Democratizing Native Hawaiian and Pacific Islander Data: Examining Community Accessibility of Data for Health and the Social Drivers of Health

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Making data accessible to communities is essential for developing community-driven solutions to address health inequities. In this analytic essay, we highlight the importance of democratizing data for Native Hawaiians and Pacific Islanders (NHPIs)—diverse populations that historically have had little access to their data—in the context of achieving equity in health and the social drivers of health.

We provide a framework for evaluating community accessibility of data, which includes concepts of data availability, salience, cost, and report back. We apply the framework to evaluate community accessibility of NHPI data from 29 federal data sources. In addition, we provide results from a survey of NHPI-serving community organizations in California conducted from December 2021 to February 2022 to assess community data needs.

Findings reveal federal gaps in data accessibility, as well as NHPI community organizational needs for increased data accessibility, data saliency, and technical capacity. Furthermore, organization leads expressed concerns about data privacy, security, and misuse. We provide recommendations for data custodians to improve accessibility of timely, accurate, and robust data to support NHPI communities. (*Am J Public Health.* 2024;114(S1):S103–S111. https://doi.org/10.2105/AJPH.2023.307503)

The accessibility of data for use by community members whom the data represent is of paramount importance for improving community health. This is especially true for minoritized groups that are often omitted from large data sets or historically lack data on health and the social drivers of health (SDOH) to demonstrate and address inequities.[1–3] In this article, we highlight the imperative of democratizing data to make data on health and SDOH accessible to Native Hawaiians and Pacific Islanders (NHPIs)—a diverse grouping of people representing many nationalities, languages, and cultures across Oceania. In doing so, we have several aims. The first is to provide a model for assessing whether needed data are accessible to minoritized communities. The second is to apply this model to empirically evaluate whether data are accessible to NHPI communities through a review of federal data sources and a survey of community-based organizations. Lastly, we present suggestions for data custodians—those who collect, analyze, and produce data products—to ensure data accessibility for minoritized communities.

In 1997, the Office of Management and Budget (OMB) revised Statistical Policy Directive Number 15 (OMB 15)[4] to include "Native Hawaiian or Other Pacific Islander" as 1 of 5 categories in the minimum set for data on race, alongside American Indian or Alaska Native, Asian, Black or African American, and White, with the ethnicity overlay of Latino/Hispanic identity. This new category was defined as "A person with

origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands."[5–7]

Despite the OMB mandate and the eventual increase in the availability of data that represent NHPI communities, there remains a lack of access to existing data among the communities that would benefit from it.[3,8] Data democratization—the process of making data accessible to a wide range of users, regardless of technical and statistical skill levels—is even more urgent during public health crises.[1,9,10] During the COVID-19 pandemic, NHPI communities were limited in their ability to adequately respond to the crisis in US states and localities that improperly aggregated NHPI case and death rates with Asians or "other" races (against the OMB-15 directive) or that hid NHPI data from public access.[5,10] In states that had available and accessible NHPI data, the data showed that NHPI populations were in most cases faring the worst during the pandemic.[2] The NHPI Data Policy Lab responded by providing timely access to COVID-19 data to communities by consolidating the available state-level statistics into a national NHPI COVID-19 Data Dashboard.[10] This allowed communities to respond and advocate for resources and programs to support NHPI communities. However, when data are inaccessible to the communities that they represent, community members are deprived of their ability to exhibit their strengths and needs and to use data for their benefit.[2,6]

The COVID-19 pandemic highlighted the need for data custodians to make data on NHPIs and other minoritized groups more accessible to mitigate inequities.[11] At the same time, increasing data access must be done ethically so that data are not used to continue historical harms such as proliferating stereotypes, discrimination, abuse, and disinvestment.[12,13] These harms can be mitigated by providing minoritized communities with agency over how their data are used.[12]

