

Powering Health Equity Action with Online Data Tools: 10 Design Principles

PolicyLink



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Introduction

Achieving health equity—when everyone has a just and fair opportunity to be as healthy as possible regardless of race, income, or other socially defined characteristics—is essential to building resilient communities, a prosperous economy, and a just society. Without optimal health, it is impossible for people to reach their full potential. Yet today in the United States, health disparities are persistent and growing. These inequities are not natural or inevitable, but stem from structural racism and discrimination, as well as the inequitable policies, practices, and resource allocations that create the vastly unequal conditions in which people live.

Community-based organizations play a crucial role in advancing health equity. These institutions help put in place new policies, plans, and programs that improve neighborhood environments and opportunities for low-income communities, communities of color, and others unjustly and unfairly burdened by poor health. And community-level data that is disaggregated by race, income, neighborhood, and other demographics is an essential tool to increase the effectiveness and impact of these organizations.

This report strengthens community-driven efforts to achieve health equity by improving the online data tools that make health equity data readily available to them.

Robust local data can help community groups at every stage of the policy process, from understanding local conditions and inequities, to framing and building support for issues and policy solutions, to monitoring progress toward equity results. Neighborhood-level data that can be mapped and layered is also valuable for revealing the relationships between different issues such as financial security and displacement, community assets and potential development and market opportunities, as well as the cumulative effects of varied risks, harms, or barriers. Disaggregated data and community mapping can also illuminate the experiences of marginalized people and communities to decision makers, and shed light on issues made purposefully invisible.

But while we live in the age of data, the *right* data and the tools for analyzing, displaying, and sharing it are often elusive for underresourced community groups.

Over the past decade, community leaders and a growing array of institutions have begun building new data tools with the explicit purpose of addressing this mismatch and advancing equity. In 2007, Portland, Oregon’s Coalition for a Livable Future launched the nation’s first “regional equity atlas,” a printed volume of maps documenting the vast disparities in access to resources and opportunities across the region and supporting successful advocacy to target investments to communities of color and low-income communities. Other communities—Atlanta, Denver, and Los Angeles—followed suit and created their own atlases, mapping a multitude of indicators across the various domains that influence health, from employment to transportation to housing to community safety and more.

At the national level, more data tools for equity have emerged. Some comprehensively depict equity conditions for multiple communities, such as the [National Equity Atlas](#) and [diversitydatakids.org](#). Others provide disaggregated community data for specific issues and policy areas, such as [Mapping Police Violence](#) (community safety and justice) or [Clocking-In](#) (wages and workers’ rights).

These equity data tools are supporting policy development, organizing, and investment for health equity in myriad ways:

- Housing advocates used the [Portland Regional Equity Atlas](#) maps to successfully advocate for a 30 percent funding set-aside for the development and preservation of affordable housing in disinvested areas. During the five years that followed, this policy raised about \$125 million for affordable housing.
- [Mapping Police Violence](#) estimates that 90,000 users have contacted their local, state, or federal elected officials about their positions on police reform through a widget on the website titled “Demand Action from Your Representatives.”
- The Public Health Institute of Metropolitan Chicago recently incorporated [diversitydatakids.org](#)’s Child Opportunity Index, a measure of relative opportunity across a metropolitan area calculated based on 19 indicators of educational, health, environmental, social, and economic opportunity, into its criteria for allocating \$875,000 in Healthy Chicago 2.0 Seed Grants devoted to promoting health equity.

We believe that the equity data field is on the verge of rapid growth and, with it, the vast potential to strengthen community-driven advocacy and organizing—if these tools are designed with equity in mind.

In the spirit of nurturing this nascent field and contributing to its evolution, this report offers up a set of 10 design principles for online data tools intended to advance health equity. It was developed for researchers, advocates, community members, planners, funders, and others interested in building, improving, or investing in such data tools. The principles were developed by PolicyLink and Ecotrust and vetted with community advocates and practitioners, equity data tool creators, and funders at a convening held in Portland, Oregon, in July 2017. The principles draw upon our knowledge and experience as equity data tool creators, eager observers, and scholars of the data democratization and community indicators movement over the past two decades.

Following the presentation of each of the 10 principles, we share several challenges and suggestions for how to advance the equity data field.

A couple of the challenges deserve a few words at the outset. First is the desire for greater community ownership of data and data tools. Throughout the process of developing this report, we heard mounting interest in data tools that put communities in the driver's seat of data collection, analysis, and display, with the goal of self-determination. In this model, communities decide what data should be collected to inform community efforts to advance health equity. Yet most existing equity data tools are created by nonprofit advocacy organizations or public agencies, not community members themselves.

Second is the reliance on secondary data that is collected by public or private sources, rather than primary data such as resident surveys. While primary data collection requires considerably more resources and time, it may be necessary for some tools. If, for example, there is scant data on the community of interest (as is true for many small populations) or the topic area (like the number or quality of police–community interactions), tool developers may need to collect primary data.

Related to this challenge, data tool creators need to ensure that the lack of data availability for smaller geographies (like cities or neighborhoods) does not override their acknowledgement of inequities that they know exist based on other research. The True Colors Fund, for example, estimates that up to 40 percent of homeless youth nationwide identify as LGBTQ. But this type of data is not widely available at the local level. When data is unavailable for populations known to experience adverse health outcomes, including LGBTQ, homeless, or formerly incarcerated people, and primary data collection is not feasible, policy recommendations and narratives should still lift up the experiences of these populations.

We are hopeful that the democratization of data and technology leads to new opportunities and examples of community-driven and community-owned tools. We are excited about the potential of emerging and existing data tools and hope others will join us in building upon these principles and examples in service of health equity.

