# Texting 4 Sexual Health to American Indian and Alaska Native Teens & Young Adults

By

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This is to certify that the PhD Dissertation of

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## **Acknowledgements**

I could not put words eloquently together to express all that I gained from the two years of working with the Northwest Portland Area Indian Health Board, so I found a poem.

### Perspective

The narrowest mind, is the one Who looks upon the world Merely through its own eyes.

The noisiest, is the one
Who has yet to learn
How to listen with his ears.

The most condescending, is the one Who has yet to learn How to respect other opinions.

The most tolerant, is the one Who sees through many eyes And understands.

Copyright Wayne Scott of Swan Lake First Nation Reserve of Manitoba Canada <a href="http://www.firstpeople.us/html/Perspective.html">http://www.firstpeople.us/html/Perspective.html</a>

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To my family, near and far - WOW! Who would have thought, eh?

## **Chapter 1: Introduction**

### **Background**

The CDC reports an estimated 20 million new sexually transmitted infections (STIs) occur annually, with the cost of treating these new STI cases estimated to be about 16 billion.(DSTDP, 2013) With more than 50% affecting people between the ages of 15-24 years of age, (DSTDP, 2013) and 15-24 year olds comprising only one quarter of the US population, (DSTDP, 2013) there is a disproportionate weight of STI cases affecting American youth. And although schools provide sexual health education, they cover the subject matter very broadly and with less focus; young people want practical guidance and help in avoiding STI and pregnancies. (Woodcock et al., 1993) All ethnic and racial groups are affected, but American Indian/Alaska Natives (AI/AN), as one of the smallest ethnic and racial groups in the United States, (National Congress of American Indians, 2015) have experienced persistent disparities related to STI/HIV and teen pregnancies among their youth (Centers for Disease Control and Health Service, 2014). Demographically, the AI/AN population is one of the smallest ethnic groups in the United States, constituting 0.9-1.7% of the total US population, and has a higher proportion of their total population in younger age groups. (Norris, Vines and Hoeffel, 2012) American Indian/Alaska Natives constitute 403,426 of 14-24 year olds (138,999 of 14-17 year olds, and 264,427 of 18-24 year olds.(National Center for Education Statistics, 2011)

In 2013, AI/AN girls had the third highest teen birth rate in the U.S. (31.0 per 1,000 compared with 26.5 per 1,000 nationally)(Martin *et al.*, 2015) and AI/AN youth 15-24 years experienced the second highest rates for chlamydia and gonorrhea(Centers for Disease Control, 2014) among all ethnic and racial minorities. Although pregnancy rates fell for teens and young adults in the United States overall between 2011 to 2012, AI/AN teens (15-19 years) experienced the lowest decrease in birth rates.(National Center for Health Statistics, 2013) And despite the decline, AI/AN teen birth rates remained almost twice the rate of white teen birth rates.(*CDC* -

About Teen Pregnancy - Teen Pregnancy - Reproductive Health, no date) The higher teen birth and STI rates within the AI/AN community indicate earlier sexual activity without the use of protective measures. These disparities underscore the need for effective sexual health interventions for AI/AN youth. Poverty,(Kaufman et al., 2007) rural geography, and inadequate health services(Rights, 2004) further aggravate the problems experienced by AI/AN teens and young adults.

A variety of structural and cultural factors have contributed to the sexual health disparities that AI/AN youth have experience. Distrust of the federal government with their attempts to annihilate the Native population, lack of adequate funding for health services, and inability to access health services(Rights, 2004) — have all posed challenges to the Native community. Cultural differences exist with respect to sexual health that conflicts with contemporary messages, that otherwise have been shown to improve sexual health outcomes for teens and young adults.(Rushing and Stephens, 2012; Guse *et al.*, 2012) AI/AN culture considers a more holistic approach to adolescent health, embracing emotional, physical, social and spiritual facets that conventional practices do not include. Given that the AI/AN populations comprise less than 2% of the U.S. population, teenage births are celebrated, eluding the stigma that is often assigned to teen births outside of the AI/AN culture. Messages that reflect this worldview are needed to better meet the needs of AI/AN youth.(Rushing and Stephens, 2012)

#### **Aims**

Three aims were the focus of this study. The first aim included a literature review of previous messaging studies to inform the design of text messages that could be used to recruit and consent study participants, promote condom use and appropriate STI testing, and evaluate the effectiveness of intervention.

**Aim 1:** Design a series of text messages that improve sexual health knowledge, attitudes, intention, self-efficacy, and behavior among AI/AN teens and young adults (ages 15-24), and a series of pre-post survey text messages that can be used to evaluate the text messaging service.

The goal of Aim 1 was to develop sexual health messages to decrease the transmission of sexually transmitted infections (STIs), including human immunodeficiency virus (HIV), among AI/AN teens and young adults. The objective was to use health behavior theories, and recommendations based on the published literature to create a series of intervention messages. Messages were developed and tailored to convey important sexual health concepts to promote risk reduction and protective factors associated with STIs/HIV transmission, targeted specifically to the health needs and social context of American Indian/Alaska Native teens and young adults. Crafting messages is not trivial when succinct, relevant sexual health information must be conveyed clearly, be compelling, and connect with the target audience within a 160-character limitation. The purpose for developing these sexual health text messages was to not only disseminate, but also stimulate thoughtful processing of information.

**Aim 2:** Ensure the messages speak to a range of perspectives and readiness levels, by pilot testing the messages with AI/AN youth of varying genders, ages, and sexual orientations.

The goal of Aim 2 was to pilot test the messages with advisory panels of young adults and small groups of teens. The objective of this aim was to measure and gauge response to sexual health text messages from sample groups of the target audience. The second aim incorporated focus groups, surveys, and pilot tests, working with the target audience to test the functionality of the text messaging software, and make certain the relevance, acceptability, and understandability of the messages for AI/AN teens and young adults. Given the heterogeneity of the young people who would participate in the study, the messages needed to resonate with youth who were: male and female, sexually active and not yet sexually active, and any sexual orientation (heterosexual, lesbian, gay, bisexual, transsexual, two spirit (LGBT2S)). Using a variety of community-based

participatory research (CBPR) and qualitative methods, the formative research phase informed the development of the messages, its timing in delivery, the recruitment of participants, and consent.

**Aim 3:** Quantify the effectiveness of the text messaging intervention, designed to promote condom use and STI/HIV testing, by measuring change in sexual health knowledge, attitude, self-efficacy, intention, and ultimately improve overall sexual health behavior.

The goal of Aim 3 was to execute the study with the goal of collecting evidence for analysis. The study was launched with over 400 teens and young adults. Over a period of 10 months, recruitment, consent, surveys, intervention, and incentives were delivered through text messaging. Responses delivered by text messaging were downloaded from the web server. A mixed effects logistic regression model was used to analyze data.

Throughout the study, lessons were learned – both positive and negative. These findings were the focus for an additional chapter that can inform future studies about issues that can impact health information tied to mobile health technology.

#### **Innovation**

To my knowledge, no previous studies had recruited, consented, tested, sent interventions, and incentivized youth, all via text message, and no previous studies had evaluated text messaging as a sexual health promotion strategy among AI/AN teens and young adults (ages 15-24). This study explored the applicability and utility of text messaging to promote sexual health with this underserved population.

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## **Chapter 2: Literature Review**

Public health has developed a growing awareness that the environment and social issues like poverty, inadequate housing, lack of employment opportunities, racism, and powerlessness (Hernández, 2000; Israel, 2013) all contribute to poor health. There is increased sensitivity to culture, with the realization that marginalized populations often experience challenges socially, politically and economically. Partnerships between private and public organizations are helping to change the landscape, and allowing for a more comprehensive, integrated approach to addressing issues in public health. (Trochim, 2006; Chehimi and Cohen, 2013)

The literature reviewed for this study encompassed several topics: social determinants of health, health disparities, Indigenous populations, community-based participatory (CBPR) research, health behavior theories, text message interventions, intervention message development, and consent/assent. This background sets the context for why this study was important, and sheds light on how texting was selected as the medium for communication, along with the various aspects involved in executing this study.

