# Hawaiʻi Journal of Medicine & Public Health

## A Journal of Pacific Medicine & Public Health

March 2018, Volume 77, No. 3, ISSN 2165-8218

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### Hawai'i Journal of Medicine & Public Health

A Journal of Pacific Medicine & Public Health ISSN 2165-8218 (Print), ISSN 2165-8242 (Online)

The Journal's aim is to provide new scientific information in a scholarly manner, with a focus on the unique, multicultural, and environmental aspects of the Hawaiian Islands and Pacific Rim region.

Published by University Health Partners of Hawai'i (UHP Hawai'i) [formerly University Clinical, Education & Research Associates, UCERA] Hawai'i Journal of Medicine & Public Health 677 Ala Moana Blvd., Suite 1016B, Honolulu, Hawai'i 96813 http://www.hjmph.org; Email: info@hjmph.org

The Hawai'i Journal of Medicine & Public Health was formerly two separate journals: The Hawai'i Medical Journal and the Hawai'i Journal of Public Health. The Hawai'i Medical Journal was founded in 1941 by the Hawai'i Medical Association (HMA), which was incorporated in 1856 under the Hawaiian monarchy. In 2009 the journal was transferred by HMA to University Health Partners of Hawai'i (UHP Hawai'i). The Hawai'i Journal of Public Health was a collaborative effort between the Hawai'i State Department of Health and the Office of Public Health Studies at the John A. Burns School of Medicine established in 2008.

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### The Electronic Health Literacy and Utilization of Technology for Health in a Remote Hawaiian Community: Lana'i

Nash A.K. Witten MD and Joseph Humphry MD

#### Abstract

The Lana'i Community Health Center (LCHC) like other health care organizations, is striving to implement technology-enabled care (TEC) in the clinical setting. TEC includes such technological innovations as patient portals, mobile phone applications, wearable health sensors, and telehealth. This study examines the utilization of communication technology by members of the Lana'i community and LCHC staff and board members in the home and in their daily lives and evaluates the community's electronic health literacy. Quantitative surveys and qualitative focus groups were utilized. These revealed that members of the Lana'i community and LCHC staff and board members regularly utilize technology, in the form of smart cell phones, WiFi, and internet texting. This community has integrated technology into their daily lives, even though they live on an isolated island with 3,102 people; however, despite this integration, the electronic health literacy of this population appears insufficient for proper understanding and utilization of TEC, limiting the potential of patient portals or remote monitoring of patient generated data for chronic disease prevention and management without additional education and mentoring. It is therefore in the best interest of the LCHC and other health organizations wishing to implement TEC in a rural community such as Lana'i to include a strong educational component with use of TEC, and perhaps establish a mentor/partnership program for the highly-challenged patient.

**Keywords** 

health literacy, rural health, electronic health records, chronic disease

#### Abbreviations

LCHC = Lana'i Community Health Center HCPs = health care providers TEC = technology-enabled care eHEAL = Electronic Health Literacy Scale<sup>1</sup> ANOVA = analysis of variance VCT = video conferencing technology

#### Introduction

Electronic health literacy is defined as "the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem."1 It requires the following six core literacy skills: traditional, information, scientific, media, and computer.<sup>1</sup> Lana'i Community Health Center (LCHC) is incorporating technology-enabled care (TEC) into its clinical practice, to better meet the needs of this rural community, a community that lacks access to both primary care and specialty health care providers (HCPs). Although LCHC has successfully implemented various TEC initiatives, including a patient portal, Bluetooth enabled blood pressure monitors, a clinic website, and telemedicine, understanding the patient's knowledge, literacy, and use of available communication technology is valuable in planning and implementing further enhancements, particularly for older patients with chronic conditions. These efforts to use technology to improve the health status follow national trends, as 95% of Americans own a cell phone, 77% own a smart phone,<sup>2</sup> and 88% use internet.<sup>3</sup> Patients can now access personal medical records and communicate securely with HCPs via patient portals. In 2016, the physician shortage in the United States was nearly 94,700, and is projected to increase toward 95,900 by 2025; using TEC as an interface between providers and patients helps to address this barrier to accessing healthcare,<sup>4,5</sup> with the goal of improving health outcomes.

LCHC is a Federally Qualified Health Center located in Lana'i City, which has a population of 3,102 people living within 1.1 square miles, on the island of Lana'i, whose total land area is 141.07 square miles.<sup>6,7</sup> The median age on the island is 38.4 years, with 16.7% of the population older than 65 and 27.7% under 20.<sup>7</sup> Being isolated from the major hospitals and medical specialists in Honolulu, O'ahu and those in Kahului, Maui, the population of Lana'i relies on two outpatient clinics and a small critical access hospital for its acute and chronic medical needs. This study examines how communication technology is utilized by members of the Lana'i community and LCHC staff and board members in their daily lives and examines the study participants' electronic health literacy.

#### Methods

This research project was approved by the University of Hawai'i Human Studies Program, CHS # 2016-30924, which declared this study "exempt." LCHC staff identified three populations for this study: people who attend the Lana'i Senior Center; middle and high school students in biology classes at the Lana'i High and Elementary School; and LCHC staff and board members. All of the LCHC staff working during the time the focus groups were held were invited to participate in the research project. All staff members were given thirty minutes away from their work duties in order to participate in the focus groups. The LCHC board members were invited to participate in a focus group that was held prior to their scheduled board meeting. Two additional focus groups were also conducted with participants from one of the LCHC's free zumba fitness classes and with members of a nurse assistant program at the local community college. Not all members of the targeted groups participated in the focus groups. LCHC provided food and refreshments for the majority of the focus groups. The first author of this article facilitated all eleven focus groups in this study. Individuals willing to participate in a focus group were asked to sign the IRB approved consent form and to indicate whether they agreed to be audio-recorded (which was to be used for later transcription). Anyone under eighteen years of age had their parent or guardian sign the consent form prior to participating and was verbally asked by the facilitator if they wished to participate in the focus group. A quantitative questionnaire was administered before each focus group, including demographic questions and questions adapted from the Electronic Health Literacy Scale (eHEAL) (see Appendix 1 and 2.) The eHEAL questionnaire is a validated tool to reliably and consistently capture electronic health literacy "consumer comfort and skill in using information technology for health."<sup>1</sup> Two questions were added to the validated eHEAL questionnaire to assess for participant feelings toward the usefulness of the internet to make health decisions and the importance of being able to access health information on the internet (questions 1 and 2, respectively).

Upon completion of the quantitative questionnaire the survey instrument was collected and the standardized focus group introduction, assembled by the authors, was read and included the purpose of the project, introduction of the facilitator, and ground rules for the session (see Appendix 3). At this point, the audio-recording of the focus group began, using a conference room speakerphone connected to a MacBook Air laptop running the Audacity 2.1.0 audio-recording software (Audacity Team; https://audacityteam.org). The same standardized focus group questions were used in all focus groups, with three additional questions included in those focus groups containing LCHC healthcare providers (see Appendix 4.) The audio-recording software was stopped once all participants were given the chance to contribute to the final focus group question.

Eleven focus groups were completed and transcribed by the same facilitator. Each participant was assigned a number to mask their identity. The transcriptions were then analyzed for themes, based on the theme analysis methodology described by Krueger and Casey<sup>8</sup> and grouped into the following categories: people who attend the Lana'i Senior Center; middle and high school students in biology classes at the Lana'i High and Elementary School; and LCHC staff and board members. Basic statistical analysis of the quantitative questionnaire data, including mean, median, and mode, were conducted with Microsoft Excel, version 15.33 (Microsoft; Redmond, Washington). Advanced statistical analysis was performed with SPSS, version 23 (IBM; Armonk, New York), including an independent sample t-test and multiple one-way analysis of variance (ANOVA).9 The independent sample t-test was used to determine whether there was a significant difference between male and female responses to the adapted eHEAL questions. ANOVA were conducted on each eHEAL question to determine where there was a statistically significant difference between the answers of various age groups (10-19, 20-29, 30-39, 40-49, 50-59, 60-69, and 70-89) and education levels (some school, high school, some college, associate degree, bachelor degree, master degree, and advanced degree) of the participants. The 70-79 and 80-89 age groups were combined for data analysis due to the limited number of participants in each group. One participant reported that she completed a trade school for the education level question and was included in "some college" group for data analysis.

#### Results

Sixty-nine participants completed both focus groups and questionnaires. Average age of all participants was 43 with both mean and mode for the study group being 34.5 years of age. Sixty-nine percent of the participants were female (one participant did not answer the gender question). Most participants (67%) were full or part Filipino and 25% were full or part Native Hawaiian. Fifty-seven percent of participants had at most a high school level of education, with sixteen percent having a bachelor's degree or higher level of education, as seen in Table 1. Most participants had a smart cell phone (83%), but only 57% had a cell phone data plan. Most participants regularly use Bluetooth (54%), WiFi (86%) and internet texting capabilities (74%). Few participants use a patient portal (16%), either available at LCHC, through their insurance company, or at another clinic, despite most participants having a portable or tablet computer, 62% and 58%, respectively, as seen in Table 2.

Based on responses to the eHEAL questionnaire, participants felt that the internet is useful in helping them to make decisions regarding their health and they feel it is important to be able to access health resources on the internet, as seen in Table 3 and Figure 1.

There was a statistically significant difference between the age groups as determined by one way ANOVA for all but one of the eHEAL questions as seen in Table 4 (question 7, see Appendix 2).Regarding education level, there was a statistically significant difference between the education groups for all but two of the eHEAL questions as determined by one way ANOVA as seen in Table 4 (questions 7 and 10, see Appendix 2). There was no statistically significant difference between males and females for any of the eHEAL questions, nor for questions regarding the utilization of health information found on the internet and confidence using information from the internet to make health decisions, as seen in Table 4.

None of the four participants in the Senior Center focus group use technology to access healthcare information. They observed that, in general, HCPs are too busy and unable to provide adequate patient education, and that using at home medical devices are difficult when living alone. One senior noted: "I take pretty good care of myself without technology" and others agreed that they lived to be elderly without using technology. They did not like the use of TEC by their HCPs. The seniors did not feel that the lack of HCP time to provide health education would adversely affect their overall health, as one participant noted: "What you don't know won't hurt you." All seniors agreed that if they had a medical question they would ask their peers at the Senior Center in person, or call one another over the phone, rather than attempting to use a computer to answer their question. One participant also noted that she had been given a home blood pressure cuff by her HCP, but due to the size of her arm, it was impossible to place the instrument properly to obtain a blood pressure.

