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Resource Paper

Building a Community Health Center Data Warehouse to Promote Patient-Centered Research in the Asian American, Native Hawaiian, and Pacific Islanders Population

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Abstract

In 2010, the Health Resources and Services Administration (HRSA) established the Community Health Applied Research Network (CHARN) to build research infrastructure and capacity at community health centers (CHCs) and to promote comparative effectiveness research in these safety-net settings. A data warehouse with standardized data was created to capture, manage, and share patient-level data with all eighteen participating CHCs, including four CHCs primarily serving Asian American, Native Hawaiian, and Other Pacific Islanders (AANHOPi). AANHOPi patients face unique health risks, yet these large and diverse populations are historically understudied. The CHARN data warehouse provides important opportunities for understanding the health needs of this heterogeneous population.

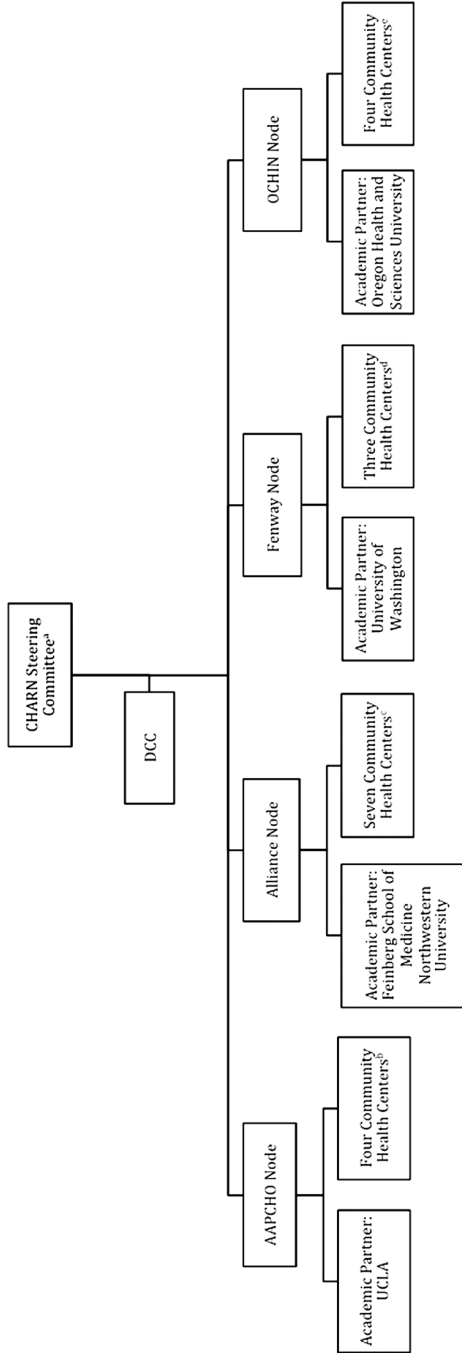
Introduction

The Health Resources and Services Administration (HRSA) established the Community Health Applied Research Network (CHARN) in 2010 in an effort to increase research capacity and promote comparative effectiveness research at community health

centers (CHCs). CHARN consists of four safety-net research nodes, each of which has affiliated CHCs and an academic/research partner. Each node includes three or more CHCs (eighteen in total). Participating CHCs are located in nine states across the country. The four nodes are the Alliance of Chicago Community Health Services (Alliance; Chicago, Illinois), Association of Asian Pacific Community Health Organizations (AAPCHO; Oakland, California), The Fenway Institute (Fenway; Boston, Massachusetts), and OCHIN (formerly the Oregon Community Health Information Network, but shortened to OCHIN when other states joined; Portland, Oregon). A data coordinating center (DCC) at the Kaiser Permanente Center for Health Research in Portland, Oregon, supports the network (see Diagram 1). CHARN's mission is to enhance research capacity at CHCs, to create the infrastructure for conducting research in the CHC setting, and to improve the ability of transmitting research results to safety-net treatment settings. This is the first time such a large and diverse group has come together to engage in research to improve health care for underserved groups.

Nationally, over 1,200 CHCs provide safety-net health care for more than 22 million patients in over 9,000 locations across America. They serve a crucial role in the health care system, delivering health services to many patients with limited access. Many CHC patients are members of racial and ethnic minorities (34% nonwhite and 34% Hispanic/Latino), homeless, unemployed, limited English proficient (22.9%) and/or have incomes under federal poverty level (72% at or below FPL, 93% below 200% FPL) (HRSA, 2013; NACHC, 2013). These patients face unique barriers and challenges accessing care. Studies on CHCs patients are limited due to their underrepresentation in large health system databases, which is attributed to their unemployment and/or lack of insurance (36% uninsured) (NACHC, 2013). A key goal in the establishment of CHARN was to rectify this paucity of data by creating an electronic database with information on CHC patients. A large electronic health records (EHR) database with an emphasis on safety-net populations provides a critical opportunity and strong foundation for patient-centered research on issues affecting them and supplies necessary data to help better understand their health care needs. For more information on EHR, see "Electronic Health Records Overview" by NIH National Center for Research Resources (2006).