#### **Social Determinants of Health**

The Commission on Social Determinants of Health (2005-2008) was founded on the goal to help countries support and address health inequities, directing the world's attention towards the social inequities that precipitate poor health. (CSDH, 2008) In 2008, the Commission on Social Determinants of Health released a report that identified several factors that contributed to poor health:

- Lack of material resources for health
- Diffusion of advances in medical and health technology
- Psychosocial stress
- High levels of economic inequality
- Unhealthy lifestyles

These social determinants are the conditions under which people are born, grow, live, work and age, and include the health system. (CSDH, 2008) These circumstances that sway health are also influenced by the distribution of money, power and resources at the global, national and local levels, which in turn are influenced by policy decisions and ultimately drive the unfair and avoidable differences seen in health status between and within countries.(CSDH, 2008)

Poor social policies are observed in the unfair work practices in China (Barboza, 2008) or the lack of education for women in Pakistan. (Latif, no date) Poor programs are exemplified in the lack of affordable child care (Fiorita, 2010) for women who want to go to school but also need to work. Over three billion people – almost half the world, live on less than \$2.50 a day. (Shah, 2015) Lacking economic earning power is a powerful contributor towards poor health, but education, the physical environment, and the social structure are equally important. The challenge of leveling the playing field for all is a task for everyone, not just for those who are poor.

#### **Health Disparities and Indigenous Populations**

Shamefully, health disparities are not unique to developing countries. Countries leading in economic prosperity like the United States are also susceptible to the plague of social inequities that lead to health disparities. And like developing countries, high-income countries are no less challenged with the monumental task of eliminating health disparities.

In the United States, there are strong associations between certain factors and disparities. Race and ethnicity are strongly associated with health disparities - African Americans, Hispanics, American Indians/Alaska Natives, and Hawaiian/Pacific Islanders suffer the highest rates of health disparities.(CDC, no date) With respect to the indigenous populations of the world, they suffer health disparities with the highest incidence of most health conditions,(CDC, no date) when compared to the non-indigenous populations. They are afflicted disproportionately with

cardiovascular disease, HIV/AIDS, diabetes, and tuberculosis among many diseases, and they are also affected by alcohol and drug abuse, and high rates of suicide. (CDC, no date) Historical trauma can be attributed as one of the greatest contributors for the current health status of American Indians/Alaska Natives.

Historical trauma is the theory that focuses on the historical subjugation of a people to long-term, mass trauma – whether through war, enslavement, genocide, and the prevalence of these effects in later generations.(Sotero, 2006) Taking the upstream approach and understanding how historical trauma might be influencing the health of a given race or ethnic group might be informative towards eliminating health disparities.

#### American Indians/Alaska Natives

An Indian Tribe is recognized as a self-governing entity by the United States, essentially, a 'domestic dependent nation' with three parameters: Indian Tribes are their own Nation, subject to the United States as a superior sovereign, and the US Federal government has a guardian-like trust role. (NIHB, no date) In the US, the American Indian and Alaska native (AIAN) populations constitute ~2% of the total US population.(OMH, no date) 22 percent of the AI/AN people live on reservations or other trust lands while another 60 percent live in metropolitan areas.(OMH, no date) Despite there being 566 federal and over 100 state recognized tribes, there are still many tribes not yet recognized at either the federal or state level.(OMH, no date)

As part of its role in being a guardian, the US provides federally funded health care and services directly to the AI/AN population. The Indian Health Service (IHS) under the US Department of Health and Human Services is the government agency that delivers health service to about 2 million American Indians and Alaska Natives, mostly on reservations and in rural communities.(OMH, no date) This is only a small portion of the population and consequently, AI/AN typically experience a higher frequency of poor health and access to health care services can be limited to those off reservations or urban areas. There are also cultural differences,

geographic isolation, and low income that take its toll on AI/AN health. As a result, AI/AN populations are faced with higher rates of cardiovascular disease, cancer, injuries, and diabetes, along with disproportionate rates of mental health, teen pregnancy, and HIV/AIDs.(OMH, no date)

#### **Sexual Health Interventions**

Since 1980, the Department of Health and Human Services has launched a comprehensive, nationwide agenda for health promotion and disease prevention, providing a roadmap for the goals of that decade.(DHHS, 2008) In the health agenda for Healthy People 2020, one of the goals is to promote healthy sexual behavior and access to quality services to prevent sexually transmitted diseases and their complications. (DHHS, 2008) Sexually transmitted infections encompass more than 25 infectious diseases with the primary mode of transmission through sexual activity.

As noted earlier, racial and ethnic groups suffer higher rates of health disparities and this is true with sexual diseases. African Americans, Hispanic and America Indians/Alaska Natives have higher rates of STDs compared to the rates of whites. (Centers for Disease Control and Prevention (CDC), no date) In 2009, the Chlamydia rate for AI/AN was 1.9 times higher than that of whites, the gonorrhea rate was 4.2 times higher than the rate of whites, and the primary and secondary syphilis rates were comparable to the rates of whites. (Centers for Disease Control and Health Service, 2014) For American Indian/Alaska Native youth, prevalence estimates for multiple sex partners and recent sexual intercourse with at least one partner, initiating intercourse before the age of 13, and pregnancy rates were invariably higher compared to the white youth. (Urban Indian Health Institute, 2009) Education on sexual issues like HIV infection were also less likely for AI/AN youths. {Nakai A, Manuelito D, Thomas WK, Yarber WL, Milhausen RR, (Race/Ethnicity, Socioeconomic Status, and Health, 2004)

Several sexual health interventions have successfully reduced teen pregnancy rates and STI transmission among teens and young adults.(Card *et al.*, 1996; Bearinger *et al.*, 2007; Hindin and Fatusi, 2009; Collin, 2015) These theory-based programs were designed to increase youth's knowledge, attitudes, intentions and self-efficacy related to condom use and appropriate STI testing. Few such interventions, however, have been purposefully designed for or rigorously evaluated with AI/AN teens and young adults (Baldwin *et al.*, 1996; Hernández, 2000; Aguilera and Plasencia, 2005; Israel, 2013), for whom mainstream sexual health messages are often inappropriate and ineffective (Trochim, 2006; Chino and DeBruyn, 2006; Gilley, 2006; Rushing and Stephens, 2011; Chehimi and Cohen, 2013). Sexual health inventions tailored to the unique needs and culture of AI/AN youth are still critically needed.

#### Internet, Social Media, & Texting

Technology is a component of life today that many adolescents and teens have lived with all their lives. And with each passing year, the technology only gets faster, more diverse in applications, and more sophisticated. In fact, the technology is moving faster than we are able to harness its power in addressing current social issues. And that is the challenge with using technology – capitalizing on it to improve health/social issues.

For example, the Internet has become a tool for patients to access information on health conditions and to communicate their condition with others. (Fox, 2011) The term e-patients coined by Ferguson (Ferguson, 2007) reflects a new age of patients informed by Internet searches. Patients do not have to be wholly dependent on their care provider for information—there is so much information available online. If there is disagreement or dissatisfaction with provided care, one can always investigate independently, albeit one takes a chance on the quality of the information. However, health consumers today have become more informed thanks to the Internet. (Cline and Haynes, 2001)

What has developed with the Internet, beyond information access, is the facilitated access to information sharing. "Social network sites, blogs, online communities, email groups and listservs, and other tools allow people to express themselves in ways that respond immediately to people." (Fox, 2011) It allows people to communicate and even engage the community in providing care. (Seliger, no date)The Internet has not only become a source of entertainment and information but a place where people can meet, chat and even find a life-long partner. (Rosenfeld and Thomas, 2012)

So what are social networks' roles in healthcare? Or more specifically, how can social media be leveraged in healthcare to take advantage of the power of social networks? To be clear, social networking is the "what" and social media is the "how". (Goddard, 2008) Social media is a group of various online media sharing several characteristics: participation, openness, conversation, community and connectedness. (Mayfield, 2015) Other than having an Internet connection and unrestricted access, these features allow people to interact with one another in varying degrees (social networking). There are essentially six kinds of social media today (although change and innovation is second nature to the Internet and can change this fact at any time), defined by Mayfield.(Mayfield, 2015)

- Social networks allow people to build personal web pages and connect with friends e.g. MySpace, Facebook and Bebo
- Blogs online journals e.g. Blogger
- Wikis websites allowing people to add content to or edit information to a communal document e.g. Wikipedia
- Podcasts audio and video files available by subscription by services like <u>Apple</u>
  Itunes
- Forums online discussion sites for specific topics and interests. Forums
  preceded the term 'social media' and are a very popular aspect of the online
  community.
- Content Communities organize and share specific content e.g. <u>Flickr</u>, del.icio.us and YouTube
- Microblogging social networking using updates both online and through mobile phone network e.g. <u>Twitter</u>

Social media is the new medium to communicate thoughts, ideas and within the healthcare arena, it has the potential to become a powerful tool for support intervention. (Shaw *et al.*, 2015) Social media includes the implementation of mobile technology in health, including personal digital assistants (PDAs) and cell phone devices. The encouraging feature of mobile technology is not only are they prevalent in developed countries but in low-income countries as well (Feldmann, 2003; Gillwald, 2005), and applications are having success in these regions. (Blaya, H. S. F. Fraser and Holt, 2010) The Economist featured an article on the upward mobility of Kenyans and how African tech firms are developing applications for mobile phones rather than computers. (Marx, Stoker and Suri, 2013)The beauty of mobile phones is its widespread applicability around the world, regardless of socioeconomic status.