Table 1. Demographics of all participants in the focus groups, by age group and gender.								
Focus Group*	Age Group	Gender	Number of Participants	Ethnicities Identified With	Current/ Maximum Education			
	10 – 19	Female	15	Chinese, Filipino, Native Hawaiian, Other, Other Asian, Other Pacific Is- lander, Portuguese, White	Some School			
Biology	10 - 19	Male	15	Chinese, Filipino, Japanese, Native Hawai- ian, Other, Other Asian, Portuguese, White	Some School			
	10 -19	Unknown	1	Other Pacific Islander	Some School			
	20 -29	Female	1	Filipino, White	High School			
CNA	60 -69	Female	1	White	Advanced Degree			
	70 – 79	Female	1	White	Associates			
	20 – 29	Female	6	Filipino, Native Hawaiian, Other Pacific Islander	High School, Some College, Associates, Bachelor Degree			
	30 – 39	30 – 39 Female		Chinese, Filipino, Native Hawaiian, Other Asian, White	High Schoo, Bachelor Degree, Master Degree			
LCHC	40 – 49	Female	5	Filipino, Native Hawaiian	Some College, Master Degree			
	60 - 69	Female	2	Japanese, White	Associates, Advanced Degree			
	30 – 39	Male	3	Filipino, Japanese, Native Hawaiian, Portuguese	Associates, Master De- gree, Bachelor Degree			
	50 -59	Male	1	Filipino	Some College			
	50 – 59	Female	1	Chinese, Native Hawai- ian, Portuguese	High School			
Senior	70 – 79	70 – 79 Female		Chinese, Filipino, Japa- nese, Native Hawaiian, White	High School			
	80 – 89	Female	1	Filipino	High School			
	20 – 29	Female	1	Hispanic, White	Some College			
Zumba	30 – 39 Female		4	Chinese, Filipino, His- panic, Native Hawaiian, White	High School, Trade School, Some College			
	50 – 59	Female	1 Hispanic, White		Some College			
	40 – 49 Male		1	Other	Master Degree			
	60 – 69	Male	1	White	Some College			

\* "Biology" refers to high school biology class focus groups at the Lana'i High and Elementary School; "Zumba" class refers to the focus group with the LCHC zumba class; "LCHC" refers to the LCHC staff and board member focus groups; "CNA" refers to the focus group from the local community college nurse assistant program; and "Senior" refers to the focus group at the Lana'i Senior Center. Table 2. Percentage of participants regularly utilizing the below technology types or who have the following technology in their home, by age group. See Appendix 1 for complete set of questions used.

Age Group	10 - 19 (n = 31)	20 - 29 (n = 8)	30 - 39 (n = 13)	40 - 49 (n = 6)	50 - 59 (n = 3)	60 - 69 (n = 4)	70 - 89 (n = 4)	Total (N = 69)	
Basic Cell Phone	16%	0%	0%	83%	0%	0%	100%	13%	
Smart Cell Phone	97%	100%	92%	33%	33%	25%	0%	83%	
Land Line	52%	38%	23%	83%	33%	50%	50%	42%	
Portable CPU	61%	75%	54%	67%	67%	100%	0%	62%	
Tablet CPU	55%	75%	77%	33%	33%	50%	0%	58%	
Fitness Tracker	10%	25%	15%	0%	33%	0%	0%	14%	
Other	10%	0%	80%	67%	0%	0%	0%	60%	
WiFi	97%	100%	92%	33%	67%	50%	25%	86%	
Wired Internet	45%	25%	46%	50%	0%	50%	25%	39%	
Bluetooth	68%	88%	38%	67%	33%	0%	0%	54%	
Video Conference	65%	75%	62%	83%	33%	50%	0%	59%	
Cell Photo Data Plan	58%	38%	69%	50%	67%	50%	0%	57%	
Internet Texting	87%	88%	77%	33%	33%	75%	0%	74%	
Patient Portal	60%	25%	38%	0%	0%	0%	0%	16%	
Other	0%	0%	0%	0%	0%	0%	0%	0%	

Table 3. Total Adapted eHEAL Questionnaire Average.*							
Questions	Average	Interpretation					
How useful do you feel the internet is in helping you in making decisions about your health?	4.2	Unsure - Useful					
How useful do you feel the internet is in helping you in making decisions about your health?	4.2	Unsure – Useful					
I know what health resources are available on the internet.	3.7	Disagree – Undecided					
I know where to find helpful health resources on the internet.	3.7	Disagree – Undecided					
I know how to find helpful health resources on the internet.	3.8	Disagree – Undecided					
I know how to use the internet to answer my questions about health	3.9	Disagree – Undecided					
I know how to use the health information I find on the internet to help me	3.8	Disagree – Undecided					
I have the skills I need to evaluate the health resources I find on the internet	3.6	Disagree – Undecided					
I can tell high quality health resources from low quality health resources on the internet	3.3	Disagree – Undecided					
I feel confident in using information from the internet to make health decisions	3.4	Disagree – Undecided					

See Appendix 2 for questions adapted from the Electronic Health Literacy Scale included in the pre-focus group questionnaire.

Table 4. One Way ANOVA and Independent T-Test Tables for Statistical Analysis of eHEAL Questionnaire for each Age Bracket, Educational Level, and Gender.											
eHEALQuestion		1	2	3	4	5	6	7	8	9	10
	df	F(6,62)									
Age	F	9.300	10.282	8.859	4.322	5.964	7.020	1.904	3.576	3.902	4.761
	Р	.000	.000	.000	.001	.000	.000	.094	.004	.002	.000
Education Level	df	F(6,62)									
	F	7.308	3.579	2.956	3.313	3.183	4.031	1.376	5.228	3.229	1.884
	Р	.000	.004	.013	.007	.009	.002	.238	.000	.008	.098
Gender	df	6.6	6.6	6.6	6.6	6.6	6.6	6.6	6.6	6.6	6.6
	t	-1.343	-1.035	-0.565	-0.309	-1.057	-1.623	-0.004	-1.076	-1.035	-1.547
	Р	.184	.304	.574	.758	.294	.109	.997	.286	.305	.127

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Eleven community adults participated in focus groups. These adults acknowledge that technology is integral to health, has improved access to healthcare, and should be further utilized. Google search is the first place they go to seek medical advice, primarily related to diagnosis and triaging concerns, and to determine whether or not they or a family member require a physician. Common websites visited for health information included PubMed, WebMD, the Mayo Clinic, health insurance websites, YouTube, and forums. Overall, adult participants agreed that websites like Wikipedia also serve as a good starting place to find general information about a symptom or diagnosis but, as one participant noted, "I just wouldn't take it to the bank."

The community adults that had accessed patient portals explained that online health information provided by patient portals has improved access to healthcare by enabling them to interact "intellectually" with HCPs. They noted that previously they were reliant on the HCPs review of their lab data and for patient education. Since this information is now available online via a patient portal, patients can present to clinic knowing more about their condition and ask their HCP more thoughtful questions. However, participants did not feel that emails following clinic visits were useful: "They show results of an appointment I was at a couple hours ago; so, I figure I know; I was there." Community adults felt comfortable using video conferencing technology (VCT) for clinic visits with HCPs who were not located on their island. For children needing to see a HCP not available on island, the group felt that they would only be comfortable using VCT if the child was physically with the off-island HCP, and the parent could participate from Lana'i via VCT.

Participants in these community adult groups had numerous suggestions on how healthcare systems and organizations could improve the utilization of technology, agreeing that an online VCT urgent care-style clinic would "revolutionize medicine as [we] know it." Participants requested online appointment scheduling through the patient portal. They did not feel that including additional health information, such as patient education materials related to diabetes mellitus management, on the clinic patient portal would be helpful, as it would require logging into the patient portal and they felt that Google results are more conveniently accessed and reasonably reliable. Several participants appreciate the number of health education materials available on YouTube, preferring to listen to a presentation by a HCP rather than read and interpret health information themselves.

Twenty-three LCHC staff and board members participated in five focus groups. Two main topics that emerged in these groups were that technology has improved access to medical knowledge and that technology should be further utilized by healthcare systems and organizations. Unlike the other non-LCHC focus groups that use Google as the first place to look for health information online, the staff at LCHC use more advanced medical search engines with subscriptions provided through their employer to look for health information online. Members of the LCHC focus groups agreed that they avoided using Google due to the lack of peer reviewed material in the results. Participants generally trusted online health information from websites with the "trust" logo on the web browser or any website with "American" or "Association" in the title. Websites with many advertisements, such as Wikipedia or WebMD, were seen as less trustworthy. Participants also appreciated accessing online lab results, allowing patients to be reassured more quickly than waiting for a HCP to call them with the results. Interestingly, not a single participant in the LCHC employee focus groups had logged into the patient portal, despite receiving emails after every HCP visit. They agreed that VCT on a cell phone or laptop to access HCPs for urgent care consults would be helpful, and stated that they would follow their HCPs on social media as they generally trust their HCPs opinions. LCHC staff also agreed that a digital, universal, immunization record online would be extremely helpful. Similar to other groups, participants requested being able to schedule clinic appointments online, with one participant stating, "I can even do it for my vet!"

HCPs within the LCHC focus groups felt that technology has improved access to and quality of healthcare. One HCP commented that "without access to what we have now, the patients on Lana'i would be at a significant disadvantage [compared to patients on the other Hawaiian Islands]." HCPs did mention that a single, universal electronic medical record would be ideal. The HCPs worried about reliance on technology, particularly as demonstrated during power outages on the island, when neither patients nor HCPs know medication lists or medical histories often needed for a clinic visit (though, LCHC has a generator that provides power in the event of outages). Finally, there was mutual concern that the patient-HCP relationship deteriorates due to technology in the exam room during every clinical encounter.

