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# ***A Novel Recruiting and Surveying Method***

## **Participatory research during a Pacific Islander community's traditional cultural event**

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This article describes how an unincorporated community coalition, Gaps in Services to Marshallese Task Force (GAPs), joined with the Northwest Arkansas Hometown Health coalition, state health department and local university to conduct a special population health survey of Marshallese, a Pacific Islander community living in Northwest Arkansas. The Marshallese originate from the Republic of the Marshall Islands (RMI). GAPs was the coordinating organisation and the state health department and university played a supportive role. The results of the study will be discussed in a separate publication. The purpose of this article is to describe how this community coalition engaged in a community-based participatory research (CBPR) process to select and refine validated questionnaires and then used a novel method to recruit and survey participants during a traditional cultural event. The article focuses on the successes, failures and lessons learned.

### **BACKGROUND**

The number of Pacific Islanders in the United States is growing rapidly, increasing 40 per cent between 2000 and 2010 (Hixson, Hepler & Kim 2012). However, Pacific Islanders remain under-represented in health research (Ro & Lee 2010; Roehr 2010; Working Group of Applied Research Center and National Council of Asian Pacific Americans 2013). Specific health information on Pacific Islanders is often obscured in aggregated data on Asian Americans and Pacific Islanders (Ro & Lee 2010; Roehr 2010). The Health and Human Services (HHS) Action Plan to Reduce Racial and Ethnic Health Disparities recognises the need for better health data on Pacific Islanders and recommends the development of 'other methods to capture low-density populations including Native Americans, Asian Americans and Pacific Islanders' (Department of Health and Human Services n.d.). While there is little data on Pacific Islanders living in the US, there is even less health information available on Marshallese specifically and no published data on the health status of Marshallese living in Arkansas. While most Pacific Islanders in the US live in Hawaii and California, many Pacific Islander subpopulations, including Marshallese, are

dispersing across the United States (Hixson, Hepler & Kim 2012), increasing the need to conduct smaller community surveys to better understand the health status, beliefs and attitudes of new Pacific Islander communities in the US. In this article we focus on one Pacific Islander population, the Marshallese, who have established a significant and growing community in Northwest Arkansas.

The Marshallese population in the United States has been growing since the Compact of Free Association (COFA) was signed in 1986, granting the Marshallese free entry into the US to live and work without a visa or permanent resident card (Shek & Yamada 2011). Marshallese migrants are defined by the US government as 'non-immigrants without visas'; 98 per cent of the Marshallese in Arkansas do not claim US citizenship (Jimeno & Rafael 2013). They are referred to as 'COFA migrants' or 'COFA residents' (Shek & Yamada 2011).

According to the US Census, the Marshallese population in the US more than tripled from 2000 to 2010, growing from an estimated 6700 in 2000 to 22 400 in 2010 (Hixson, Hepler & Kim 2012). Because of the limited documentation required to enter the US as COFA migrants and frequent travel both within the US and between the US and the RMI, estimating the US Marshallese population is difficult. The Marshallese Consulate estimates the actual population of Marshallese in the US to be around 40 000, which is almost double the US Census figure (McElfish 2013). This estimate is supported by school enrolment data. In 2010, Arkansas had the largest population of Marshallese living in continental US – approximately 10 000 (McElfish 2013).

Prior to the 2009 Centers for Disease Control and Prevention (CDC) Marshallese Health Survey, local health-care providers and non-profit organisations were working to meet the acute health needs of the Marshallese community including diabetes, Hansen's Disease and hepatitis. However, there was a dearth of local data on the Marshallese to help them improve the appropriateness of the health services provided. Health-care providers and non-profit organisations needed information for program planning and to document health disparities in order to apply for local, state and national grant funding to meet the needs of the Marshallese community.

In 2007, a local community advocate formed the Gaps in Services to Marshallese Task Force. GAPs comprises educators, elected officials, health-care providers, social service providers, non-profit agencies, the Marshallese Consulate, Marshallese pastors and Marshallese community members who are dedicated to improving the lives and welfare of the Marshallese. The Marshallese Task Force has the trust of and a strong relationship with the Marshallese community.

## **METHOD**

Dialogue concerning possible funding from the CDC began in December 2008. The agreed upon purpose of the Marshallese

Health Survey was to promote the success of established public health programs in achieving identified objectives within this specific population. From December 2008 to April 2009, there was ongoing communication as revised proposals were submitted to the CDC to conduct a health survey among Marshallese that would coincide with the Marshallese Constitution Day celebration that takes place annually over a one-week period around Memorial Day. The event attracts thousands of Marshallese who participate in the celebration and team competitions. The Jones Center for Families (a local non-profit organisation and GAPS partner) in Springdale, Arkansas, was identified as the fiduciary for the CDC funding. Notification was received on 20 April 2009 that the project had been funded to the amount of \$78 045.