An innovative application of social networks are social programs applying specific concepts and techniques to promote voluntary behavior change. Project Masiluleke (Curioso and Mechael, 2010) involved educating people in South Africa about HIV and tuberculosis prevention by adding a brief message about call centers to any "please call me" text message, taking advantage of available extra space. This resulted in four times the usual number of calls to the South African National AIDS Helpline in the first five months post launch. (Curioso and Mechael, 2010) Another study found that 11 motivational text messages sent by short message service (SMS) had a statistically significant impact on people getting tested for HIV. (Mbuagbaw *et al.*, 2014)

Mobile-based technology has shown to effectively provide interventions for a variety of psychological and physical symptoms and related health behaviors (Heron and Smyth, 2011) Tracking dementia patients when they are lost with global positioning systems (GPS)(Miskelly, 2004) text-messaging smoking cessation on college campuses (Obermayer *et al.*, 2004) and deploying a diabetic support system using web and SMS (Victoria Louise Franklin, no date) all exemplify opportunities using cell phone technology.

If there is one population that is adapting to social media faster than any other, it is the adolescent/teen/youth population. Youth often accept and adapt to change quickly (Anderson and Rainie, 2012) and as the most ardent users of social networks (73%)(Lenhart, Purcell and Smith, no date), they are using social media to play, talk, and meet people of similar (and dissimilar) interests. People are no longer limited to interacting within physical boundaries but have the Internet to connect with others around the world.

America's youth are immersed in media; what was known as the digital divide in reference to different access to technology based on socioeconomic status (SES), gender, race, etc. still exists but in addition to type of access, how the technology is used by different SES and ethnic groups is also included. (Donald F Roberts and Ulla G Foehr, 2008) Today's adolescents can be referred to as the "Media Generation" (Donald F Roberts and Ulla G Foehr, 2008) because with the ubiquity of media and its portability, it has become the driving force for the multitasking phenomenon characteristic of adolescents and teens today.

Valkenburg (Valkenburg and Peter, 2009) discusses how the Internet used to be perceived as a medium for adolescents to form superficial online relationships. Online was considered less favorably than real-world relationships (NIE, 2001) and it was believed that the social well-being and connections that resulted from in-person relationships would be negatively impacted. Today, however, online interactions occur through so many different mediums that Internet social opportunities for adolescents is not a concern. (Valkenburg and Peter, 2009) In fact, Valkenburg and Peter have developed an interesting hypothesis that posits the positive effects of social interactions on the Internet is explained by enhanced online self-disclosure. (Valkenburg and Peter, 2009) Online self-disclosure refers to the revelations of personal topics that may not otherwise be put forward. Within a computer-mediated communication (CMC), there are less visual, auditory and contextual cues and in such an environment, CMC participants become less bothered by external perceptions. One becomes less inhibited in discussing personal issues.

In keeping with this concept, there is a social compensation hypothesis that suggests that adolescents who are anxious are less inclined towards in-person social interactions and would resort to online communications more often. In fact, Schouten et al has found that online communications do reduce the auditory and visual cues that can often constrain an in-person interaction.(Schouten, 2007) By reducing the inhibition that one might otherwise feel, online communication can facilitate a more open interaction.

Another important assumption Valkenburg et al(Valkenburg and Peter, 2009) proposes is that online self-disclosure enhances the quality of a relationship. If disclosure of personal information is conducted online, it is another facet of in-person communication related to the closeness and quality of adolescent relationships.(Valkenburg and Peter, 2009) Finally, Valenburg et al suggests that self-disclosure on the Internet encourages adolescents' well-being because it indirectly enriches the quality of the relationship. And this is very important because in the adolescent years, high-quality friendships can act as a powerful buffer against adolescent stressors. (Valkenburg and Peter, 2009) In this respect, instant messaging is one technology that is becoming more prevalent among all ages but especially so for adolescents and teens.

Krishna et al in their systematic review of healthcare via cell phones (Krishna, Boren and Balas, 2009) confirmed that among all socioeconomic groups, cell phone presence is high. Successful outcomes have been linked to interventions related to cell phones using voice or text messages (Vilella *et al.*, 2004; Bramley *et al.*, 2005) and Krishna determined that text-messaging interventions through cell phones experienced measurable successes.(Krishna, Boren and Balas, 2009) Diseases that require regular management like diabetes and asthma, and smoking cessation that requires ongoing support, have experienced the most benefits with cell phone intervention. This is encouraging evidence towards leveraging social media in healthcare. A key point by Krishna et al is that wireless mobile technology may help towards removing disparities with hard-

to-reach populations.(Krishna, Boren and Balas, 2009) This is particularly exciting in considering the disparities experienced by AI/AN populations living on reservations.

Rideout et al examined the prevalence of media in the lives of 8- to 18-year-olds, noting that 7.5 hours a day, seven days a week was the average time spent on media – and this was in 2010 (Rideout, Foehr and Roberts, 2010) He points out that with the massive amounts of information streaming at the younger generations, understanding how adolescents and teens use media is important towards influencing how this tool can be used to educate them, informing those who are in a position to guide the media. At the time of Rideout's study, about 46% of 8- to 18-year-olds used text messaging on cell phones.

Lenhart of the Pew Research Center found that from 2009 to 2011, text messages increased from 50/day to 60/day.(Lenhart, 2012) Its longevity is clearly impacted by the utility of the cell phone, and with the advances in technology, it is easily portable with increasing functionality. Stubblefield et al (Stubblefield, Carter and Jones, 2010) even suggests that the cell phone is used as a way to maintain social capital – the value of social networks.

Recent studies (Fiorita, 2010; Cole-Lewis and Kershaw, 2010) have shown that text messaging is being used more frequently as a tool to instigate behavior change. Because of its availability and low cost, cell phones health services are now referred to as mobile health or mHealth. The promise lies in how text messaging may improve upon disease prevention and management support. (Cole-Lewis and Kershaw, 2010)

Adolescents and teens who engage in socialization and communication through social media are enhancing their communication skills and social connections, both which can be awkward for this age group. (O'Keeffe, Clarke-PearsonCouncil on Communications and Media, 2011) In fact, a large proportion of teens' emotional and social development is happening on the Internet and on cell phones. However, social issues such as bullying and cliques are not excluded

from social media and in fact, merit attention because of the problems that can ensue. (O'Keeffe, Clarke-PearsonCouncil on Communications and Media, 2011) Similar to this study, Bryant et al also explored instant messaging and text messaging, referred to as socially interactive technologies (SIT), among adolescents. (Bryant, Sanders-Jackson and Smallwood, 2006) Their findings, in contrast to O'Keeffe et al, indicated that socially interactive technologies did not overlap with offline social networks and that socially isolated adolescents were less likely to use SITs. Despite variable findings in these studies, social media is a moving target with technology always changing.

#### **Social Networks**

This segues into an interesting phenomenon researched by Damon Centola, who found that individual behavior adoption was more likely to occur when participants within the same social network practiced the same behavior (social reinforcement). (Centola, 2011) The behavior also became more widespread within a clustered-lattice network than over random networks. Centola even suggested that public health interventions would be more effective in targeting clustered residential networks rather than focusing on casual contact networks, where disease typically spreads more quickly.

An interesting approach to social media relates to homophily – the similarity of social contacts. Essentially, homophily can increase adoption of new health behaviors and especially for those in most need of behavior. (Centola, 2011; Shah, 2015) Centola's work demonstrated that homophily can allow a behavior to spread effectively across a heterogenous population but leveraging the exposure to individuals with more health concerns, and that the likelihood of healthy practices can be increased over dyadic ties. In other words, for those in need of adoption of healthy behaviors, it may be a function of the composition of their social networks and less dependent on their own reluctance to make a change. Centola's work demonstrated that homophily can allow a behavior to spread effectively across a heterogenous population; by

focusing on the individuals with more health concerns, the likelihood of their practicing healthy behaviors can be doubled if they are partnered with someone who practices the healthy behavior. In other words, those who need to adopt healthy behaviors have a better chance of changing if they interact with people who already practice healthy behaviors, rather than being dependent on their own resolve to make a change.