10 Design Principles for Online Data Tools for Health Equity Action

Data tools hold tremendous power to amplify community efforts to advance health equity through policy and systems change—if they are designed with equity in mind. PolicyLink and Ecotrust offer the following principles to guide data tool creators in building tools that strengthen community action toward health equity: when everyone has a just and fair opportunity to be as healthy as possible, regardless of race, income, or other socially defined characteristics.

1. Build Community Power

Communities that bear the brunt of health inequities must be at the forefront when creating data tools to advance health equity. Community knowledge is paramount to accurately understanding problems and crafting solutions that work. Intentional community partnerships and thoughtful design processes strengthen community capacity and can result in stronger advocacy and better data tools.

2. Address the Root Causes of Inequity

Online data tools for health equity should acknowledge the root causes of health inequity, which are not primarily individual health behaviors but rather stem from structural inequities and systematic differences in the social, economic, and environmental resources and assets that affect health and well-being.

3. Lead With Your Health Equity Goal, Not the Data

The broader equity outcome—e.g., preventing displacement, building healthy communities, or ending police violence—should drive the design of the tool rather than the data or technology. Be clear about the tool's purpose, then provide data, maps, and analysis to help users achieve that goal.

4. Make Data Actionable

Ensure that your tool inspires and supports community actions toward policy and systems change. Offer viable solutions to improve material conditions that incorporate the experiences of marginalized people, including those for whom data may not be readily available.

5. Disaggregate Data

Understanding how conditions and opportunities vary for different groups, including their histories and the policies affecting them, is critical to developing and advancing tailored equity solutions. Disaggregate data by race/ethnicity, gender, nativity, ancestry, income, and other factors to the extent possible.

6. Move Beyond Maps and Numbers

Maps and statistics are important staples of equity data tools, but different types of visualizations and qualitative data can help convey information that builds political will, supports community action, and provides a more comprehensive view of an equity issue.

7. Emphasize Assets and Opportunities

While uncovering disparities can be valuable for compelling action, it can have the unintentional effect of perpetuating inaccurate and negative stereotypes about communities. Data tools should also focus on community assets and strengths that can be built upon.

8. Provide Clear Explanations

Make your tools as user friendly as possible by providing clear explanations of what the data shows, why it matters, and what users can do about it. Provide definitions of indicators and data sources.

9. Contribute to Data Democracy

Open access to public data is critical for fair representation and transparency, and to allow advocates access to the data they need. Ensure that the data and metadata are affordable and available to impacted communities to ensure long-term accountability.

10. Honor Indigenous Data Sovereignty

Sovereign tribal nations have the right to govern the collection, ownership, and application of data about indigenous nations and people. Data on or about indigenous people should be subject to the laws and governance of indigenous nations.

#1 Build Community Power

Communities that bear the brunt of health inequities should be at the forefront when creating data tools to advance health equity. These communities possess knowledge and wisdom that is fundamental to accurately understand problems and develop solutions that work; however, they are often over studied and underserved. Too often, researchers come into communities, mine them for data and research purposes, and take that knowledge outside of the community, potentially to be misapplied, applied elsewhere, or even to pathologize those communities. Understandably, marginalized communities are often skeptical or distrustful of data efforts.

Equity data tools must go beyond extracting data from or about a community. Tool creators should ensure that the data is meaningful to the community and applied correctly. Accompanying analyses and stories should be culturally relevant and challenge or replace existing harmful or inaccurate narratives.

This requires, at the minimum, community engagement and partnership. While the mechanisms for community input will vary depending on the nature of the tool and whether it has a large geographic scope or a narrow one, all data tool developers can and should be intentional about engaging community partners in the process from the inception and ensuring the tool is accountable to the communities it represents.

The process of developing an equity data tool creates opportunities to build community power. When done well, the development of an equity data tool can strengthen community capacity to drive policy and systems change through the effective use of data to advocate and organize for change. Intentional community partnerships and thoughtful design processes can result in stronger community advocacy, more equitable outcomes, and better data tools.

Portland Regional Equity Atlas: Using a Research Justice Framework to Build v3.0

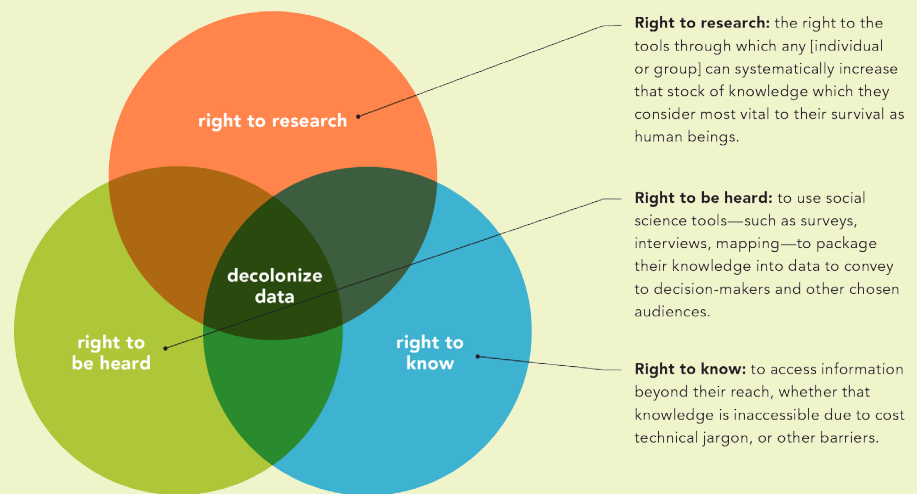
Stewards of the Portland [Regional Equity Atlas](#) have adopted a research justice framework for the development of the Regional Equity Atlas 3.0. They are committed to ensuring that community-based organizations are involved throughout the process and actively use the tool, including:

- setting project goals
- identifying data metrics and indicators from secondary data
- planning for, collecting, analyzing, and interpreting community-generated data.