We frame the issue of data accessibility for NHPI populations within broader discussions about Indigenous Peoples' rights to control and access data.[14] The Research Data Alliance developed the principles of FAIR and CARE to guide Indigenous governance of scientific data.[15] Data on Indigenous peoples should follow FAIR—findable, accessible, interoperable, and reusable—as well as CARE principles—collective benefit, authority to control, responsibility to engage respectfully with communities, and ethical standards to minimize harm and promote justice.[16] In this essay, we apply these Indigenous data principles to evaluate whether data are accessible for NHPI communities. Although our application is to NHPI communities in the US context, this model may be applicable to other minoritized communities that lack access to data. Increasing minoritized community access to data helps to promote social justice and health equity by facilitating culturally appropriate use and application of data for community benefit.[12,15]

In this essay, we propose four aspects of community accessibility of data that can be measured based on CARE and FAIR principles and our experience with accessing NHPI data: availability, salience, cost, and report back. Then, we apply this model to empirically evaluate the accessibility of NHPI data on health and SDOH in federal data sets based on these four components. Next, we describe a survey of community-based organization leaders serving NHPI communities in California about their access to data on health and SDOH to further inform needs for data accessibility and potential drawbacks of widely accessible data. Last, we provide suggestions for ethically making data more accessible for NHPI and other minoritized communities.

COMMUNITY ACCESSIBILITY OF DATA

The first component of data accessibility that we describe is whether data are readily available to community members. This component especially aligns with FAIR principles of findability and accessibility.[15] Data custodians, such as researchers or government entities, may collect data on NHPI communities, but data sets must be publicly available to the community for the data to be accessible. The most available data are likely on public-facing Web sites that community members can visit.[10] These websites may visualize the data or make data available for download.[11,17,18] For data that are less readily available, the community members may make a request to the lead researchers or government administrators to obtain the raw or formatted data. Other collected data on NHPIs may not be made available to the public in any way, rendering the data completely inaccessible.

Data Salience

The second component of data accessibility is whether data are presented in a way that is salient (i.e., relevant, meaningful, understandable, useful) to members of a community. This component is necessary to uphold CARE principles.[15] Salience captures whether the data reflect the community desires and needs for data to be used to represent the community accurately for priority setting and public health planning.[19,20] What matters in terms of data saliency depends on the community being represented, necessitating input from

community members in terms of which data and how data are presented.[15] Ideally, this includes having data visualizations reflect issues that are important to the community, highlighting what is important so that it is visually compelling, using plain language that is easily understandable, and telling a story using interpretable quantitative or qualitative data.[19]

Data visualizers have provided tips for making data most salient to communities, including recognizing the audience needs, using language with racial equity in mind, involving communities in contextualizing data, and being thoughtful with colors and labels.[21] When data are represented in clear and meaningful ways with community usage and equity in mind, then data are salient.[22] However if data are not readily interpretable, difficult to navigate, irrelevant to communities, or require specialized skills or specific costly software (e.g., Tableau, SAS, R, Stata) to make the information relevant, then data are not readily accessible to the community.

Data Costs

Third, there are costs that may limit community data accessibility. Costs incurred may involve time, travel, or monetary expenditures to access data. If costs are too high, then this renders data inaccessible to communities, contrary to both FAIR and CARE principles.[15] Often, costs are proportionately higher for smaller, minoritized groups such as NHPI communities that have fewer resources to access their data.[12] An example is the cost associated with accessing restricted Census microdata. Census microdata provide more detailed data for smaller geographic areas and for smaller populations. Currently, the https://data.census.gov Web site

will generate publicly available population counts for "Native Hawaiian and Other Pacific Islanders" in aggregate in the entire United States and for most states and counties. It will also provide population estimates for specific NHPI subpopulations (e.g., Native Hawaiian, Chamorro, Fijian, Marshallese, Samoan, Tongan) in the entire nation and only in certain states. Restricted Census microdata are needed to find more specific demographic data on NHPI subpopulations nationally and in many states, as well as at the county or smaller geographic level. These data are useful for highlighting inequities and informing targeted programs and policies.[10,19]

The costs of accessing Census microdata are high. Census microdata can only be accessed at 1 of 33 select Research Data Centers (RDCs), most of them at research institutions in major US cities.[23] The process of gaining access to an RDC takes time and effort; the approval process takes several months.[24] In addition, financial costs for accessing data at an RDC are substantial—in the thousands of dollars.[24] Researchers affiliated with universities or other research institutions can often use grant funding to cover these costs. However, the high costs make Census microdata inaccessible to community members not affiliated with these institutions.