Thirty-one community middle and high school students participated in three focus groups, reporting that technology has improved their access to medical knowledge; however, they noted reservations about personal health information being available online. Similar to the other focus groups, students utilize Google search for online health information, but specifically avoid using Wikipedia, because teachers tell them it is not reliable, and WebMD, due to the number of advertisements. Most students also used online health information to decide whether or not to see a HCP in person, and some observed that they and their families used online health information to ensure the HCP gave them the correct medication, one participant stating: "My family kind of doesn't trust the doctors [on Lana'i]."

Some students were resistant to using a patient portal to access personal health information online or using VCT to see a HCP, fearing that "people could hack [the patient portal]," that the patient portal is not a safe repository for private information. Cyberbullying was also of concern, where someone might be able to access their private health information online via a patient portal and use the information to bully them. Consequently, most students agreed that they would "rather go see my doctor [in person] than use VCT."

For all focus group participants who do use technology to access healthcare information, the general workflow to find health information online went as follows: type symptom, disease, or medication into Google search; look for familiar trustworthy website names in the top three search results, such as PubMed, WebMD, or the Mayo Clinic; review the online material to triage a symptom, learn more about a disease, or to find out more information about a medication; if unfamiliar words were present in the material, the participants would then type the name into Google search to determine its meaning; and once educated by the material, the participants would decide whether they needed to see a HCP for help.

#### Discussion

TEC will increase access, improve quality, and lower cost of health care if effectively implemented. There is a general sense that technology will drive the transformation of the health care system; however, technology is viewed as enabling patients to receive better care. This study provides valuable insight into two essential aspects of using technology to better manage patients. The first is access and current knowledge of communication technology, ie, phones, tablets, and computers, and the second is the electronic health literacy of this population.

The population in Lana'i utilizes smart phones (83%) more than laptops (62%) or tablets (58%); with the mobile technologies being more common than the standard landline house phone (42%). The use of technology is following a general trend of using smaller unit mobile technology. The economic status of the Lana'i population may explain the decision to drop the traditional house phone in favor of a smart phone. As expected, mobile technology is more popular with the younger study participants. In addition, internet texting (74%) and video conferencing (59%) are common, but more so with the younger population.

Based on the statistical analysis of the resulting adapted

eHEAL questionnaire comparing gender, age, and educational levels, the main statistical differences were found between age groups and education levels, as expected. Of note, only one question had no statistical difference noted between any of the sub-categories of analysis, the adapted eHEAL question regarding the utilization of health information found on the internet. This suggests that all participants, despite education level, gender, or age, feel that they lack the ability to utilize information they find on the internet to make health decisions. There is a high use of TEC to access health information, but most of the population has concerns related to interpreting the information and making medical decisions. Again, the use of TEC is most common in the younger, well-educated persons. Yet, the patients who would most benefit from appropriate use of TEC are older patients with chronic conditions and multiple co-morbidities, such as hypertension and diabetes, which require patient self-management and monitoring.

It is notable that even though potential access to the EHR patient portal through communication technology is high in the Lana'i community, only 16% of respondents had actually used the patient portal. Currently roughly one third of patients at LCHC are enrolled in the LCHC patient portal. In comparison, the Kaiser Permanente Health Maintenance Organization, which utilizes a patient portal called My Health Manager, reports that 5.37 million patients out of their 10.2 million patient population are enrolled on their patient portal, 70% of eligible adult members.<sup>10</sup> Of note, the Kaiser data looks only at the number of registered users, similar to the LCHC patient portal enrollment data, not the utilization of patient portals, which was the goal of this study. The Lana'i population is comfortable using communication technology to connect to the outside world, access information and entertainment, communicate with friends and family through videoconferencing, but has limited knowledge of how best to use technology to improve access to health care. Patients at LCHC are offered access to the patient portal as part of meaningful use, a Centers for Medicare & Medicaid Services incentive program for electronic health record technology implementation,<sup>11</sup> but the uptake has been slow, and it has not been a high priority of the LCHC to educate and train patients beyond the educational information provided when patients elect to sign-up; the majority of LCHC patients indicate that they highly value the 'face-time' spent with their HCP, and encouraging patients to use the patient portal is contradictory in some ways to the organization's emphasis on personal care. Meaningful use requires that the patient is offered access and does not require utilization. In addition, the content and usability of the patient portal may limit the value for patients particularly those with low health literacy. Availability does not assure value and is very vendor dependent related to structure and usability of the patient portal.

This study provides valuable information to structure our remote monitoring and community-based care program. Most households have access to a smart phone or other communication devices that have Bluetooth capabilities. The older patient may not be the owner, but by working with the family, remote monitoring of home blood pressure and glucose results can be shared with the care team through TEC. In addition, with the HIPAA compliant telehealth technology licensed by LCHC, virtual visits are supported by existing technology to the patient's home.

The challenge is to provide staff and patient education to effectively use the technology in a community that owns devices for purposes other than health. The vast majority of patients are motivated to self-manage chronic conditions in collaboration with their health care team. TEC can make access and support much easier, but it will require improved patient electronic health literacy in addition to general health literacy.

#### Limitations

Although diverse groups of the Lana'i community participated, inclusion of a greater number of community adults and seniors would have improved assessment of this portion of the Lana'i population. Despite all members of the LCHC employee and board member focus group belonging to this targeted demographic, due to their advanced medical training, an accurate reflection of the senior and adult electronic health literacy was not captured in this study. Also, the large proportion of middle and high school students in this study, who likely rely on parents or guardians to access such TEC as patient portals for them, further skewed the dataset toward a lack of electronic health literacy. Finally, the focus of this study was on the electronic health literacy of the Lana'i community, not general health literacy, but it appears that a lack of general health literacy which was not the focus of this study in this population contributes to the lack of electronic health literacy.

#### Conclusion

Members of the Lana'i community and LCHC staff and board members utilize technology, in the form of smart cell phones, at a greater rate, than the rest of the United States (83% vs 77%).<sup>1</sup> Most participants also regularly use WiFi and texting services, demonstrating that this community has integrated technology into their daily lives, despite living on an isolated island with 3,102 people.<sup>5,6</sup> However, both general and electronic health literacy of this population is insufficient to understand and properly utilize TEC, such as patient portals. Consequently, this community is unable to determine what, where, and how to find useful online health resources and how to effectively use these resources.

If LCHC, and other health systems, plan to continue to implement TEC initiatives, a campaign to increase general and electronic health literacy must first be undertaken. Also, with the goal to increase patient self-management and monitoring of chronic conditions through the use of TEC, which mainly impacts those patients over forty years of age, it is especially important to target this age group with educational interventions. Simultaneous with a general and electronic health literacy program, though, LCHC (and other organizations) must carefully assess what methods their patients are most comfortable using; all the electronic education in the world will not help the patient who prefers face-to-face contact. Therefore, it is critical for organizations to determine a balance of TEC and human contact that meets the patients' needs, and results in improved health. LCHC has initiated efforts to improve the overall general and electronic health literacy of the Lana'i community through educational sessions for all community members, in order for this community to be able to better utilize TEC. LCHC also continues working with its staff and providers to more accurately identify the best methods for communication with patients – using both TEC and face-to-face contact.

#### **Conflict of Interest Statement**

We certify that we have no financial affiliation/interest (eg, employment, stock holdings, consultantships, honoraria) in the subject matter, materials, or products mentioned in this manuscript. Neither of the authors of this article have any conflict of interest to report, nor any interests represented with any products discussed or implied.

#### **Acknowledgements**

The authors would like to thank Olivia Pascual RN, for helping to organize the focus groups; Jennifer Metz, for helping to organize food and to reserve rooms for the focus groups; Diana M. V. Shaw PhD, MBA, MPH, FACMPE, Executive Director of LCHC, for allowing the authors to undertake this study and with help editing the article; Gregory Maskarinec PhD, for his assistance organizing and analyzing the study; Seiji Yamada MD, MPH, for his approval for the author to conduct the study during medical school; and the Area Health Education Center for their financial support of the first author to conduct the study on the island of Lana'i.

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#### Appendix 1. Demographic questions used in the pre-focus group questionnaire.

Please circle ONE box under each category that is applicable to you:

1. Current age:

- a. 10 19 b. 20 – 29
- c. 30 39
- d. 40 49
- e. 50 59 f. 60 - 69
- g. 70 79
- h. 80 89
- i. 90 99
- 2. Gender:
- a. Male
- b. Female
- c. Other
- 3. Ethnicity you identify with:
- a. Native Hawaiian
- b. Filipino
- c. White
- d. Portuguese e. Chinese
- f Japanese
- g. Other Pacific Islander
- h. Other Asian
- i. Other
- j. Not Stated
- 4. Current/Maximum education:
- a. Some School High School
- b. Some College
- c. Associate Degree (ie, AA, RN-AA)
- d. Bachelor Degree (ie, BA, BS)
- e. Master Degree (ie, MS, MA)
- f. Advanced Degree (ie, PhD, MD, JD)
- g. Other
- 5. Technology in the home (please place a mark in each box if you own, or someone
- in your home, owns the following:)
- a. Basic Cell Phone (ie, flip phone)
- b. Smart Cell Phone (ie, iPhone, Android)
- c. Land Line (ie, home phone)
- d. Portable Computer (ie, laptop)
- e. Tablet Computer (ie, iPad, Nook)
- f. Fitness Tracker (ie, Jawbone, Apple Watch)
- g. Other
- 6. Technology use (Please place a mark in each box of the items you are familiar with and regularly use:)
- a. Wireless Internet (ie, WiFi)
- b. Wired internet (ie, Ethernet)
- c. Bluetooth (ie, phone, fitness tracker)
- d. Video Conferencing (ie, Skype, FaceTime)
- e. Cell Phone Data Plan
- f. Internet Texting (iMessage, Skype, Facebook)
- g. Patient Portal
- h. Other

## Appendix 2. Questions adapted from the Electronic Health Literacy Scale included in the pre-focus group questionnaire.<sup>7</sup>

LCHC would like to ask you for your opinion and about your experience using the internet for health information. For each statement, tell me which response best reflects your opinion and experience right now.

