

# Hawai‘i Journal of Medicine & Public Health

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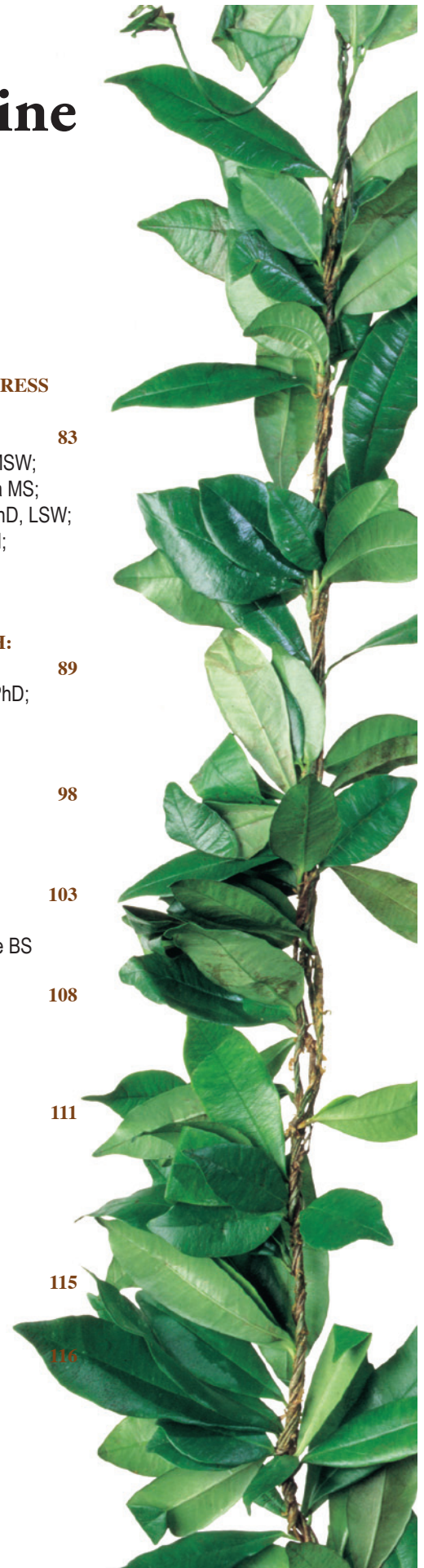
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# Hawai'i Journal of Medicine & Public Health

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# Advancing Community-Based Participatory Research to Address Health Disparities in Hawai'i: Perspectives from Academic Researchers

Katherine I. Yang MPH; Jane J. Chung-Do DrPH; Loren Fujitani MPH; Alyssa Foster MSW; Shannon Mark MEd; Yuito Okada PhD; Zeyana Saad-Jube PhD, MPH; Fadi Youkhana MS; Kathryn L. Braun DrPH; Kevin Cassel DrPH; Susana Helm PhD; Lana Sue Ka'opua PhD, LSW; Peter J. Mataira PhD; Christy Nishita PhD; Scott K. Okamoto PhD; Angela U. Sy DrPH; Claire Townsend Ing DrPH; Kristine Qureshi PhD, RN, CEN, PHNA-BC, FAAN; and Karen Umemoto PhD

## Abstract

*Community-based participatory research (CBPR) continues to be recognized as an effective research approach in which academic researchers work in partnership with communities to address health disparities. Although the literature suggests benefits associated with CBPR, more needs to be done to advance CBPR to ultimately reduce health disparities. Hawai'i presents a research-rich opportunity for CBPR because of its ethnic diversity and geographic location, resulting in close-knit communities with unique experiences and concerns. This study aims to better understand the experiences of academic researchers who are conducting CBPR in Hawai'i and their perceptions of its benefits and challenges as well as recommendations to advance the field. Twelve academic researchers with Hawai'i-based CBPR experience were interviewed. Four major themes emerged from their responses: the importance of prioritizing relationship-building; reciprocal learning and other benefits of CBPR; navigating the tensions between CBPR and funding priorities; and building an academic setting that supports CBPR. Increasing awareness of CBPR and its benefits, as well as transforming the culture in all spaces where CBPR occurs may maximize its potential to ultimately promote health equity.*

## Keywords

*Community-Based Participatory Research, university, academia, faculty, qualitative research, community engagement, minority communities, culture, power dynamics*

## Abbreviations

CBPR — Community-Based Participatory Research  
U.S. — United States  
NCBI — National Center for Biotechnology Information  
IRB — Institutional Review Board  
AI — American Indian  
AN — Alaska Native

Community-Based Participatory Research (CBPR) is an approach that aims to address pervasive health disparities in minority communities<sup>1,2</sup> and is defined as “a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strengths that each brings”.<sup>3</sup> CBPR begins with a research topic important to the community and combines knowledge and action for social change to improve community health.<sup>3</sup> CBPR recognizes that community members have expertise on cultural knowledge, attitudes, rules of interaction, and context that shape the experiences of the community. CBPR advocates for community members to be equal and active partners in determining the research agenda

and process and has shown promising results to address health disparities that affect diverse communities.<sup>4,6</sup>

Hawai'i has one of the most diverse populations in the United States (U.S.) with three quarters of residents identifying themselves as Native Hawaiians, Pacific Islanders, and/or Asians.<sup>7</sup> The state has a high rate of interracial and interethnic marriages, with 50% of newborns being of mixed race/ethnicity.<sup>8</sup> Currently, one in four residents (24%) identifies as being multiracial.<sup>8</sup> Hawai'i is often ranked as one of the healthiest states in the country because of the high average life expectancy and high rate of residents with health insurance.<sup>9</sup> In Hawai'i, 52.3% of adults are reported to be overweight or obese,<sup>10</sup> compared to 70.2% of all U.S. residents.<sup>11</sup> In 2014, 9.7% of the population in the state had been diagnosed with diabetes and 14.4% had pre-diabetes compared to 9.3% diagnosed with diabetes and 27.8% diagnosed with pre-diabetes in the U.S. population.<sup>12,13</sup> Despite these outcomes that are above national averages, ethnic and racial health disparities in Hawai'i disproportionately affect Native Hawaiians, the indigenous population of Hawai'i, as well as other Pacific Islanders. For example, 14.8% of Pacific Islanders are afflicted with diabetes compared to 5% of Caucasians in Hawai'i.<sup>12</sup> Life expectancy varies by ethnicity, which is 76.6 years for Native Hawaiians compared to 87.7 years for people of Chinese ancestry.<sup>9</sup> These disparities are due to the social determinants of health, such as educational and income disparities. For example, 18% of Native Hawaiians and Pacific Islanders are living below the poverty rate compared to the state average of 9.6%.<sup>9</sup> These ethnic disparities are rooted in the impacts of colonization that decimated the Native Hawaiian population as well as acculturative challenges faced by many Pacific Islander migrants.<sup>14,15</sup>

In addition to these disparities, a history of unethical research practices in the Pacific has led to community members' reluctance and wariness to engage with researchers who are not familiar with the community's culture.<sup>16,17</sup> For example, the U.S. government tested nuclear bombs in the region of Micronesia that destroyed human life and ecological systems of the islands.<sup>18</sup> Native Hawaiians have been also subjected to exploitive treatment by medical researchers, including the exile of Native Hawaiians with Hansen's disease to a remote northern

peninsula on the island of Moloka'i. Unethical medical studies were conducted by government physicians to identify the mode of transmission of Hansen's disease without consent or regard of this vulnerable population.<sup>19,20</sup> Community members also express their frustration with researchers "taking from the community without giving back to it," being disrespectful of cultural protocols, holding damaging stereotypical notions of their community, and providing no perceivable benefits to the community.<sup>17</sup> These behaviors lead to many communities to distrust research and researchers. CBPR principles, which are grounded in the long-term commitment to relationship-building and sustainability, aim to establish research pathways that redress the distrust and the inherent power imbalances of the research enterprise.<sup>1-3</sup> These principles are (1) Recognize community as a unit of identity, (2) Build on the strengths and resources of the community, (3) Facilitate a collaborative and equitable partnership in all phases of research, (4) Integrate knowledge and action for mutual benefits of all partners, (5) Promote co-learning and empowering process that attends to social inequities, (6) Involve a cyclical and iterative process, (7) Address health from a positive and ecological perspective on multiple determinants of health, and (8) Disseminate findings and knowledge gained to all partners and involve them in the wider dissemination of results.

Given the ethnic diversity and unique socio-political context of Hawai'i, CBPR is an ideal research approach to address Hawaii's health disparities.<sup>21,22</sup> With CBPR projects steadily growing in Hawai'i,<sup>22,26</sup> the purpose of this study was to interview academic researchers who actively practice CBPR in Hawai'i and elicit their perspectives on CBPR benefits, challenges, and recommendations for future research praxis. This study was conducted through a public health graduate-level class at the University of Hawai'i Office of Public Health Studies. Six students from the course led the recruitment, data collection, and analysis with guidance from their instructor.

## Methods

### Participants

Academic researchers who have or are actively conducting CBPR across the state of Hawai'i were eligible to be recruited for this study. Participants initially were identified by searching the peer-reviewed literature for Hawai'i-based CBPR projects using "Community-Based Participatory Research," "Community Action Research," "Participatory Action Research" as well as "Hawaii" and "Hawaiian" as keywords. Databases that were used for literature search included PubMed, EBSCO, JSTOR, and other databases hosted by National Center for Biotechnology Information (NCBI). The database search was conducted in September-October of 2016. Names of researchers identified by the database search were compiled with names of CBPR researchers who were known to the students and instructor.

Snowball sampling was used to identify and recruit other CBPR researchers in the study. Snowball sampling is a common technique for recruiting study participants that are hard to reach

or difficult to identify due to narrow eligibility criteria, such as the present study. Current participants were asked to refer other CBPR researchers from their personal networks based on participant eligibility.<sup>27</sup>

### Measures

A semi-structured interview guide comprised of 10 questions was developed de novo by the group of graduate public health students working on this study as part of their coursework. The interview guide was tested with the instructor of the class (JCD), who is also a co-author of this study. Questions were designed to capture participants' motivation for conducting CBPR, perceived benefits and challenges associated with CBPR, and their recommendations on how CBPR could be advanced in Hawai'i. A total of twelve interviews (seven in-person, and five by phone) were conducted based on participants' preference and availability during the interview phase of the study. Interviews were scheduled during the semester in which the students were enrolled in the course. Interviews lasted between 30-120 minutes. All participants provided oral consent. To ensure accuracy of understanding, interviews were audio-recorded and notes were taken by student interviewers. Study procedures were approved by the University of Hawai'i Office of Research Compliance.

### Data Management and Analysis

Interview notes were first transcribed by the interviewer and then verified with audio recordings. Each transcript was de-identified and analyzed using content analysis. First, each transcript was individually reviewed by one or more members of the student research team to identify descriptive codes based on the interview guide. Codes were defined from a reoccurring word or a short phrase related to specific concepts and constructs that predominately emerged from the interviews for each interview question.<sup>28</sup> These codes emerged from the data, as opposed to being fitted into previously defined codes. Second, the group of student researchers convened to discuss each code, then grouped the codes into preliminary themes using consensus coding. Third, the preliminary themes were shared and validated with participants at an in-person dissemination gathering. Those who were not able to attend were provided a copy of the completed paper and were asked to provide comment and/or feedback. Based on the participants' feedback, themes were refined and the final themes are presented below.

### Results

Twelve CBPR academic researchers participated in the study. Other CBPR researchers expressed interest in participating but were not available for the interview phase of the study. The majority of participants were employed by the University of Hawai'i at Mānoa with 11 affiliated with the University of Hawai'i at Mānoa and one affiliated with Hawai'i Pacific University. Three were male and nine were female. Participants had an average of 19 years of experience conducting CBPR, with 16 of these years in Hawai'i (across the state). Ethnicity-

ties of participants included Native Hawaiian, Filipino, Maori (the Indigenous people of Aotearoa New Zealand), Japanese, African-American, and Euro-American. Participants came from diverse academic disciplines and research areas, including social work, public health, gerontology, health science informatics, indigenous studies, nursing, and behavioral and mental health. Current employment status of participants ranged from lecturer, research faculty, instructional faculty, and administrators. All worked on research that included community partners in O'ahu as well as in neighboring islands. Participants reported receiving funding from various sources, such as nonprofit, and state and national government agencies to conduct CBPR in Hawai'i.

Four major themes emerged from the content analysis: the importance of prioritizing relationship-building; reciprocal learning and other benefits of CBPR; navigating the tensions between CBPR and funding priorities; and building an academic setting that supports CBPR. There was much agreement among the participants throughout the interviews and across the themes.

### **Theme 1: Importance of prioritizing relationship-building**

All participants emphasized the importance of prioritizing relationship-building to learn about the specific cultures and contexts of each community that they are partnering with. Relationship-building was considered essential to cultivate a place-based understanding of specific communities in Hawai'i, and to avoid making assumptions and generalizations that may hamper the CBPR process. As one participant stated, "*CBPR researchers have to make a long-time relationship with the community. To me, it is necessary, it is the process.*"

CBPR approaches were viewed as aligning well with the cultures of Hawai'i, which tend to be collectivistic and relational. Collectivism and relational emphases were attributed to the indigenous host culture as well as the significant presence of Asian and Pacific Islander communities. An aspect of relationship-building is the awareness of positionality in terms of insider/outsider status, which participants recognized as important for navigating community dynamics. As one participant stated, "*in Hawai'i, we are relationship driven. There is sense of an outsider/insider mentality.*" The importance of outsider researchers needing to take the time to engage in an authentic relationship-building process by demonstrating their commitment was also emphasized in the responses collected. "*A lot of these smaller communities are all families. You are invited into very tight-knit communities. You will be spending a lot of time there, you need to demonstrate that you are real and that you care about them and their community.*"

### **Theme 2: Reciprocal learning and other community benefits of CBPR**

Words used to describe the benefits of CBPR were *collaboration, recognition, research insight, confidence, and active participation*. The reciprocal learning process and recognizing

the community's expertise can positively shape and guide the research process, which produces lasting and direct benefits to the community. As one participant expressed, "*they are excellent partners because they can define the need, what the project should be about, and what would work/not work within their organization.*" Another participant spoke about how collaborating with community members can help: "*researchers identify and learn new approaches that they may not have thought about prior to collaboration within the community.*" CBPR can also create a "*comfortable space*" for community members to connect and engage with researchers and academia. Participants reported that this has helped transform the community's prior perceptions about research and academia, which often is perceived to be a disconnected enterprise occurring in the "*ivory tower*". As a participant stated, "*community exposure, engagement, and involvement in research can lead to interest in how research can benefit [the] community.*" Furthermore, CBPR's principle to share and make the findings accessible to the community allows for community members to be informed and able to take action. This point was summarized by a participant who stated, "*CBPR can serve as a bridge between the community and those in academia. Policy change can happen when academia and the community work together.*"

### **Theme 3: Navigating the tensions between CBPR and funding priorities**

Regarding challenges, CBPR principles unanimously were viewed as conflicting with institutional expectations. For example, building trusting relationships is a necessity of CBPR, but academic time constraints were repeatedly mentioned as a challenge to fulfilling this principle. As one participant stated, "*from a science perspective, the grants are very time-limited. It takes years to establish relationships in communities. Trying to convince funders you need a lot of time is a challenge.*" They also expressed the need for funders to allow for more "*flexibility in research designs.*" Many expressed that this would be helpful in conducting CBPR, which tends to be iterative and dynamic. The challenge of short-term funding was also raised as posing barriers to sustaining programs and services. Once a grant ends, finding resources to sustain the efforts initiated was often cited as a major challenge: "*Funding is always a challenge especially after the grant period. You want to be able to sustain the new program/model.*"

Participants acknowledged the nature of research funding, which traditionally is awarded to universities, poses challenges to truly addressing power imbalances. Although CBPR promotes community members as equitable partners in research and intellectual leadership, upholding this in practice was notably difficult. Participants recognized this predicament and stated the need for more systematic support to build capacity within the community so that research leadership may be equitable.

#### **Theme 4: Building an academic setting that is conducive to CBPR**

Multiple ideas and identified challenges to advance CBPR in academia were given. For instance, participants spoke about the lack of high-impact journals that publish CBPR findings, lack of academic incentives in community dissemination activities, such as producing and distributing community-friendly research products, and the need for other avenues for publication, such as a “*Web journal for CBPR products [that] would count towards tenure.*” Integrating CBPR principles and priorities into the Institutional Review Board (IRB) process was also cited as playing an important role in advancing CBPR. “*The IRB needs to be aware of CBPR. IRB requires specific roles in research... only one person can be the principal-investigator and not more than one. Therefore, educating IRB about the specific roles of CBPR is necessary.*”

Furthermore, CBPR generally was perceived to be unknown to bench and biomedical researchers, and thus problematic because academic standards for conducting studies is conducive to lab research, but not appropriate for CBPR. These limitations and constraints restrict the CBPR process and diminish the potential and capacity of CBPR’s benefits. If universities gave greater recognition to CBPR and the work it entails, there may be more support for this approach to be integrated and promoted across various fields and disciplines. Offering more training in CBPR across disciplines was suggested to potentially increase the number CBPR researchers to advance the field. This was summarized by a quote from one of the study participants: “*A lot of people don’t understand it. [We need] more training on what good CBPR research is and why it’s important to conduct it. [We need] more people who do it and more people who could train people to do CBPR.*” Responses collected also reported encouraging students to analyze and question CBPR practices from the past, and critique what is currently in place by asking, “*Are current CBPR practices, policies, and procedures effective? If not, why are they ineffective, and what can we do to improve and make changes that will benefit everyone?*” Another recommendation was to create “*interprofessional and interdisciplinary collaboration, like writing groups*” to build CBPR learning communities across academia.

#### **Discussion**

The mission of many universities often includes a call to serve the community. Despite the progress that has been made in partnering with communities, academic institutions, are often seen as “*ivory towers*” that are not accessible and friendly to the community.<sup>29</sup> Community members do not always see the direct benefits and social action of the research and instead perceive research as a distant activity, that is disconnected from the community’s lived experiences. CBPR offers a way to shift the paradigm of research to promote equitable partnerships between communities and academic researchers. With CBPR projects steadily growing in Hawai‘i,<sup>22-26</sup> it is necessary to understand how CBPR is being conducted and identify the facilitators and barriers of conducting this type of research approach.

The findings of this study suggest that the foundation of CBPR is based in relationship-building that leads to reciprocal learning between academia and the community. To support the relationship-building process, systems-level changes may be needed to demonstrate and realize the full benefits of CBPR. A key finding in this study focused on the relationship between the researcher and community as a major influencer of CBPR. The importance of trusting relationships in CBPR research has been found by other studies.<sup>16-17, 21-26</sup> Jagosh, et al, found that investing in research partnerships can potentially lead to significant returns unforeseeable prior to the start of the project.<sup>30</sup> Establishing and maintaining a long-term relationship with community may take on even more prominence in Hawai‘i due to the collectivist nature of the many small, tight knit communities.<sup>17,21</sup>

Although Hawai‘i is a relatively small state with approximately 1.4 million residents,<sup>31</sup> it is the most diverse state in the nation. CBPR has helped researchers to recognize the nuanced differences in needs and resources between various communities across the islands. Furthermore, the community’s involvement can influence policy changes to directly address the community’s needs and promote sustainable collaborations.<sup>20</sup> Continual co-learning can increase community ownership and co-governance, which is essential to making systems change to advance initiatives.<sup>32-34</sup>

Building trusting relationships in CBPR is challenged by systemic barriers identified in this study, such as the academic promotion system and funding structures, which have been documented in other studies.<sup>35-36</sup> Investments such as time and funding are required to build strong academic-community partnerships. This creates tensions between the requirement of the researcher’s institution and funding sponsor and the requirements of building a strong community-academic partnership.<sup>30</sup> In an assessment of how well federally-funded community network programs integrated CBPR principles, most programs scored well on conducting strength-based and action-oriented projects that facilitated co-learning and capacity-building but scored lower on equitable sharing of resources and sustainability.<sup>32</sup>

Although some evaluations of federally-funded CBPR have suggested that achieving equality is genuinely unrealistic due to an underfunded service orientation of community partners and the social and institutional systems that perpetuate imbalances of power,<sup>35</sup> participants in this study provided suggestions to address these tensions. These suggestions are also reflected in the wider CBPR literature, such as integrating community dissemination efforts in tenure and promotion guidelines,<sup>36</sup> increasing the number of high-impact CBPR journals, implementing CBPR trainings for students and junior researchers,<sup>37</sup> and infusing CBPR principles and practices into institutional research ethics review boards.<sup>29</sup> These suggestions may be conducive to universities that integrate the importance of community engagement and placed-based learning in their mission or strategic plans, such as University of Hawai‘i, which is a land-grant institution and has the mission of cultivating a Hawaiian Place of Learning.<sup>37</sup> Others suggested using evaluative measures to assess the partnering process and outcomes.<sup>38</sup>



A study by Allen, et al,<sup>39</sup> recommended providing education and facilitation programs to support partnership building, and to increase the capacity for CBPR within communities and research institutions. Previous literature also emphasized the importance of recognizing one's biases from the researcher's perspective and understanding how researchers' inherent identity and privilege can influence the quality of CBPR studies.<sup>30,34</sup> Because the importance of relationships in small close-knit communities of Hawai'i were emphasized by the participants, the *Hilina'i: Trust and Cultural Safety in Research Praxis* framework may serve as guidelines and a teaching tool for students and researchers who hope to collaborate with communities to conduct CBPR.<sup>17</sup> *Hilina'i* is a Hawaiian word for "trust" and also serves as a mnemonic to emphasize the importance of: **H**onoring community history of strength and resilience, **I**ntrospecting of one's biases, **L**earning community ways of knowing and transmitting knowledge, **I**nvolving oneself in community activities, **N**urturing meaningful community participation across the phases of the research, **A**cting to enhance research capacity of the community, and **I**nsurrecting relationships of unequal power and control through culturally-grounded processes. Using similar placed-based frameworks that are grounded in the worldview of the specific community that researchers hope to work with may advance the field of CBPR. Participants in this study also suggested integrating community members into CBPR trainings to promote the exchange of knowledge and co-learning. Furthermore, the community's involvement can influence policy changes to directly address the community's needs and promote sustainable collaborations.<sup>40</sup> Continual co-learning can increase community ownership and co-governance, which is essential to making systems change to advance initiatives.

