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1 **Title**

2 Taking Our Lives into Our Own Hands: A Community-Driven Data Response to Native
3 Hawaiian and Pacific Islander COVID-19 Mortality Disparities

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Title

Taking Our Lives into Our Own Hands: A Community-Driven Data Response to Native Hawaiian and Pacific Islander COVID-19 Mortality Disparities

Abstract

More attention is necessary to lower the toll of COVID-19 on the Native Hawaiian and Pacific Islander (NHPI) population, but NHPI risks are rarely elevated in policy discussions. We discuss the formation of the community-led NHPI COVID-19 Data Policy Lab to address the evidence gap for NHPIs. The dashboard highlights the disproportionate burden of COVID-19 on NHPIs. The Lab democratized NHPI data, and directly contributed to the creation of resources, development of community infrastructure, and great strides towards health equity.

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113 **Intervention**

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115 The Native Hawaiian and Pacific Islander (NHPI) population experiences some of the
116 highest case and death rates from COVID-19 compared to all other racial and ethnic groups in
117 the United States (U.S.) [1, 2]. At the UCLA Center for Health Policy Research, the NHPI
118 COVID-19 Data Policy Lab (hereafter, referred to as the Lab) formed to support NHPI
119 community data needs. The Lab represents a close partnership between NHPI community leaders
120 and researchers working to inform national, state, and local COVID-19 prevention efforts

121

122 **Place and Time**

123

124 When the COVID-19 pandemic began, a coalition of community leaders and researchers
125 known as the National Pacific Islander COVID-19 Response Team (NPICRT) convened to
126 protect NHPI health. NPICRT expressed an urgent need for a data infrastructure to support their
127 efforts. This led to the formation of the Lab in March 2020, which is powered by graduate
128 students and early career professionals, several of whom identify as NHPI. Within its first 6
129 months, the Lab responded to community guidance to generate data products and launch a NHPI
130 COVID-19 online dashboard, revealing COVID-19 impacts on NHPIs across the U.S. This is the
131 first time a research university on the U.S. continent committed resources to sustaining a
132 dedicated pipeline of NHPI researchers to meet the community’s data needs.

133

134 **People**

135

136 There are over 1.2 million NHPIs in the U.S. with a diverse set of traditions, cultures, and
137 languages. According to the Office of Management and Budget, NHPI is defined as a person
138 having origins in any of the original peoples of Hawaii, Guam, Samoa, or other Pacific Islands
139 [3]. Approximately 20 NHPI subgroups are counted and fall under three main groups: Polynesia,
140 Melanesia, and Micronesia.

141 High COVID-19 case and death rates among NHPIs are attributable to health and
142 socioeconomic inequities that existed before COVID-19. NHPIs have disproportionately high

143 rates of chronic health conditions linked to increased risk of severe illness from COVID-19,
144 including heart disease, diabetes, and asthma[4][5]. As with other vulnerable communities
145 NHPIs have relatively high poverty and uninsurance rates [5].

146

147 **Purpose**

148

149 The Lab’s data dashboard indicates higher NHPI COVID-19 death rates than any other
150 racial or ethnic group in 10 of 18 states reporting disaggregated NHPI death data. Figure 1 shows
151 a total of 290 NHPI COVID-19 deaths reported in the U.S. The top three states with the highest
152 number of NHPI COVID-19 deaths are California (78), Arkansas (44), and Hawai’i (39).
153 Louisiana currently has the highest NHPI death rate (640.71 per 100,000). Prior to the Lab’s
154 research and advocacy efforts, lack of timely reporting of NHPI disaggregated data curtailed
155 public health program efforts to address COVID-19 in communities.

156

157 **FIGURE 1 HERE**

158

159 The OMB mandate to provide NHPI disaggregated data in disease reporting plays a
160 critical role in holding health agencies accountable in releasing accurate racial and ethnic data.
161 This allows NHPIs a voice in policy decision-making, including decisions regarding allocation
162 of resources to address community health needs.

163 States lack uniformity for collecting and reporting NHPI disaggregated data, as seen in
164 Table 1[6]. Only 42% and 36% of states report NHPI disaggregated case data and death data,
165 respectively.

166

167 **TABLE 1 HERE**

168

169 **Implementation**

170 The Lab’s methodology consisted of faculty researchers visiting online state and county
171 COVID-19 information dashboards to manually scrape case and death count data as requested by
172 the NPICRT. At first, the Lab routinely collected data for 11 states and counties.

173 Researchers calculated case and death rates using 2018 American Community Survey 1-
174 year population denominators, matching the different tabulations of race and ethnicity on the
175 state and county COVID-19 dashboards. Dashboards differed in reporting race as single race or
176 alone or in combination, and in reporting ethnicity (i.e. Hispanic/Latino identification) with race
177 together or separately.