A new partnership with the Coalition of Communities of Color, Right 2 Root, and Streetwyze is building the groundwork for a community-driven Atlas 3.0.

A framework for research justice*

Communities are experts in their own lives, possessing experiential, historical, & cultural knowledge which must be centered in any data research initiative. To that end, we believe that communities have a:



*Coalition of Communities of Color adaptation of the framework from DataCenter: Research For Justice

Source: Graphic courtesy of Sarah Cline at Ecotrust.

How to apply this principle:

- Partner with local organizations to hold community engagement sessions before building out the tool to ensure that community members inform the goals of the project and research questions that lead to the selection of data and indicators. If you are building a national tool, consider forming a community advisory committee of local advocates to inform the process.
- Flatten the unequal power dynamics that exist in multisector collaborative processes by ensuring that community partners' voices and participation are comparably weighted to other partners and by informing powerful interests like businesses and funders about the importance of community input and remaining accountable to community visions and goals.
- Go into communities to share major findings throughout the development of the tool, test for their relevance within the community, and adjust as necessary. The more frequent and inclusive the engagement, the more trust is built and the more likely the tools will be used.
- After launching the tool, hold free or affordable trainings in accessible locations for community members and organizers on how to use the tool for change.

#2 Address the Root Causes of Inequity

Online data tools for health equity should acknowledge the root causes of health inequity. Contrary to popular wisdom, health inequities are not primarily caused by individual health behaviors but instead stem from systematic differences in the social, economic, and environmental assets and resources that affect health and well-being. These differences are caused by structural racism, unequal power relations, and policies and resource allocations that create the inequitable conditions in which people live, work, and play. From redlining to voter ID laws to exclusionary zoning practices and more, public policies have fostered racial inequities in health, wealth, and opportunity at the federal, state, and local levels. For data tools to advance health equity, they need to support community decision making and actions that address these “upstream” drivers of health inequity. The tools should also help educate the public about the drivers of inequity.

While a considerable amount of national health data focuses on health behaviors, health equity means reducing and ultimately eliminating disparities in health and its determinants that

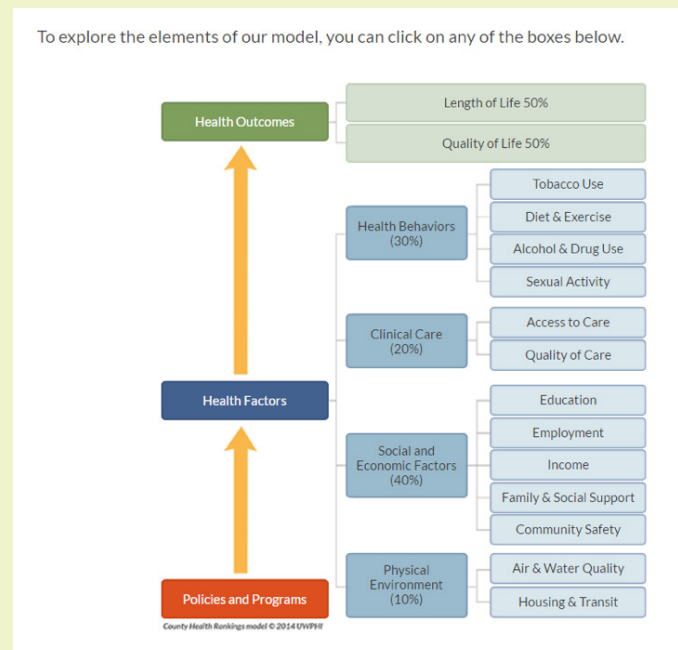
adversely affect excluded or marginalized groups.¹ Social determinants of health (the nonmedical factors like employment and access to healthy food that make up where people live, work, learn, and play) also influence health outcomes. The seven key social determinants of health—education, employment, income, family and social support, community safety, air and water quality, and housing and transit—account for half of health outcomes while health behaviors account for just 30 percent.²

How to apply this principle:

- When visualizing health behaviors, include data on the social determinants of health that may impact those behaviors.
- Include narratives that describe the root causes of health inequity (the forthcoming report “Right 2 Root: A Community Centered System for Equitable Development in N/NE Portland” is a great example).
- Describe the broader policy context that influences the selected indicator or data.

County Health Rankings & Roadmaps: Building Knowledge About the Social Determinants of Health

The [County Health Rankings & Roadmaps](#) not only detail health outcomes across all counties in the United States, but also describe the health factors that influence those outcomes. These factors are broken out across health behaviors, clinical care, social and economic factors, and the physical environment—the latter two account for half of health outcomes. Each of the sections in the Rankings includes a range of indicators, like employment, children in poverty, and drinking-water violations. The model used is shown in the screenshot at right.



Source: “Our Approach,” County Health Rankings & Roadmaps, <http://www.countyhealthrankings.org/our-approach>.

#3 Lead With Your Health Equity Goal, Not the Data

Data alone does not lead to policy or systems change, so the broader equity outcome or goal should drive design rather than the data or technology. Data tool developers should clearly articulate the tool's purpose and then leverage data, maps, and analysis to achieve the community-defined goal (ideally, per Principle #1, through a community-driven process). Articulating the desired equity goal at the front end helps to determine who the target users are, and then allows the developers to select data and indicators that deliver on that result. Equity data tools have done this in different ways:

- The [Denver Regional Equity Atlas](#) visualizes “the benefits and opportunities that a robust public transportation network can create” in order to advocate for transit funding.³
- The [Anti-Eviction Mapping Project](#) documents the “dispossession and resistance” of San Francisco Bay Area residents to put pressure on elected officials and developers.⁴
- [Clocking-In](#) highlights the racial and gender inequities in the restaurant, retail, and domestic industries to build power among those workers and inform organizing campaigns.⁵

Leading with the equity outcome will also help to reconcile the tradeoff between scope and depth that is inevitable with equity atlases and other data tools. While some tools may share data covering several issue areas, other tools may delve deeply into

a single topic or subset of topics. Designing the tool with the outcome in mind will not only help to organize the tool, but also will support the selection of datasets that are most relevant to driving the outcome. As one participant in the July 2017 workshop stated, “I’ve never seen a piece of data I didn’t like.” But that does not mean that they all need to be included in a tool. It is true that many pieces of critical data do not exist; however, usually the issue is not the lack of data, but rather the presentation of data without a desired outcome or buy-in of the community.