### Limitations & Future Directions

The findings of this study were based on the responses from twelve CBPR researchers in Hawai'i. Participants came from diverse fields, but were limited to university-based researchers residing on the island of O'ahu with the majority affiliated with the University of Hawai'i at Mānoa. Academic researchers from colleges including community colleges in the neighboring islands, which are primarily rural and recognized as underserved areas, were not recruited for this study. However, the majority of the participants have conducted or currently are conducting CBPR across the State of Hawai'i. In addition, this study only focused on CBPR researchers who are situated in academic settings and affiliations. To expand on the present study and the extant literature, future studies could focus on gathering the perspectives from organizations focusing on Native Hawaiian health and/or minority health, and community partners and community researchers who have been or are involved in CBPR.<sup>17,21</sup> In addition, CBPR would benefit from studies that

examine the structural factors that impede or promote CBPR with populations that are relevant to Hawai'i's context. For example, a review of federally funded community engaged research studies indicated that American Indian (AI)- and Alaska Natives (AN)-serving projects have higher rates of written partnership agreements, research integrity training, and data ownership.<sup>34</sup> However, these AI/AN projects receive less federal funding, yet have comparable research productivity compared to research with other communities of color. It would be important to assess if this pattern of funding and outcomes applies to CBPR occurring in Hawai'i.

### Concluding Remarks

The results from this study suggest that there should be more CBPR trainings offered to students and researchers to promote CBPR, as well as bring awareness to this research approach. Also, research review boards may need to consider different types of research by adjusting their submission process so it's more inclusive of studies like CBPR. Lastly, institutions could modify their criteria for tenure and promotion to value the activities in which CBPR researchers engage, such as allowing researchers more time to build relationships with a community and have community members involved in every step of the research project. CBPR has the promise to close this gap to ensure that communities benefit from the research enterprise. Insights shared by the CBPR researchers in this study can play an important role in advancing CBPR to address health disparities and promote health equity.

### Conflict of Interest

None of the authors have any conflict of interest to report.

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## References

1. Israel B, Schulz A, Parker E, Becker A. Review of community-based research: assessing partnership approaches to improve public health. *Annual Review of Public Health*. 1998;19(1):173-202. doi:10.1146/annurev.publhealth.19.1.173.
2. Wallerstein N, Duran B. Community-Based Participatory Research Contributions to Intervention Research: The Intersection of Science and Practice to Improve Health Equity. *American Journal of Public Health*. 2010;100(S1):S40-S46. doi:10.2105/ajph.2009.184036.
3. Minkler M, Wallerstein N. *Community-Based Participatory Research For Health: From Process To Outcomes (2Nd Edition)*. Jossey Bass Inc; 2010:6.
4. Rhodes SD, Vissman, AT, Stowers, J, Miller, M., McCoy, TP, Hergenrather, KC, Wilkin, AM, Reece, M, Bachmann, LH, Ore, A., Ross, MW, Hendrix, E., Eng, E., A CBPR Partnership Increases HIV Testing Among Men Who Have Sex with Men (MSM): Outcome Findings From a Pilot Test of the CyBER/testing Internet Intervention. *Health Education & Behavior* 2011 Jun;38(3):311-20. doi: 10.1177/1090198110379572.
5. Tung T, Nguyen, Stephen J, McPhee, Ngoc Bui-Tong, Thien-Nhien Luong, Tuyet Ha-Iaconis, Thoa Nguyen, Ching Wong, Ky Q. Lai, Hy Lam. 2006. Community-Based Participatory Research Increases Cervical Cancer Screening among Vietnamese-Americans. *Journal of Health Care for the Poor and Underserved* Volume 17, Number 2, p. pp. 31-54. 10.1353/hpu.2006.0078
6. Cacari-Stone L, Wallerstein N, Garcia A, Minkler M. The Promise of Community-Based Participatory Research for Health Equity: A Conceptual Model for Bridging Evidence with Policy. *American Journal of Public Health*. 2014;104(9):1615-1623. doi:10.2105/ajph.2014.301961.
7. Bureau U. Statistical Abstract of the United States: 2012. *Census.gov*. 2017. Available at: <https://www.census.gov/ua/facets-publications/2011/compendia/statab/131ed.html>. Accessed November 11, 2016.
8. Krogstad J, Krogstad J. Hawaii is home to the nation's largest share of multiracial Americans. *Pew Research Center*. 2017. Available at: <http://www.pewresearch.org/fact-tank/2015/06/17/hawaii-is-home-to-the-nations-largest-share-of-multiracial-americans/>. Accessed July 25, 2017.
9. America's Health Rankings. (2017). *2015 Annual Report*. [online] Available at: <https://www.americashealthrankings.org/learn/reports/2015-annual-report> [Accessed 10 Jun. 2017].
10. State of Hawaii, Department of Health. (2012). *Hawaii Health Survey*. Retrieved from <http://health.hawaii.gov/hns/files/2015/07/3.1-Number-and-Percent-Overweight-Including-Obese-By-County-Gender-Age-and-Ethnicity-%E2%80%93-Adult-Population-of-Hawaii-Table-and-Figure.pdf>.
11. Overweight & Obesity Statistics. National Institute of Diabetes and Digestive and Kidney Diseases. <https://www.niddk.nih.gov/health-information/health-statistics/overweight-obesity>. Published August 1, 2017.
12. Hawaii Health Data Warehouse. (2015). Diabetes: 2011-2014. Available at: [http://hhdw.org/wp-content/uploads/BRFSS\\_Diabetes\\_IND\\_00001\\_2011.pdf](http://hhdw.org/wp-content/uploads/BRFSS_Diabetes_IND_00001_2011.pdf).
13. Centers for Disease Control and Prevention. *National Diabetes Statistics Report, 2017*. Atlanta, GA: Centers for Disease Control and Prevention, US Department of Health and Human Services; 2017.
14. Jonathan Y. Okamura. *Ethnicity and Inequality in Hawaii*. Philadelphia, PA: Temple University Press; 2008.
15. Mayeda DT, Chesney-Lind M, Koo J. Talking Story with Hawaii's Youth. *Youth & Society*. 2001;33(1):99-128. doi:10.1177/0044118x01033001004.
16. Fong M, Braun KL, Tsark JAU. Improving Native Hawaiian Health Through Community-Based Participatory Research. *Californian Journal of Health Promotion*. 2003;1(Special Issue: Hawaii):136-148.
17. Kaopua LS, Tamang S, Dillard A, Kekauoha, BP. Decolonizing knowledge development in health research cultural safety through the lens of Hawaiian Homestead residents. *Journal of Indigenous Social Development*. 2017; 5(2): 20-42.
18. Palafox N, Riklon S, Esah S, et al. The Micronesians. In: McDermott JF, Naupaka NN, eds. *People and Cultures of Hawaii: The Evolution of Culture and Ethnicity*. Honolulu: University of Hawaii Press; 2011:295-315.
19. Au, M. (2015). *Healing Generations of Historical Trauma in a Hawaiian Body of Knowledge. A Case Study of an Act to Prevent the Spread of Leprosy, 1865*. M.A. University of Hawaii at Manoa.
20. Mouritz AASM. The Path of the Destroyer: a History of Leprosy In the Hawaiian Islands, And Thirty Years Research into the Means by Which it Has Been Spread. *Honolulu Star Bulletin*. 1916.
21. Chung-Do J, Look M, Mabellos T, Trask-Batti M, Burke K, Mau M. Engaging Pacific Islanders in Research: Community Recommendations. *Progress in Community Health Partnerships: Research, Education, and Action*. 2016;10(1):63-71. doi:10.1353/cpr.2016.0002.
22. Matsunaga DS, Enos R, Gotay CC, Banner RO, DeCembra H, Hammond OW, Hedlund N, Ilaban EK, Issell BF, Tsark JA. Participatory research in a Native Hawaiian community. The Wai'anae Cancer Research Project. *Cancer*. 1996 Oct 1;78(7 Suppl):1582-6.
23. Kaholokula JK. Community-Based Participatory Research (CBPR) with Native and Pacific Populations: Addressing Cultural Competency Issues. *Hawaii J Med Public Health*. 2013;72(8Suppl3):6.
24. Mau MK, Kaholokula JK, West MR, et al. Translating Diabetes Prevention into Native Hawaiian and Pacific Islander Communities: The PILI 'Ohana Pilot Project. *Progress in community health partnerships : research, education, and action*. 2010;4(1):7-16. doi:10.1353/cpr.0.0111.
25. Kaopua LSI, Park SH, Ward ME, Braun KL. Testing the Feasibility of a Culturally Tailored Breast Cancer Screening Intervention with Native Hawaiian Women in Rural Churches. *Health & Social Work*. 2011;36(1):55-65. doi:10.1093/hsw/36.1.55.
26. Helm S, Lee W, Hanakahi V, Gleason K, McCarthy K, Haumana. (2015). Using photovoice with youth to develop a drug prevention program in a rural Hawaiian community. *American Indian and Alaska Native Mental Health Research*, 22(1), 1-26. doi: 10.5820/aian.2201.2015.1. PMID: PMC4401743.
27. Sadler GR, Lee H-C, Lim RS-H, Fullerton J. Research Article: Recruitment of hard-to-reach population subgroups via adaptations of the snowball sampling strategy. *Nursing & Health Sciences*. 2010;12(3):369-374. doi:10.1111/j.1442-2018.2010.00541.x.
28. Saldana J. *The coding manual for qualitative researchers*. Thousand Oaks, CA: Sage Publications; 2016.
29. Shore N, Brazauskas, R, Drew E, Wong KA, Moy L, Baden AC, Cyr K, Ulevicus, J, Seifer SD. Understanding Community-Based Processes for Research Ethics Review: A National Study. *Am J Public Health*. 2011 December; 101(Suppl 1): S359-S364. doi: 10.2105/AJPH.2010.194340.
30. Jagosh J, Bush PL, Salsberg J, et al. A realist evaluation of community-based participatory research: partnership synergy, trust building and related ripple effects. *BMC Public Health*. 2015;15(1). doi:10.1186/s12889-015-1949-1.
31. Census. Census | 2015 State Population Estimates. <http://census.hawaii.gov/home/population-estimate/>.
32. Braun KL, Nguyen TT, Tanjasiri SP, et al. Operationalization of Community-Based Participatory Research Principles: Assessment of the National Cancer Institute's Community Network Programs. *American Journal of Public Health*. 2012;102(6):1195-1203. doi:10.2105/ajph.2011.300304.
33. Helm S, Davis K, Haumana, AYP. Challenges and lessons learned in implementing a community-academic partnership for drug prevention in a Native Hawaiian community. *Puerto Rico Health Sciences Journal*. 2017;36(2):101-106.
34. Muhammad M, Wallerstein N, Sussman AL, Avila M, Belone L, Duran B. Reflections on Researcher Identity and Power: The Impact of Positionality on Community Based Participatory Research (CBPR) Processes and Outcomes. *Critical Sociology*. 2014;41(7-8):1045-1063. doi:10.1177/0896920513516025.
35. Pearson CR, Duran B, Oetzel J, et al. Research for Improved Health: Variability and Impact of Structural Characteristics in Federally Funded Community Engaged Research. *Progress in Community Health Partnerships: Research, Education, and Action*. 2015;9(1):17-29. doi:10.1353/cpr.2015.0010.
36. Nyden P. Academic incentives for faculty participation in community-based participatory research. *J Gen Intern Med*. 2003;18(7):576-85.
37. Hawaiian Place of Learning Implementation Task Force. Ka Ho'okō Kuleana: Fulfilling Our Responsibility to Establish the University of Hawaii at Mānoa as a Hawaiian Place of Learning. January 2016. [https://manoa.hawaii.edu/strategicplan/pdf/ka\\_hooko\\_kuleana\\_implementation\\_report.pdf](https://manoa.hawaii.edu/strategicplan/pdf/ka_hooko_kuleana_implementation_report.pdf).
38. Oetzel JG, Zhou C, Duran B, et al. Establishing the Psychometric Properties of Constructs in a Community-Based Participatory Research Conceptual Model. *American Journal of Health Promotion*. 2015;29(5). doi:10.4278/ajhp.130731-quan-398.
39. Allen ML, Culhane-Pera KA, Pergament S, Call KT. A Capacity Building Program to Promote CBPR Partnerships between Academic Researchers and Community Members. *Clinical and Translational Science*. 2011;4(6):428-433. doi:10.1111/j.1752-8062.2011.00362.x.
40. Brush BL, Baiardi JM, Lapidus S. Moving Toward Synergy: Lessons Learned in Developing and Sustaining Community-Academic Partnerships. *Progress in Community Health Partnerships: Research, Education, and Action*. 2011;5(1):27-34. doi:10.1353/cpr.2011.0003.



# Patient Perspectives in Comparing Hospitals for Childbirth: Insights from Hawai'i

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## Abstract

Childbirth is a national priority area for healthcare quality improvement. Patient perspectives are increasingly valued in healthcare, yet Asian American and Pacific Islander (AAPI) perspectives of healthcare quality are often understudied, particularly from individuals with limited English proficiency (LEP). Our study goal was to understand factors that consumers in Hawai'i, including AAPI and those with LEP, use to compare patient care in hospitals, especially for childbirth. A total of 400 women ages 18 years and older with a recent childbirth completed an in-person interview in English (n=291), Tagalog (n=42), Chinese (n=36), or Marshallese (n=31) on O'ahu, Hawai'i. Participants described if (yes/no), and how (open-ended), they believed hospitals in the state varied in providing patient care. Open-ended responses were coded by two independent raters using the framework approach. Respondents were 53.3% Asian, 30.8% Pacific Islander, 13.5% White, and 2.5% other race/ethnicity; 17.8% reported limited English proficiency. Overall, 66.8% of respondents affirmed that local hospitals varied in patient care; Marshallese, other Pacific Islanders, and non-English speakers were significantly less likely to say that Hawai'i hospitals varied in patient care. Among those who endorsed hospital variation, commonly reported themes about this variation were: (1) patient experience, (2) patient overall impression, (3) childbirth options (eg, waterbirths), (4) staff, (5) facilities (eg, "emergency capabilities"), (6) high-tech levels of care, and (7) the hospital's area of focus (eg, "women and children"). We provide insights into factors that diverse patients use to compare patient care in hospitals in Hawai'i to add value, relevance, and engagement to healthcare quality research and dissemination efforts.

## Keywords

Asian American, Pacific Islander, limited English proficiency, hospital quality, childbirth

## List of Abbreviations

AAPI: Asian American/Pacific Islander

LEP: Limited English proficiency

AHRQ: Agency for Healthcare Research and Quality

IRB: Institutional Review Board

Despite substantial national, state, and local investment in building a publicly-available evidence base on hospital quality that consumers can use to compare facilities, these data are underused by the public generally.<sup>1-14</sup> Many patients are not aware of these measures, find them confusing, and/or are not using them to make healthcare decisions.<sup>11-13</sup> Healthcare quality can indeed be complex, conflicting, and even, controversial to measure.<sup>15</sup> Yet there is an expectation that if healthcare quality information can be measured and presented to consumers in a way that is meaningful to them, they will choose healthcare facilities delivering higher quality care, thus driving overall healthcare quality improvement.<sup>9-11</sup> Hence, there is a growing interest in understanding what patients value in comparison of healthcare

facilities in order to improve the relevance of, and engagement in, public reports of hospital quality.<sup>13,16</sup> These developments align with a growing interest in consumer perspectives on healthcare generally, including efforts by the Patient-Centered Outcomes Research Institute to align clinical research with outcomes of high relevance to consumers.<sup>17</sup>

Asian American and Pacific Islander (AAPI) perspectives on healthcare and healthcare quality may be distinct, but are often understudied, particularly from individuals with limited English proficiency (LEP).<sup>18,19</sup> AAPI subgroups experience health disparities across a diverse array of healthcare outcomes, including low birth weight, preterm deliveries, and inefficient prenatal care.<sup>20-25</sup> LEP presents a significant barrier to healthcare and is associated with poor outcomes, including poorer communication in healthcare.<sup>21,25</sup> AAPI patients may not have access to culturally competent care, or care that is sensitive to their unique social, cultural, and linguistic needs.<sup>18,19,21-26</sup> It is critical to consider the perspective of AAPI patients as they comprise a growing proportion of the population in the United States (U.S.).<sup>27</sup> About eight percent of the total U.S. population over the age of 5 has LEP.<sup>28</sup>

Our study goal was to understand factors that consumers in Hawai'i, including AAPI population groups and those with LEP, used to compare patient care across hospitals, especially for childbirth. Hawai'i is racially and ethnically diverse with 28% of individuals ages 18 years and older speaking a language other than English at home.<sup>29</sup> We focused on childbirth as childbirth is a national priority area for healthcare quality improvement,<sup>30,31</sup> and the most common reason women are hospitalized in the U.S.<sup>32</sup> Childbirth is particularly well-suited for comparative quality engagement as pregnant women are typically engaged consumers with advanced notice about their upcoming hospitalization and interest in choosing a facility for delivery that is right for them.<sup>8,13,14,19</sup>

## Methods

### Study Design

This was a mixed-methods study in which women ages 18 years and older who had delivered a baby in the previous two years (N=400) were interviewed on O'ahu, Hawai'i between July 2013 and January 2015. This study was designed as a convenience sample for insights from specific major ethnic and linguistic groups in the state, not as a comprehensive surveillance of the opinions of all population groups in the state. Our recruitment goal was 400 women with targeted racial/ethnic/

linguistic combination of approximately 50 participants in each group to capture diverse perspectives and to ensure that no racial/ethnic group dominated results. This sample size met the need for a sufficient sample size to detect quantitative differences for moderate effects of at least 85% statistical power both across racial/ethnic groups and within racial/ethnic groups by LEP, while maintaining a realistic sample size to reach thematic saturation for qualitative analyses. To ensure diversity of this sample, women were recruited across a variety of locations, following recruitment methods used in previous studies of mothers in Hawai'i.<sup>33</sup> We used community-based recruitment activities, such as tabling in-person at several new baby exhibitions and local events, and posting advertisements on the bus and Craigslist. Interested recruits were interviewed in-person at a location of their choice after completion of an informed consent.

### Interview

In-person interviews, including both closed-ended questions (for quantitative analyses) and open-ended questions (for qualitative analyses), were conducted for about one hour in English (n=291), Tagalog (n=42), Chinese (n=36), or Marshallese (n=31). As it was not feasible to interview individuals across all relevant linguistic groups, we chose three non-English speaking groups of high policy relevance to Hawai'i. These included Chinese and Tagalog, two of the three most commonly spoken non-English languages in Hawai'i. Two Chinese dialects (Mandarin and Cantonese) were included because in Hawai'i, only 37.9% of Chinese speakers can speak English very well and Chinese is the most common non-English language spoken in the U.S. after Spanish.<sup>34</sup> Tagalog, a Filipino language, was included because Filipinos are a large and growing AAPI population in the U.S.<sup>34</sup> In Hawai'i, Tagalog is the leading non-English language spoken at home.<sup>35</sup> Finally, Marshallese, a language from the Republic of the Marshall Islands, was included due to the growing population of these individuals in Hawai'i and the U.S., and because they have significant health disparities and a unique immigration status.<sup>36</sup>

Bilingual research assistants translated all interview and consent materials. A separate bilingual individual then back-translated the instruments into English for each language. The two translators met to resolve discrepancies to ensure reliable instruments.<sup>37</sup> Interviews were pilot tested with members of the focal population in all study languages to ensure comprehension and relevance. More detail on interview methods can be found elsewhere.<sup>19</sup> Multilingual respondents within these linguistic categories could choose to interview in the language of their preference. Participants received a \$30 gift card to a local drug store as an incentive.

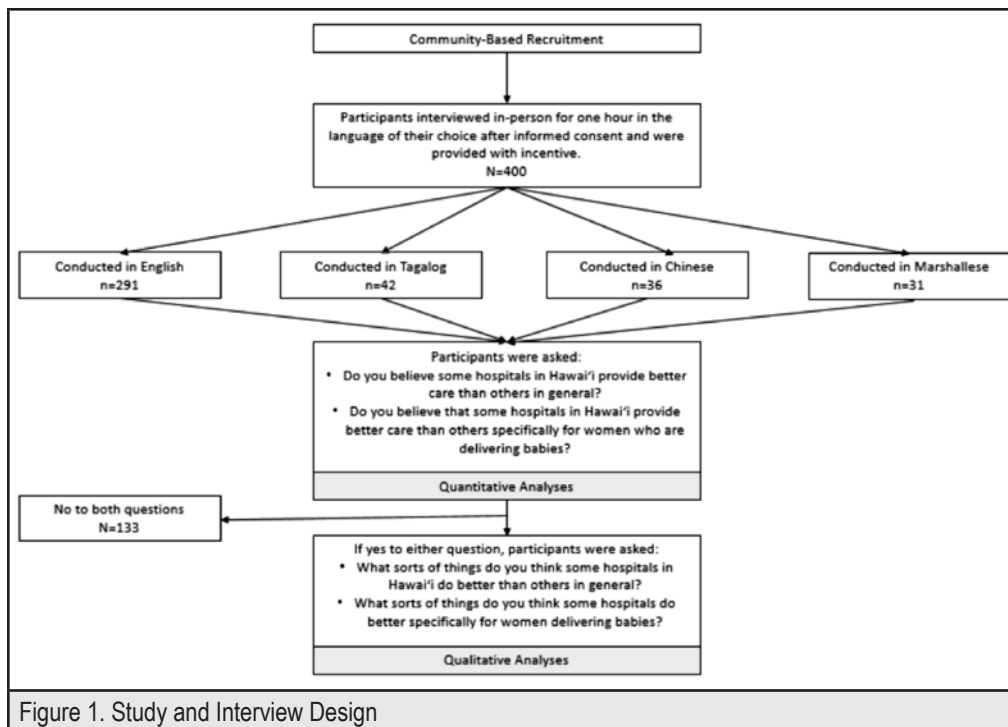
### Variables

**Personal Characteristics and Demographics.** Race/ethnicity was self-reported using an established method for the multiethnic and multiracial population of Hawai'i; participants were asked to report all racial/ethnic groups with which they identified and

then also asked for their primary racial/ethnic identity.<sup>38</sup> Primary race/ethnicity was used as the race/ethnicity variable. Those interviewed in a non-English language were asked to report their level of spoken English proficiency across four levels. Following standard procedures, any rating of less than the highest level (corresponding to "very well") was considered as limited English proficiency.<sup>39</sup> Age, education, and location of the participant's birth were obtained. Self-reported low health literacy was assessed with the commonly used, validated question,<sup>40</sup> "How confident are you filling out medical forms by yourself?" Response choices were: not at all, a little bit, somewhat, quite a bit, and extremely. Those who reported less than "quite a bit" of confidence were considered to have low self-reported health literacy. Self-reported high-risk pregnancy was obtained from a "yes" answer to the question: "Have you ever been told by a doctor or other healthcare provider that you had, a high-risk pregnancy?" To determine if this was their first baby delivered in Hawai'i, respondents were asked to self report if this was either their first baby or their first baby delivered in the state.