In keeping with this concept, Diehr et al. (Diehr et al., 2011) conducted an experiment that focused on the stages of change for smokers but included never smokers and dead segments (those who had died from smoking) of the population. The study identified that to maximize the nonsmoking life expectancy instead of the healthy life expectancy, the best intervention at the individual level may not actually be the best decision at the population level. The focus on a smoker is to stop their smoking and typically, attention is provided at specific stages of a smoker's readiness to quit. Since public health has long-term objectives, and it cannot provide interventions at all stages for economic reasons, the focus must be on the intervention that will yield the highest nonsmoking life expectancy. An intervention that focuses on 'never smokers' will generate the highest nonsmoker life expectancy. This approach of focusing on the 'healthy' population conceptually works well with Centola's concept of homophily because smokers and non-smokers will both receive the public health intervention (remember, the intervention is delivered at a population level.) This approach of focusing on the 'healthy' population conceptually works with Centola's concept of homophily; his premise is that individual behavior adoption would be socially reinforced among participants within the same social network.

#### Social Media and AI/AN

Social media is everywhere – accessible with cell phones and computers, it is truly a ubiquitous phenomenon. Rushing (Rushing and Stephens, 2011) quantified the use of technology-based interventions targeting American Indian/Alaska Native (AI/AN) youths living in Pacific Northwest tribes and urban communities, and identified patterns in their health information-

seeking and media preferences. AI/AN youth, similar to youth in general, presented patterns of technology use with 75% using the Internet and 78% using cell phones. Not unlike young adults who comprise almost half of cell Internet users, AI/AN youth are believed to conduct most of their online browsing using their phone. (Scott and Chur-Hansen, 2008)

Interventions delivered via text message offer a number of compelling advantages. Mobile phones and text messaging have several features that are unparalleled by any other technology: they are portable, real-time, affordable, asynchronous, location independent, time independent, discreet, private, personal, message storable, one-to-many capacity, interactive, bi-directional, independent of socio-economic status, and above all, convenient. With these qualities, and given the penetration of cell phones within the United States (penetration rate in the United was 78.1% in 2013, estimated to be 80.1% in 2015 and 81.5% in 2018.) (Sotero, 2006; Statista, no date), it becomes an optimal tool for public health.(Rosenberg, 2013; OMH, no date) As cell phones have become ubiquitous among U.S. teens, text messaging has become a promising avenue to promote adolescent sexual health. (Bryant, Sanders-Jackson and Smallwood, 2006; Lenhart, 2012; OMH, no date)

Text messaging offers users privacy and discretion (Perry *et al.*, 2012; OMH, no date) which is especially suitable for sexual health, often a sensitive subject for young people. Text messages can also be disseminated across large geographic regions with ease, while maintaining intervention fidelity. (Allison *et al.*, 2012; Shegog *et al.*, 2013; UNESCO, 2014; OMH, no date) Additionally, over 90% of all SMS messages are read within three minutes of being received (Card *et al.*, 1996; Bearinger *et al.*, 2007; Hindin and Fatusi, 2009; Collin, 2015). Given an average SMS open rate of 98% (versus 22% for email), and the accessibility of any mobile device to receive text messages (Collin, 2015), short message service (SMS) has an incredibly wide reach. And given the limited length of SMS, most messages are read in their entirety unlike many email messages. (Collin, 2015) Other studies have also shown that populations of both

lower socioeconomic status and poorer health have higher cell phone penetration (Koivusilta, Lintonen and Rimpelä, 2007; Lajunen *et al.*, 2007), which could facilitate public health efforts to promote and improve the health of Americans.

## **Community-Based Participatory Research**

Intervention studies have historically been designed by an etic (outsider's) perspective. (Gittelsohn *et al.*, 1999; Hernández, 2000) The outsider has most likely done their homework, and has expanded his frame of reference to encompass as broad of a viewpoint that is possible. However, the insider's perspective still needs to be considered – it can inform investigators of issues that are not always obvious. This is what formative research is – "research designed to obtain both viewpoints before developing an intervention in a target population." (Gittelsohn *e al.*, 2006) Formative research has other names – needs assessment (Gittelsohn *et al.*, 1999; Hernández, 2000), pre-program research (Gittelsohn *et al.*, 1999) developmental research (Gittelsohn *et al.*, 2006; Hernandez, 2000) – and all collect information to inform program design. Data collection methods can include focus-group discussions, in-depth interviews, surveys and much more. (Gittelsohn *et al.*, 2006) The information collected during the formative research phase should resolve intervention design questions. (Gittelsohn *et al.*, 2006)

One methodology used in formative research is community-based participatory research, where collaboration is key between research scientists and the study community. Community-based participatory research (CBPR), also known as participatory action research (Kemmis and McTaggart, 1988) or soft system approaches(Baldwin *et al.*, 1996; Albarracín) - all recognize and build on community strengths and resources. These strengths and resources – organizations, social networks, and individual skills, are used to address identified concerns. (Brown, DiClemente and Park, 1992; Israel, 2013) CBPR nurtures partners to build capacity and learn together, fostering an exchange of skills and knowledge. By recognizing that all parties bring a diversity of experiences, expertise, perspectives, and skills to the table, community issues are

approached with a collaborative, concerted effort. (Israel, 2013)Researchers become partners with the participants and share insights towards a particular issue. CBPR also integrates cultural aspects of the community (Baldwin *et al.*, 1996) which can lead to more accepting outcomes.

Cultural tailoring has become a focal point in delivering public health services, becoming the building blocks in sharing normative values, and understanding and relating issues of cultural relevance in health. (Rock, 2005; Airhihenbuwa, Ford and Iwelunmor, 2014) One of the driving forces behind cultural sensitivity can be attributed to the gaps in access to health care services and prevention measures. (Temin et al., 1999; Dutta, 2007) By including cultural sensitivity in developing messages or service programs, the strategy can effectively respond to the cultural characteristics of a community, and promote behavior change within the community as a whole. (Dutta, 2007) Ultimately, involving the community in developing solutions to problems results in their becoming engaged and invested in resolving health needs/issues within the community.(Dutta, 2007) Culture is not a trivial issue. A good example of conflicting cultural practices is direct eye contact. It is a common teaching that direct eye contact is a reflection of effective, engaged conversation. However, among elders and traditional American Indian/Alaska Natives, direct eye contact can be disrespectful and looking down is a form of respect and interaction. (Pharmacists, no date) The use of the word 'lonely' is another example where there can be lack of cultural awareness. When used in the Northern Plains, bilingual Native patients can be describing a form of depression because to them, it can refer to a feeling of social detachment from their family or community. (Shore and Manson, 2010) Understanding these cultural differences can help lessen the gap in disparities in health care, providing a forum where health conversations can happen without cultural differences thwarting efforts. (Clark, 2001)

#### **Health Behavior Theories**

Health behavior theories are often the launching pad for programs that aim to change health behaviors. The theories provide the guidance for designing how to inform and promote healthy practices. Such an approach is no different for sexual health, which is essential to the overall health and well-being of every individual.(Glanz, Rimer and Viswanath, 2008) Practicing good sexual health indicates an understanding and recognition of the responsibilities and outcomes that occur with sexual activity. (Glanz, Rimer and Viswanath, 2008)

A theory itself, "is a set of interrelated concepts, definitions, and propositions that present a *systematic* view of events or situations by specifying relations among variables, in order to *explain* and *predict* the events or situations."(Glanz, Rimer and Viswanath, 2008) Theories are abstract, and only start to make sense within the domain of public health and health behavior when they are applied to real topics, goals, and problems."(Glanz, Rimer and Viswanath, 2008) Theories become useful in the planning, implementation and evaluation of interventions – addressing the Why? What? and How? (Glanz, Rimer and Viswanath, 2008)Why aren't people following public health and medical advice, but instead jeopardizing their health? What do we need to know before developing and organizing an intervention program; what needs to be tracked, measured and compared in program evaluation? And how should programs be designed to make an impact on people and organizations? (Glanz, Rimer and Viswanath, 2008)

Essentially, theories "explain behavior and suggest ways to achieve behavior change. (Glanz, Rimer and Viswanath, 2008)

Concepts are the building blocks of a theory – they can stand on their own outside of a theory. When a concept is applied in a particular theory, it is called a construct. A simple example would be the concept of a shirt – it is a generalized abstraction because a shirt has texture, size, color and other characteristics. But when you think of a shirt, you classify it into two groups: shirts and everything else.(Sabet, 2015) A construct would be clothing because it encompasses many little concepts – shirts, pants, ties, and so on.(Sabet, 2015)

To instigate change in behavior, there are different theories and many share constructs.

In this study, we considered five different constructs: knowledge, attitude, intention, self-efficacy, and behavior.