How to apply this principle:

- Identify the population(s) of interest and community-based organizations to partner with early in the process.
- If the goal is scope, as is the case in many equity atlas efforts, identify core community-based partners who comprise or represent the impacted communities and bring in a broad coalition of other partners to advise.
- Beware of mission creep as the project develops and additional partners weigh-in. Do not lose sight of the tool's purpose to serve the people bearing the brunt of injustice.
- Exclude important data that might be interesting but not relevant to furthering the stated equity goals.
- If data that can advance the equity outcome does not exist, use the lack of data as a point of advocacy (more details on this point are provided under Principle #4).

Mapping Police Violence: Strategies to End Police Killings

[Mapping Police Violence](#) was born out of the Movement for Black Lives to fill the void of comprehensive national data on police killings. The data provided also focus on the impact of police violence on Black people, especially those who are unarmed when killed by law enforcement officers. The site helps users take action on the disparities shown by the data through a widget titled “Demand Action from Your Representatives.”



Source: Homepage, Mapping Police Violence, <https://mappingpoliceviolence.org/>.

#4 Make Data Actionable

To ensure the tool not only serves up data and indicators, but also inspires and supports community action, share potential solutions that community members can help advance to see change on these indicators. Provide users with information and examples about how they can use your data to effect change. Depending on the intended audience, this can include model legislation for certain policies, contact information and voting records of their elected officials, or ways to connect to relevant community- or membership-based organizations in their area.

In some cases, the lack of data on certain issues or populations can also be a point of advocacy. Given the dearth of disaggregated data on policing from departments across the country, for example, demand is growing for more and better data to improve accountability. In other cases, the lack of data on small populations can serve as a call to action. This is true among the American Indian and Alaska Native, Black, Latino, and Asian or Pacific Islander communities. It is also rare to find local data on populations known to experience adverse health

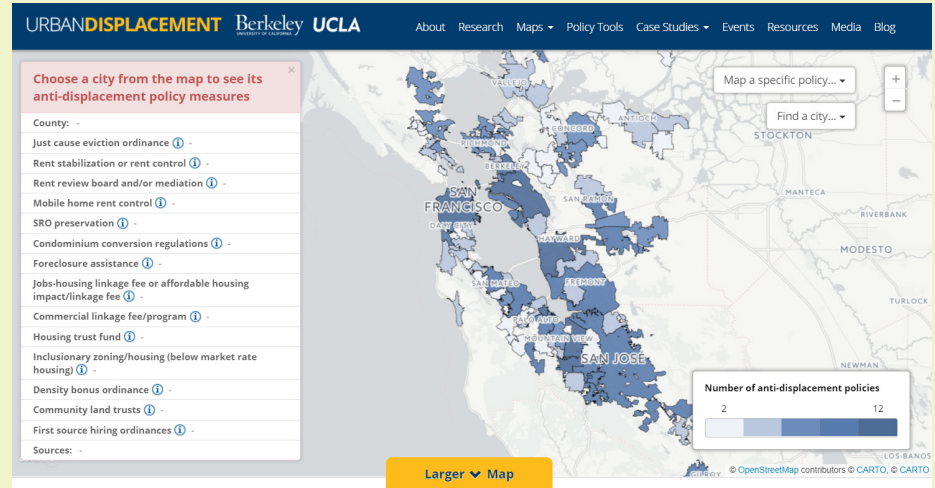
outcomes, including formerly incarcerated, lesbian, gay, bisexual, transgender, two-spirit, gender non-conforming, or homeless people. In some cases, primary data collection may be warranted. But even when this data is unavailable at the local level, data tool developers should draw on existing national data about marginalized populations to inform their solutions and to spur community action.

How to apply this principle:

- Provide a list of policies that have been proven to address or ameliorate each indicator.
- Provide the contact information of local, state, or federal elected officials who influence the recommended policies.
- Connect users to advocacy or membership-based organizations who work on issues related to the data.
- Because action often happens locally, both national and local tools should address how the data is relevant in a local setting.

The Urban Displacement Project: Equipping Advocates with Effective Local Policies

The [Urban Displacement Project](#) is a research and action initiative of UC Berkeley in collaboration with researchers at UCLA, community-based organizations, regional planning agencies and the State of California's Air Resources Board (ARB). The tool maps gentrification in the Bay Area and Los Angeles over time and features an interactive map of anti-displacement policy measures. Users can explore whether Bay Area cities have adopted a set of policies including just cause eviction, rent control, or foreclosure assistance.



Source: "Policy Tools," The Urban Displacement Project, <http://www.urbandisplacement.org/policy-tools-2>.

#5: Disaggregate Data

Understanding how conditions and opportunities vary for different groups, is critical to developing and advancing tailored equity solutions. Data should be disaggregated by race/ethnicity, gender, nativity, ancestry, income, sexual orientation, geography, and other relevant factors to the maximum extent possible. When disaggregation is not possible because of small sample sizes or other data collection issues, be clear about the limitations of the data and how aggregated data categories may hide disparities within that population.