**Comparison Information.** Factors of relevance to patients in comparing patient care across hospitals was measured with both closed- and open-ended questions. As illustrated in Figure 1, we first asked if respondents felt that "some hospitals in Hawai'i provided better care than others in general" and "specifically for women who are delivering babies" to which they could respond yes or no. Respondents who responded "yes" to either item were considered to endorse a belief in variation of patient care across hospitals. These respondents were then asked the open-ended questions: "...what sorts of things do you think some hospitals in Hawai'i do better than others in general" and specifically, "for women delivering babies." All answers to open-ended questions, as well as detailed notes of the answers, were recorded using the *iSurvey* tool (Harvest Your Data, Wellington, NZ).

**Quality-specific Themes.** All interviews were reviewed by at least one reviewer. Two of the three independent reviewers (CM, CD, or NC) listened to a 10% sample of audio recordings to standardize the transcription process. Due to the large sample size and the length of the interview, not all open-ended questions for all participants were transcribed. These transcription notes were compared descriptively with interviewer notes for content overlap of salient issues. Strong content overlap was seen between the interview notes and the targeted transcriptions from the two independent reviewers, but was not assessed with formal metrics. For the rest of the interviews, one independent reviewer listened to the audio recording and made a targeted transcription for each open-ended question. In targeted transcriptions, reviewers transcribed responses only when respondents answered questions of relevance to the analyses, rather than creating a verbatim transcription of the full interviews. When coding themes in the qualitative analyses, independent reviewers had at least one targeted transcription as well as interview notes to consider, ensuring all salient details were captured.



### Quantitative Analyses

Demographics and belief that quality varied were compared descriptively in univariate analyses using chi-square tests for categorical variables by race/ethnicity and English proficiency combinations. Quantitative analyses were performed in STATA 12.0 (StataCorp, 2011; College Station, TX). Statistical significance was set at a *P*-value of < .05.

### Qualitative Analyses

Using both interview notes and targeted transcripts, themes were identified using the framework approach by two of three independent raters (TS, CM, or MN) with expertise in childbirth, healthcare quality, and/or AAPI communities.<sup>41</sup> Coders first reviewed and coded all material independently, then met and used an iterative approach to confirm themes. Coders also met regularly with the study team (including a provider, researcher, and healthcare quality expert) to discuss and contextualize emerging results. After 400 responses were all reviewed, coders re-reviewed consensus coding documents to ensure congruence with the final study themes. The final consensus coding was used for analyses.<sup>42</sup> Responses could be coded to one or more themes. Coders considered respondent-reported thoughts about healthcare quality, capturing expected issues from previous research and theory (eg, cleanliness, patient-centeredness) and emerging factors based on their perspectives.<sup>1,5,13,15</sup>

To be clear about our distinct themes, “staff” were the type of staff that were employed ubiquitously across hospitals, for example, nurses, or front desk staff. While in some health systems midwives are commonly part of healthcare staff, this has not been the case in Hawai‘i.<sup>43</sup> Only some hospitals in the

state had midwives on staff during the study period. Yet some women have a strong preference for midwives and make hospital decisions specifically to have access to midwives. Thus, we put this in the “childbirth options” theme. Waterbirths are similarly part of the “childbirth option” category as only some hospitals allow waterbirths and some women have strong preferences for them. “Facilities” included factors like its cleanliness, parking, or location.

### Availability of Data and Materials

Data from the notes and transcripts used for coding and codebooks are available from the authors.

### Institutional Review Board (IRB)

This study was approved by the University of Hawai‘i IRB (CHS # 20533).

### Results

#### Demographics

As seen in Table 1, the sample was diverse with 53.3% Asian (22.5% Filipino, 13.8% Chinese, 14.0% Japanese, 3.0% other Asian, which included Korean, Thai, and Vietnamese), 30.8% Pacific Islander (13.0% Native Hawaiian, 13.3% Marshallese, 4.5% Other Pacific Islander, which included Samoan and Tongan), 13.5% White, and 2.5% Other (which included Black, Hispanic, Native American, Multiracial, or “Don’t Know”) race/ethnicity. This was the first baby delivered in Hawai‘i for 83.0% of the sample. Almost 18% of the sample reported LEP. Compared to those who with English proficiency, those with LEP were significantly less likely to be educated or self-report



Table 1. Demographic Characteristics by Level of English Proficiency (N=400)				
	English Proficient	Limited English Proficiency	P-value	Total
n (%)	329 (82.2%)	71 (17.8%)		400 (100%)
	%	%		%
<b>Education</b>				
Less than high school	6.1	29.6	<.001	10.3
High school	44.7	39.4		43.8
College degree or more	49.2	31.0		46.0 <sup>a</sup>
<b>Race/ethnicity</b>				
Chinese	7.0	45.1	<.001	13.8
Filipino	22.2	23.9		22.5
Japanese	17.0	0		14.0
Other Asian <sup>b</sup>	3.6	0		3.0
Native Hawaiian	15.8	0		13.0
Marshallese	9.4	31.0		13.3
Other Pacific Islander <sup>c</sup>	5.5	0		4.5
White	16.4	0		13.5
Other <sup>d</sup>	3.0	0		2.5
<b>Self-reported low health literacy</b>	21.3	35.2		.013
<b>Mother's age group</b>				
18-24 years	26.4	22.5	.65	25.8
25-34 years	55.9	62.0		57.0
35 years and older	17.6	15.5		17.3
<b>Had baby in last year</b>	89.1	70.4	<.001	85.8
<b>U.S.-born</b>	68.4	2.8	<.001	56.8
<b>Health insurance</b>				
Quest/Medicaid	31.0	65.2	<.001	37.0
Tricare/Department of Defense	12.0	1.4		10.1
Private	50.9	31.9		47.6
More than one insurance	5.5	1.4		4.8
None	0.6	0		0.5
<b>Self-reported high-risk pregnancy</b>	30.4	22.5		.186

<sup>a</sup>Numbers do not total 100% due to rounding. <sup>b</sup>Other Asian included Korean, Thai, and Vietnamese. <sup>c</sup>Other Pacific Islander included Samoan and Tongan. <sup>d</sup>Other included Black, Hispanic, Native American, Multiracial, or "Don't Know."

health literacy. They were more likely to have public health insurance and did not differ significantly from the English speakers in terms of age group or if they had a high-risk pregnancy.

### Quantitative Findings

As seen in Table 2, overall, 66.8% of our sample reported a belief that patient care varied by hospital; 74.2% of those who spoke English proficiently and 32.4% of those who were LEP reported a belief that patient care varied by hospital ( $P<.001$ ). This finding varied significantly by LEP and race/ethnicity. Among those who spoke English, only 29.0% of Marshallese and 50.0% of Other Pacific Islanders believed that hospitals vary in patient care compared to 84.6% of Native Hawaiians,

85.7% of Japanese, and 77.8% of Whites ( $P<.001$ ). Among those with LEP, only 9.1% of Marshallese and 34.4% of Chinese reported the belief that hospitals in Hawai'i varied in patient care compared to 58.8% of Filipinos ( $P<.004$ ).

### Qualitative Findings

Key themes, brief descriptions, and illustrative quotes to explain factors that patients believed to be important from their responses to open-ended questions are seen in Table 3. The most common themes noted to describe relevant variations in patient care across hospitals were (1) the patient experience (reported by 44.6% of those who believed in variation); (2) overall impression (39.5%); (3) high-tech levels of care

Table 2. Participants Endorsing the Belief That Hospitals Vary in Patient Care by Level of English Proficiency (N=400)						
n	English Proficient <sup>a</sup>	Standard Error	Limited English Proficiency <sup>b</sup>	Standard Error	Total <sup>c</sup>	Standard Error
	329		71		400	
	%		%		%	
<b>Race/ethnicity</b>						
Chinese	60.9	.10	34.4	.09	45.5	.07
Filipino	80.8	.05	58.8	.12	76.7	.04
Japanese	85.7	.05	--	--	85.7	.05
Other Asian <sup>d</sup>	83.3	.11	--	--	83.3	.11
Native Hawaiian	84.6	.05	--	--	84.6	.05
Marshallese	29.0	.08	9.1	.06	20.8	.06
Other Pacific Islander <sup>e</sup>	50.0	.12	--	--	50.0	.12
White	77.8	.06	--	--	77.8	.06
Other <sup>f</sup>	90.0	.10	--	--	90.0	.10
<b>Total</b>	<b>74.2</b>	<b>.02</b>	<b>32.4</b>	<b>.06</b>	<b>66.8</b>	<b>.02</b>

<sup>a</sup>The comparison by race/ethnicity among those with English Proficiency varied significantly ( $p < .001$ ). <sup>b</sup>The comparison by race/ethnicity among those with LEP varied significantly ( $p = .004$ ). <sup>c</sup>The comparison by race/ethnicity including the full sample varied significantly ( $p < .001$ ). <sup>d</sup>Other Asian included Korean, Thai, and Vietnamese. <sup>e</sup>Other Pacific Islander included Samoan and Tongan. <sup>f</sup>Other included Black, Hispanic, Native American, Multiracial, or "Don't Know."

Table 3. Factors that Patients Described as Varying in Patient Care by Themes and Subthemes (N=267)*			
Main Code	Percentage and Number Reporting	Theme Description	Example(s)
<b>Patient Experience</b>	44.6% (n=119)	This focuses on patient experiences of care. Subthemes include communication with providers, having a "family" atmosphere, having a good relationship with providers, cultural competency, discrimination, and the importance of the patient being treated as a unique individual rather than just a number.	<i>"Some nurses, they take care of other people nicely just because of their race... If they know that you're Micronesian, it's like they don't really give you the same treatment as if it was a local person."</i> (Marshallese respondent)
<b>Impression Focused</b>	39.5% (n=105)	Individuals report the hospital's area of focus (eg, "women and children") as a main variation in quality, which they claim contributes to "better care." These factors seemed likely to be influenced by advertising, rumors, or impressions and were often from hearsay.	<i>"Everybody comes to [Hospital Name], even from outside the state."</i> (Japanese respondent)  ----- [Because of their specialization on women and children] <i>"I think [Hospital Name] has a better understanding of the nature of the woman in labor."</i> (Mixed-race respondent)
<b>High-Tech/Level of Care</b>	25.8% (n=69)	The ability to provide high-tech levels of care, including access to the "NICU" and "emergency capabilities," was an important area of variation in terms of quality.	<i>"There's no NICU in some hospital[s], so you'd have to be separated from babies if there's a problem. That would be a big factor in deciding for me. Not having a NICU would be a no-go."</i> (Native Hawaiian respondent)
<b>Staff</b>	17.6% (n=47)	This focuses on adequate staffing, and wanting staff to be kind, engaged, available and knowledgeable.	<i>"They're just more family-like [Hospital Name], to me they care more for you especially with the nurse that I had, she just kept me comfortable, she kept talking to me, and didn't make me feel uncomfortable whatsoever. She was very helpful."</i> (Filipina respondent)

Table 3. Factors that Patients Described as Varying in Patient Care by Themes and Subthemes (N=267)\* Continued from previous page

<p><b>Childbirth Options</b></p>	<p>25.1% (n=67)</p>	<p>This includes options for different types of childbirth techniques, classes, and access to midwives.</p>	<p>“Access to prenatal care, and support. [Hospital Name] has breast feeding classes, car seat 101 tips, infant CPR.” (Native Hawaiian respondent)</p> <p>-----</p> <p>“[Hospital A] talk[s] with patients about financial availability.” (Native Hawaiian respondent)</p> <p>-----</p> <p>“[Hospital A] took care of husband, in addition to the mother and baby.” (Hispanic respondent)</p> <p>-----</p> <p>“Some hospitals offer more options to the midwives, more personalized options, like the option for a midwife, or the option for different sorts of supplies that they can bring into the birthing room, or better equipment. Like I mentioned before some hospitals offer birthing pools, where you can have a water birth, or at least you can be in the water before you give birth. At least at [Hospital X] what I can say is they have very nice showers, and so, I don’t think it’s standard amongst all the hospitals. Each hospital has its own area that is slightly better than the other, depending on what you like. I like the showers, it was very helpful. Also, some hospitals have more advanced equipment that allow you to not always be hooked up to the machine, so you’re free to walk around if you need, if you like. That’s supposed to be very important for the process anyways, to be able to walk around, and so you’re not just stuck in bed the whole time.” (Hispanic respondent)</p>
<p><b>Facilities</b></p>	<p>14.2% (n=38)</p>	<p>This includes patient impressions on the physical facilities, including the size of the hospital and/or individual rooms, the age of the hospital, and security on hospital grounds.</p>	<p>“Some hospitals are bigger, so that means they have more room for rooms or specialty stuff.” (Filipina respondent)</p> <p>-----</p> <p>“The post delivery is different in different hospitals. For [Hospital Name], everything is on the same floor, and the rooms are big—delivery and post-delivery, recovery rooms—and you get to stay in the same room. [Hospital Name], you have to move around a lot, and it really depends on how many people give birth, no matter where you are, to how much to move. But, the rooms at [Hospital Name] are smaller.” (Chinese respondent)</p>
<p><b>Specific clinical outcome</b></p>	<p>2.2% (n=6)</p>	<p>Patients consider specific outcomes, such as rates of cesarean sections, which are commonly reported to the public as quality measures.</p>	<p>“Some support women in their decisions for natural birth than others. And that’s simply based on the results of cesarean rates; women who go in intending to have a natural birth and end up having a C-section, or end up having inductions etc., or interventions.” (Chinese respondent)</p>

\*Others, don’t know, or vague descriptions” are not listed in this table. Forty-seven individuals made a statement that was coded into this category.



(25.8%); (4) childbirth options (25.1%); (5) staff (17.6%); (6) facilities (14.2%); and (7) others, don't know, or vague descriptions (16.4%). Individuals could report more than one theme within a statement. Participants seldom reported a specific clinical outcome (eg, rates of cesarean sections) as something they compared across hospitals. In fact, only eight respondents noted considering specific patient clinical outcomes, which are commonly shared with the public as quality measures. Also, few (10%) of the respondents among those who reported that hospitals varied, were able to explain why they felt that hospitals did so. In considering whether hospitals varied, at least seven respondents – who all had reported they believed hospitals varied – emphasized a theme of personal experience as necessary to understand quality variation (eg, “*I did not go to another hospital, so how would I know how quality varied?*”).

Another major qualitative finding was that patients were very cognizant of quality trade-offs across different domains. For instance, as shown by this respondent's quote, hospitals known for high-tech levels of care may operate efficiently at the expense of patient-centeredness: “*From what I hear from my friends who delivered at [HOSPITAL NAME], they definitely focus more on the laboring to make sure that it's a very good experience. So, they take the time to teach you how to breast-feed, they take the time to labor with you, they really try to follow your birth plan without endangering you or the baby... [HOSPITAL NAME], on the other hand, does better with high risk pregnancies because, like I mentioned before, they do see a higher population of pregnant women, but sometimes I feel like it is like a baby factory. It's almost like you have a time limit. You have to have your birth before this time or else we might have to C-section you...but...I like [HOSPITAL NAME] because they see more complicated pregnancies, I feel they do so much better handling them. They have access to the NICU.*”

Similarly, another respondent stated: “*I think they provide care in different type of ways that some maybe have more higher experience level or higher specialty level, while others are more likely to listen to the individual and treat the individual as a person instead of just using general policy.*”

## Discussion

As public reporting of hospital quality grows, it is critical to understand what factors patients value in their decisions around healthcare facilities.<sup>8,13,14</sup> Childbirth is a particularly relevant moment in which patients often compare facilities.<sup>8,13,14</sup> Yet over 30% of women did not endorse our question of whether they believed hospitals varied in patient care. Some respondents, especially LEP Chinese, and both English proficient and LEP Marshallese were less likely than other groups to endorse this variation. Thus, some AAPI ethnic and linguistic subgroups may be less aware of quality variation across hospitals. Developers of hospital quality reports should consider these issues to engage diverse audiences in effective comparison of healthcare quality information. Even the premise that hospitals do vary in quality in meaningful ways might need to be deliberately established.

Our study showed that commonly-used obstetric hospital

quality metrics, such as cesarean delivery rates, are likely relevant to women, but the publicly-reported metrics around this topic were not commonly used by women in decision-making about hospital preference for childbirth. While many women mentioned a strong preference to not have a cesarean delivery, only two respondents specifically noted variation across hospitals on cesarean delivery rates. This is despite the fact that this term is one of the most commonly reported metrics in public reports of hospital quality and is generally understood by women.<sup>14,44</sup>

At the same time, women had interesting and sophisticated understanding of healthcare factors, many of which may be relevant for quality comparisons, and their trade-offs. Many women with a recent delivery characterized hospital quality in terms of patient-focused experience (43.9%), general impressions (39.2%), and the general desire for high-tech levels of care (25.8%). Patient-reported factors may be challenging to measure systematically by an objective source. However, some experiences that women described as varying across hospitals, such as availability of medical specialties at the hospital and staff to patient ratio, are distinctly recognizable as factors that would come up in conversations. Recent research on the value of Yelp to hospital quality has shown the value of the narrative description of quality.<sup>2,45</sup> Research shows consumers feel increasingly comfortable giving detailed personal histories online and most of us are now very familiar with using such anecdotal information to make decisions across many consumer domains.<sup>2,45</sup> There is a need to determine how to include this familiar type of information into public reports of hospital quality. This need is also congruent with the relevance of personalized information from family and friends among some AAPI groups, especially those with LEP, to make decisions.<sup>19</sup>

Given the complexity of measuring, explaining, and providing data that may measure quality for consumers, it is important to mention that not all metrics are of equal value to the healthcare system. One individual reported she appreciated one hospital for “better service, better doctors, better food.” These factors are not necessarily of equal importance. Although patient satisfaction is clearly critical to high quality care, clinicians still hold a responsibility to the patients that is beyond “maximizing satisfaction.”<sup>1</sup>

Health literacy is also important to consider in this domain. Innovative solutions to present easy-to-interpret healthcare information are critical, particularly for individuals with low health literacy and/or educational attainment.<sup>5-7</sup> Diverse dissemination and engagement strategies, such as clinical-based programs,<sup>8</sup> may be important for these populations, as well as for non-English speakers.

As we move towards greater patient-centered care, it is important to understand the perspectives of Asian American and Pacific Islander populations, two of the fastest growing racial groups in the United States.<sup>27</sup> Our sample included substantial numbers of AAPI participants as well as many respondents with LEP and provides quotes and details from these respondents. Our study highlights the importance of considering differences by race/ethnicity and by LEP.

## Strengths and Limitations

This study has many strengths and some limitations. We allowed participants to provide answers around factors they believed varied by hospitals, allowing for diversity in patient-reported outcomes that were coded in our qualitative analyses. Closed-ended questions could have provided different insights. The study was performed in Hawai'i, did not provide a one-to-one representation of the population, and focused on only three of the more than 60 Asian and Pacific Islander languages, targeting some particularly relevant languages in Hawai'i.<sup>46</sup> Our findings may not apply to other locations, cannot provide comprehensive data to represent the state population, and/or for speakers of other languages. This study focused on LEP, rather than language of preference, which can be distinct.<sup>39</sup> We focused on healthcare quality information during childbirth, an event when consumers often have the luxury of time to decide on a preferred hospital, which is not always the case in healthcare decisions. Use of healthcare quality information may be lower generally in times of greater stress and urgency.<sup>47</sup> This study was a convenience sample. Due to our large sample size, we did not have verbatim transcripts for all participants and did not calculate concordance across targeted transcripts and interview notes using traditional metrics.

## Conclusions

Patient conceptualization of factors relevant to variation in patient care may not align with available public reports of healthcare quality data. Some AAPI ethnic and linguistic subgroups may be less aware of quality variation across hospitals. Efforts to engage diverse AAPI populations in healthcare quality information should consider: (1) more languages, (2) better explanation of the value of existing quality metrics, and (3) integration of quality metrics with factors valued by women in healthcare decisions.

## Conflict of Interest

None of the authors identify any conflict of interest.