Diagram 1. CHARN Relationship



^a Overall governance of the network is the responsibility of the CHARN Steering Committee (SC). The SC is responsible for approving final decisions, establishing subcommittees, affirming their charters and appointing subcommittee chairs.

^b Asian Health Services, CA, Charles B. Wang Community health Center, NY, Waianae Coast Comprehensive Health Center, HI, Waimanalo Health Center, HI.

^c Erie Family Health Center, IL, Glide Health Services, CA, Heartland Health Outreach, IL, Howard Brown Health Center, IL, Near North, IL, North Country Health Care, AZ, PCC Community Wellness Center, IL.

^d Beaufort Jasper Hampton Comprehensive Health Services (BJHCHS), SC, Chase Brexton Health Services, MD, Fenway Health, MA.

^e Multnomah County Health Department, OR, Richmond Clinic, OR, Open Door Community Health Center, CA, Virginia Garcia Memorial Health Center, OR.

As a key element of the CHARN project, the CHARN data warehouse was developed to be a comprehensive, routinely updated data resource, to carry out approved CHARN studies using secondary data, and to facilitate the design, implementation, and interpretation of CHARN observational and interventional studies. As such, a national central data warehouse was created to capture, manage, and share patient-level data with all participating CHCs and, ultimately, with other researchers with experience on issues affecting safety-net clinics. As the first crucial step, multi-level data use agreements (DUAs) between nodes and their participating member CHCs, and between the DCC and the nodes were developed and implemented. The project was reviewed and approved by the institutional review boards (IRBs) of all CHCs' and/or their research committees, as required by their organizations. While these agreements and approval processes were time-consuming, they provided protections for the CHCs' EHR data and ensured the CHCs' ownership of the data (Laws et al., 2014). Given that this is the first effort of its kind, it was necessary to establish the legal and regulatory framework that would assure participating CHCs that the data would be used in accordance with their mission of providing high quality care to medically underserved populations while maintaining confidentiality.

A team of health care providers, researchers, and programmers was created to collaborate on defining data elements needed in the CHARN data warehouse. A CHARN data subcommittee was created to oversee the development, implementation, maintenance, and documentation of the data warehouse. The committee was composed of representatives from all four nodes, the DCC, and some CHCs. The committee meets biweekly to discuss data requests, project developments, and updates. In the first funding cycle of CHARN (CHARN I, 2010–13), the data warehouse was designed to capture patient demographics, encounter (patient visit) data, diagnosis data, laboratory results, and medication data. Version 1 (V1) of the data warehouse included patients who had at least one primary care encounter in one of the participating CHCs between January 1, 2008, and December 31, 2010, comprising of a total of 586,808 unique patients across the CHARN network. Version 2 (V2) of the data warehouse, planned for completion in 2014, captures more data elements and includes a larger patient population (see Table 1).

Table 1. Areas CHARN^a Data Warehouse Captures

Area	Types of Data Included
Version 1	
Patient Demographics	Patient ID, birth and death dates, birth and current sex, transgender status, sexual orientation, ethnicity, primary language, interpretation services needs, CHC enrollment date, U.S. born or not, veteran status, migrant or seasonal worker
Encounter Data	Encounter ID, encounter start date and time, encounter end date and time, encounter duration, encounter type, department, location, provider, insurance for encounter, federal poverty level
Diagnosis Data	Patient ID, encounter ID, diagnosis code and coding system, date diagnosis was made, diagnosis descriptive name and where data was collected (patient reported, provider coded, billing data), diagnosis order (primary or secondary)
Laboratory Results	Patient ID, encounter ID, lab code and coding system, lab descriptive name, collection and results dates, lab result, reference units (including high and low values), interpretation
Medications Ordered	Patient ID, encounter ID, medication code and coding system, medication names (generic and brand names), form, total dose, units, route, frequency, refills, start and end dates, stop reason, diagnosis associated with medication, data source
Scheduled to Be Completed in Version 2^b	
Vital Signs	Patient ID, encounter ID, date vitals were taken, height, weight, BMI, temperature, pulse, respiration rate, systolic and diastolic blood pressure
Procedures	Patient ID, encounter ID, date procedure was done, procedure code and coding system, procedure name, diagnosis associated with procedure
Tobacco Use	Patient ID, encounter ID, date tobacco data was collected, tobacco status, tobacco type, years of use, smoking packs per day (only for cigarettes), if counseling was given, if ready to quit
Provider	Provider ID, specialty, job description
Problem List	Patient ID, encounter ID, problem code and coding system, problem name, problem start and end date, problem status
Referral	Patient ID, encounter ID, referral ID, date of referral, description of the referral, code for the specialty service referred to, status of referral
Referral Procedures	Patient ID, encounter ID, referral ID, procedure code and coding system for the referral, procedure name, node, CHC
Referral Diagnoses	Patient ID, encounter ID, referral ID, diagnosis code and coding system for the referral, diagnosis name
Enabling Service	Patient ID, encounter ID, sequence number for multiple services, service code, start date and time, end date and time, insurance, language, minutes, encounter type, appointment type, encounter scope (group or individual), provider ID