Small sample sizes or data quality may limit the extent of disaggregation or the power of statements made about different communities. Be transparent about these limitations and the tendency for this to render small populations invisible. The National Congress of American Indians Policy Research Center characterizes American Indian and Alaska Native people as the “Asterisk Nation” because many national health surveys and studies refuse to disclose data specific to American Indian and Alaska Native people, instead writing asterisks and explaining that the small size of the population prohibits reporting.⁶ This severely limits the ability of tribal nations and peoples to access critical information about their communities. Data quality is also a concern when a lot of data is missing, which may lead to flawed or impartial stories about communities. Acknowledge these uncertainties and caveats within the data so that users can interpret accordingly.

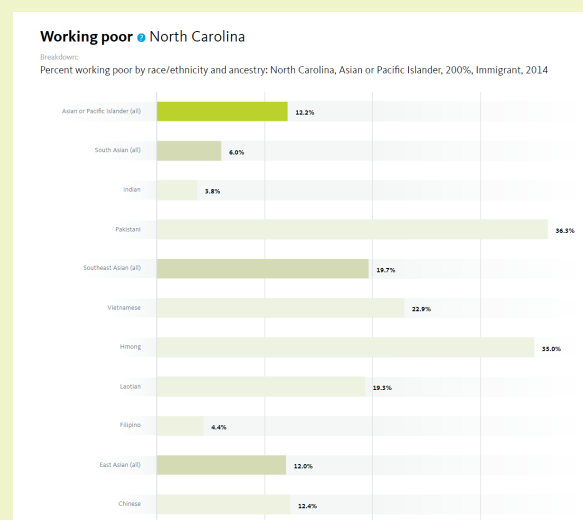
Make clear to users that just because disaggregation may not be possible, it does not mean that a given problem does not exist or that a given population is not impacted.

How to apply this principle:

- Disaggregate all data by race/ethnicity and allow users, where possible, to disaggregate below the major race/ethnic categories.
- Include data on American Indian and Alaska Native people to the extent possible and encourage advocacy when data is not reported.
- Include as many social dimensions of difference as possible for users to examine the data, including, but not limited to, gender, nativity, country of origin, language proficiency, ancestry, income, and sexual orientation.
- To underscore why place matters, include maps, when possible, that show which neighborhoods or areas are most impacted by a given indicator.
- Be intentional about the names of categories and vet language and displays with community members to ensure fidelity with how people self-identify.
- Advocate for more disaggregated data in public institutions, as advocates within the Asian or Pacific Islander community successfully did for state health and education data in California (AB 1726).

National Equity Atlas: Disaggregating Economic Indicators by Ancestry and Nativity

The [National Equity Atlas](#) currently disaggregates eight economic indicators by race/ethnicity, nativity, and ancestry to highlight inequities even within major race/ethnic groups like Asians or Pacific Islanders and Latinos. This allows for better targeting of resources across communities and counters the invisibility of smaller subgroups. While the 2014 working-poverty rate (the share of 25- to 64-year-olds who worked full-time but had a family income below 200 percent of the federal poverty level) for the overall Asian or Pacific Islander population in North Carolina was 11.9 percent, it was 12.2 percent among all Asian or Pacific Islander immigrants and this varied from 3.8 percent among Indian immigrants to 36.3 percent among Pakistani immigrants.



Source: “Working Poor,” National Equity Atlas, [http://nationalequityatlas.org/indicators/Working_poor/By_ancestry:40281/North_Carolina/false/Race-ethnicity:Asian_or_Pacific_Islander/Nativity:Immigrant/Poverty_Level:200/Year\(s\):2014/](http://nationalequityatlas.org/indicators/Working_poor/By_ancestry:40281/North_Carolina/false/Race-ethnicity:Asian_or_Pacific_Islander/Nativity:Immigrant/Poverty_Level:200/Year(s):2014/).

#6 Move Beyond Maps and Numbers

Maps and statistics are important staples of equity data tools, but different types of visualizations and qualitative data can help convey information that leads to community action. While maps can allow users to visualize differences by geography and why places matter in a powerful way, sometimes charts, graphs, or tables can more effectively show differences by race/ethnicity or other demographics.

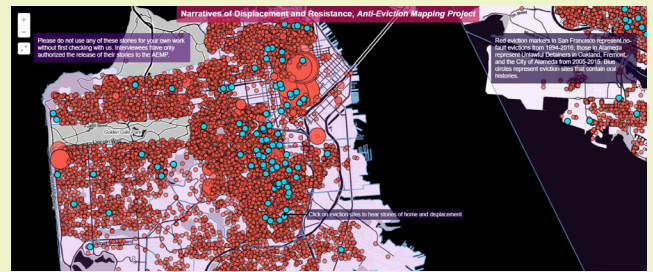
Integrating qualitative data as well as community perspectives and knowledge into data tools can also provide a more comprehensive view of an equity issue and its impact and meaning for people affected by it. A common assumption is that quantitative data holds more truth or objectivity than qualitative data. But data is subjective and informed by larger social and cultural assumptions. Often times, reporting quantitative data while attempting to remain neutral or impartial reinforces the status quo. Qualitative data, on the other hand, can be better equipped to capture the nuances of health equity issues, and community knowledge can help to connect those issues to root causes.

How to apply this principle:

- Supplement maps and charts with explanatory narratives and community member perspectives.
- Include indicators and displays based on qualitative data and community knowledge.
- Integrate arts into the tool by commissioning local artists to create data displays.

Anti-Eviction Mapping Project: Documenting the Stories of Tenants Facing Eviction

The [Narratives of Displacement and Resistance Oral History Project](#) by the Anti-Eviction Mapping Project maps nearly 40 stories from tenants who have faced eviction over the last decade in the San Francisco Bay Area, and from youth who are impacted by the displacement crisis. “By placing the stories on an online map, we aim to create a living archive, documenting deep and detailed neighborhood and personal histories.”⁷



Source: Homepage, Narratives of Displacement and Resistance Oral History Project, <http://www.anti-evictionmappingproject.net/narratives.html>.

