



## Moana: Alternate surveillance for COVID-19 in a Unique Population (MASC-UP)

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### A B S T R A C T

**Objective:** Create a longitudinal, multi-modal and multi-level surveillance cohort that targets early detection of symptomatic and asymptomatic COVID-19 cases among Native Hawaiian and Pacific Islander adults in the Continental US and identify effective modalities for participatory disease surveillance and sustainably integrate them into ongoing COVID-19 and other public health surveillance efforts.

**Materials and methods:** We recruited cohorts from three sites: Federal Way, WA; Springdale, AR; and remotely. Participants received a survey that included demographic characteristics and questions regarding COVID-19. Participants completed symptom checks via text message every month and recorded their temperature daily using a Kinsa smart thermometer.

**Results:** Recruitment and data collection is ongoing. Presently, 441 adults have consented to participate. One-third of participants were classified as essential workers during the pandemic.

**Discussion:** Over the past 18 months, we have improved our strategies to elicit better data from participants and have learned from some of the weaknesses in our initial deployment of this type of surveillance system. Other limitations stem from historic inequities and barriers which limited Native Hawaiian and Pacific Island representation in academic and clinical environments. One manifestation of this was the limited ability to provide study materials and support in multiple languages. We hope that continued partnership with the community will allow further opportunities to help restore trust in academic and medical institutions, thus generating knowledge to advance health equity.

**Conclusion:** This participatory disease surveillance mechanism complements traditional surveillance systems by engaging underserved communities. We may also gain insights generalizable to other pathogens of concern.

### 1. Introduction

Marshallese, Native Hawaiian, and Pacific Island populations are some of the fastest growing populations in the Continental US [1]. Since 1986, the US Marshallese population has increased from fewer than 100 to 27,000 individuals [2]. Initially, the Marshallese primarily relocated to Hawai'i, Los Angeles, and the West Coast, but due to a lower cost of living, most now reside in the Midwest (Arkansas, Oklahoma, Missouri, Kansas, Iowa). For instance, the Marshallese community has grown by 300 % in Arkansas between 2000 and 2010. Arkansas now has the largest population of Marshallese outside the Marshall Islands (~15,000) [3–6]. Furthermore, Marshallese, Native Hawaiian, and Pacific Island populations continue to grow rapidly in parts of the Pacific

Northwest (Oregon and Eastern Washington).

Many Marshallese adults work in low paying, blue-collar jobs, such as in food processing, machine, and manufacturing plants, and in the service industry in hotels and restaurants, typically without health or retirement benefits [7–9]. For example, 12,000 Marshallese reside in Springdale where the Tyson chicken processing plant is located, and 30 % of Tyson's Springdale workforce is Marshallese [2,9,10]. Many low paying, blue-collar jobs are considered essential employment but have limited paid sick leave and do not allow work from home [9,11]. Such occupational exposures to COVID-19 place multigenerational households at very high risk of rapid transmission of COVID-19, especially to the elderly and other high-risk individuals [9,11–13].

COVID-19 infections, hospitalizations, and deaths disproportionately

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affect minority communities in the US [14–17]. Even among highly vulnerable populations, the extremely high incidence rates among Pacific Islander communities stand out as striking disparities. In the few states that report disaggregated data, COVID-19 incidence among the Pacific Islander community was higher than among Whites and other minority groups [13,15–19]. A July 2020 CDC report detailed the striking and disproportionate impact of COVID-19 on Marshallese people in Benton and Washington Counties, Arkansas [15]. As previously noted, Marshallese make up 1.5–3 % of the total population in Northwest Arkansas; yet they account for 19 % all the COVID-19 cases [15]. Nine percent of Marshallese cases require hospitalization compared with 1 % nationally, representing 43 % of all COVID-19-related hospitalizations in Northwest Arkansas. Most alarmingly, Marshallese account for 38 % of COVID-19 deaths in this region [15]. In Washington, Pacific Islanders were 17 times more likely than Whites to contract COVID-19 [20]. In short, the Marshallese bear a disproportionate burden of COVID-19 infection, hospitalization, and death, with rates across these indicators 4 to 25 times higher than in other racial and ethnic minorities [14,15].