- 1. How useful do you feel the internet is in helping you in making decisions about your health?
- a. 1 Not useful at all
- b. 2 Not useful
- c. 3 Unsure
- d. 4 Useful
- e. 5 Very Useful
- 2. How important is it for you to be able to access health resources on the internet? a. 1 – Not very important
- b. 2 Not important
- c. 3 Unsure
- d. 4 Important
- e. 5 Very important
- 3. I know what health resources are available on the internet
- a. 1 Strongly disagree
- b. 2 Disagree
- c. 3 Undecided
- d. 4 Agree
- e. 5 Strongly agree
- 4. I know where to find helpful health resources on the internet
- a. 1 Strongly disagree
- b. 2 Disagree
- c. 3 Undecided
- d. 4-Agree
- e. 5 Strongly agree
- 5. I know how to find helpful health resources on the internet
- a. 1 Strongly disagree
- b. 2 Disagree
- c. 3 Undecided
- d. 4 Agree
- e. 5 Strongly agree
- 6. I know how to use the internet to answer my questions about health
- a. 1 Strongly disagree
- b. 2 Disagree
- c. 3 Undecided
- d. 4 Agree
- e. 5 Strongly agree
- 7. I know how to use the health information I find on the internet to help me
- a. 1 Strongly disagree
- b. 2 Disagree
- c. 3 Undecided
- d. 4 Agree
- e. 5 Strongly agree
- 8. I have the skills I need to evaluate the health resources I find on the internet
- a. 1 Strongly disagree
- b. 2 Disagree
- c. 3 Undecided
- d. 4 Agree
- e. 5 Strongly agree
- 9. I can tell high quality health resources from low quality health resources on the internet
- a. 1 Strongly disagree
- b. 2 Disagree
- c. 3 Undecided
- d. 4 Agree
- e. 5 Strongly agree
- 10. I feel confident in using information from the internet to make health decisions
- a. 1 Strongly disagree
- b. 2 Disagree
- c. 3 Undecided
- d. 4 Agree
- e. 5 Strongly agree

#### Appendix 3. Focus group ground rules.

- 1. I/WE WANT YOU TO DO THE TALKING.
- a. I/We would like everyone to participate.
- b. I may call on you if I haven't heard from you in a while.
- 2. THERE ARE NO RIGHT OR WRONG ANSWERS
- a. Every person's experiences and opinions are important.
- b. Speak up whether you agree or disagree.
- c. I/We want to hear a wide range of opinions.
- 3. WHAT IS SAID IN THIS ROOM STAYS HERE
- a. I/We want folks to feel comfortable sharing when sensitive issues come up.
- 4. WE WILL BE TAPE RECORDING THE GROUP
- a. I/We want to capture everything you have to say.
- b. I/We don't identify anyone by name in our report. You will remain anonymous.

#### Appendix 4. Focus group questions.

Questions for all focus groups:

- 1. Where do you search for information regarding your health online?
- 2. What online/digital resources do you trust/not trust?
- 3. Regarding your health, what subjects or topics have you looked up information on online in the previous 12 months?
- 4. How do you use the health information you gain from digital/online sources?
- Do you feel safe accessing or sharing healthcare information online and in what scenarios do you feel safe/not safe?
- 6. How has technology improved access to healthcare services?
- 7. What apps are you using for your health?
- 8. What technologies would you be interested in having in the future that would support the way that you live your life today?
- 9. Is there someone in your household that uses technology to access digital/ online health information for you or are you the digital/online health resource person for your household?

Questions for only those focus groups containing HCPs:

- 10. Do you feel that access to digital/online health information has improved patient healthcare access?
- 11. Do you feel that access to digital/online health information has improved the quality of patient healthcare?
- 12. Do you feel that the current movement to increase the use of technology in the clinical setting is a movement in the right direction?

### Immediate Versus Delayed Insertion of the Levonorgestrel Intrauterine Device in Postpartum Adolescents: A Randomized Pilot Study

Reni Soon MD, MPH; Katie McGuire MD;, Jennifer Salcedo MD, MPH, MPP; and Bliss Kaneshiro MD, MPH

#### Abstract

This pilot study assessed the feasibility of conducting a larger randomized controlled trial comparing the proportion of adolescents using a levonorgestrel intrauterine device (LNG IUD) at six months postpartum when it is inserted immediately after vaginal delivery (within 10 minutes after placental expulsion) compared to insertion four to six weeks postpartum. Pregnant adolescents (14 to 19 years) who desired a LNG IUD for postpartum contraception were randomized to insertion of the LNG IUD either within 10 minutes of delivery of the placenta or at 4-6 weeks postpartum. Study follow-up visits were conducted at 4-6 weeks postpartum. 10 weeks postpartum, and 6 months postpartum. From November 2013 to June 2015, eleven adolescents were randomized six participants to the immediate postpartum LNG IUD insertion group, and five to the delayed insertion group. All six women in the immediate insertion group had successful immediate postpartum insertion; two of five women in the delayed insertion group had an IUD inserted. At six months postpartum, four of six women in the immediate insertion group had a LNG IUD in place; of the five women in the delayed group, three did not have a LNG IUD in place and two were pregnant. The study was discontinued after 19 months because of suboptimal enrollment. Though insertion of a LNG IUD immediately after delivery is an appropriate option for some adolescents, a larger prospective study comparing immediate to delayed LNG IUD insertion is unlikely to be feasible at our institution.

#### Keywords

long-acting reversible contraception (LARC), adolescent contraception, postpartum contraception, intrauterine device (IUD)

#### Abbreviations

LARC – Long-acting reversible contraception IUD – intrauterine device LNG – levonorgestrel OCPs – oral contraceptive pills DMPA – Depot medroxyprogesterone acetate UH – University of Hawai'i OB/GYN – Obstetrics and gynecology

#### Introduction

Immediate postpartum insertion of long acting reversible contraception (LARC) is increasingly recognized as a useful approach to reduce unintended pregnancies.<sup>1</sup>Among adolescents, 75% of pregnancies are unintended<sup>2</sup> and one in five adolescent mothers becomes pregnant again within 12 months of delivery.<sup>3</sup> In Hawai'i, 17% of all births among women age 15 to 19 years are repeat births.<sup>4</sup> To avoid increasing the socioeconomic hardship,<sup>5-8</sup> and pregnancy complications<sup>9</sup> associated with repeat adolescent births, access to immediate postpartum contraception is particularly important in this population. LARC methods, including the copper and levonorgestrel (LNG) intrauterine devices (IUDs) and the contraceptive implant, are described as first-line contraceptives for adolescents and adults by the American College of Obstetricians and Gynecologists.<sup>10</sup> LARC methods require little action on the part of the patient after insertion, resulting in typical-use effectiveness of 99.8% in the first year of use.<sup>11,12</sup> Women using the oral contraceptive pill, patch, and ring are 22 times more likely to become pregnant in the first year of use compared with women using a LARC method.<sup>13</sup>

Programs most successful at reducing rapid repeat adolescent pregnancy have generally included promotion of LARC methods.3,14,15 Immediate postpartum IUD insertion, defined as insertion of an IUD within ten minutes of placental delivery, has been studied in adult women. Insertion in this setting is convenient for the patient and the provider, by passes many of the barriers that are present when women wait the standard four to six weeks following delivery for IUD insertion, and ensures that the woman is not pregnant at the time of insertion. An increasing number of studies have investigated immediate postpartum insertion of the LNG IUD,16-20 but most lack randomization and fail to provide adequate information on adolescents. Not only do adolescents disproportionately experience unintended pregnancy, but they also may be differently affected by factors like expulsion rates and the desire for reinsertion of the device compared to adults. Furthermore, adolescent mothers typically face more barriers to care following discharge from the hospital.<sup>21</sup>

The aim of this pilot study was to determine the feasibility of conducting a large randomized controlled trial comparing the proportion of adolescents using a LNG IUD at 6 months postpartum when it is placed within 10 minutes of delivery of the placenta following vaginal delivery (immediate insertion) versus four to six weeks postpartum (delayed insertion). We also aimed to identify methodological challenges and the percent attrition in both study groups. Additional outcomes included patient satisfaction, expulsion, bleeding patterns, and breastfeeding rates.

#### **Materials and Methods**

This prospective, randomized pilot study was conducted at Kapi'olani Medical Center for Women and Children in Honolulu, Hawai'i, which is the primary training site for the University of Hawai'i (UH) John A. Burns School of Medicine Department of Obstetrics and Gynecology (OB/GYN) residency program. We enrolled pregnant adolescents (14 to 19 years old) who planned to use a LNG-IUD after delivery and randomized participants to immediate postpartum or delayed insertion of the LNG-IUD. We excluded women with an allergy to the LNG-IUD; chlamydia or gonorrhea during pregnancy without a negative test-of-cure result; an anomaly distorting the uterine cavity; current cervical cancer; a desire for a repeat pregnancy within one year; plans to move from Oahu less than six months after delivery; a planned cesarean delivery; or a delivery at less than 34 weeks gestation. This study received approval from the Western Institutional Review Board.

Potential participants were identified either at their presentation to the labor and delivery suite or at their prenatal visits at the UH resident or faculty practice clinics. Potential participants were approached about the study at 24 weeks gestation or greater, and were assured that their care would not be affected whether they chose to participate in the study or not. If an antepartum patient expressed interest in enrolling, a notation was made in her chart. Patients were then screened for eligibility and enrolled in the study at the time of presentation to the labor and delivery suite. After consent was obtained, participants completed a demographic and medical information questionnaire. Study personnel placed one of the sequentially numbered, opaque sealed envelopes with the participant's allocation assignment in the delivery room. A statistician not involved with the conduct of the study used a true random number generator to develop the 1:1 randomization scheme using block sizes of six. Subsequent exclusion criteria included: chorioamnionitis, postpartum hemorrhage, unanticipated cesarean delivery, and delivery at a time when a study investigator was unavailable. To limit post-randomization exclusions, the envelope with the participant's allocation assignment was opened after delivery. If exclusion criteria were met after consent, the unopened envelope with the study allocation assignment was returned to the stack of envelopes to maintain sequential numbering.

