

Data Disaggregation: Principles, Promising Practices, and Lessons Learned To Advance Health Equity



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Introduction

Disaggregated data refers to data that are broken down into smaller categories. Disaggregated data is crucial as it helps identify disparities in health care access and outcomes within marginalized communities. By understanding the unique challenges faced by different racial and ethnic subgroups, community health centers (CHCs) can tailor interventions and allocate resources more effectively to address health disparities.

Between 2023 and 2024, the Association of Asian Pacific Community Health Organizations (AAPCHO) conducted an environmental scan focused on understanding and improving the collection and utilization of disaggregated data for Asian American (AA) and Native Hawaiian/Pacific Islander (NH/PI) communities. CHCs play a critical role in advancing health equity, particularly for historically marginalized populations, through collection of disaggregated data. This report aims to summarize findings from the environmental scan to inform training resources to enhance data collection protocols for CHCs that serve AAs and NH/PIs.

This report includes a summary of the environmental scan and key strategies for disaggregated data collection and utilization. The findings will help CHCs improve targeted interventions and policies, supporting collaborative community engagement (i.e., patient-centered care, health education, outreach), and centering healthy equity-minded impact to continue to improve access and care for AA and NH/PI communities.

Conducting the Environmental Scan

The goal of the environmental scan was to gather evidence and insights on disaggregated data collection protocols from the past five years to the present. The scan included a literature review and a survey of current CHC data collection practices. The primary questions this environmental scan aimed to answer were:

- 1. How do AA and NH/PI-serving CHCs and other providers collect disaggregated data for ethnicity and language?**
 - a. What subcategories do they collect and what is the completion rate?
 - b. What disaggregated categories are used in the literature, and how are they effective in impacting patient lives?
- 2. What are the sociodemographic characteristics (e.g., ethnicity, language) of the patients at these CHCs?**
- 3. How do these CHCs use the data to impact patient lives?**
 - a. What are they doing for improving patient care, treatment, outcomes, effectiveness, and advocacy?
 - b. Are patients given services that would have not been received had data been aggregated?
- 4. What training resources would be most helpful for clinics and networks across the nation serving these populations?**

Literature Review

The environmental scan used a search strategy to identify inclusion criteria for the literature collected. Search methodology used search words that included “Asian Americans, Native Hawaiians, and Pacific Islanders.” Publications within the last five years were considered and more than 130 resources were analyzed for this literature review. AAPCHO used nationally recognized race and ethnicity categories with stakeholder insights to identify the distinct AA, NH, and PI subgroups. The purpose was to generate consensus-driven categories to submit to federal, state, and health organizations to improve standardization of disaggregated data collection for AA and NH/PI communities. Creating national standards for disaggregated data collection will improve patient care, effectiveness, and outcomes for smaller racial/ethnic subgroup populations.

Existing research shows that AA and NH/PIs include more than 50 detailed race groups, each with distinct linguistic, cultural, and historical differences. However, data aggregation often combines AAs and NH/PIs into a single category that creates and perpetuates a deceptive homogenous story about AA and NH/PI peoples’ needs and challenges in the United States.* Due to shared experiences of historical exclusion, systemic barriers, SDOHs, and varying cultural practices, communities from different racial and ethnic backgrounds do not experience health care in equal ways. Measuring health outcomes using aggregated data masks the experiences of individual communities and obscures unique challenges that impact specific populations.** This lack of data has negatively influenced health care access and interventions by overgeneralizing the health challenges faced by AA and NH/PI subgroups.

Disaggregated data is a pathway to advancing health equity. Disaggregated racial and ethnic categories are broken down into more specific subgroups to enhance the understanding of health disparities (e.g., Burmese, Chinese, Fijian, Filipino, Japanese, Korean, Lao, Samoan, Thai, etc). Disaggregated data for AA and NH/PI populations identifies factors for improving individualized interventions and culturally- and linguistically- responsive resources.

Racial discrimination, socioeconomic status, and mistrust in the health care system play significant roles in health disparities. For example, Pls' experience with COVID-19 highlights how systems issues like historical trauma, systemic exclusion, and racial discrimination can exacerbate health inequities. While the pandemic has had a notable impact on health care delivery and perceptions, COVID-19 restrictions also played a significant role in worsening existing barriers and mistrust in health care. Overall, the literature review presented a complex health landscape influenced by cultural backgrounds, language access, socioeconomic status, systemic issues, and broader historical contexts. The environmental scan supports person-centered, integrated, and culturally-responsive approaches to addressing health disparities in AA and NH/PI communities.

**Data Disaggregation Deconstructed: AANHPI Communities*, The Leadership Conference on Civil and Human Rights (2022).

***Disaggregation of Public Health Data by Race & Ethnicity: A Legal Handbook*, [The Network for Public Health Law](#) (2022).