178 In April 2020, volunteer graduate students and early career professionals joined the Lab
179 to increase capacity for manually recording data. By June 2020, the NPICRT expanded its data
180 requests to 32 states and counties. Experienced graduate student programmers joined the Lab to
181 facilitate the automation process of scraping data from sources using Python.

182 To increase efficiency, in August, the Lab shifted to the COVID Racial Data Tracker
183 (CRDT) Dashboard as a primary source of state-level data to calculate case and death rates with
184 selected denominators [7].

185 To increase speed of diffusion, the Lab developed and launched an online dashboard in
186 September 2020 featuring NHPI-specific national COVID-19 data which includes state-level
187 summaries of NHPI cases and death counts, a U.S. heat map of NHPI case and death rates, and
188 line graphs of NHPI case and death rates over time. The dashboard describes how states not
189 disaggregating NHPI data treat the NHPI category: NHPIs aggregated with Asians, NHPIs
190 aggregated under the “other race” category, or no explanation of how NHPIs are counted.

191

192 **Evaluation**

193

194 Advocates worldwide have used the Lab’s data to increase awareness of COVID-19
195 impacts on NHPIs and urge decision makers to support community-driven efforts.

196 The Inland Empire Pacific Islander COVID-19 Response Team (IE PICRT) utilized the
197 Lab’s data to advocate for NHPI data to be disaggregated from Asians on Riverside County’s

198 COVID-19 dashboard. The county’s improved data reporting practices showed that NHPIs
199 exhibit the highest COVID-19 case rate compared to other racial and ethnic groups. This
200 motivated the health department to support the IE PICRT with over \$60,000 to combat COVID-
201 19 among NHPIs through interventions.

202 At the state level, the NPICRT utilized the Lab’s research to advocate for equitable
203 COVID-19 action during a meeting with the director of the California Department of Public
204 Health (CDPH), in September 2020. This resulted in the CDPH’s commitment to prioritize
205 NHPIs in California’s COVID-19 efforts.

206 In September 2020, the Lab supported a national campaign that demanded the National
207 Academies of Sciences, Engineering and Medicine (NASEM) to include NHPIs in their plan for
208 equitable allocation of the COVID-19 vaccine by sending in advocacy letters and providing
209 public comments. These efforts advised the NASEM’s final vaccine plan, which recognized
210 NHPI as a priority population. On September 14, 2020, the Lab submitted video, dashboard, and
211 research materials from the Lab to the National Committee on Vital and Health Statistics Virtual
212 Hearing on Privacy, Confidentiality and Security Considerations for Data Collection and Use
213 during a Public Health Emergency.

214

215 **Adverse Effects**

216

217 Due to the size of the NHPI population, public reporting of the community’s data is a
218 privacy concern. Nevertheless, the vast health disparities among NHPIs and the deadly impact of
219 COVID-19 suggest that arbitrary threshold requirements for reporting are barriers to prevention.
220 We argue that NHPI data reporting, even when numbers are small, is necessary to inform swift
221 action to protect populations. The long-standing lack of NHPI disaggregated data pre-pandemic
222 likely contributed to the under-resourcing of the few organizations with the expertise to
223 implement cultural and linguistically competent COVID-19 programs.

224

225 **Sustainability**

226

227 Investment of resources in community-academic partnerships such as the Lab would
228 increase community capacity and resiliency to address the current COVID-19 pandemic and
229 future health challenges.

230

231 **Public Health Significance**

232

233 The Lab's accomplishments uplift the conscious community effort to democratize NHPI
234 disaggregated data. This work demonstrates that community-engaged research is effective and
235 ensures the completeness and appropriateness of public surveillance and action. We provide a
236 model that is community-driven, pipeline building, and scalable for other population subgroups
237 that are invisible or misrepresented in public health data system.