Patients randomized to immediate insertion had their procedure performed within ten minutes of delivery of the placenta by study investigators or UH OB/GYN residents under the direct supervision of study investigators. Insertions were performed using a technique similar to that described by O'Hanley, et al,<sup>22</sup> and Hayes, et al.<sup>16</sup> After placental expulsion and uterine massage, the IUD was removed from the inserter and placed by hand at the uterine fundus. The other hand palpated the fundus abdominally to ensure that the hand inserting the IUD was at the fundus. If placement by hand was not possible due to patient discomfort, ring forceps were used to insert the IUD using a technique described by Speroff and Mishell<sup>23</sup> and employed in the study by Dahlke, et al.<sup>18</sup> Strings were trimmed three centimeters from the external os. While ultrasound was not a routine part of the study protocol, use was left to the discretion of the treating physicians. Participants randomized to delayed insertion had the LNG IUD placed four to six weeks following delivery using the standard technique by their obstetrician (residents with faculty supervision or faculty).

Study visits were scheduled at four to six weeks, ten weeks, and six months postpartum. Participants were given a \$5 online gift card at each study visit as compensation for their time. A study coordinator scheduled the four to six week follow up visit prior to hospital discharge. At each study visit, a pelvic exam was performed and if the IUD strings were not visible, an ultrasound was performed to confirm intrauterine position. If the IUD was visible in the cervix, it was considered an expulsion and was removed. Any patient who experienced an expulsion during the six-month study period was counseled about all contraceptive options and was given the option of insertion of another LNG IUD at no cost. Participants were also asked about bleeding, cramping, fever, pain, sexual activity, and breastfeeding. Participants rated their satisfaction with the LNG IUD on a 10-cm Visual Analog Scale, anchored at 0 being very unsatisfied and 10 being very satisfied. Participants who wished to have the LNG IUD removed could return at any time during the 6-month postpartum study period to do so at no cost.

Three phone calls were made to participants who did not return for their follow up visits. If a participant declined an in-person visit, phone follow-up was done and participants were asked all the questions that would have been asked in an in-person visit, as well as additional questions to assess the likelihood of IUD expulsion. The patient's medical record was reviewed to determine if she sought care related to the IUD or had a postpartum complication.

The sample size of this pilot study was estimated to determine feasibility of a larger study. We used principles outlined by Hertzog<sup>24</sup> to estimate that a sample size of 30 participants, 15 in each group, would be needed to adequately describe recruitment, post-enrollment exclusion, and attrition to determine the feasibility of a larger study. With this sample size and an observed 15% attrition rate we could be 68% confident that our estimates would be accurate within 8 percentage points.

The study was discontinued prior to meeting our sample size goal due to suboptimal enrollment. We had planned to compare the proportion of participants who continued to use the LNG IUD at six months with Chi-square or Fisher's exact tests. Patients who experienced an expulsion but had an IUD reinserted would have been classified as using an IUD, and we were planning to analyze using intention-to-treat principles. However, because the study had to be discontinued, the participants and their follow-up are described.

#### Results

From November 2013 to June 2015, 18 women verbally agreed to participate. Seven women were excluded prior to randomization – three women had a cesarean section, one developed chorioamnionitis, one delivered at less than 34 weeks gestation, one declined insertion of an IUD, and for one participant the reason for exclusion was not recorded. Of the eleven women remaining, six were randomized to immediate insertion and five to delayed insertion. Patient demographic factors are described in Table 1. The mean age of participants was 18.4 years. Six participants had been previously pregnant, and three had experienced a prior delivery. Five of the participants had never used a form of contraception; four had used condoms; and four had used a short-term hormonal contraceptive.

All of the participants and their course through the study are detailed in Table 2 and Figure 1. Of the six participants randomized to immediate IUD insertion, all six had successful insertion of their IUDs immediately postpartum (100% insertion), and four (67%) had the IUD in place at six months postpartum. One participant in the immediate insertion group had an IUD expulsion prior to her 4-6 week follow-up visit and did not desire IUD replacement. She was unable to be reached for the 10-week follow-up and 6-month follow-up visits. The other participant randomized to immediate insertion requested removal of her IUD at her 10-week visit because of some discomfort she attributed to the IUD and requested a contraceptive injection. She could not be reached for her 6-month follow-up.

Of the five participants randomized to delayed IUD insertion at follow-up, only two had an IUD inserted (40% insertion). At six months, one of the two had had her IUD removed a month after insertion and was pregnant; the other was unable to be reached. Of the three participants randomized to delayed insertion who never had an IUD inserted, one of them presented to the labor and delivery suite eleven months postpartum with a term pregnancy, and two declined IUD insertion at their follow-up visits. At six months postpartum, three of the five participants randomized to delayed IUD insertion did not have IUDs in place and two of the three were pregnant.

Some of the participants followed up at outside facilities instead of the resident clinic where study visits were conducted. Of the 18 follow-up visits among the immediate insertion participants, 14 were completed (78%); of the 15 follow-up visits among delayed insertion participants, six (40%) were

Table 1. Participant Characteristics						
Characteristic	Immediate Postpartum Group (n=6)	Delayed Group (n=5)				
Mean age (years ± SD)	18.33 ± 1.03	18.40 ± 0.89				
Race*						
Non-Hispanic white	1 (17%)	1 (20%)				
Non-Hispanic black	1 (17%)	0 (0%)				
Asian	1 (17%)	1 (20%)				
Native Hawaiian/Pacific Islander	4 (67%)	4 (80%)				
Previously used contraception**	3 (50%)	3 (60%)				
Previously used IUD or implant	0 (0%)	0 (0%)				
Previously pregnant	1 (17%)	5 (100%)				
Previous delivery	0 (0%)	3 (60%)				

\*Participants could identify more than one race

\*\*Contraceptive methods asked about: IUD, implant, injection, oral contraceptive, patch, ring, condoms

completed, but two were completed over the phone and two were completed at an outside facility. Because of this, we have data on contraceptive method at the time of the visit but do not have data for most participants on bleeding patterns, breastfeeding, sexual activity or contraceptive method satisfaction. Therefore we are unable to comment on any differences in these outcomes between groups. Of the six participants who had follow-up visits in the resident clinic, five were in the immediate insertion group. Four of these five expressed a preference for IUD insertion immediately postpartum over delayed insertion and rated their experience as "very satisfied." One participant who had an immediate insertion and had an IUD expulsion prior to her 4-6 week visit stated she would prefer delayed IUD insertion over immediate. One participant in the delayed insertion group, and the only one from that group who followed-up in the resident clinic and therefore the only one who was asked the question, stated she did not have a preference for immediate or delayed IUD insertion.

#### Discussion

Although we found that a larger randomized controlled trial comparing immediate to delayed postpartum LNG IUD insertion among adolescents is not feasible at our institution, we describe a small cohort of adolescent women in Honolulu who appear to have benefitted from immediate postpartum IUD insertion. Of the women randomized to immediate insertion, four of the six had an IUD in place at six months postpartum. Four of the six women expressed a preference of immediate insertion over delayed insertion and were "very satisfied" with their experience. Of the five women randomized to delayed insertion, three of them did not have an IUD in place at six months postpartum and two of the women had again become pregnant. Our findings are consistent with other studies in adult women showing that many women who have immediate postpartum insertions of a LNG IUD are using an IUD at six months postpartum.<sup>18-20</sup> Most of these studies also report high patient satisfaction with immediate postpartum placement.

Suboptimal enrollment and difficulty in following up with participants precluded conduct of any of the planned analyses. While LARC use among adolescents is increasing, overall rates of use are still low and most of the increase seen has been in the use of the contraceptive implant. In an analysis of contraceptive method use among sexually active women age 15-19 years from 2011-2015, 2.8% had used an IUD (increase from 2.5%) in 2006-2010) and 3.0% had used an implant (increased from 0.6% in 2006-2010).<sup>25</sup> Our suboptimal enrollment reflects this overall low rate of IUD use among adolescents. In addition, follow-up with our adolescent participants was challenging. Only 78% of potential follow-up visits were conducted in the immediate insertion group compared to 40% in the delayed insertion group. While it is not surprising that the participants who received the intervention were more likely to follow-up, this leads to ascertainment bias in addition to poor overall obtainment of outcome data.

Table 2. Study Participants and Follow-up										
Age	Pregnancy history	Previous birth control used	4-6 wk f/u – IUD in place?	10 wk f/u – IUD in place?	6 mo f/u – IUD in place?	IUD in place at 4-6 weeks	IUD in place at 6 months	Preference for timing of IUD placement (asked at all f/u visits)		
Immediate insertion group										
19	G1P0	None	No – expulsed. Did not want replacement	Unable to contact	Unable to contact	No	Unknown	Delayed		
19	G1P0	OCPs	Yes	Yes	Yes	Yes	Yes	Immediate for all 3 visits		
19	G2P0	None	Yes	Yes	Yes	Yes	Yes	Immediate for all 3 visits		
17	G1P0	None	Yes	Unable to contact	Yes (visit was at 9 months postpartum)	Yes	Yes	Visit was at out- side facility and was not asked		
19	G1P0	Condoms	Yes	Yes	Yes	Yes	Yes	Immediate for all 3 visits		
17	G1P0	Condoms, DMPA	Yes	Requested IUD removal; got DMPA	Unable to contact	Yes	Unknown	Immediate for 2 visits		
Delayed insertio	n group		•	•		•	•			
18	G2P1	Condoms, OCPs	IUD inserted	Unable to contact	Unable to contact	Yes	Unknown	"Do not care"		
17	G2P1	Condoms	IUD inserted at outside facility	Unable to contact	Presented to outside facility for pregnancy test (positive). Stated had IUD removed 1 month after it was placed	Yes	No	Was not asked		
19	G2P0	None	Unable to contact	*Stated she received DMPA injection post- partum and was not sure what method she wanted to use	*Stated she did not have an IUD and was not sure what method she wanted to use	No	No	Was not asked		
19	G3P2	DMPA	No f/u, but 11 mos later admitted to hospital in labor with another full-term pregnancy			No	Was not asked			
19	G2P0	None	No. Stated she wanted the contraceptive implant but never returned	Unable to contact	Unable to contact	No	Unknown	Was not asked		

\*Follow-up by phone Abbreviations: G=gravidity (number of pregnancies), P=parity (number of deliveries), DMPA=Depot medroxyprogesterone acetate (contraceptive injection), OCPs=oral contraceptive pills



Despite the challenges of this study, the randomized controlled study design is critical to examining whether adolescents benefit from access to immediate postpartum IUD. While one cohort study of 82 adolescent (13-22 year-old) women who chose immediate postpartum IUD insertion found that 71% were still using an IUD at six months postpartum,<sup>20</sup> cohort studies are subject to selection bias. Unrecognized differences between patients who choose immediate insertion versus women who choose standard delayed insertion can affect outcomes. In addition, a healthcare provider may be more likely to recommend immediate postpartum insertion to a patient thought to be at higher risk of short interval pregnancy or poor follow-up. Ways to mitigate challenges in a study such as this may include use of a closed healthcare system, higher compensation for study visits, and alternative methods of follow-up such as text messaging or online surveys.