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## References

1. Saver BG, Martin SA, Adler RN, et al. Care that Matters: Quality Measurement and Health Care. *PLoS Med*. 2015;12(11):e1001902.
2. Huesch MD, Currid-Halkett E, Doctor JN. Public hospital quality report awareness: evidence from National and Californian Internet searches and social media mentions, 2012. *BMJ Open*. 2014;4(3):e004417.
3. Giordano LA, Elliott MN, Goldstein E, Lehrman WG, Spencer PA. Development, implementation, and public reporting of the HCAHPS survey. *Med Care Res Rev*. 2010;67(1):27-37.
4. Lantz PM, Evans WD, Mead H, Alvarez C, Stewart L. Knowledge of and Attitudes Toward Evidence-Based Guidelines for and Against Clinical Preventive Services: Results from a National Survey. *Milbank Q*. 2016;94(1):51-76.
5. Hibbard JH, Greene J, Daniel D. What is quality anyway? Performance reports that clearly communicate to consumers the meaning of quality of care. *Med Care Res Rev*. 2010;67(3):275-293.
6. Sofaer S, Hibbard J. *Best Practices in Public Reporting No. 2: Maximizing Consumer Understanding of Public Comparative Quality Reports: Effective Use of Explanatory Information*. Rockville, MD: Agency for Healthcare Research and Quality;2010.
7. Sofaer S, Hibbard J. *Best Practices in Public Reporting No. 3: How to Maximize Public Awareness and Use of Comparative Quality Reports Through Effective Promotion and Dissemination Strategies*. Rockville, MD: Agency for Healthcare Research and Quality;2010.
8. Goff SL, Pekow PS, White KO, Lagu T, Mazor KM, Lindenauer PK. IDEAS for a healthy baby—reducing disparities in use of publicly reported quality data: study protocol for a randomized controlled trial. *Trials*. 2013;14:244.
9. Bardach NS, Hibbard J. *Users of Public Reports of Hospital Quality: Who, What, Why, and How?* Rockville, MD: Agency for Healthcare Research and Quality;2011.
10. Hibbard JH, Greene J, Sofaer S, Firminger K, Hirsh J. An experiment shows that a well-designed report on costs and quality can help consumers choose high-value health care. *Health Aff (Millwood)*. 2012;31(3):560-568.
11. *Public Reporting as a Quality Improvement Strategy: A systematic review of the multiple pathways public reporting may influence quality of health care*. Agency for Healthcare Research and Quality;2011.
12. Christianson JB, Volmar KM, Alexander J, Scanlon DP. A report card on provider report cards: current status of the health care transparency movement. *J Gen Intern Med*. 2010;25(11):1235-1241.
13. Maurer M, Firminger K, Dardess P, Ikeler K, Sofaer S, Carman KL. Understanding Consumer Perceptions and Awareness of Hospital-Based Maternity Care Quality Measures. *Health Serv Res*. 2016;51 Suppl 2:1188-1211.
14. Gourevitch RA, Mehrotra A, Galvin G, Karp M, Plough A, Shah NT. How do pregnant women use quality measures when choosing their obstetric provider? *Birth*. 2017;44(2):120-127.
15. Friedman MA. Issues in measuring and improving health care quality. *Health Care Financ Rev*. 1995;16(4):1-13.
16. Beattie M, Murphy DJ, Atherton I, Lauder W. Instruments to measure patient experience of healthcare quality in hospitals: a systematic review. *Syst Rev*. 2015;4:97.
17. Fleurence R, Selby JV, Odom-Walker K, et al. How the Patient-Centered Outcomes Research Institute is engaging patients and others in shaping its research agenda. *Health Aff (Millwood)*. 2013;32(2):393-400.
18. Ghosh C. A national health agenda for Asian Americans and Pacific Islanders. *JAMA*. 2010;304(12):1381-1382.
19. Davis CM, Guo M, Miyamura J, Chang A, Nelson-Hurwitz DC, Sentell T. Key Factors in Obstetric Delivery Decision-Making among Asian and Pacific Islander Women by English Proficiency. *Hawaii J Med Public Health*. 2017;76(10):279-286.
20. Wong EY, Solet D. Maternal, Pregnancy, and Birth Characteristics of Asians and Native Hawaiians/Pacific Islanders—King County, Washington, 2003–2008. *Morbidity and Mortality Weekly Report*. 2011;60(7):211-213.
21. Sentell T, Chang A, Ahn HJ, Miyamura J. Maternal language and adverse birth outcomes in a statewide analysis. *Women Health*. 2016;56(3):257-280.
22. *2001 Health Care Quality Survey*. The Commonwealth Fund;2002.
23. *National Healthcare Disparities Report, 2013*. Agency for Healthcare and Quality;2014.
24. Morisako AK, Tauai'i M, Ambrose AJH, Withy K. Beyond the Ability to Pay: The Health Status of Native Hawaiians and Other Pacific Islanders in Relationship to Health Insurance. *Hawaii J Med Public Health*. 2017;76(3 Suppl 1):36-41.
25. Jang Y, Kim MT. Limited English Proficiency and Health Service Use in Asian Americans. *J Immigr Minor Health*. 2018.
26. (CDC) CfDCaP. Maternal, pregnancy, and birth characteristics of Asians and Native Hawaiians/Pacific Islanders—King County, Washington, 2003-2008. *MMWR Morb Mortal Wkly Rep*. 2011;60(7):211-213.
27. *The Asian Population: 2010*. United States Census Bureau;2012.
28. Whatley M, Batalova J. *Limited English Proficient Population of the United States*. Migration Policy Institute;2013.
29. *Non-English Speaking Population*. Hawaii: Department of Business, Economic Development & Tourism: Research & Economic Analysis Division;2016.
30. Institute of M. *Priority Areas for National Action: Transforming Health Care Quality*. Washington, DC: The National Academies Press; 2003.
31. Sakala C, Corry M. *Evidence-Based Maternity Care: What It Is and What It Can Achieve*. Co-published by Childbirth Connection; The Reforming States Group; Milbank Memorial Fund;2008.
32. *HCUP Facts and Figures: Statistics on Hospital-Based Care in the United States, 2009*. Rockville, MD: Agency for Healthcare Research and Quality;2011.
33. Albright CL, Steffen AD, Novotny R, et al. Baseline results from Hawai'i's Nā Mikimiki Project: a physical activity intervention tailored to multiethnic postpartum women. *Women Health*. 2012;52(3):265-291.
34. Ryan C. *Language Use in the United States: 2011 American Community Survey Reports*. U.S. Department of Commerce Economics and Statistics Administration;2013.

35. Detailed Languages Spoken at Home in the State of Hawaii. Hawaii State Data Center Research and Economic Analysis Division Department of Business, Economic Development and Tourism. [http://files.hawaii.gov/dbedt/census/acs/Report/Detailed\\_Language\\_March2016.pdf](http://files.hawaii.gov/dbedt/census/acs/Report/Detailed_Language_March2016.pdf). Published 2016. Accessed.
36. Riklon S, Alik W, Hixon A, Palafox NA. The "compact impact" in Hawaii: focus on health care. *Hawaii Med J*. 2010;69(6 Suppl 3):7-12.
37. dela Cruz FA, Padilla GV, Agustin EO. Adapting a measure of acculturation for cross-cultural research. *J Transcult Nurs*. 2000;11(3):191-198.
38. Kaneshiro B, Geling O, Gellert K, Millar L. The challenges of collecting data on race and ethnicity in a diverse, multiethnic state. *Hawaii Med J*. 2011;70(8):168-171.
39. *Chapter 4: Defining Language Need and Categories for Collection (cont.)*. Rockville, MD: Agency for Healthcare Research and Quality.
40. Chew LD, Bradley KA, Boyko EJ. Brief questions to identify patients with inadequate health literacy. *Fam Med*. 2004;36(8):588-594.
41. Smith J, Firth J. Qualitative data analysis: the framework approach. *Nurse Res*. 2011;18(2):52-62.
42. Bradley EH, Curry LA, Devers KJ. Qualitative data analysis for health services research: developing taxonomy, themes, and theory. *Health Serv Res*. 2007;42(4):1758-1772.
43. Cain CL. Hawaii's hospitals slowly open doors to midwives - Pacific Business News. 2001. Published 8 April 2001. Accessed 24 July 2018.
44. Guo M, Quensell M, Chang A, Miyamura J, Sentell T. Understanding of Key Obstetric Quality Terminology by Asian and Pacific Islander Subgroups: Implications for Patient Engagement and Health Equity. *Matern Child Health J*. 2018.
45. Ranard BL, Werner RM, Antanavicius T, et al. Yelp Reviews Of Hospital Care Can Supplement And Inform Traditional Surveys Of The Patient Experience Of Care. *Health Aff (Millwood)*. 2016;35(4):697-705.
46. *Hawaii-- Ability to Speak English by Language Spoken at home for the Population 18 Years and Over: 2000*. United States Census Bureau;2004.
47. Shaller D, Kanouse DE, Schlesinger M. Context-based strategies for engaging consumers with public reports about health care providers. *Med Care Res Rev*. 2014;71(5 Suppl):17S-37S.



# Tricuspid Valve Infective Endocarditis Due to *Klebsiella pneumoniae* in Intravenous Drug User

Tanawan Riangwiwat MD and Jonathan Dworkin MD

## Abstract

Infective endocarditis is a high morbidity-mortality condition despite advancements in supportive care and medical therapy. One of the strongest risk factors is intravenous drug use, which has high prevalence in the Hawai'i population. *Klebsiella pneumoniae* is a rare but aggressive pathogen causing infective endocarditis. There is no strong evidence to guide management. We present a rare case of isolated tricuspid valve infective endocarditis due to *Klebsiella pneumoniae* in an intravenous drug user causing septic pulmonary emboli and multiple abscesses. The patient was managed with combined 6-week ceftriaxone and 2-week gentamicin together with early tricuspid valve repair.

## Keywords

*Klebsiella pneumoniae*, tricuspid valve infective endocarditis, intravenous drug use

## Abbreviations and Acronyms

CRP = C-reactive protein

CT = Computed tomography

ESR = Erythrocyte sedimentation rate

HIV = Human immunodeficiency virus

hvKP = Hypervirulent *Klebsiella pneumoniae*

IE = Infective endocarditis

IV = Intravenous

IVDU = Intravenous drug use

MRI = Magnetic resonance imaging

TEE = Transesophageal echocardiogram

WBC = White blood cell

## Introduction

Despite advancements in medicine, infective endocarditis (IE) still causes a high rate of mortality and morbidity. Right-sided IE is less common than left-sided IE accounting for only 5%-10% of cases.<sup>1</sup> However, it is strongly associated with intravenous drug use (IVDU), which is responsible for 50%-65% of tricuspid valve IE cases.<sup>2</sup> The mortality and morbidity of IE depends on the type of pathogen, virulence factors, systemic complications, and the valve involved.<sup>3</sup> About 5%-16% of patients with right-sided IE require surgical intervention.<sup>1</sup>

*Klebsiella pneumoniae* is the second most common overall cause of gram-negative bloodstream infections after *Escherichia coli*.<sup>4</sup> While, the most common causative pathogen of IE is *Staphylococcus aureus*. *Klebsiella* species caused only 1.2% of cases of native valve endocarditis and up to 4.1% of cases of prosthetic valve endocarditis.<sup>5</sup> This low rate of IE may be related to the poor adherence of *Klebsiella* species to cardiac valves compared to gram-positive and other gram-negative organisms.<sup>6</sup> There is no guideline on management of patients with right-sided IE due to *Klebsiella pneumoniae*.

We present a case of *Klebsiella pneumoniae* IE of isolated native tricuspid valve with septic pulmonary emboli together

with systemic abscesses including osteomyelitis, epidural abscess and prevertebral abscess in an intravenous drug user.

## Case Presentation

A 55-year-old woman with intravenous heroin and methamphetamine abuse presented with a 1-week history of acute back pain, fever, chills, and productive cough with blood-tinged sputum. Vital signs on admission showed heart rate of 112 beats per minute and hypotension at 79/45 mmHg, but she responded well to fluid resuscitation. Physical examination showed tachycardia with pansystolic murmur grade 2. There was diffuse midline and paraspinous tenderness over the back. She had three ulcerative lesions in her right popliteal area measuring up to 1 cm in maximal diameter with purulent drainage. The right upper arm had a punctate area with easily expressed purulent drainage, which was painful, warm, and indurated. There was a sclerosed vein in the area. There were no stigmata of endocarditis.

Completed blood count showed leukocytosis [White blood cell (WBC) 13290 /microL] with neutrophil 85.7% and lymphocyte 8.3%. There was elevated C-reactive protein (CRP) at 32.3 mg/L (reference range 0-10 mg/L) and sedimentation rate (ESR) at 61 mm/hr (reference range 0-30 mm/hr). She had normal lactic acid level and a negative HIV Antibody/Antigen test. Chest radiography showed focal consolidation in the right middle lung (Figure 1). Computed tomography (CT) of the chest revealed ground-glass opacity and consolidation in the anterior segment of the right upper and middle lobe with associated cavitation concerning for necrotizing infection (Figure 2). Blood culture grew *Klebsiella pneumoniae* (in 2 of 2 sets) that was susceptible to ceftriaxone and was string test negative. Sputum culture grew 2 strains of *Klebsiella pneumoniae*, one with negative string test and the other with positive string test. Magnetic resonance imaging (MRI) of the spine showed C6-7 developing discitis osteomyelitis and L4-5 discitis osteomyelitis with 15 x 4 x 9 mm epidural abscess and surrounding phlegmon mildly effacing the ventral thecal sac and mildly narrowing the neural foramina. There was a paraspinous abscess extending from the abnormal L4-5 disc space associated with surrounding myositis and cellulitis (Figure 3). Transesophageal echocardiogram (TEE) found large mobile echogenic vegetation mass (1.94 x 1.79 cm) on the atrial and ventricular aspect of the tricuspid valve septal leaflet and subvalvular apparatus. There was mild tricuspid regurgitation (Figure 4).

The patient was empirically treated with vancomycin, ceftazidime and metronidazole. After culture results returned, antibiotics were changed to ceftriaxone and gentamicin. Repeated blood culture which was taken 5 days after empiric antibiotics

showed no growth. She had CT-guided left paraspinal abscess drainage at L4-5, and 12 ml of bloody purulent material was aspirated. Given multiple septic pulmonary embolism, a cardiothoracic surgeon suggested the patient have valvular repair surgery. She underwent tricuspid valve repair using 28 mm Carpentier-Edwards Physio tricuspid annuloplasty ring, removal of vegetation, and partial resection of the posterior leaflet. TEE after the procedure showed a well-seated tricuspid

valve annuloplasty ring with trace leak posteriorly. The tricuspid vegetation showed 4+ white blood cells (WBC) but no growth for aerobic, anaerobic and fungus which was not unexpected given she was on antibiotics for 2 weeks before the surgery. The patient completed 2 weeks course of gentamicin and 6 weeks of ceftriaxone without further complication. At 6 weeks follow-up, she had no recurrent signs or symptoms of endocarditis.

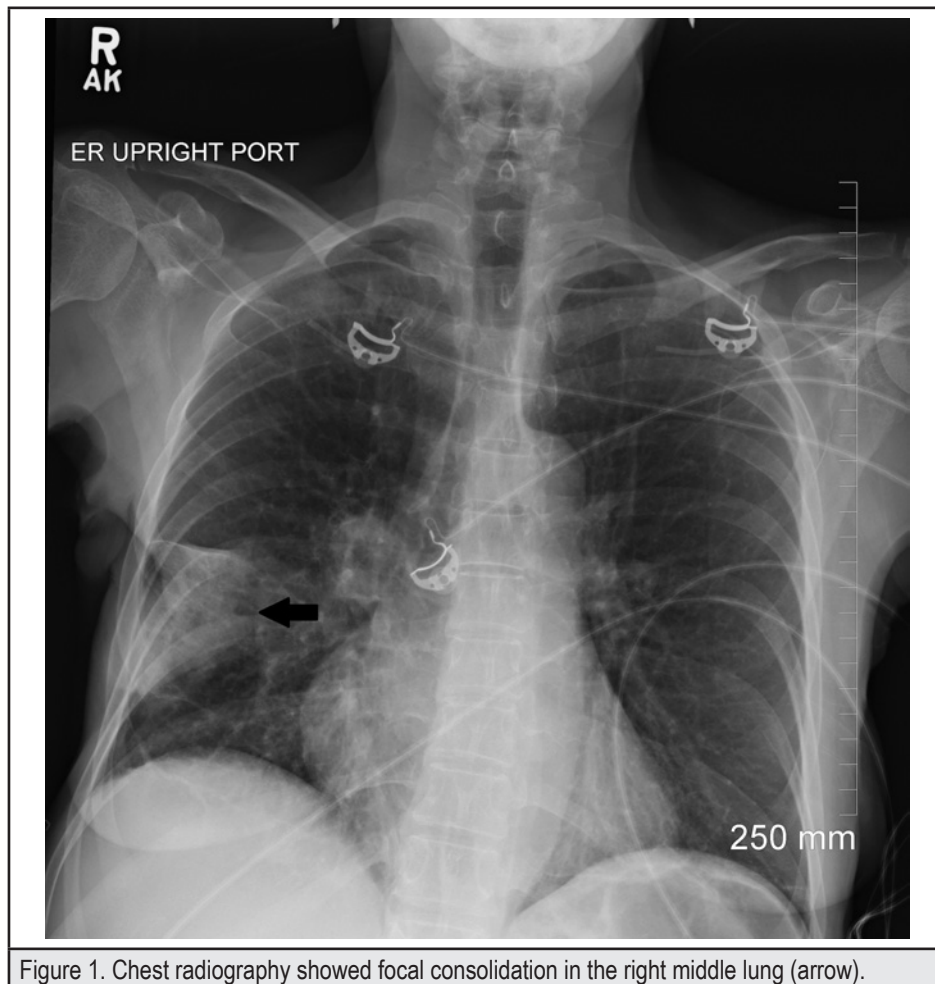


Figure 1. Chest radiography showed focal consolidation in the right middle lung (arrow).

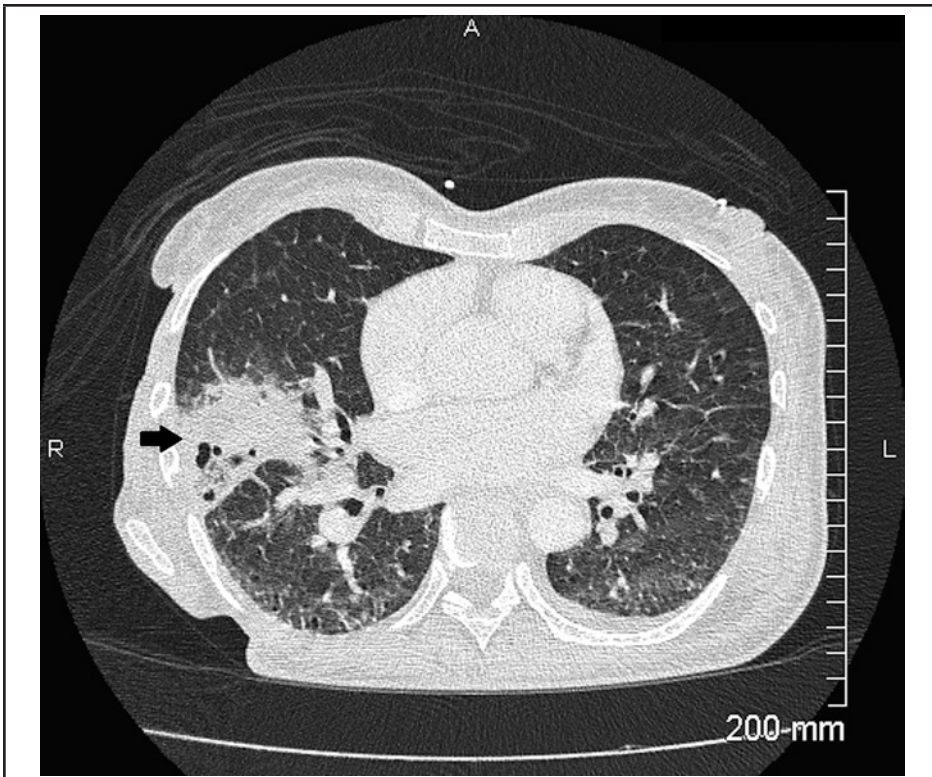


Figure 2. Computed tomography of the chest showed area of necrotizing infection (arrow) within the anterior segment of the right upper and middle lobe.

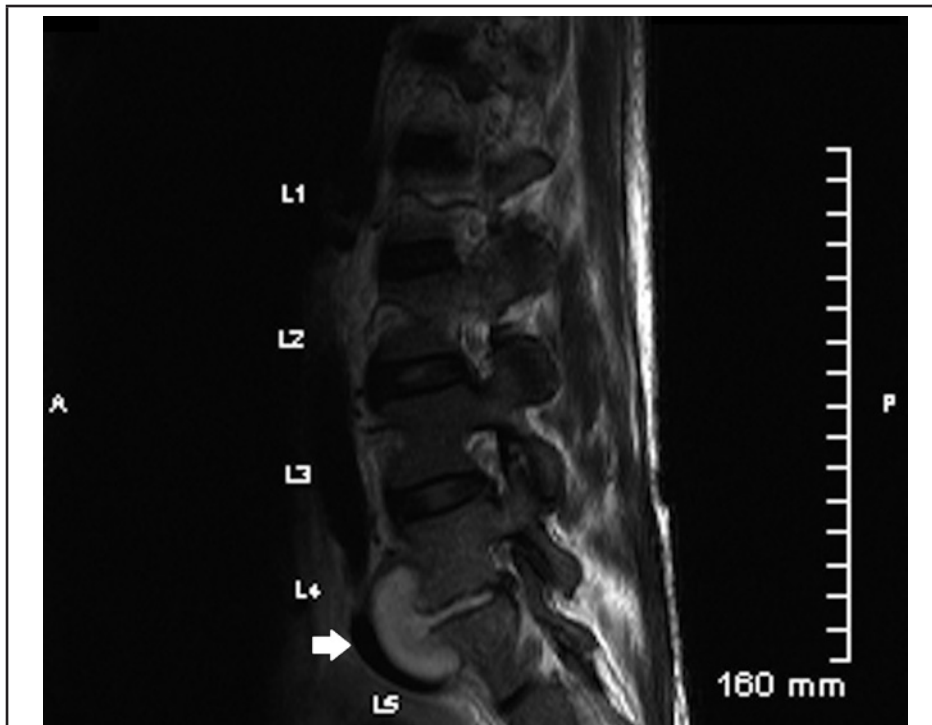


Figure 3. Magnetic resonance imaging of the lumbar spine showed discitis osteomyelitis with abscess (arrow) at L4-L5 disc.

