Using a Short Message System to Increase Cervical Cancer Screening Uptake among Chuukese Women in Guam: Lessons Learned from Linking Distance Technology Between Carriers and Using Telehealth Communication in a Cross-Cultural Context

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Abstract

This paper reports on a project aimed at using a short message system (SMS) to increase cervical cancer screening uptake among Chuukese women in Guam. It documents the process and identifies the unexpected challenges which led to the early termination of the study. Although the original aims of the project were not met, there were some lessons learned about technology incompatibility in the context of Guam's and the United States' cell phone technology interface, the cultural nuances of cell phone use in the study population, and the necessity to follow a protocol for the termination of a project.

Keywords

SMS, cervical cancer screening, technology challenges

Abbreviations

BCCEDP = Breast and Cervical Cancer Early Detection Programs
COFA = Compact of Free Association
FGD = focus group discussion
FSM = Federated States of Micronesia
HC = HealthCrowd
PSC = Program Steering Committee
RDS = respondent-driven sampling
SMS = short message system
US = United States

Introduction

The use of mobile phones to promote cancer screening, smoking cessation, healthy diets, and to reduce harmful behavioral risk factors has been spurred by the rapid development of technology. The growing body of research within the last two decades through the use of the short message system (SMS) technology to influence health behaviors in various populations has resulted in different levels of efficacy. The differential results have encouraged further investigation into the factors that influence responses to SMS, including those focused on increasing cancer screening rates.

While studies have reported small to moderate increases in screening rates for cancer, the benefit of using SMS to increase the uptake of screening was observed in countries that were resource-poor and had non-English speaking populations.[1] A systematic review of the impact of text message (SMS) interventions on cancer screening rates revealed that individuals who received SMS interventions had up to 15% higher screening rates than those who did not receive SMS messages.[1]

Based on the results of previous research,[2] a study to test the efficacy of SMS to increase cervical cancer screening among Pacific Islander women in Guam and Hawai'i was developed. The study in Guam focused on Chuukese women, the biggest group of migrants from the Federated States of Micronesia (FSM) in Guam. The FSM 2013-2018 Comprehensive Cancer Control Plan noted that only 6% of eligible women received Pap tests in Chuuk.[3] Chuukese women bear a disproportionate burden of cervical cancer morbidity and mortality.[4,5] The data presented in the Cancer in the US Affiliated Pacific Islands 2007-2015 indicate that 73% of cervical cancer cases in Guam were diagnosed at advanced stages[5] and that Chuukese women comprised a higher proportion of the advanced stage cases based on an unpublished analysis from the Centers for Disease Control and Prevention National Program of Cancer Registries.

Target Population

The FSM is one of the three sovereign Pacific island nations which are in free association with the United States (US) via their respective treaties called Compacts of Free Association (COFA). The COFA allows the US military oversight, called strategic denial, over the three freely associated COFA nations. In exchange, COFA citizens are allowed free entry and the right to work in the US and any US Territory in perpetuity. Chuuk is the most populous state of the FSM with about 50,000 inhabitants,[6] many of whom rely on subsistence agriculture and fishing, and the funds from the compact with the US.[7]

The overall population of Freely Associated States citizens living on Guam – which remains to be the primary destination for FSM migrants – has increased by 9 percent between 2013 and 2018.[8] Guam was home to 18,874 Freely Associated State migrants, accounting for 11% percent of the island's total population.[8,9] Chuukese migrants comprise the largest number of FSM migrants to Guam, primarily because Chuuk State is only 1 hour and 45 minutes by air to Guam. According to the Guam Statistical Yearbook 2016, there are an estimated 11,500 Chuukese citizens in Guam, which accounts for about 60% of all migrants from the Freely Associated States.[10]

Cervical cancer disparities in migrant Chuukese women (ie, those who have recently migrated to the US) likely reflect a lack of health behaviors related to the utilization of cervical cancer screening.[4,5] Focus groups with Chuukese women held in 2016 revealed cultural characteristics that would affect their response

to messages about cervical cancer screening. Information about the customary use of mobile phones among Chuukese women was obtained through the 2016 focus group discussions (FGD). For instance, there were generational differences with younger women more adept at using mobile phones and more likely to use them in a variety of contexts. The majority tended to rely on prepaid cellular services with no or limited data plans, which provided inconsistent services. Consequently, FGD participants noted that members of the Chuukese community would often rely on free Wi-Fi access obtained at gas stations, laundromats, etc., and suggested that Facebook Messenger or WhatsApp may also be viable channels for conveying health behaviors messages.[2]

In addition, the degrees of acculturation differs among Chuukese women, which was associated with their willingness to discuss sensitive health topics outside the family, especially with someone who was not of the same gender. The FGD participants pointed out that a few women come from households where electrical power was not reliable and would pose a challenge to the study because mobile devices require charging. While limited in generalizability, these insights were valuable in the design of this study and the development of SMS messages.