At our institution in Honolulu, adolescents are offered immediate postpartum IUD insertion because follow-up rates for postpartum visits are low in this group. While we found that a larger randomized controlled trial to examine this question is not feasible at our institution, we were able to describe a small group of local adolescents who benefitted from immediate postpartum IUD placement. In contrast, of the five adolescents who were randomized to delayed IUD insertion, two were pregnant again by six months after their delivery. Immediate postpartum IUD insertion may be an effective way to increase use of a highly effective contraceptive method in a group of young women at high risk for unintended pregnancy.

#### **Conflict of Interest**

None of the authors identify a conflict of interest.

#### Acknowledgements

The authors wish to thank Erin Yamamoto and Faapisa Soli (research assistants), the University of Hawai'i OB/GYN residents and faculty, Hawai'i Pacific Health Research Institute, Kapi'olani Medical Center for Women and Children Outpatient Clinic, and Sarah Prager MD, MPH from the University of Washington.

This study was supported by a grant from the National Institute on Minority Health and Health Disparities of the National Institutes of Health under award number U54MD008149.

This study was also supported by the University of Hawai'i Department of Obstetrics, Gynecology & Women's Health, Ryan LARC Program.

Drs. Kaneshiro, Salcedo, and Soon receive research funding unrelated to this project from Merck, Gynuity Health Products, Mithra Pharmaceuticals, and Contramed.

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# Facilitating Philanthropy at JABSOM — University of Hawai'i Foundation

Elaine Evans BA and Christie Leidholm BS

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 University of Hawai'i at Manoa, John A. Burns School of Medicine (JABSOM) is a public medical school responsible for financially managing all the schools operations for its campus and offsite facilities. Despite being a State institution, only 17% of the medical school's revenue comes from the legislature and the University.

Nationally, government funding for higher education is being greatly reduced, shifting much of the burden to student tuition and fees and driving the need for revenue diversification to support school operations. As a consequence, private philanthropy to support projects, programs, student well-being, research, and innovation have become critically important in recent years.

#### **Fundraising at JABSOM**

The University of Hawai'i Foundation (UHF) is an independent organization established in 1955 to encourage private support for the University of Hawai'i (UH). Today it is the central fundraising organization for the University of Hawai'i System and is contracted by the Board of Regents to be the sole provider of fundraising and alumni services for all schools and colleges including JABSOM. The Foundation's mission is to unite donors' passions with UH aspirations by raising philanthropic support and managing private investments to benefit UH, the people of Hawai'i, and future generations.

For the medical school, one part-time and three full-time UHF employees are assigned to raise funds for JABSOM and to engage its alumni. In addition, UHF manages nearly 300 gift accounts for the benefit of the JABSOM and its students. JABSOM development officers are primarily focused on identifying, engaging and soliciting prospective donors for major and leadership gifts that support the school and its students. In the past five years, in partnership with JABSOM and UHF colleagues, more than \$36M dollars have been raised to support school operations and its students.

JABSOM funding priorities for academic year 2017-18:

• Rural and Neighbor Island training opportunities for JABSOM students to experience medical practice in rural settings where physician shortages are disproportionately high. Such opportu-

nities have proven to impact where future physicians choose to practice.

• Medical student travel to support research presentations at scientific conferences, in order to enhance their learning experience and research opportunities, and recognize their achievement in medical research.

• Scholarships that enable JABSOM to recruit exceptional students from diverse backgrounds to attend JABSOM, regardless of their financial circumstances.

Additionally, there is a need for unrestricted gifts that provide flexible resources for the Dean to invest in areas important to the future of JABSOM.

Recent philanthropic highlights include the Thomas J. Whelan, Jr. MD Whelan Endowed Chair in the Department of Surgery and the Kosasa Endowed Professorship in Gynecologic Oncology and the Colin C. McCorriston, MD Endowed Professorship in the Department of Obstetrics, Gynecology & Women's Heath. Most recently, when Vice Dean Dr. Satoru Izutsu announced his intent to retire in December 2017 after nearly 38 years at JABSOM (22 of them as Director of Admissions) his good friend and faculty member, Dr. Thomas Kosasa, established the Satoru Izutsu, PhD Endowed Professorship of Medical Education in his honor.

In celebration of JABSOM's 50th anniversary in 2015, UHF staff supported alumni and faculty volunteers in planning and hosting the Anniversary Gala that drew a record 1300 guests to the Sheraton Waikiki Hotel. The Gala netted \$950,000 for medical student scholarships.

JABSOM development officers coordinate their efforts with UHF team members on the Mānoa campus who support fundraising efforts for JABSOM. They include the offices of Donor Relations, Scholarships, Annual Giving, Corporate and Foundation Relations, and Estate and Gift Planning. The latter helps donors integrate charitable intent with tax, estate, and financial planning. They coordinate with donors and their tax professionals to not only maximize the tax benefits of philanthropic gifts, but also to create a lasting legacy for donors that will make a difference at JABSOM and for Hawaii's health care future.

#### **Internal Giving**

Philanthropy at JABSOM begins in the center of the circle: family first. We believe that if we're asking others to give, our 'ohana should be the first to give. For the past nine years, JAB-SOM development officers have conducted an internal giving campaign, *Starting From the Inside Out*, that asks faculty and staff to provide financial support for the school. Each year, a majority of those who work at JABSOM, from the Dean to the janitor, demonstrate that those who know the school best believe in its mission and support it with their personal philanthropy.

To date, employees have donated nearly \$3 million to support the projects and programs at JABSOM that matter most to them. As Dean Jerris Hedges said "There is a difference between being paid for the work you do – your job – and your personal commitment." Employee donations effectively say, "We believe in this school enough to actually invest in it, to give of our personal resources."

#### **JABSOM Alumni**

In addition to generous faculty and staff donors, JABSOM's more than 2400 physician alumni also give generously of their time. They are loyal supporters and great role models for current students. The JABSOM Alumni Association works hard to engage alumni and provide opportunities for them to stay connected. Its mission is to promote and support the activities of the school by unifying all physician alumni, establishing ties between the classes, and promoting relationships with the medical students, resident physicians, faculty and staff, and the local community. For example, annually, many JABSOM alumni participate in Career Night, where they donate their time to offer insights about their specialties to medical students.

The Alumni Engagement team supports the JABSOM Alumni Association and helps plan and execute events, communication, and opportunities for alumni. This includes RECONNECT reunions, mainland and neighbor island alumni events, and the HOST program. The HOST, *Help Our Students Travel*, program provides an opportunity to build connections and share aloha between students and alumni that lasts a lifetime. Each fall, fourth year students embark on the exciting and often stressful residency match process. Many JABSOM students must make multiple trips to the mainland for interviews for residency. This program connects alumni HOSTs with students to offer housing in the area of their interview sites, helping to ease the financial burden and stress of the interview process.

Communication with alumni is key. The Alumni Engagement team keeps them informed of alumni events, such as the Basketball Pre-Game mixer in February and Casino Night in the spring. School achievements and opportunities for alumni to give back are communicated through newsletters, social media and email.

#### **JABSOM** Appreciation

Stewardship is one of UHF's most meaningful activities. Most important of these is simply saying "thank you." Each year, second year medical students volunteer an entire day of their time to call donors to say "mahalo." Donors, are usually very surprised by these calls and are delighted to hear from students. The calling room buzzes with chatter as students share stories about dreaded exams and favorite classes and talk with donors about their motives for giving to JABSOM.

JABSOM now offers patients a way – beyond a hug and a handshake – to say "mahalo" to the physicians who treat them. For the first time last year, UHF and JABSOM actively promoted Grateful Patient gifts with custom brochures and posters for faculty clinicians to display in their offices. Patient gifts to JABSOM honoring doctors who have made a difference in their lives will provide critical funding for the future health of the community.

#### Why Give?

There are several theories on what motivates philanthropy. These include the desire to help others, address a community need, the wish to give back, a feeling of obligation, and belief in an organization. Alumni, especially those who have received scholarships or had strong relationships with mentors, are often motivated to give back. Whatever the motivation, philanthropy is an important revenue source for universities. It strengthens programs, assists students, and contributes to the overall success of the school. Investing in JABSOM, Hawaii's only medical school, and only US accredited medical school in the Pacific, helps ensure that the State has a sufficient number of physicians to care for Hawaii's people, and a place for scientists to conduct research and innovate.

To support a program or area at JABSOM of special interest to you, please contact Director of Development Elaine Evans at 808-692-0991 or elaine.evans@uhfoundation.org.

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# **Could School-based Asthma Initiatives in Hawai'i Help Keep Kids in Class?**

### Olivia Uchima MA, CCC-SLP

Insights in Public Health is a monthly solicited column from the public health community and is coordinated by HJMPH Contributing Editors Tetine L. Sentell PhD from the Office of Public Health Studies at the University of Hawai'i at Manoa and Donald Hayes MD, MPH from the Hawai'i Department of Health in collaboration with HJMPH Associate Editors Lance K. Ching PhD, MPH and Ranjani R. Starr MPH from the Hawai'i Department of Health.

Rebecca Grennon MS, Asthma Program Specialist in the Chronic Disease Prevention & Health Promotion Division at the Hawai'i State Department of Health was a contributing editor on this month's column.

