Implementing Data Disaggregation Laws and Regulations

Part 2: Challenges, Solutions, and Community Roles

Challenges, Solutions, and Community Roles

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Topics

1. How did AB 1726 come to be and what role did your organization play?

2. What has happened since it has passed? What are you seeing as the implementation victories and challenges?

3. What lessons have we learned from your implementation activities? What more needs to be done to have data disaggregation help achieve health equity?

California Pan-Ethnic HEALTH NETWORK

Advancing Health Equity through Data Disaggregation

Disaggregation Nation! A Data Equity Summit: Oct. 24, 2023

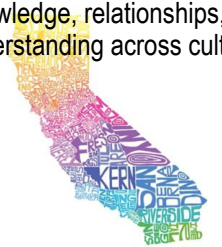
Cary Sanders, Senior Policy Director/CPEHN

California Pan-Ethnic HEALTH NETWORK

CPEHN ensures health justice and equity are on the agendas of policymakers and that communities are leading policy efforts

We build people power to educate and influence policymakers through lived experience and community expertise for better health equity

We connect data, stories, partners, and regions to build knowledge, relationships, and understanding across cultures



We pass, change, and implement policies that reflect community needs for better health

We invest in communities of color to build leadership, sustainability, and advocacy

To create equitable conditions that promote health equity and allow communities of color and all residents to thrive and prosper

California Pan-Ethnic HEALTH NETWORK

CA Efforts to Advance Data Disaggregation

Medi-Cal Quality Disparities Report

Background

- DHCS collected demographic data but was not stratifying health outcomes by race/ethnicity, language or gender

Policy Efforts and Challenges

- Unsuccessful legislation to require stratification; later adopted by DHCS in contract requirements
- Took 3 years to produce first report (2015 data in 2018)

Status

- First report looked at 12 of 30 External Accountability Set (EAS) metrics at the state and regional levels, future reports will look at all 30 metrics
- Health plans must now stratify and report progress on 11 cross-cutting measures

Disparities Reduction in Covered California

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Self-Reported Data

- Health plans required to collect 80% self-reported identity data from enrollees

Year-Over-Year Improvements

- Health plans are required to show improvements in health disparities by race, ethnicity and language in:
  - Diabetes
  - Hypertension
  - Asthma; and
  - Behavioral health

COVERED CALIFORNIA

APIAHF ASIAN & PACIFIC ISLANDER AMERICAN HEALTH FORUM

CPEHN California Pan-Ethnic Health Network

EPIC

Southeast Asia Resource Action Center SEARAC

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The AHEAD Act (AB 1726) - Frequently Asked Questions

Q: What is data disaggregation?

A: Data disaggregation means breaking down big categories into sub-categories. AB 1726 would add more "check boxes" so that each Asian subgroup can be identified, like in the U.S. Census.

CA State Code - 8310.5 categories	AB 1726 Add-Ons to 8310.5
- Asian ○ Chinese ○ Japanese ○ Filipino ○ Korean ○ Vietnamese ○ Asian Indian ○ Laotian ○ Cambodian	- Asian ○ Bangladeshi ○ Hmong ○ Indonesia ○ Malaysian ○ Pakistani ○ Sri Lankan ○ Taiwanese ○ Thai
- Pacific Islander ○ Hawaiian ○ Guamanian ○ Samoan	- Pacific Islander ○ Fijian ○ Tongan

ASIAN AMERICA

California Data Disaggregation Bill Sparks Debate in Asian-American Community

As of Friday morning, one online petition in support of the bill collected roughly 1,700 signatures. The other against it had approximately 14,000.

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Looking Forward:
Standardizing Data Collection Across All State Agencies

- CPEHN's Time for Change report showed, California lacks clear and consistent state standards for demographic data collection and reporting:
  - Demographic data sets are outdated and lack granularity
  - Accuracy and completeness of data sets vary across agencies, making data difficult to use
  - Lack of clarity on how data that is available is being used to drive change
  - Data is not intersectional (e.g. stratified by REAL-D and SOGI)
- Legislative efforts including, AB 1726 and SB 435 are trying to change this!
- But leadership from the Administration is lacking

CA Health and Human Services Agency

- Over the next year and a half, CPEHN hopes to partner with Cal-HHS, HOS network partners, and leaders from the LGBTQ+ and Disability rights communities to:
  - Compile an inventory of data collection and reporting capacities and gaps at all Cal-HHS related departments
  - Convene an external stakeholder group with the goal of establishing state standards to be applied across all Cal-HHS departments for demographic data collection
  - Establish a timeline for implementation
  - Develop a multilingual public education campaign to encourage all Californians to share critical demographic data

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Questions?