^a Community Health Applied Research Network.

^b CHARN Version 2 is planned for full completion in 2014.

A standardized data dictionary was created to define the CHC data for submission. A data submission process was also defined to instruct CHCs on compiling, querying, and transmitting the data. All levels (CHCs, nodes, the DCC) used Microsoft SQL Server for managing the data. Individual CHCs submitted de-identified patient data to their respective node level warehouse. Nodes validated the data before transmitting it to the DCC through a secure site. The DCC merged the data across nodes for future cross-network data queries, analyses, and reports (Laws et al., 2014). For more information, please visit the CHARN website (www.kpchr.org/CHARN).

The Importance of the Inclusion of Asian American, Native Hawaiian, and Other Pacific Islander Patients Data in Data Warehouses

Asian American, Native Hawaiian, and Other Pacific Islanders (AANHUPI) face unique health risks. For example, among the estimated 1.2 million people with chronic Hepatitis B living in the United States, over 50% are AANHUPI, while AANHUPI make up less than 6% of the total American population. This means approximately one in twelve AANHUPI are living with chronic Hepatitis B, but most are unaware of their diagnoses. The death rate from Hepatitis B among AANHUPI is seven times greater than the rate among whites (CDC, 2014). Given its lack of symptoms until late in its course, Hepatitis B diagnoses are often delayed. Moreover, AANHUPI face unique barriers for diagnosis and successful treatment of this disease, including limited English proficiency, cultural beliefs stigmatizing Hepatitis B, and lack of financial resources, all of which can lead to delayed care-seeking and treatment. A needs-assessment survey conducted in thirteen CHCs also identified insufficient financial and/or staffing resources for Hepatitis B services as the greatest barrier for provision of Hepatitis B-related care (Caballero et al., 2012).

Diabetes is another example. A 2007–9 national survey found that among people twenty years or older, the risk of diagnosed diabetes was eighteen percent higher in AANHUPI compared to non-Hispanic whites. Some AANHUPI are at particularly high risk for type 2 diabetes (the most common type among adults, CDC, 2011) and, therefore, its complications. Some social determinants of health (SDOH), including lack of access to healthy foods and easy availability of fast foods, contribute to the high rate of diabetes

among AANHOPi and negatively affect its management (Leonard, Nkenge, and Hayes, 2012).

Even though AANHOPi face unique health disparities and barriers, few large-scale quantitative studies have explored these populations and assessed their health care needs. From 1986 to 2000, only 0.2% of federal health-related grants involved AANHOPi (Ghosh, 2009). Though scholars and researchers have been making efforts to understand AANHOPi health, this population is still relatively understudied. Some reasons include lack of access to high quality data, inconsistent definitions used in data collection, lack of disaggregated data among ethnic subgroups, and the uneven national geographic distribution of the AANHOPi populations (Devers et al., 2013). AANHOPi populations are also often underrepresented in national EHR databases. For example, the database of the Department of Veterans Affairs includes over eight million enrollees. However, with its focus being veterans, in 2011 AANHOPi comprised only 1.3% of the total veteran population, compared to 5.8% of the total American population (NCVAS, 2013; OMH, 2014). The characteristics of the veteran population are also drastically different from that of the average AANHOPi population. Veterans are American citizens (citizenship is a requirement for military service, with some exceptions), predominantly men (approximately 93% in 2011; among the 7% women, 1.8% are AANHOPi), and significantly older (median age around 62, compared to 43 for nonveterans¹) (NCVAS, 2013).