#7 Emphasize Assets and Opportunities

Health equity strategies often begin with community assets and strengths that can be built upon to catalyze positive change. Data on inequities is important for understanding where to target resources, making the case for policy change, and tracking progress over time. But it is important to provide a balanced view of communities that reveals opportunities and resilience as well as challenges and needs (while avoiding the default to individual behavior as the cause of health disparities).

Focusing solely on disparities can unintentionally further what sociologist Maggie Walter calls the “deficit data/problematic people (DD/PP)” correlation.⁸ Because dominant narratives around racial disparities are informed by the values and racial hierarchies of settler states and slavery, this correlation posits that “the problematic people are the ones who, through their behavior and their choices, are ultimately responsible for their own inequality.”⁹

Equity data tools must move beyond this flawed and damaging conclusion by highlighting the systems and policies that cause racial health inequities. Situating data, especially cross-sectional data that does not capture change over time, within

the broader institutional context helps users to understand the role of public policy in establishing and perpetuating racial health inequities. Failing to provide this context can undermine community strengths and cohesiveness and perpetuate harmful stereotypes and the stigmatization of marginalized communities.

Relatedly, online equity data tools should strive to alleviate harm and safeguard against potential harm relating to privacy and confidentiality. This is especially true when it comes to collecting and publishing more sensitive information about individuals (e.g., immigration status, eviction history, etc.). Even if the tool development process is community-centered, the potential for harm is still present because it is hard to control how others might use the data.

How to apply this principle:

- Identify community assets and resources to highlight throughout the tool.
- Avoid publishing identifiable data.
- Anticipate how might others misuse or misrepresent data.
- Allow for community members to share their stories and experiences of their community.

Streetwyze: Visualizing Local Knowledge of Community Assets

[Streetwyze](#)'s mobile mapping platform allows community members to share local knowledge about how they are experiencing their neighborhoods and cities and turns them into actionable analytics. The power of the app is that it makes local knowledge accessible within and outside of government by allowing everyday people to share community assets and opportunities—creating two-way feedback loops and data visualizations between neighborhoods and cities so that they co-produce policies that help secure shared benefits. By integrating community-generated data with public datasets, cities and community leaders are empowered with forward-looking knowledge that can track equity indicators and social determinants of health in real time.



Source: Image courtesy of Streetwyze.

#8 Provide Clear Explanations

Minimize unnecessary work on the part of users by providing clear explanations and using accessible language. Make your tools as user-friendly as possible by stating and depicting what the data is showing, why it matters, and what users can do about it. While these descriptions may vary depending on the target audience, ensure that users without much data facility can interpret the main findings. Even if indicators are well-known, provide indicator definitions and the sources of the data.

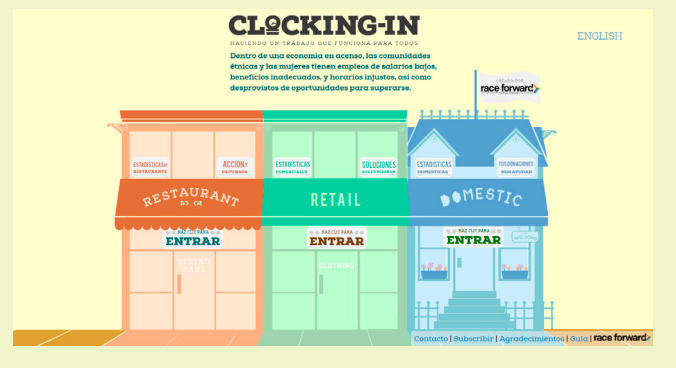
Accessibility might also mean offering the tool in multiple languages. This is especially true for data tools developed for non-English speaking communities. Though this may require significantly more resources than an English-only tool, depending on the stated equity outcome, it might not be negotiable. Develop visual elements like colors, video, and text in partnership with people with disabilities.

How to apply this principle:

- Supplement maps and charts with explanatory narrative.
- Use clear and concise language and infographics that are accessible to young people and those with a range of educational and cultural backgrounds.
- Offer the tool in languages other than English.
- Be sure that color-coded maps and charts are distinguishable to all users, including those with colorblindness.
- Anticipate user workflows (i.e., how people use data) and design tools accordingly. The likelihood of use increases if the tool does not have a huge learning curve.

Clocking-In: Building Worker Power Through a Fully Bilingual Scenario-Based Game

[Clocking-In](#) is fully bilingual and available in both English and Spanish. As Race Forward was developing the tool, their partners at the National Domestic Worker's Alliance expressed concern over a tool that was only in English, considering that many of their members speak only Spanish. In response, Race Forward secured additional funding to fully translate their tool into Spanish.



Source: "Homepage," Clocking-In, <https://clockingin.raceforward.org/domestic/clock-in>.

#9 Contribute to Data Democracy

Data sharing is crucial for advocates to access the data they need. One of the biggest challenges in health equity mapping is accessing health data at a scale that is meaningful for understanding the linkages between people and the systems they interact with as well as their environments. Open data and the increased sharing of data among government agencies and other university–community partnerships can facilitate the blending of such datasets. Ensuring that this data and metadata are transparently available to impacted communities also ensures long-term accountability.

As the role of “big data” grows and data and information are increasingly monetized and valuable, data democracy is a central health equity issue. The ability of communities to own and organize information and influence traditional knowledge production processes hinges on these communities’ access to data. But without a pipeline to share power and prepare community members and leaders with the data skills necessary to be able to take advantage of open data, the equity impacts of these efforts will be limited. In contributing to open data, tool developers must also consider potential privacy and confidentiality concerns.