Community-engaged participatory strategies are effective in building alliances with minority, immigrant communities when health disparities result from systematic disadvantage, racism, and historical trauma [21–23]. Participatory disease surveillance is particularly useful during outbreaks in rural areas and among hard-to-reach populations [24]. Therefore, the World Health Organization recommended participatory disease surveillance for COVID-19 [25]. To encourage collaboration and incorporate the concerns of the community, the population at risk submits relevant data through a variety of survey tools in participatory disease surveillance [26]. The resulting data can facilitate a better understanding of risk and transmission patterns in clustered populations, more rapid responses to public health emergencies, and improve dissemination about disease prevention and treatment efforts. In addition, such direct engagement also offers an opportunity for participants to better understand pandemic disease risks which may result in subsequent behavior changes to reduce risk of infection. Both of our study sites have successfully used Community Health Workers (CHW) and community-engaged participatory strategies to engage US Marshallese and Pacific Islanders [27]. Of note, CHW and participatory strategies have been used to effectively surveil other infectious diseases among the Marshallese (e.g., mumps, Hansen’s disease, tuberculosis) [28–31]. Contact tracing efforts in infectious outbreaks proved crucial in disease containment and vaccine distribution. Culturally appropriate messages and modes of communication were also crucial to ending these outbreaks and were available largely due to community buy-in Refs. [13,19,32].

With the historic success of other participatory disease surveillance projects, we launched Moana: Alternate Surveillance for COVID-19 in a Unique Population (MASC-UP) in Autumn of 2021. The results from MASC-UP will demonstrate the value of culturally tailored, participatory disease surveillance developed and tested in real-world settings to mitigate COVID-19 disparities in a high-risk, clustered population that has been profoundly underserved by public health efforts to date. Our methods and findings can be adapted and disseminated for improved surveillance and disease prevention in other high-risk, non-institutionalized US minority groups.

## 2. Methods

### 2.1. Study aims

The MASC-UP study has three primary aims. We sought to: 1) create a longitudinal, multi-modal and multi-level surveillance cohort that targets early detection of symptomatic and asymptomatic COVID-19 cases among Native Hawaiian and Pacific Islander adults in the Continental US; 2) characterize the social contact network among surveillance cohort members to identify community structures and networks

that put individuals at increased risk of acquiring COVID-19; and 3) identify effective modalities for participatory disease surveillance and sustainably integrate them into ongoing COVID-19 and other public health surveillance efforts for the Native Hawaiian and Pacific Islander adult populations.

### 2.2. Overview and Design

To address these aims, we recruited cohorts from three sites. Two were in-person sites, located in Springdale, Arkansas and Federal Way, Washington. The first site was at the Center for Pacific Islander Health at the University of Arkansas for Medical Sciences (UAMS)—a community focused research center that is integrated into the medical school and University of Arkansas medical system. The second site was Pacific Islander Community Association of Washington (PICA) located in Federal Way, Washington—a community organization where wellness navigators link local Pacific Islander individuals with various health and social services. The final site was a remote, nationwide site based in Seattle, Washington. Study procedures and eligibility criteria were similar across sites.

Though eligibility criteria were originally restricted to Marshallese individuals, we expanded the scope of the population included in the study by inviting those of any Native Hawaiian or Pacific Islander identity to participate, thereby being more inclusive of all populations served by our community partners. Participants were eligible to participate in the study if they self-identified as Native Hawaiian or Pacific Islander and were at least 18 years of age. Participants also needed to have access to a smart phone, an email address, and regular internet access. For participants recruited at the UAMS and PICA sites, they were additionally required to be living in the area and not planning on moving for the duration of the study. Participation in the remote study also required that an individual be fluent in English; however, the UAMS and PICA sites also had options for participants who preferred to communicate in Marshallese.

After enrolling in the study, participants received an orientation with study staff. During this orientation, site staff guided participants through study procedures and helped them download the Kinsa smartphone application [33]. This application was used in conjunction with the smart thermometers that participants used to take their temperature regularly. After completing the orientation, participants received a survey that included demographic characteristics and questions regarding COVID-19 (details of the survey are below) as well as a contact diary to record recent interactions and the risk of transmitting COVID-19. Participants also completed monthly symptom check-ins. At the end of the study period, participants answered the original survey and contact diary a second time. The study measures were the same across all study sites, though there were some differences in the modality

**Table 1**  
Data collection timeline and mechanism by study site.

	PICA	UAMS	Remote
Recruitment	In-Person	In-Person	Social Media, Community Events
Follow-up Duration	12-months	6-months	6-months
Survey: Timing	Baseline, 12-Months	Baseline, 6-Months	Baseline, 6-Months
Survey: Mechanism	Email, Phone, In-Person	Email, Phone	Email
Contact Diary: Timing	Baseline, 6-Months	Baseline, 6-Months	Baseline, 6-Months
Contact Diary: Mechanism	Email, Phone, In-Person	Email, Phone	Email
Symptom Check: Mechanism	Phone, MyCap	Phone, Text Message	Text Message
Languages Available	English, Marshallese	English, Marshallese	English



whether they had physical contact, the context and location of the interaction (home, work, leisure, travel, shopping, or another context), and the approximate duration of their time together. The surveys provided space for participants to list up to 33 contacts, though to date, the maximum number of contacts entered by any single participants is 19.

