of banking partners.

While housing advocates acknowledge that the Lending Equity Ordinance is not a comprehensive solution for the deeply rooted, systemic causes of lending inequities in the city, the broad coalition that came together to pass the ordinance saw value in forcing a regular and transparent conversation about the lending records of Chicago's major banks seeking business with the city.

Recommendations to Counteract Elite Omitted Variable Bias

What can an individual data analyst do about elite OVB? Indeed, many of the issues discussed in this essay point to structural challenges without straightforward solutions. That said, data analysts can intervene in following ways, alone and collectively, to mitigate these issues:

- 1. Think critically about what data on elites have been left out of the public datasets your analyses use** and the consequences of the omission. One intervention is to include a section detailing how missing datasets or variables shape results and policy framings.
- 2. Participate in public processes and analyze data collection proposals from a data equity perspective**, including paying attention to potential elite OVB. This could involve submitting written feedback in response to public comments, proposing rule changes, and drafting letters of support or concern.
- 3. Join coalitions of community-engaged researchers and frontline community members to collectively advocate** for a more just data collection approaches that counter the prevalence of elite OVB and the power dynamics that lead to them.
- 4. Explore alternative approaches to gathering data on elites**, including linking across diverse datasets and data scraping. One option is to use commercial or proprietary datasets that collect information on elites, although there may be ethical considerations for spending money on these data sources.

Greater transparency and data availability on economic and social elites do not, on their own, lead to improved social equity. But having more data on advantaged groups can help recalibrate the terms of debate and catalyze new policy framings. Our data equity conversations are enriched by thinking more expansively about what data equity truly requires. Data analysts need to acknowledge and address the systematic gaps in data collection on the activities of elites as well as the effect these omissions have on research findings and policymaking. When researchers grapple with the implications of elite OVB, even if they do not share the same normative motivations for data equity, policy research will be more rigorous and, to use a fraught term in this discourse, more objective.

The goal of researchers should not be to create a mass data-surveillance state. Data equity does not mean that the advantaged should be just as tracked as the disadvantaged. Data analysts should always question what data are appropriate to gather and why. Researchers need to seriously scrutinize the limitations of quantitative data and the many ways social inequities can be embedded within seemingly apolitical data collection and analytical practices. Despite these challenges, thoughtful data analysis is still an important tool for understanding the world and driving towards a more just society—as long as we remember who and what we are missing.

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Rural Definitions and Their Consequences



MARK REMBERT



CAMDEN BLATCHLY

When discussing rural development, a common adage goes: “If you’ve visited one rural area, you’ve only visited one rural area.” Spread across the country, rural communities boast unique attributes, from their histories and physical terrains to their populations. This makes it challenging to describe rural America. Even residents often have conflicting views on what defines a rural community.

With more than 10 federal definitions and a range of state-specific definitions, it is difficult for data users, such as researchers, policymakers, and journalists, to categorize rural areas (see **box 1**, next page). This complexity of definitions, coupled with inherent differences among communities, can lead to data users choosing a framework that may poorly suit the intended purpose, resulting in unintended outcomes, skewed data interpretations, and potentially misinformed decisions and policies that affect rural communities.

The varying definitions of rural America are more than just semantic; they affect the country’s socioeconomic and demographic landscape and the allocation of federal resources. In 2017, geography-based allocations accounted for approximately \$773 billion in federal resources, with 92 programs employing rural definitions to set eligibility criteria for over \$139 billion in funding. This underscores how significantly definitions influence the real-world distribution of resources. As a result, it is crucial for data users to define rural America with intention and to navigate the complexities of existing frameworks carefully.

BOX 1: RURAL DEFINITIONS

Federal Housing Finance Agency designates US census tracts as rural if they are located within the Office of Management and Budget (OMB) definition of nonmetropolitan county or are located within an OMB-defined metropolitan county and meet the Rural-Urban Commuting Area (RUCA) code and housing density requirements.

Frontier and Remote Area Codes designate zip codes into four categories based on population size and travel time from Census-defined urban areas.

Health Resources and Services Administration designates US census tracts as rural if they are located within an OMB-defined nonmetropolitan county or are located within an OMB-defined metropolitan county and meet the RUCA code and population density requirements.

National Center for Education Statistics Locale Classification divide all territory in the US into four types: rural, town, suburban, and city. Each type is further divided into three subtypes based on population size or proximity to Census-defined urban areas.

National Center for Health Statistics Urban-Rural Scheme subdivides the OMB definition into four metropolitan and two nonmetropolitan categories. Notably, the scheme separates counties within large metropolitan areas (population of 1 million or more) into two categories: central (e.g., inner cities) and fringe (e.g., suburbs).

Office of Management and Budget (OMB) designates counties as metropolitan, micropolitan, or noncore based on population density and the presence of urban centers; micropolitan and noncore counties are considered nonmetropolitan.

Rural-Urban Commuting Area (RUCA) Codes classify US census tracts into 10 categories using measures of economic integration, such as population density, urbanization, and daily commuting. The codes are published by the US Department of Agriculture (USDA).

Rural-Urban Continuum Codes subdivide the OMB definitions into three metropolitan and six nonmetropolitan categories. Metropolitan counties are distinguished by population size, while nonmetropolitan counties are distinguished by degree of urbanization and adjacency to a metropolitan area. The codes are published by the USDA.

Urban Influence Codes subdivide the OMB definition into 2 metropolitan and 10 nonmetropolitan categories. Metropolitan counties are distinguished by population size, while nonmetropolitan counties are distinguished by degree of urbanization, population size, and/or presence of an adjacent metropolitan area. The codes are published by the USDA.

US Census Bureau defines rural as US census blocks not in an urban area, which is classified using population size and housing density.

Existing Frameworks for Defining Rural America

The most commonly used frameworks for defining rural America are provided by the US Census Bureau and the Office of Management and Budget (OMB). The two frameworks diverge significantly in their approach to categorizing areas as rural, creating distinct pictures that can lead to different conclusions about the same geographic region. Such conflicting approaches often make it difficult to understand rural issues and can create discrepancies in data interpretation, policymaking, and resource allocation.

The Census Bureau classifies rural areas by first classifying urban areas, which it defines as densely settled cores of census blocks that meet minimum housing unit density and/or population density requirements; rural areas are then classified as all

areas that are not urban. This broad definition of rural includes a vast range of areas, from sparsely populated landscapes to open countryside to areas on the fringes of larger cities. Categorized at the census block level, this Census Bureau definition is the most geographically detailed. But while it is broad enough to capture a range of rural characteristics, its inclusion of metropolitan fringes—areas that often share more common characteristics with suburban areas than with rural areas—can skew interpretations of rural issues. Coweta County, Georgia, for example, is a county in the Atlanta metropolitan area with a population of 146,000 and is among the fastest growing counties in Georgia. Yet, because of the suburban density of the area, nearly half the county is categorized as rural.

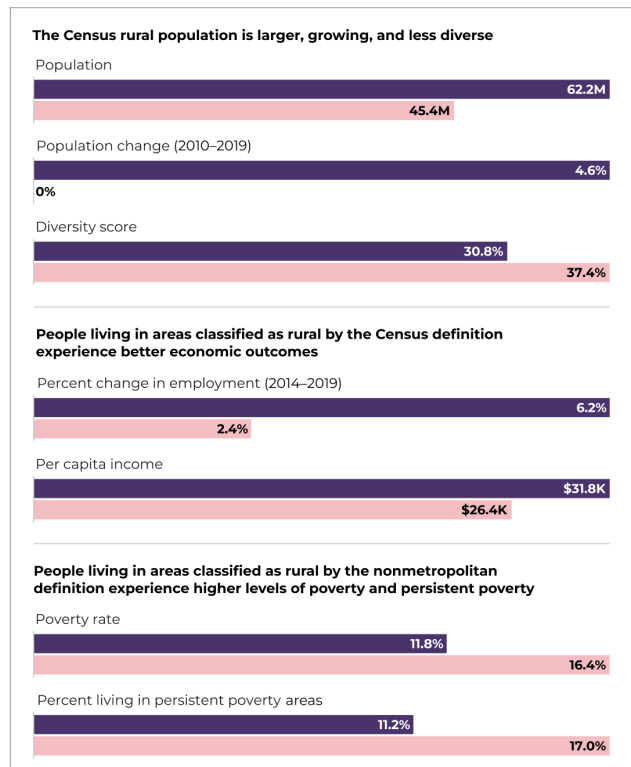
In contrast to the Census Bureau, the OMB classifies entire counties as metropolitan or nonmetropolitan based on various factors, such as population density, urbanization level, and the presence of urban clusters. This classification more accurately reflects the mix of smaller economies and areas with low population density that many associate with the word “rural.” However, this framework also has limitations. Notably, it excludes some areas within metropolitan counties that share rural characteristics, such as those in California and Arizona, where the geographic scale can obscure the truly rural areas within metropolitan counties. Blythe, California, for example, is a small town of 18,000 people located in Riverside County, which has a population of more than 2.5 million and a landmass larger than Connecticut and Rhode Island combined. Despite being part of a metropolitan county, Blythe is rural in character, located more than 200 miles from Los Angeles and 150 miles from Phoenix. Because of areas like Blythe, it is estimated that the OMB’s definition probably undercounts the rural Hispanic or Latino population by 40 percent.¹

These two frameworks count people and places differently, leading to significantly different pictures of rural America. Demographic trends between 2010 and 2019 based on the Census Bureau criteria show a growing rural population (**figure 1**). Using the OMB criteria, however, rural population appears to be stagnant. Furthermore, the diversity index, which calculates the likelihood that two randomly chosen individuals will be from different racial or ethnic backgrounds, is 20 percent higher in rural areas using the OMB criteria than the Census criteria, even though the OMB definition undercounts the rural Hispanic or Latino population. This difference arises because rural Black and Hispanic or Latino populations are more likely to reside in small towns, which are included in the OMB definition but excluded from the Census definition.

A similar divergence of rural America characteristics can be seen using economic indicators. Between 2010 and 2019, under the Census Bureau definition, the rural economy expanded and experienced lower

FIGURE 1

Different Stories about Rural Places Based on Census and Nonmetropolitan Rural Data



Source: Center on Rural Innovation. Data based on American Community Survey 2019 five-year estimates and US Economic Development Administration 2022 persistent poverty classifications.

Note: “Census rural definition” estimates are calculated using the 2010 Census rural definition. “Nonmetro rural definition” estimates are calculated using 2019 Core-Based Statistical Areas, which are defined by the Office of Management and Budget. A county is experiencing persistent poverty if its most recent poverty rate estimate equals 20 percent and its poverty rate was at least 20 percent in the 1990 and 2000 Censuses (i.e., 20 percent or greater poverty over the past 30 years). “Percent living in persistent poverty areas” is the share of the rural population that lives in persistently poor counties. The diversity score represents the probability that two randomly selected people in a county will have different racial or ethnic identities.

poverty levels, whereas under the OMB definition, economic growth was sluggish and poverty more prevalent.

Federal agencies like the US Department of Agriculture (USDA) have developed unique definitions that address some of these issues. The USDA’s Rural-Urban Commuting Area (RUCA) codes, for instance, classify census tracts as rural based on population density, urbanization, and daily commuting. They offer a nuanced perspective by incorporating elements from

both the Census Bureau and the OMB definitions. According to RUCA codes, Coweta County, Georgia, is not rural, given its suburban nature, whereas Blythe, California, is rural. Although increasingly employed by researchers and policymakers, the RUCA codes are typically not used for publicly reported data and require high-level technical skills to implement, such as performing complicated spatial crosswalks at the census tract level. Additionally, current RUCA codes are only available based on the 2010 Census, and updated codes based on the 2020 Census are not expected to be released until fall 2024.

Given the complexity of rural definitions and their constructions by federal agencies, it can be difficult for data users to fully understand the implications of their data work and make informed decisions. The selection of a definition is not just a technical choice; it has substantive implications for how people understand rural America and the narratives surrounding it. Definitions shape people's understanding of the rural population, economic conditions, racial or ethnic diversity, and access to resources. A nuanced understanding of these definitions is critical to ensuring a more accurate and fair representation of rural America in data analysis, policymaking, and media narratives.

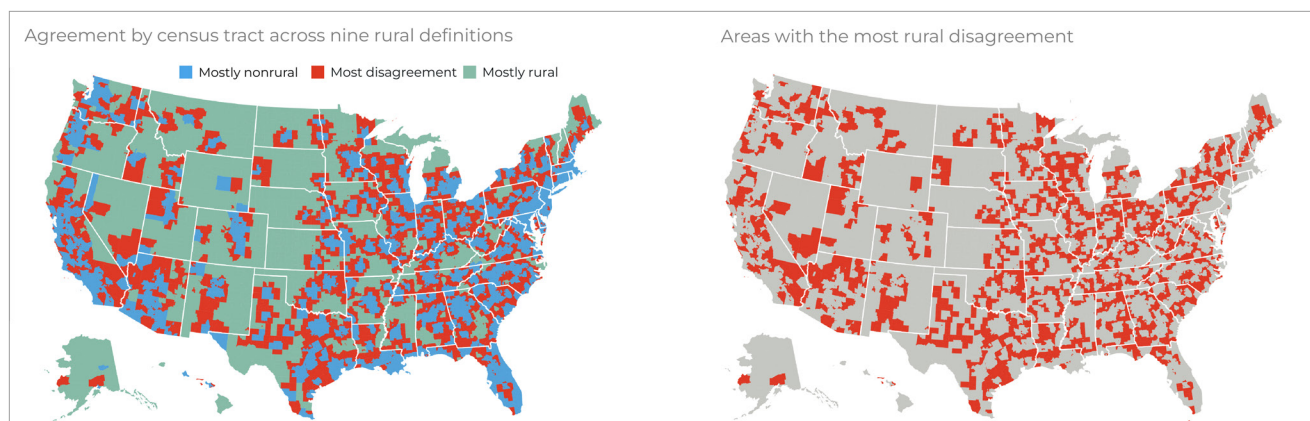
Consequences of Diverging Definitions

When definitions diverge, complications arise regarding resource allocations and policy interventions. Regions in the gray areas of **figure 2** must navigate a complex web of requirements, fluctuating between rural and nonrural classifications depending on the agency or program in question. This ambiguity breeds confusion and frustration for local leaders and communities, as well as wasted time and missed opportunities for accessing federal programs and resources that could have a transformational effect.

Communities that fall through the definitional crack often find themselves competing with both large urban areas and more remote rural regions for resources. In an environment of limited resources, deciding which definition to use can determine whether an area receives much-needed federal assistance.

There are 37.5 million people in these gray areas (figure 2). These areas have experienced almost stagnant population growth since 2010 and continue to struggle with high poverty rates. Yet, because of the conflicting definitions, they are often left behind in the race for federal resources, exacerbating existing socioeconomic disparities.

FIGURE 2
Places with the Most Disagreements across Rural Definitions



Source: Center on Rural Innovation.

Notes: Rural definitions by (1) Federal Housing Finance Agency, (2) Frontier and Remote Area codes, (3) Health Resources and Services Administration, (4) National Center for Health Statistics Urban-Rural Classification Scheme, (5) Office of Management and Budget, (6) Rural-Urban Commuting Area codes, (7) Rural-Urban Continuum codes, (8) Urban Influence Codes, and (9) US Census Bureau. “Mostly nonrural” tracts are classified as rural by 1 to 3 rural definitions. “Most disagreement” tracts are classified as rural by 4 to 6 rural definitions. “Mostly rural” tracts are classified as rural by 7 to 9 rural definitions.

Overall, rural definitions not only shape the narrative but also influence policy decisions, resource allocations, and the economic and demographic understanding of rural America. When the definition includes more prosperous areas, such as the Census Bureau definition, policies might underinvest in rural communities and exclude areas like small towns that could benefit most from policy interventions. When the definition fails to account for people and places that are left out of the nonmetropolitan definition, such as small towns and rural areas in California and Arizona, policies can unintentionally exclude the very people they intend to target.

Ensuring Integrity in Rural Data Use

Until there is a more standardized definition, the responsibility for framing rural America as accurately as possible rests on those who gather and disseminate data. Researchers, journalists, government agencies, and others working with data must undertake a collective effort to ensure that the definitions used reflect its complexity and diversity. When forced to choose between the Census Bureau and OMB definitions, we believe that the OMB definition best describes rural communities that share common characteristics, more accurately represents the diversity of rural America, and represents the critical social and economic dynamics of smaller economies that link open land areas and small towns. When possible, using the RUCA definition adds additional quality, although we note that it has its own limitations.

The following are a few best practices when working with data related to rural America:

- **For researchers:** Be diligent and transparent about the definition used. Prioritize using a definition that most accurately represents the issue, and explain the choice clearly in your methodology. For example, the Census Bureau definition may be most appropriate when considering land use or environmental topics, because it is based on housing density and the built environment; the

OMB or RUCA definition is likely better suited for research focused on socioeconomic issues, given that it is designed to represent the interconnected social and economic dynamics of communities within rural regions. Be cautious about creating new definitions unless there is a robust justification for doing so. It is equally important to examine other research critically to understand the definition used and the potential biases or limitations that definition may introduce.

- **For journalists:** Always clarify the definition applied in the reporting and discuss why the selected definition provides the most meaningful perspective on the issue at hand. Scrutinize the research the reporting is based on and be aware of the possible effects different definitions could have on the story.
- **For government agencies:** Strive for simplicity and clarity in the definitions used to allocate resources and set eligibility criteria. Be mindful that the current, complex definition structure forces many rural communities to navigate a confusing array of requirements. Establishing an official federal definition for rural areas could create a baseline for evaluating alternative rural definitions. Transparency and thorough analysis should accompany resource allocation decisions, especially given their significant effects on communities.
- **For data providers:** Make it easier for data users to access data across different rural definitions, such as options to view or export data using various definitions. Also provide data at the census tract level, which can facilitate more thoughtful and nuanced analyses of rural America.
- **For all data users:** Understand that different definitions yield different demographic and economic data. Be cautious when drawing conclusions based on the data, considering the limitations of the definition used, and understand that the chosen definition could have implications for policy decisions and resource allocations.

How rural America is defined profoundly affects people's understanding and the actions they take to support these communities. To tell more accurate and nuanced stories about the diversity and dynamism

of rural America, data users must choose definitions wisely and be transparent about their decisions. While defining rural America is complex and multidimensional, it is an essential task.

NOTES

1. See "Who Lives in Rural America? How Data Shapes (and Misshapes) Conceptions of Diversity in Rural America," Center on Rural Innovation, January 12, 2023, <https://ruralinnovation.us/blog/who-lives-in-rural-america-part-i/>.

Changing Institutional Review Boards Can Put Power Back into the Hands of Communities



DAWN X. HENDERSON

In 1974, after the passage of the National Research Act, higher education institutions established institutional review boards (IRBs) to safeguard researchers and research participants under the three ethical principles of beneficence, justice, and respect for persons listed in the *Belmont Report* (HHS 1979; Moon 2009). The National Research Act and the subsequent establishment of IRBs aimed to rectify a history of experiments, research, and harm enacted on vulnerable and underserved communities.

Beneficence



"Protect persons from harm and make efforts to secure their well-being; do not harm, maximize possible benefits and minimize possible harms."