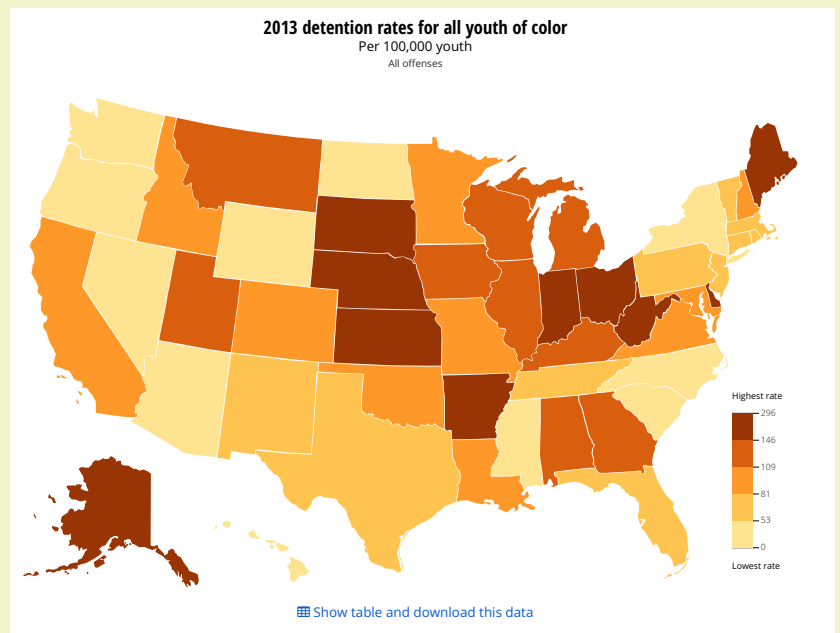
Data democracy should not override indigenous data sovereignty (see Principle #10). Diane Smith refers to open data from an indigenous peoples’ perspective as a double-edged sword: “On the one hand, open data could be used to inform development, allocate resources and set a future vision—and to influence wider public opinion and debates. On the other hand, opening up data may be accompanied by concern about protecting indigenous cultural information, rights and intellectual property.”¹⁰ This could be extended as a best practice for all historically excluded and vulnerable communities, and is a call to action.

How to apply this principle:

- Allow users to download underlying datasets.
- Provide a detailed methodology.
- Prepare community members to use data from the tool in their own advocacy and research.

The W. Haywood Burns Institute: Providing Downloadable Data on Juvenile Justice

The [W. Haywood Burns Institute for Juvenile Justice Fairness & Equity](#) publishes an interactive map on youth detention, focusing specifically on the impact of the juvenile justice system on youth of color. Users can view the map, a table of the data, or download the full dataset directly from the tool.



Source: “National Map,” The W. Haywood Burns Institute for Juvenile Justice Fairness & Equity, <http://data.burnsinstitute.org/#comparison=2&placement=1&rac=2,3,4,5,6&offenses=5,2,8,1,9,11,10&year=2013&view=map>.

#10 Honor Indigenous Data Sovereignty

Indigenous data sovereignty refers to the right of sovereign tribal nations to govern the collection, ownership, and application of their own data. It explains the process by which American Indian and Alaska Native tribes “regulate all aspects of tribal data, including access, collection, management, analysis and reporting.”¹¹ Data for equity means honoring indigenous data sovereignty, which is more than just a data practice—it is a legal concept. Indigenous data sovereignty is required by treaties the U.S. government signed with indigenous nations and it accords with international declarations to which the United States has become a signatory, including the United Nations Declaration on the Rights of Indigenous Peoples.¹²

The U.S. Indigenous Data Sovereignty Network (USIDSN), based out of the Native Nations Institute at the University of Arizona, helps ensure that data for and about indigenous nations and peoples in the United States is used to advance indigenous aspirations for collective and individual well-being. The USIDSN asserts that when data is collected from the people and communities of an indigenous nation, it comes under the control of that indigenous nation, even if it is collected by federal, state, or local governments. Desi Rodriguez-Lonebear, co-founder of the USIDSN, characterizes

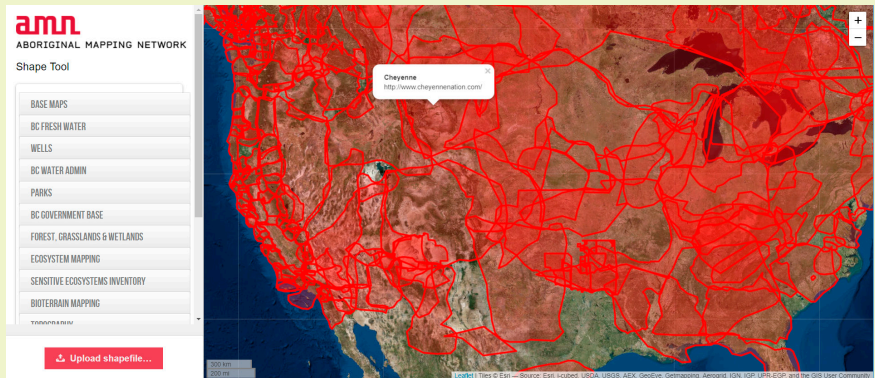
indigenous/tribal data sovereignty as two-pronged: “On the one side, it involves tribes exercising their sovereignty by developing tribal data sources; on the other, it involves improved collection of official statistics on tribal citizens and finding ways to make those statistics maximally useful to tribes.”¹³ Rodriguez-Lonebear explains that while data sovereignty is about tribal control over all data projects on or about tribal citizens or resources, this does not exclude the participation of partners and experts outside of Indian country.

How to apply this principle:

- C. Matthew Snip describes three features of decolonized indigenous data: (1) The power of indigenous people to determine who should be counted among them. (2) The data must reflect the interests, values, and priorities of tribal people and nations. (3) Tribal nations must have the power to determine who has access to this data.¹⁴
- When reporting data on or about American Indian or Alaska Native peoples, at a minimum, consult with the respective and/or local tribal leaders on the analysis and interpretation of the data.
- Advocate for meaningful partnership, not just consultation, between federal, state, and local agencies and American Indian tribes.