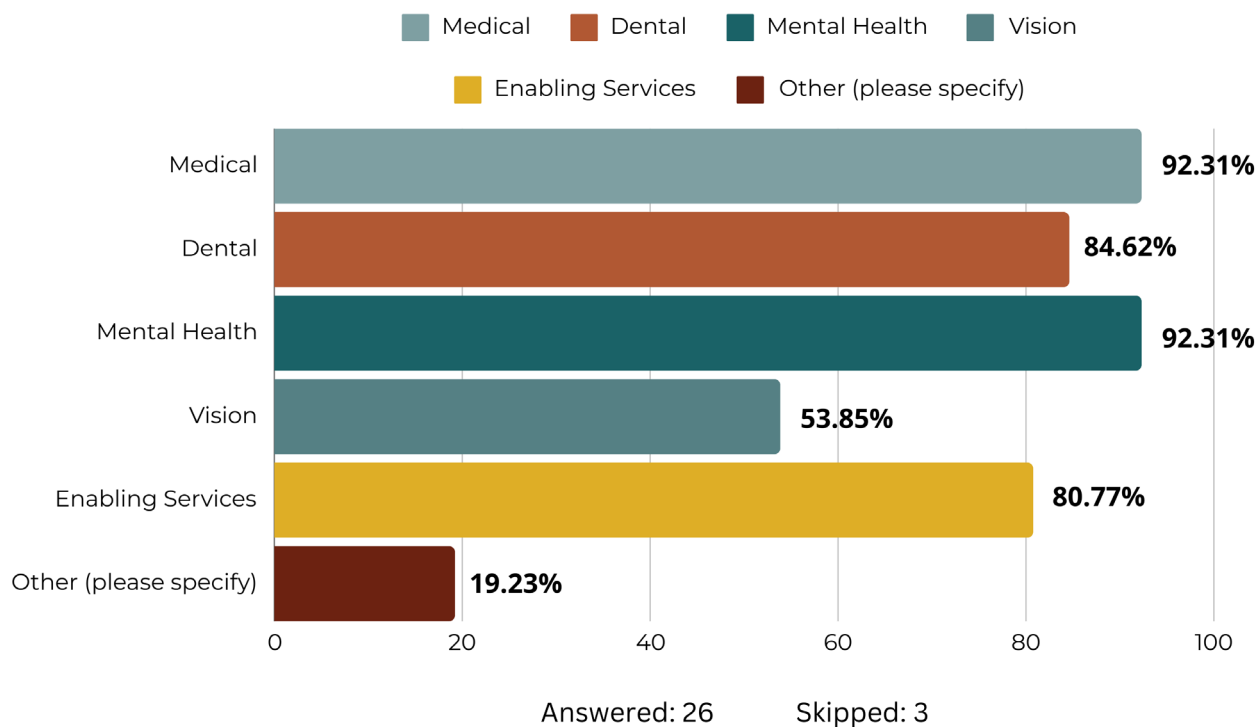
Survey of Data Disaggregation Practices at CHCs

Based on the goals of the environmental scan, AAPCHO developed the “Data Disaggregation Practices at Community Health Centers” survey. This survey aimed to understand and assess health centers’ current data disaggregation practices, particularly for AA and NH/PI populations, and their readiness to submit disaggregated data for the Health Resources and Services Administration’s (HRSA) Uniform Data Set (UDS) Modernization Initiative or UDS+. The UDS+ includes the collection of de-identified, patient-level data to better understand factors that influence care-seeking behavior, care received, and health outcomes. Information from this survey will inform resources, training, and technical assistance needs to support the collection of disaggregated data in the national UDS+ implementation.

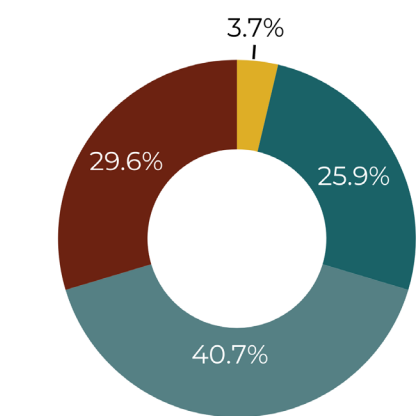
Between March and April 2024, AAPCHO surveyed CHCs across a broad geographic and demographic distribution. Given our interest in understanding which AA and NH/PI racial/ethnic and language categories CHCs collect data on, our targeted approach was to select a sample of CHCs that serve a large AA and NH/PI population. AAPCHO collected 29 responses, resulting in an 86% response rate. Most respondents identified themselves as federally-qualified health centers (FQHC).