2.5.3. Symptom check-ins

In addition to the longer surveys at baseline and follow-up, participants received short monthly surveys about COVID-19 symptoms they may have experienced and whether they or members of the household had tested positive for COVID-19. Depending on the site, participants completed this survey via phone, MyCap [35], or text message. The first 10 questions asked about different symptoms of COVID-19. If a participant endorsed any of the symptoms, they were asked if they had seen a clinician regarding their symptoms, ever thought that the illness might be attributable to COVID-19, taken a COVID-19 test, and, if so, what the result was. Participants were also asked if any members of their household had tested positive for COVID-19 in the past month.

2.5.4. Temperature checks

Participants were asked to take their temperature daily using Kinsa smart thermometers. The thermometer is connected to a smartphone application which could record temperatures and electronically transmit the timestamped temperature readings. Each thermometer could be linked to the correct participant via the serial number. If a thermometer was lost or broken, the study team sent a replacement thermometer. Additional replacement thermometers were provided on a case-by-case basis.

At the initial launch of the study, adherence to temperature readings was low. While the study protocol provided an incentive for taking temperatures (\$50 for 300 readings for the 12-month protocol and \$50 for 150 readings for the 6-month protocol), it was determined that this threshold for incentive may be too high. There were concerns that if participants felt that they would be unable to reach the threshold to receive the incentive, they would not be as motivated to complete any temperature readings. After consulting with site staff, the threshold was reduced from 150 readings to 100 temperature readings. Since reducing the threshold, the number of participants regularly monitoring their temperature notably increased.

2.6. Data management

Study data were managed and stored in REDCap [36,37]. The contact diary and questionnaire administered at baseline and follow-up was either entered by the participant as a survey or by site staff via direct entry if administered over the phone. Temperatures logged with the Kinsa thermometer are immediately transmitted to Kinsa. The Kinsa staff provided researchers with this information in weekly, secure file transfers via REDCap. Serial numbers from each thermometer were matched to participant ID at baseline allowing study staff to match individuals to their temperature readings.

The monthly symptom checks were entered into REDCap in one of three ways: 1) direct entry by site staff while conducting the symptom check via phone, 2) through the MyCap application, which provides the symptom check via a survey form, or 3) via text messaging through Mosio. The Mosio text messaging platform can link to a REDCap API and, using unique participant identifiers, populate field in REDCap directly from participant text message responses. The Mosio platform also allows researchers to administer the same REDCap instrument with different text for pre-assigned groups; this makes it possible for participants to receive text messages in English, Marshallese, or both languages without creating separate instruments for each version of the survey. The symptom check-in instruments entered via Mosio were not automatically flagged as complete, allowing research staff to easily identify newly completed surveys for data quality and incentive distribution.

2.7. Analytic plan

To date, we have recruited 490 participants across the three sites (Table 2). Of the 329 who have completed the baseline survey, 40.4 % of participants identify as Micronesian, 7.9 % as Melanesian, and 50.2 % Polynesian. About 40 % said that their health was “Very Good” or “Excellent.” Roughly one-third were employed as an “essential worker.”

2.7.1. Retention

Several analyses are planned with the data collected. First, we will evaluate cohort retention and engagement with each aspect of the study protocol (survey/contact diary, symptom check-ins, and temperature logs). These results will elucidate the strengths of this community engaged surveillance system and the feasibility of implementation in other tight-knit communities. These results will be stratified by site to