Kaiser Permanente is the source of another large EHR database with over nine million enrollees. However, the database includes only those who have health plans or insurance through Kaiser Permanente. AANHOPi are more likely to be poor, undocumented, unemployed, and/or with limited English proficiency (Chang Weir et al., 2011) and are therefore less likely to have access to health plans or insurance, and thus less likely to be included in such insurance-based EHR databases. These more vulnerable AANHOPi are also those at higher risk of health problems.

Federal survey data provides another source for information on medically underserved or less-studied communities, but limitations exist for this source, as well. Often, there is inconsistent race/ethnicity categories used in data collection. Also, sample sizes calculated to collect information on the general population of Americans often lack the power to accurately test hypotheses regarding AANHOPi populations (and other small populations). This problem is

magnified in research aimed at studying specific health conditions within disaggregated AANHOPi racial/ethnic groups (Devers et al., 2013). A few surveys have relied on approaches designed to increase the representation of small populations, such as oversampling techniques or in-language administered questionnaires (e.g., in the California Health Interview Survey). However, these strategies are not typically used in national surveys (Devers et al., 2013).

AAPCHO is one of the four CHARN nodes and is a national association of thirty-four community health organizations, mostly federally qualified CHCs serving AANHOPi. Since its founding in 1987, AAPCHO has been dedicated to promoting advocacy, collaboration, and leadership that improve the health status and access of the medically underserved AANHOPi patient populations. To address the unique health risks that AANHOPi face and to support quality improvement and research on AANHOPi populations, an AAPCHO data warehouse was initiated prior to CHARN in 2007 through the Pacific Innovation Collaborative (PIC) project funded by HRSA, in which specific quality and performance metrics were identified by and collected from three CHCs in Hawaii (Waianae Coast Comprehensive Health Center [WCCHC], Waimanalo Health Center [WHC], Kalihi-Palama Health Center [KPHC]) and six CHCs in Washington (Community Health Centers of King County, Country Doctor Community Health Centers, International Community Health Services, Family Health Centers, Puget Sound Neighborhood Health Centers, and Yakima Neighborhood Health Services). The PIC project funding ended in 2011, but part of the AAPCHO data warehouse built through PIC became the CHARN AAPCHO node data warehouse under the CHARN project and increased the amount and types of data (AAPCHO, 2010b). The AAPCHO CHCs involved in building CHARN data warehouse were WCCHC, WHC, Asian Health Services (AHS), and Charles B. Wang Community Health Center in New York City. Currently, AAPCHO has eleven CHCs transmitting data to the AAPCHO data warehouse that houses data from 328,564 unique patients, accounting for 5,795,797 encounters between 2006 and 2012.

Patient Characteristics in the CHARN-AAPCHO Data Warehouse

The AAPCHO node contributes unique populations to the CHARN data warehouse by contributing 88.6% of CHARN data warehouse's AANHOPi patient data. In this section, we compare

patient characteristics between the AAPCHO node (four CHCs) and the other three nodes combined: Alliance (seven CHCs), Fenway (three CHCs), and OCHIN (four CHCs). All comparative statements in this section have undergone Chi Square tests and are significant at the 95% confidence level.

When compared to the total of the other three nodes, AAPCHO CHCs had significantly more female patients (59.4% vs. 53.7%), patients older than sixty-five (9.5% vs. 5.5%), more non-white patients (93.1% vs. 54.1%), more AANHOPi among non-white patients (96.6% vs. 80.8%), more patients with a primary language other than English (60.2% vs. 39.1%), and more uninsured patients (21.4% vs. 14.4%). CHARN CHCs in general serve a high volume of vulnerable populations, and AAPCHO CHCs serve primarily AANHOPis. The above characteristics are all well-known characteristics of vulnerability associated with access to care (see Table 2) (Shi and Stevens, 2005).

CHARN reports all diagnostic codes (ICD9 codes, see Table 3) related to one disease, so the data below is only an indication of a disease, not confirmation that a patient has the disease. Compared to the rest of CHARN, AAPCHO CHCs' patients had significantly more diabetes indication (6.1% vs. 4.3%), Hepatitis B indication (4.4% vs. 0.2%), hypertension indication (16.2% vs. 11.6%), and Dyslipidemia indication (15.6% vs. 7.0%). However, AAPCHO patients had less HIV indication (0.1% vs. 1.4%) and Hepatitis C indication (0.5% vs. 1.2%). These disease indication characteristics are similar to the findings of the Centers for Disease Control and Prevention (CDC) on AANHOPi (see Table 3) (CDC, 2013a; CDC 2013b).