Because of the smaller size of NHPI subpopulations and other minoritized communities, their data are more likely to fall below data suppression thresholds and be considered "restricted."[12] While these thresholds are put into place to protect respondents' confidentiality and to produce reliable estimates, they also serve to hide data that could be useful for smaller groups.[2] Compared with larger communities, smaller communities have a greater need to

access restricted data to gather useful information.[12] This means that groups interested in NHPI issues face a higher transaction cost to access even basic data that can be used to describe NHPI and other relatively small communities.[20] When costs are too high, the data are inaccessible to communities. For data to be more accessible, efforts can be made to thoughtfully reduce the transaction costs for smaller communities that rely on the collected data for addressing inequities.

Data Report Back

Community report back of data findings that are relevant to communities is vital for data accessibility and fidelity to CARE principles of respectfully and ethically engaging communities in use of data for their benefit.[15] If data exist, but community members are unaware of the data or how to access them, then data are underutilized and not valuable for advancing community health. Furthermore, community members may perceive that very little is accomplished or changed as a result of data collection efforts or, at worst, that the data have been used to discriminate against or harm NHPI communities.[2,12] These sentiments reflect gaps in data custodians' engagement with communities.[22,25]

Effective engagement allows communities to exert control over how their data are used, see their data being put to use, or mobilize the data for action that will improve community health.[25] Data may be presented in a community venue for accurate report back.[10] Ideally, reported data should be approved and interpreted by trusted community sources to ensure that data reflect community desires for use and to prevent misuse.[14] Community report back may at times involve some training on how to

best access and interpret the data so that the public understands the appropriate uses and limitations of the data.[22] Community engagement through report back creates space for data to be accessible for advancing community health and addressing historical inequities.[11]

To evaluate the accessibility of data on health and SDOH for NHPI communities in the United States, we assessed selected federal data sources based on availability, salience, cost, and report back. We selected 29 total federal data sources that collect information relevant to health or the SDOH (e.g., income, education, housing, incarceration) for NHPI populations. Data sources were housed in 1 of 6 federal agencies: Department of Commerce, Department of Health and Human Services, Department of Education, Department of Agriculture, Department of Housing and Urban Development, and Department of Justice. Based on a previous review of national data sources,[7] we only included the 26 sources that at minimum collect race data for NHPIs separately from other race categories and release at least some data publicly. We included three additional data sets that were not included in the previous review: American Community Survey Public Use Microdata, Restricted-Use Census Bureau Microdata, and NHPI National Health Interview Survey. We included these because they are data sets known to have data that may be relevant to the work of people trying to assess the health or SDOH for NHPI communities.

We evaluated each data source for whether it met the four criteria of community accessibility. We determined availability by visiting the data source's public-facing Web site to see whether disaggregated data on NHPI populations were available to the public via download or request. We rated salience on a three-point scale of A, B, or C. An "A" rating indicated that data for NHPIs are salient (i.e., readily useable) for someone serving the NHPI community. A "B" rating indicated that some training or self-learning would be needed to make NHPI data salient. A "C" rating indicated the most difficult to make salient—someone accessing NHPI data would likely need formal data visualization training or specialized software. We evaluated 2 aspects of cost: time (if one must apply to access the data and wait for approval) and monetary (if any financial payment is required to access the data). We assessed community report back by skimming data source Web sites to determine if there was any evidence of NHPI data being reported directly back to the community (e.g., a news release or report of an event in which data on NHPIs were being reported in a community setting).

Data Review Results

Table A (available as a supplement to the online version of this article at https://ajph.org) shows the results. Of the 29 federal data sources reviewed, 22 (76%) made NHPI data available to the public. In all but 3 of these cases, NHPI data were available in aggregate, but not for specific NHPI subgroups. For the other 7 (24%) data sets in which NHPI data were unavailable, NHPI data were not publicly available in any way, even if the data set had some publicly available data for other race and ethnicity groups. This was attributable to either omission or suppression of NHPI data or aggregation of NHPI data with "Asian" or "other race" categories, or it was unclear why NHPI data were unavailable.