**Table 2**  
Baseline Description of cohorts to-date by site.

	PICA		UAMS		Remote		Total	
Number Consented	160		80		250		490	
Number Completing Baseline Survey	159		52		118		329	
Age	44	16.75	35	11.74	40	13.70		
Assigned Male at Birth	50	31.4 %	16	30.8 %	25	21.6 %	91	27.7 %
Hispanic Ethnicity	1	0.6 %	2	3.9 %	21	18.6 %	24	7.3 %
Race (In Addition to NHPI) <sup>a</sup>								
American Indian/Alaska Native	1	0.6 %	0	0.0 %	6	5.2 %	7	2.1 %
Black or African American	1	0.6 %	0	0.0 %	4	3.4 %	5	1.5 %
Asian	0	0.0 %	0	0.0 %	45	38.8 %	45	13.7 %
White	0	0.0 %	0	0.0 %	33	28.4 %	33	10.0 %
Other	0	0.0 %	3	5.8 %	9	7.8 %	12	3.6 %
Pacific Islander Ethnicity <sup>a</sup>								
Micronesian	73	45.9 %	52	100.0 %	8	6.8 %	133	40.4 %
Melanesian	25	15.7 %	0	0.0 %	1	0.8 %	26	7.9 %
Polynesian	61	38.4 %	0	0.0 %	104	88.1 %	165	50.2 %
Other	0	0.0 %	0	0.0 %	3	1.6 %	3	0.9 %
Education								
<HS	30	18.9 %	4	7.7 %	0	0	34	10.3 %
HS or GED	68	42.8 %	24	46.2 %	7	6.0 %	99	30.1 %
Some College	28	17.6 %	12	23.1 %	27	23.3 %	67	20.4 %
Associate Degree or Vocational Training	18	11.3 %	7	13.5 %	19	16.4 %	44	13.4 %
Bachelor's Degree +	12	7.5 %	5	9.6 %	63	54.3 %	80	24.3 %
General Health								
Poor/Fair/Good	92	57.9 %	30	57.7 %	72	61.0 %	194	59.0 %
Very Good/Excellent	65	40.9 %	22	42.3 %	44	37.3 %	131	39.8 %
Employed as an "Essential Worker"	40	25.2 %	29	55.8 %	48	41.4 %	117	35.6 %

NHPI: Native Hawaiian or Other Pacific Islander.

<sup>a</sup> Categories are not mutually exclusive.

provide additional information on participant engagement as our recruitment and retention strategies changed between cohorts.

### 2.7.2. Population-specific risk factors

We will publish information on the descriptive statistics of COVID-19 symptoms and test results captured by the monthly check-ins. We will additionally use simple linear and logistic regression models to evaluate associations with age, sex, and other demographic factors of interest, such as occupation. In this analysis, we additionally plan to assess the benefit of incorporating temperature data into the surveillance system. By assessing temperatures logged across time, we can determine with upward deviations from a participant's baseline temperature coincide with reported symptoms and subsequent positive test results. These results will indicate if regular temperature logging could be one way to routinely screen for COVID-19 or other respiratory infections with ease.

### 2.7.3. Social networks

The final aim of the study focuses on contact tracing and social networks. We plan to use the information from the ego-based contact survey. This type of data collection allows us to make statistical inference using exponential random graph models [38]. The choice to study three Pacific Islander communities is rooted in one (Arkansas) having a shared source of employment in the form of a meat processing plant – itself a dense, highly connected space likely to contribute to transmission – while the other two (Washington and Remote) do not. Worksite-related contact will be collected in both populations, but the importance is seeing what impact, if any, a single centralized employer vs. many decentralized employers has in the resulting connections. This information elucidates the role of the workplace in the epidemiology of COVID-19 within these communities and can inform interventions.

These models will be estimated using the well-documented and -supported *stannet* package [39]. The spread of SARS-CoV-2 over the simulated network will use an extension of the classic SEIR epidemic model in a network context [40]. This optimization allows us to perform this research in a dense and highly clustered, difficult to reach community, whereas many such analyses consider much larger but less specific populations. It is also broadly applicable, as the same methods may be adapted for other pathogens and the deployment of vaccines or other pharmaceutical interventions [41]. Should the model have free parameters that need to be fit, this will be performed using Approximate Bayesian Computation [42,43], a technique being used by the investigators [44–47] and others [48] to estimate parameter values for epidemic models from summary statistics and with analytically intractable likelihood functions.

## 3. Discussion

### 3.1. Current challenges and lessons learned

Over the past 18 months, we have improved our strategies to elicit better data from participants and have learned some of the weaknesses of this type of surveillance system. The first challenge we faced was participant retention and completeness of data in the first cohort. This was, in part, because several of the study activities (e.g., monthly symptom checks) were not tied to an incentive, which may have left participants feeling that those activities were not important. Additionally, the population from which this cohort was recruited was more difficult to follow-up with. One of the primary services PICA provides is assistance in navigating social services; during the pandemic, their clients' biggest need was housing support. While these participants were able to consent and complete baseline activities, the instability in housing and other uncertainties made follow-up more difficult. Similarly, completing research activities was, understandably, not a priority. Understanding the other vulnerabilities of the population that the surveillance system is trying to reach is critical in successful implementation.