These results demonstrate that AANHOPi patients differ uniquely from the rest of the CHARN patients on specific characteristics. AANHOPi accounts for 84.5% of AAPCHO CHCs' patients and only 3.4% of the other CHCs' patients. Recognizing the importance of and the need for further research among AANHOPis, the AAPCHO data warehouse provides AANHOPi disaggregated racial/ethnic and language data (see Table 4).

The Importance of Capturing Enabling Services in the CHARN Data Warehouse

The CHARN data warehouse is prepared to incorporate a unique AAPCHO innovation—coding for enabling services (ES). AAPCHO's original data warehouse includes ES (Chang Weir et

Table 2. Descriptions of Patient^a Characteristics of Community Health Centers at AAPCHO Compared to Other and All Community Health Centers within CHARN

	AAPCHO ^b	Alliance, Fenway and OCHIN ^c	CHARN Total ^d
Total Number of Patients	200,946 (100%)	652,937 (100%)	853,883 (100%)
Gender			
Male	81,640 (40.6%)	299,706 (45.9%)	381,346 (44.7%)
Female	119,295 (59.4%)	350,517 (53.7%)	469,812 (55.0%)
Age (2012)			
Less than 18	48,038 (23.9%)	146,363 (22.4%)	194,401 (22.8%)
18–25	31,937 (15.9%)	99,971 (15.3%)	131,908 (15.4%)
26–39	43,001 (21.4%)	177,248 (27.1%)	220,249 (25.8%)
40–64	58,890 (29.3%)	193,197 (29.6%)	252,087 (29.5%)
65 and older	19,077 (9.5%)	36,158 (5.5%)	55,235 (6.4%)
Race (Single)			
White	13,906 (6.9%)	285,964 (43.8%)	299,870 (35.1%)
Black	3,857 (1.9%)	160,534 (24.6%)	164,391 (19.3%)
American Indian	330 (0.2%)	18,122 (2.8%)	18,452 (2.2%)
Asian/Pacific Islander ^e	169,822 (84.5%)	21,938 (3.4%)	191,760 (22.5%)
Multiracial	1,774 (0.9%)	9,536 (1.5%)	11,310 (1.3%)
Other	11,257 (5.6%)	127,277 (19.5%)	138,534 (16.2%)
No Race Indicated	0 (0.0%)	29,566 (4.5%)	29,566 (3.5%)
Primary language			
English	78,639 (39.1%)	393,006 (60.2%)	471,645 (55.2%)
Spanish	1,047 (0.5%)	94,675 (14.5%)	95,722 (11.2%)
Cantonese	47,709 (23.7%)	50 (0.0%)	47,759 (5.6%)
Mandarin	41,147 (20.5%)	123 (0.0%)	41,270 (4.8%)
Russian	16 (0.0%)	2,346 (0.4%)	2,362 (0.3%)
Other	20,386 (10.1%)	10,946 (1.7%)	31,332 (3.7%)
Unknown	12,002 (6.0%)	151,791 (23.2%)	163,793 (19.2%)
Insurance (single)			
Uninsured/Self-pay only	43,058 (21.4%)	94,293 (14.4%)	137,351 (16.1%)
Medicaid only	62,140 (30.9%)	141,823 (21.7%)	203,963 (23.9%)
Medicare only	8,160 (4.1%)	20,063 (3.1%)	28,223 (3.3%)
Commercial only	14,444 (7.2%)	78,338 (12.0%)	92,782 (10.9%)
Other only	14,844 (7.4%)	55,924 (8.6%)	70,768 (8.3%)
Mixed	57,373 (28.6%)	91,661 (14.0%)	149,034 (17.5%)
Missing (left blank)	927 (0.5%)	169,450 (26.0%)	170,377 (20.0%)
No Encounter records	0 (0.0%)	1,385 (0.2%)	1,385 (0.2%)

^a Patients with at least one primary encounter between January 1, 2006, and December 31, 2012.

^b Percentages in parentheses are the row category of AAPCHO total.

^c Percentages in parentheses are the row category of the total of the other three CHARN nodes.

^d Percentages in parentheses are the row category of CHARN total (including AAPCHO node data).

^e CHARN-AAPCHO CHCs have the disaggregated data and plan to provide it for the CHARN data warehouse by ethnic groups once there are more CHCs to ensure confidentiality.