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AB 1726 - Overview

Assembly Bill 1726, the Accounting for Health and Education in API Demographics (AHEAD) Act, was passed in 2016 and requires the California Department of Public Health, starting on or after July 1, 2022, to collect and release disaggregated demographic data for an expanded set of Asian and Pacific Islander ethnic subgroups for reports that include:

- rates for major diseases,
- leading causes of death per demographic,
- subcategories for leading causes of death in California overall,
- pregnancy rates, or
- housing numbers

AB 1726 - Overview

AB 814 Changes CA State Code 8310.5 categories (all state agencies)	AB 1088 & AB 1726 Add-Ons (Industrial Relations, Fair Housing & Employment, Public Health)
- Asian o Chinese o Japanese o Filipino o Korean o Vietnamese o Asian Indian o Laotian o Cambodian - Pacific Islander o Hawaiian o Guamanian o Samoan	- Asian o Bangladeshi o Hmong o Indonesian o Malaysian o Pakistani o Sri Lankan o Taiwanese o Thai - Pacific Islander o Fijian o Tongan

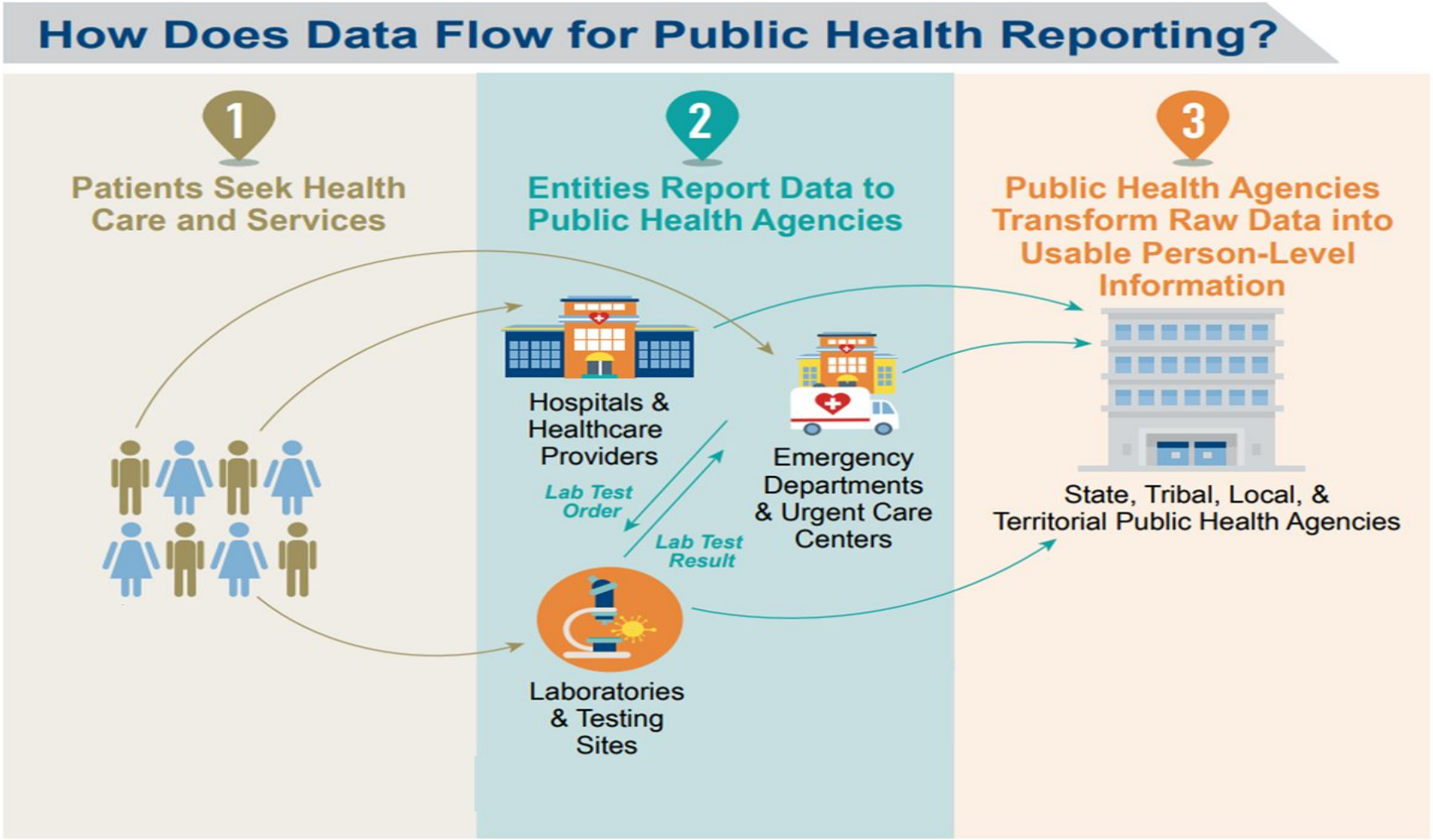
AB 1726 - Lessons Learned from the Campaign

- A missed opportunity: a multi-racial, cross-community approach
- Cultivate champions and build relationships with leadership, like Governor’s office
- Data equity represents a significant culture shift in how the state conducts its business; be flexible in a multi-year fight that will take multiple efforts