To address the high rates of cervical cancer morbidity and mortality among Chuukese women in Guam, this study was aimed at using culturally-appropriate SMS as an intervention to increase cervical cancer screening.

Methods

The research design was based on the Fogg Behavior Model[11] and utilized concepts from the conceptual framework of Community-Based Prevention Marketing as described by Bryant and colleagues.[12] The behavior change models were founded in a community-based research approach to guide the development, planning, and implementation of evidence-based strategies.

This study was conducted in two phases (Figure 1).

In Phase 1, the team developed SMS messaging materials encouraging cervical cancer screening in English and Chuukese languages. Formative research was conducted to determine knowledge, attitudes, and beliefs about barriers and effective strategies to promote cervical cancer screening. The research was conducted among recently migrated Chuukese women age 21-65 who qualified for the Centers for Disease Control and Prevention's Breast and Cervical Cancer Early Detection Programs (BCCEDP) and other insurance programs designed for lower-income women (ie, Medically Indigent Program).

This study also sought to understand how the target populations used SMS on their cell phones. SMS messages for Chuukese women were developed, pretested, and were culturally and linguistically adapted for initiation and completion of cervical

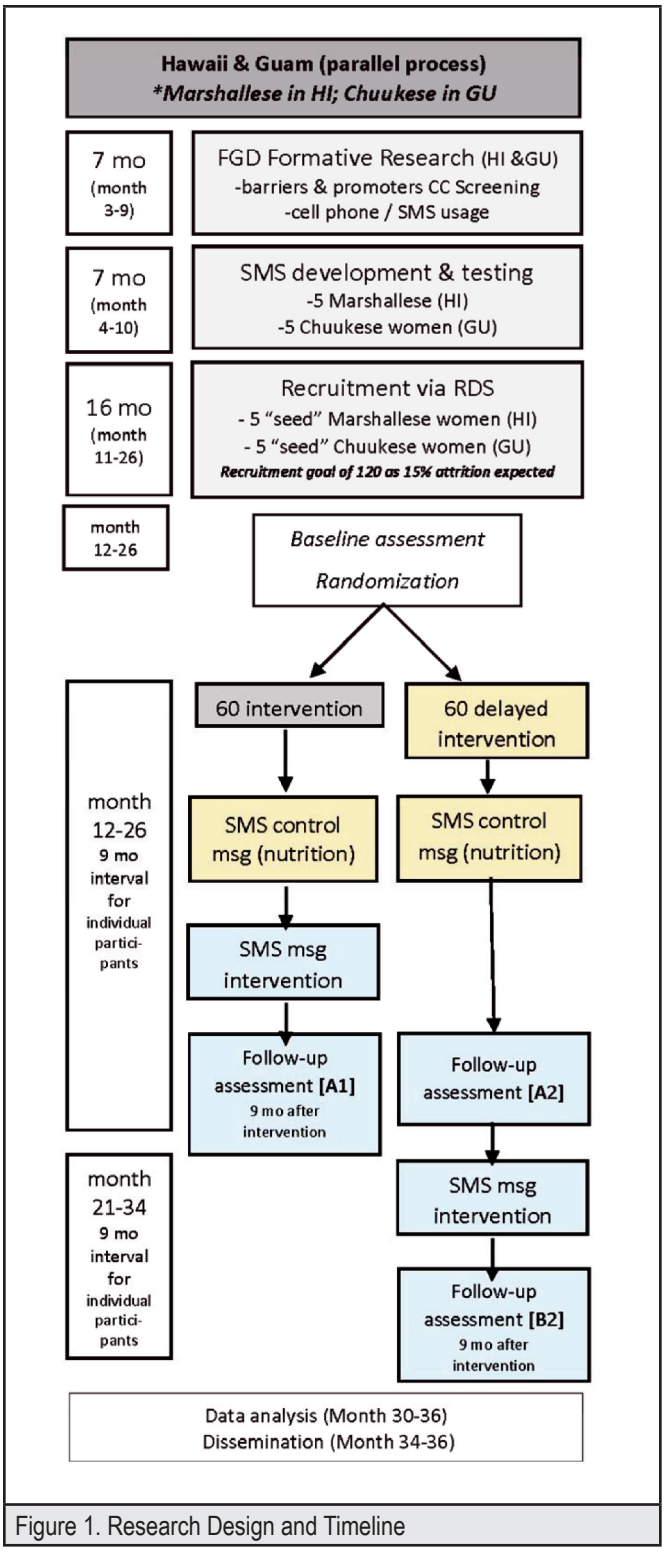

Figure 1. Research Design and Timeline

cancer screening. The weekly SMS messages about cervical cancer screening were interspersed with other messages the participants may have received which were competing for their attention. Some messages required a brief one-word response, such as "yes" or "no" and "true" or "false," with the option to text back and ask for additional information.

In Phase 2, the team implemented the SMS intervention and assessed the impact on intent to screen, as well as to increase cervical cancer screening rates among Chuukese women. A total of 60 Chuukese women were enrolled in the Guam study, with a parallel study of Marshallese women in Hawai'i. A delayed cervical cancer SMS intervention for the women randomized to nutrition SMS, to be carried out over the subsequent nine months, was incorporated into the intervention design.

Message Development

The SMS intervention was to be delivered to the intervention group immediately and after nine months to the delayed control group. Both groups were also to receive a 'control' SMS message encouraging healthful nutrition choices. The enrollees would be surveyed at baseline and again at nine months to assess post-intervention intention to screen and the completion of screening, as well as questions on other covariates.

HealthCrowd (HC), a consulting company in California, was contracted to develop the initial SMS. Two sets of SMS were developed, one for the intervention group (initiate and complete cervical cancer screening) and another for the control group (adopt / increase healthy nutrition behaviors). During the November 2016 U54 workshop, project team members met to review the messages, develop additional messages, and categorize the SMS based on components of the Health Belief Model.[13] The sequence of the messages was matched with the components of the model (perceived severity, susceptibility, benefits, and barriers, modifying variables, cues to actions, and self-efficacy). Both sets of messages for the intervention and control groups were translated into Chuukese by certified translators hired for that purpose. Translations were validated by the members of the Community Advisory Group composed of Chuukese women who represented different sectors of the Chuukese community.