Table 3. Description of Patient^a Disease Indication for Community Health Centers at AAPCHO Compared to Other and All Community Health Centers within CHARN

	Diagnosis Code ^b	AAPCHO ^c	Alliance, Fenway and OCHIN ^d	CHARN Total ^e
Total		200,946 (100%)	652,937 (100%)	853,883 (100%)
Diabetes Indication ^f	'250.01', '250.03', '250.11', '250.13', '250.21', '250.23', '250.31', '250.33', '250.41', '250.43', '250.51', '250.53', '250.61', '250.63', '250.71', '250.73', '250.81', '250.83', '250.91', '250.93', '250.00', '250.02', '250.10', '250.12', '250.20', '250.20', '250.30', '250.32', '250.40', '250.42', '250.50', '250.52', '250.60', '250.62', '250.70', '250.72', '250.80', '250.82', '250.90', '250.92'	12,332 (6.1%)	27,949 (4.3%)	40,281 (4.7%)
HIV Indication	'042', '079.53', 'V08'	119 (0.1%)	9,066 (1.4%)	9,185 (1.1%)
Hepatitis B Indication	'070.2', '070.20', '070.21', '070.22', '070.23', '070.3', '070.30', '070.31', '070.32', '070.33', '070.42', '070.52', 'V02.61'	8,751 (4.4%)	1,264 (0.2%)	10,015 (1.2%)
Hepatitis C Indication	'070.41', '070.44', '070.5', '070.51', '070.52', '070.54', '070.59', '070.7', '070.70', '070.71', 'V02.62'	1,001 (0.5%)	7,642 (1.2%)	8,643 (1.0%)
Hypertension Indication	'401', '401.0', '401.1', '401.9', '402', '402.00', '402.01', '402.1', '402.10', '402.11', '402.9', '402.90', '402.91', '403.00', '403.01', '403.1', '403.10', '403.11', '403.9', '403.90', '403.91', '404', '404.00', '404.01', '404.02', '404.03', '404.1', '404.10', '404.11', '404.12', '404.13', '404.9', '404.90', '404.91', '404.92', '404.93', '405.11', '405.19', '405.91', '405.99', '796.2'	32,611 (16.2%)	75,648 (11.6%)	108,259 (12.7%)
Dyslipidemia Indication	'272.2', '272.1', '272.2', '272.3', '272.4', '272.7', '272.9'	31,354 (15.6%)	45,641 (7.0%)	76,995 (9.0%)

^a Patients with at least one primary encounter between January 1, 2006, and December 31, 2012.

^b The diagnosis codes are ICD9 code.

^c Percentages in parentheses are the row category of AAPCHO total.

^d Percentages in parentheses are the row category of the total of the other three CHARN nodes.

^e Percentages in parentheses are the row category of CHARN total (including AAPCHO data).

^f The diagnosis codes (ICD9 codes) listed are all the codes related to one disease, so the data is only "indication" of a disease—it is not confirmatory that a patient has the disease.

Table 4. Disaggregated Racial Data in AAPCHO Data Warehouse^a

	AAPCHO ^b		AAPCHO ^b
Total Number of Patients:		200,946 (100%)	
Chinese	102,734 (51.11%)	Mien	400 (0.20%)
Native Hawaiian	26,221 (13.05%)	Laotian	376 (0.19%)
Filipino	9,619 (4.79%)	Tongan	319 (0.16%)
Vietnamese	4,606 (2.29%)	Guamanian/Chamorro	116 (0.06%)
Samoan	4,319 (2.15%)	Thai	96 (0.05%)
Japanese	1,727 (0.86%)	Other Asian	8,541 (4.25%)
Korean	1,539 (0.77%)	Other Pacific Islander	1,407 (0.70%)
Cambodian/Khmer	1,308 (0.65%)	Mixed AANHUPI	1,077 (0.54%)
Micronesian	1,202 (0.60%)		

^a This disaggregated racial data is in the AAPCHO data warehouse. The CHCs plan to provide it for the CHARN data warehouse once there are more CHCs in CHARN to ensure confidentiality.

^b The data is of the four CHCs participating in the CHARN project. Some races are not shown because the number of people in those racial groups does not meet the population threshold of fifty people.

al., 2010), which are defined by the National Association of Community Health Centers (NACHC) as “non-clinical services that are specifically linked to a medical encounter or provision of medical services that aim to increase access to health care, and to improve health outcomes” (Chang Weir and Proser, 2010). AAPCHO’s nonclinical support services include 1) case management assessment, 2) case management treatment or planning, 3) referrals, 4) interpretation, 5) transportation, 6) eligibility assistance, 7) health education, 8) outreach, and other ES. ES ensures that underserved patients can access and utilize health care. AAPCHO also seeks to include additional SDOH data (e.g., education, homelessness) to the already existing data (e.g., race/ethnicity, poverty, language) to better understand their impact on receipt of appropriate ES.