"Clearly, no knowledge is more crucial than health knowledge." (Allensworth, 2015) Yet, knowledge is not enough to affect change in behavior. (Coates *et al.*, 1988)People need a heightened awareness and knowledge of their risks before any self-directed change is going to happen. (Bandura, 1990) Information alone does not exert as much influence on poor health behavior, as can be seen in the continued existence of cigarette smoking despite its link to cancer, respiratory disorders and heart disease, and in intravenous drug use, a major contributor to the continued transmission of the AIDs virus. (Bandura, 1990) Information provides the reasons to change people's behavior but skills and the belief in the ability to execute a given behavior (Bandura, 1990) is necessary to effect change.

Attitude is another construct that influences behavior. It used to be a basic assumption that attitudes "guide, influence, direct, shape, or predict actual behavior." (Ajzen, 1974; Gross and Niman, 1975) But it was later learned that attitudes did not seem to support behavior consistently. (Wicker, 1969) For example, supporting a particular political party does not always result in a vote for that particular party.

Fishbein and Ajzen (Fishbein and Ajzen, 1975)proposed a different approach for measuring attitude. They suggested that beliefs were the building blocks of attitude and that overall attitude was a function of the sum total of those beliefs For example, your attitude towards a particular political party could be an overall sum of your beliefs on their stance on universal healthcare (positive), open immigration (positive) and implementation of a state-wide sales tax (negative.)

Furthermore, *attitude to an object* is different from the *attitude to the behavior towards that object*. (Fishbein and Ajzen, 1975) Supporting a political party (the object) does not equate to

voting at the next election (the behavior towards the object). (Holdershaw and Gendall, 2008) So if the object is to predict whether an individual is going to vote for a political party (attitude towards object), then it is the attitude towards voting that must be measured (attitude to behavior towards object.) (Ajzen, 2005)

At this point, it should be obvious that attitude does not directly predict behavior. However, attitude does strongly influence intention, another construct that was examined in this study. Although there are various theories on intention, Ajzen and Fishbein's conceptualize attitude as one factor that influences intention, the other being the norms that are shared by the people around an individual. (Holdershaw and Gendall, 2008). Ajzen and Fishbein also consider intention as the best predictor of actual behavior but qualify that time can affect intention because the circumstances can change. (Fishbein and Ajzen, 2003) For example, intention to drive to the post office to mail your ballot can change if a snowstorm arrives and you can't drive.

Skills and beliefs are the foundation of self-efficacy. Transforming knowledge into applicable self-protection against STDs/HIV infections involves social skills and a level of personal confidence to exercise control over sexual situations. (Bandura, 1990) "Managing sexuality involves managing interpersonal relationships." (Gagnon and Simon, 2009) The conflict that arises with safer sex practices is that self-protection can clash with personal interactions and feelings. (Bandura, 1990) "In these interpersonal situations the sway of coercive power, allurements, desire for social acceptance, social pressures, situational constraints, and fear of rejection and personal embarrassment can override the influence of the best of informed judgment." (Bandura, 1990) If self-efficacy is weak, the interpersonal demands and other affective factors can increase the possibility of risky sexual behavior.(Bandura, 1990) Perceived self-efficacy seems to be the best predictor of sexual risk-taking behavior.(Bandura, 1990)

In public health communication campaigns, fostering the adoption of healthful practices by raising beliefs in personal efficacy is effective in changing behavior. (Bandura, 2004) Rather

than instilling fear, enabling people with the belief that they could manage and take charge of their health habits is promoting self-efficacy. (Bandura, 2004) The confidence to use a condom is very much influenced by self-efficacy and people who have strong self-efficacy are more likely to engage in safer sexual behaviors. (Bandura, 2004) Within the context of condom use, Ajzen and Fishbein's theories of reasoned action predict that the extent to which people use condoms is a function of their intention to use them. Intention, in turn, is dependent upon attitudes and social norms. (Albarracín, Kumkale and Johnson, 2004) Though intention and recent behavior are significant to condom use, condom use perception by friends (social norms) are very important. (Brown, DiClemente and Park, 1992) Other studies have shown that condom use is also influenced by knowledge about reproductive health, (Prata, Vahidnia and A. Fraser, 2005) STIs, use of contraceptives, and health services (Parkes, Wight and Henderson, 2004; Prata, Vahidnia and A. Fraser, 2005; Kirby and Lepore, 2007; Socialstyrelsen, 2008; Small *et al.*, 2009). Youth with less or no knowledge of how to use a condom are less likely to use a condom than youths who have accurate knowledge.(Rock, 2005)

In terms of STI testing, a lack of knowledge with respect to sexual risks and symptoms of STI is believed to contribute to low risk perceptions. (Temin *et al.*, 1999) Perceived threat of having an STI was low for sexually active adolescents and that may have contributed to low STI testing. (Wolfers, de Zwart and Kok, 2011) The Integrative Model of Behavioral Prediction (Fishbein, 1998) by Fishbein incorporates aspects from the Theory of Reasoned Action (TRA) (Glanz, Rimer and Viswanath, 2008), the Theory of Planned Behavior (TBP) (Glanz, Rimer and Viswanath, 2008), Social Cognitive Theory (SCT) (Glanz, Rimer and Viswanath, 2008) and the Health Believe Model (HBM) (Glanz, Rimer and Viswanath, 2008), suggesting that sufficient coping skills to address behavioral constraints can lead to intention to perform a given behavior. Such intention is influenced by attitude, perceived norms and self-efficacy. (Wolfers *et al.*, 2010)

### **Text Message Interventions**

Given the rise in cellphone availability, texting has been increasingly deployed in recent years to promote smoking cessation (Obermayer et al., 2004; Bramley et al., 2005; Rodgers, 2005), weight loss (Joo and Kim, 2007; Daugherty et al., 2012), and physical activity, (Thompson et al., 2014; Collins et al., 2014) with varying levels of success. STOMP (Stop Smoking Over Mobile Phone) exemplified the second generation of texting messaging by introducing an interactive dialogue, opposed to the one-way communication that occurs with information delivery or alerts. (Fogg and Adler, 2009) Participants in this study were 15 years and older with the desire to stop smoking. This was a randomized control trial that had over 1700 participants from New Zealand, split into two groups where one group received the intervention of text messages while the control group did not. Messages provided support reinforcement, advice, and distractions. Depending on what the participant sent to their friend "STOMP," words such as CRAVE elicited responses suggesting tactics to help manage the craving for a cigarette, offering encouragement when needed most. This program was very successful with a 28 percent quit rate for the intervention group compared to the 13 percent quit rate for the control group. This program was disseminated globally as a stop smoking intervention program. Another study addressed smoking among college-aged students, employing text messages to deliver a smokingcessation intervention. Twenty-two percent (22%) quit based on a seven-day prevalence criterion. (Obermayer et al., 2004)

A meta-analysis of texting interventions for weight loss showed a mean loss of -2.56 kilograms. (Siopis, Chey and Allman-Farinelli, 2014) One study randomized people into one of two groups – one group received printed material and another received customized SMS and SMS messages, printed materials and monthly phone calls. (Patrick *et al.*, no date) The evidence indicated that text message interventions could promote weight loss but long term efficacy studies are still needed. (Patrick, Raab and Adams, 2009; Siopis, Chey and Allman-Farinelli, 2014)

Texting for exercise has also shown potential success with adults but with children, adults may need more intensive interventions to promote exercise to meet national recommendations.(Newton *et al.*, no date)

Other studies have used texting to promote diabetes self-management. One of the challenges of maintaining contact within a clinical setting, whether in-person or by phone, is the time demand - it can be both costly and impractical. (Franklin *et al.*, 2003) Text messaging was successful in engaging and supporting youth with diabetes and provided a trusted medium for communication with providers.