Only 3 of 29 federal data sets (10%) received an "A" rating for salience, with data being visualized in a way that was relevant to NHPI communities. In these cases, NHPI data were already analyzed and presented in a PDF format, or NHPI statistics could easily be generated through a user-friendly online interface. The remaining 31% received a "B" rating for being less salient because of users having to navigate deeply into the Web site to find or generate the desired NHPI statistics, while the majority of data sets (59%) received a "C" rating for needing data visualization training or specialized software to generate salient statistics for NHPIs.

Regarding cost, 21% of data sets required time and effort to access NHPI data through an application process, and 14% of data sets had monetary costs associated with accessing NHPI data. Some data sets had their own centralized process for applying to access the restricted NHPI data, but in other cases the national data sets were only accessible through a federal RDC. In 1 case, the NHPI National Health Interview Survey had free data for NHPIs in aggregate available, but substantial time and monetary costs were associated with accessing the detailed NHPI subgroup data.

None of the Web sites for the federal data sets had indications of data being reported back directly to NHPI communities.

Community Organization Survey Methods

Next, we evaluated community accessibility to data on health and SDOH by conducting a survey of NHPI community organizations in California—the state with the second-largest NHPI population in the United States.[26] The Addressing Health Equity and Data (AHEAD)

SDOH Needs Assessment Survey was developed and implemented by the NHPI Data Policy Lab. The purpose of the survey was to assess organizational capacity, access, interest, and currently used sources of data on the SDOH for NHPI populations. Known NHPI-serving and NHPI-led community organizations across California were contacted via e-mail based on a list generated by established NHPI community leaders. A total of 36 NHPI-serving organizations responded to the online survey between December 2021 and February 2022, with 1 representative or leader responding on behalf of the organization.

We defined SDOH for participants as the "conditions in the places where people live, learn, work, play, worship, and age that affect a wide range of health and quality-of-life risks and outcomes: health care access and quality, education access and quality, social and community context, economic stability, and neighborhood and built environment." The survey included 15 questions on topics such as general organization characteristics, barriers to accessing NHPI data, organizations' needs for health data, technical skills that would be most useful to organizations, community concerns about NHPI data availability, and how organizations access SDOH data. We provide the AHEAD SDOH Needs Assessment Survey questionnaire in Appendix A (available as a supplement to the online version of this article at https://ajph.org). We summarized some of the survey findings by calculating the frequencies and percentages. Full results are available upon request.

Community Organization Survey Results

Table 1 shows organization characteristics. The number of staff members for

TABLE 1— Characteristics of Native Hawaiian and Pacific Islander (NHPI)–Serving Organizations in California: December 2021–February 2022

Characteristic	Mean ± SD (Range) or No. (%)
Mean no. of staff members	17.3 ± 50.5 (0–300)
Mean no. of staff members, excluding 2 largest organizations	7.0 ± 6.1 (0–28)
Organization includes	
Policy staff	7 (19)
Researchers	7 (19)
Data analysts	6 (17)
Communications staff	21 (58)
Community outreach/engagement staff	35 (97)
Organization uses data on SDOH	
No	5 (14)
Yes	31 (86)

Note. SDOH = social drivers of health. The sample size was n = 36.

the 36 NHPI-serving community organizations surveyed ranged from 0 to 300. Excluding the 2 largest organizations of 84 and 300 staff members, the average number of staff members was 6.97 (range = 0–28). Staff members were both paid and volunteer, with some organizations being run completely by volunteer staff or having no full-time paid staff members (which is why some respondents answered 0 for number of staff).