The Marshallese Constitution Day events were to be held at the Jones Center for Families during the week of 19–26 May 2009. This allowed only five weeks until the target date for the survey implementation. This short timeframe necessitated the formation of a Marshallese Health Survey subcommittee. Each subcommittee member was also a member of GAPS. The following organisations had representatives on the subcommittee: Jones Center for Families, Hometown Health Improvement, Community Clinic, Marshallese Consulate and Marshallese Pastors. Marshallese community members also sat on the subcommittee. In addition, representatives from the University of Arkansas and the Arkansas Department of Health were present for support. The subcommittee used a consensus model to make all implementation decisions.

### **Survey Construction**

The subcommittee reviewed several validated surveys provided by the University of Arkansas and the Arkansas Department of Health. The University of Hawaii and the Ministry of Health from the RMI also provided survey instruments that had been used with the Marshallese population. The subcommittee then established and prioritised categories of questions that were most important, using a consensus model of decision-making. Categories included demographics, health status, access to health care, barriers to health care, body weight and height, physical activity, health history, current health condition, reproductive health, oral health, alcohol consumption, tobacco use, knowledge about AIDS, sexually transmitted diseases, tuberculosis, physical check-up for cancer, domestic violence, and community health problems.

After survey questions were selected by the subcommittee, a survey draft was constructed and sent to the broader CBPR group, which included the full membership of GAPS, the Department of Health and academic partners, for comments and suggestions. All comments and suggestions were discussed and incorporated by the subcommittee and a final version was constructed. The final survey included 64 questions that were taken from five validated survey instruments. These included Behavior Risk Factor Surveillance System, Siloam Springs Rural Health Corporate

Survey, Jones Family Institute Homeless Survey, Kaiser Permanente Health Survey and the 2007 Republic of the Marshall Islands' Health Survey.

The survey was reviewed for cultural appropriateness by Marshallese members of the subcommittee. The final version of the survey was translated into Marshallese by a local Marshallese pastor and then confirmed by the Marshallese Consulate. The survey was pilot tested with a small group of Marshallese who worked at the Jones Center for Families. A University of Arkansas doctoral student created an online version of the survey using Survey Monkey. The process of reviewing, drafting, editing and translation took place in only five weeks.

### **Survey Implementation Process**

The survey was conducted over the one-week period of the Marshallese Constitution Day celebration, 19–26 May 2009. The Marshallese Constitution Day celebration is a traditional cultural event that celebrates the signing of the Marshallese Constitution in 1979. This event includes ceremonies that honour the signing of the Marshallese Constitution as well as team sporting events and traditional cultural dance and singing events. The Marshallese Constitution Day celebration is held annually during the last week of May in many locations, including the RMI, Arkansas, California, Hawaii, Oregon and Washington state. From 2000 to 2009, the Marshallese Constitution Day celebration was held in Arkansas at the Jones Center for Families. In 2008, the year prior to the survey, more than 3000 Marshallese took part in the Marshallese Constitution Day events held in Arkansas. Because of the large number of Marshallese at the celebration, it was determined to be an ideal time to achieve a large convenience sample.

The survey was administered through computer-assisted self-administered questionnaires in both English and Marshallese. Participants completed the survey at the Jones Center for Families in a large computer centre with 24 desktop computers and a computer classroom with 12 computers.

Five Marshallese individuals who were bilingual in English and Marshallese and highly computer literate were hired to recruit participants and assist people with questions during the survey process. To promote study participation, flyers were distributed during the Marshallese Constitution Day and the study was announced on a popular Marshall Islands website: <http://yokwe.net/>

The needs assessment was reviewed by the Institutional Review Board and granted an exemption. Participants were 18 years of age or older. Each participant was assigned a unique participant identification number, and participants were given a \$20 Walmart gift card as remuneration for their participation.

### **Post-event Process**

Upon completion of the data collection, the raw data was sent to the Arkansas Department of Health (ADH) for statistical analysis.

ADH staff cleaned the data, imported the data into Statistical Analysis Software (SAS), cross-tabulated the data and developed the initial tabulation of results.

Two participatory data-analysis events occurred following the initial tabulation of the data. The first event was a joint meeting of GAPs and Northwest Arkansas Hometown Health Improvement Project, where the Arkansas Department of Health presented the summary data of the 2009 Health Survey of Marshallese. There was an opportunity for questions and discussion about what the information meant and how it could be used. Sixty-three people attended this event. While some Marshallese were present at the first meeting, the majority of participants were service providers to the Marshallese.