Aboriginal Mapping Network: Data to Support Indigenous Nation Building

The [Aboriginal Mapping Network](#) (AMN), a joint initiative of the Gitksan and Ahousaht First Nations and Ecotrust Canada, is a resource for practitioners of traditional knowledge mapping around the world. According to their website, the AMN has a mandate “to support aboriginal and indigenous peoples facing similar issues, such as land claims, treaty negotiations, and resource development, with common tools, such as traditional use studies, GIS mapping and other information systems.”¹⁵ The AMN Shape Tool, shown at right, allows users to upload a shapefile and visualize it alongside treaties, indigenous languages, and tribal lands.



Source: “The AMN Shape Tool,” Aboriginal Mapping Network, <http://v2.terratruth.info/map/VY8gymW8yZZQx-Q-mkdcwhAo8bH84XIIIFmftdA%3D%3D#000000000000000000000000100000002>.

Moving Forward: Overcoming Barriers and Leveraging Data Tools to Advance Health Equity

As data proliferates and local and national equity data efforts continue to grow, now is the time to address challenges, such as those described below, that prevent users from maximizing the potential of data tools to advance health equity.

- **Inadequate funding for community engagement.** For equity data tools to be owned and used by community-based groups, community engagement and vetting, also called “ground truthing,” is essential at every stage of the process, from inception to roll out to evolution. Effective community engagement requires significant resources, yet several tool developers we spoke with indicated a disconnect between this need and the interests of funders, expressing that community engagement is the most difficult element of tool development to get funded. They described a challenge in which larger, more resourced organizations are funded to create the tool, but the tool is ultimately underutilized because not enough funding is allocated to community capacity building and engagement.
- **Funding for community partners.** A related concern is the allocation of funds across partnering organizations and the value of different types of work. In many cases, particularly in the development of national tools, larger organizations often rely on smaller ones for information and community access. One best practice is for national organizations that are working on data projects to include sub-grants to local groups for locally based projects. Equity data tool developers should be mindful of the amount of resources (i.e., social and cultural capital, intellectual property, etc.) they are taking from communities to ensure that they are giving at least as much in return. Similarly, if tool developers and data analysts are getting paid to create knowledge, so should community members who are sharing their expertise for the benefit of the tool, including both young people and seniors.
- **Tension between the data needs of planners versus community advocates.** Government agencies and regional planning organizations are often key partners in local equity data efforts and they hold a lot of influence over the social determinants of health, but they may approach data from a more technocratic perspective and resist a comprehensive equity frame. For example, they may prefer to share data without providing the narrative, interpretation, and solutions that are central to making data tools actionable. Community-based organizations, on the other hand, may be committed to including community narratives and interpretation for less technical audiences through an explicit equity lens, but these groups may have less power and control over the tool development process. A resolution to such tensions can be negotiated, but it takes a willingness on both sides to listen, learn, and compromise.
- **The cost of developing equity data tools.** The sheer cost of these tools can be a barrier for community organizations interested in building them. While the price tag of tools varies considerably, most are very expensive to create. The cost to build the Metro Atlanta Equity Atlas, for example, was more than the entire operating budget of the Partnership for Southern Equity, the organization that developed it. Beyond the initial development, maintenance and sustainability require both updating data as it becomes available and ensuring the interface does not look too dated given the pace at which technology develops. Some projects rely on partnerships with public agencies that wield greater resources to support the sustainability and governance of equity data tools beyond their release. In at least two cases of regional equity atlases, regional planning organizations are the technical hosts of the tools. While there may be limitations to this approach, hosting these sites can be burdensome to community-based organizations already strapped for resources.

These challenges suggest several areas ripe for investment to create more effective tools to advance health equity.

- **Creating a network of equity data practitioners and community members.** While there are a growing number of online equity data tools and efforts at the local and national level, there are few venues for developers and community members to come together and share learnings. A network of equity data practitioners and impacted community members could expand on the principles stated in this report and address a major barrier to drawing comparisons across data tools: the lack of standardization. One of the first action items to tackle in this network could be developing a set of key indicators that should be collected in all local equity data efforts, with an eye toward the most effective policy levers.
- **Developing better methods for evaluating impact.** Many tool developers express difficulty in tracking how people used their tools and thus lack an understanding of the full impact the tools have on advancing health equity. Developing a way to track users while also preserving low barriers to tool access is a key tradeoff to measuring results. Creating fully public tools unfortunately also means forgoing a better understanding of who the users are. Better internal knowledge of how people are using the data will likely generate additional funding and resources for equity data tools.
- **Increasing community data capacity.** One way to prepare the next generation of equity data practitioners, further democratize data, and advance indigenous data sovereignty is to prepare and fund community members and leaders with the data facility necessary to be able to, as one July 2017 meeting participant described, “sit at the table, stay at the table, take charge of the table, or build a new table.” Without the technical skills necessary to manage, collect, code, analyze, and report data, Black, indigenous, and other people of color must rely on information provided by those outside of their communities to inform decision making. Training community members to be able to manage and use their own equity data tools is an important step toward community ownership.

- **Creating less expensive tools through non-traditional partnerships.** Some organizations, like Streetwyze, are reimaging bottom-up partnerships and community-generated data on top of existing tools. Strategies to leverage and mine data from social media can also be used. If privacy and confidentiality are ensured, these methods have the potential to generate previously unavailable knowledge about perceptions and potential for action. Reusing common platforms that are developed in open environments can greatly reduce the cost of tools without compromising quality or usability.

Conclusion

As the equity data field evolves, there is strong interest in developing more community-oriented data tools that support action and build community power. We hope that these principles provide inspiration and ideas, leading to stronger, more impactful equity data tools, and ultimately greater progress toward health equity.

Notes

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