Survey participants were recruited and sampled from health centers that directly collect patient data and submit to the HRSA Health Center Program UDS. To avoid multiple responses from the same organization, we asked that respondents assign one staff “champion” who could speak to the organization’s capacity and experience with disaggregated data collection. The survey included 24 questions, and respondents were able to complete the survey in 10-15 minutes.

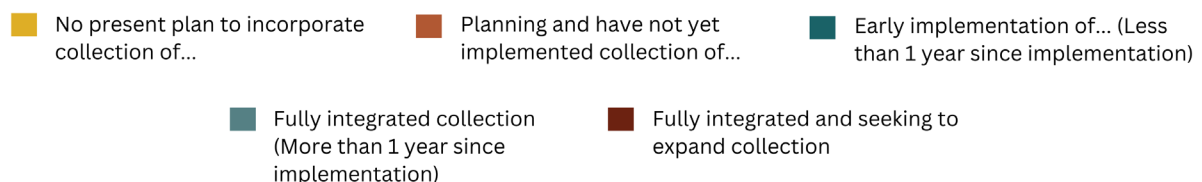
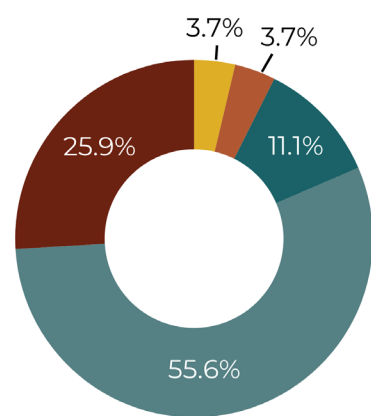
Percent of disaggregated racial/ethnic and/or language data collected by health centers for various services



Percent of organizations in various stages of collecting disaggregated racial/ethnic data (e.g. Vietnamese, Chuukese)



Percent of organizations in various stages of collecting patient primary language data



AA and NH/PI Categories Collected by Surveyed Organizations

- Afghan
- Asian Indian
- Bangladeshi
- Bhutanese
- Burmese
- Cambodian
- Chamorro / Chamoru
- Chinese
- Chuukese
- Fijian
- Filipino
- Guamanian
- Hmong
- Indonesian
- Iu Mien
- Japanese
- Ka'ren
- Kiribati
- Korean
- Kosraean
- Laotian
- Malaysian
- Marshallese
- Melanesian
- Micronesian
- Mon
- Mongolian
- Native Hawaiian
- Nepalese
- Pakistani
- Palauan / Belauan
- Pohnpeian
- Polynesian
- Rohingya
- Saipanese
- Samoan
- Sikh
- Tahitian
- Taiwanese
- Thai
- Tokelauan
- Tongan
- Vietnamese
- Yapese

AA and NH/PI Language Categories Collected by Surveyed Organizations

- American Sign Language
- Afghan
- Amharic
- Arabic
- Bengali
- Burmese
- Cantonese
- Chuukese
- English
- Farsi
- French
- German
- Hawaiian
- Hindi
- Hmong
- Ilocano
- Japanese
- Khmer
- Korean
- Kosraean
- Laotian
- Mandarin
- Marshallese
- Pohnpeian
- Portuguese
- Russian
- Somali
- Samoan
- Spanish
- Swahili
- Tagalog
- Tamil
- Thai
- Tibetan
- Tongan
- Urdu
- Vietnamese
- Visaya

In total, as many as 44 distinct AA and NH/PI racial and ethnic categories were collected among the sampled AA and NH/PI-serving CHCs. However, given the limited sample, it is likely that CHCs across the nation but especially CHCs who serve a predominantly AA and NH/PI population are collecting even more racial and ethnic categories than are listed above.

Respondents were asked to select the language categories collected at their organizations from a list of 35 of the most commonly spoken languages among AA and NH/PI populations. Respondents were also allowed to specify languages or dialects beyond this list. Among these other primary language categories, several respondents listed specific dialects of languages such as the Filipino dialects Ilocano and Visayan, and the Cantonese dialect Yue. A few respondents shared Chinese Sign Language, in addition to American Sign Language. Furthermore, respondents collected data on the primary language spoken by patients that are not spoken by the majority of the population in that country of origin. For example, while Hindi is the predominant language spoken in India and the most commonly spoken language among the population, respondents also listed languages such as Tamil, Bengali, or Urdu, which are not as widely spoken nationally but are significant within specific regions or communities.