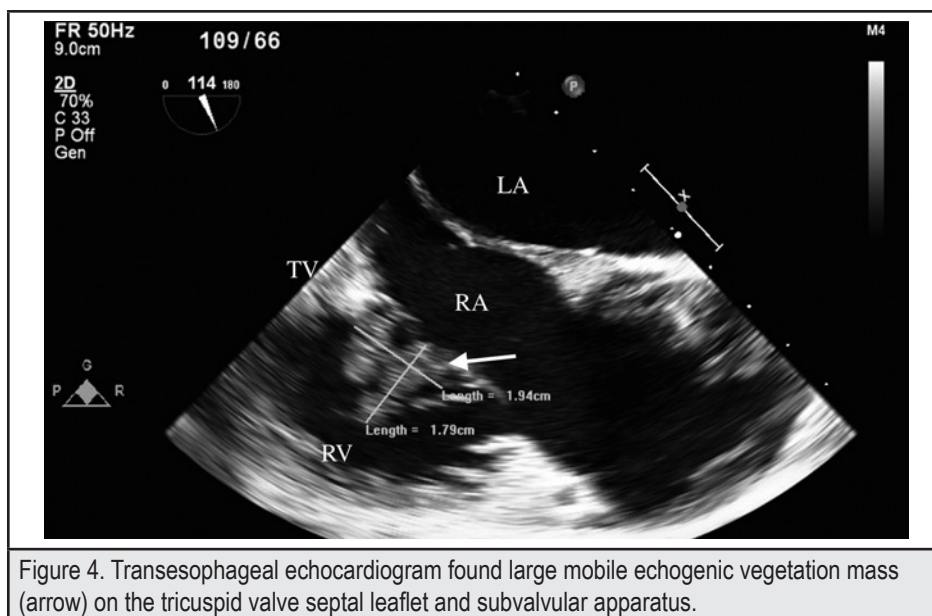


Figure 4. Transesophageal echocardiogram found large mobile echogenic vegetation mass (arrow) on the tricuspid valve septal leaflet and subvalvular apparatus.

## Discussion

Our patient presented as a rare case of isolated native tricuspid valve endocarditis due to *Klebsiella pneumoniae*. The case was complicated with septic pulmonary embolism and multiple systemic emboli-like focal infections including injection site purulent drainage, osteomyelitis of L4-5, epidural and paraspinous abscess. All the culture results showed *Klebsiella pneumoniae*. These complications occurred despite no evidence of intracardiac shunt causing paradoxical embolism on TEE. The patient was successfully treated with combined 6-week ceftriaxone and 2-week gentamicin together with early tricuspid valve repair and drainage of paraspinous loculation.

*Klebsiella pneumoniae* rarely causes endocarditis likely due to its poor adherence to cardiac valves.<sup>6</sup> The mechanism of infection could be due to abnormal blood flow across a previously damaged valve leading to focal deposition of platelets and fibrin, creating a site for bacterial colonization and growth.<sup>3</sup> Right-sided IE most commonly involves the tricuspid valve and is usually found in IV drug users.<sup>7</sup> The most common complication of right-sided IE is septic pulmonary embolism causing pulmonary infarction and acute congestive heart failure.<sup>3</sup> On the other hand, systemic embolism is a rare presentation of isolated tricuspid valve infective endocarditis without co-existent left-sided vegetation.<sup>8</sup> There was no left-sided involvement, no intracardiac right-to-left shunt and no evidence of intrapulmonary shunt found in our reported case. Hypervirulent *Klebsiella pneumoniae* (hvKP) has been reported since the 1980s.<sup>9</sup> To determine hvKP, the organism needs to meet at least 2 indicators: a positive string test, amplification of *rmpA* (regulator of mucoid phenotype A), and amplification of aerobactin.<sup>9</sup> According to Wu, et al, 92.9% of hvKP has a positive string test.<sup>9</sup> Therefore, not all hvKP strains exhibit the hypermucoviscous phenotype. Unfortunately, bloodstream isolated *Klebsiella pneumoniae* was not tested for amplification of

*rmpA* and aerobactin in this case. Yet, her clinical presentation with metastatic infection, as well as the presence of a string test positive strain in the sputum, raises suspicion of hypervirulent strain *Klebsiella pneumoniae* as the cause of multiple focal infections.

*Klebsiella pneumoniae* IE patients tend to worsen quickly without evidence of preceding microbiological failure, and emergent valve replacement is often necessary.<sup>5</sup> The most commonly used antibiotics are aminoglycosides and cephalosporins (86% and 67% of cases, respectively) with the optimal duration of 6-week course therapy.<sup>5</sup> Non-operative management of tricuspid valve IE with antibiotics alone successfully clears the bacteremia in 70%–85% of cases and is associated with 7%–11% in-hospital mortality.<sup>2,10</sup> However, those statistics do not take hvKP into account. Expert sources disagree about indications for surgery, but common indications include large vegetation ( $\geq 20$  mm), septic pulmonary embolism, failed medical therapy, infected prosthetic valves, and severe tricuspid regurgitation.<sup>1,8,11</sup> Dawood, et al, suggested that early surgical intervention could avoid on-going leaflet tissue destruction and increase the likelihood of tricuspid valve repair instead of replacement.<sup>12</sup> Most importantly, valve repair with annuloplasty ring showed a significant protective effect against recurrent IE compared to valve replacement.<sup>12</sup> Therefore, early tricuspid valve repair should be considered in IE when possible.<sup>2</sup> As noted above, our patient who experienced septic pulmonary embolism underwent early surgical intervention, tricuspid valve repair surgery with annuloplasty ring.

In conclusion, *Klebsiella pneumoniae* is a rare but extremely dangerous cause of bacterial infective endocarditis. Systemic metastatic infection could occur in hypervirulent *Klebsiella pneumoniae* infection. Combined antibiotic and early surgical intervention are an optimal management for isolated tricuspid valve infective endocarditis.



## Conflict of Interest

None of the authors identify a conflict of interest.

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## Reference

1. Hussain ST, Witten J, Shrestha NK, Blackstone EH, Pettersson GB. Tricuspid valve endocarditis. *Annals of Cardiothoracic Surgery*. 2017;6(3):255-261.
2. Shrestha NK, Jue J, Hussain ST, et al. Injection Drug Use and Outcomes After Surgical Intervention for Infective Endocarditis. *The Annals of Thoracic Surgery*. 2015;100(3):875-882.
3. Byramji A, Gilbert JD, Byard RW. Sudden death as a complication of bacterial endocarditis. *The American Journal of Forensic Medicine and Pathology*. 2011;32(2):140-142.
4. Kantarcioglu B, Bekoz HS, Olgun FE, et al. Allogeneic stem cell transplantation in a blast-phase chronic myeloid leukemia patient with carbapenem-resistant *Klebsiella pneumoniae* tricuspid valve endocarditis: A case report. *Molecular and Clinical Oncology*. 2016;5(4):347-350.
5. Anderson MJ, Janoff EN. *Klebsiella* endocarditis: report of two cases and review. *Clinical Infectious Diseases*. 1998;26(2):468-474.
6. Gould K, Ramirez-Ronda CH, Holmes RK, Sanford JP. Adherence of bacteria to heart valves in vitro. *The Journal of Clinical Investigation*. 1975;56(6):1364-1370.
7. Tak T, Reed KD, Haselby RC, McCauley CS, Jr., Shukla SK. An update on the epidemiology, pathogenesis and management of infective endocarditis with emphasis on *Staphylococcus aureus*. *WMMJ*. 2002;101(7):24-33.
8. Habib G, Lancellotti P, Antunes MJ, et al. 2015 ESC Guidelines for the management of infective endocarditis: The Task Force for the Management of Infective Endocarditis of the European Society of Cardiology (ESC). Endorsed by: European Association for Cardio-Thoracic Surgery (EACTS), the European Association of Nuclear Medicine (EANM). *European Heart Journal*. 2015;36(44):3075-3128.
9. Wu H, Li D, Zhou H, Sun Y, Guo L, Shen D. Bacteremia and other body site infection caused by hypervirulent and classic *Klebsiella pneumoniae*. *Microbial Pathogenesis*. 2017;104:254-262.
10. Musci M, Siniawski H, Pasic M, et al. Surgical treatment of right-sided active infective endocarditis with or without involvement of the left heart: 20-year single center experience. *European Journal of Cardio-Thoracic Surgery*. 2007;32(1):118-125.
11. Habib G, Lancellotti P, Antunes MJ, et al. [2015 ESC Guidelines for the management of infective endocarditis. The Task Force for the Management of Infective Endocarditis of the European Society of Cardiology (ESC)]. *Giornale Italiano di Cardiologia*. 2016;17(4):277-319.
12. Dawood MY, Cheema FH, Ghoreishi M, et al. Contemporary outcomes of operations for tricuspid valve infective endocarditis. *The Annals of Thoracic Surgery*. 2015;99(2):539-546.

# Ill-defined Causes of Death in the Republic of Kiribati, 2005 to 2014

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## Abstract

*This was a retrospective descriptive study of deaths in the Republic of Kiribati from 2005 to 2014. We determined the proportion of all deaths that are ill-defined and described the characteristics of these ill-defined deaths.*

*There were 5618 deaths between 2005 to 2014; of these 1049 (18.7%) were ill-defined. Of these, 576 (54.9%) were male. Those aged 65 years and above had the highest proportion of ill-defined deaths at 40% (n= 415), followed by children aged 0-15 years (29.6%, n=310). Further, 47.7% (n=500) of ill-defined deaths were reported by staff from health dispensaries.*

*When the ill-defined deaths were further categorised according to their R code (with the R code being a group of ill-defined deaths, with sub-groups), 30.5% (n=320) had unknown cause of death, while 29.3% (n=307) had general symptoms and signs.*

*Almost one fifth of deaths in Kiribati were ill-defined, indicating that the reporting on cause of death can be improved through Medical Certification on Causes of Death training and by other means. Improved cause of death reporting will allow the Ministry of Health and Medical Services to better allocate resources, plan health care service delivery and support the development of evidence based preventative and curative policies.*

## Abbreviations

ICD – International Classification of Diseases

KCRO – Kiribati Civil Registration Office

MCCD- Medical Certification of Causes of Death

MHMS- Ministry of Health and Medical Services

MS – Monthly Statistics

SORT-IT – Structured Operational Research Training Initiative

SPC- Secretariat of the Pacific Community

TDR- The Special Programme for Research and Training on Tropical Diseases

WHO – The World Health Organization

## Introduction

The Republic of Kiribati is a Micronesian Pacific island nation located in the central Pacific Ocean. It is comprised of 33 atolls scattered over a vast area of 3.5 million square kilometres and has a population of 110,110 people.<sup>1</sup> Approximately half of the population live on the capital island of Tarawa, a narrow atoll of only 17 square kilometres. Kiribati is classified as a lower middle income country<sup>2</sup> and the main resources are copra and fishing licences.<sup>3</sup>

Kiribati faces numerous challenges with regards to the health of its population including a large burden of non-communicable diseases,<sup>4</sup> a persistent burden of infectious diseases, and the impending health effects of climate change.<sup>5</sup> A number of health statistics trail behind other nations including life expectancy at 70 years for males and 80 years for females, and the under-five mortality rate which is 59 per 1000 live births.<sup>6</sup> The crude birth and death rates are 28.7 births per 1000 population and 4.6 deaths per 1000 people, respectively.<sup>6</sup> In neighbouring Pa-

cific Island countries such as Federated States of Micronesia, Marshall Islands and Palau the crude death rates are similar at 5.3, 3.8 and 6.8 deaths per 1000 people, respectively.<sup>7</sup>

Morbidity and mortality data are important indicators which allow countries to plan for health resources, health systems, health policies and interventions. In Kiribati, the International Classification of Diseases (ICD)-10 is used to code morbidity and mortality data.<sup>8</sup>

Despite the adoption of ICD-10 codes in 1999, the Ministry of Health and Medical Services (MHMS) in Kiribati has identified that reporting on the causes of death could be improved. For example, there is no comprehensive cause of death data included in the World Health Organization (WHO) statistical profile for Kiribati.<sup>9</sup> According to the ICD-10, the codes R00-R99 are used for ill-defined or unknown causes of death which have the general classification of “symptoms, signs and abnormal and laboratory findings, not elsewhere classified.”<sup>8</sup> The percentage of ill-defined causes of death has been used as an indicator of the quality of coding and national vital registration systems, with a percentage of over 20% indicating low quality data.<sup>10</sup> In Kiribati the number of ill-defined causes of deaths in 2011 was 16.6% of all deaths recorded, indicating that the quality of the data could be improved.<sup>6</sup> These data suggest that health care staff may not be completing death certifications appropriately. In response to this problem, the MHMS organised training in death certification for Medical Officers in 2015. Further trainings for medical assistants are planned. It is anticipated that improved documentation of causes of death will improve mortality reporting overall and will allow the MHMS to better plan health services, programmes, and interventions.

To provide up to date and longitudinal information on ill-defined causes of death we undertook a study to describe causes of death over a ten year period (2005 to 2014) including the proportion of ill-defined causes of death in Kiribati, using national mortality data. Our ultimate aim is to strengthen cause of death reporting, ICD-10 coding and also to reduce the proportion of deaths that are recorded as ill-defined or unknown. Our data will provide a baseline against which future improvements can be measured. The study supports the fifth strategic objective of the Kiribati MHMS National Strategic Plan 2016-2019, ie, to “address gaps in health service delivery and strengthen the pillars of the health system.”<sup>11</sup>

The specific objectives of our study were to report the total number of deaths per year recorded by hospitals and public health facilities from 2005 to 2014; to determine the number

and proportion of ill-defined causes of death stratified by gender, age group and type of health facility where the death was recorded and to report all ill-defined causes of death according to their ICD-10 code categories.

## Methods

This was a retrospective descriptive study using national mortality data from the Health Information Unit, MHMS. The health system is primarily funded by the national Government with very little involvement of the private sector. It covers the 33 atolls (of which 21 islands are inhabited)<sup>3</sup> and is further divided into six health districts. Healthcare is provided by government staff located in 4 hospitals, 34 health centres and 66 health dispensaries.<sup>6</sup> Medical Officers are responsible for recording the cause of death for people who die in hospitals. In health centres and health dispensaries, Medical Assistants and Public Health Nurses are responsible for recording causes of death for both inpatients and outpatients.

The MHMS head office is located in South Tarawa (the capital island) and has a Health Information Unit which maintains a database of all deaths and causes of death. For deaths that occur in the main referral hospital on South Tarawa (Tungaru Central Hospital), Medical Coders collect information on the cause of death from the patient's medical record and enter this information into the Kiribati Health Information System, which is an online system available via the MHMS intranet. For all other deaths in the country, including those that occur at the other three hospitals, at health centres and health dispensaries, Medical Officers, Medical Assistants and Public Health Nurses report deaths and causes of deaths to the Health Information Unit on a monthly basis using a Monthly Statistics 1 (MS1) form. For people who die elsewhere (ie, at home or in the community) the death is reported on an MS-1 form as an outpatient death. The MS1 is a paper form that is posted or e-mailed to the Health Information Unit. Coding of deaths is then carried out by trained Medical Coders according to whatever is on the MS-1 form. This information is then entered into the MS1 system on the MHMS intranet. Therefore, information on mortality is available in two information systems, both of which are managed by trained staff at the Health Information Unit.

Our study population included all people whose deaths were registered in Kiribati between January 2005 and December 2014.

We extracted data from the Kiribati Health Information System and the MS1 System. Data variables extracted were: age group (under 1 year, 1-4 years, 5-14 years, 15-44 years, 45-54 years, 55-64 years, 65 years and above, and not recorded), gender, type of health facility in which the patient died (hospital, health centre, health dispensary), year of death, district of residence for the person who had died (Northern, Tarawa and Banaba, Central, North west, North east, Line and Phoenix), ICD-10 code and causes of death. For deaths which occurred at home, the nurse aid reported on the death to the public health nurse or medical assistant and these were recorded as outpatient deaths, from either health dispensary or health centre. The one who

assigned the cause of death was the public health nurse at the health dispensary or the medical assistant at health centre.

Data were analysed using Epi Info version 7 (Centers for Disease Control and Prevention, Atlanta, United States of America) and a descriptive analysis was performed. The number and proportion of all deaths for the years 2005 to 2014 were calculated, and the proportion of all deaths that were ill-defined was determined (ie, deaths in the R code family; the family that includes deaths that have symptoms, signs and abnormal laboratory or clinical findings not classified elsewhere). For all ill-defined deaths, numbers and proportions were calculated, stratified by year, gender, age group, and health facility in which the death was recorded. The ill-defined causes of death were then grouped according to ICD-10 categories (within the R code family) and we calculated numbers and proportions of ill-defined deaths per year.

## Ethics Approval

Ethics approval was obtained from the Ethics Advisory Group of the International Union against Tuberculosis and Lung Disease, Paris, France. The Government of Kiribati does not have a human research ethics committee; however, the MHMS provided approval for the study.

## Results

Between 2005 and 2014 there were 5618 deaths in Kiribati, ranging from 340 -788 deaths per year (Table 1; Figure 1). Of these, the majority of deaths occurred in the hospital setting (n=2588, 46.1%) while one fifth of deaths (n= 1170, 20.8%) occurred in a health centre and 33.1% (n=1860) in a health dispensary (Table 1). Table 1 provides information on the type of health facility in which patients died (or from where the death was reported), by year, for the years 2005-2014.

Table 1. Number and Pproportion of Total Deaths in Kiribati by Year (2005-2014) and Type of Health Facility in Which the Death was Recorded

Year of Death	Death in Hospital N (%)	Death in Health Centre N (%)	Death in Health Dispensary N (%)	Total N
2005	266 (44.0)	132 (21.9)	206 (34.1)	599
2006	277 (45.0)	139 (22.6)	200 (32.5)	616
2007	174 (37.7)	112 (24.2)	176 (38.1)	462
2008	201 (39.6)	112 (22.1)	195 (38.4)	508
2009	71 (20.9)	102 (30.0)	167 (49.1)	340
2010	365 (61.9)	85 (14.4)	140 (23.7)	590
2011	281 (57.2)	72 (14.7)	138 (28.1)	491
2012	347 (44.0)	178 (22.6)	263 (33.4)	788
2013	235 (44.2)	104 (19.6)	193 (32.4)	532
2014	371 (54.0)	134 (19.5)	182 (26.5)	687
Total	2588 (46.1)	1170 (20.8)	1860 (33.1)	5618

Of the 5618 deaths, 1049 (18.7%) were classified as ill-defined. The number of ill-defined deaths ranged from 76 - 153 per annum, with a peak in 2012 (Table 2). Of the 1049 ill-defined deaths, 576 were male (54.9%) (Table 2; Figure 1). Those aged 65 years and above has the highest proportion of ill-defined deaths at 40% (n= 415), however in children aged 0-15 years almost 30% (29.6%, n=310) were ill-defined (Table 2). Almost half of all ill-defined deaths (47.7%, n=500) were reported by health dispensary staff (Table 2).

When the causes of ill-defined deaths were categorised according to their R code, the largest proportion of cases (30.5%, n=320) had an unknown cause of death, while 29.3% (n=307) had general symptoms and signs (Table 3). There was missing data for 5.4% (n=57) of ill-defined causes of death (Table 3).

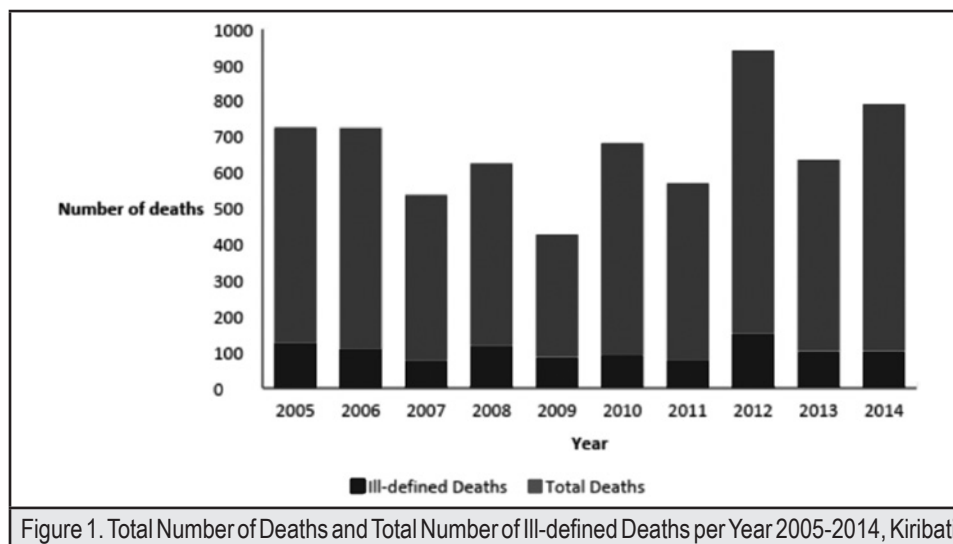


Figure 1. Total Number of Deaths and Total Number of Ill-defined Deaths per Year 2005-2014, Kiribati

Table 2. Number and Proportion of All Deaths that are Ill-defined in Kiribati by Year (2005-2014), Gender, Age Group, and Type of Health Facility Where the Death was Recorded