ES are important to AANHUPI, especially to those with SDOH who are medically underserved and who face substantial financial, cultural, and linguistic barriers that keep them from obtaining appropriate care. Providing patients earlier and easier access to health care, in turn, prevents costly visits to the emergency room (ER). Studies have shown that among diabetic patients, ES users are more likely to have their HbA1c² levels under control than ES nonusers (CPCA, 2013; AAPCHO, 2011; Chang Weir, 2014). The same studies

also showed that ES users are more likely to have received all recommended vaccines by the age of two than ES nonusers. Still, little data is available for assessing the impact of ES on the improvement of care quality and health outcomes. Without data-based supportive evidence, the value of ES is overlooked and has not been reimbursed or adequately funded by payers. This is also the reason AAPCHO developed the ES data collection protocol and advocated for its collection in the CHARN data warehouse.

Discussion

Lessons Learned

1) Benefits of a Data Warehouse: In the development of our data warehouse, CHCs serving primarily AANHOPHI populations who had less experience with Electronic Medical Records (EMRs) were able to learn from other CHCs in CHARN. Because of the validation steps in transferring data from CHCs to nodes and then to the DCC, some unrecognized data issues at CHCs were brought up and in turn helped CHCs to better understand and validate their patient data. The node-level reports and analyses produced in the process also helped AAPCHO CHCs to compare and evaluate themselves to other CHCs that serve large AANHOPHI populations. Reports and analyses across CHARN CHCs helped AAPCHO CHCs to identify and better understand the unique AANHOPHI issues and patient care needs that are common to all safety-net patients.

2) Network Governance: Given the magnitude of the data warehouse undertaking and the inclusion of patients from CHCs around the nation, it was important to establish a strong governing structure. The process of IRB approvals and DUAs was necessary and important, for it provided protection for patient privacy as well as ownership and usage rules regarding CHC data. Constant communication was also found to be essential in gaining trust and assistance from participating CHCs. It also helped speed up data transfer processes.

3) Data Sharing Requirements: Through the experience of a few projects with the data warehouse, it became clear that a more explicit data sharing strategy was necessary. In January 2014, all member CHCs agreed to “unblinding” (sharing the linkage between CHARN CHC Identifications (IDs) and CHARN CHC names), as long as the unblinding remains at the DCC level, such

that the data will be de-identified when it is presented to the public. Unblinding allows the DCC to link the appropriate summary characteristics with corresponding providers and their CHCs for projects that need the DCC to produce such reports. We learned that building a data warehouse and refining its rules and regulations is a process, and the data sharing policies will have ongoing review and will likely continue to evolve.

4) Disaggregated Racial/Ethnic Data and ES: Through the experience of the AAPCHO data warehouse, we also learned the importance of and necessity to include disaggregated racial/ethnic and language data as well as ES data. ES data is planned for inclusion in the CHARN V2 data warehouse, and we hope it will help serve a large range of research needs.

The building of this centralized data warehouse with AANHOPHI populations has shown many benefits. The PIC ES funded by HRSA and the Pay-for-Performance (P4P) project funded by the Robert Wood Johnson Foundation both benefited from having such a data warehouse. For more information on these two projects, please see AAPCHO's fact sheets included in this article's reference list. The CHARN data warehouse supports large AANHOPHI sample sizes, informs research on less common or unique conditions, and provides a platform to share information and resources.

Limitations

1) Different EHR Systems: The CHARN data warehouse is built upon EHR data provided by CHCs. A limitation for using EHR data for research is the ability to extract it from the system. EHR data is not captured for the purpose of research. EHR holds the information, but it is not the place where the data can be cleaned, reformatted, and analyzed for research purposes (Devers, 2013). The CHARN central data warehouse serves the function of extracting, pooling, and linking the data in EHR for research; however because of different data recording methods used by CHCs, this has been a labor intensive and time-consuming process, and validation is still ongoing. For example, we were unable to make a comparison of the ER encounters between AAPCHO and the rest of CHARN because CHCs have different definitions for encounters, and some just pooled ER visits with outpatient visits thus lacking unique identifiers for ER encounters. Therefore, separate ER encounters are not available from all CHCs.

2) Funding: CHARN I was funded by HRSA from 2010–13, but CHARN II encountered an eight-month funding hiatus before receiving funds in April 2014. The essential functions of the warehouse, such as data queries and producing reports and analyses, were still in progress during the hiatus, but the efforts to extend the data warehouse were suspended. CHCs and nodes did not have the resources to provide more data without CHARN II funding. Funding is also an issue for more frequently refreshing data. The current protocol is annually refreshing, which is not sufficient for some research, and real-time quality improvement efforts require more recent data. However, refreshing data requires a significant amount of time and work from staff at all levels (nodes, CHCs, DCC), and without more resources, it is challenging to refresh data more frequently than annually.