Disaggregated racial/ethnic and language data is critical to understanding the specific needs within diverse communities. In follow up interviews, respondents discussed the changes made in their services and operations based on disaggregated racial/ethnic and language data. Using their CHC's data, some respondents shared that they intentionally hired providers who spoke specific languages based on identifying language needs shared by patients. Tracking demographic changes among CHC populations can identify emerging trends in social risk factors and migration.

Challenges/Limitations

AAPCHO's data collection, particularly the survey portion of the environmental scan, encountered the following challenges. Some CHCs were unable to identify "staff champions" to complete the survey for their organization. This resulted in delays while CHCs determined which staff should complete the survey. Initial outreach targeted CHCs that serve a high proportion of AA and NH/PI patients, which may have contributed to confusion among respondents about the survey and its purpose.

After the two-week initial collection period for the survey, many respondents began the survey but did not complete it. Many CHCs and their staff are experiencing survey fatigue. Survey fatigue occurs when respondents are tired, disengaged, or overwhelmed by the process of completing surveys. This can be a result of a single, complicated survey or can occur after being asked to complete numerous surveys over time. This may have affected data collection and response rates. To motivate and support participants, AAPCHO staff scheduled time with each CHC to conduct a walkthrough of the questionnaire and engage respondents in dialogue with interviewers. This offered a more engaged alternative to respondents completing the survey independently.



Opportunities and Next Steps

Continue Data Collection

The initial group of survey respondents was selected using purposive sampling. This group consisted of AA and NH/PI- and NH/PI-serving organizations, including CHCs and community based organizations. In later phases, there is an opportunity to expand data collection to health centers beyond AA and NH/PI- and NH/PI serving health centers. Conducting more surveys will provide further insight into the data disaggregation practices and race, ethnicity, and language (REL) categories at CHCs that do not serve as large a proportion of AA and NH/PI populations. This will still expand knowledge of the AA and NH/PI categories CHCs are using for their REL data collection. Including a broader range of CHCs in the survey will ensure that the experiences and needs of AAs and NH/PIs served by these CHCs are not overlooked.

Conduct Short Semi-Structured Interviews

Walking through the questionnaire with respondents proved to be an effective way of ensuring completion. Respondents often talked through their answers aloud, which provided further detail and context than was asked in the questionnaire. For example, respondents were asked about the stage of their CHCs' initiatives to collect disaggregated REL data. When presented with multiple choice answers, some respondents commented on what their goals were regarding their data disaggregation practices and then selected one of the multiple choice responses. Therefore, while unintended, walking through the questionnaire resembled a semi-structured interview. The questionnaire asked if respondents were interested in being contacted for follow-up interviews. Since the survey walkthrough yielded useful commentary and discussion, it is likely that short structured interviews may also result in further insight on data disaggregation.

Key Takeaways and Conclusion

Nationally Standardized Categories

Data disaggregation practices at CHCs are crucial for informing the development of national, standardized REL categories. When asked what additional information or resources are needed to implement or more effectively use disaggregated data, a national standardized data collection model that is appropriate for our populations was the top answer (48%) among respondents. National, standardized REL categories are important for ensuring consistency and accuracy in data collection, analysis, and health policymaking. They can support equitable resource allocation and targeted interventions for AA and NH/PI subgroups that are often overlooked. By understanding how CHCs currently collect and categorize data on patient demographics, policymakers and researchers can identify common practices, challenges, and areas for improvement in data disaggregation collection. This can in turn enable the refinement of national standards to ensure they are practical, feasible, and reflective of the diverse populations served by CHCs nationwide. This information can contribute to the development of more inclusive and culturally-affirming categories at CHCs that accurately capture the nuances of race, ethnicity, and language diversity.

Further Training and Resources on Disaggregation Data Collection

By enhancing CHCs' capacity to collect and analyze disaggregated data, they can ensure that healthcare services are equitable and responsive to the specific needs of all individuals, regardless of their demographic characteristics. From this survey, we learned that CHCs experience various challenges to collecting disaggregated data. Among survey respondents who are not collecting disaggregated racial/ethnic, or language data, the top reasons were that data collection takes too long, their organization has too many competing initiatives, and experience a lack of sufficient training and guidance to facilitate implementation of disaggregated data collection. Furthermore, it should be noted that some CHCs are in the early stages of adopting and integrating electronic health records (EHRs), which can present additional obstacles to the effective collection and analysis of disaggregated data. Despite these challenges, prioritizing culturally-responsive training and resources can significantly enhance CHCs' ability to collect and leverage disaggregated data to provide more equitable care.

CHCs are essential in promoting health equity by ensuring that high-quality, culturally-responsive, and comprehensive health care services are available to all. Their role in collecting and utilizing disaggregated data, engaging communities, and addressing SDOH makes them pivotal in the fight against health disparities and the promotion of equitable health outcomes for all populations.

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