A related concern for participants and some prospective participants has been access to technology. Many older adults are less familiar with smart phone technology; the Bluetooth thermometer and accompanying application required a learning curve. While site staff could help with set-up during an orientation, if the thermometer became unlinked during follow-up it was more difficult to schedule a time to assist them. We also found that smartphones using older operating systems were unable to use the Kinsa application. For many participants, their operating system was the product of an older model of phone and could not be easily remedied by downloading an update. Similarly, many participants across all sites are in precarious financial situations; it was not uncommon for people to periodically lose cell phone service due to cost. Future projects could alleviate the financial burden of technology access by either subsidizing mobile phone plans or providing loaned equipment for the duration of the study. Any disease surveillance system relying on technology will need to ensure that the priority population has access to the technology being used or risks inequitable participation.

Finally, while community partners were and are crucial in making this work happen, a long-term partnership with ongoing training is necessary to maximize the success of this type of program. Research is not the primary mission of most community organizations, and the additional workload brought on by this project in the midst of the pandemic was overwhelming. While we did provide funding for their staff, this time was split between several staff members who were only able to dedicate a few hours per week to MASC-UP in addition to their typical duties. Ideally, a project like this would have funded one or two staff members at near full time so they could have dedicated their workload to this project rather than having to spread their time across tasks. This would ensure consistency in the amount of time dedicated to the project each week and allow these staff members to become well versed in research, public health, and data processes. An arrangement like this would also allow people without access to technology to complete the monthly symptom check-ins by visiting the community organization in person.

### 3.2. Study limitations

In addition to the challenges listed above, there are other limitations to this surveillance system and proposed analyses. These limitations stem from historic inequities and barriers which limited Native Hawaiian and Pacific Island representation in academic and clinical environments. One manifestation of this was the limited ability to provide study materials and support in multiple languages. The two in-person study sites can provide all information in English and Marshallese, however, the research staff for the remote study are only fluent in English. This will result in unrepresentative samples and likely prevent participation among people who are most vulnerable. It would be ideal to hire members of the community who are fluent in Marshallese or another Pacific Island language to assist in the remote study. Due to the cyclical nature of grant funding, there were concerns that we would not be able to provide long-term employment security. Organizations that have a consistent source of funding and strong relationships with Pacific Island communities would be the most well poised to lead this type of work.

Mistrust of healthcare and government entities among historically marginalized communities is also a concern. This may contribute towards the issue of incomplete data. However, this incomplete data is still an improvement over no data. Though allowing participants to skip questions may limit analytic power around some measures, it does allow for *some* data gathering that may not have otherwise been possible. To demonstrate our commitment to rebuilding trust with the community and protecting participants' identities, some data will be presented at a higher level of aggregation than would ordinarily be ideal. This is especially true of any non-simulated contact network data. We have also incorporated transparency into our dissemination plan. We are preparing data products for each of the participating sites that will use lay language to relay the site-specific findings of the study. This includes a

one-page flyer that highlights the findings most likely to be of interest to participants as well as a more detailed report for the partner organizations that includes data from all survey questions and may be useful in planning future programming. We hope that continued partnership with the community will allow further opportunities to help restore trust in academic and medical institutions, thus generating knowledge to advance health equity.

### 3.3. Implications for disease surveillance

This participatory disease surveillance mechanism complements traditional surveillance systems by engaging communities in reporting COVID-19 symptoms. The strengths of this system lie in the speed at which data can be made available and the ability to scale the technology to obtain data at a low cost, especially in populations that may otherwise be missed by existing surveillance systems. By combining the symptom reporting with contact diaries, we may also gain insights that would be generalizable to other underserved, high-risk, clustered populations that may be hard to reach and have applications for other pathogens of public health concern.

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### Code availability

Not Applicable.

### Ethics approval

This research was approved by the Washington State University and University of Arkansas for the Medical Sciences Institutional Review Boards.

### Consent to participate

All participants provided verbal consent and received printed copies of the consenting information.

### Consent for publication

Not Applicable.

### CRedit authorship contribution statement

**Erin R. Morgan:** Formal analysis, Investigation, Methodology, Project administration, Writing – original draft. **Denise Dillard:** Investigation, Project administration, Supervision, Writing – review & editing. **Eric Lofgren:** Conceptualization, Formal analysis, Funding acquisition, Methodology, Writing – review & editing. **Benetick Kabua Maddison:** Writing – review & editing. **Sheldon Riklon:** Conceptualization, Funding acquisition, Investigation, Methodology, Writing – review & editing. **Pearl McElfish:** Conceptualization, Funding acquisition, Investigation, Methodology, Writing – review & editing. **Ka'imi Sinclair:** Conceptualization, Funding acquisition, Investigation, Methodology, Project administration.

### Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.conctc.2023.101246>.

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