Characteristics	2005 N (%)	2006 n (%)	2007 n (%)	2008 n (%)	2009 n (%)	2010 n (%)	2011 n (%)	2012 n (%)	2013 n (%)	2014 n (%)	Total n (%)
<b>Gender</b>											
Male	72 (56.7)	52 (47.7)	39 (51.3)	59 (50)	40 (6.9)	47 (51.1)	47 (59.5)	98 (64.1)	66 (63.5)	56 (53.9)	576 (54.9)
Female	55 (43.3)	57 (52.3)	37 (48.7)	58 (49.2)	47 (10.0)	43 (46.7)	31 (39.2)	54 (32.3)	38 (36.5)	48 (46.2)	468 (44.6)
Not Recorded	0 (0)	0 (0)	0 (0)	1 (0.9)	0 (0)	2 (2.2)	1 (1.3)	1 (0.7)	0 (0)	0 (0)	5 (0.1)
<b>Age Group (Years)</b>											
Under 1	14 (11.2)	1 (0.9)	0 (0)	1 (0.9)	2 (2.3)	6 (6.5)	7 (8.9)	15 (9.8)	8 (7.7)	12 (11.5)	66 (6.3)
1-4	10 (7.9)	5 (4.6)	7 (9.2)	3 (2.5)	5 (5.8)	2 (2.2)	2 (2.5)	8 (5.2)	9 (8.7)	1 (0.1)	52 (5.0)
5-14	2 (11.8)	3 (2.8)	0 (0)	0 (0)	3 (3.5)	1 (1.1)	1 (1.3)	3 (2.0)	1 (0.1)	3 (2.9)	192 (18.3)
15-44	25 (19.7)	26 (23.9)	9 (11.8)	23 (19.5)	16 (18.4)	15 (16.3)	13 (16.5)	29 (19.0)	19 (18.3)	17 (16.4)	121 (11.5)
45-54	13 (10.2)	14 (12.8)	10 (13.2)	12 (10.2)	13 (14.9)	14 (15.2)	5 (6.3)	18 (11.8)	10 (9.6)	12 (11.5)	17 (1.6)
55-64	18 (14.2)	11 (10.1)	9 (11.8)	11 (8.9)	14 (16.1)	9 (9.8)	15 (19.0)	17 (11.1)	13 (12.5)	7 (6.7)	124 (11.8)
65+	45 (35.4)	40 (36.7)	34 (44.7)	46 (39.0)	34 (39.1)	39 (42.4)	32 (40.5)	58 (37.9)	37 (35.6)	50 (48.1)	415 (40.0)
Not Recorded	0 (0.0)	9 (8.3)	7 (9.2)	22 (18.6)	0 (0.0)	6 (6.5)	4 (5.1)	5 (3.3)	7 (6.7)	2 (1.9)	62 (6.0)
<b>Type of Health Facility</b>											
Hospital	23 (18.1)	25 (22.9)	13 (17.1)	21 (7.8)	12 (3.8)	38 (41.3)	21 (26.6)	52 (34.0)	31 (29.8)	21 (20.2)	257 (24.5)
Health Centre	37 (29.1)	39 (35.8)	20 (26.3)	34 (28.8)	26 (29.9)	22 (23.9)	16 (20.3)	37 (24.2)	26 (25.0)	35 (33.7)	292 (27.8)
Health Dispensary	67 (52.8)	45 (41.3)	43 (56.6)	63 (53.4)	49 (56.3)	32 (34.8)	42 (53.2)	64 (41.8)	47 (45.2)	48 (46.2)	500 (47.7)
<b>Total</b>	<b>127</b>	<b>109</b>	<b>76</b>	<b>118</b>	<b>87</b>	<b>92</b>	<b>79</b>	<b>153</b>	<b>104</b>	<b>104</b>	<b>1049</b>



Table 3.: Proportion of ICD-10 Categories of Code of Ill-defined dDeath in Kiribati by Year, 2005 - 2014											
Year	Symptoms and Signs — Circulatory and Respiratory Systems  R00-R09  n (%)	Symptoms and Signs — Digestive System and Abdomen  R10-R19  n (%)	Symptoms and Signs — Skin and Subcutaneous Tissue  R20-R23  n (%)	Symptoms and Signs — Genito-urinary System  R30-R39  n (%)	Symptoms and Signs — Speech and Voice  R47-R49  n (%)	General Symptoms and Signs  R50-R69  n (%)	Abnormal Findings on Examination of Blood, Without Diagnosis  R70-R79  n (%)	Abnormal Findings on Diagnostic Imaging and Function Studies, Without Diagnosis  R90-R94  n (%)	Unknown Cause of Mortality  R99  n (%)	Missing  n	Total  n
2005	26 (20.5)	25 (19.7)	2 (1.6)	1 (0.8)	0 (0)	41 (32.3)	2 (1.6)	0 (0)	24 (18.9)	6 (4.7)	127
2006	8 (7.3)	22 (20.2)	2 (1.8)	0 (0)	0 (0)	26 (23.9)	2 (1.8)	1 (0.9)	37 (33.9)	11 (10.1)	109
2007	7 (9.2)	13 (17.1)	2 (2.6)	0 (0)	0 (0)	23 (30.3)	0 (0)	0 (0)	24 (31.6)	7 (9.2)	76
2008	20 (17.0)	12 (10.2)	4 (3.4)	0 (0)	0 (0)	37 (31.4)	1 (0.9)	0 (0)	39 (33.1)	5 (4.2)	118
2009	10 (11.5)	15 (17.2)	0 (0)	0 (0)	0 (0)	25 (28.7)	3 (3.5)	0 (0)	28 (32.2)	6 (6.9)	87
2010	18 (19.6)	20 (21.7)	0 (0)	1 (1.1)	1 (1.1)	23 (25.0)	2 (2.2)	0 (0)	19 (20.7)	8 (8.7)	92
2011	11 (13.9)	9 (11.4)	2 (2.5)	0 (0)	0 (0)	26 (32.9)	3 (3.8)	0 (0)	25 (31.7)	3 (3.8)	79
2012	23 (15.0)	25 (16.3)	4 (2.6)	1 (0.7)	2 (1.3)	38 (24.8)	3 (2.0)	0 (0)	49 (32.0)	8 (5.2)	153
2013	11 (10.6)	17 (16.4)	0 (0)	0 (0)	1 (0.1)	29 (27.9)	1 (0.1)	0 (0)	45 (43.3)	0 (0)	104
2014	13 (12.5)	15 (14.4)	1 (1)	0 (0)	0 (0)	39 (37.5)	3 (2.9)	0 (0)	30 (28.9)	3 (2.9)	104
<b>Total</b>	147 (14.0)	173 (16.5)	17 (1.6)	3 (0.3)	4 (0.4)	307 (29.3)	20 (1.9)	1 (0.1)	320 (30.5)	57 (5.4)	1049

## Discussion

This is the first time that the Kiribati MHMS has examined completeness and consistency of the reporting of mortality data by staff from health facilities over a ten-year period. We showed that there are approximately 500 deaths per year in Kiribati and of these, almost one fifth of deaths (18.6%) are ill defined or unknown. This confirms our hypothesis that further efforts to improve death certification and reporting on cause of death are needed. We also showed that an ill-defined cause of death is more common among certain groups of people, including the elderly (aged 65 years and above), children (aged 0-14 years) and those whose death was reported by health dispensary staff. In addition, when ill-defined causes of death were further classified, approximately 60% had general signs and symptoms or an unknown cause of death.

The strength of this study was that it included national mortality data from the MHMS over a ten-year period. The information on where the death was recorded (ie, from which health facility) was fully completed. Another strength is that we reported our study according to STROBE and ReCORD guidelines.<sup>12,13</sup> There were, however, some limitations. The main limitation was that we did not compare our data with the mortality data from the Kiribati Civil Registration Office (KCRO) system, which is managed by the Ministry of Internal Affairs. The MHMS systems for mortality reporting and the KCRO system are separate systems maintained by different Government Ministries. It may be of interest to compare the mortality data from the

two systems. Another limitation is that we attempted to verify some of the missing causes of death against medical records; however, these records were archived and were not available for our access. In addition we acknowledge that the proportion of ill-defined deaths may be higher than those found using the R codes alone as there are other unspecific ICD-10 codes that are not useful for public health planning and policy making.

Deaths reported by staff from health centres and dispensaries are recorded by Medical Assistants and Public Health Nurses who have not undergone Medical Certification of Causes of Death (MCCD) training. In 2015, Medical Officers took part in MCCD training, provided by staff from the World Health Organization (WHO). There are future plans to train and certify Medical Assistants using the same MCCD training. It is anticipated that training will further improve cause of death reporting and death certification. In addition to this, Kiribati will soon implement a system of carbon copy death certificates with three copies of a death certificate - one for the Ministry of Internal Affairs, one for the Health Information Unit, MHMS and one for the family of the deceased. Currently, death certificates are a single sheet of paper.

There are sparse data on the proportion of deaths that are ill defined in other Pacific Islands. However one study, conducted in 2005 estimated the proportion of all deaths that were ill-defined for 115 countries; 12 were Pacific Islands.<sup>8</sup> Of these, five (42%) had complete data.<sup>10</sup> In these countries, the proportion of all deaths that were ill-defined ranged from 0% in Niue

to 35% in Kiribati.<sup>10</sup> Other countries with a high proportion of ill-defined deaths were Fiji (29%) and Tuvalu (27%).<sup>10</sup> While that study is not directly comparable to ours, the proportion of ill-defined deaths in our study is lower than that reported in the 2005 paper.<sup>10</sup> This paper also classified countries into data quality groups (ie, high, medium and low) based on three main criteria: a) type of cause of death coding used, b) completeness of cause of death data, and c) the proportion of deaths that were ill defined.<sup>10</sup> Using this classification, Kiribati was classified as having medium data quality.<sup>10</sup>

We reported that a large proportion of deaths are ill-defined in Kiribati and therefore reporting on the cause of death needs to be improved. While training of Medical Officers on death certification has begun, Medical Assistants are yet to be trained and there may be a need to train Public Health Nurses as well. In addition, it may be useful to provide feedback to health professional on the completeness of mortality data including new policies regarding death certification.

## Conclusion

Almost one fifth of all deaths in Kiribati were ill-defined and this could be improved by the introduction of MCCD training to all the health personnel who are responsible for certifying deaths. Improved quality of mortality data should allow the MHMS to better target health services, programs and interventions.

This study has some applications that can be recommended and implemented in the Kiribati context. It is recommended to provide training on death certification to all classes of health care professionals who might certify deaths. In addition continuous feedback to health care professionals on the completeness of mortality data is needed. This can be done by distributing annual health bulletins from the Health Information Unit to all the health centers and hospitals including Head of Departments and Directors in the main Hospital.

## Conflict of Interest

None of the authors identify a conflict of interest.

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## References

1. Kiribati National Statistics Office. 2015 Population and Housing Census Preliminary Report. Tarawa, Kiribati: National Statistics Office. <http://www.mfed.gov.ki/sites/default/files/Revised%20Census%20Preliminary%20Report%202%20020516%20update%20%5B1306646%5D.pdf>. Accessed February 13, 2017.
2. The World Bank. Kiribati. Washington DC, United States of America: The World Bank. <http://data.worldbank.org/country/kiribati>. Accessed February 13, 2017.
3. Government of Kiribati, About Kiribati. Tarawa, Kiribati: Government of Kiribati. <http://www.president.gov.ki/about-kiribati/>. Accessed February 13, 2017.
4. Commonwealth Health Online. *Non-communicable diseases in Kiribati*, Cambridge, United Kingdom: Commonwealth Health Online. [http://www.commonwealthhealth.org/pacific/kiribati/non\\_communicable\\_diseases\\_in\\_kiribati/](http://www.commonwealthhealth.org/pacific/kiribati/non_communicable_diseases_in_kiribati/). Accessed February 13, 2017.
5. McIver L, Kim R, Woodward A, et al. Impacts of climate change in Pacific Island countries: A regional assessment of vulnerabilities and adaptation priorities. *Environmental Health Perspectives*. 2016;124(11):1707-1714.
6. Ministry of Health and Medical Services. Kiribati Annual Report 2011. Tarawa, Kiribati: Kiribati Ministry of Health and Medical Services. 2011.
7. The Pacific Community. 2018 Pocket statistical summary. Noumea, New Caledonia: The Pacific Community. <https://prism.spc.int/> Accessed September 4 2018.
8. World Health Organization. ICD-10: Version 2016. Geneva, Switzerland: World Health Organization. <http://apps.who.int/classifications/icd10/browse/2016/en>. Accessed 13 February 2017.
9. World Health Organization. Kiribati: WHO statistical profile. Geneva, Switzerland: *World Health Organization*. <http://www.who.int/gho/countries/kir.pdf?ua=1> Accessed September 4 2018.
10. Mathers CD, Ma Fat D, Inoue M, Rao C, Lopez AD. *Counting the death and what they died from: an assessment of the global status of cause of death data*. Bulletin of the World Health Organization, 2005; 83(3): 171-177.
11. Ministry of Health and Medical Services. *Ministry Strategic Plan 2016-2019*. Tarawa, Kiribati: Kiribati Ministry of Health and Medical Services. 2015.
12. Benchimol EI, Smeeth L, Guttman A, et al. The Reporting of studies Conducted using Observational Routinely-collected health Data (RECORD) Statement. *PLoS Medicine*. 2015;12(10):e1001885. doi:10.1371/journal.pmed.1001885.
13. Von Elm V, Altman DG, Egger M, Pocock SJ, Gøtzsche PC, Vandenbroucke JP. *Strengthening the reporting of observational studies in epidemiology (STROBE) statement: guidelines for reporting observational studies*. *British Medical Journal*. 2007; 335 doi: <https://doi.org/10.1136/bmj.39335.541782.AD>.

## Dying of AIDS in 2018: Urgent Interventions to Curb the Fastest-Growing HIV Epidemic in the Western Pacific

Louie Mar A. Gangcuangco MD

*In 1993, the Medical School Hotline was founded by Satoru Izutsu PhD (former vice-dean UH JABSOM), it is a monthly column from the University of Hawai'i John A. Burns School of Medicine and is edited by Kathleen Kihmm Connolly PhD; HJMPH Contributing Editor.*

The Philippines has the highest growth rate of human immunodeficiency virus (HIV) infection in the western Pacific region with approximately 900 new cases per month, increasing in incidence by over 170% since 2010.<sup>1</sup> The virus leads to decreased CD4 T helper lymphocyte count, causing increased susceptibility to infection, a condition called acquired immunodeficiency syndrome (AIDS). The Joint United Nations Programme on HIV and AIDS (UNAIDS) estimates that only 67% of persons living with HIV in the country know their status. Fifty-five percent have CD4 count less than 200 cells/uL, at the time of diagnosis.<sup>2</sup> HIV disproportionately affects men having sex with men (MSM) who account for 86% of all cases.<sup>1</sup> In 2009, a study found an 11.8% HIV prevalence among MSM in Metro Manila.<sup>3</sup>

June 2018: I lost a friend to AIDS. Angelo had just turned 31. He had a lot of dreams – including a better life for his parents and younger siblings.

Angelo was first diagnosed with HIV in 2014 after his boyfriend tested positive for the virus. Living in the Philippines, a country where HIV is often equated to promiscuity and immorality, Angelo was rightfully worried. I had known him since we were teenagers and, as a friend who is in the field of HIV research, Angelo reached out to me. I was a first year Internal Medicine resident in Connecticut, about 8,400 miles away from Manila.

Angelo had a lot of questions. How will he tell his family? Is he being punished by God for being gay? Most importantly, is he going to die soon? After allaying his anxiety and explaining the importance of early treatment, he agreed to start antiretroviral therapy (ART).

Initial work-up revealed that Angelo's CD4 count was 190 cells/uL and that he was co-infected with pulmonary tuberculosis (TB). Quadruple therapy for TB (isoniazid/rifampicin/pyrazinamide/ethambutol) was promptly started. ART (lamivudine, tenofovir and efavirenz; LTE) was introduced a few weeks later. Angelo was feeling dizzy every morning and could not focus since ART was initiated. He went back to his treatment hub and learned that his liver tests had significantly increased. Medications were stopped and he was lost to follow-up.

Angelo spent the next four years battling depression and multiple co-infections that slowly devoured his body: cutaneous

tuberculosis, oropharyngeal candidiasis, pneumocystis pneumonia, and recurrent diarrhea. Despite constant reminders and encouragement, he remained in denial and sought alternative therapies. He had lost his job, which further contributed to his depression. He had no money for transportation. The nearest HIV treatment center was two hours away from his house. He agreed to restart ART in January 2018 after episodes of blurred vision. His CD4 had dropped to 4 cells/uL. Ophthalmologic exam confirmed retinal detachment and CMV retinitis.

By June 2018, I had returned to the Philippines. I immediately called Angelo. He was complaining of shortness of breath. I advised him to go to the hospital urgently. A government vehicle brought him to the hospital with his parents. His family could not afford an ambulance, as his father makes less than \$10 per day, the minimum wage in the Philippines.

On arrival, I could barely recognize the friend whom I had last seen four years ago. He had sunken eyes, temporal wasting, icteric sclerae, and dry scaly skin. He was struggling to breathe. He looked at me and – with lips trembling – he begged, “*Louie, please help me.*”

Angelo spent the next four weeks in the hospital. He deteriorated despite escalating antibiotics, inotropes, and ventilatory support. After three weeks on source isolation for multidrug-resistant tuberculosis and *Acinetobacter baumannii* pneumonia, he finally succumbed.

Angelo's story is but one of the 2,518 people who have died from AIDS since it was first reported in the Philippines in January 1984.<sup>1</sup> Although these numbers seem small, death from AIDS is likely underreported due to the stigma associated with the diagnosis. The use of euphemisms such as ‘immunocompromised condition’ in death certificates is a common practice to protect the patient's privacy.

Programs in the Philippines have focused primarily on the ABCs of HIV prevention: **A**bstinence from sex, **B**eing faithful, and **C**onsistent condom use. Free condoms are available at various social hygiene clinics and could also be purchased from pharmacies. However, the stigma of using condoms in a predominantly Catholic country like the Philippines remains prevalent. Among heterosexuals, condoms are perceived primarily as a birth control measure rather than a barrier against sexually-transmitted infections (STIs). Purchasing condoms,

especially in small towns where majority of people know each other, can be embarrassing and is associated with pre-marital sex or infidelity.<sup>4</sup> Among MSM, low condom use was attributed to trust in one's partner (34.4%), decreased pleasure (32%), and unavailability (23.4%).<sup>3</sup>

The first urgent intervention to curb the HIV epidemic in the Philippines is to overcome stigma by integrating sexual health and gender sensitivity in school curriculums. The Department of Education plans to include comprehensive sexuality education in response to the increasing incidence of HIV, teen pregnancy, and sexual violence.<sup>5</sup> For this program to be successful, teachers and guidance counsellors must also undergo training to ensure that classes are delivered in an age-appropriate and culturally-sensitive manner.

The second urgent intervention is the integration of HIV testing and counselling in primary healthcare settings. Although HIV testing is available for free in various social hygiene and HIV clinics nationwide, the stigma associated with being seen in these clinics deter people from getting tested. Encouraging HIV testing as part of routine healthcare maintenance in primary care clinics would facilitate early detection and serve as an opportunity for HIV and STI education.

There are more than 7,000 islands and over 100 languages in the Philippines. This serves as a major barrier in providing HIV services especially to those who live outside major cities. An untapped workforce that can be mobilized to improve access to HIV services in rural areas are the *barangay* (community) healthcare workers (BHWs). There are more than 100,000 BHWs in the Philippines. BHWs are residents of their respective municipalities who usually don't have formal medical education but are trained by the Department of Health to provide basic primary care services, such as blood pressure monitoring and directly-observed TB treatment. Training the BHWs in HIV counselling and testing will help improve HIV awareness, especially within rural areas in the country.

Third, pre-exposure prophylaxis (PrEP) must be made accessible nationwide as part of comprehensive HIV prevention programs. PrEP, a daily pill that contains the antiretrovirals emtricitabine and tenofovir, has been shown to be highly effective in preventing HIV transmission.<sup>6</sup> PrEP currently has limited availability in the Philippines. Primary care physicians must be educated on how to prescribe and monitor patients on PrEP. The use of PrEP must be coupled with counselling and education on STI prevention.<sup>7</sup>

The fourth intervention is to institute integrase strand transfer inhibitors as first-line medications for HIV. To date, LTE is the only fixed-dose combination available and integrase inhibitors are reserved for drug-resistant cases. The UNAIDS estimates that only 32% of Filipinos living with HIV are on ART and only 82% remain on ART 12 months after starting treatment.<sup>2</sup> Clinical trials have shown that 53% of patients on efavirenz reported central nervous system symptoms.<sup>8</sup> Like Angelo, many Filipinos complain of bothersome side effects from LTE. Although the side effects of efavirenz can be mitigated by lowering its dose or switching to rilpivirine, this increases pill burden. A meta-analysis has shown that higher pill burden is associated

with both lower ART adherence and worse viral suppression.<sup>9</sup>

A new co-formulated tablet of tenofovir/lamivudine/dolutegravir (TLD) has been rolled out in several low- and middle-income countries (LMICs) for a median price of \$75/patient/year, which is estimated by the World Health Organization (WHO) to be 10–15% less expensive than current efavirenz formulations in LMICs.<sup>10</sup> A dolutegravir-based regimen has lower total costs, lower rates of treatment failure, and provide better clinical outcomes overall.<sup>10</sup> The safety of dolutegravir in pregnancy needs to be further studied; however, the Philippines would continue to benefit from DTG, as the majority of HIV infections are among men. Furthermore, the better side effect profile of TLD is expected to improve ART adherence, translating to a greater proportion of patients with undetectable viral load (lower community viral load), preventing further HIV transmission.<sup>11</sup>

PrEP and integrase inhibitors have only been approved by the US FDA in the past decade and are slowly being introduced to LMICs. Because of this, there is a gap in knowledge and practice among Filipino physicians in prescribing these medications. 'Treatment as Prevention' and the benefits of decreasing the community viral load are newer concepts that need to be disseminated among healthcare providers.<sup>11,12</sup> The importance of early detection and HIV as a chronic manageable disease must be emphasized in medical and nursing curriculums. In July 2018, the World Health Organization included dolutegravir as first-line medication for patients initiating ART.<sup>13</sup> Stakeholders and HIV specialists must convene to revise the Philippine Antiretroviral Treatment Guidelines for it to be at par with international guidelines and cope with the increasing HIV incidence, rising nucleoside reverse transcriptase inhibitor resistance, and shift towards the CRF01\_AE subtype in the country.<sup>14</sup>

Fifth, mental health and substance abuse must be addressed using evidence-based interventions. Alcohol and recreational drugs are associated with lower condom use and increased risk of HIV transmission.<sup>13,15</sup> Although sharing needles among injecting drug users (IDUs) account only for 4.0% of the HIV cases in the Philippines,<sup>1</sup> estimating the real magnitude of substance abuse among Filipinos remains problematic because of fear of discrimination and criminal prosecution. Extrajudicial executions of suspected drug users have also been reported and has caught international attention.<sup>16</sup>

In 2010, an outbreak of HIV and hepatitis C occurred in Cebu City, one of the largest cities in the Philippines. Over 50% of IDUs were found to be infected with HIV and 93% co-infected with hepatitis C.<sup>17</sup> Furthermore, consistent condom use among IDUs was reported to be only at 15%. Needle exchange programs (NEPs) are community-based programs that provide access to sterile needles and syringes and provide an avenue for safe disposal of used needles and syringes. NEPs have been shown to effectively reduce HIV transmission in both high-income and LMICs.<sup>18</sup>

The Philippine Department of Health Epidemiology Bureau in 2016 acknowledged that sterile needles are needed to avert another HIV and hepatitis C outbreak among IDUs.<sup>17</sup> However, an official communication from the Dangerous Drugs Board



(DDB) of the Philippines issued in May 2017 stated that needle and syringe exchange programs cannot be implemented in the country, as the Comprehensive Dangerous Drugs Act of 2002 (Republic Act 9165) prohibits the possession of equipment, instrument, apparatus, and other drug paraphernalia for dangerous drugs.<sup>19</sup> The root cause of substance abuse among Filipinos is intricate and includes poverty, domestic abuse, stigma, and discrimination. The Philippine government should reconsider NEPs or provide alternative humane evidence-based interventions to help people struggling with addiction.