Texting for sexual health has also been successful. SexINFO, a text-based messaging service based in San Francisco, has shown success in promoting sexual health and clinic referrals. (D. Levine et al., 2008) Several other studies have employed text messaging to promote or evaluate sexual health awareness. (Lim et al., 2008; D. Levine et al., 2008; Cornelius and Lawrence, 2009; Gold, Lim, Hocking and Keogh, 2010; Gold, Lim, Hocking, Keogh, et al., 2010; Rushing and Stephens, 2011; Lim et al., 2011; Perry et al., 2012; Hensel, 2012; Sheoran et al., 2014) and findings looked promising. Lim, in 2008, discussed how SMS communications were being used between sexual health clincs and patients, for partner notification and contact tracing, for contraception reminders and sexual health promotion and education. However, very few of these applications had been evaluated. SexINFO (D. Levine et al., 2008) received greater than expected responses with at-risk adolescents accessing sexual health services, and preliminary evaluations indicated "positive associations between demographic and geographic risk factors for STIs and campaign awareness." African American adolescents were receptive to text messaging enhancing an HIV-prevention curriculum in a focus-group assessment. (Cornelius and Lawrence, 2009) Two studies by Gold et al confirmed that SMS was a feasible, population and effective method for sexual health promotion, providing an opportunity to engage a large number of individuals at low cost. (Gold, Lim, Hocking, Keogh, et al., 2010; Gold, Lim, Hocking and

Keogh, 2010) In Western Australia, the Department of Health used SMS as part of their multimedia chlamydia awareness campaign, to educate and inform young people. (Wilkins, 2007)

#### **Design of Text Messages Based on Literature Review and Formative Work**

Published literature was consulted to design the series of text messages to improve sexual health knowledge, attitude, self-efficacy, intention, and behavior among AI/AN teens and young adults (ages 15-24), and the series of text messages to evaluate the efficacy of the intervention. One of the biggest challenges in the planning and execution of this study was to limit recruitment messages, consent messages, pre-post survey questions, and intervention messages to 160 characters – the maximum limit for a text message. And to design pre-post survey questions that included unique shortcode options needed to capture participant responses.

Hookup (www.teensource.org/hookup), a statewide text-message sexual health information and clinical referral service for youth, launched in April 2009 by the California Family Health Council, provided preliminary content for the sexual health text messages used. Another website – It's Your (Sex) Life (http://www.itsyoursexlife.com/stds-testing-gyt), which promotes getting tested for STDs, provided additional content for the study. Both sites offer information on birth control, STIs, relationships – areas that youth might find confusing to navigate and need information.

## Survey Question Development

The pre-post survey questions were particularly challenging to design because to date, most validated instruments used to assess sexual health knowledge, attitude, intention, self-efficacy or behavior have included 5-10 questions per construct. Specific parameters were required for this part of the study as well – only six questions per topic (condom use and STI/HIV testing) could be asked because high drop-off beyond six questions was anticipated.

The first condom test question addressed condom use knowledge. To reduce failures in using a condom and increase condom use, knowledge of how to use a condom is important. (Rock, 2005; Glanz, Rimer and Viswanath, 2008) In reviewing the literature, any validated measure that could reflect condom use knowledge was considered. Bankole (Bankole *et al.*, 2007; Glanz, Rimer and Viswanath, 2008) selected three questions from Indiana University's Kinsey Institute for Research in Sex, Gender and Reproduction's Condom Use Errors Survey for Adolescent Males, that identified most clearly knowledge on condom use, "Condom should always be put on before sexual intercourse starts"; "condoms should be put on the penis only if the penis is fully erect or stiff"; and "condom can be used more than once". This study used the single question "condoms should be put on the on the penis only if the penis is fully erect or stiff" since it was identified to be the most basic query, using terminology that was at least at the grade 8 level, and could reflect knowledge without necessarily having had actual sexual experience.

The second question assessed condom use attitude about the importance of condom use by asking, "Condoms should always be used if a person has sex, even if the 2 people have known each other a long time." This measure came from Basen-Engquist et al's study on condom use consistency but was modified slightly from the original, "I believe a condom should always be used if a person my age has sex, even if the two people know each other very well." (Basen-Engquist *et al.*, 2015)

Under the same theories of TPB and TRA, behavioral intentions influence behavioral actions. (Bandura, 1990; Brown, DiClemente and Park, 1992; Redding *et al.*, 2000) Two questions that measured intention to use condoms, "If I were to have sex, I would use a condom every time or have a partner use one to protect myself from getting STI/HIV," and "Honestly, if I were sexually active, I probably would have intercourse without protecting myself against AIDS".) (Brown, DiClemente and Park, 1992) They were revised as, "If you decided to have sex, how likely is it that you'd get your partner to use a condom? Text back DEFINITELY, POSSIBLY, or

UNLIKELY" and "If you decided to have sex, how sure are you that you would use a condom EVERY time, to protect yourself from getting an STD or HIV? Text back SURE or UNSURE."

The last two questions regarding condom use were to assess behavior. The fifth question asked if the participant had had sex in the previous three months. If the response was yes, then the follow-up question asked if a condom had been used, with offered responses of never, sometimes, or always. This question was also used in Bankole's study to assess consistency of condom use. (Bankole *et al.*, 2007) This provided an opportunity to assess whether a change in behavior had occurred over the six-month study period.

With respect to STI/HIV testing questions, the first two questions focused on self-efficacy based on Westmaas et al's (Westmaas et al., 2012) study for determinants for intention to get tested for STI/HIV. Self-efficacy represents the belief in one's ability to do a specific task. Although the measure used four questions to measure self-efficacy, 'I think I am able to ... find information about how and where I can get tested, visit the testing facility, discuss my sexual behavior with a nurse, make an appointment to get tested)'," we used only two questions and revised them as "True or False? I am able to make an appointment to get tested for STDs" and "How sure are you that you could talk to your healthcare provider about your sexual behavior? Text back 'SURE or UNSURE'." Since the target population of AI/AN teens and young adults included those on reservations, it was felt that both rural and urban living would have obvious sites where information could be obtained about STI/HIV testing, and where to go for testing. It was more important to assess their level of self-efficacy with actually being able to make an appointment and to be able to speak to a provider, given the limited number of questions that could be asked through the texting study.

The third question addressed attitude towards both condom use and STI testing.

Borrowed from Crosby and Danner's study in 2008 (Crosby and Danner, 2008), participants were asked to agree with whether 'It would be a big hassle to do the things necessary to completely

protect yourself from getting an STD." Since the statement was felt to be vague, it was modified to "It would be a big hassle to use a condom & get tested for STDs to completely protect myself from getting a STD."

The fourth question looked at intention for STI/HIV testing, taken again from Westmaas et al's study (Westmaas *et al.*, 2012) as a predictor of behavior. The original statement, 'I intend to get tested (again) for (STI – HIV) in the coming six months' was modified to better fit with youth, "How likely are you to get tested for STDs the next time you change partners? Text back 'DEFINITELY, POSSIBLY, or NOT LIKELY'." Youth's ability to plan ahead are among the last of basic brain functions to mature (Holdershaw and Gendall, 2008) so this question within a six month plan seemed unrealistic.

The final two questions for STI/HIV testing related directly to behavior, asking "Have you ever been tested for HIV or STDs? Text back 'NEVER, ONCE, or MORE' " and if the response was 'once' or 'more, ' a follow-up question was sent, "When did you last get tested? Text back TIME followed by how long ago you were tested. Like 'TIME 2 months ago or TIME 1 year'." This allowed an opportunity to measure whether STI/HIV testing occurred over the sixmonth study period.

# **Consent and Assent**

One of the unique aspects of this study was the approach used for all phases of the study: recruitment, consent, intervention, incentives and data collection were all conducted using text messaging. Consent by text messaging raised some concerns with youth assent and parental consent, especially given that the subject matter was sexual health. The National Commission released recommendations on research involving children that included the following statement:

"A number of states have specific legislation permitting minors to consent to treatment for certain conditions (e.g., pregnancy, drug addiction, venereal diseases) without the permission

(or knowledge) of their parents. ... Assent of such mature minors should be considered sufficient with respect to research about conditions for which they have legal authority to consent on their own to treatment." (National Commission, 1977; Santelli, 2003; Holdershaw and Gendall, 2008; R. J. Levine, 2008)

Rogers et al (Rogers, D'Angelo and Futterman, 1994) proposed guidelines for adolescent participation in research if investigators: designed the study for anonymity, ensured privacy and confidentiality of study participants, and implemented a strategy to interact with community representatives and submit reports to the IRB on an annual basis. In keeping with this strategy, We R Native offered to share information about the study and methods through the Indian Health Service (IHS) STD/HIV listsery, the NPAIHB's Health News and Notes newsletter, blog posts on the *We R Native* website, and other appropriate channels.

Chapters 3-5 present the research and findings from this study as three separate and distinct manuscripts.

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# **Chapter 3: Designing a Text Messaging Intervention for American Indian Teens and Young Adults: Texting 4 Sexual Health**

# **Abstract**

**Purpose:** To design a text message intervention that could be delivered to improve sexual health outcomes among American Indian and Alaska Native (AI/AN or Native) teens and young adults (15-24 years old) using the We R Native text messaging service, and to design a series of text message survey questions that could be used to evaluate the impact of the intervention.

**Methods:** We designed a series of theory-based text messages and survey questions to promote and measure condom use and testing for sexually transmitted infections (STI/STD). We carried out formative research activities with 60 AI/AN youth living throughout the U.S. to refine the implementation plan and tailor the intervention messages to the needs and concerns of Native teens. Iterative advisory groups and paper-based surveys elicited feedback on the proposed messages and survey questions. A brief intervention pilot was then used to test the functionality of the text messaging software.