#### Background

Asthma is a chronic inflammatory disorder caused by episodes of reversible breathing problems due to narrowing and obstruction of the airway.<sup>1</sup> The prevalence of asthma has increased since 1980 and is now the most common chronic childhood disease in the United States (US) and in Hawai'i.<sup>1.3</sup> In 2014, approximately 47,200 (16.0%) of Hawaii's children and 102,100 (9.2%) of Hawaii's adults were diagnosed with asthma by a health care professional and currently still have asthma, providing a recent measure of asthma prevalence.<sup>4.5</sup>

Asthma is associated with high health care utilization and is the primary diagnosis for 10.5 million physician office visits, 1.6 million emergency department (ED) visits, and over 400,000 inpatient services annually in the US.<sup>6</sup>The treatment and management for children and adults with asthma costs the US \$56 billion annually.<sup>7</sup> Asthma costs Hawaii's economy approximately \$10.5 million in emergency department (ED) visits and more than \$24 million in hospitalizations each year.<sup>8</sup>

#### **Asthma Disparities**

People of every race, sex, and age are affected by asthma; however, asthma prevalence differs by race/ethnicity and income.<sup>9-17</sup> Racial/ethnic minorities are disproportionately affected by asthma compared to Caucasian children. For example, in 2015, the asthma prevalence in non-Hispanic black (13.4%) and Puerto Rican (13.9%) children younger than 18 years was about twice that of Caucasian children (7.4%).<sup>9</sup> Asthma prevalence among families was significantly lower for each successively higher poverty level group in the US.<sup>10</sup> For example, in 2015, the asthma prevalence among persons with family income below 100% of the federal poverty level was 11.1% compared to 8.4% for 100% to less than 250% of the poverty level, 6.3% for 250% to less than 450% of the poverty level, and 6.9% for at or above 450% of the poverty level.<sup>9</sup>

In Hawai'i, Native Hawaiian (NH) children have the highest asthma prevalence (28.3% or 25,700) compared to Caucasian (17.1% or 9,400), Chinese (16.4% or 2,200), Filipino (20.4% or 8,200), Japanese (17.7% or 6,100), or all other (19.8% or 9,900) children.<sup>18</sup> Therefore, NHs experience disproportionate

rates of asthma compared to the other major ethnic groups in Hawai'i, and thus experience the greatest burden in regards to missed days from work for parents and school for children, increased urgent care services, outpatient physician office visits, and inpatient services.

Disparities in asthma prevalence are also seen by region. Children living in the Hawai'i and Maui county areas and the Nanakuli/Waianae sub-county area on the island of O'ahu were more likely to have asthma compared to children living in other areas throughout the state.<sup>18,19</sup> As reported in a recent Civil Beat article in 2015, about one-third of the 890 children at Nanaikapono Elementary in Waianae reported having a chronic illness, with one in four children having asthma.<sup>20</sup>

## Asthma-related School Absenteeism and Academic Achievement

Asthma-related school absenteeism affects 59% of school-aged children with asthma.<sup>13</sup>This absenteeism can be a result of asthma exacerbations, poor asthma control, poor health care access (ie, financial costs), routine clinic visits, poor air quality (eg, vog, secondhand- smoke exposure), prolonged hospitalizations, and/or home environmental triggers (eg, dust mites, mold, and cockroaches).<sup>8,13,14,21</sup>In 2013, childhood asthma was responsible for 13.8 million missed school days and was the leading cause of chronic disease-related school absenteeism in the US.<sup>21,22</sup>

Pediatric asthma is associated with poor academic outcomes such as learning disabilities, reading problems, behavior problems, grade repetition, and high school drop-out rates.<sup>23</sup> Increased school absences among students with asthma are likely to help explain these associations of strained peer relationships, the disruption of the learning process, and reduced involvement in physical activities, including extracurricular activities.<sup>14</sup>Previous data showed both prolonged and multiple, intermittent or asthma-related absences contribute negatively to a child's academic performance.<sup>17</sup>Interestingly, research has found racial/ethnic minority children with asthma were more likely to be absent from school compared to Caucasian peers with asthma.<sup>19</sup>

Chronic absenteeism is one of the most powerful predictors of a student's academic success. Even after controlling for other confounding variables like socioeconomic status (SES) or previous performance, children who are chronically absent still perform worse than their counterparts. Research has shown chronic absenteeism accounts for lower grade-point averages (GPAs) in the year the child was chronically absent as well as in the following school-year. Chronic absenteeism is also associated with lower reading and math standardized test scores and slower academic performance gains.<sup>24,25</sup> For example, a study conducted by Indiana State University investigated the effects of absenteeism and cognitive skills index on various achievement indicators, such as school-based English and math tests. Results showed a negative correlation between absenteeism and achievement on certain standardized scores (eg, math, reading comprehension, reading vocabulary, and reading total). Therefore, as the number of absences increased, reading and math scores decreased.<sup>26</sup>

Previous studies indicated children with asthma perform worse than their non-asthmatic peers on classroom performance measures of academic functioning, particularly reading.<sup>14,25,27,28</sup> Furthermore, recent evidence suggests that asthma-related absenteeism can negatively impact a student's achievement not just in classroom performance, but also on standardized tests.<sup>25</sup> A study that included a majority of African-American students in a Missouri school district investigated the relationship between asthma severity level and standardized test level performance. They found a non-significant association with asthma severity and decreasing standardized test scores.<sup>26</sup> For example, students with persistent asthma were 90% more likely to score below 'Nearing Proficient' when compared to students with mild asthma.

Outcomes like the ones illustrated above can negatively impact not only individuals and families, but also community-level economic sustainability. Research suggests that schools, parents, and caregivers are impacted by a child's asthma. Schools face an economic impact for absences as funding and accreditation are associated with attendance and school achievement measures. Parents and caregivers are placed in an economic disadvantage when their child is out from school as they are also forced to miss work and other activities due to their child's asthma.<sup>22</sup>Additionally,missing substantial amounts of elementary or intermediate school increases the likelihood of the child dropping out of high school, which can impact the future of that individual, and may also negatively impact a community's economic sustainability.<sup>24</sup>

#### **Chronic Absenteeism in Hawai'i**

In Hawai'i, a child is labeled as chronically absent when he/she is absent from school at least 15 days out of the schoolyear.<sup>29</sup> The statewide chronic absenteeism rate for all 256 Department of Education (DOE) public schools and 36 public charter schools in Hawai'i is 15%.<sup>30</sup>The public schools in the Nanakuli/ Waianae area on the Leeward Coast experience the highest rates of chronic absenteeism in the state. For example, the rate of chronic absenteeism at Nanakuli Elementary School rose from 24% in the 2014-15 school year to 30% in 2015-16.<sup>29</sup> In Hawai'i, chronic absenteeism disproportionately affects racial/ ethnic minority children and children living in poverty.<sup>30</sup> For example, NH and Pacific Islander children missed the most school days during the 2016-2017 academic year compared to all other ethnic groups in Hawai'i.

The dean of the University of Hawai'i at Manoa (UHM) School of Nursing, Mary Boland, attributes that "two-thirds of absenteeism is caused by health problems."<sup>26</sup>Asthma is a common health issue among school-aged children on the Leeward Coast, however it is unclear if this is associated with vog or non-vog factors (eg, indoor air quality).<sup>29,31,32</sup>

#### **School Nurses**

The presence of school nurses is extremely important given the high rates of asthma among Hawaii's children. Emerging research supports the belief that embedded school nurses have a positive impact on student health and academic outcomes. Research has shown that "higher nurse-to-student ratios have been associated with significant increases in referrals and followup care for students with asthma, diabetes, vision problems, psychosocial problems, and injury prevention and reporting, as well as fewer school absences and emergency room visits, in particular for students diagnosed with asthma."<sup>22</sup> These results were evidenced among schools with nurses who were employed full-time.

Current federal guidelines recommend one trained nurse for every 750 students; however, the Hawai'i DOE only had three nurses on staff for every 180,000 students during the 2013-2014 academic year.<sup>26</sup> The lack of medically-trained personnel (ie, school nurses) to provide effective asthma management for children with asthma contributes to the high rates of school absenteeism.<sup>26</sup> At many Hawai'i public schools, all healthrelated issues are handled by school health assistants (SHAs) to reduce overall costs. However, the DOE contracts nurses from the Department of Health (DOH) for more medically compromised conditions.<sup>20</sup>

The Hawai'i DOE requires SHAs to have a high school diploma and current completion in first aid and certification in child and adult cardiopulmonary resuscitation (CPR). Due to their limited scope of practice in providing health services, SHAs are unable to perform clinical assessments to determine a child's need for asthma medication or appropriateness to return to class.<sup>26</sup> They are only eligible to administer first aid for minor injuries <sup>31</sup> Therefore, children with asthma are often kept home if parents notice any respiratory distress. The Hawai'i self-carry law (HRS302A-1164) does allow children with asthma to carry and self-administer an emergency inhaler while in school.<sup>33</sup> However, the DOE's policies and legal forms make this a difficult practice to implement and children are ultimately sent home for the day after any use of the inhaler.<sup>26,28,31</sup>

#### **New Strategies/Initiatives**

The burden of asthma and absenteeism due to asthma may have a direct impact on Hawaii's children and public schools. Efforts to curb asthma-related school absenteeism are thus imperative for Hawai'i public schools. School-based asthma interventions will not only mitigate chronic absenteeism, but also improve productivity and academic success among children with asthma.

Public health officials, educators, policy makers, investigators, and others working with schools can work to develop intensive clinical, environmental, or case management services for children with asthma to reduce asthma-related absenteeism and promote greater school performance. Identifying children with asthma who are chronically absent from school and are performing below their peers might also benefit from a homebased environmental intervention by public health practitioners, community health workers, and/or clinical specialists. Family, school, and community partnerships can help reduce asthma morbidity among NH children in Hawai'i by offering schoolbased health clinics where child asthma prevalence is the highest

Some useful solutions include hiring more medically trained nurses in Hawai'i public schools. That could reduce the amount of children being sent home from school as nurses are able to diagnose the severity of an asthma attack and administer asthma medications like an inhaler. Additionally, expanding the scope of practice of school health assistants (with additional training) to include the ability to administer medications could also help to keep children with asthma in school.