Lastly, international cooperation and capacity-building is warranted. As part of my advocacy to improve HIV research and healthcare delivery in the Philippines, I coordinated the visit to the Philippines of Dr. Cecilia Shikuma and Dr. Lishomwa Ndhlovu, my mentors at the John A. Burns School of Medicine (JABSOM), University of Hawai'i at Manoa. A pilot study on immune activation and neuroAIDS has been launched at the Philippine General Hospital through a joint funding from the Philippine Department of Science and Technology and JABSOM's Hawai'i Center for AIDS. Local physicians and personnel were trained on laboratory techniques and neuropsychiatric testing. Grants are underway to further expand training and research that are geared towards HIV cure and improving HIV care in the country.

Stigma reduction must start among healthcare providers. In November 2018, I was invited to deliver a lecture on HIV among nursing students and clinical instructors in Mindanao, one of the largest islands outside of Manila. A questionnaire revealed that misconceptions on HIV exist even among nursing students, with only 25% having heard about PrEP. Continued collaboration and volunteerism are needed to support local efforts in promoting HIV awareness, especially among healthcare providers.

The Philippines has recently made progress towards access to healthcare and HIV services with the recent approval of the Universal Healthcare Law (Senate Bill 1986), Philippine Mental Health Law (RA 11036), and strengthening of the Philippine AIDS Prevention and Control Act of 1998 (RA 11166).<sup>20-22</sup> The Sexual Orientation and Gender Identity and Expression (SOGIE) Bill, which aims to reduce gender discrimination and inequality, was passed by Congress of the Philippines in September 2017 but needs Senate vote to become a law.<sup>23</sup> These legislations would only be meaningful with proper implementation and require appropriate budget allocation towards healthcare.

The HIV crisis in the Philippines is a national emergency. Sexual health education, increased awareness among healthcare providers, national access to PrEP and integrase inhibitors, harm reduction, legislative changes, and international cooperation are needed to urgently curb the epidemic that is affecting the lives of many young Filipinos.

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## References

1. Department of Health Epidemiology Bureau. HIV/AIDS & ART Registry of the Philippines. <http://www.aidsdatahub.org/hivaids-and-art-registry-philippines-june-2018-epidemiology-bureau-department-health-2018>. Accessed August 1, 2018.
2. UNAIDS. Country Factsheets. Philippines 2016. <http://www.unaids.org/en/regionscountries/philippines>. Accessed October 15, 2018.
3. Gangcuangco LM, Tan ML, Berba RP. Prevalence and risk factors for HIV infection among men having sex with men in Metro Manila, Philippines. *The Southeast Asian journal of tropical medicine and public health*. 2013;44(5):810-7. Epub 2014/01/21.
4. Lucea MB, Hindin MJ, Gultiano S, Kub J, Rose L. The context of condom use among young adults in the Philippines: implications for HIV prevention. *Health care for women international*. 2013;34(3-4):227-48. Epub 2013/02/12.
5. Department of Education. Comprehensive sexuality education: developing responsible youths vs rising risks (DepEd Order No. 31). Pasig, Philippines. August 2018. <http://www.deped.gov.ph/2018/08/04/comprehensive-sexuality-education-developing-responsible-youth-vs-rising-risks/> Accessed October 15, 2018.
6. World Health Organization. Policy Brief: WHO expands recommendation on oral pre-exposure prophylaxis of HIV infection (PrEP). November 2015. [http://apps.who.int/iris/bitstream/handle/10665/197906/WHO\\_HIV\\_2015.48\\_eng.pdf?sequence=1](http://apps.who.int/iris/bitstream/handle/10665/197906/WHO_HIV_2015.48_eng.pdf?sequence=1). Accessed August 12, 2018.
7. Chen YH, Guigayoma J, McFarland W, Snowden JM, Raymond HF. Increases in Pre-exposure Prophylaxis Use and Decreases in Condom Use: Behavioral Patterns Among HIV-Negative San Francisco Men Who have Sex with Men, 2004-2017. *AIDS and behavior*. 2018. Epub 2018/10/12.
8. FDA. Sustiva (efavirenz) highlights of prescribing information. 1998.
9. Nachege JB, Parienti JJ, Uthman OA, Gross R, Dowdy DW, Sax PE, et al. Lower pill burden and once-daily antiretroviral treatment regimens for HIV infection: A meta-analysis of randomized controlled trials. *Clinical infectious diseases : an official publication of the Infectious Diseases Society of America*. 2014;58(9):1297-307. Epub 2014/01/25.
10. World Health Organization. Dolutegravir (DTG) and the fixed dose combination (FDC) of tenofovir/lamivudine/dolutegravir (TLD). Briefing note - April 2018. <http://www.who.int/hiv/topics/treatment/dtg-td-briefing-web/en/>. Accessed June 30, 2018.
11. Das M, Chu PL, Santos GM, Scheer S, Vittinghoff E, McFarland W, et al. Decreases in community viral load are accompanied by reductions in new HIV infections in San Francisco. *PLoS ONE*. 2010;5(6):e11068. Epub 2010/06/16.
12. Eaton JW, Johnson LF, Salomon JA, Barnighausen T, Bendavid E, Bershteyn A, et al. HIV treatment as prevention: systematic comparison of mathematical models of the potential impact of antiretroviral therapy on HIV incidence in South Africa. *PLoS medicine*. 2012;9(7):e1001245. Epub 2012/07/18.
13. World Health Organization. Updated recommendations on first-line and second-line antiretroviral regimens and post-exposure prophylaxis and recommendations on early infant diagnosis of HIV. (Geneva). July 2018. License: CC BY-NC-SA 3.0 IGO.
14. Salvana EMT, Schwem BE, Ching PR, Frost SDW, Ganchua SKC, Itable JR. The changing molecular epidemiology of HIV in the Philippines. *International journal of infectious diseases : IJID : official publication of the International Society for Infectious Diseases*. 2017;61:44-50. Epub 2017/06/13.
15. Walkup J, Blank MB, Gonzalez JS, Safren S, Schwartz R, Brown L, et al. The impact of mental health and substance abuse factors on HIV prevention and treatment. *J Acquir Immune Defic Syndr*. 2008;47 Suppl 1:S15-9. Epub 2008/04/09.
16. Hincks J. 'My Only Sin': Philippine President Rodrigo Duterte admits extrajudicial killings occurred. *Time Magazine*. Sept. 2018. Available at: <http://time.com/5409425/philippines-duterte-extrajudicial-killings-icc/>.
17. Department of Health Epidemiology Bureau. The state of the Philippine HIV epidemic 2016. [https://www.doh.gov.ph/sites/default/files/publications/publication\\_nonSerials\\_State%20of%20HIV%20Epidemic%20in%20the%20Philippines.pdf](https://www.doh.gov.ph/sites/default/files/publications/publication_nonSerials_State%20of%20HIV%20Epidemic%20in%20the%20Philippines.pdf). Accessed October 15, 2018.
18. Hurley SF, Jolley DJ, Kaldor JM. Effectiveness of needle-exchange programmes for prevention of HIV infection. *Lancet*. 1997;349(9068):1797-800. Epub 1997/06/21.
19. Dangerous Drugs Board. Statement of the Dangerous Drugs Board on the supposed adoption of harm reduction measures. May 2017. <https://www.ddb.gov.ph/newsroom/331-statement-of-the-dangerous-drugs-board-on-the-supposed-adoption-of-harm-reduction-measures>. Accessed October 20, 2018.
20. Senate of the Philippines. Bill of the Philippine HIV and AIDS Policy Act. March 13, 2017. <https://www.aseanlip.com/philippines/general/legislation/bill-of-the-philippine-hiv-and-aids-policy-act/AL14204>. Accessed October 20, 2018.
21. DOH. Universal Health Coverage Bill. July 2017. <https://www.doh.gov.ph/node/10646>. Accessed October 15, 2018.
22. Congress of the Philippines. Philippine Mental Health Law (Republic Act 11036). July 2017. [https://www.plo.gov.ph/images/Documents/Downloads/RepublicActs-JointResolutions/RA.11036\\_mental.health.act.pdf](https://www.plo.gov.ph/images/Documents/Downloads/RepublicActs-JointResolutions/RA.11036_mental.health.act.pdf). Accessed October 15, 2018.
23. Senate of the Philippines. An act prohibiting discrimination on the basis of sexual orientation and gender identity or expression (SOGIE) and providing penalties therefor (Senate Bill No. 1271). <https://www.senate.gov.ph/lisdata/25179216931.pdf>. Accessed October 15, 2018.

# INSIGHTS IN PUBLIC HEALTH

## ***Hana Pu No Ke Ola O Hana* (“Working Together for the Health of Hana”): Our 14-year CBPR Journey**

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### **Abstract**

*There are substantial and persistent health disparities among Native Hawaiians that are best addressed through multilevel socio-ecological approaches, which are tailored to the needs of the community. Partnerships that link academic investigators with grass roots community members have the potential to profoundly reduce health disparities and improve health and wellness by increasing the capacity of community-based organizations to provide leadership in health advocacy, support community health promotion, and participate in health research. We describe a 14-year partnership to reduce Native Hawaiian health disparities between investigators from The Queen’s Medical Center and University of Hawai‘i John A. Burns School of Medicine (QMC-JABSOM) and community members in Hana, a geographically isolated, underserved, rural community with the second largest concentration of Native Hawaiians in the state. Our relationship started as an investigator-initiated, National Institutes of Health-sponsored study to explore familial cardiomyopathy, and transitioned to a community-based project that combined community cardiovascular health screening fairs with a qualitative research study to understand attitudes towards genetic research. Most recently, QMC-JABSOM has partnered closely with Ma Ka Hana Ka ‘Ike, an award-winning construction skills training program for at-risk youth in Hana, to develop innovative, culturally based interventions to improve health and well-being among Native Hawaiians using principles of community-based participatory research.*

### **Introduction**

There are substantial and persistent health disparities among Native Hawaiians that are deeply imbedded in the social, political, and economic power inequities common to many indigenous peoples and their communities.<sup>1</sup> Difficulties in reducing Native Hawaiian health disparities highlight the need for a multilevel socio-ecological approach that moves beyond reductionist, disease-based interventions to one that embraces ancestral ways of knowing and a broader sense of “self” and “community.”<sup>2-5</sup>

Hana is a small, rural, predominantly Native Hawaiian community on the island of Maui that is one of the most remote communities in Hawai‘i. Economically distressed, with over 30% of families living below the federal poverty level and nearly 80% of students eligible for school lunch assistance,<sup>6</sup> Hana also has significant health disparities, including high rates

of substance abuse, obesity, diabetes, and hypertension. Despite these inequities, Hana is resilient and navigating towards a place of health and wellbeing. In this article, we describe a 14-year collaborative journey between a team from The Queen’s Medical Center and University of Hawai‘i John A. Burns School of Medicine (QMC-JABSOM) and community partners in Hana.

### **Phase 1: From Hospital to Community-based Research (2005-2011)**

#### **Introduction to Hana: Patterns of Heritable Cardiomyopathy (2005-2009)**

In 2005, The Queen’s Medical Center received a National Institutes of Health (NIH)—National Heart Lung and Blood Institute (NHLBI) funded grant to develop family trees of Native Hawaiians with heart failure to better understand patterns of heritable cardiomyopathy and lay the groundwork for future genetic analyses. We identified 45 probands from the hospital inpatient and outpatient services and created family trees that generally demonstrated sporadic or autosomal dominant patterns of inheritance.

In the course of our work, one family in Hana challenged us to do more. Mrs. Patsy Kaina had already recognized that heart failure and premature death extended across at least four generations of her family, and she shared their history and genealogy, first at an office visit, then at a family member’s home on O‘ahu, and then during invited visits to her home in Hana. From the start, Mrs. Kaina recognized the benefits of a partnership, and moved us beyond the narrow focus of our study. As we constructed a family tree of more than 300 family members, we spoke with community members about the complexity and reality of delivering heart disease care and conducting research in Hana. These conversations addressed the need for cultural context and community ownership, how past harms influence current attitudes, and the need for mutual trust and respect.

### **Moving Forward: Heart Screening Program and Qualitative Research Study (2010- 2011)**

Recognizing the sensitivity about performing genetic research with Native Hawaiian communities,<sup>7-9</sup> we conducted semi-structured interviews with families affected by heart failure during a community heart screening program that included blood pressure checks, EKGs, cardiac ultrasound, and individualized health education. More than 80 community members participated in these biannual screening events, which were coordinated by Mrs. Kaina and supported by a grant from the University of Hawai'i Center for Native and Pacific Health Disparities Research. We found that the community was open to participating in genetic research if there was adequate trust, mutual benefit, and a key community voice.<sup>10</sup>

### **Phase 2: From Community-based to Community-based Participatory Research (CBPR) (2012-2013)**

#### **Hana Ulu Pono Project (2012-2013)**

Encouraged by our community partners to move beyond health screening to test interventions that improve well-being, we followed CBPR principles to develop a culturally relevant, community-based program that built on the cultural wisdom and practices within Hana. With funding from the Office of Hawaiian Affairs (OHA) and matching funds from QMC, and with Dr. Seto and Mrs. Kaina as co-principal investigators, the Hana Ulu Pono Project recruited community members to participate in community-developed activities consistent with indigenous practices, including net fishing, *lauhala* (leaves of the hala tree) gathering and weaving for *kupuna* (elders), walking groups, gardening, and *kalo* (taro) farming. With community-members recruiting participants, running the activities, and tracking attendance, the QMC-JABSOM team developed individualized exercise prescriptions, led health education and screening events, and performed endpoint assessments, including measures of hypertension, diabetes, and obesity.

#### **Hana Ulu Pono Project 2 (2013)**

With the continued support of OHA and QMC, community partnerships were expanded to include Maui County Department of Parks and Recreation, the Hawai'i State Department of Health, and local businesses to provide expanded programs for *keiki* (children), public health nurse visits for the home-bound, and water-based activities for *kupuna*. The unfortunate passing of Mrs. Kaina, our partner and key community voice, was a great loss for the community and a setback for our program.

### **Phase 3: Extending the Concept of Health with Ma Ka Hana Ka 'Ike (2014-18)**

#### **Ma Ka Hana Ka 'Ike Hana Ola Project (2014-18)**

In January 2014, a new partnership was developed between QMC-JABSOM and *Ma Ka Hana Ka 'Ike* (MKHKI) (“In

working one learns”), an award-winning construction skills training program for at-risk youth based at Hana School. An important and trusted fixture in the Hāna community for more than 14 years under the leadership of Mr. Rick Rutiz and his team, MKHKI’s perspectives on building community resilience through education, mentoring, protecting natural resources, caring for the vulnerable, and honoring cultural practices made it a natural partner for efforts to improve the community’s health.

The new partnership, called the MKHKI Hana Ola Project, was developed following the principles of CBPR. The project recruited Hana community members into two core activities that integrated physical activity, health education, and ancestral and cultural practices. The Youth Community Program engaged youth and young adults in a building skills program that included a focus on mentorship and community service. Completed projects included cottages for *kupuna* and home improvements that increased safety and access for people with disabilities (Figure 1). Additional activities for participants included hula and fishing. The Mahele Farm Program, based at a 10-acre farm that serves Hana as an educational, sustainable, and health food resource, offered participants nutrition education, hand-on experience with cooking and sustainable farming techniques, helping with the harvest, and sharing with the community (Figure 2). The addition of a satellite garden at Hana School allowed school-aged participants to more regularly participate in activities.

In 2015, a third program, Malama Haloa, arose from MKHKI’s expanded infrastructure and the community’s overwhelming interest in the weekly *ku'i 'ai* (poi pounding). Under the direction on Mr. Viliami Tukuafu, the program included multiple components: (1) restoring and gaining stewardship of *lo'i kalo* (wetland taro fields) in Wailua Nui; (2) *malama 'aina* (caring for the land before planting); (3) learning Hawaiian chants, *mo'olelo* (stories, myth, legends, history), values, and protocols associated with food and eating; (4) carving *papa* and *pohaku* (poi pounding boards and stones); (5) pounding *kalo* to make *pa'i 'ai* and poi (Figure 3); (6) workshops and weekly *kalo* subscription service for families; (7) classes and field trips for students; (8) *mala kalo* (dry-land *kalo* gardens) at Hana School and Mahele Farm (Figure 4).

As part of Malama Haloa, we were awarded a pilot grant from the Mountain West CTR-IN to conduct a randomized controlled trial, *Ke Ala Haloa: Reclaiming Cardiometabolic Health in Hana*, which measured the impact of a Traditional Hawaiian Eating Pattern (THEP) on cardiometabolic risk factors and quality of life. The intervention and study protocol was developed by Mr. Tukuafu, who also oversaw recruitment and study implementation. The QMC-JABSOM team helped to design the study, select study endpoints, and perform endpoint assessments. During the 1-year study, we randomized 50 participants to THEP or their usual diet, and found that those on THEP had significantly lower rates of obesity and overweight, less sedentary time and more physical activity, with a trend towards less hypertension.<sup>11</sup>





Figure 1. MKHKI Youth: Building a *kupuna* cottage as community caretakers.



Figure 2. Youth participants with Mahele Farm harvest.



Figure 3. *Keiki* participant pounding poi.



Figure 4. Talk story in the taro patch at Mahele Farm.

**Phase 4: *Ho’oma’ama’a a pa’a i ka mana’o* (“Practice Until it is Firm in One’s Thoughts”) (2019)**

A new project currently under design builds on the infrastructure developed in Malama Haloa. *Na ‘Umeke Piha Pono* (“A Perfectly Full Bowl of Poi”) will provide families with weekly access to *kalo*, *mea ku’i*, and *mana* to help participants fill their *‘umeke* (a poi calabash) every week. In addition, all Hana High and Elementary School students will have the opportunity to participate in an annual 10-part Haloa-based educational program, which will promote mentorship opportunities in *ku’i ‘ai*, *mahi ‘ai kalo* (*farming kalo*), *‘olelo Hawai’i* (the Hawaiian language), and community engagement. The *Kumu Ku’i*

(teacher) will allow students to have project-based activities that help them to learn in traditional ways alongside more modern methods. It is our hope that the *Na ‘Umeke Piha Pono* project will nurture and encourage a new generation of *mahi ‘ai kalo* practitioners through MKHKI-grounded partnerships that will provide intergenerational mentorship and apprenticeship opportunities.

**Discussion**

Efforts to reduce racial and ethnic health disparities often require a multilevel socio-ecological approach, particularly among indigenous and geographically isolated communities.<sup>1-6,12</sup> The ongoing 14-year relationship between QMC-JABSOM and the



community of Hana is a story of friendship, mutual trust, shared benefit, and continued learning. What started as an academic project to understand heart failure inheritance has evolved into a multilevel, community-embraced program to improve health and wellness that builds on the community's strength and resources, and embraces local traditions and ancestral ways of knowing.

Our experience is consistent with recommendations that the multi-level "upstream" changes needed to reduce health disparities require an increase in the capacity of community-based organizations to provide leadership in health advocacy, support community health promotion, and participate in community health research.<sup>1,4,5</sup> In many ways, MKHKI was the ideal partner: The organization was trusted in the community, had developed an extensive network of partners, maintained strong administrative leadership and key community voices, cultivated a strong link to cultural practices, and fostered a spirit of innovation and creativity.

We encountered several challenges. First, while we have been fortunate to obtain support from the NIH, OHA, and QMC, it is increasingly difficult to secure extramural funding, particularly for CBPR studies that may take several years to develop.<sup>12</sup> Second, we occasionally struggled to balance outcome measures that are meaningful to the community (eg, quality of life, engagement) and those that may be meaningful to grant funders and the scientific community (eg, HbA1c levels, inflammatory markers). Third, while we were able to successfully run a community-based randomized, controlled clinical trial, the burden on the community was tremendous as the constraints of randomization are essentially disconnected from the social fabric cohesiveness that is a core strength of this community. This means that implementing clinical research studies in the community setting will necessitate innovative, pragmatic designs.

In conclusion, through our partnership, we have developed the capacity to provide community-designed, culturally informed, and community-implemented interventions to reduce Native Hawaiian health disparities and improve health and well-being in Hana.

## Acknowledgements

This project was supported, in part, by grants from the National Institutes of Health (NIH) National Institute on Minority Health and Health Disparities (U54MD007584) and National Heart Lung and Blood Institute (U01HL079152), and Office of Hawaiian Affairs. We thank Mr. Arthur Ushijima and The Queen's Medical Center for their support of the Hana community. Our work is dedicated to Mrs. Patsy Kaina, our original key voice in Hana.