Type of Data	CDPH Program	Expected 2022 Data Availability Date	Link to Program Data
Vital Statistics (Birth/Death) Data	Center for Health Statistics and Informatics (CHSI)	Fall 2024 (Preliminary data may be available sooner.)	VSB Data Applications
Infectious Diseases	Center for Infectious Diseases (CID)	Fall 2023	Tuberculosis Data
Health equity, social determinants of health	Office of Health Equity (OHE)	October 2023	Link not available, Sources include American Community Survey, and U.S. Census Bureau
Leading Causes of Death	Office of Policy and Planning	Fall 2023 (Preliminary data may be available sooner)	California Community Burden of Disease System

AB 1726 - Our Implementation Work

- 2 main interactions: Dec. 2022 webinar & Office of Health Equity meetings
- Difficulties getting access to the right people at the state → research meetings with 7 diverse county public health departments
- Challenges include:
  - External, non-state data protocol rules
  - Multiple data systems/technology, with complex data flows
  - Technical data limitations
  - Uncommon data standards
  - Un-centralized data enforcement
  - Data equity as institutional culture shift
  - Uncoordinated data equity efforts between agencies & advocates



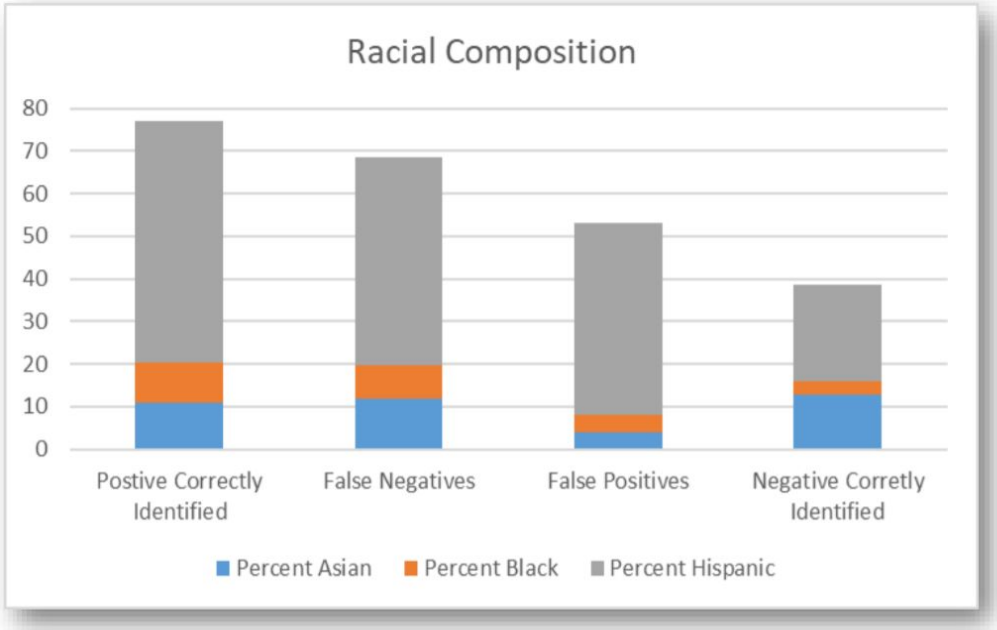
Addressing Gaps in Public Health Reporting of Race and Ethnicity Data for COVID-19. Council of State and Territorial Epidemiologists (CSTE). https://preparedness.cste.org/wp-content/uploads/2022/04/RaceEthnicityData_FINAL.pdf

COVID-19 test positivity rates by racial/ethnic groups for those tested at Asian Health Services in Alameda County, California between August 1, 2020 and April 30, 2021 (N=36,204).

Race/ethnicity	Count (n)	Test Positivity Rate (%)
Asian	20,766	2.77%
Indian	1408	5.02%
Vietnamese	1912	4.76%
Laotian	166	4.29%
Cambodian	292	3.52%
Native Hawaiian	248	3.25%
Chinese	7,049	2.38%
Filipino	2,088	2.34%
Samoan	53	1.96%
Japanese	622	1.31%
Korean	746	1.22%
White	7,479	1.05%
Hispanic or Latino of any race	3,602	4.97%
Black or African American	1,703	2.50%

CA Healthy Places Index

Assessment Results – Race Missing Factor



Evaluation of the HPI in San Diego for assessing risky and impacted places.

- Found Asians and Blacks high for false negatives (although Asian high for false positives too)
- Evaluation of HPI finds mixed results
- Serious limitation because misclassification related to race
  - Fails to capture elements and components of systemic racism
- If used, should be complemented by other factors, including race

AB 1358: Disaggregated Data and Health Equity

- Improve and **standardize** data collection by public agencies to *include demographic, employment status, disaggreg race, ethnicity, language, occupation*
- Ensure state, counties collect and **release** standard and disagg data
- Include **additional** sub-groups to data collection efforts:
  - Hispanic, Latino, or Spanish groups
  - Major Caribbean groups
  - Black and African American groups
- Require state supported or assisted **health equity efforts** to use expanded disagg data with emphasis on lang and ethnicity
- **Require health care providers**, including vaccination sites, to collect and report disaggregated data set information to the County Local Health Officers

AA & NHPI
Health Equity Convening