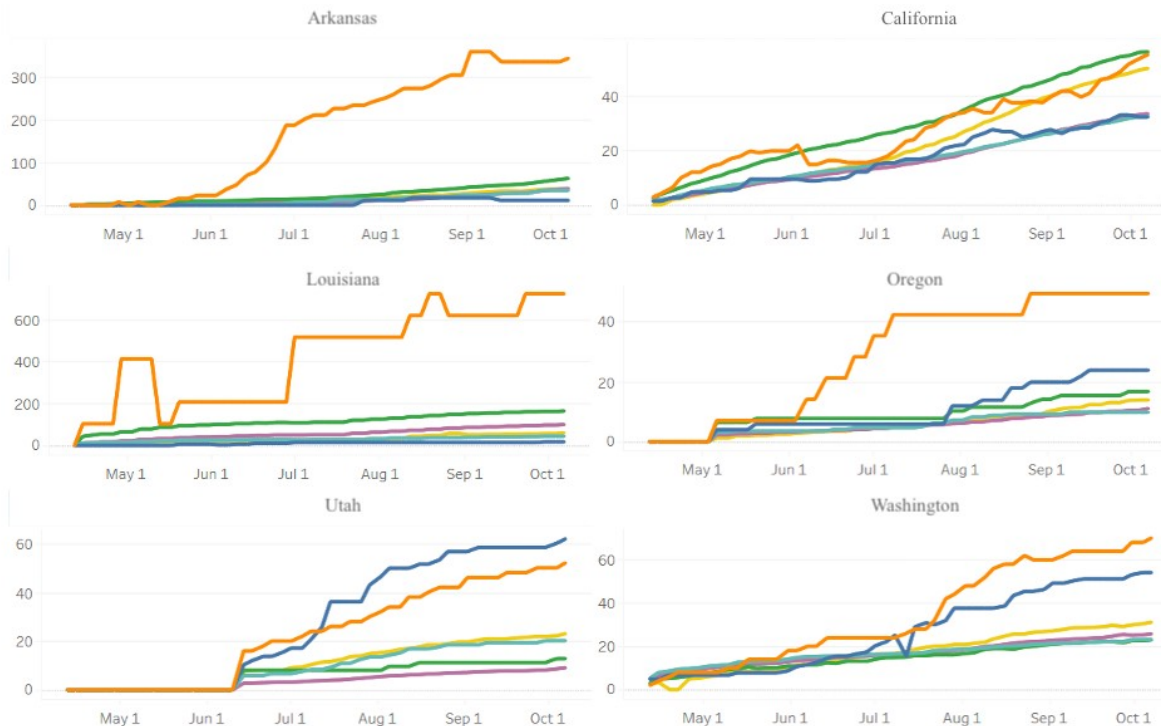
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Figure 1. State Racial and Ethnic Death Rates per 100,000 as of October 7, 2020. NHPI population indicated in orange.



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Note: In October 2020, the Lab updated the population denominators for calculating case and death rates to use the 2019 American Community Survey 1-Year population estimates (instead of 2018 data). The updated calculations continue to match the different definitions of the race and ethnicity utilized by states in their COVID-19 reporting.

Table 1. State status of disaggregated NHPI COVID-19 case and death data as of October 7, 2020

State	Status of Disaggregation of NHPI COVID-19 Cases	Status of Disaggregation of NHPI COVID-19 Deaths

Alabama	Alabama does not specify NHPI are included under a grouping it labels "Other."	Alabama does not specify NHPI are included under a grouping it labels "Other."
Alaska	Disaggregates NHPI Cases	Disaggregates NHPI Deaths
Arizona	Arizona reports Asian as a panracial category including Asian Pacific Islander and Native Hawaiian.	Arizona reports Asian as a panracial category including Asian Pacific Islander and Native Hawaiian.
Arkansas	Disaggregates NHPI Cases	Disaggregates NHPI Deaths
California	Disaggregates NHPI Cases	Disaggregates NHPI Deaths
Colorado	Disaggregates NHPI Cases	Disaggregates NHPI Deaths
Connecticut	Connecticut reports Asian as a panracial category including Asian Pacific Islander and Native Hawaiian.	Connecticut reports Asian as a panracial category including Asian Pacific Islander and Native Hawaiian.
Delaware	Delaware reports Asian as a panracial category including Asian Pacific Islander and Native Hawaiian.	Delaware reports Asian as a panracial category including Asian Pacific Islander and Native Hawaiian.
Florida	Florida includes NHPI under a grouping it labels "Other."	Florida includes NHPI under a grouping it labels "Other."
Georgia	Disaggregates NHPI Cases	Disaggregates NHPI Deaths

Hawaii	Disaggregates NHPI Cases	Disaggregates NHPI Deaths
Idaho	Disaggregates NHPI Cases	Idaho does not report disaggregated NHPI death data.
Illinois	Disaggregates NHPI Cases	Disaggregates NHPI Deaths
Indiana	Indiana includes NHPI under a grouping it labels "Other."	Indiana includes NHPI under a grouping it labels "Other."
Iowa	Disaggregates NHPI Cases	Disaggregates NHPI Deaths
Kansas	Kansas does not specify if NHPI are included under a grouping it labels "Other race."	Kansas does not specify if NHPI are included under a grouping it labels "Other race."
Kentucky	Disaggregates NHPI Cases	Kentucky does not report disaggregated NHPI death data.
Louisiana	Disaggregates NHPI Cases	Disaggregates NHPI Deaths
Maine	Disaggregates NHPI Cases	Disaggregates NHPI Deaths
Maryland	Maryland does not specify if NHPI are included under a grouping it labels "Other (Non-Hispanic)."	Maryland does not specify if NHPI are included under a grouping it labels "Other (Non-Hispanic)."
Massachusetts	Massachusetts does not specify if NHPI are included under a grouping it labels "Non-Hispanic Other."	Massachusetts does not specify if NHPI are included under a grouping it labels "Non-Hispanic Other."