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## References

1. Iton AB. The ethics of the medical model in addressing the root causes of health disparities in local public health practice. *J Public Health Manag Pract.* 2008;14(4):335-339.
2. Bertoni AG, Foy CG, Hunter JC, Quandt SA, Vitolins MZ, Whitt-Glover MC. A multilevel assessment of barriers to adoption of Dietary Approaches to Stop Hypertension (DASH) among African Americans of low socioeconomic status. *J Health Care Poor Underserved.* 2011;22(4):1205-20.
3. Boddington P, Räisänen U. Theoretical and Practical Issues in the Definition of Health: Insights from Aboriginal Australia. *J. Med. Philos.* 2009;34:49-67. doi: 10.1093/jmp/jhn035.
4. Vallesi S, Wood L, Dimer L, Zada M. «In Their Own Voice»-Incorporating Underlying Social Determinants into Aboriginal Health Promotion Programs. *Int J Environ Res Public Health.* 2018;15(7):1514. Published 2018 Jul 18. doi:10.3390/ijerph15071514.
5. Okihiro M, Sehgal V, Wilkinson T, Voloch KA, Enos R, O'Brien J. Addressing health disparities by building organizational capacity in the community: a case study of the Wai'anae Coast Comprehensive Health Center. *Hawaii J Med Public Health.* 2014;73(12 Suppl 3):34-9.
6. Healthy Communities Institute. (2015). *Maui County community health needs assessment.* Healthcare Association of Hawai'i. Honolulu, HI.
7. Singe L. The patentability of the Native Hawaiian genome. *Am J Law Med.* 2007;33:119-139.
8. Chang RM, Lowenthal PH. Genetic research and the vulnerability of Native Hawaiians. *Pac Health Dialog.* 2001;8:364-7.
9. Association of Hawaiian Civic Clubs. Resolution urging the University of Hawai'i to cease development of the Hawaiian genome project or other patenting or licensing of Native Hawaiian genetic material until such time as the Native Hawaiian people have been consulted and given their full, prior and informed consent to such project. 2003. [cited 2013 Mar 3]. Available from: [http://www.ipcb.org/pdf\\_files/hi\\_GenReso.pdf](http://www.ipcb.org/pdf_files/hi_GenReso.pdf).
10. Vawer M, Kaina P, Leonard A, et al. Navigating the cultural geography of indigenous peoples' attitude toward genetic research: the Ohana (family) heart project. *Int J Circumpolar Health.* 2013;72:10.3402/ijch.v72i0.21346. Published 2013 Aug 5. doi:10.3402/ijch.v72i0.21346.
11. Tukuafu V, Sreejayan N, Seto TB. "Malama Haloa," paper presented at the Mountain West Clinical and Translational Research Infrastructure Network 5th annual meeting, June 11-12, 2018.
12. Harris DA, Pensa MA, Redlich CA, Pisani MA, Rosenthal MS. Community-based participatory research is needed to address pulmonary health disparities. *Annals ATS.* 2016;13(8):1231-8.

# HAWAI'I JOURNAL WATCH

KAREN ROWAN MS

**Highlights of recent research from the University of Hawai'i and the Hawai'i State Department of Health**

## CHINA'S FIRST GLOBAL HEALTH BACHELOR CURRICULUM

With rapid development and growing health inequalities, China is facing an increasing demand for a highly-trained public health workforce. Yuanan Lu PhD, with UH Public Health, recently collaborated with other global health experts to create the first global health bachelor curriculum in China. The experts conducted a consensus-building process to construct the program, which will include modules in global health issues, intercultural communication, and health policy and program management. The program is now offered at Wuhan University and can serve as a guide for developing similar programs in China. More such programs are needed to help the country to address health issues and conduct research to provide evidence for policy-making decisions. The researchers reported (<https://bit.ly/2TbMd9V>) the outline of the curriculum and the process that they used to design it in *BMJ Open*.

## 'PARTNER SERVICES' STRATEGY IS EFFECTIVE IN FINDING UNDIAGNOSED HIV CASES

An effective way to find people with undiagnosed HIV infections is to use a strategy called partner services, new research shows. Partner services involves interviewing people newly diagnosed with HIV to find information about their sex and needle-sharing partners, and then confidentially contacting those partners and offering testing and other services. In a test of implementing partner services in Hawai'i and New Mexico, researchers including Michelle Wozniak MPH, of the Hawai'i State Department of Health, found that 18% of people tested as the result of partner services were diagnosed with new cases of HIV. Along with the high testing yield, the project also improved collaboration between the health departments, providers, and HIV services organizations, the researchers reported (<https://bit.ly/2zinA2M>) in the *Journal of Public Health Management and Practice*.

## THE LOKAHI WHEEL OFFERS A CULTURALLY-SENSITIVE APPROACH FOR SOCIAL WORKERS

Social work researchers have developed a culturally-sensitive approach to use in family assessments by adding natural imagery to a LokaHI Wheel, which is a diagram depicting the Native Hawaiian worldview of interrelationships between humanity, the spiritual realm, and the environment. Researchers including senior author Meripa Godinet PhD, with the Myron B. Thompson School of Social Work, said social workers could use the wheel when assessing Native Hawaiian and Other Pacific Islander families receiving involuntary services, such as child protective services, that are often seen as stigmatizing. The approach was designed to help engage families in an egalitarian manner that acknowledges their narrative. In early work, graduate students reported the tool was useful in fostering communication. The study is published (<https://bit.ly/2MsGk5C>) in the *Journal of Indigenous Social Development*.

## RACIAL AND ETHNIC DIFFERENCES IN MENTAL HEALTH SERVICES IN HAWAI'I

Asians and Native Hawaiian/Pacific Islanders (NHPIs) in Hawai'i are less likely than whites to use health services for mental health reasons, new research of Medicaid data suggests. Researchers led by Eunjung Lim PhD, MS, of the John A. Burns School of Medicine, investigated differences in the use of services for mental health disorders using 2010 claims data from Hawai'i residents ages 21 to 64. They found that Asians were 44% less likely and NHPIs were 39% less likely to have a mental health outpatient visit compared with whites. For inpatient visits, Asians had 70% and NHPIs had 79% of the expected number of visits compared with whites. Further research is needed to evaluate whether these data reflect an unmet need, the researchers wrote in their study (<https://bit.ly/2TgGQGI>) published in the *Journal of Mental Health*.

## NURSE-LED PROJECTS IN HAWAI'I IMPROVE OUTCOMES AND SAVE MONEY

The Hawai'i State Center for Nursing is working to educate nurses on conducting evidence-based practice (EBP) projects, and a new paper highlights some recent accomplishments of the program. Senior author Katherine Finn Davis PhD, APRN, with the School of Nursing and Dental Hygiene, and colleagues report that the program teaches nurses to use the Iowa Model of EBP and includes a two-day workshop and a one-year internship. In one project, nurses saved their hospital \$25,000 and freed up 380 nursing hours annually by demonstrating that a procedure to prepare the perineum with iodine prior to vaginal deliveries was not routinely needed. In another project, nurses developed a new extubation readiness protocol and successfully lowered their unit's rate of failed extubations, which occur when patients do not begin breathing spontaneously after an artificial airway is removed. The paper (<https://bit.ly/2Bdvpsd>) is published in the *Journal of Hospital Librarianship*.

## HOW TO MANAGE SOFT TISSUE SARCOMAS

Soft tissue sarcomas (STSs) are very rare tumors that arise in tissue such as muscle, fat, and blood vessels. In a new review, Shane Y. Morita MD, PhD, with the UH Cancer Center, writes that the key to managing STSs that involve the trunk is a multi-disciplinary team that includes pathologists and radiologists, along with medical, radiation, and surgical oncologists. Surgery to remove the sarcoma is the cornerstone treatment for STS, and it is important to achieve negative margins around the tumor (meaning that there are no cancer cells left behind), but still preserve the patient's function as much as possible. There is a trend in the field toward treating patients who have high-grade STSs with chemotherapy or radiation prior to surgery. The paper (<https://bit.ly/2Sdf54z>) is published in *Chinese Clinical Oncology*.

# THE WEATHERVANE

RUSSELL T. STODD MD; CONTRIBUTING EDITOR

## STAYING ALIVE: SMOKING ISN'T COOL ANY MORE. CANCER DEATHS DECREASE.

More good medical news for 2019 came from the American Cancer Society. Driven mostly by the drop in smoker's deaths, an estimated 2.6 million fewer people died in the past 25 years according to the American Cancer Society. For most of the last century cancer fatalities rose gradually until a peak in 1991 when efforts to reduce smoking began to take effect. Since that date the death rate has dropped 1.5% each year through 2016. Added to the decrease in tobacco consumption, are the improved methods of cancer detection to apply remedies earlier in the disease. Still this reduction does not mean cancer deaths are nearing zero. Some improvement yes, but cancer remains one of the leading causes of death for Americans.

## TAKE IT WITH A GRAIN OF SALT, BUT WATCH YOUR BLOOD PRESSURE.

Specialists in food science and food microbiology have spent years in research determining what is and what is not safe for human consumption. Along the way they have exploded some myths. For example; the five second rule: people want to believe that a piece of food dropped to the floor is safe to eat if you pick it up quickly enough. Five seconds is plenty of time for nasty bacteria to leap onto a piece of your lunch, or a cookie fragment. In the lab at Clemson University after dropping bologna and bread on a surface contaminated with salmonella, technicians recovered between 100,000 and 10,000,000 bacteria after five seconds. True, letting the sample sit for 60 seconds was about 10 times worse, but five seconds was bad enough. Another popular fallacy relates to ice cubes; they are believed not to carry bacteria, but the Journal of Food Research found that 60% to 80% of ice scoops carried E.coli that was easily introduced to drinks. Lemon slices in drinks are thought to produce acid that reduces harmful bacteria. A study published in Journal of Environmental Health found that 70% of lemon slices taken from the rim of glasses in restaurants carried up to 25 different microbial species. Eat and drink at your own risk, but be wise and careful.

## WOMEN DON'T BELONG IN COMBAT UNITS.

The Obama administration policy of integrating women into ground fighting units is a misguided social experiment. The next defense secretary should quickly dump it. Recently, the Marine Corps released a study comparing the performance of gender integrated and male-only infantry units in simulated combat. It was no surprise that the male-only units greatly outperformed the integrated teams in shooting, surmounting obstacles, evacuating casualties. The female Marines were injured at more than six times the rate of men. It follows since male hormones produce stronger bones and muscles. These were the fittest females and had to work at full capacity to carry 80 lb. packs, climb 20 foot ropes multiple times, and scale an 8 foot barrier. The purpose of the test is to ensure that officers can hump their own equipment, and still arrive at a battleground mentally and physically able to command troops. Because most female applicants failed the test, it was redefined from pass/fail requirement to an unscored exercise with no bearing on the candidate's ultimate evaluation. Moreover, the 10 mile hike has been altered "gender neutral" so that officers can hand their pack to a buddy if they get tired. Another effect that has become taboo to talk about is the inevitable introduction of Eros.

Putting young hormonally charged men and women into stressful close quarters often for extended periods invites sexual liaisons, rivalries, breakups that undermine the bonding necessary to a fighting force. This combination of effects seriously reduces the American military's lethality. The incoming Pentagon chief will get aggressive grilling on gender integration from the Senate Armed Services Committee. He must resolve the absurd claim that when it comes to combat there are no significant physical differences.

## ELECTRIC VEHICLE DISCOUNTED PURCHASE DON'T DELAY.

President Trump's top economic adviser said the administration is looking to eliminate subsidies and other benefits that go with electric cars. This move could seriously hamper the auto industry's push to broaden the market for battery-operated vehicles. Lawrence Kudlow, the President's top financial analyst said, "As a matter of policy we want to end all these subsidies imposed during the Obama administration. We are a free market." Specifically the president was referring to an Obama-era stimulus that created a \$7500 consumer tax credit for the purchase of luxury electric cars. Nice work if you can afford a Tesla.

## FIRST CHECK OUT THE TERRITORY.

In Brisbane, Australia, a woman at first thought she was bitten on her bottom by a frog. She said she did not turn on the lights before she began her nocturnal bathroom task. "I felt this sharp tap on my bottom along with some pain." The tap was from a 5-foot long python hanging outside her toilet. She pulled up her knickers, shut the toilet lid on the invader and called the professional snake handlers. Her bum has recovered and her sense of humor is intact. In the future, she will not fail to turn on the light before doing her business.

## LYING PRONE ON THE HIGHWAY IS NEVER A GOOD IDEA.

In West Palm Beach, Florida, two 24-year-olds chose to view the January 20, 2019, eclipse rare super blood wolf moon by lying prone in the middle of a dark road. All seemed to be going well until around 11:30 P.M. a West Palm Beach police officer patrolling the area ran over the pair. He was cruising at just 5 mph and the human speed bumps sustained only non-life-threatening injuries.

## ADDENDA

- The first person killed by train was run over during the opening ceremony of the Liverpool and Manchester Railway in England, September 15, 1830.
- Princeton professor John W. Tukey coined the term "software" in 1958.
- My grandmother's brain was dead, but her heart was still beating. It was the first time we ever had a Democrat in the family.
- It's more fun contemplating someone else's navel than your own.
- I've known what it is to be hungry, but I always went right to a restaurant.
- Churches welcome all denominations, but most prefer tens and twenties.

## ALOHA AND KEEP THE FAITH rts

*(Editorial comment is strictly that of the writer.)*

# Hawai‘i Journal of Medicine & Public Health

## Instructions to Authors

The Hawai‘i Journal of Medicine & Public Health (HJMPH) publishes original contributions, reviews, balanced viewpoints (ie, point/counterpoint articles), editorials, and other categories of articles. Topics of interest include scientific articles related to the practice of medicine and public health, with a focus on the unique, multicultural and environmental aspects of the Hawaiian Islands and Pacific Rim region. Some frequently published types of articles are described herein. Authors interested in published other types of articles may contact the journal.

**Original articles** are usually research-related, quantitative or qualitative papers.

**Reviews** summarize the literature, address current practice or issues within the medical or public health communities, and are intended to promote a discussion of different viewpoints.

**Case Reports** are original and interesting reports that contribute significantly to medical knowledge. They generally describe unreported or unusual side effects, unexpected or unusual presentations of a disease, diagnoses and/or management of new and emerging diseases, unexpected events during treatment, or observations that highlight the need for new practice standards in the management of certain disease conditions.

**Viewpoints** presented opinionated pieces on a topic of current controversy. Viewpoint pieces should nevertheless independently meet the scientific rigor for a published article through the inclusion of appropriate citations, and the use of non-inflammatory language. It is the journal’s policy to present balanced opinions (ie, each viewpoint article must be paired with a counter-point article). Therefore, authors who submit a viewpoint article without the corresponding counter-point article may be delayed until an appropriate author for the counter-point piece can be found, and the article written. Authors are encouraged to work with colleagues to submit point-counterpoint articles together.

**Editorials** are usually solicited by the editors. The journal currently publishes four editorials, Public Health column, Medical School column, Pharmacy column, and the UH Cancer Center column. Authors interested in editorial pieces should contact the respective hotline editor.

For authors/editors interested in commissioning a HJMPH supplement, please view additional guidelines at <http://hjmph.org/submit.htm>.

### Manuscripts

Manuscripts are reviewed by the editors, the peer review panel, and other experts in the particular specialties. The HJMPH only accepts articles that have not been published or currently under review by other journals.

### I. Word Limit, Font, and Formatting:

Keep manuscript to 3,000 words maximum (title page, abstract, keyword, abbreviations, references, tables/figures not included).

- Use Times font in 10 point size.
- Do not underline and do not use full caps.
- Use double spaces between lines. Do not use 1-1/2 spacing.
- Use a single space between sentences. Do not use two spaces.
- Number pages consecutively beginning with the title page.

### II. Tables and Figures:

Tables and figures may be submitted as part of your manuscript. Each table or figure should be carefully selected or designed to add value to the manuscript by showing a relationship of ideas, data, or objects that would be difficult to describe precisely or completely using words alone. Authors must be judicious in their use of tables and figures.

- All illustrations (ie, graphs, flow charts, diagrams, drawings, maps, and photographs) are identified using the word “Figure.” Do not mix in alternatives such as “Photo” or “Chart.”
- Tables and figures may be up to 7-1/2 inches in width.
- Tables and graphs must be prepared in Microsoft Word, PDF, or Excel.
- Flow charts, diagrams, drawings, maps, and photos must be submitted as a high resolution (300 dpi is optimal) in JPEG, TIFF or PDF format.
- All tables and figures must be numbered sequentially, and include a caption. They must be well-labeled, stand alone, and not require the reader to refer back to the text.
- All tables and figures must be referenced within the text (ie, readers must be appropriately referred to all tables and figures that are part of the article.)
- Data points on graphs should be labeled. Numerical data should accompany graphs.
- Do not embed tables, figures, and graphs within the text; their placement must be at the end of the manuscript.

### III. Cover Letter

A cover letter should contain the following components:

1. The title of the submission
2. The names of all contributing authors, listed in the order in which they will appear in the manuscript. List first name, middle initial and last name of each author with highest academic degrees; and name of department and institution to which the work should be attributed.
3. Please provide each co-author’s role in the preparation of the manuscript. As needed, please identify the primary author responsible for each of the following areas:
  - Guarantor of integrity of entire study
  - Study concept design
  - Data acquisition/analysis
  - Manuscript drafting/revision for intellectual content
  - Literature review
  - Clinical studies
  - Statistics
  - Manuscript editing
4. Name of the corresponding author; include an address, phone number, and email address.
5. Information on whether the article submitted is Medical, Public Health or Cross Cutting
6. The names of two potential peer reviewers for the article, along with their contact information (email address at minimum).



#### IV. Title Page, Abstract, Keywords, and Abbreviations

**Title Page**— The title page of the manuscript should note the title, full names and highest academic degrees of all authors and word count. On the title page, please also notate if you are submitting an article that is medical, public health, or cross-cutting (both medical and public health).

**Abstract**— The second page of the manuscript should include an abstract that highlights for the reader the essence of the authors' work. It should focus on facts rather than descriptions and should emphasize the importance of the findings and briefly list the approach used for gathering data and the conclusions drawn. The abstract must be written as a standalone paragraph, and not be broken up into sections. \*\*\*\***Keep abstract to 250 words maximum.**

A few specific guidelines to consider in preparing an abstract follow:

- Do not begin the abstract with a repetition of the title.
- Cite no references.
- Avoid abbreviations.
- Use the salt or ester of a drug at first mention.
- If an isotope is mentioned, when first used spell out the name of the element and then, give the isotope number.
- Avoid the use of trademarks or manufacturers' names unless they are essential to the study.
- Include major terms in the abstract, since the abstract can be text searched in many data retrieval systems.
- Include Keywords

#### Include Keywords

#### Include Abbreviations: for example, Abbreviations and Acronyms

BP = blood pressure

CI = Confidence Interval

#### V. Sections of the Manuscript

We recommend that articles be divided into sections with headings. The traditional layout described below may not apply to all submission types (eg, editorials or case reports). Nevertheless, the journal recommends that authors create 3-5 sections with appropriate headings to optimize the organization and flow of their write-ups. In addition, a background/review piece, and a summary/discussion piece is recommended for all types of articles submitted to the journal. *Note:* If your manuscript includes more than five abbreviations, please include a list of abbreviations, along with their definitions in a table.

**Introduction**—Describe the purpose of the article and rationale for the study. Review the existing literature, and identify any gaps in the literature that the submission seeks to fill. Define any terms or concepts discussed in the remainder of the paper, and state any hypotheses associated with the study. For case reports, it may be useful to include the current body of knowledge and/or standard practice guidelines to provide context for the case described.

**Methods/Case Report**—Describe the patients or experimental animals clearly. For review articles, describe the methodology used for searching and identifying the appropriate articles to include in the review. Identify the methods, apparatus, and procedures in sufficient detail to allow other researchers, public health professionals, or physicians to reproduce the results.

NOTE: Ethical Approval of Studies and Informed Consent. For human or animal experimental investigations, formal review and approval, or review and waiver, by an appropriate Institutional Review Board (IRB) or ethics committee is required and should be described in the Methods section. For those investigators who do not have formal ethics review committees, the principles outlined in the Declaration of Helsinki should be followed. For investigations of human subjects, state in the Methods section the manner in which informed consent was obtained from the study participants (ie, oral or written). Where applicable, the manuscript must explicitly state that IRB approval was obtained, and provide a reference number whenever possible.

**Results**—Present the results in logical sequence. Do not repeat all of the data in the text; summarize important observations. Do not include any inferences or interpretations within this section. The results section may not be appropriate for all types of contributions to the journal (for example, editorial pieces, or case reports). If the results section includes statistical analyses, it may be helpful to additionally consult the HJMPH Statistical Guidelines at <http://hjmph.org/submit.htm>.

**Discussion**—Emphasize the new and important aspects of the study and conclusions taken from them. Do not repeat data in Results section. It is important to interpret the results or observations reported in the paper in the context of the background information presented in the introductory section, and discuss the implications of the results. State new hypotheses that emerge from the findings of the paper when warranted, but clearly label them as such. Please include study limitations, and recommendations that naturally flow from the conclusions.

**Acknowledgments**—Acknowledge only persons who have made substantial contributions to the study. Authors are responsible for obtaining written permission from everyone acknowledged by name; readers might believe those acknowledged are endorsing the study and conclusions.

#### VI. Disclosure Statement

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## VII. Conflict of Interest

Authors must disclose all relationships that could be viewed as presenting a potential conflict of interest.

## VIII. Citing References

Use JAMA style for in-text citations and references. A few key styling guidelines are presented below. For more details, please consult the AMA Manual of Style.

### *In-text Citations:*

- Identify references with superscript Arabic numerals corresponding to the item in your reference list.
- If you are using the same citation in more than one location within the paper; you can refer to the same citation number.
- Place citations outside of punctuation marks.

### *Creating your References:*

- List the citations in their order of appearance within your paper.
  - Examples of reference style:
1. Garbutt JM, Banister C, Spitznagel E, Piccirillo JF. Amoxicillin for acute rhinosinusitis: a randomized controlled trial. *JAMA*. 2012;307(7):685-692.
  2. Steinbrook R, Ross JS. “Transparency reports” on industry payments to physicians and teaching hospitals [published online ahead of print February 14, 2012]. *JAMA*. doi:10.1001/jama.2012.211.
  3. Centers for Medicare & Medicaid Services. CMS proposals to implement certain disclosure provisions of the Affordable Care Act. <http://www.cms.gov/apps/media/press/factsheet.asp?Counter=4221>. Accessed January 30, 2012.
  4. McPhee SJ, Winker MA, Rabow MW, Pantilat SZ, Markowitz AJ, eds. *Care at the Close of Life: Evidence and Experience*. New York, NY: McGraw Hill Medical; 2011.

### *Additional JAMA Styling Tips:*

- Statistical Probability P (upper case, italics)
- Standard Error SE
- Standard Deviation SD
- Relative Risk RR
- Title of books Italics
- Title of Journals Italics
- Use the objective case, such as “the team determined” or “the study involved,” not I or we, and avoid medical jargon.
- Use generic drug names unless citing a brand name relevant to your findings. Do not use abbreviations in the title and limit their use in the text.
- Use human terms, ie, men and women instead of males and females.
- Use a comma before the conjunction (and, or, nor, but) that precedes the last item in a series.
- Do not use periods with eg, ie, etc, vis, or similar abbreviations. Follow these with a comma and enclose the entire expression in commas or parentheses — (eg, eggs, apples, and nuts)
- Use close parentheses in numbered items (1), (2), (3), etc.

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