Justice

"Each person asked to be involved in research is equally so, based on an equal need, an equal share, an equal contribution, and [equal] merit. The burden of research participation should not fall on the vulnerable while the benefits from research improve others."



Respect for Persons

"Respect all persons' decisions. All individuals should be treated as autonomous agents, and second, that persons with diminished autonomy are entitled to protection."

Source: Image created by the author based on the *Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research* (Washington, DC: US Department of Health and Human Services, 1979).

Fifty years later, agencies like the US Department of Health and Human Services and the National Institutes of Health continue to funnel billions of research dollars into higher education institutions and their IRB processes and less into the communities of research participants (Chicago Beyond 2018; Gibbons 2022; Lauer and Roychowdhury 2021). These agencies often position colleges and universities as the primary purveyors of knowledge and leave out the communities being researched. As a result, communities are rarely put in positions to inform the solutions needed to amend the social and economic systems that increase their vulnerability and keep them underserved.

In my role as director of research at Village of Wisdom, a nonprofit organization dedicated to putting power back into the hands of Black parents and families, and in my work as a university faculty member and community researcher, I know firsthand the shortsightedness of IRBs and the barriers to getting IRB approval for community-driven research. Researchers must closely review IRBs to redress how they disempower and perpetuate harm against the country's most underserved and racially marginalized groups. In this essay, I offer recommendations for how researchers and data practitioners can rethink IRBs and their foundational ethical principles to improve community data collection, analysis, and dissemination governance.

Adding a Social Responsibility and Justice Lens to the IRB Principles

More than a decade ago, Charles Lidz and Suzanne Garverich (2013) decided to critically examine IRBs in higher education institutions. They found that IRBs spent more time discussing research methods and sampling techniques than adhering to the ethical principles of beneficence, justice, and respect for persons. They concluded that IRBs often protected the researchers' fidelity to scientific methodologies but afforded less protection to participants in the research. Other researchers have noted that IRBs

prioritize protecting institutional power through legal jargon on consent forms and in intellectual property clauses, thereby keeping the knowledge gathered under the control of researchers and higher education institutions rather than under the control of community members (Brown et al. 2010; Singer et al. 2022). The ethical principles do little to ameliorate this power imbalance and fail to rectify past harms and protect racially and economically marginalized communities.

To minimize exploitation, knowledge extraction, and the erasure of these community members, I recommend that researchers apply a broader social responsibility and social justice lens to the ethical principles of IRBs. By doing so, they can increase community decisionmaking and power to control and allocate resources.

The first ethical principle of *beneficence* instructs researchers to maximize benefits and minimize harm. In practice, this usually means researchers offer participants gift cards, meals, information, or treatment. IRBs could expand this practice and require researchers to put resources toward addressing social, health, and education inequities.

Furthermore, numerous IRBs fail to adhere to the second ethical principle of *justice* by not addressing the injustices in a system where academic power and privilege remains intact. Today, researchers continue to extract data from communities to advance the knowledge-generating machines of higher education institutions (Chicago Beyond 2018; Muhammad et al. 2015). The unequal distribution of research funding into higher education institutions has largely fueled this same body of research institutions reinforcing negative biases, stereotypes, and deficit attributions of racially marginalized groups (Call et al. 2022). While the ethical principle of justice affords increased opportunities for those in vulnerable communities to serve as participants in research studies, community members are not granted governance over how research should be conducted and carried out in their communities.

The third ethical principle of *respect for persons* instructs researchers to respect individuals' autonomy. IRBs can promote and acknowledge individuals' autonomy by allowing community members to design research and decide how research should happen.

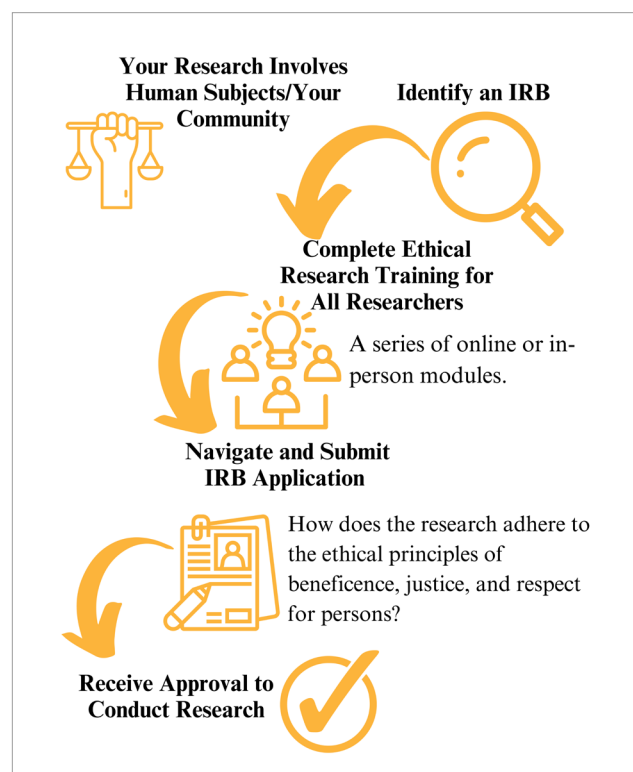
Adding a social responsibility and social justice lens to the ethical principles would require researchers to reexamine how they extract knowledge from communities in research, especially research conducted in racially and economically marginalized communities. To better strengthen community power through IRB-supported work, researchers should do the following:

- **Add an equity statement under *beneficence*.** The IRB application should ask researchers to share how the research will improve the social, health, and education conditions of community members who are most underresourced, underserved, and marginalized.
- **Add a social justice statement under *justice*.** The IRB application should ask researchers to share how monetary or other resources from the project will be distributed and allocated so community members can leverage them to overcome injustice.
- **Add a statement on how cultural identities and beliefs align with *respect for persons*.** The IRB application should ask researchers to identify specific partners that share the community's cultural and racial identities and state how these partners will support translation and dissemination as well as receive compensation that aligns with the needs and aspirations of their community.

IRBs should spend more time addressing the ethical issues of research in ways that honor a broad commitment to community members, whether they are local or international, and researchers should be positioned to put power back into the hands of the people, not extract it from them.

Changing the Location of IRBs and the Certification and Consent Processes

For nonprofits and communities that prefer to conduct their own research, having IRBs embedded in higher education institutions is a major barrier. Because most research projects are required—either by federal regulations, funder requirements, or organizational requirements—to receive IRB approval whenever research involves human subjects, community members are left to either partner with a researcher at a higher education institution or complete the IRB process independently. To go through the process independently, they must rely on IRBs at higher education institutions to approve their research pro bono or for a fee, the latter of which can pose financial challenges. Also, when IRB approvals may be dependent on projects that partner with a higher education institution, such requirements hinder community's ability to conduct research.



Source: Image created by the author.

After identifying an IRB that will oversee the research, nonprofits and community organizations must complete ethical research training, which usually requires community members to receive certifications from higher education institutions or programs like the Collaborative Institutional Training Initiative (CITI Program) for a fee.

My team and I at Village of Wisdom in North Carolina found that this certification process can pose harm to communities. In a recent research project, we needed to prepare Black parents for the certification, but the content in the training modules set off a series of negative emotional triggers (e.g., anger and frustration); for example, some parents encountered peripheral harm when reading about the Tuskegee study. As cited in Alsan, Wanamaker, and Hardeman (2020), exposure to harmful racially and ethnically targeted events can lead to peripheral harm and feelings of erasure. While reading the *Belmont Report*, those Black parents were reminded of the federal agency's negligence, the harm that the study posed to Black men, and the complete erasure of their wives and children who also suffered. Black communities have experienced harm throughout history, and they are still experiencing harm as they navigate a health system where they remain underdiagnosed, misdiagnosed, and disproportionately mistreated (Washington 2006).

Furthermore, the IRB application often requires a statement on how the researcher will gain consent from participants (usually under the ethical principles of beneficence and respect for persons) and a copy of the consent form, but there is often very little space for researchers to narrate how they will build trust with participants.

Researchers may unintentionally gain consent from racially and economically marginalized communities using coercive practices rather than relying on community members' personal agency. In an analysis of the consent process, Michelle Brear (2018) expounds on the often ignored and misrecognized

symbolic power associated with the term "voluntary consent." According to Brear, the word "voluntary" can involve exploitative and coercive methods when respect for authority remains deeply tied to the cultural ethos of racially marginalized communities. While consent is voluntarily given, the process elicits cultural expectations and the social desirability of saying yes. The process can also be alienating when consent forms are lengthy, complex, and full of legal jargon that protects the researcher and institution (Lidz and Garverich 2013). These forms allow the IRB to say, "Yes, we did our job," without giving greater autonomy and agency to community members.

I recommend that higher education institutions lean into their broader mission of serving local communities and work to change IRBs, the certification modules, and the consent process. They can start by doing the following:

- **Increase community members' decisionmaking power and support nonprofits in establishing their own community IRBs.** Bringing in members of racially and economically marginalized groups to develop certification modules is a way to elevate community power. These groups may identify ways to build knowledge around the ethical principles without retriggering memories of past and present harms. Additionally, higher education institutions should partner with nonprofits to establish community IRBs. One organization that has established its own IRB is [Beloved Community](#), a nonprofit recognized as a model in youth participatory action research.¹
- **Reduce financial barriers to the IRB application and certification process.** Higher education institutions should reduce financial barriers by offering either a pro bono or tiered pay option with lower costs to nonprofits and community organizations. To date, limited information exists on whether higher education institutions offer such services around IRB governance.

- **Change the consent process and the consent form.** Consent forms should be more visual than textual and include less jargon for accessibility and to ensure active consent. The process of gaining consent also should be more communal than individual when working across racially and culturally marginalized communities (Brear 2018). A group of representative community members should be allowed to collectively decide how a research project will be beneficial and how research findings will address inequities in their community.

Community members' lived experiences and understanding will be sidelined as long as IRBs keep higher education institutions as the primary purveyors of knowledge (Muhammad et al. 2015). At Village of Wisdom, we seek to put power into the hands of communities, which means recognizing Black families, parents, and caregivers as cocreators, designers, and

leaders in research. We strive to change the process of IRBs, the application, and the consent that often conflicts with our community-driven approach and our broader social responsibility to the communities we serve.

Changing IRBs' predominant position in higher education institutions and applying a social responsibility and social justice lens to the ethical principles of *beneficence*, *justice*, and *respect of persons* will allow research to be less about extracting knowledge and resources from communities and more about having communities leverage research in ways that advance social justice. When researchers grant power to racially and economically marginalized communities and create ways for them to generate knowledge and drive solutions, the next 50 years of research will move closer toward *doing no harm* rather than perpetuating it.

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NOTES

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Part Two

How Is Data Equity Implemented?

When Communities Lead, Change Can Heal



LESLIE GROVER

As researchers, it is easy to be lulled into tunnel vision. We review the literature, examine different methodologies, and build hypotheses. But what about the people we seek to learn more about? Too often, we fail to make room for their lived experiences. We instead try to fit their stories into a world where we decide the questions, the framing, and sometimes even the worthiness of participants.

In spring 2019, my colleague and I conducted a research project with a community of unhoused women to explore how they experience stigmatization. We wanted to learn about their lived experiences and how the stigma of being unhoused affects them. To do so, we partnered with a local organization that provided temporary housing for women and planned 10 sessions with the residents.

We spent the first session getting to know one another. We centered our conversations on three questions: How did they come to be at the shelter? What did they want people to know about them? How did they envision our time together? During this session, we laughed and enjoyed a few jokes. The second session was more focused. We divided the group into pairs and asked them to exchange stories about a time they tried to make someone understand their situation but could not get through to the person. This session was more emotional, but by the end, the women seemed comfortable with one another as well as with us.

The first and second sessions went smoothly. All the women who showed up seemed to enjoy spending time together and happily participated in each activity. They answered every question we asked and enthusiastically discussed art and poetry with us. We even asked questions beyond what we had planned. They were easy to talk with, and we got to learn more about them and their experiences. They asked about upcoming sessions, and everything was moving along well.

Or so we thought.

At the third session, Jane (not her real name) joined the group for the first time. She cheerfully greeted us and the other women, but then seemed to shut down. She did not speak during the check-in session or participate in the group activity, where we asked the women to share a time they felt discriminated against and to draw self-portraits using words they felt best described their response to the discrimination they had experienced. Jane did not share her experience or ask questions when we debriefed about the activity. She just remained quiet.

At the end of the session, we invited everyone to share any final remarks, concerns, or feedback. They were initially positive. One woman shared that the portrait exercise helped her feel a sense of closure, because it gave her a chance to address how she felt. There were no concerns aside from one woman asking if it would be all right to be late for the next session.

Then, Jane spoke up.

“Not trying to be rude, but I didn’t really want to come here,” she said, looking into the distance. “But I came because I had to. Y’all have come in here using nice words and pretending like we’re people, but you’re really doing the same thing as all the others. You’re picking apart our lives and taking what you need to get more resources for yourself. And what do we get? The pain of retelling our stories, a gift card, and maybe a pat on the back from the administrators here for being good community members. Do you know how many people have come in here to spend time with us, not because they want to know us or see us as regular people, but because they need something from us? Or they feel sorry for us? And I just can’t sit here and smile in y’all’s faces like some of the others in this room because I don’t feel positive. What choice do we have except to come here? If we don’t come, we could get a bad report sent to our social worker, the case worker, the judge, or something.”

The room was silent, but a few of the women nodded their heads. My colleague and I sat quietly and

listened. From the start, we promised the women they had a safe space to say whatever they wanted in each session, and Jane had the floor.

After what felt like an eternity, Jane spoke again. “If you want to know what it’s like, you need to ask the right questions. You’re asking us about our stories and how we react to people who don’t respect us. These questions are similar to the ones they ask me everywhere else, except now you want me to process my feelings around being in the system and getting dumped on. You could never know what it’s like to always have somebody writing something down about you or talking to you like you cannot think on your own. And this activity we’re doing and being invited to share out in isn’t a real invitation. It’s a nice way for you to write a report about us and what we say or draw or whatever else. You make me feel like I’m in the zoo. I’m tired of people examining me and tossing me peanuts to perform.”

That last statement almost brought tears to my eyes. But I sat looking directly at Jane and took in everything she was saying. Her words were tough to hear, and even though she did not come across as angry, the emotions behind what she said were undeniable. Later, my colleague and I went back to the office and reviewed every word of our initial proposal and research questions, as well as every activity we had planned for each session.

From a research point of view, our project appeared equitable. Our activities did not make demands on the women. We made sure the women did not feel obligated to participate. We avoided jargon. We prepared every activity in Spanish and African American Vernacular English. Our proposal used politically correct terms. Many of our demographic questions were open ended. But then, we realized all of them were done from a singular perspective. They were *our* story. Had we truly taken the time to see everything through the lens of justice, inclusivity, and integrity for the women at every step in our research? What else were we missing?

It turns out, a lot.

Our activities were potentially emotionally violent for the women. Asking them to share their stories—no matter how many relaxing activities we couched them in—could have retraumatized them. Asking them to respond to past discrimination or times when they felt unheard or upset could have triggered them or halted the strides they were making toward mental wellness. Above all, while we told the women they had the freedom to not participate, the way we set up the activities and interacted with them communicated a different story. We did not provide a separate space for those who did not wish to participate, and we opened the activities with the unspoken expectation of full participation, instead of inviting the women to participate if they wanted.

Though research is often painted as clinical, objective, and knowledge-based, conducting research around marginalized communities is political. Our work often informs public policy and programming, and the distribution of resources. For this reason, as researchers, we must go beyond equity with marginalized populations. Equity is not enough.

Deva Woody's (2021) politics-of-care model provides clues about how this can be done. According to Woody, care is not about coddling or feeling sorry for marginalized populations; care is an ethical consideration. At the heart of that consideration is accountability to act responsibly with populations that are already traumatized, to honor their rights to participate or not participate in research, and to frame research equitably (de la Bellacasa 2017; Woody 2021). Research methods must include a way to "imagine, prefigure, and enact alternative ways of being together in a fundamentally nonexclusionary, nonsentimental manner" (Woody et al. 2021, 916).

Our fourth session went differently. Initially, we had planned to ask the women to act out a scenario where they wish they had stood up for themselves, then to take turns offering solutions and changing the outcome—a method similar to Augusto Boal's *Theater of the Oppressed* (1993). But now that we understood

that such activity might trigger them, we stopped asking the women to share or reenact experiences of discrimination. We instead decided to learn what we needed to know about their stories through interviews with their case workers. We reframed our activities to focus on positive outcomes and feelings; for example, we asked the women to create a game that focused on showing support for one another.

In the fifth session, we changed the layout of the room and asked the women who wanted to participate to create a space that felt comfortable for them. We also set up a separate area with water, snacks, journals, cards, and a laptop to stream TV or movies for those who did not want to participate in the activities.

Jane was back for the sixth session, and we let her know that we heard what she said. We also let all the women know that it was critical for us to address their concerns, because we respected them and genuinely enjoyed getting to know them and hearing their stories. We invited them to share their thoughts and experiences working with researchers. At the center was a simple, straightforward question: What do you need to feel safe and whole working with us in these sessions? We showed them a sample of our planned activities and discussion questions and asked the group to analyze them with us. What are we missing? What questions are we asking that we should not? What questions are we not asking that we should?

By the end of the sixth session, our relationship with the women began to transform. They shared that often research starts amicably, but then becomes more clinical and colder as it progresses. They told us they feel used and thrown away when researchers come in, ask questions, then leave. Jane said she was tired of discussing the hard times and pain that contributed to her being unhoused. In the end, they wanted to know: Why do researchers not focus on how far they have come or their identities outside of being unhoused? Why has not one researcher ever taken the time to build relationship with them, instead of keeping everything about the work and nothing else?

We asked the women if they would work with us as an advisory committee. We offered to pay them the same rate as other consultants on the grant: \$55 an hour. Three women agreed but said the facility needed an upgrade in technology for them to be able to truly participate. So we donated the funds and equipment.

From this research project, we learned several lessons:

- 1. Include the people you want to learn from at the beginning of the research process, even when forming the initial research question.** Working with Jane and the other women was a rich experience, and it transformed the underlying way we conceptualized our research approach. Our approach became more open and centered on collaboration between us and the community. We focused less on controlling the human participation element and more on supporting the women, encouraging them to voice their concerns, and responding to their feedback in ways that they could recognize and participate.
- 2. Using marginalized communities for research and then discarding them is a form of oppression.** Think of ways you can contribute to improving the lives of the community after the research is completed. How can you include a restorative element? The women mentioned technology, so we took the opportunity to show them support. We helped the facility upgrade its internet access and donated laptops for all the women, not just those who participated in our sessions. This increased their access to job postings, their ability to communicate with loved ones, and their learning opportunities.
- 3. Although your research project is important, center the needs of the community.** The women told us they wanted to know about the activities beforehand, so they would not feel bombarded. The advisory committee led the seventh session, and they presented the future sessions to their peers. Participation went up to 100 percent after that.
- 4. A rejection of your research questions or activities can be a learning experience.** Jane's words about feeling as if she were "in a zoo" stuck with us over the years.
- 5. Marginalized populations may often be mandated to participate in research by those in power, such as administrators, managers, or directors.** In the eighth session, we discussed the group's experience with administrators and how it could be improved. We ended the session by writing letters to administrators about how they could improve the bureaucracy the women have to go through.
- 6. Only after we focused our sessions on empowering activities, rather than on painful experiences, the group opened up and started telling their stories.** Even the most trauma-informed questions and activities can be triggering. In the ninth session, again led by the advisory committee, we worked to identify spaces that made them feel safe as unhoused women. They identified a well-lit park within walking distance, the arboretum at the local library, and even a local restaurant where one of the women worked.
- 7. Consider making space for those who wish to opt out but cannot disengage fully.** If possible, provide separate activities or space for them.
- 8. Understand that mistakes are part of the process.** Unintended consequences are always possible. In such cases, Woodly's politics-of-care model calls researchers to do their best to address the harm through repair and restoration, not merely acknowledge it. Our research project allowed us to bring in unhoused women as equal partners.