Of the 36 organizations surveyed, 28 responded to questions regarding their use of SD0H data. Table 2 summarizes their responses. Starting with barriers, all 28 community organizations reported not knowing what relevant data sources for NHPIs were available. An additional barrier includes not having the capacity to analyze data, reported by 79% of respondents. Community organizations reported many needs for disaggregated NHPI health data. The most common needs included community education, programs, services, funding applications, and communication campaigns. When community organization leaders

were asked about the technical skills needed, they reported needing to know how and where to find data as well as training or skills in using data in program planning, resource allocation, grant writing, and policy development. In addition, community organizations would like more capacity to understand and interpret data, which included learning about methodology, analytic tools, data and visualizations; analyzing raw data; using data query systems; and interpreting scientific articles.

Community leaders have concerns about detailed NHPI population data being made more available, including concerns about privacy, confidentiality, and security. Notably, 86% of participants were concerned that the data would be used against NHPI communities by enabling discriminatory treatment or targeting Pacific Islander immigrants. Some of the participants' concerns expressed fears of data availability making their communities more vulnerable to abuse, discrimination, scams, or neglect.

When asked how organizations access SDOH most often, 61% reported

TABLE 2— Results From Native Hawaiian and Pacific Islander (NHPI) Population Social Drivers of Health (SDOH) Data Needs Assessment Survey: December 2021–February 2022

Result	No. (%)
Reported barriers to accessing NHPI data	
NHPI data not collected	19 (68)
NHPI data collected and aggregated with others	24 (86)
NHPI data disaggregated, but not reported	19 (68)
Don't know relevant data sources available	28 (100)
Don't have capacity to analyze data	22 (79)
Needs for health data	
Apply for funding	24 (86)
Allocated resources or funding	22 (79)
Analyze or develop policy	19 (68)
Policy or program advocacy	20 (71)
Plan, implement, or evaluate programs or services	25 (89)
Research	20 (71)
Teaching, training, or in-class assignments	17 (61)
Write stories for news or media	15 (54)
Community education	27 (96)
Develop messages for communication campaigns	23 (82)
Other[a]	3 (11)
Technical skills that would be most useful to organizations' work	
How and where to find data	26 (93)
Understanding data language and graphics	24 (86)
Interpreting and understanding data	23 (82)
Ability to use data in program planning, resource allocation, grant writing, and policy development	26 (93)
Analyzing raw data files	20 (71)
Using data query systems	19 (68)
Data visualization	22 (79)
Reading and interpreting scientific articles	17 (61)
Useful data methodology and tools development	22 (79)
Qualitative analytic tools	22 (79)
Other[b]	2 (7)
Community concerns about more detailed NHPI population data being available	
Privacy, confidentiality, and security	25 (89)
Will be used against us or by wrong people	24 (86)
Harder to get people to be so specific when we are asking them to give the data	21 (75)
Makes our groups likely to be discriminated against	14 (50)
Fear for safety and targeting for scams	19 (68)
Other[c]	4 (14)
How do you access SDOH data most often?	
Collect our own data	17 (61)
Citation of published statistics	6 (21)

Continued

collecting their own data for NHPIs. Another fifth of organizations cited published statistics. Only 18% reported using an online query system. No organizations reported analyzing data files by using statistical software.

Summary of Evaluations of Community Data Accessibility

Overall, most federal data on NHPIs are not accessible to NHPI communities because of problems with availability, salience, and cost. There appears to be a considerable gap in federal data being reported back to NHPI communities, with no visible efforts being made in this regard. Although some NHPI data are accessible in aggregate, detailed NHPI subgroup data are nearly completely inaccessible from federal data custodians.

The AHEAD survey revealed further disconnects between data custodians and NHPI leaders who have high needs for data to address inequities and benefit communities.[2,5] Lack of community engagement in data collection and reporting processes by custodians likely contributes to gaps in community knowledge about where to find NHPI data that could be useful.[22] Community leaders are asking for more technical capacity to help make NHPI data meaningful to their communities. NHPI-serving organizations are collecting their own data when existing data are inaccessible or to demonstrate local needs, so additional skills training will build upon existing capacity. In addition, NHPI leaders fear that more accessible data will raise confidentiality issues and can be used to harm communities, reflecting past experiences of exploitation and

TABLE 2— Continued

Result	No. (%)
Online query system	5 (18)
Data file analysis with statistical software	0 (0)

Note. The sample size was n = 28. Item instructions were to "check all that apply," with the exception of the question "How do you access SDOH data most often," for which respondents could only select 1 option.