HC was responsible for delivering the SMS texts on a weekly basis, tracking the responses, and conducting the analytics. The HC platform was able to send both pre-scheduled and "on the fly" text messages, and could receive replies from patients. Back-end analytics were utilized to parse incoming messages from patients, display self-reported measures such as intent to screen, confirm that they made an appointment for screening / received their screening on password-protected population and individual patient dashboards. At meetings with the HC team prior to the actual intervention, there were trial runs which were reassuring about connectivity and message transmission.

The Guam BCCEDP screening program was tasked to provide a formal report regarding the research participants who agreed to release their medical information and who completed cervical cancer screening during the duration of the project. The SMS research team was responsible for following up with other non-BCCEDP health providers to determine receipt of cervical cancer screening.

Participant Recruitment

As these populations were hard to reach, respondent-driven sampling (RDS) was utilized to recruit study participants. The RDS method is a cost-efficient, non-probability sampling strategy that can generate reasonable population estimates for minority and hard-to-reach populations in a timely fashion.[14] In this chain-referral sampling method, respondent "seeds" recruit others who are eligible within their social networks; those recruited by the initial "seeds" then recruit others, with a limit of recruits per "seed" to prevent over-recruiting by some individuals. As a result, the composition of the final RDS sample is independent of the arbitrary selection of the initial "seeds."

While the previous study demonstrated the efficacy of RDS in the recruitment of study participants, it was not as effective in this particular study. The "seeds" were not prolific and other recruitment strategies were employed, including face-to-face recruitment at health fairs and traditional snowball sampling (participants were asked to recruit their friends to participate in the study outside of the RDS process). The team also sought the assistance of other research staff, as well as non-profit organizations in the community, who worked closely with Micronesian migrants.

Enrolled participants were randomly assigned to the intervention and control groups. Blocked randomization, with random block sizes, was used to avoid a significant imbalance in size between the two study groups at any time during recruitment.

Project Implementation

While the SMS messages for the intervention and control groups were being developed, the research team recruited participants for the study. By the second week of May 2017, a full sample of 60 participants were recruited (Intervention=30, Control=30) and the team was ready to launch the project.