Adopting evidence-based, multi-sector interventions that have proven successful in other locations may be another way the state of Hawai'i can address the issue of asthma in schools. One such successful example is the Asthma 411 Initiative, a community-based, multi-organizational, and multi-institutional project developed and evaluated to reduce asthma morbidity among African American children from a school district in Saint Louis, Missouri.<sup>34</sup>The project began in 2001 when the St. Louis Regional Asthma Consortium was awarded funding from the Centers for Disease Control and Prevention. The Asthma 411 Initiative provides tools, methods, and strategies to school health and administrative entities to help control asthma-related symptoms, reduce asthma-related school absenteeism and improve academic achievement. The most critical element of the project is the utilization of a consulting physician to enhance the role of the school nurse. Many schools throughout the US who have adopted and implemented Asthma 411 have seen a statistically-significant increase in the identification of students with asthma. These schools have also seen an increase in the development of patient Asthma Action Plans by physicians, a decrease in children being sent home due to asthma-related symptoms, a decrease in 911 calls, and most importantly, a decrease in asthma-related absences. However, further research is needed to assess if school-based asthma interventions like the Asthma 411 Initiative are effective at reducing school absences and improving academic performance scores on standardized tests among other racial/ethnic minority children (ie, NHs or Pacific Islanders) with severe and persistent asthma.

#### Hawai'i Initiatives

Given the prevalence of asthma in Hawai'i, many innovative programs are currently underway to address this important health issue. In developing effective interventions, it is important to consider that the prevalence of asthma may be compounded by other social inequities like unsafe housing, homelessness, poverty, and access to health care.<sup>35</sup> The DOH's Public Health Nursing Branch (PHNB) convenes an Asthma Advisory Council to help identify and address issues related to asthma in the school setting. This Council includes various stakeholders, such as health care professionals (eg, pediatricians) and local organizations, including the DOH Chronic Disease Management Branch and the American Lung Association (ALAH) in Hawai'i.

The ALAH also delivers programs to provide direct asthma self-management education. For example, the ALAH delivers programs to caregivers or parents of children with asthma in order to improve asthma self-management skills, decrease asthma-related emergencies, and raise awareness of asthma among families and school personnel. Additionally, the ALAH is working on ways to address home-based interventions with community health workers to identify asthma triggers in the home setting.

In partnership with the Hawai'i Public Health Institute (HI-PHI) and Hawai'i Primary Care Association (HPCA), local community health centers are also engaged in quality improvement activities and system-level linkages regarding asthma. For example, through the DOH's partnership with HPCA, there are now three school-based health clinics (Waianae High School, Waianae Intermediate School, and Ko'olauloa at Kahuku High and Intermediate School) that are successfully treating students for various medical conditions without being sent home.

The DOH's Hawai'i State Asthma Control Program (HSACP) partners with these local organizations to identify gaps in the delivery of asthma-related programs and services in order to improve Hawaii's existing asthma system of care. Currently, the HSACP is in the initial stages of developing a telehealth pilot program to address the issue of students with asthma being sent home after the use of their inhaler.

Furthermore, the DOE recently partnered with the UHM Nursing school in a program called Hawai'i Keiki. The goal of the Hawai'i Keiki program is to have UHM Nursing master's prepared registered nurses (eg, Nurse Practitioners) on-site at project schools to deliver screening, direct health services, and guarantee continuity of care for students with chronic conditions like asthma. The Hawai'i Keiki program also collaborates with Public Health Nurses from the DOH to ensure these responsibilities are met.<sup>36</sup>

#### Conclusion

Asthma is one of the leading reasons for school absenteeism in the US and in Hawai'i. The consequences of chronic absenteeism from asthma are associated with lower standardized test scores, GPAs, and high school drop-out rates. Hawai'i public schools are significantly affected by the high rates of chronic absenteeism among children with asthma. Therefore, solutions for asthma in the school setting in Hawai'i must be addressed to reduce rates of chronic absenteeism and improve academic success. Critical local initiatives include partnerships with HIPHI, DOH, HPCA, and PHNB, to name a few, to address asthma disparities in the school setting. Public schools in Hawai'i could also benefit by hiring more full time nurses, expanding the scope of practice among SHAs, adopting more school-based health clinics and evidence-based asthma interventions, and/or implementing telehealth services to help link students to appropriate health care services for asthma.

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### THE WEATHERVANE RUSSELL T. STODD MD; CONTRIBUTING EDITOR

#### FLU VIRUS EXTENDS ITS REACH TO THE ISLANDS.

In one of the worst seasons for flu virus in nearly ten years, the disease has spread across the entire continent and out to Hawai'i as well, the Centers for Disease Control and Prevention (CDC) announced last week. Although the vaccine might not fully protect them, the agency urged Americans to take precautions and get flu shots. This flu season has been particularly bad because the vast majority of cases so far have been caused by a strain known as H3N2, a virus dreaded by doctors and public-health nurses. It is known to take a heavy toll on the elderly and children with more hospitalizations and deaths than usual. Moreover the virus has a penchant for mutating rapidly, making it difficult to provide protection. The CDC reported the rate of hospitalization increased from 13.7 to 22.7 in just one week. Rates are high and rising especially among those 65 years old and older, traditionally hardest hit by flu. The hospital rate among children under 5 years old also nearly doubled. Pediatric deaths increased to a total of 20. Get your flu shot.

#### IMMUNOTHERAPY FOR CANCER IS GAINING MOMENTUM.

The National Cancer Institute recently disclosed that a patient with metastatic breast cancer is now cancer-free. Using immunotherapy the patient is joyously walking about free from her disease due to harnessing her own immune system to target cancer. The approach doesn't work in all patients, but its success against some hard-to-treat cancers makes it the most closely watched area in cancer pharmaceuticals. Because of rapid advances in immunotherapy, the National Institutes of Health and the NCI released a \$215 million medical collaboration with ll medical companies, including Johnson and Johnson, Novartis AG and AbbVie. In a significant development the NCI's prominent chief of surgery, Steven A. Rosenberg, detailed for the first time an immunotherapy against metastatic breast cancer. His patient had her first immunotherapy two years ago when her own cells were multiplied billions of times and then reinfused. She is now disease free. She previously underwent multiple regimens of chemotherapy and other standard treatment, to little avail. She learned of the NCI research in August 2015, went to Bethesda, Md where her immune cells were harvested, concentrated and reinfused. In May 2016 her scans came back clean-no detectable cancer. Only one case, of course, but an indicator of hope in cancers that do not respond to conventional methods.

#### SAVE LIVES AND ALLOW PAYMENT FOR DONORS.

Doug Grant has a start up company called Hemeos. He wants to save lives, thousands of them, and he wants to do it faster, safer and for less money then anyone else. Hemeos is aimed at the shortage of bone-marrow donors to combat deadly blood disease. Thousands of Americans are waiting for a lifesaving donor, and thousands more have died waiting. Donating is as easy as donating blood to the blood bank. The process is called apheresis where blood is drawn from one arm, blood cells are skimmed out, and the blood returned through the other arm. Donated marrow cells regenerate quickly and fully. Despite the ease of donating, patients with leukemia or other bloodrelated conditions are desperately searching for donors because a specific genetic match is required. Yet even when a match is located in the National Marrow Donor Program, more than half of prospective donors are unwilling or unavailable to donate. Hemeos plans to revolutionize donor recruitment by the simple method of compensating donors with a check for \$2,000. Doug Grant says that we will get more marrow cells when we pay for them. It's Econ 101. The problem is in 1984 the National Organ Transplant Act (NOTA) made it a crime to pay donors. Unlike plasma, sperm and egg donations (for which compensation is legal and common) paying marrow donors remains illegal. Legal precedent was established in 2012 when Doreen Flynn, a Maine mother with three girls with Fanconi anemia successfully sued the Justice Department to end the ban for compensating donors. Still a year later, DHHS announced it might enact a regulation nullifying the court's ruling. A public comment was offered seeking help. Hundreds poured in favoring compensation for blood stem cell donors who use apheresis. Only a handful of comments were negative. The faceless lumbering bureaucracy smothers innovation and optimism. It is past time for HHS to act. Either allow firms like Hemeos to revolutionize marrow donation, or endorse the ban and face an immediate challenge over a delay that is causing needless deaths.

#### GEEEZZZZUH KEEEECRIMUNNEE/// OH SHHH----T//// ARGO ----YOURSELF//I AM REALLY P----D OFF.

During childhood years (and after) most of us were raised to think of cursing as a vice that needs to be cured. But there is a reason that swearing is such a widespread practice. It actually has many benefits. Consider the capacity of swear words to help us withstand pain. Psychologist Richard Stephens at Keele University in Staffordshire, England, found that people can keep their hands submerged in ice water about 50% longer when they swear as compared to using a neutral word. Volunteers reported that the water felt less cold when they were swearing. Dr. Stephens found that swearing worked equally well for everyone, whether they were inclined to swear or not. We know that swearing does something to our physiology. When you hear or use swearing, your heart rate accelerates, your palms become sweaty, and your emotional state intensifies. Not just any words will do. They need to be genuinely taboo words. Euphemisms such as geehossafat, fudge or sugar don't cut it when it comes to withstanding pain. They leave your heart rate and emotions unchanged. So, the next time you drop an expensive dish, or pinch your thumb in a car door, or twist your knee on a stairway, just let it all hang out. You will feel better.

#### ADDENDA

- According to a poll by Progressive Insurance 63% of Americans talk to their cars.
- Saint Lydwina is the patron saint of ice-skating.
- There are some things only intellectuals are crazy enough to believe.
- How many of these dead animals you see on the highway are actually suicides.
- I was going to be a nice guy and mow my grandmother's grave, but then I thought, "Hey the cemetery takes care of that."

#### 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 pointcounterpoint 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 <u>http://hjmph.org/submit.</u> <u>htm</u>.

#### 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).

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**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 <u>http://hjmph.org/submit.htm</u>.

**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.

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#### **VII. Conflict of Interest**

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

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#### In-text Citations:

- Identify references with superscript Arabic numerals corresponding to the item in your reference list.
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#### 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 rhinonusitis: a randomized controlled trial. JAMA. 2012;307(7):685-692.
- 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.
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- 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) SE
- Standard Error
- Standard Deviation SD RR
- · Relative Risk
- · 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.
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- Use a comma before the conjunction (and, or, nor, but) that precedes the last item in a series.
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