Our last session together was a celebration. The women told us they would continue to do creative activities together and make space for new women—a concept Woodly (2021) calls *futurity*. Lived experiences are ongoing, and each one is an opportunity for change, which highlights our final takeaway:

- 9. What may be true at one point does not define the trajectory of marginalized communities.** When the community leads, change can heal.

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Data Collection in School Settings: Rebuilding Trust and Cocreating Relational Capital with McKinney- Vento Students and Families



LEEANE KNIGHTON

Across the country, students come to school every day from unstable living situations. They may be sleeping on living room floors or living in hotels, cars, or vacant buildings unsuitable for habitation. They are among the more than 1 million students considered “homeless” by the schools that educate them (NCHE 2022).¹

As a credentialed school counselor living and working in Los Angeles, California, I work with families whose housing insecurity qualifies their children for specific types of supports to mitigate the emotional, psychological, and physical toll of not having a safe, comfortable, and stable home environment. But the data on the number of unhoused students and their test scores, attendance patterns, and graduation rates tell an incomplete story of the students’ performance and well-being and do little to shed light on the actual needs of these students and their families.

Authors Shane Safir and Jamila Dugan call these statistics satellite data and map data (Safir and Dugan 2021). The function of satellite data is to let school communities know which students (and how many) require intentional connections with housing and support. Map data includes information such as high absenteeism, low graduation rates, or stagnant academic achievement. Schools collect these data at least annually to comply with the legal mandate to track how well they are, in fact, supporting unhoused students over time. To better serve this group of students, however, schools and other resource providers need to collect street data—the qualitative and experiential data that contextualize the lived experiences of students (Safir and Dugan 2021).

While satellite data give the big picture and map data present more of the acute barriers, street data is collected only when the students and families self-disclose their homelessness. But many do not feel comfortable or have enough trust in school administrators to reveal such private and sensitive information—oftentimes out of fear that their homelessness might be reported to a child protection agency.

Measuring Student Homelessness in the US

Schools strive to be welcoming and inclusive physical and emotional safe spaces for students; in fact, food pantries, clothing closets, laundry facilities, and mental health appointments have become increasingly common essentials in elementary, middle, and high schools. These efforts highlight the barriers educational professionals must identify and eliminate so students can show up and participate as vital members of school communities.

While various pieces of federal legislation have unfolded over the past century to protect the rights of any child to attend school in the US, the McKinney-Vento Homeless Assistance Act of 1987 (amended in 2015 by the Every Student Succeeds Act) specifies the steps schools must take to increase the likelihood of academic, social, and emotional success among students who lack housing stability. The McKinney-Vento Act defines “homeless” as any living situation that is not fixed, adequate, or regular.² These living situations include cars or RVs, garages, shelters, hotels, and other buildings not suitable for habitation. In these types of dwellings, a student would lack the quiet space needed to complete school assignments. They would also have less physical space for restful sleep and may not have access to heat, plumbing, or electricity. All these factors affect a student’s ability to wake up prepared to face the challenges of a typical school day. The law also requires all publicly funded schools to have a designated “homeless liaison,” who is responsible for training school staff to identify students whose housing status falls under the law’s definition. The liaison is also responsible for reporting the data to the state education agency, while maintaining student and family confidentiality.

State and federal funding streams support community organizations and numerous charities that help people experiencing homelessness, including unhoused

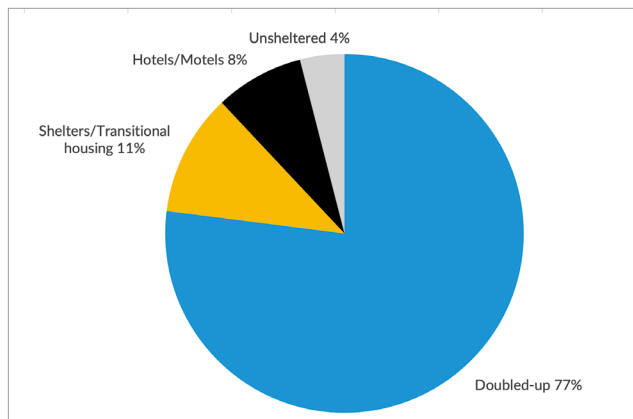
children. The US Department of Housing and Urban Development (HUD), and shelter providers that receive funding from HUD, apply a much more limited definition of homelessness. HUD focuses on providing shelter, while the laws around education focus on removing barriers that impede student success. A family who stays in a crowded apartment with another family would not be considered homeless by HUD, but they would be considered homeless by the public education system.

The narrower HUD definition causes some children experiencing homelessness to slip through the cracks and miss receiving housing benefits. If a family stays in a converted garage, for example, HUD considers them and the child “sheltered,” not homeless, and therefore does not fund a program that could improve their condition. The crowded housing condition may result in distractions that make it hard for the child to complete school assignments or sleep uninterrupted. A converted garage might not even have heat or plumbing, leaving the child to find a public restroom every night. While these circumstances might present a “sheltered” setting, they affect the student’s ability to wake up early enough to get to school every day. For these reasons, the McKinney-Vento definition of homelessness encompasses a broader definition that includes the viability of living conditions for a growing child.

Children often experience multiple forms of homelessness, all of which fall under the McKinney-Vento Act definition (Hallett and Skrla 2016). For example, a family may start off sleeping in the living room of a family friend, but because the landlord threatened to evict them, they had to move into a hotel. The school representative working with the family would classify them as “homeless” in both situations. This classification is necessary for the data collection required by the law (**figure 1**).

FIGURE 1

More than Three-Quarters of Students Who Experienced Homelessness in the 2019–2020 School Year “Doubled-Up”



Source: National Center for Homeless Education, *Student Homelessness in America: School Years 2018–19 to 2020–21* (Browns Summit, NC: National Center for Homeless Education, 2022).

Notes: “Doubled-up” refers to students living with another family. “Unsheltered” refers to students living in, for example, cars, parks, campgrounds, temporary trailers, or abandoned buildings. The figure includes students in kindergarten through grade 13, children ages 3–5 not enrolled in kindergarten, and students not assigned to a particular grade level.

According to the US Department of Education, for students to be classified as “homeless,” they must be living in one of the following four situations or places: doubled-up (e.g., living with another family), unsheltered (e.g., living in cars, parks, campgrounds, temporary trailers, or abandoned building), hotels/motels, and shelters/transitional housing. This classification provides a clear picture that could guide programmatic outreach, facilitation of services, and professional awareness mandated by the law. Additionally, states must post the total number of unhoused children and youth (ages 18 to 22) on their state education agency website annually. This ensures that everyone (researchers, parents, elected officials, etc.) has access to the number of unhoused students in their local school, district, or state.

Understanding the Benefits and Shortcomings of Satellite Data

The yearly student homelessness data provide a road map for states to identify schools or districts that have the greatest need and how assistance programs can better service and be tailored to families. But, for families experiencing homelessness, this data

collection process poses an added hurdle to receiving assistance, including bus passes and school clothes. To get the “homeless” classification, a family has to confide in a school representative who enters their information into confidential records, which then prompts a homeless liaison to connect the family to basic needs.³ It is important to note that, although school officials are required to connect families with assistance programs for basic needs, they are not required to collect data on the assistance given. Many districts, however, will document a wide range of services they provide, depending on their capacity. For instance, some school districts may have the funding to supply hotel vouchers; data collection for this assistance is not required by law, but school administrators would likely maintain records to ensure equitable distribution.

To mitigate these hurdles, homeless liaisons should have ongoing conversations with families, exploring how their circumstances change from year to year (or from one day to the next). Collecting street data means that liaisons listen more than they talk. They hear from the child or the family about what they need, which can differ for every family because of their unique settings. Families might request a coat, shoes, or school supplies, with the intention of arriving at school on time every day and doing well. To maximize the benefits of data collection and minimize the burdens for families, liaisons must anticipate families’ needs and make themselves available to families. And families who struggle but have not disclosed their housing instability would benefit from visible posters that outline available federal protections with contact information of the liaisons who could help.

The McKinney-Vento Act requires schools to carry out specific responsibilities throughout the year. The law requires homeless liaisons to work with students who have a hard time getting to school (typically because they are sheltered in a different part of town or even in a different city). Liaisons must ensure that these students have the materials they need to be successful at school, which might mean supplying

them (or their family) with backpacks, clothes, or shoes. Because students' circumstances can change at any point, liaisons typically enroll them in schools immediately, at times without proper documents, to secure their rights to free public education. Liaisons' responsibilities also include training school staff, administrators, paraprofessionals, and other personnel on the legal rights of unhoused students and what classifies a student as unhoused; that is, does the family or student stay in overcrowded doubled-up apartments, hotels/motels, shelters, or cars? Additionally, liaisons provide referrals for families with mental health needs.

Homeless liaisons work diligently to comply with the federal mandates by ensuring that transportation, supplies, and other resources are provided to students (even resources not earmarked by the McKinney-Vento Act). But the trajectories of families and students take shape far away from the data shown in tables, charts, or graphs. Safir and Dugan (2021) write that such illustrations only tell a vague story of the realities students face. According to the authors, satellite data hover far above the real challenges and successes of students; they highlight the topic of student homelessness and other trends but leave out the private decisions students and families make every day. For instance, if a student is bullied at school for always wearing the same clothes or for not having the ability to launder their clothes or bathe, that student will likely often miss school, reducing their chance of graduating on time. The law does not require the liaison to collect data on these personal matters. However, the liaison has a responsibility to continually communicate with students so they feel supported and have the resources they need to attend school without disruption.

Moving Beyond Satellite Data Collection to Prioritize More Equitable Analysis

The Every Student Succeeds Act of 2015 reauthorized the McKinney-Vento Act and expanded the responsibilities of the state education agency. The Every Student Succeeds Act requires state

report cards to show graduation rates, enrollment, absenteeism, and achievement among specific student subgroups, such as unhoused students, English language learners, and students in foster care. While satellite data show the numbers of unhoused students and their types of shelters, this next level of data—which Safir and Dugan call map data—show statistical inequities in educational outcomes, pulling back the curtain a little more to reveal the realities unhoused students experience.

Figure 2 shows map data for a high school in California with precise indicators of achievement—in this case, the graduation rate. As shown in the table, all student subgroups have higher graduation rates than unhoused students.

FIGURE 2
2021–2022 Graduation Rate by Student Group
(Four-Year Cohort Rate)

2021-22 CAASPP Test Results in Science by Student Group					
This table displays CAASPP test results in Science by student group for students grades five, eight, and High School. Double dashes (--) appear in the table when the number of students is ten or less, either because the number of students in this category is too small for statistical accuracy or to protect student privacy.					
Student Group	Total Enrollment	Number Tested	Percent Tested	Percent Not Tested	Percent Met or Exceeded
All Students	1280	1206	94.22	5.78	15.92
Female	651	613	94.16	5.84	13.38
Male	629	593	94.28	5.72	18.55
American Indian or Alaska Native	--	--	--	--	--
Asian	16	16	100	0	43.75
Black or African American	253	231	91.3	8.7	6.93
Filipino	46	45	97.83	2.17	40
Hispanic or Latino	702	668	95.16	4.84	14.22
Native Hawaiian or Pacific Islander	--	--	--	--	--
Two or More Races	90	81	90	10	16.05
White	164	157	95.73	4.27	26.75
English Learners	74	69	93.24	6.76	0
Foster Youth	24	23	95.83	4.17	8.7
Homeless	13	11	84.62	15.38	9.09
Military	14	14	100	0	7.14
Socioeconomically Disadvantaged	833	--	93.16	6.84	11.6
Students Receiving Migrant Education Services	--	--	--	--	--
Students with Disabilities	159	153	96.23	3.77	4.58

Source: California Department of Education, School Accountability Report Card, accessed December 1, 2023, <https://sarconline.org/public/findASarc>.

Despite the multipronged efforts to support McKinney-Vento students and families, the outcomes show persistent inequities. Unhoused students statistically fall behind their peers in all areas of academic achievement. Graduation rates for unhoused students are typically below the average rate in most schools. Figure 2 shows an unsettling reality: efforts to assist and support McKinney-Vento students have yet to lead to equitable outcomes.

In addition to low graduation rates, map data often show that unhoused students have high absenteeism, low achievement in state testing, and more suspensions and expulsions. Although educational practitioners and partners may experience depression, frustration, and confusion when they do not see any improvement in the data, they should move from a mind-set of *engaging* families to *empowering* them. To empower families, educators need to prioritize the third and most transformative data type: street data.

Street data do not replace satellite data or map data; they provide asset-based qualitative and experiential data points and builds “on the tenets of culturally responsive education by helping educators look for what’s *right* in students, schools, and communities instead of seeking out what’s *wrong*” (Safir and Dugan 2021, 57). This approach humanizes the data and brings increased focus on actions that work in concert *with* students and families, rather than on actions that *direct* them. Street data dismantle deficit-based mental models because they require qualitative data collection; they go beyond simply quantifying how many students are unhoused or how far below they are in educational outcomes.

Homeless liaisons understand that type of shelter or graduation rate does not describe a student; they must gain insight into the community and the cultural wealth surrounding a student. This understanding affirms that the lives of these students and their families are not without success. With street data, educational programs better serve the unique needs of McKinney-Vento students by liberating them from the narrative that excludes their multifaceted talents, strengths, and knowledge (Yosso 2005).

Working to Collect Street Data to Support Students Experiencing Homelessness

In response to the overall increase in homelessness, all liaisons for unhoused students should reflect and consider how their work can better serve the community. Liaisons can ask about the housing situation of a family, while also inquiring about the circumstances around it to better understand their

lived experiences. Liaisons can provide information to students about the laws that protect their rights to attend school, while also having the awareness that students already learn quite a lot on their own, in their own ways. Liaisons can connect families with mental health or housing providers or supply them with gift cards, food, shoes, clothes, haircuts, and backpacks in compliance with the law, while also listening deeply and garnering feedback on how to improve outreach and supportive services.

Alongside a needs assessment, liaisons can conduct an asset inventory. This might look like a T chart, with one side listing needs and the other side listing positive actions taken. How powerful would it be to see all that the students and families have accomplished on their own? This includes actions such as “I left a violent situation,” “I filed my taxes and have money to put into a savings account,” “I completed a parenting course,” or “I began vocational training to get a job.” Even going through the process of obtaining food assistance could be listed as a positive action taken. Conducting an asset inventory like this can also help refine programs. If a family has completed a parenting course, the outreach services may require just a parenting support group, rather than a structured course. If a family mostly receives public benefits, the social services agency may need to come by only once a month, rather than every week.

Furthermore, this positive side of the asset inventory chart could be photocopied and given to parents or caregivers, so they can refer to it as an affirmation—or even post it on a bathroom mirror as a daily reminder. This list can be shown to a school administrator, a child welfare judge, or a hostile ex-partner, who might ask why they should have custody of their children.

Collecting qualitative data can bring data collectors and families closer by sharing stories and experiences. This asset-based approach assures families and students that they can find success, because they have already proven they are capable of doing so. Collaboration builds relationships—and, in the end, the process itself is healing.

NOTES

1. While this number accounts for 2.2 percent of all students enrolled in public schools, according to 2022 National Center for Education Statistics data, it undercounts the scores of students unidentified because of extended school closures during the COVID-19 outbreak. Additionally, according to the McKinney-Vento Act, the term *homeless* in education includes families and students in both sheltered and unsheltered situations.
2. “The McKinney-Vento Definition of Homeless,” National Center for Homeless Education, accessed November 15, 2023, <https://nche.ed.gov/mckinney-vento-definition/>.
3. This homeless classification, along with other aspects of the McKinney-Vento Act, protects and supports youth (ages 18 to 22) who are not in the company of an adult or caregiver and who wish to enroll, or remain enrolled, in school; they may have been kicked out or pushed out or may have run away from their homes because of a variety of circumstances. Additionally, the Individuals with Disabilities Education Act allows students with a disability to attend local high schools through age 21 so that they can continue to access services. See section 1412 of the Individuals with Disabilities Education Act, US Department of Education, accessed November 30, 2023, <https://sites.ed.gov/idea/statute-chapter-33/subchapter-ii/1412>.

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Minimizing Harm When Collecting Gender Data



MADISON CALL

Historically, researchers have excluded and erased trans people from their work. Well-known, long-running, and highly influential population surveys—for example, the American Community Survey, the Survey of Consumer Finances, and the Panel Study of Income Dynamics—have consistently provided just two gender categories: “man” and “woman” (Westbrook and Saperstein 2015).

Only recently, certain surveys—for example, the General Social Survey and the National Health Indicators Survey (**table 1**)—have started to broaden the number of available options. Furthermore, some data collection efforts assume sex and gender to be so obvious that at times interviewers are instructed to determine a participant’s gender by appearance or even voice alone; other efforts assume changes to gender over time are “errors” and retroactively erase them (Westbrook and Saperstein 2015). While researchers have worked to correct these issues, good intentions may still produce problematic and suboptimal outcomes, such as categorizing all nonbinary persons as “other” (Puckett et al. 2020; Schwabish et al. 2023).

TABLE 1
Summary Reconstruction of the 2023 National Health Interview Survey Questions

QUESTION TEXT	VARIABLE NAME	RESPONSES	INTERVIEW NOTES
For this next question you may select more than one answer. Do you currently describe yourself as male, female, transgender, nonbinary, or another gender?	GENDER_A	1 Male 2 Female 3 Transgender 4 Nonbinary 5 Another gender 7 Refused 9 Don't Know	
<i>If the respondent selects option 1 (Male) or 2 (Female) only, they are asked the following question:</i>			
Is [GENDER_A] the sex you were assigned at birth, on your original birth certificate?	ASATB1_A	1 Yes 2 No 3 Refused 4 Don't know	
<i>If the person selects more than one answer or selects option 3 (Transgender), 4 (Nonbinary), 7 (Refused), or 9 (Don't know), they are asked the following question:</i>			
What sex were you assigned at birth, on your original birth certificate?	ASATB2_A	1 Male 2 Female 3 Refused 9 Don't know	
<i>If the person selects option 5 (Another gender), they are asked to write in their gender:</i>			
What term do you use to describe your gender?	GENDSPEC_A	Verbatim 97 Refused 99 Don't know	
<i>In all three cases, if the answers to the questions do not match, the respondent is asked to confirm the discrepancy, and the data are recorded as the respondent answered.</i>			
Just to confirm, your sex assigned at birth is [GENDER_A] and [ASATB1_A/ASATB2_A/GENDSPEC_A]. Is that correct?	GICHECK_A	1 Yes 2 No 7 Refused 9 Don't know	(For brevity, we only include one of the more than 25 options included in the NHIS codebook.) If [GENDER_A] IN (2,3,4), fill "you describe yourself as female, transgender, and nonbinary"

Sources: Jonathan Schwabish, Donovan Harvey, Vincent Pancini, Amy Rogin, Mel Langness, and Gabi Velasco, *Do No Harm Guide: Collecting, Analyzing, and Reporting Gender and Sexual Orientation Data* (Washington, DC: Urban Institute, 2023). Survey questions are from “National Health Interview Survey: 2023 NHIS,” Centers for Disease Control and Prevention, National Center for Health Statistics, last reviewed July 5, 2023, <https://www.cdc.gov/nchs/nhis/2023nhis.htm>.