**Results:** Grammar, spelling, punctuation, and frequency of text messages were all refined, based on youth feedback. Privacy and confidentiality were noted as important considerations that must be disclosed during the recruitment process to ensure participation. Iterative formative research with the target audience improved the content and credibility of the text messages and survey questions, ensuring relevance, acceptability, and interest in participating in the intervention.

**Conclusion:** The use of theory-based messages aligned the intervention to known behavior change constructs. The final messages and questions addressed the sexual health needs of AI/AN youth of varying genders, ages, and sexual orientations, while maintaining cultural relevance and sensitivity.

# **Implications and Contributions**

To our knowledge, no previous studies have evaluated the impact of a behavioral intervention delivered entirely via text message, including participant recruitment, consent, intervention messaging, and pre-post surveys. In preparation for this, our team carried out formative research to design a culturally sensitive text messaging intervention on sexual health for AI/AN youth, a high-risk, underserved population.

# Introduction

The Centers for Disease Control and Prevention (CDC) reports an estimated 20 million new sexually transmitted infections (STIs) occur annually, including human immunodeficiency virus (HIV), with more than 50% affecting young people between the ages of 15-24 years (Centers for Disease Control, 2014b).

Although all ethnic and racial groups are affected, American Indian and Alaska Native (AI/AN) youth experience notable disparities related to sexual health (Centers for Disease Control and Health Service, 2014; Centers for Disease Control, 2014b). In 2013, AI/AN girls had the third highest teen birth rate in the U.S. (31.0 per 1,000 compared with 26.5 per 1,000 nationally) (Martin *et al.*, 2015) and AI/AN youth 15-24 years experienced the second highest rates for chlamydia and gonorrhea (Centers for Disease Control, DSTDP and NCHHSTP, 2014) among all ethnic and racial minorities. These disparities underscore the need for effective sexual health interventions for AI/AN youth.

Several technology-based interventions have been shown to improve sexual health outcomes for teens and young adults, particularly those designed to increase youth's knowledge, attitudes, self-efficacy and intentions related to condom use and STI testing (Rushing and Stephens, 2011; Guse *et al.*, 2012). Few such interventions, however, have been purposefully designed for, or rigorously evaluated with AI/AN teens and young adults, for whom mainstream sexual health messages are often inappropriate and ineffective (Baldwin *et al.*, 1996; Chino and DeBruyn, 2006; Gilley, 2006; Rushing and Stephens, 2011; Centers for Disease Control, 2014b). Western frameworks typically do not incorporate the more holistic view of adolescent health that AI/AN cultures embrace, including emotional, physical, social, and spiritual dimensions (Rushing and Stephens, 2012; Centers for Disease Control and Health Service, 2014; Centers for Disease Control, 2014b). Native communities often celebrate new life regardless of the parent's age – a

perspective that conflicts with conventional messaging related to teen pregnancy (Rushing and Stephens, 2012; Martin *et al.*, 2015). Sexual health messaging is thus highly nuanced in Indian Country, requiring thoughtful consideration. New media technologies offer great promise for filling this gap in ways that are familiar, accessible, and culturally-appropriate for AI/AN youth (Rushing and Stephens, 2012; Centers for Disease Control, DSTDP and NCHHSTP, 2014).

As cell phones have become ubiquitous among teens, text messaging has become a promising avenue to promote adolescent sexual health (Bryant, Sanders-Jackson and Smallwood, 2006; Rushing and Stephens, 2011; Guse *et al.*, 2012; Lenhart, 2012). Sexual health is often a sensitive subject for young people, and text messaging offers users privacy and discretion (Perry *et al.*, 2012; National Center for HIV/AIDS Viral Hepatitis STDCenters for Disease Control, 2013; Centers for Disease Control, 2014a; 2014b). Interventions delivered via text message thus offer a number of compelling advantages. Mobile phones and text messaging are portable, real-time, affordable, asynchronous, personal, possess one-to-many capacity, interactive, and above all, convenient. With these qualities, and given the penetration of cell phones within the United States (78.1% in 2013, estimated to be 80.1% in 2015 and 81.5% in 2018) (Centers for Disease Control and Health Service, 2014; Statista, no date), cell phones and text messaging have become optimal tools for health education.

Text messages can be disseminated across large geographic regions with ease, while maintaining intervention fidelity (Allison *et al.*, 2012; Guse *et al.*, 2012; Shegog *et al.*, 2013; Martin *et al.*, 2015). Of added benefit, over 90% of all short message service (SMS) messages are read within three minutes of receipt (Centers for Disease Control, DSTDP and NCHHSTP, 2014; Collin, 2015). Given an average SMS open rate of 98% (versus 22% for email), and the "anytime, anywhere" capability of mobile devices to receive text messages (Rushing and Stephens, 2011; Guse *et al.*, 2012; Collin, 2015), interventions delivered via SMS have the potential to reach an incredibly large audience. And with a maximum length of 160 characters, most SMS messages

are read in their entirety (Baldwin *et al.*, 1996; Chino and DeBruyn, 2006; Gilley, 2006; Rushing and Stephens, 2011; Collin, 2015). An SMS intervention tailored to the unique needs and culture of AI/AN youth has the potential to improve sexual health outcomes for AI/AN youth.

The primary aims of this study were to design a sequence of text messages that could be delivered to improve sexual health outcomes among AI/AN teens and young adults (ages 15-24) using the We R Native text messaging service, and to develop a series of text message survey questions that could be used to evaluate the efficacy of the text messaging intervention. The team also sought to design messages that would address a wide range of perspectives and sexual readiness levels, by pilot testing messages with AI/AN youth of varying genders, ages, and sexual orientations. Given the heterogeneity of youth expected to participate in the study, the messages needed to resonate with young adults who were: male or female, sexually active or not yet sexually active, and of differing sexual orientations (heterosexual, lesbian, gay, bisexual, transsexual, two spirit1 (LGBT2S).

To our knowledge, no previous studies have evaluated the impact of a behavioral intervention delivered entirely via text message, and no previous studies have evaluated text messaging as a sexual health promotion strategy among AI/AN teens and young adults. In preparation for this, our team carried out formative research to design a culturally-sensitive text messaging intervention for this high-risk, underserved population.

# **Methods**

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The study – Texting 4 Sexual Health – was conducted in partnership by the Northwest Portland Area Indian Health Board (NPAIHB) and Oregon Health & Science University (OHSU), using We R Native, a multimedia health resource for Native teens and young adults. Established in 2012 by the NPAIHB, the service includes an interactive website (www.weRnative.org), a text

<sup>&</sup>lt;sup>1</sup> Two-spirit is a gender identity recognized by some AI/AN tribes, in which both a masculine and feminine spirit are embodied by the same person (thewhiterabbit13, 2011; Rushing and Stephens, 2012).

messaging service (Text NATIVE to 24587, with over 2,500 subscribers nationwide), a Facebook page, and a YouTube channel. We R Native offers over 350 health and wellness pages covering a variety of topics important to Native youth, including sexual health (Rushing and Stephens, 2012; NPAIHB, no date). Through these platforms, We R Native had an existing relationship with Native teens and a working SMS provider from which to recruit study participants and carry out intervention activities.

The research protocol received Institutional Review Board (IRB) approval from both OHSU and the Portland Area Indian Health Service IRB (#476310 – Formative Research to Design Sexual Health Text Messages for AI/AN Teens and Young Adults). Thereafter, OHSU deferred oversight to the PA IHS IRB to monitor study progress. All participants received \$15 gift certificates as compensation for their feedback and advisory group participants received a \$50 check as compensation for their time in testing and surveys.

# Formative research

The research team consulted the published literature to design a series of text messages to improve sexual health among AI/AN teens and young adults (ages 15-24), and a series of text messages to evaluate the efficacy of the SMS intervention. To enhance their effectiveness, the messages were designed to address factors known to affect health behavior: knowledge, attitude, intention, and self-efficacy. The conceptual framework blended insights from the health behavior model, social cognitive theory, and the theory of planned behavior (Glanz, Rimer and Viswanath, 2008; Rushing and Stephens, 2012). Among the constructs, knowledge is necessary but not sufficient to effect behavior change; attitude and self-efficacy are strongly linked to intention, which is a strong predictor for behavior.