The second event focused specifically on the Marshallese community. Using Marshallese churches as the point of contact, Marshallese were invited to attend an event at the Jones Center for Families to review summary data of the 2009 Marshallese Health Survey. Lunch was provided to all attendees, then males and females were invited to separate meetings in accordance with Marshallese custom. Marshallese staff who worked at the Arkansas Department of Health presented the summary data to the 89 people in attendance.

After the summary data was presented, people were invited to attend focus groups to share their reactions to the survey results and help interpret the information. Again, males and females attended separate focus groups, three for each gender, each with a Marshallese facilitator. Participants in each group were asked open-ended questions related to their interpretation of the information presented.

Information from the focus groups was used to create the final needs assessment document and an Action Register based on the input and prioritisation of the broader Marshallese community stakeholders. Individuals and organisations took ownership of specific topics and reported each month on progress toward solutions. Those action items continue to be active in 2015.

## **RESULTS**

Event organisers estimated that 4000 people attended the 2009 Marshallese Constitution Day event. The number of survey respondents (n=1289) far surpassed the target number of 600. The event also attracts many Marshallese from other states. Out-of-state participants were allowed to participate; however, Arkansas residents were the primary focus of the study, so all non-Arkansans were removed from the sample, reducing the total to 874 respondents. The Arkansas sample was slightly more educated, but had higher rates of unemployment than the rates reported in the 2010 US Census for the Marshallese population living in Arkansas (see Table 1).

## **DISSEMINATION AND ACTION**

The Arkansas Department of Health printed 100 copies of the 2009 Marshallese Health Survey summary data for distribution.

Table 1: Demographic characteristics of survey respondents residing in Arkansas

	2010 Arkansas US Census*		Health Study		Difference in Percentage
	Percentage	Frequency	Percentage	Frequency	
<b>Age</b>					
18 to 34	66.6%	(1520)	66.8%	(584)	-0.2%
35 to 64	31.8%	(725)	31.2%	(273)	0.3%
65 and older	1.7%	(38)	1.3%	(11)	0.4%
Don't know/no answer	-		0.7%	(6)	-
<b>Gender</b>					
Males	51.3%	(1171)	43.6%	(381)	7.7%
Females	48.7%	(1112)	56.1%	(490)	-7.7%
Don't know/no answer	-		0.3%	(3)	-
<b>Education</b>					
Less than 9th grade	14.5%	(222)	9.2%	(80)	6.1%
High school	70.5%	(1077)	71.2%	(622)	-2.3%
College	14.9%	(228)	16.5%	(144)	-0.8%
Graduate or professional	0.0%	(0)	0.2%	(2)	-0.1%
Other	-		1.5%	(13)	-
Don't know/no answer	-		1.5%	(13)	-
<b>Employment</b>					
Employed	58.6%	(951)	39.4%	(344)	17.5%
Unemployed	14.3%	(233)	24.0%	(210)	-11.0%
Not in labor force	27.1%	(440)	32.8%	(287)	-2.6%
Don't know/no answer	-		3.8%	(33)	-

\*2010 US Census data is for Arkansas residents who report race as Marshallese alone or in any combination with other groups (U.S. Census Bureau 2010a, 2010b, 2010c).

The Marshallese Task Force (including Marshallese members) and the Northwest Arkansas Hometown Health Improvement Project had a joint meeting in January 2010 to present the results of the survey; 68 people attended the event. This event was covered in the Northwest Arkansas section of the *Arkansas Democrat-Gazette* newspaper, with three separate articles during 2010. Additionally, Marshallese were invited to attend a luncheon at the Jones Center for Families on 23 April 2010, where they learned the results of the survey and were invited to participate in focus groups to interpret the findings and prioritise issues to be collaboratively addressed; 89 Marshallese attended.

## DISCUSSION

The novel method of implementation during a traditional cultural event allowed for targeted, high-yield recruitment of participants. The goal was initially 600 participants, and the total recruitment was more than double that number. While time between the grant submission and approval was almost a year, the team only had five weeks to construct, pilot and implement the survey. As a result, there were limitations and many lessons learned during the process.

### Limitations

The Marshallese Health Study was not without challenges. There were limitations on the methods used to conduct the study. The primary limitation of the study was the use of a convenience sample. While the subcommittee considered other sampling methods, there were no clear, acceptable alternatives for sampling small, hard-to-reach populations who had limited health-care access (Faugier & Sargeant 1997; Goel & Salganik 2010; Heckathorn 1997; Magnani et al. 2005; Marpsat & Firdion 1999; Valenzuela Jr 2002). However, few differences were identified when the sample was compared with the 2010 US Census data for Marshallese living in Arkansas. The sample was similar in age, had slightly more females and education, and higher unemployment rates than the 2010 US Census data reported.