Beyond erasing trans people from research, such exclusionary actions that may seem small and inconsequential in the moment can culminate in serious harm over time and with repetition. Research has shown that misgendering (referring to a person using the wrong gender) and deadnaming (referring to a person using a former and discarded name), for instance, can be associated with depressive symptoms, anxiety, suicidal ideation, and other negative impacts among transgender people (James et al. 2016; Pollitt et al. 2021). Feelings of being accepted in a community can also affect the well-being of trans people. According to The Trevor Project’s 2022 National Survey on LGBTQ Youth Mental Health, 21 percent of LGBTQ youth living in “very unaccepting” communities attempted suicide, compared with 8 percent living in “very accepting” communities.¹

Researchers need to take steps to recognize and include trans people in their work as much as possible. Even if a study’s influence on participants’ lives is relatively small, the sheer scale of possible harm to the greater trans community more than justifies making a minimal effort to avoid the most common problems, such as respectfully asking about gender.

Understanding Gender Identity and Assigned Gender at Birth

Gender identity refers to the gender a person identifies as theirs, and it is connected with a variety of legal and social constructs, including cultural expectations about behavior. A person’s gender identity influences how they dress, behave, and interact with the world. *Assigned gender at birth (AGAB)* is based primarily on genital appearance at birth, and its usual designation in the US includes “male” and “female.”² About 1.7 percent of the US population is considered “intersex,” meaning they do not have an anatomy that fits into the male/female binary category (Fausto-Sterling 2000).

A *transgender* person has a gender identity that differs from their AGAB. In this essay, I use the

term to encompass a wide range of individual identities, including man, woman, nonbinary, agender, genderfluid, and Two-Spirit. A *cisgender* person, meanwhile, has a gender identity that matches their AGAB.

Other terms that are important to fully understand gender are *legal gender*, which refers to the gender the government has on file, and *biological sex*, which is closely related to AGAB but consists of a host of factors, including chromosomal, anatomical, and biological variables. Many of these variables may change over time as people take medications, get diseases, or undergo other changes.³ For instance, trans people on hormone therapy have baseline reference ranges that do not match their AGAB on several pathology tests (Cheung et al. 2021). Throughout this essay, I use the term AGAB, because it acknowledges that the term *biological sex* may fail to describe a person’s current, lived experience.

Barriers to Inclusively Asking about Gender Identity

When collecting data on gender status, researchers often provide insufficient options for respondents to select from on surveys (Schwabish et al. 2023). Typically, a gender identity question provides only “man/woman” options, which excludes anyone who identifies outside that gender binary. While adding a longer list of options may help, adding too many options risks making surveys too long and driving down response rates (GenIUSS Group 2014).

Another form of exclusion occurs when survey questions allow respondents to select only one option. This renders trans participants who are genderfluid, genderqueer, have other gender identities, or identify with multiple genders invisible (Bivens 2017). Such enforced single-response questions create equity and inclusivity issues. For example, having radio-button-style options for “man/woman/transgender” or “man/woman/trans man/trans woman” implies that these identities are fundamentally different and that trans people cannot

be “real” men or women. Beyond their transphobic implications, these types of questions can hinder accuracy. A trans woman, for example, is by definition a woman, a trans woman, and a transgender person. But when forced to choose one from these equally correct options, a participant may default to whichever identity they most identify with at the time of the survey.

The specific terms and ways questions are worded in surveys can also cause harm by their lack of inclusivity or questionable content. The term *transsexual*, for instance, has become less acceptable because of its inherent focus on a person’s sex and the recognition that many trans people do not seek or need gender-affirming care to validate their identities. While some people may still identify with such terms, using them as if they apply to *all* trans people is no longer appropriate.

Similarly, using a catch-all gender category, such as “other” or “something else,” can be marginalizing (Puckett et al. 2020; Schwabish and Feng 2021). Some terminology may not be explicitly harmful but can convey unfamiliarity with trans people. A common example is putting “transgender” as an option to a question about gender identity. This would be inaccurate because transgender is an adjective used to describe someone who has a different gender identity from their AGAB and is not a gender identity on its own (Schwabish et al. 2023).

Mandatory gender questions can cause another form of harm—self-misgendering—when participants are not given accurate options to choose from. This can also happen when they do not feel comfortable or safe identifying their gender. According to ethical research principles, participants can drop out of a study because of mandatory questions that force them to misgender themselves. This allows trans people to avoid harm but risks researchers collecting unrepresentative samples with relatively fewer trans people finishing the study. Furthermore, as Scheurman and colleagues (2021) report, some trans

people may decide it is “worth” self-misgendering to gain sufficient incentives. As such, mandatory gender questions can potentially cause coercion, harm, and biased sampling simultaneously.

All these challenges affect data accuracy. Trans people who have been harmed in the past are less likely to trust researchers and participate in surveys, which limits future participation. Although the inaccuracies caused by poorly worded gender questions may be minimal for any single study, they may be significant for some studies. This is especially true if the population of interest includes a large number of trans people or if the sample has a larger proportion of trans participants. Lack of accurate data means that researchers will be unable to collate studies together for wide-reaching meta-analyses, such as seeing how trans people are affected by various issues, which contributes to the erasure of trans people in research.⁴

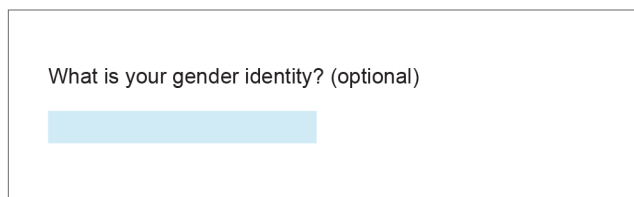
Best Practices for Asking about Current Gender Identity

There are no universal best practices for asking about gender identity, as the methods are still being developed. The three recommendations outlined below represent some of the best guidance to date on ways to generate accurate data without causing harm.

First, consider what information about gender and sex is truly necessary. Include a gender identity question if it is relevant to the research or if a sample needs to be checked for gender diversity. Do not collect the information if there is no clear plan to use it.

Second, if a gender identity question is needed, consider in what format the information should be collected. If there are a relatively small number of participants, a free text box may be the best choice (**figure 1**). This option treats all genders equally, and because of the small sample size, it would be easy to manually code responses for statistical analysis (Spiel, Haimson, and Lottridge 2019).

FIGURE 1
Free Text Box for Gender Identity Question

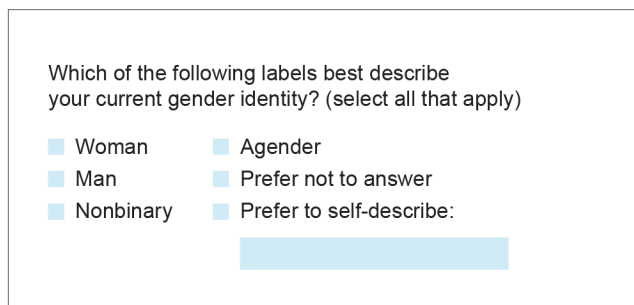


What is your gender identity? (optional)

Source: Author created.

If the sample size is too big for manual coding, check boxes that allow for multiple selections may be the best choice (**figure 2**) (Spiel, Haimson, and Lottridge 2019). In this case, including a few common nonbinary identity choices like “agender” can help generate trust among trans participants. Radio buttons—circles that fill in when selected and permit just a single selection—should be used only if the statistical analysis for the study is not compatible with a check-box style.

FIGURE 2
Check-Box Style for Gender Identity Question that Can Be Converted to Radio Buttons



Which of the following labels best describe your current gender identity? (select all that apply)

- Woman
- Man
- Nonbinary
- Agender
- Prefer not to answer
- Prefer to self-describe:

Source: Author created.

Note: More nonbinary identities can be added to this question.

Both options, however, still risk not enabling respondents to accurately provide their full identities. To address this, gender identity questions should always include a text box where participants can write in their responses. It would also help to include some kind of prompt, such as “not listed” or “I am: ____.” Even with this text box, the question should be optional so participants are not forced to provide inaccurate or uncomfortable responses.

Some researchers may be concerned that a write-in option would allow “trolls” to enter harmful, misleading, or nonsensical responses, as occurred in the 2020 US Census (Bates, Trejo, and Vines 2019; Jaroszewski et al. 2018). For this reason, Spiel, Haimson, and Lottridge (2019) recommend revealing the write-in text box *only* after the participant selects the “not listed” option. Alternatively, a follow-up, free-response question could be asked *only* to participants who have selected the write-in option. While nothing can fully resolve this problem short of removing the write-in option completely—and therefore excluding many gender-diverse people—these recommendations could minimize it.

Best Practices for Asking about Legal Gender or Assigned Gender at Birth

Data on AGAB should be collected only if it is specifically needed, because forcing trans participants to associate with their AGAB can cause harm and lead to further misgendering (Puckett et al. 2020). Many trans people have not changed their legal gender from their AGAB, so this guidance applies to legal gender as well. If data on legal gender or AGAB must be recorded, separate questions should be used (GenIUSS Group 2014; Schwabish et al. 2023). This is called a two-step process, and it communicates to trans participants that researchers are respecting their identity and not reducing them to just their AGAB.

Unlike questions about gender identity, when constructing legal gender or AGAB questions, a free text box option is not entirely necessary if all possible legal or AGAB options are included (**figures 3 and 4**). In the US, for instance, “X” is now a legal gender in many states and localities, and on passports, so it should be included as an option when researching US citizens. If the study population includes people from multiple countries, a free text box could account for each country’s legal definition of nonbinary genders.

FIGURE 3

Question about Legal Gender

What is your legal gender?

- Man
- Woman
- X
- Prefer not to answer
- Not listed:

Source: Author created.

Note: “X” is included because it is a legal gender in the US. “Not listed” is included to account for future legal gender identities and different legal definitions used in other countries. Both could be omitted if researchers restrict their sample to a certain population/time and make sure to include all legal gender designations for that population.

FIGURE 4

Question about Assigned Gender at Birth

What is your assigned gender at birth? (This is the gender that was originally listed on your birth certificate.)

- Male
- Female
- Intersex
- Prefer not to answer

Source: Author created.

Best Practices for Asking about Transgender Status

Collecting data about trans status is difficult. Researchers must ask a question that includes people with varying gender identities or no gender identity and who are intersex. There is also a widespread, and sometimes willful, ignorance about the terms *transgender* and *cisgender*.

The most common practice is to use the two-step process: ask gender identity and AGAB questions, and then cross-reference the results to identify responses that do not match. Using survey data from a sexually transmitted disease clinic in Seattle, Washington, Tordoff and colleagues (2019) found that the two-step process resulted in a fivefold increase in the response rate among transgender and gender nonconforming people compared with the one-step process.

However, this gender identity and AGAB cross-referencing approach is still not ideal, because some survey respondents may find needing to associate with their AGAB harmful. Ideally, a question about transgender status would not use AGAB. Unfortunately, there is limited successful validation for alternative questions. For example, asking “Do you identify as trans?” can lead to potential undercounting, as not every person who meets the definition of being trans identifies as trans (GenIUSS Group 2014). The question in **figure 5** attempts to avoid this undercounting and having to select one’s AGAB by asking if people meet the definition of being cisgender. Alternatively, the question in **figure 6** uses a more action-focused definition of being transgender to achieve the same aims.

FIGURE 5

Question about Transgender Status

Do you have the same gender as the one originally on your birth certificate? (If your gender was listed as “female” and your current gender is “woman,” select yes. Do the same if your gender was listed as “male” and your current gender is “man.”)

- Yes
- No
- Unsure
- Prefer not to answer

Source: Author created.

Note: A “Yes” would mean the respondent is cisgender, and a “No” would mean they are transgender. The “Unsure” option is included in case respondents find this question confusing.

FIGURE 6

Question about Transgender Status Using Action-Focused Definition

Have you ever tried to change your gender? (For instance, your gender was listed as “male” on the birth certificate but your current gender is “woman.”)

- Yes
- No
- Unsure
- Prefer not to answer

Source: Author created.

Note: A “Yes” would mean the respondent is transgender, and a “No” would mean they are cisgender. The “Unsure” option is included in case respondents find this question confusing.

The 2023 National Health Indicator Survey (shown in table 1) offers a practical example of an attempt to minimize having to select AGAB information while still collecting that information. In this latest survey, men and women are asked if their AGAB is the same as their current gender, whereas all other genders are still asked to select their AGAB. While avoiding AGAB entirely is recommended, if a study has a legitimate need for AGAB information, this approach minimizes the harm for the trans population.⁵

In general, questions about biological sex should be avoided because of the ambiguity of the term and how it can cause harm to trans people. If information on a person's biological characteristics is needed, it is better to ask about AGAB and use anatomical inventory forms that ask about those characteristics directly. These forms are not only more inclusive but also more accurate in cases where someone's characteristics differ from their AGAB (Deutsch et al. 2013; Grasso et al. 2021).

Data analysts should make sure to use up-to-date data security and storage practices and avoid releasing participants' information to any third party without permission, including family members. Revealing a person's trans status to the wrong people at the wrong time could have serious consequences, ranging from harassment to death.⁶ Outing a trans person to family members can result in a much higher chance of that person attempting suicide (James et al. 2016). More than 10 percent of trans people have been evicted from their homes because of their gender identity,⁷ and 30 percent who had a job in the past year reported that they have been

fired, been denied a promotion, or experienced other mistreatment because of their gender identity or expression (James et al. 2016). Keeping data on trans people safe and secure is paramount. If the data cannot be fully secured, reconsider collecting the data at all or simply delete the data after using them. Ideally, researchers will meet these requirements if they comply with the standard ethical research rules, such as those enforced by the institutional review boards (also see Dawn X. Henderson's essay in chapter 4).

One final point to consider is that the common definition of transgender still excludes many gender-nonconforming or gender-diverse people across cultures. It also excludes people who may not identify strongly with Western transgender communities. There is thus ample room for future research, and asking alternative questions may be necessary for different purposes.

Conclusion

Researchers should always strive to ask survey questions about gender in inclusive ways to prevent harm to trans people and increase the accuracy of their work. Doing so will not only benefit trans people by allowing research to support them but also benefit research in general by increasing the accuracy of gender-based metrics. While there is no universal, perfect solution, there are several simple, low-cost measures that can lead to more accurate and inclusive data, such as those outlined in this essay. All researchers dealing with human subjects should put effort into making their studies inclusive and staying up-to-date on recommendations and best practices.

NOTES

1. "2022 National Survey on LGBTQ Youth Mental Health," The Trevor Project, accessed November 9, 2023, <https://www.thetrevorproject.org/survey-2022/>.
2. "Sex and Gender Identity," Planned Parenthood, accessed November 9, 2023, <https://www.plannedparenthood.org/learn/gender-identity/sex-gender-identity>.
3. "Sex and Gender Identity," Planned Parenthood.
4. This essay focuses only on developing survey questions. Additional steps are needed to ensure that researchers treat trans people respectfully during the consent, analysis, and reporting processes (Marshall et al. 2022). See also Morgan Klaus Scheuerman, Katta Spiel, Oliver L. Haimson, Foad Hamidi, and Stacy M. Branham, "HCI Guidelines for Gender Equity and Inclusivity," Morgan Klaus Scheuerman personal website, last modified May 21, 2020, <https://www.morgan-klaus.com/gender-guidelines.html#>.

5. "National Health Interview Survey: 2023 NHIS," Centers for Disease Control and Prevention, National Center for Health Statistics, last reviewed November 2, 2023, <https://www.cdc.gov/nchs/nhis/2023nhis.htm>.
6. "Fatal Violence Against the Transgender and Gender Non-Conforming Community in 2021," Human Rights Campaign, accessed December 4, 2023, <https://www.hrc.org/resources/fatal-violence-against-the-transgender-and-gender-non-conforming-community-in-2021>.
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Engaging Refugee and Immigrant Communities through Safe, Trauma-Informed Research Designs



AIMEE HILADO

Every day, people across the globe are either forced to or decide to leave their home countries, their communities, their families, and everything they have ever known for new places. Many who are forced to flee because of war, conflict, or persecution often have problematic relationships with authority figures, because they have been threatened and/or exploited by people or systems of power. It is important for researchers to understand what people who have experienced such trauma need in terms of services and supports. But the research process—and the relationship between researcher and participant—can often mimic the same threatening power dynamics, eliciting past experiences of harm.

I have supported people through clinical practice and research in my 16 years of working with forcibly displaced, newcomer refugee and immigrant communities. I know how valuable research designs can be to advancing and leveraging knowledge that promote change for individuals, communities, and societies. Researchers collect stories; administer surveys; and test medicines, tools, and behavioral interventions to understand what works for whom, when, and under what conditions. These efforts inform how to improve the human condition through program development, human services, workforce development, and even policy.

The Refugee Wellness Lab, my lab at the University of Chicago, is dedicated to elevating the voices and experiences of trauma-experienced refugees and immigrants to advance understanding of culturally and linguistically responsive mental health care. My work seeks to ensure there is caution, clear strategies, and assurances that refugee and immigrant participants will remain emotionally and psychologically well throughout the research process, especially when conducting randomized controlled trials (RCTs).

RCTs are the gold standard for understanding the effects of interventions or treatment, because they are the most rigorous study designs that reduce bias when trying to explain the relationship between interventions and outcomes. In RCTs, a group that is relatively the same in background, experience, and other key factors is randomly divided into two groups: one receiving and one not receiving the intervention. The differences in outcomes between the groups are then attributed to the intervention (e.g., Shadish, Cook, and Campbell 2002). Though RCTs look simple on paper, they are challenging to implement.

Common pitfalls with RCT designs, such as an unclear hypothesis, inadequate randomization, or small sample sizes, can directly affect the quality of the findings. The challenges increase when engaging populations that are skeptical of research, may be unfamiliar with the research process, and have cultural or language barriers—all characteristics that commonly apply to forcibly displaced, newcomer refugee and immigrant communities.

It is important to include newcomer refugee and immigrant voices in research. Researchers need to take critical steps to help participants experience research as trauma-informed, intentional, informative, and safe—rather than unhelpful, unclear, or, even worse, exploitative (Andrews, Parekh, and Peckoo 2019; Chicago Beyond 2018). In this essay, I describe my work with [RefugeeOne](#) using the Baby TALK Family Engagement Model (Hilado, Leow, and Yang 2018), and how my team and I embedded an equitable and thoughtful approach to the project from the very beginning.