The initial sign-in SMS was received as expected. In essence, the welcome message was received, and the team anticipated monitoring responses on HC's dashboard, and on the project phones which the research team used to monitor the SMS weekly messages. Within the first month, several glitches with the SMS transmissions were noted. The next section discusses the challenges that transpired during the project implementation and the factors that eventually led to the project's early termination.

Results and Discussion

Analysis of the Project Implementation and Subsequent Challenges

As described in the research design, the SMS intervention involved the transmission of weekly messages aimed at raising awareness about cervical cancer screening and persuading research participants to get screened. In contrast, participants in the control group received messages about nutrition. HC sent the weekly messages. A local telephone service provider in Guam, IT&E, was used to deliver the messages. IT&E was the only local provider willing to work with this project, given the limited resources. In Guam, Blu Zoey flip phones with unlimited SMS text service were purchased; however, these flip phones did not have the capacity to make phone calls or to access the Internet.

In the parallel project in Hawai'i, participants in Hawai'i signed up for the Lifeline Program and used low cost smartphones for the project. Lifeline provided a discount on monthly service of $9.25 per month for eligible low-income subscribers.

SMS texts were transmitted from HC in California. To avoid long-distance rates, messages were relayed from the area code from California (415) through Hawai'i (808) and finally on to Guam (671). As the project progressed, the connection from HC and the local Guam IT&E company using the Blu Zoey phones did not function well.

SMS text messages were set up with HC and were scheduled to be sent weekly to the participants at 7:00 PM Guam time (when most participants were expected to be home and would be more likely to check and respond to messages). The SMS messages did not arrive consistently at the scheduled time. There was a time lag with several messages, some messages were truncated, or messages were not received at all. The project leader's smartphone, set to receive the SMS messages, noted truncated SMS, as shown in the screen shots in Figure 2.

The examples in Figure 2 are just two of many instances where "?" appeared on the screen instead of complete messages. Inquiries with both HC and IT&E did not resolve the situation. The team was unable to determine the cause of the problem. The length of the message may have been part of the issue as