Michigan	Michigan reports Asian as a panracial category including Asian Pacific Islander and Native Hawaiian.	Michigan reports Asian as a panracial category including Asian Pacific Islander and Native Hawaiian.
Minnesota	Disaggregates NHPI Cases	Disaggregates NHPI Deaths
Mississippi	Mississippi does not specify if NHPI are included under a grouping it labels "Other (Non-Hispanic)."	Mississippi does not specify if NHPI are included under a grouping it labels "Other (Non-Hispanic)."
Missouri	Missouri includes NHPI under a category it labels "Other."	Missouri includes NHPI under a category it labels "Other."
Montana	Montana does not specify if NHPI are included under a grouping it labels "Other race."	Montana does not specify if NHPI are included under a grouping it labels "Other race."
Nebraska	Disaggregates NHPI Cases	Disaggregates NHPI Deaths
Nevada	Nevada does not specify if NHPI are included under a grouping it labels "Other."	Nevada does not specify if NHPI are included under a grouping it labels "Other."
New Hampshire	New Hampshire includes NHPI under a grouping it labels "Other."	New Hampshire includes NHPI under a grouping it labels "Other."

New Jersey	New Jersey includes NHPI under a grouping it labels "Other (non-Hispanic)."	New Jersey includes NHPI under a grouping it labels "Other (non-Hispanic)."
New Mexico	New Mexico does not currently report disaggregated NHPI data.	New Mexico does not currently report disaggregated NHPI data.
New York	Race/ethnicity data is reported separately by New York City and the rest of New York State. NYC reports Asian as a panracial category including Asian Pacific Islander and Native Hawaiian. New York State excluding NYC reports a grouping it labels "Asian."	Race/ethnicity data is reported separately by New York City and the rest of New York State. NYC reports Asian as a panracial category including Asian Pacific Islander and Native Hawaiian. New York State excluding NYC reports a grouping it labels "Asian."
North Carolina	Disaggregates NHPI Cases	Disaggregates NHPI Deaths
North Dakota	North Dakota does not report any racial or ethnic COVID-19 case or death data.	North Dakota does not report any racial or ethnic COVID-19 case or death data.
Ohio	Disaggregates NHPI Cases	Disaggregates NHPI Deaths

Oklahoma	Oklahoma reports Asian as a panracial category including Asian Pacific Islander and Native Hawaiian.	Oklahoma reports Asian as a panracial category including Asian Pacific Islander and Native Hawaiian.
Oregon	Disaggregates NHPI Cases	Disaggregates NHPI Deaths
Pennsylvania	Pennsylvania does not specify if NHPI are included under a grouping it labels "Other."	Pennsylvania does not specify if NHPI are included under a grouping it labels "Other."
Rhode Island	Rhode Island does not specify if NHPI are included under a grouping it labels "Non-Hispanic other."	Rhode Island does not specify if NHPI are included under a grouping it labels "Non-Hispanic other."
South Carolina	South Carolina does not specify if NHPI are included under a grouping it labels "Other."	South Carolina does not specify if NHPI are included under a grouping it labels "Other."
South Dakota	South Dakota does not specify if NHPI are included under a grouping it labels "Other."	South Dakota does not specify if NHPI are included under a grouping it labels "Other."
Tennessee	Disaggregates NHPI Cases	Disaggregates NHPI Deaths

Texas	Texas does not specify if NHPI are included under a grouping it labels "Other."	Texas does not specify if NHPI are included under a grouping it labels "Other."
Utah	Disaggregates NHPI Cases	Disaggregates NHPI Deaths
Vermont	Vermont does not specify if NHPI are included under a grouping it labels "Other race."	Vermont does not specify if NHPI are included under a grouping it labels "Other race."
Virginia	Virginia reports Asian as a panracial category including Asian Pacific Islander and Native Hawaiian.	Virginia reports Asian as a panracial category including Asian Pacific Islander and Native Hawaiian.
Washington	Disaggregates NHPI Cases	Disaggregates NHPI Deaths
West Virginia	West Virginia does not specify if NHPI are included under a grouping it labels "Other."	West Virginia does not specify if NHPI are included under a grouping it labels "Other."
Wisconsin	Wisconsin reports Asian as a panracial category including Asian Pacific Islander and Native Hawaiian.	Wisconsin reports Asian as a panracial category including Asian Pacific Islander and Native Hawaiian.
Wyoming	Disaggregates NHPI Cases	Wyoming does not report disaggregated NHPI death data.

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