RefugeeOne Study

The RefugeeOne Study using Baby TALK Family Engagement Model RCT was an attempt to understand the impact of home visiting services on child development and parent mental health outcomes for refugee families with children from birth to age 3. Early childhood home visiting services are often designed to promote child development

outcomes and positive parenting practices so young children start school ready to engage and learn. These interventions are also generally designed to promote family well-being. My team and I were able to overcome many challenges researchers usually face when conducting RCTs with refugee populations, because we approached our work with an equitable lens, namely by implementing the program in a refugee-serving organization rather than a typical childhood education setting. In doing so, we were able to engage diverse nationalities and languages through our intentional recruitment strategies, which enabled us to work effectively with 200 refugee participants, representing 12 nationalities and 9 languages.¹

To successfully create this RCT, we asked and answered a number of questions to ensure that we were not doing harm to these communities: How can we identify, recruit, and retain such a diverse study sample? How can we navigate language and education barriers? How do we acknowledge the effects of trauma and displacement or risk factors such as poverty and unemployment on participants? How do we navigate randomization when the health needs, mental health needs, and adjustment needs (e.g., case management, employment services, English-language training, and school enrollment) of the sample population are quite high? From these questions and our subsequent research, we came away with five key lessons learned.

1. Clearly Communicate the Purpose of Research and Consent

Use Plain Speech in the Participant's Native Language to Describe the Purpose of the Research

When we approached a Rohingya family, who were initially skeptical about the project, we took the time to partner with a Rohingya speaker to explain our work and goals. We told the family that our goal was to make sure their young children grow up healthy and start preschool ready to learn and to help parents feel supported. We also told them that by participating they would be helping us understand whether home visiting services can support Rohingya children and

their families. We found that avoiding technical language and explaining the intention behind the project were critical to engaging participants.

Understand That Consent Requires Time, Patience, and Autonomy

Participants often describe their refugee experience as never having a say on where and how they can live their lives. Their main goal is to have a chance to live life with dignity and safety. For this reason, we made sure that during the consent process newcomer participants knew they had full authority in deciding whether to participate and that there were no penalties for declining. We also made sure they had at least a week to think about the project and had time to ask questions, so they did not feel pressured to say yes immediately. We told them: “We would learn so much from you and your family if you chose to participate. But your participation is your decision, and you can say no if you are not comfortable. Our study can work only if we partner together, and partnership means you feel ready and able to work with us.”

2. Prioritize Ethics When Recruiting for a Randomized Controlled Trial

Remove Candidates When Needs Are Evident and Connect Them with Resources

Researchers need a strong moral compass when conducting RCTs; that is, they need to be able to let go of a participant (and an ideal sample size) when it serves a greater good. The measures in our study included child development screeners for children and mental health screeners for adults, and there were times when we identified a child whose scores suggested a need for early intervention or when a caregiver showed significant signs of mental distress. In those instances, we stopped the data collection process and referred the child, parent, or family to the appropriate support systems.

Provide Follow-Up Even If Participants Are Not Sampled to Build Trust in the Community

At times, during the participant recruitment phase, we found that given our study criteria a participant or family was not an ideal fit, but there were needs we could not ignore. Once I made a home visit with a Kinyarwanda interpreter to meet with a prospective Congolese family. Upon entering the home, we learned that the child was above the age range for the study. However, we saw that, despite the home being tidy, it had a terrible roach infestation. The family informed us they had contacted the landlord multiple times but were unable to get a response. We contacted the building management directly and leveraged our knowledge of housing requirements and the authority of the family’s resettlement agency to have the apartment fumigated. Participant engagement is not for research purposes alone; researchers must work as community partners and advocates as well.

3. Know That Small Things Matter

Manage Study Incentives

Participants in our sample often lived in cluster communities, along the same block or sometimes even in the same building. To help retain our sample, we asked participants what supplies they needed most and periodically delivered incentive packages of diapers, wipes, and other baby goods to treatment and comparison groups. We soon learned that packaging matters. The color, size, and style of the delivery bags were topics of conversations, and some participants said a few of them received more goods than others. The team quickly pivoted to make sure every delivery bag looked the same and was delivered around the same time to avoid such misperception. One small change dispelled concerns of favoritism.

Provide Additional Support and Case Management

At times, questions would arise during data collection and periodic check-ins with the sample participants who were outside the scope of the project. These

check-ins were important opportunities to learn what participants needed and to provide resources and referrals. This type of case management work was essential in communicating that the team was a resource partner as well as a research partner, which further supported engagement. As evidence of effectiveness, we had very low attrition rates (less than 10 percent) over the 12-month period.

4. Integrate Trauma-Informed Strategies

Enter Research Recognizing the Universal Effects of Trauma in Participants and Interpreters

Our study sample primarily consisted of refugees who had been displaced outside their home countries for 9.3 years, on average, before resettling in the US; some had waited 15 or more years.² Working with trauma-experienced participants (and interpreters) requires emotional sensitivity to ensure that the research process does not replicate past traumatic experiences. Researchers must be aware that not all participants have experienced trauma en route to their destination or that not all participants have experienced trauma to the same degree. Such awareness directly influences engagement and responsiveness in research.

Be Mindful of Trauma and Stress Responses

Basic knowledge of mental health can be essential when engaging trauma-experienced participants. As a licensed mental health professional, I trained my team to recognize common trauma and stress responses that may arise during the consent and data collection processes. The team was instructed to pay attention to participants who showed an inability to concentrate or make decisions, who were easily startled by sudden noises, who appeared on guard and alert all the time, or who seemed distant and detached during conversations. They were trained to listen for remarks about upsetting dreams or memories or that suggested losing hope for the future. When any of these responses were identified,

we consulted on the necessary mental health referrals and resources that could be shared and whether the participant should be removed from the study. This level of trauma-informed research ensured the safety of participants and provided gentle transfer of care to the appropriate services. We made sure that the right supports would be in place after the study period.

5. Give Back Beyond Data Collection

Disseminate Findings

At the end of each data collection period, we developed an overview of what we learned about each family. We collected information on how the children were progressing in their development and on the changes in trauma and stress symptoms of caregivers. We then communicated our findings to participants through interpreters. We wanted participants to have the opportunity to hear and interact with our study directly, which also gave us a chance to share with them how families across the study were doing and how their participation helped us understand the benefits of home visiting services for child and parent outcomes.

Provide Access to Study Interventions

The comparison groups in RCTs do not get the intervention, which is a necessary part of the study design. In our initial analysis, we saw the positive benefits of home visiting services for refugees, so once the research was complete, we provided participants in our comparison groups the same opportunity to receive the intervention. They were given priority enrollment at the end of the study period, because we wanted to make sure they would receive the service before we opened it up to the general community.

Build Relationships for Future Research

To understand how we could improve research engagement in the future, at the end of the study, we asked families what it was like to participate

in the project. Their feedback provided insight on what we got right (e.g., slowing down the consent process, using nontechnical language, having materials translated in home language, and sharing findings) as well as what we could have done better. Specifically, we could have explained the computer software's randomization process more clearly and that participants are assigned to groups by the program, not the researchers or other participants. We also learned that community leaders, who serve as protectors as well as informants for the community, can be important allies for future research opportunities.

Conclusion

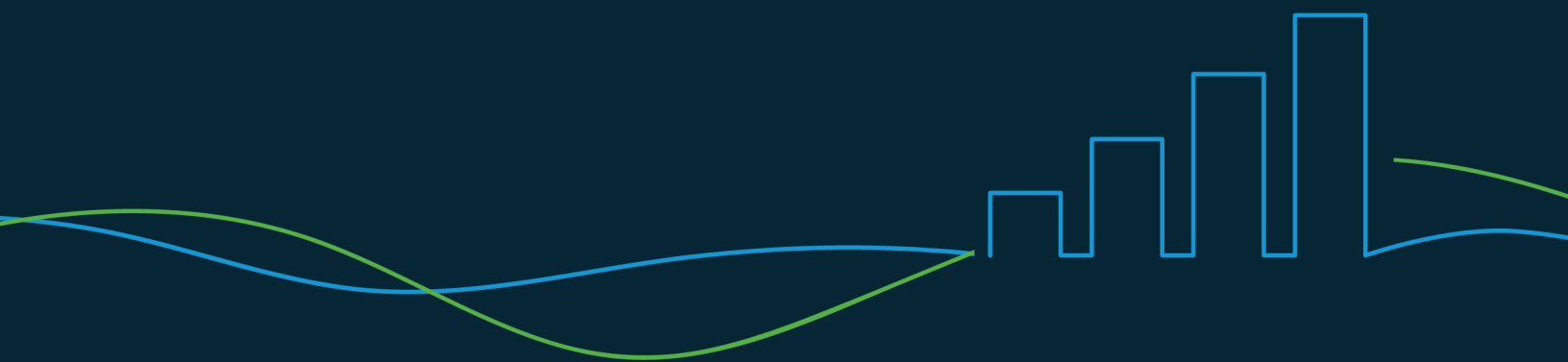
There are many ways to engage underrepresented groups in research, but we must always be sensitive to the history of exploitation and harm done to different communities—particularly to the minoritized, economically and socially disadvantaged refugee and immigrant communities. We must also prioritize the importance of including diverse needs, voices, and experiences in research and expanding our knowledge in ways that support all communities. I hope this essay helps researchers and data practitioners understand how to better support refugee and immigrant communities before, during, and after the research process.

NOTES

1. Our participants came from Afghanistan, Burma, Columbia, Cuba, DR Congo, Ecuador, Ethiopia, Iran, Iraq, Mexico, Sudan, and Syria, and they spoke the following languages: Arabic, Burmese, Kinyarwanda, Malay, Rarsi, Rohingya, Spanish, Swahili, and Tigrinya.
2. We use the term *refugees* for people who have left their home countries because of well-founded fear of persecution; trauma often threads through their stories.

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Part Three

What Presentations Uplift Data Equity?

CHAPTER NINE

Uplifting Communities with the California Healthy Places Index: The Power of Positive Framing in Data Visualizations to Advance Health Equity



COLINE BODENREIDER



HELEN DOWLING



TRACY DELANEY



NEIL MAIZLISH

Everybody deserves the opportunity to live a long and healthy life. Because neighborhood factors—for example, access to good jobs, educational opportunities, clean air, and potable water—shape our health, by ensuring that the places where people live, learn, work, and play have the essential conditions for good health, everyone is given the chance to thrive.

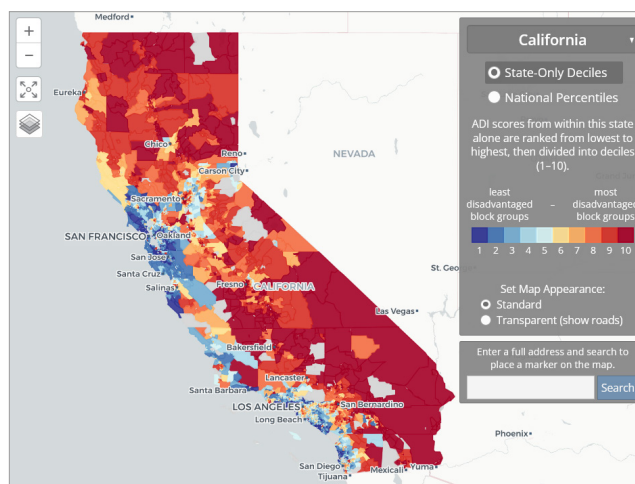
When researchers lead with values and a clear, hopeful goal, they create opportunities for change, which is one of the many benefits of using a positive asset-based framing to communicate data. Yet, researchers and data visualization practitioners do not often approach health and community data with this mind-set. More often than not, a deficit or negative framing—which focuses on what is lacking, problematic, or deficient—is the de facto standard. News articles describe individual and community suffering, and researchers go to great lengths to quantify the extent of such suffering. Of course, characterizing the full depth and breadth of a problem can be an important first step toward further action. But is deficit framing really the best approach?

To answer this question, it is worth exploring how deficit framing came about. In the US, social welfare programs established in the 1960s during Lyndon B. Johnson’s War on Poverty focused on providing targeted assistance to people in need. This focus spurred the development of the federal poverty thresholds in 1965, which were used to determine eligibility for foundational programs, such as Medicare, Medicaid, and the Supplemental Nutrition Assistance Program. If a family’s or individual’s income fell below the poverty threshold set for their family size, they could apply to receive assistance. These thresholds have been—and still are—essential to determining eligibility for assistance programs.

On the surface, this deficit framing makes sense. But in the context of American individualism—the idea that if people just work hard, they can overcome anything—social welfare programs are perceived as handouts for those too “lazy” to work. This perception led to the 1996 welfare reforms that restricted funding and enacted work requirements. Ultimately, deficit framing contributed to a backlash against these equity-driven policies.

Yet, deficit framing is still used today. A common example in data visualization occurs in the form of online, interactive mapping tools that identify areas of disadvantage or vulnerability with red or orange hues, which in Western cultures suggest danger or negativity; see, for example, the Area Deprivation Index in **figure 1** (Kind and Buckingham 2018). These tools improve income-based thresholds by incorporating additional factors, such as unemployment, education, housing conditions, built environment, and sensitive populations. But they still employ the same problematic framing by using negative phrases and words, as well as the red or orange hues.

FIGURE 1
Area Deprivation Index, Version 4.0



Source: “Neighborhood Atlas,” University of Wisconsin, School of Medicine and Public Health, Center for Health Disparities Research, accessed September 8, 2023, <https://www.neighborhoodatlas.medicine.wisc.edu/>. Reused with permission.

Deficit framing is so ubiquitous that not many people realize there are other ways to tell a story, visualize data, or describe the challenges people or communities face. A compelling perception-changing alternative is positive asset-based framing, which leads with values—ideally, values that are shared by society like the one stated above: everybody deserves the opportunity to live a long and healthy life. This values orientation centers opportunity, not deficit, and leads to a focus on solutions. Most importantly,

it is hopeful. Describing problems ad nauseum without offering concrete solutions or opportunities for improvement can have the paradoxical effect of promoting apathy and disengagement (Kensicki 2004).

Positive asset-based framing effectively describes a problem in the context of what researchers want to achieve (e.g., visualize the percentage of people *above* the poverty threshold), and it has the dual effect of focusing on the goal (e.g., move people out of poverty) while measuring the gap (e.g., anything less than 100 percent offers an opportunity for improvement). Furthermore, it avoids stigmatizing communities by focusing on the structural sources of disproportionate advantage, not disadvantage. For example, positive framing of poverty data can nudge people toward a critical question: Why are certain communities so much more prosperous than others? With this framing, it becomes possible to view inequities as a consequence of policies that disproportionately advantage some groups over others (e.g., structural racism), instead of as a consequence of individual deficiencies. This approach has been shown to increase support for redistributive policies (Rosette and Koval 2018), which has the added benefit of making such policies more politically feasible. It also complements the **targeted universalism framework**—a philosophy focused on setting universal goals for everyone and targeting processes to achieve those goals—which can garner widespread support for equity-focused solutions (Powell, Menendian, and Ake 2019).

When researchers go beyond problems and deficits, it creates opportunities to talk about community *assets*. Although assets are just as important as challenges, they are infrequently measured and visualized. If researchers measure “high school graduation rate” instead of “high school dropout rate,” they lead with a goal (e.g., more high school graduates) and create an indicator that is asset-oriented by default. Education is easily uplifted as a community strength in neighborhoods where many teenagers graduate high school.

But there are challenges to adopting and implementing positive asset-based framing. The ubiquitous nature of deficit framing means that researchers can unconsciously fall back on that kind of language. Shifting the way they present and visualize data requires thoughtful attention. Importantly, practitioners of positive framing must uplift community assets without obscuring opportunities for improvement. They also must understand their audience. Leveraging shared values as a cornerstone of positive framing can fall short if those values are not held by the audience they are engaging. Similarly, positive asset-based data and visualizations can be difficult to communicate if the audience is inexperienced with this approach. People may require more time to process the information, especially if they are primed for problem-focused data visualization and messaging.

Beyond communication difficulties, certain community assets are simply harder to measure or are infrequently collected, such as social cohesion, civic engagement, feelings of inclusivity or belonging, and perceptions of safety. Barriers to having these data available include a lack of tested and standardized definitions, as well as the need to recognize that race, ethnicity, sexual orientation, gender identity, class, ancestry, and other identities strongly influence people's experiences. More data is the answer here; ideally, data that are collected in partnership with the community and reported in ways that reflect the diversity of experiences (see, for example, Torres Rodríguez et al. 2023).

Positive Framing in Action: California Healthy Places Index

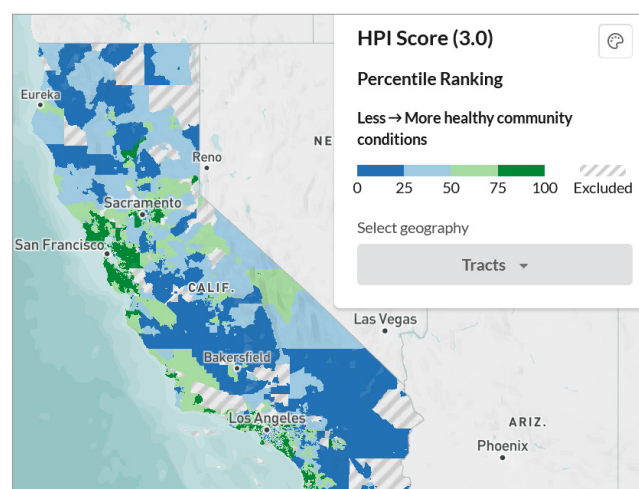
In 2017, our organization, the Public Health Alliance of Southern California, began working on a comprehensive update to a statewide public health indicator project, formerly known as the Health Disadvantage Index. Designed to inform resource prioritization and allocation decisions across California, the project measured the cumulative effect of the social determinants of health (e.g., economic,

social, neighborhood, education, and other factors) to identify communities facing the greatest “deprivation.” It was originally developed using a deficit orientation, so we felt it was necessary to reorient the framing to better engage with communities and fully reflect our goal of advancing health equity.

We rebuilt the project from the ground up using positive asset-based framing, including a name change—from the negatively framed “Health Disadvantage Index” to the positively framed “Healthy Places Index (HPI).”¹ Leveraging our values as public health practitioners, we then carefully assessed every indicator to ensure that the focus was on goals: “Unemployed” became “Employed,” “No Nearby Supermarket” became “Supermarket Access,” and “No Kitchens” became “Housing Habitability,” among many other shifts. As a result, the eponymous index score transformed from a measure of community *disadvantage* to a measure of community *opportunity*.

This positive reframing extended to how we visualized the data. Instead of mapping community scores using a red-to-green color palette, we used blue-to-green, sidestepping the negative and stigmatizing connotations of red and orange to identify communities with lower HPI scores (**figure 2**).