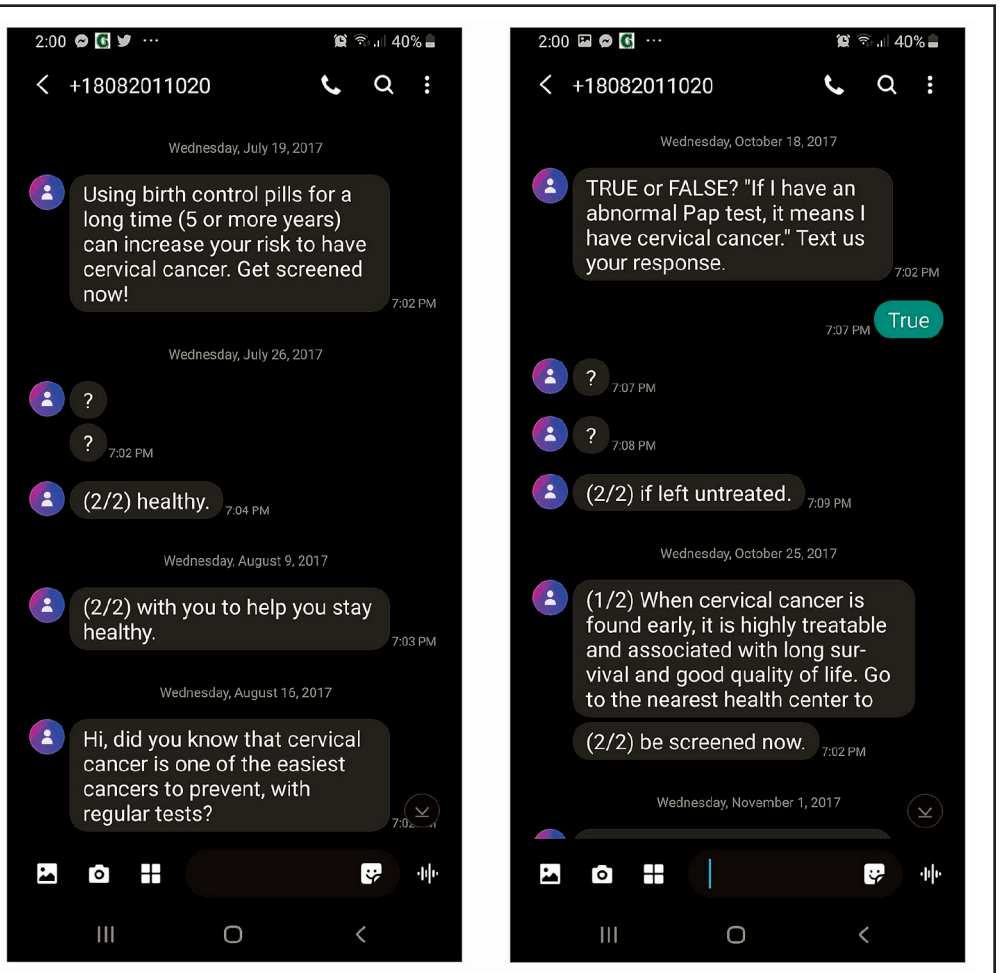

Figure 2. Examples of Truncated Messages on a Smartphone

dropped messages were more frequent when a long message was transmitted as a single text. Translation of SMS into the Chuuk language resulted in longer text messages.

The local provider IT&E informed the researchers that if the individual phone was not turned on at the time when the SMS message came in on the Blu Zoey phones, their system would automatically attempt to resend the message multiple times within 48 hours. Unlike smartphones (eg, Androids or iPhones), the project phones did not automatically store messages for later review if the phones were turned off at the time the SMS was delivered. According to the provider, the messages were dumped/dropped from the system if they were not retrieved within 48 hours. They were only saved on the phones if they had been opened within that critical period. The Guam research team did not know this before the intervention started.

Regarding HC, the data and tracking information on their dashboard was unable to accommodate the necessary tracking information under a more nuanced interface. Response rates were presented in graphs such as the one shown in Figure 3. The rates were shown for 30-day periods, and expanded graphs were not available. The research staff had to take screen shots of the four-week graphs, as data on more extended time frames could not be viewed.

Figure 3 illustrates that between the October 2017 to November 2017 time frame, which was six months after the project was implemented, the total incoming text messages, ie, the SMS received by the participants ranged from 34 to 37 out of 60 SMS which should have been received for the respective intervention and control groups. For the SMS that required a response (yes/no, true/false), the responses ranged from 2 to 4. The green line, which indicates the number of phones which were turned on at a given time was erratic, ranging from 3 to 36 out of 60.

The information on the HC dashboard was not consistent with the records of Guam IT&E phone service and thereby reliable information was not robust throughout the six months of the intervention. These results and findings were presented at the annual U54 Program Steering Committee (PSC) in November 2017. Terminating the project was discussed with the PSC and the study's Internal Advisory Board in January 2018. The conclusion by the project leads, PSC, Internal Advisory Board, and Principal Investigators was that the technological problems were insurmountable and that the possibility of rectifying them, although attempted on several occasions, was not possible. While the pretesting of the technology worked, it failed when the SMS frequency was scaled up over time.

Although the incompatibility of the technology was the main factor that led to the project's termination, there are some cultural nuances of cell phone use in this population that are worth noting, as they could inform future studies.