[a]Other needs for health data included "program development," "art exhibits," and "identify gaps and/or differences in coverage, service, need, and health assets."
[b]Other technical skills that would be most useful included "expand our NHPI Data Policy Lab/ Regional teams" and "having reoccurring NHPI data set as a reference that could be used year after year for longitudinal studies."
[c]Other community concerns about more detailed NHPI population data included "others not from the NHPI community making inaccurate assumptions," "difficulty understanding data and survey process," "fear of opening up and being left behind after the data is collected," and "potential confusion as people try to compare/combine different reports such that apples are being compared to oranges."

discrimination.[2,14] These findings demonstrate that there is much to be done to work alongside communities to increase data accessibility while keeping community values and ethics in mind.

IMPROVING DATA ACCESSIBILITY

The following are our recommendations to data custodians for improving community data accessibility for health and SDOH. Although we created this set of recommendations based on our review of data accessibility for NHPI populations specifically, these recommendations may be applicable to other minoritized populations who face issues of data access.

1. Make data more readily and easily interpretable when data are available on smaller, minoritized populations through simple visualizations or reports on public-facing Web sites. These visualizations and reports should be released with transparency about how statistics are being collected and reported.[21,22] Some examples of federal data sets that can improve in this area include the Survey of Income and Program Participation, Behavioral Risk Factor Surveillance System, National Household Education Surveys, and National Crime Victimization Survey (see Table A).

2. Waive or lower fees and reduce time barriers associated with accessing data for smaller, minoritized populations for those who are trusted community leaders and allies who need the data to address inequities. This would reduce costs for those communities that rely on the data for advocacy and policymaking.[18] A working group with community representation can help determine when and how restricted data can be made available. Examples of data sources that can thoughtfully lower costs for minoritized communities include Census Microdata, National Health Interview Survey, and the Medical Expenditure Panel Survey.

3. Waive restricted access fees for research published on data for smaller, minoritized populations. This is especially true when the data are needed by community leaders to highlight and address inequities.[20]

4. Increase community outreach and report back of existing data and ensure community input at all stages of future data collection and reporting. For communities considered "need to try harder to reach" because they are smaller, more effort is required to collect the data in the first place.[12] When community input is gained from the beginning of a project, then data may be easier to collect.[20] Furthermore, with the amount of effort demanded from smaller, underresourced communities to provide data, it is essential for data custodians to create and implement plans for report back so that data can be useful to the communities that provide and rely on the data. Such a process may build community trust and limit data misuse.[15]

5. Offer skills-building training for community-serving organization leaders to learn where and how to access, analyze, interpret, and use data to address health inequities. Building capacity within communities to access data will ensure appropriate interpretation and wider dissemination of data.[22]

6. Increase federal funding for making data more accessible to community members. The Native Hawaiian Health Care Improvement Act states that the federal government has a responsibility to bring up Native Hawaiian standards of health to the highest possible level.[27] Providing federal funds to increase data accessibility to communities is a step in the right direction of achieving this goal for NHPI and other minoritized communities. Grants may be internal to the federal government's efforts or external grants to help data custodians work with communities to identify and effectively use data.

CONCLUSIONS

Applying principles of democratization of data,[15,18] we highlighted 4 components of data accessibility that can be measured: availability, salience, cost, and report back. Our review of federal NHPI data finds major weaknesses with community data accessibility, especially regarding salience and report back, that can be improved upon. Organization leaders serving NHPIs in California report needs for data access and technical skills to support their communities. These findings show that data custodians have the responsibility to ethically engage with minoritized communities throughout the data collection, analysis, and reporting phases to ensure that these communities have access to data that will advance health and social equity. AJPH

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to disclose.

HUMAN PARTICIPANT PROTECTION

Ethics approval was granted by the institutional review board of University of California Los Angeles. All study participants provided their informed consent.

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