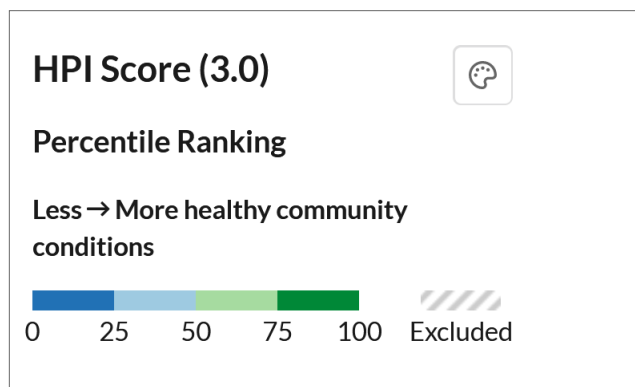
FIGURE 2
California Healthy Places Index, Version 3.0, Map Platform



Source: “California Healthy Places Index,” Public Health Alliance of Southern California (data) and Axis Maps (visualization), accessed October 26, 2023, <https://www.healthyplacesindex.org/>.

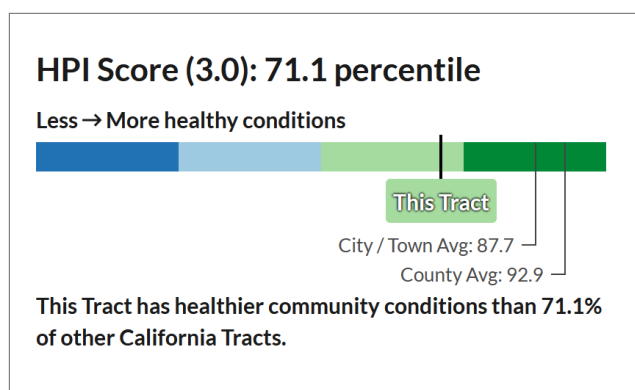
Recognizing that positive framing is still uncommon among similar indicator projects—for example, the Area Deprivation Index (Kind and Buckingham 2018), Indices of Deprivation (Noble et al. 2006), and Distressed Communities Index²—we were careful to provide explanatory language alongside visual cues, such as clearly labeled map legends (figure 3) and interpretive sentences for the overall HPI scores (figure 4).

FIGURE 3
California Healthy Places Index, Version 3.0, Map Legend



Source: Source: “Healthy Places Index,” Public Health Alliance of Southern California (data) and Axis Maps (visualization), accessed October 26, 2023, <https://www.healthyplacesindex.org/>.

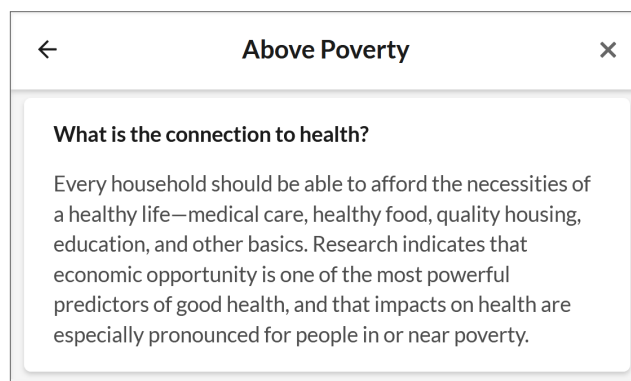
FIGURE 4
California Healthy Places Index, Version 3.0, Interpretive Sentence for Percentile Ranking in the Community Conditions Panel



Source: “California Healthy Places Index,” Public Health Alliance of Southern California (data) and Axis Maps (visualization), accessed October 26, 2023, <https://www.healthyplacesindex.org/>.

We also made our values orientation explicit with short texts describing why each indicator represents an important community asset that supports health (figure 5).

FIGURE 5
California Healthy Places Index, Connection to Health Description for “Above Poverty” Indicator



Source: “California Healthy Places Index,” Public Health Alliance of Southern California (data) and Axis Maps (visualization), accessed October 26, 2023, <https://www.healthyplacesindex.org/>.

Finally, we wrote a comprehensive policy guide for each indicator, with recommendations for action.³ It was important for us to go beyond providing data showing community opportunities; we wanted to ensure that we build a bridge to solutions that directly respond to concerns of compassion fatigue, disengagement, and apathy.

We have seen an incredible response to the new HPI. Since its launch in 2018, it has been widely adopted by state, regional, and local agencies; community-based organizations; research institutions; and other stakeholders to inform resource allocation and program prioritization decisions that help build healthier, more resilient communities. We have tracked hundreds of use cases, including for active transportation planning, affordable housing programs, food security and nutrition assistance, climate investments, and arts and culture projects. HPI was also a cornerstone of California’s COVID-19 pandemic response. The California Department of Public Health referred to HPI in its innovative “Blueprint for a Safer Economy: Health Equity Metric” (Largent et al. 2021). The metric, which compared COVID-19 test positivity rates between neighborhoods in the lowest HPI quartile in each county with test positivity rates for the county overall, was used to determine the intensity and duration of social-distancing activities (Largent et al. 2021). HPI’s positive framing, which

highlights community assets alongside opportunities for improvement, provided users with a more holistic view of communities—enabling them to craft more effective interventions as a result. In sum, HPI has been used to equitably direct over \$4.2 billion to communities across the state.

Lessons Learned

As part of our framing shift, we had to provide more intentional and specific training on how to interpret HPI scores and indicators. For many people, the positive framing was not immediately intuitive, especially when similar indexes use the more familiar deficit framing.

We also found that not all measures of community conditions can or should be framed positively. Indicators describing certain environmental pollutants, for example, do not have a meaningful positive frame. We kept measures of low-income housing cost burdens in the negative frame as well, because the positive orientation (e.g., high-income housing affordability) would obscure the issue of housing affordability among populations under a certain income threshold. We made trade-offs to keep an overall positive, opportunity orientation without compromising meaningful measures of neighborhood conditions.

Overall, we believe there has been greater adoption of HPI because of its positive framing. It has positioned HPI as a more acceptable and accessible tool, particularly for communities and community-based organizations. Given that stakeholder engagement and community collaboration were critical components of our development process, the framing shift has facilitated our collective approach. It is much easier to use or endorse a tool that leads with assets and opportunities for communities rather than one that underlines where communities fall short.

To use positive framing in your own organization, we recommend the following key considerations:

- 1. Begin by identifying the values associated with the data you are communicating**, and use those values to help frame the data within a context of hope,

positive change, and collective action toward a shared goal.

- 2. Foster collaboration and engagement by involving stakeholders** in the data collection and interpretation processes, emphasizing shared goals and collective efforts.
- 3. Use inclusive, empowering, and people-first language** that does not stigmatize or label communities or populations.
- 4. Make conscious graphic design choices**, such as avoiding red-to-green color palettes on maps, which can inadvertently “re-redline” communities (e.g., using discriminating practices that deny services, such as financial services, in specific areas) and mask community assets.
- 5. When explaining the historical and structural factors that shape outcomes**, focus on disproportionate advantage, instead of disadvantage, to convey the importance of equitably distributing resources to communities and populations that faced historical disinvestment.
- 6. Highlight strengths and assets, showcasing what is working well.** Do not provide only measures of problems or challenges, even if positively framed.
- 7. Emphasize solutions and opportunities for improvement.** If resources allow, connect the data to tangible actions and policy recommendations that can lead to positive outcomes.

By leading with values, focusing on solutions, and engaging in hope, positive asset-based framing is a powerful tool for effecting change. The success of HPI exemplifies how positive framing can yield significant results. But keep in mind that people unfamiliar with this approach may need more context to fully grasp its language and data visualizations. Positive framing can shift the narrative surrounding community challenges by acknowledging the assets present in every neighborhood while still identifying opportunities for improvement. Ultimately, it orients people toward a shared goal: *everybody deserves the opportunity to live a long and healthy life.*

NOTES

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CHAPTER TEN

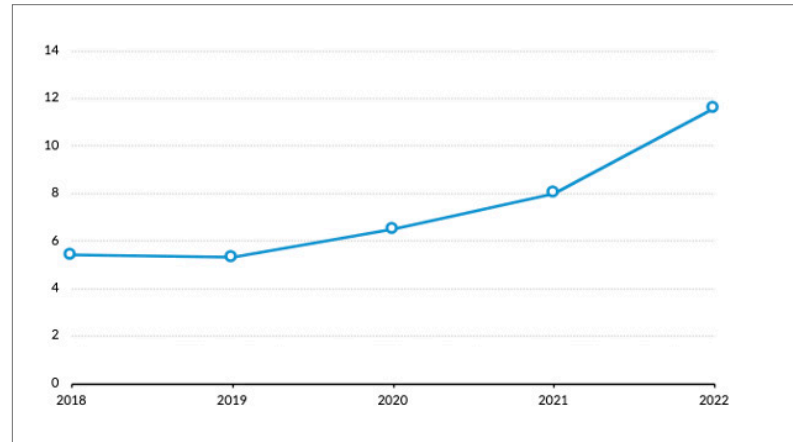
Considerations for Using Contextual Language in Research and Reporting



DANEQUA FORREST

Imagine seeing in your local newspaper the headline “Homicide on the Rise in San Antonio, Texas,” along with a line chart showing a dramatic increase in the homicide and manslaughter rate between 2018 and 2022. You would probably feel uneasy.

FIGURE 1
Homicide and Manslaughter Rate per 100K in San Antonio, Texas



Source: “Homicide and Manslaughter Rate (per 100K),” Texas Department of Public Safety, 2022. Processed and published by Community Information Now for Bexar Data Dive, accessed November 6, 2023, <https://dive.cinow.info/about-data?indicator=13&lang=en>.

But while the chart may show real data, the hypothetical headline is missing context, giving the false impression that murder is a significant problem in San Antonio.

In 2022, in a tragic human smuggling operation, 53 migrants died after being loaded into a sweltering tractor trailer and then abandoned. Adding this context, which can be found in the data notes of the original source, reframes the conversation from a “homicide” problem to an “illegal immigration” problem. San Antonio residents would know that the city’s public safety issue is that migrants need a safer, more accessible way to immigrate and that there is a need for greater restrictions to prevent predatory smugglers. But without research and relevant information, they could negligently assume the headline is true.

Though data are a powerful tool, they can be misunderstood and used for harm if not accompanied by appropriate context. When reporting or speaking about data, it is important to consider the connotations of the wording and the presence or lack of context. People use language to shape their social and cultural understanding of the world and vice versa (Duranti and Goodwin 1992). Therefore, without contextual language, data can be used to shield the systems that are causing social problems. It is negligent to not communicate data mindfully, because language can have a powerful effect on how people are viewed, the resources they receive, and the experiences they have.

What Is Contextual Language, and Why Is It Important in Research and Reporting?

Using contextual language means writing or speaking in a way that provides context and relevant information to create a more complete understanding of a situation or data. For example, a community-needs health assessment released by the San Antonio Area Foundation and the San Antonio Area African American Community Fund, with data prepared by Community Information Now, includes a section on disability (SAAF and SAAAACF 2022). In the report, Community Information Now offers context about how socioeconomic status affects disability, rather than just showing racial and ethnic breakdowns of people with disabilities. Because the report was intended to prompt action on key community issues, it was particularly important to provide context so that community leaders could properly address the disparities in the data.

The report included more than 40 indicators, and by adding just a couple of sentences of context for each indicator, it provided greater perspective on what to consider when thinking about disability and why the values at times may show disparities. For example, the report noted the following about the relationship between socioeconomic status and disability:

The work of Link and Phelan ... details how socioeconomic status [SES] is a fundamental cause of disability, which can in turn affect access to housing, employment, education, and transportation. SES affects access to healthcare, education about healthcare and preventative care, and resources regarding health. At 22%, American Indian or Alaska Natives have the largest percent of noninstitutionalized residents with a disability of some kind ... followed by Black or African Americans (16%), people of some other race (15%), and Hispanic or Latinos (14%). (SAAF and SAAAACF 2022, 11)

By contrast, providing misleading context to describe data can lead to misinterpretation. In 2016, for example, news organizations—including *The Root*, *Upworthy*, *Salon*, and *Good*—covered a report from the National Center for Education Statistics, which showed, as Salon declared in its headline: “Black Women Are Now the Most Educated Group in the United States.”¹ The data do not bear out that simple story, however; given context, Black women are the most educated in the US *compared with their male counterparts*.² The news headlines did not provide readers the full information to assess the report accurately.

The National Center for Education Statistics report included a table showing the race and gender distribution of educational attainment *by degrees* (figure 2). The numbers sum to 100 percent across the rows for quick and easy comparisons, but they are not as easy to summarize as portrayed in the headlines. The same data can be rearranged to show that Black women received a larger share of degrees *within* their racial or ethnic group than women in any other racial or ethnic group—not that Black women received a higher percentage of degrees compared with white women, or any other race or gender besides Black men (table 1). In other words, Black women received 71 percent of the master’s degrees awarded to Black

people, and white women received 62 percent of the master’s degrees awarded to white people. In both scenarios, women outperformed men, but it is misleading to directly compare the 71 percent of Black women with the 62 percent of white women.

By repeating this misleading comparison in the headlines, which are often people’s first and only takeaways from articles, news organizations perpetuate a narrative that disregards the systematic and institutional structures that have denied Black people—especially Black women—access to education, health care, housing, and other resources for decades.

FIGURE 2
Fast Facts from the National Center for Education Statistics

Level of degree and sex	Total	Percentage distribution of degrees conferred to U.S. citizens and permanent residents					
		White	Black	Hispanic	Asian/Pacific Islander	American Indian/Alaska Native	Two or more races
Associate's degree							
Male	1,012,202	52.4	12.4	24.4	6.3	0.9	3.6
Female	396,254	54.7	10.4	23.4	7.1	0.8	3.6
	615,948	51.0	13.6	25.0	5.8	1.0	3.6
Bachelor's degree							
Male	1,911,018	62.3	10.3	14.9	8.2	0.5	3.9
Female	803,184	64.3	8.8	13.9	8.8	0.4	3.8
	1,107,834	60.8	11.4	15.7	7.7	0.5	3.9
Master's degree							
Male	695,616	64.3	13.4	11.3	7.5	0.5	2.9
Female	250,842	65.9	11.0	10.9	8.7	0.4	3.0
	444,774	63.4	14.7	11.6	6.8	0.5	2.9
Doctor's degree¹							
Male	163,677	65.7	9.2	8.6	12.9	0.4	3.1
Female	71,337	68.4	7.1	8.4	12.6	0.4	3.0
	92,340	63.6	10.9	8.8	13.1	0.4	3.2

Source: “Degrees Conferred by Race/Ethnicity and Sex,” National Center for Education Statistics, accessed October 30, 2023, <https://nces.ed.gov/fastfacts/display.asp?id=72>.

TABLE 1
Rearranged Data Table from the National Center for Education Statistics

LEVEL OF DEGREE AND SEX	WHITE	BLACK	HISPANIC	ASIAN/PACIFIC ISLANDER	AMERICAN INDIAN/ALASKA NATIVE	TWO OR MORE RACES
Associate's Degree						
MALE	41%	33%	38%	44%	35%	39%
FEMALE	59%	67%	62%	56%	68%	61%
Bachelor's Degree						
MALE	43%	36%	39%	45%	34%	41%
FEMALE	57%	64%	61%	54%	58%	58%
Master's Degree						
MALE	37%	30%	35%	42%	29%	37%
FEMALE	63%	70%	66%	58%	64%	64%
Doctor's Degree¹						
MALE	45%	34%	43%	43%	44%	42%
FEMALE	55%	67%	58%	57%	56%	58%

Source: Author’s calculations using National Center for Education Statistics data from figure 2.

How to Use Contextual Language

Researchers and reporters can reveal systemic inequities by framing data around a social problem rather than around individuals. Following are three ways to use active contextual language in data (the first two are inspired by the work of social activists Blair Imani Ali and Madison Werner³):

1. Nomenclature (way indicators, demographics, or situations surrounding data are named). Using “unhoused people” instead of “homeless people,” for example, can draw attention to the need for more affordable housing and avoid attributing the systemic housing problem to the individual. Representing homelessness as a housing issue, not as an individual choice issue, can help government agencies, local organizations, and other community partners allocate resources toward housing accessibility. It can also help create a culture with less stigma around unhoused people.

2. Causal implication (implied causes of any effect shown in the data). Consider the differences in the two phrases:

Black people are less likely to get loans from banks.
Banks are less likely to give loans to Black people.

The first places the blame on Black people: What are they doing wrong? What policies might be implemented to assist them? The second shifts the focus on what the banks may be doing wrong.⁴ Reframing the data this way helps humanize people of color, while naming the structural causes of their oppression. The language used to describe data, trends, and social phenomena should be active and clear regarding who and what is causing the outcomes.

3. Additional context (information provided to give a more complete understanding of the data). A neighborhood report about eating habits might also include a map of food deserts in the area, because it is easier to explain why people eat differently by giving additional insight on access and affordability. Another example is how to accurately present crime rates, particularly when

broken down by geography, to answer questions such as: Are property crime rates higher in areas with less access to resources? Are some areas over- or underpoliced compared with others? Though it is impossible to take into account every question that could arise from the data, it should be part of general methodology to consider and present some context alongside the data.

Though ways of using contextual language may vary depending on time, place, culture, and social norms, it is still important to try to present, report, and speak about data appropriately. Researchers should live not in fear of being corrected but in acceptance of imperfection, coupled with a desire to improve. Contextual language is imperative for offering a complete and accurate understanding of what the data represent. And, through inclusive research design, communities and those with lived experience can help form this language—data without context will not lead to positive and impactful policy outcomes.

What to Consider when Using Contextual Language

When considering what information to include using active contextual language, researchers should ask the following questions:

- **Who are the data about?** Explain from whom the data was collected, which population the data narrative is referring to, and what audience can use the data.
- **How do the people referenced in the data prefer to be spoken about?** This question can refer to the people in the data or the people researchers make inferences about based on the data. Data practitioners should also consider how much community input about terminology and context they can include in their work. It is always a bonus to have direct community input, but it is not always possible. Minimum due diligence should include reviewing and citing research based on community input. In a study by Mavhandu-Mudzusi and colleagues (2023), firsthand qualitative interviews of people who identify as LGBTQIA+ showed that terms like “queer” and “LGBTQIA+ individuals” were seen as positive and inclusive, whereas terms like “moffie” and “stabane” were considered discriminatory. As the authors explained, it is important to raise community awareness about the most relevant terms for groups and to move away from using language that has been weaponized against marginalized people and deemed derogatory. Because terms evolve, present context using first- or secondhand community sources must be considered. To learn more about including community perspectives, see the Urban Institute’s *Community Voice and Power Sharing Guidebook* (Sankofa, Daly, and Falkenburger 2021).
- **Are the data presented in a way that draws attention to social context, rather than individuals?** Consider whether the data narrative implies that the cause of the trend or correlation is an individual problem. Data should go beyond individuals and show implications for systems and structures as a whole. Random, generalizable samples of people are collected to make inferences about larger patterns, so data work should reflect that broader purpose.
- **Would any other relevant information provide a more well-rounded understanding of the data?** Research the patterns, structures, and overarching trends that underlie the data. When people see data—whether raw numbers, qualitative interviews, or charts and graphs—they ultimately want to know the “why” behind the numbers. Though there is rarely a definitive answer, providing additional information on what has been uncovered thus far can point people in a general direction.