A second limitation was a malfunction with the skip patterns of the computerised survey. The electronic survey program did not allow for skip patterns. While skip pattern instructions were provided, respondents did not always follow those instructions. This may have caused some confusion. Skip patterns were inserted for data analysis, but the fact that respondents answered some questions that should have been skipped showed evidence of some misunderstanding.

In addition, there were logistical challenges. On 21 May 2009, the fire alarm at the Jones Center for Families went off and all occupants, including study participants, were required to leave the building. Those who were actively taking the survey had to start the survey again. In addition, the server for the computer laboratory crashed and some surveys were lost. At peak periods, there were significant waiting times to take the survey and some potential respondents were lost due to this.

The information was limited to self-reported health status and health behaviours. The study would have benefited from combining health-screening information with self-reported information to provide a more complete and empirical picture of the health of the Marshallese community. Organisers had planned to link health-screening information with the survey results, but the short timeline did not allow for implementation of that plan.

### LESSONS LEARNED

The following lessons learned were compiled by the GAPs subcommittee, which included representatives from the Marshallese Consulate, Marshallese pastors and Marshallese community, as well as health-care provider, non-profit organisation, Arkansas Department of Health and University of Arkansas representation. The list of lessons learned was then distributed to the broader group via email. Additional edits were made based on the input of the larger group. Final lessons learned were confirmed by the subcommittee and presented back to the broader group. These lessons are presented below.

**Collaboration is important at all levels**

There was significant cooperation between the health-care providers, non-profit agencies and the Marshallese community. In addition, both the University of Hawaii and the Ministry of Health from the Marshall Islands were involved in the collaboration process, provided survey instruments and shared information about previous surveys with the Marshallese. The Arkansas Department of Health and the University of Arkansas played a more peripheral and supportive role. All parties worked together to ensure their unique contribution focused on the collective goal.

**Engagement of leaders is imperative**

Support from the Marshallese Consulate and Marshallese pastors was identified as one of the elements critical to the success of the project. If time had allowed, the organisers would have also included additional Marshallese elders in the pre-implementation planning process.

**Community-driven and organised processes can allow for rapid implementation**

While the study would have benefited from additional time to plan and implement the health survey, the subcommittee was able to implement it within five weeks from the award notice. Furthermore, more than 1200 people participated, with only one week available for data collection. The flexibility and dedication of the community-based organisations allowed for rapid implementation.

**The post-event process is just as important as the survey information**

The post-event interpretation, discussion and dissemination of the data led to an Action Registry. This Action Registry is viewed as the biggest success of the project and it is still being used in 2015. The Action Registry has led to changes in organisational practices and allows local organisations to receive grant funding. This will be described further in a later article. Elders in the Marshallese community thanked organisers for the post-event luncheon and discussion, noting that they appreciated their involvement in determining how the information was interpreted, presented and used to improve their community.

**Cultural sensitivity is imperative**

Throughout the process, Marshallese were involved in choosing the questions, recruitment, data collection, interpretation, dissemination, action and implementation. This allowed the organisers to be sensitive in many critical areas. For example, the entire group ate lunch together, and then the genders were divided for the results discussion. Both the shared meal prior to important discussions and the separation of genders when discussing health information were in accordance with Marshallese cultural tradition.

**The short timeframe increased limitations**

While proud of the accomplishment, the organisers saw the timeframe as 'nearly impossible'. To achieve the best results, the



survey needed a more intensive field test prior to implementation. Additional testing with the online system would have helped improve implementation logistics and the survey instrument, and many of the skip pattern issues may have been avoided with more time to test the computerised survey.

### **Information is power**

While limitations exist with self-reported data from a non-representative sample, the information can still be powerful for planning and advocacy purposes. Local health-care providers and non-profit organisations have used the information to collaboratively meet the needs of the community.

### **CONCLUSION**

This article describes a community-driven needs assessment process aimed at better understanding the health status and concerns of the Northwest Arkansas Marshallese community, for which there was a complete absence of health status data. The implementation process was novel and provided the basis for program planning and increased dialogue between service providers, the Marshallese community and researchers.

While random population-based samples will continue to be the gold standard of health-surveillance research, special populations with significant health disparities are often under-represented in these studies, or aggregated with other populations in a way that provides information that is of little value to particular communities, health-care providers, and non-profit organisations. As communities of Pacific Islanders move further from the west coast into rural Southwestern states, such as Arkansas, the lack of data, combined with the necessity to better understand the health status of the new population, make it crucial to conduct non-traditional health surveys. Without health data, new minority communities and their providers do not have the information required to advocate for the programs and services needed. Additional methods are required to provide practical, inexpensive and methodologically sound sampling strategies to access low-density minority communities that are not represented in traditional population-based studies.

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