3) Disaggregation and Patient Identification: While typically aggregated into one broad racial/ethnic category, the AANHOPi population is, in fact, highly heterogeneous. There is an ongoing need to disaggregate this population to unmask important differences and health disparities both within and between groups. However, since the efforts to establish this important data warehouse included eighteen CHCs in its first implementation phase, the four participating AAPCHO CHCs serving AANHOPi were concerned that disaggregated ethnic data would enable specific patient identification. For example, given the small number of Cambodian patients in the data warehouse, detailed ethnic information on this group could potentially identify which CHC the patient is from and even down to some of the geography and health characteristics. Thus, the CHCs provided detailed racial/ethnic data to AAPCHO, which then sent the data to the DCC in an aggregated level of AANHOPi. However, once there are more participating CHCs that serve AANHOPis in the data warehouse, there is an intentional plan to provide more detailed ethnic data for this population in order to advance the research agenda around disaggregated data.

Future Plans

As mentioned in previous sections, the V2 CHARN data warehouse captures additional content areas, including vital signs, procedures data, tobacco use, provider data, problem list, referral data, referral diagnoses, and ES data. V2 data was also extended to all patients with at least one primary encounter between January

1, 2006 and December 31, 2012. It is scheduled to be completed in 2014. AAPCHO is also committed to expanding its contribution with more member CHCs and new CHCs, and capturing more domains within the data warehouse with every funding mechanism (Cook et al., 2012). For example, Hepatitis B data is planned for addition to the warehouse through the Hepatitis B project funded by the National Institutes of Health (NIH). In addition, CBWCHC and AHS were not originally in AAPCHO's data warehouse but included as new sites under CHARN.

More sustainable approaches are currently being planned through CHARN II. AAPCHO has a board research advisory committee consisting of members who will develop data warehouse policies and protocols with objectives to expand the data warehouse with more content and to more members. In addition, AAPCHO is engaged in efforts with UCLA, AAPCHO's academic partner on the CHARN project, and its member CHCs to build a web-query tool, called "AskCHC," that will allow CHCs to query their achievements in reaching quality performance goals. The intention is not only to increase capacity to conduct research that focuses on underserved patients across disaggregated AANHOPIs, but also to identify disparities and similar patterns of health across CHCs nationally.

Consistent with the AAPCHO board of directors' strategic plan, AAPCHO will continue to build research capacity for its members through its data warehouse. AAPCHO's data warehouse initiative is unique, because AAPCHO is the only national organization advocating on behalf of medically underserved AANHOPIs and the CHCs that serve them. Since its inception in 1987, AAPCHO has been working in national multisite partnerships with community-governed members. AAPCHO's position places the organization and its members in a very distinctive and important role to find ways to successfully work together to reduce health disparities for AANHOPi populations with strategies that are data driven. As an ideal setting for research to generate new knowledge of their medically underserved populations, and to disseminate findings to other CHCs and health care providers, AAPCHO and its members have yet to take full advantage of the vast potential for advancing a community-based research agenda that would help enable us to complete our mission to promote advocacy, collaboration, and leadership that improve the health status and access of AANHOPIs across the nation. The data warehouse expan-

sion to additional members is a step in this direction, but funding mechanisms are sparse for AANHOPi research and data capacity building (Ghosh, 2009).

Together, AAPCHO members are at the forefront of providing community-responsive, culturally and linguistically appropriate primary health care services. AAPCHO's member CHCs serve over 450,000 patients, annually, and provide comprehensive primary medical care as well as community outreach, patient education, and interpreter services to AANHOPis in more than fifteen languages (AAPCHO, 2010a). AAPCHO CHCs are governed by majority community stakeholders and thus play a critical role in articulating the health concerns of grassroots communities.

Conclusion

The CHARN data warehouse with AANHOPi data serves as an important foundation to support patient-centered research in the AANHOPi population. The data warehouse facilitates research on the heterogeneous groups that comprise AANHOPis (specifically medically underserved AANHOPis), provides an evidence-base for directing policy and practice efforts to improve particular health outcomes (e.g., Hepatitis B and diabetes) where there are obvious disparities, and allows for comparisons of patterns of health across CHCs. Beyond the data warehouse product, the process of establishing this warehouse helped the nodes in building warehouse infrastructure and capacity, and underscored the importance of collective information to drive the research agenda around health and health disparities.

Notes

1. Including nonveterans of all races.
2. HbA1c is a measure for diabetes outcome. Diabetes is considered to be controlled if $\text{HbA1c} \leq 7\%$.

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