- **What should be done if data work has outdated language?** Contextual language evolves with culture, generational popularity, reactions to events, and other factors. Inevitably, the way data practitioners write about data (and people) will become outdated, so they should be open to being corrected. All the degrees, expertise, research, and education in the world cannot make a person immune to correction. Rather than being defensive, approach corrections with humility and understanding, and be willing to make amendments. When possible, add notes to previous work explaining that the data narrative was written in the context of a particular time and therefore uses outdated language.

When writing or speaking about data, consider what additional information might be needed to understand the premise of the data and to interpret them appropriately. Though misinterpretations cannot be entirely avoided, they can be minimized by anticipating possible misreading of the data.

Conclusion

There are many ways to be more mindful of the social context in data. Researchers may not always have the time or word count to explain *everything* about the data, but they can provide *some* relevant contextual language, especially for data about marginalized communities. Doing so can be crucial for shaping the social and cultural discourse about certain populations, drawing attention to systems of oppression, and ensuring the populations that need resources the most receive them.

Because contextual language will change with time, the goal for researchers is not to be perfect but to always be willing to improve. It is their responsibility to report and speak about data ethically and to prevent and reduce harm. This includes using language that emphasizes the systems and social contexts behind the data, as well as providing additional information when necessary to explain the data more completely. Data affect people's lives, and so they should be handled with mindfulness and care. One year, three years, and ten years from now, contextual language will evolve. How data are presented needs to evolve with it.

NOTES

1. Asha Parker, "Black Women Are Now the Most Educated Group in the United States," *Salon*, June 2, 2016, https://www.salon.com/2016/06/02/black_women_are_now_the_most_educated_group_in_the_united_states/.
2. Philip N. Cohen, "No Black Women Are Not the 'Most Educated' Group in the US," *Family Inequality*, June 7, 2016, <https://familyinequality.wordpress.com/2016/06/07/no-black-women-are-not-the-most-educated-group-in-the-us/>.
3. Blair Imani Ali and Madison Werner, "Smarter in Seconds: Active Language," Instagram, December 5, 2022, https://www.instagram.com/p/Cly2bf-PYC_/?hl=en.
4. Amy Harmon, "BIPOC or POC? Equity or Equality? The Debate Over Language on the Left," *New York Times*, November 1, 2021, <https://www.nytimes.com/2021/11/01/us/terminology-language-politics.html>.

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Practical Tactics for Gender Inclusivity in Data Reporting



EMILIA RUZICKA

People have existed outside the gender binary definitions of “men” and “women” for nearly as long as human history. The reality of this gender spectrum, however, has not always been accurately portrayed in research and media. As the trusted voices in society, journalists and data practitioners should strive to accurately reflect all people and produce the most rigorous work possible.

Promoting gender inclusivity in data reporting and analysis can seem like a daunting task, in part because the bounds are unclear. At its core, incorporating gender inclusivity means taking a critical look at data communication and analysis practices and asking whether there are people or communities that might feel hidden, overlooked, or misrepresented. Making these communities visible by intentionally including them in data analysis, reporting, and visualizations paints a more accurate view of the world for readers and encourages nuanced and empathetic data work. Though the goal is clear, the path can be muddy. This essay—in conjunction with Madison Call’s essay in chapter 7—is written as a beginner’s manual for gender-inclusive data reporting.

What Should Researchers and Reporters Consider When Striving for Gender Inclusivity?

Currently, few published resources promoting gender-inclusive reporting specifically address data reporting. This absence is a glaring oversight, especially as data are increasingly integrated into the daily news cycle covering virtually every topic, from health and politics to entertainment and business. Audiences also are increasingly engaged by eye-catching data visualizations and top-line statistics. These easily shared graphics and data insights tend to proliferate in online discourse no matter the issue, multiplying the negative impact of each instance of noninclusive data communication, reinforcing the gender binary, and codifying the exclusion of the LGBTQIA+ community. As a result, any workplace broadcasting data-based findings needs to implement gender-inclusive data reporting practices.

Data Sources and Collection Practices

Unfortunately, most data about gender and sex are still collected under the binary assumption of men/women or male/female. This either-or framing not only excludes all other gender identities and sexes but also conflates gender with sex. According to the National Institutes of Health (NIH), sex is a “multidimensional biological construct based on anatomy, physiology, genetics, and hormones.”¹ Words used to describe an individual’s sex are medical terms, such as “female,” “intersex,” and “male.”

By contrast, *gender* is a “multidimensional construct that encompasses gender identity and expression, as well as social and cultural expectations about status, characteristics, and behavior as they are associated with certain sex traits.”² Importantly, NIH notes that gender is self-identified and does not necessarily correspond with a person’s sex traits, sex assigned at birth, or social and cultural expectations. There are many potential terms that could be used to describe someone’s gender, such as “trans woman,” “nonbinary,” “gender fluid,” and “man.” More resources explaining what these and many other terms mean can be found in **box 1**.

When considering a data source that includes gendered data, first ask a crucial question: Does this data add to my takeaways? If the answer is no, consider not separating the data by gender but instead aggregating the data as one group. If the answer is yes, be clear about how the data source collected and defined the data. What terms does the source use? Who provided the data? Were there only man/woman or male/female options available, or was there an opportunity for respondents to identify as transgender, nonbinary, intersex, or any other label they feel best fits them?

Again, many data sources, including most data from the US government, only offer binary options (see **figures 1, 2, and 3**). This does not mean that these sources cannot be used for reporting; however, they do not represent a complete or fully accurate picture of the population. Journalists and data analysts should contextualize these data sources and identify for their audience what these data mean. In addition, data reporters should avoid reinforcing the gender binary, even when their data source only includes binary categories. When possible, they should supplement the noninclusive data source with a more inclusive one and add anecdotes that provide a more expansive perspective.

BOX 1: RESOURCES FOR GENDER AND SEXUAL ORIENTATION DATA

- Associated Press Stylebook
- Do No Harm Guide: Applying Equity Awareness in Data Visualization (Urban Institute)
- Do No Harm Guide: Collecting, Analyzing, and Reporting Gender and Sexual Orientation Data (Urban Institute)
- GLAAD Media Reference Guide, 11th edition
- “Sex & Gender” (NIH)
- “Sex, Gender, and Sexuality” (NIH)
- “Sexual Orientation and Gender Identity Definitions” (Human Rights Campaign)
- Stylebook and Coverage Guide (Trans Journalists Association)

FIGURE 1

Question about Sex in the US Decennial Census

6. What is Person 1's sex? Mark ONE box.

Male Female

Source: "Decennial Census of Population and Housing Questionnaires & Instructions," US Census Bureau, accessed November 3, 2023, https://www.census.gov/programs-surveys/decennial-census/technical-documentation/questionnaires.2020_Census.html. Also see Beth Jarosz and Paola Scommegna, "Why Are They Asking That? What Everyone Needs to Know About 2020 Census Questions," Population Reference Bureau, March 23, 2019, <https://www.prb.org/resources/why-are-they-asking-that-what-everyone-needs-to-know-about-2020-census-questions/>.

FIGURE 2

Question about Gender Identity in the 2023 National Health Interview Survey

Question Text:
For this next question you may select more than one answer. Do you currently describe yourself as male, female, transgender, nonbinary, or another gender?

Response:

1	Male
2	Female
3	Transgender
4	Nonbinary
5	Another gender
7	Refused
9	Don't Know

Source: "2023 National Health Interview Survey Questionnaire," US Census Bureau, National Center for Health Statistics, July 5, 2023, <https://www.cdc.gov/nchs/nhis/2023nhis.htm>.

FIGURE 3

Question about Sex in the 2023 National Health Interview Survey

Question Text:
Are you male or female?
* Read if necessary: By sex we mean sex at birth.

Response:

1	Male
2	Female
7	Refused
9	Don't Know

Source: "2023 National Health Interview Survey Questionnaire," US Census Bureau, National Center for Health Statistics, July 5, 2023, <https://www.cdc.gov/nchs/nhis/2023nhis.htm>.

In cases where it is necessary to use gendered data and there is no other gender-inclusive data available to supplement, the limitations of the data should be made clear to the audience, specifying what portion of the analysis includes gendered data, how it affects the model or analysis, and why the data were included.

Visualizing Gender with Color and Icons

Design choices can often reinforce the idea of a gender binary just as much as gendered data categories. When it comes to visualizing gender, avoid stereotypes, such as representing men with blue and women with pink.³ These color choices not only affirm the perception that only two genders exist but can also support stereotypically masculine and feminine gender roles. When choosing colors for gender labels, there are no set rules. However, it is generally best to not pick a color that is a mix of the colors chosen for men and women, because it reinforces the idea that there is a direct progression of genders along a linear scale. In the end, choose colors with intention; for example, use a color scheme based on an organization's graphics style guide or a palette for people with color vision impairments.

By the same token, try not to use stereotypically gendered iconography in visualizations, such as people in dresses or pants. Not only do these images reinforce the gender binary, but they are also generally inaccurate. As an alternative, consider creating new icons, such as abstracted people with different shapes on their chest with a key for the shapes. If all else fails, simply label categories with words. (For more information about using inclusive and empathetic iconography, refer to the essay by Priya Dhawka and Wesley Willett in chapter 12.)

Gendered Language: Pregnancy, Birthing, and "Women's Issues"

As abortion and reproductive rights continue to occupy the media spotlight, it is important to carefully consider the language and data used when discussing these issues. Researchers and reporters should be specific about how they frame which groups of people are involved and affected, keeping in mind that anatomy does not equate gender. On the topic of pregnancy, for example, using "people who can become pregnant," "birthing people," or "pregnant people" instead of "women" includes the trans, nonbinary, and other groups of people who do not identify as women. This is especially relevant

when labeling charts and graphs, as images can easily be taken out of context and removed from any notes or captions that explain the terminology used. Depending on the length and depth of the work, it may be appropriate to include some historical context about why specific issues may disproportionately affect people with certain gender identities.

Overall, the concept of “women’s issues” is slowly being phased out as people develop a broader understanding of gender, sex, and sexuality. Therefore, try to use gender-neutral terms whenever possible, swapping words like “fireman” for “firefighter” or “mankind” for “humanity.”

Story Framing and “Othering”

Alongside all the specific considerations mentioned above, think about the analysis as a whole. Does it unintentionally villainize a certain gender through its gendered data collection? Is it fair to all sources? At any point, does it present people outside the gender binary as abnormal, dangerous, or “other”? If so, reconsider the analysis, its intended purpose and how it could better inform the public while still being inclusive.

How Can These Practices Be Implemented in a Workplace?

Implementing more gender-inclusive reporting practices can be an uphill battle, just as any other workplace changes. Adding more items to consider before publication is often seen as a hindrance, especially in an ecosystem that heavily rewards those who are first. As one example of how to make the process of implementing gender inclusivity more accessible, in the following sections, I share my own experience with bringing gender inclusive guidelines into a newsroom.

Organize a Small, Dedicated Group from the Beginning

When considering what kinds of gender-inclusive reporting practices to integrate and how to implement them, start with a smaller group. At my organization of about 50 people, we formed a core group of 4 to 6 primary stakeholders who would come to every meeting. This allowed for free-flowing discussions, made it easier to set up meetings, and laid the groundwork for those initial members to become leaders when the time came to integrate the changes into practice.

People who identify as being outside the gender binary or as LGBTQIA+ may be the initial volunteers, but try to include people with other identities. When my team was developing our gender-inclusivity guidelines (for internal use), some of the most useful voices in the room were from people who were not part of the LGBTQIA+ community. They helped identify holes in our guidelines, such as where we needed to explain terms, justify changes, or otherwise elaborate further.

Furthermore, as conversations continued, having representation from all identities encouraged buy-in from the entire workplace. Some employees felt awkward coming to me or other queer-identifying members on the team because they felt their questions might be too basic. So having other members to turn to who were not part of the LGBTQIA+ community made them feel more comfortable.

Involve Management Early

Asking trusted supervisors, human resources representatives, and other members of the management team to be involved is a great way to garner validation. Potential changes are often met with skepticism, so before launching any new guidelines, it is important to invite higher-ups early and often to build trust among the staff, even if they cannot attend all the meetings. It also demonstrates to management the time, thought, and care that have gone into the process, which can foster support.

My team and I did not have great success getting management and human resources involved. Though we extended invitations, busy schedules did not allow us to have truly involved conversations with management. As a result, the guidelines were not implemented as quickly or smoothly as they could have been. If I were to do it again, I would be more adamant that management and human resources attend our meetings and be more willing to accommodate their busy schedules.

Host Trainings

Once my team finalized the guidelines and management gave the green light for the launch, it was time to inform the rest of the staff. For this step, we created training materials, hosted live presentations, and recorded walkthroughs of the guidelines. Depending on the size of the organization, it may be necessary to hold multiple training sessions or to split the training sessions by job function and tailor the modules to specific work.

Consider providing staff with a short checklist of questions for each job function as a reminder of important issues to keep in mind. Following are some potential questions:

- Is the data gender inclusive?
- Is the subject of the story affected by the gender binary or gender roles?
- Is there any gendered language? Is that gendered language necessary?
- Is there one gender or a group of gender identities being emphasized? If so, why?

My team chose to create a separate checklist for data reporters, writers, and editors in our newsroom. We found that this made it relatively easy for staff to use as a reference as they went about their work and helped them not feel so overwhelmed.

Emphasize That Gender Inclusivity Is an Ongoing Conversation

The landscape of gender identity, sex, and sexuality is constantly evolving, so an organization's inclusivity guidelines should be responsive. Whether through a Slack channel, email chain, ongoing meetings, or other format, make sure to let everyone know that the guidelines are always open for discussion. And, as questions and new issues arise, have open conversations about how to handle them. It is important to note, however, that this openness does not mean individuals get to invalidate the identities of others.

Furthermore, especially immediately after launching the new guidelines, consider having team members host open office hours when anyone can drop in and ask questions. Make it clear that any and all inquiries are welcome and that these office hours are for everyone to talk, learn, and grow together in pursuit of a more inclusive workplace and reporting practices. Directly after my team rolled out our new gender-inclusive guidelines, we held office hours twice a week for two weeks and created a Slack channel for ongoing conversations.

Conclusion

There are many aspects of gender inclusivity to think about, such as asking people to identify their pronouns in interviews or focus groups, creating surveys that include a variety of gender options, and using gender-inclusive language. Ultimately, there cannot be an all-in-one guide for gender-inclusive data reporting. As people continue to explore themselves and their identities, there will be new ideas and issues to consider. This evolution may seem intimidating, but it gives researchers, reporters, and analysts a reason to continually engage with the communities they serve and work with and to always strive for improvement.

NOTES

1. “Sex & Gender,” National Institutes of Health, accessed November 2, 2023, [https://orwh.od.nih.gov/sex-gender#:~:text=Sex%20is%20a%20multidimensional%20biological,includin%20humans\)%20have%20a%20sex.](https://orwh.od.nih.gov/sex-gender#:~:text=Sex%20is%20a%20multidimensional%20biological,includin%20humans)%20have%20a%20sex.)
2. “Sex & Gender,” National Institutes of Health.
3. See, for example, Lisa Charlotte Muth, “An Alternative to Pink & Blue: Colors for Gender Data,” Datawrapper Blog, July 10, 2018, <https://blog.datawrapper.de/gendercolor/>.

CHAPTER TWELVE

Humanizing Data Using Demographically Diverse Anthropographics



PRIYA DHAWKA

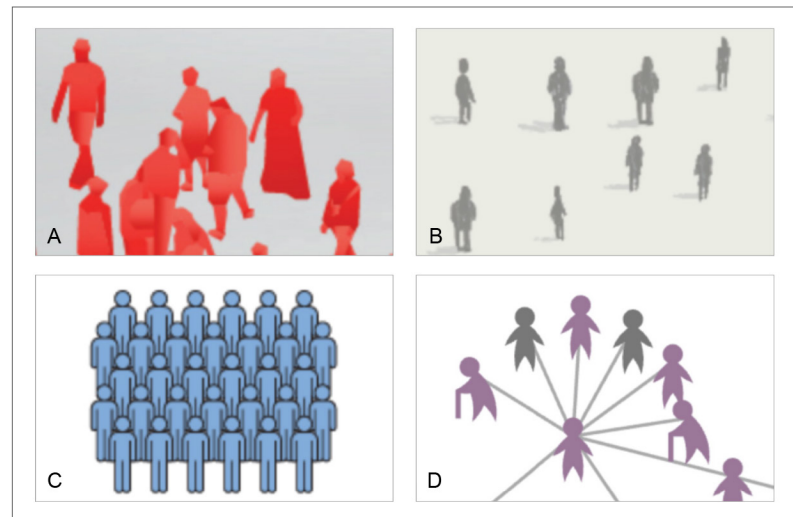


WESLEY WILLETT

Throughout 2020 and 2021, news outlets in the US emphasized the toll of the COVID-19 pandemic using anthropographics—graphs and charts composed of simple human shapes rather than abstract shapes or icons (Sorapure 2022). By showing death and infection counts using human shapes, news outlets sought to humanize victims of the pandemic and evoke a sense of togetherness among their audience. These visualizations and others like them, however, tend to rely on demographically homogeneous representations that fail to show the differences between individuals and distinct demographic groups (figure 1).

FIGURE 1

Demographically Homogeneous Anthropographics Used during the COVID-19 Pandemic

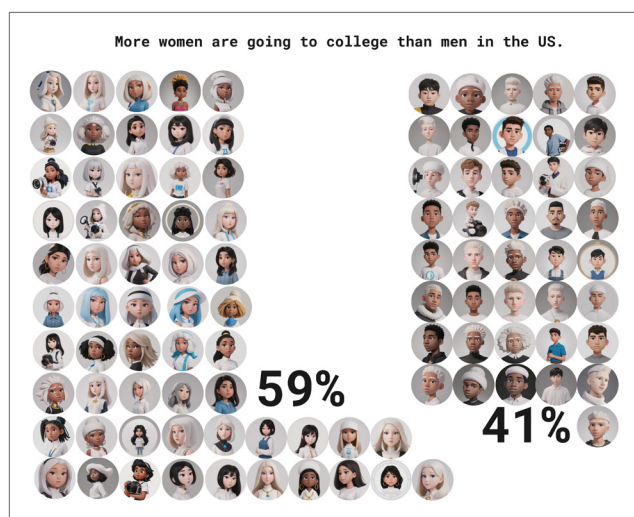


Sources: (A) Marcus Lu, “The Math Behind Social Distancing,” Visual Capitalist, March 28, 2020, <https://perma.cc/S7ZL-7AG2>; (B) Dan Barry, Larry Buchanan, Clinton Cargill, Annie Daniel, Alain Delaquerière, Lazaro Gamio, Gabriel Gianordoli et al., “The Incalculable Loss,” *New York Times*, updated May 27, 2020, <https://perma.cc/NE8S-KUXA>; (C) Marco Hernandez, Simon Scarr, and Manas Sharma, “The Korean Clusters: How Coronavirus Cases Exploded in South Korean Churches and Hospitals,” Reuters, updated March 20, 2020, <https://perma.cc/6L8Y-YST9>; and (D) Stephanie Yee and Tony Chu, “Making Sense of COVID19 through Simulations,” R2D3, March 31, 2020, <https://perma.cc/8P85-L364>.