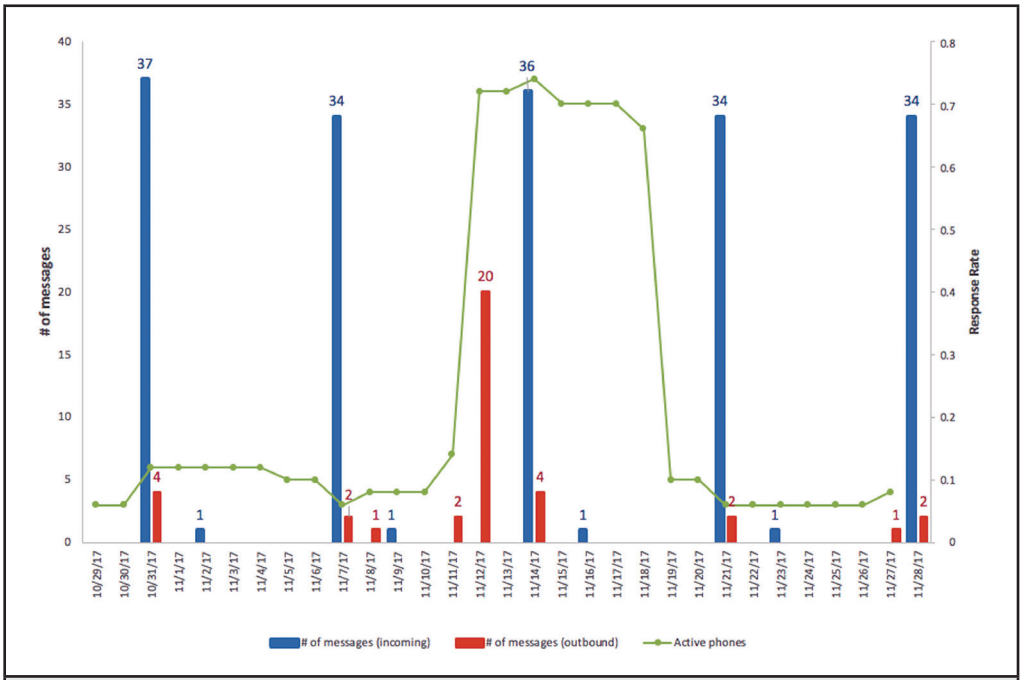

Figure 3. Response Rates of Weekly Text Messages

Cultural Nuances of Cell Phone Use Among Chuukese Women

There were cultural nuances in the use of cell phones, which were determined through the FGDs.

Familial Sharing of Phones. The women who participated in the study frequently shared phones with other family members. If the project phone was in the possession of another family member when the SMS message came from HC, the SMS may have been simply ignored. This observation was supported from the HC dashboard - interactive messages that required a brief response like "yes" or "no" remained unanswered.

In several instances when project team members attempted to follow-up with the participant on the alternate contact phone number, someone else other than the participant answered the phone. In one case, the person answering the phone questioned the motives for the research staff call and refused to give the phone to the study participant.

Transient Nature and Constant Change of Phone Numbers. While the participants were asked to give an alternate contact number and/or a Facebook account, some noted that their alternate phone numbers changed whenever they purchased new prepaid cards. It was therefore very difficult to reach the participants in several instances. Of the ones who were reachable, some indicated that they did not receive the SMS message, while others said that they received the message, but did not reply.

Limited Experience with Cell Phones. In two instances, participants indicated on their alternate phone that the Blu Zoey phone did not work. It is possible that they could have inserted the SIM card incorrectly, despite the demonstration that the research staff gave when they consented to participate in the study.

Some participants were not familiar with the technology and did not respond correctly to the interactive SMS messages. One response was gibberish; it was suspected that a child had gotten hold of the phone, and was playing with the keypad.

Following the termination of the study, the participants were contacted through all means possible (Facebook, viable alternate phone numbers, announcements in the two main local newspapers) and through a scheduled a town hall meeting to inform the participants regarding the termination of the study. The purpose of the town hall meeting was to encourage participants to see their health care providers and get screened for cervical cancer. Nine participants confirmed their attendance. Unfortunately, due to a storm on the meeting day only one participant attended. The process of locating and informing participants about the project's termination resulted in the development and strict adherence of a protocol for terminating a research project.

Implications and Recommendations (If we knew then what we know now)

The non-rectifiable issues regarding the technology incompatibility in the context of Guam's and the US cell technology interface made the early termination of the project the most prudent course of action. If there had been a local provider with the capabilities of HC for managing the SMS and tracking the response data, the issues could have been avoided or resolved. An on-site SMS provider would have made timely accessibility to technical support easier, as the time difference between Guam and anywhere in the continental US is between plus 14 to 17 hours.

Use of cell phones and SMS as an intervention was informed by prior studies and by testing the technology interface. Errors in the incompatible technology and the SMS messaging system were magnified as the frequency of SMS messages increased, and when scheduled / timely messaging was essential. Although the local Guam phone / cell service and the HC SMS company as independent entities were experienced and each company had a long positive track record with respect to their expertise and product, a longer test period (several months) and a higher volume of pre-project SMS would have been useful to test the technology interface.

The study did not work out as planned; however, the participants who were able to respond to the messages were engaged and open to this type of intervention. If the technological issues are addressed, we are confident that SMS could be a viable means of encouraging women from this particular population to get screened. Any future intervention should also take into account the cultural practices related to SMS, and ongoing shifts in the use of other communication technology. The challenges we encountered will provide some insights for other researchers who are considering future projects, which aim to increase cancer screening uptake using SMS.

Conflict of Interest

None of the authors identify a conflict of interest.

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