For data practitioners, anthropographics are a useful tool with the potential to help humanize the data so people can better connect with the context and narratives around them. Yet these generic human shapes can leave some feeling invisible and unrepresented, especially when biases and assumptions may lead people to associate the shapes with individuals from specific—and often overrepresented—demographic groups. Recent work by Robertson and colleagues, for example, highlights how people tend to perceive ostensibly universal default emojis (e.g., 🍌 and 😊) with a white identity (Robertson, Magdy, and Goldwater 2021). This suggests that the kinds of simplified and demographically homogeneous anthropographics favored by most visualization designers may not be as universal as they appear, and by using them, designers run the risk of implicitly and unintentionally prioritizing dominant demographic groups.

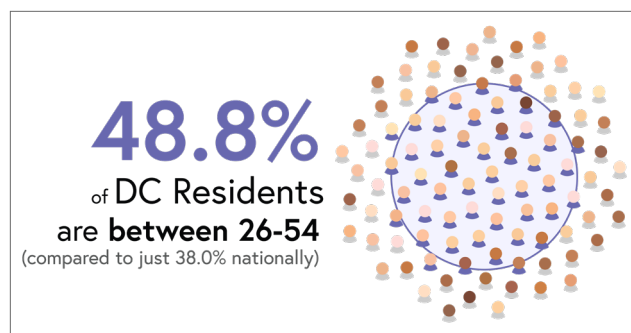
In contrast, demographically diverse anthropographics emphasize the diversity of people in a dataset by visually representing their physical and demographic characteristics (figures 2 and 3).¹ In particular, these anthropographics present opportunities for audiences to engage and better relate to the people behind the data.

FIGURE 2
Infographic Showing Gender Demographics in US College Campuses



Source: Infographic created by authors. Images are created using Stable Diffusion, a text-to-image generator, and input prompts containing demographic category labels for gender and race are from the 2020 US Census.

FIGURE 3
Infographic Using Geometric People in Various Shades



Source: Infographic created by authors. The data are a random sample of 100 residents in Washington, DC, from the 2020 US Census.

Notes: This figure shows that there is a disproportionate number of white residents ages 26–54 in Washington, DC, based on the 2020 US Census. The Census data make complicated assumptions about race and skin color, which are discussed further in Dhawka, He, and Willett (2023). The anthropographic in this figure uses geometric people in various Fenty Beauty shades. The 58 residents reported in the Census as “white” are drawn using the 12 lightest skin tones, while the 32 residents reported as “Black or African American” are drawn using the 12 darkest skin tones; the remaining 10 residents are drawn using randomly sampled shades. See “Pro Filt’r Soft Matte Longwear Foundation,” Fenty Beauty, accessed November 7, 2023, <https://perma.cc/6LLM-U6L7>.

Toward More Demographically Diverse Anthropographics

Recently, there has been renewed interest in exploring ways of designing visualizations that humanize datasets (Dhawka, He, and Willett 2023). But anthropographics are relatively new, and more research is needed about their impact on audiences and the risks associated with using them in terms of accuracy and representation. Initial experiments have demonstrated that human shapes can elicit some limited prosocial feelings toward humanitarian causes (Boy et al. 2017; Morais et al. 2020, 2021). Yet little is known about how different levels of realism and demographic details affect people’s experiences or how to best create these more anthropomorphic representations.

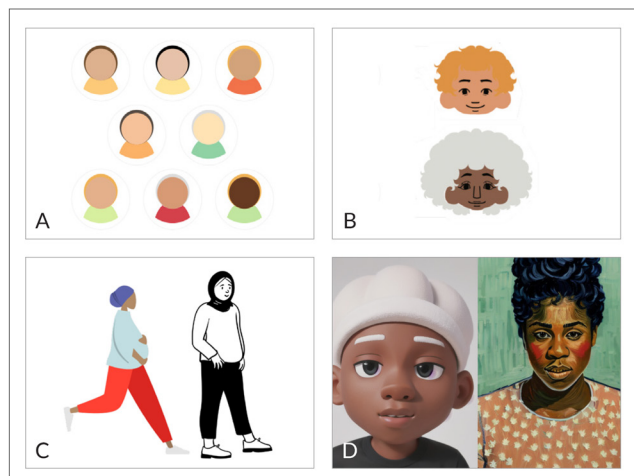
Over the past two years, our research team at the University of Calgary has explored a wide range of different approaches for creating demographically diverse anthropographics. We conducted dozens of experiments with different graphic styles and tools, including hand-drawn illustrations and illustrations

using emerging technologies like text-to-image generators. We also re-created anthropographics from popular data journalism outlets and interviewed diverse audiences to understand responses to these representations. Our experience highlights how data practitioners can use anthropographics to equitably represent demographic data—such as race—and take active steps to prevent potential harm to marginalized groups (Schwabish and Feng 2021).

While our work focuses primarily on visualizing a small number of high-level demographic attributes (e.g., race, age, and gender), designers can create diverse anthropographics using a wide range of attributes, including occupation, disability status, religion, and social groups. Furthermore, these types of visualizations do not need to be restricted to simple human icons. In fact, anthropographics can vary in visual style, expressiveness, and realism, ranging from abstract iconic representations to hand-sketched illustrations to more complex images (figure 4).

FIGURE 4

Examples of Demographically Diverse Anthropographics



Sources: Anthropographics created by authors.

Notes: (A) Simple geometric illustrations. (B) Hand-sketched illustrations from experiments. (C) Images from the Open Peeps: A Hand-Drawn Illustration Library (<https://perma.cc/PC2H-BPKW>) and the Humaans: Mix-&-Match Illustrations of People with a Design Library (<https://perma.cc/734W-QZ5P>). The images from both libraries are by Pablo Stanley, and they are composable and editable, so designers can use them to create diverse anthropographics. (D) Images created using Stable Diffusion, a text-to-image generator, with input prompts using demographic category labels for age, gender, and race.

Demographics Pose Design Challenges

Creating visualizations that capture the demographic richness of human populations is complicated by a variety of data- and design-oriented challenges. Following are best practices from our experiments.

Determining When Surfacing Demographics Is Appropriate

Designers must start with the intended purpose of the visualization and the type of demographic data they are using, and then consider whether diverse anthropographics are suitable for the dataset. We found, for instance, that diverse anthropographics are well suited for visualizing small datasets, where demographic data (e.g., gender, age, or occupation) could provide context and encourage audiences to engage with the data in a way that acknowledges the people behind it.

Diverse representations are likely less suitable for sensitive datasets, where preserving the privacy and anonymity of individuals is essential or where surfacing demographics might encourage people to interpret the data based on their existing negative biases or deficit framings. If datasets contain sensitive information about individuals, for example, abstract visual styles may offer greater privacy and anonymity than photo-realistic ones. Furthermore, some individuals may not wish to be represented in ways that emphasize certain aspects of their physical appearance. To reduce potentially harmful design decisions, whenever possible, designers should involve members of underrepresented groups in the design process.

Sourcing or Simulating Credible Demographic Data

Creating diverse anthropographics usually requires access to data that contain demographic attributes or have physical diversity. However, demographic datasets are often anchored in artificial, stereotypical categories that may not reflect how individuals personally choose to identify. Representing these data using diverse anthropographics may require designers to make a variety of decisions that balance credible representations of people and accurate representations of the dataset.

When datasets do not contain demographic attributes or descriptors of physical diversity, designers may choose to artificially augment the dataset by simulating or randomly generating additional demographic data. If a dataset only includes gender, for example, instead of simply using the standard, stereotypical binary gender icons, designers might consider simulating additional demographic data, such as age or race. Designers can then visualize this augmented data with human illustrations that depict diverse physical characteristics, such as hair, facial features, accessories, or clothing. Even though these attributes are not part of the original dataset, designers can carefully include them in the anthropographics by explaining the data source and their design decisions.

Supporting Accurate Interpretation

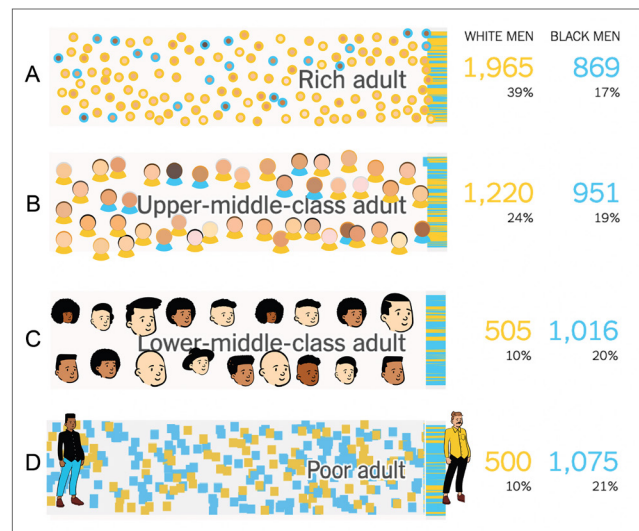
Whenever human figures are included in visualizations, designers run the risk that audiences may assume the visualizations are driven by real data or that they accurately represent the appearances of unique individuals or groups in the data, even when they do not. Because of these risks, we strongly recommend designers document all decisions and assumptions made during the design process as well as the necessary context for audiences. They can provide this information, for example, in footnotes or endnotes in static graphics or by using tooltips with descriptive text in interactive graphics.

Case Study: *New York Times's* Story on Economic Mobility

Our research team re-created *New York Times's* interactive story, “Extensive Data Shows Punishing Reach of Racism for Black Boys,” several times using demographically diverse anthropographics.² We highlight some of the potential benefits, design choices, and trade-offs we had to make from this experiment.

The original visualization in the *New York Times* showed social class outcomes for 10,000 Black and white men in the US by encoding their race using blue and yellow squares. In our re-creation, we experimented with four illustrative anthropographic styles (figure 5).

FIGURE 5
Re-creation of the *New York Times's* Story Using Multiple Anthropographic Designs

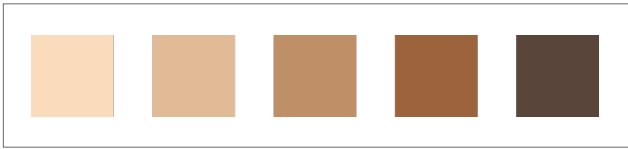


Source: (A) Anthropographics created by authors based on Emily Badger, Claire Cain Miller, Adam Pearce, and Kevin Quealy, “Extensive Data Shows Punishing Reach of Racism for Black Boys,” *New York Times*, March 19, 2018, <https://perma.cc/C3TL-3MBY>.

Notes: Anthropographics using (A) dots, (B) simple geometric human shapes, (C) hand-drawn human heads in various skin tones, and (D) hand-drawn human figures in two skin tones. Both (C) and (D) use images from Open Peeps: A Hand-Drawn Illustration Library (<https://perma.cc/PC2H-BPKW>).

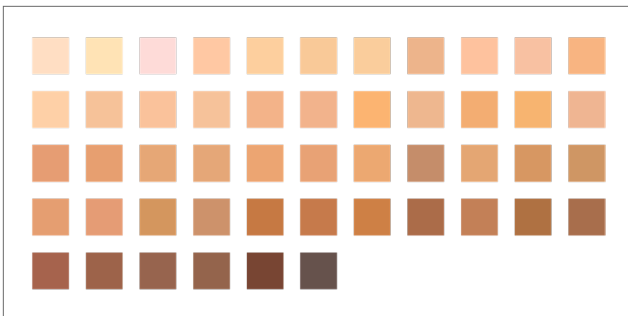
We wanted to illustrate racial diversity using skin tones, particularly because the original *New York Times* story emphasized disparate economic outcomes based on race. However, the data source for the story, from administrative tax records, contained only a “race” category (e.g., Black and white), rather than attributes describing skin color. So we introduced different skin tones based on the five standard Fitzpatrick skin phototype classification system used in Unicode emojis (figure 6), as well as the 50-shade color palette based on the inclusive Fenty Beauty makeup brand (figure 7).

FIGURE 6
Unicode Emoji Skin Tones



Source: Unicode emoji skin tones are based on categories from the Fitzpatrick skin phototype classification system. See Amanda Oakley, “Fitzpatrick Skin Phototype,” DermNet, 2012, <https://perma.cc/4VXA-5YF2>; and “Full Emoji Modifier Sequences, v15.1,” Unicode, accessed November 6, 2023, <https://perma.cc/67NY-723T>.

FIGURE 7
Skin Tones from the Fenty Beauty Brand



Source: “Pro Filt’r Soft Matte Longwear Foundation,” Fenty Beauty, accessed November 7, 2023, <https://perma.cc/6LLM-U6L7>.

Each color palette comes with trade-offs. For example, figure 5(C) uses the five-shade Fitzpatrick color palette and does not show much variation in skin tones. By contrast, figure 5(B) uses the 50-shade Fenty Beauty color palette, which more accurately reflects human skin tones and gives a clearer sense of the diversity among individuals of both races.

A more limited color palette like the Fitzpatrick color palette is easier for designers to use, given that they have fewer colors to assign to categories. Thus, we used the Fitzpatrick color palette with the more detailed human icons, as we relied on the facial features to indicate demographic diversity. A richer color palette like the Fenty Beauty color palette poses challenges for designers who must make potentially problematic decisions about which skin colors to assign to which categories (as described in the notes to figure 3).

We experimented with multiple strategies for assigning Fenty Beauty colors to the two race categories using simpler geometric shapes in figure 5(B) and (C). We found that randomly assigning skin tones to race categories may be unbiased, but in practice it can result in unrealistic visual representations that may lead people to question the credibility of the anthropographics. Manually assigning colors to demographic categories, however, involves decisionmaking that may reflect designers’ biases—particularly when relying on assumptions about the physical appearances of individuals in certain demographic groups (figure 3)—which may result in unintended harm to the populations being represented and reinforce stereotypes.

Considering these challenges, designers should weigh the various trade-offs associated with each anthropographic style. More complex hand-sketched illustrations, for example, may help people better connect with the data, but designing them requires considerable effort and so may not be suitable for visualizations with large amounts of data. Comparatively, designers can create simple anthropographics like the dots and combine them with additional visual encodings of diversity like skin tones.

Designers should document instances where biases may already be present in the data or may be introduced during the design process and highlight them for audiences. Designers should also question whether the choice of specific visual encodings (i.e., which physical characteristic to assign to which demographic category) perpetuate stereotypes and cause harm to the groups being represented, particularly in regard to choosing skin tones, where designers’ decisions may be arbitrary or biased.

Despite these risks, however, anthropographics have the potential to deeply humanize datasets and to help people visualize datasets through the lens of equity.

Questions for Practitioners to Consider

Because anthropographic visualizations—demographic ones, in particular—are still new to audiences, there are no guidelines or best practices to ensure that the populations being visualized are not harmed. Visualizing race and other kinds of demographic data with an awareness of equity requires practitioners to examine both the benefits and threats of using anthropographics, particularly when data involve marginalized and underrepresented populations. Based on our experience designing and researching the potential effects of demographically diverse anthropographics, we have created a set of questions for practitioners to consider before deciding to use anthropographics.

Possible Benefits of Demographically Diverse Anthropographics

- Could seeing anthropographics that reflect the diversity of the people in the data help combat misconceptions and dispel stereotypes about the individuals or groups being represented?
- Could demographically diverse anthropographics help people appreciate the humanity of the individuals or groups behind the data?
- Could using demographically diverse anthropographics help people see themselves in the dataset or relate to it?

Possible Risks of Demographically Diverse Anthropographics

- When visualizing the demographics of the people in the dataset, how will their privacy and anonymity be maintained?

- Could seeing anthropographics of underrepresented populations lead people to interpret the data based on their conscious or unconscious biases?
- Could a diverse anthropographic reinforce stereotypes or encode potentially biased assumptions about the physical appearances or inequities faced by individuals or groups in the dataset (particularly for marginalized ones)?
- Could simulating demographic data or data about physical characteristics (when such data are unavailable) in a way that is not connected to the original dataset being visualized mask real effects or lead to incorrect assumptions about the data?
- Could randomly assigning physical characteristics to demographic data result in unrealistic representations that may not reflect the diversity of real populations and undermine the credibility of the anthropographics?

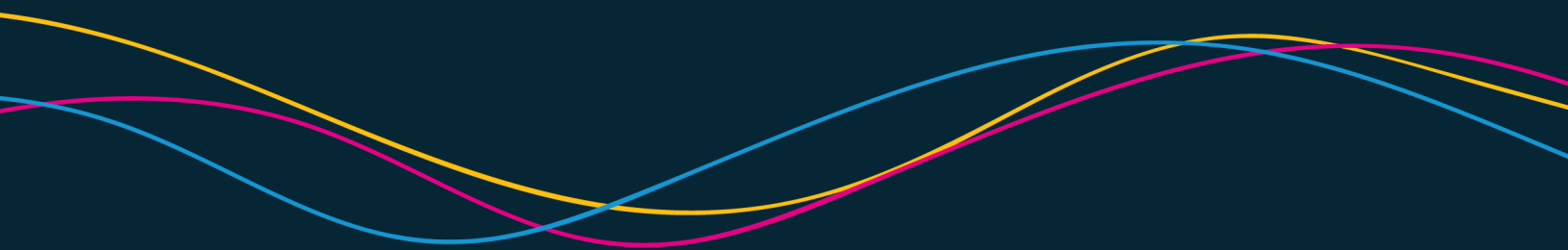
As analysts and designers, we can flexibly incorporate anthropographics into our visualization toolbox. We encourage practitioners to experiment with anthropographics in their workflow, while emphasizing that their responsibility is to do no harm when creating these kinds of visualizations. We also urge designers interested in diverse anthropographics to engage with work in this domain beyond this essay.

NOTES

1. "About the Topic of Race," US Census Bureau, accessed September 9, 2022, <https://perma.cc/46QV-GW2T>.
2. Emily Badger, Claire Cain Miller, Adam Pearce, and Kevin Quealy, "Extensive Data Shows Punishing Reach of Racism for Black Boys," *New York Times*, March 19, 2018, <https://perma.cc/C3TL-3MBY>.

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Tracy Delaney is the founder and executive director of the Public Health Alliance of Southern California, a regional coalition of 11 local health departments responsible for the health of 60 percent of California's population. She works to advance health equity, racial justice, and population health through multisector initiatives addressing policy, systems, and environmental change. Delaney has spearheaded multidisciplinary projects integrating land use and transportation, food systems, climate and water resources, and public health and hospital systems. She has launched and overseen the development of the Healthy Places Index, a positively framed data and policy platform created to advance health equity through accessible, neighborhood-level data. Before joining Alliance, Delaney was the director of chronic disease and health equity at the County of San Diego. She was also the principal investigator for the Centers for Disease Control and Prevention's Communities Putting Prevention to Work Program (the nation's largest federal obesity prevention award) and the Community Transformation Grant Program. She has served as a voluntary clinical professor for the Department of Family Medicine and Public Health at the University of California, San Diego. Delaney received a PhD in nutrition with a minor in physiological chemistry from the University of California, Davis.

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ABOUT THE PROJECT

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