# SMS message and survey development

Hookup, a statewide text-message sexual health information and clinical referral service for youth, launched in April 2009 by the California Family Health Council, provided preliminary content for the sexual health text messages (see: www.teensource.org/hookup). Another website – It's Your (Sex) Life, which promotes getting tested for STIs – was also consulted (see: www.itsyoursexlife.com/stds-testing-gyt). Both sites offer age-appropriate information on birth control, condoms, STIs, and healthy relationships – areas in which AI/AN youth have expressed interest and need for more information (Bryant, Sanders-Jackson and Smallwood, 2006; NPAIHB, 2011; Rushing and Stephens, 2012; Lenhart, 2012).

For each theory-based behavior change construct (knowledge, attitude, intention, and self-efficacy), we drafted 1-3 corresponding intervention text messages. To evaluate the efficacy of the text messages, we selected six questions to assess condom use (Table 1) and six questions to assess STI/HIV testing (Table 2) that were derived from validated survey tools. The questions were then reformatted for SMS delivery (e.g. condensed to 160 characters) with unique response options, a step that was necessary to capture participant responses and trigger the next survey question in an automated response sequence.

Table 1: Condom use behavior change constructs, survey questions, and related text messages

Behavior Change Construct	Survey Question	Related Text Messages
Knowledge (Bankole et al., 2007)	True or False? A condom should be put on the penis only if the penis is fully erect or stiff. Text back TRUE or	A condom can only be used once, and must be put on BEFORE genital contact. DON'T buy excuses. No condom, No sex.
	FALSE	Condom, 1 to som
Attitude (Basen-Engquist et	Condoms should always be used if a person has sex, even if the 2 people have known	Still wondering how to use a condom correctly? Ask Auntie will show you how: https://youtu.be/gwr4inj5jb4
al., 2015)	each other a long time. Text back AGREE or DISAGREE	now. https://youtu.oc/gwi4nij5j04
		Think using a condom will kill the mood? Getting an STD will kill the mood too! It's easier to enjoy sex when it's safe. :)
		Embarrassed 2 get condoms? If you go to a store, pick out other items first.  Order them online Use our gift card - Even Amazon.com sells them:)
Intention	If you decided to have sex, how likely is it that you'd get	You should be able to talk to your partner about sex & contraception. It
(Brown, DiClemente and Park, 1992)	your partner to use a condom? Text back DEFINITELY, POSSIBLY, or UNLIKELY	can be weird, but if you're not able to talk about it, you may not be ready for sex.
	If you decided to have sex, how sure are you that you would use a condom EVERY time, to protect yourself from getting an STD or HIV? Text back SURE or UNSURE	No glove, no love. Use a condom EVERY time for safer sexvaginal, anal and even oral sex.

Behavior
(Bankole *et al.*, 2007) How many times have you had We all care about protecting ourselves sex in the last 3 months? Text and the ones we love. Condoms protect back NONE, ONCE, or MORE against pregnancy and STDs when used every time you have sex.

How often did you use a condom? Text back NEVER, SOMETIMES, or ALWAYS

If you're going to have sex, best thing to do is just put the condom on.

Nothing even needs to be said. Your partner will be relieved not to bring it up first!

Table 2: STI testing behavior change construct, survey questions, and related text messages

Behavior Change Construct	Survey Question	Related Text Messages
Self-efficacy (Westmaas et al., 2012)	I am able to make an appointment to get tested for STDs. Text back TRUE or FALSE	Worried an adult will find out you got tested for STDs? Medical info is always kept private. If you want to know for sure, it's ok to ask at the clinic.
	How sure are you that you could talk to your healthcare provider about your sexual behavior? Text back SURE or UNSURE	Take control of your sex life. Ask your doctor to be tested for STDs and HIV. They don't always test for both. Reply MORE to determine your risk.
Attitude (Crosby and Danner, 2008)	It would be a big hassle to use a condom & get tested for STDs to completely protect myself from getting a STD. Text back AGREE or DISAGREE	Getting tested for STDs is as easy as peeing into a cup. Urine tests can check for the most common STDs.
Intention (Westmaas <i>et al.</i> , 2012)	How likely are you to get tested for STDs the next time you change partners? Text back DEFINITELY, POSSIBLY, or UNLIKELY	Nervous to ask your partner to get tested? Embrace the awkward! Try: "Heard 1 in 2 sexually active people will get an STD by age 25. I'd like us to get tested."
Behavior	Have you ever been tested for HIV or STDs? Text back NEVER, ONCE, or MORE - Remember all answers are kept private.	Schedule a confidential appontment at your tribal clinic. OR find a testing center near you@http://www.GYTNOW.or
	When did you last get tested? Text back TIME followed by how long ago you were tested. Like TIME 2 months ago or TIME 1 year	If you're having sex, consider getting tested for STDs at least once a year. Want to know more? Just text MORE

# Youth feedback

Because We R Native is available nationwide, the study team sought to garner feedback from AI/AN teens across the U.S. Four different venues attended by AI/AN youth agreed to participate in the study. Written permission was obtained from each site before soliciting youth feedback. All participants received a printed consent form. We requested and received permission to waive documentation of informed consent, because no other identifying information was collected from participants. We also requested and received a waiver for parental consent given that the subject matter posed no more than minimal risk to participants and that youth 15 years and older may legally obtain sexual health services without parental consent.

The paper-based survey took approximately 20 minutes to complete, and included mocked images of 43 text messages. Participants were asked to rate each intervention message as "cool, alright, or real bad," in addition to indicating whether or not the survey questions made sense. They were asked if they would respond to the proposed question or click on offered links. If survey respondents indicated the question did not make sense, they were asked to rephrase the question and provide edits to any messages that were "alright."

Participants were asked about acceptable frequency of messages from We R Native and the study. As part of the ongoing We R Native text messaging service, participants were already receiving one unrelated health message per week. The survey ended with two open-ended questions: What are your top three STI/HIV testing and condom questions? Do you have any other suggestions to help us improve the text messaging service?

# Software pilot test

During a two-hour University advisory group, participants used their own cell phones to test the functionality of the SMS message delivery software and test our intended data collection plan.

Messages were sent to each attendee to determine how long it would take to get messages from

different cell phone carriers, and how long it would take to receive their survey responses.

Participants were asked about their preferred survey sequencing and timing between questions.

After testing the functionality of the text messages, the University students were able to remove their phone number from our records by texting LEAVE to 24587.

#### Results

#### Formative Research

Altogether, sixty (n=60) AI/AN teens and young adults provided feedback on the intervention text messages, recruited from four venues across the U.S. Eight (n=8) youth were surveyed at the 2013 National Indian Heath Board Youth Summit, which took place August 23-26 at the Grand Traverse Resort in Traverse City, Michigan. Another thirty-one (n=31) youth were surveyed at the 2013 Native Youth Summit of Oklahoma September 21, 2013. Students at both venues reviewed a first draft of text messages, and responded to questions related to message relevance, appropriateness, and comprehension.

Fourteen (n=14) AI/AN young adults who attend a weekly Two Spirit Youth Group reviewed a second draft of the text message sequence. This group frequently reviews materials produced by the NPAIHB (e.g. health promotion posters, scripts, etc.), to improve their relevance for AI/AN LGBT2S youth.

Seven (n=7) AI/AN students at a local University participated in a Texting 4 Sexual Health advisory group that provided input on our proposed implementation plan, tested the functionality of the Mozeo software that would be used to deliver the intervention, and reviewed a third draft of the text message sequence.

# SMS Feedback and Message Development

After each round of review, qualitative data were systematically collected, transcribed, and analyzed. Recruitment messages, intervention messages, and survey questions were revised, based on youth feedback (Table 3).

Table 3: Message comments and revisions

Original Message	Comments	Revised Message
We R Native is conducting a study: Texting 4 sexual health. U are invited because ur 15-24 years old. Up to \$40 for ur time. Reply AGREE if u want to join.	-	We R Native is doing a research study: Texting 4 Sexual Health. The goal is to reduce STD/HIV rates among Native teens and young adults.
	"I think it would be better with correct grammar."	You must be AI/AN & 15-24 yrs. You will get 2 sexual health msgs per week for 3 months. All texts are private. Earn \$40 for answering 40 Q's over 6 months.
		We won't collect your name, just cell # to analyze results. To protect your privacy, you can delete our messages from your phone.
		Reply AGREE if you want to join. Reply LEAVE to quit. Go to http://mozeo.me/WoGe to learn more about the study and your rights.
If you decided to have sex, how sure are you that you could get your partner to agree to use condoms. Text back Very Sure, Sure, Unsure, or Very Unsure	"Capitalize choices"	If you decided to have sex, how likely is it that you'd get your partner to use a condom? Text back DEFINITELY, POSSIBLY, or UNLIKELY
	"I don't really like the options."	
Getting tested is as easy as peeing into a cup. Urine tests can check for the most common STDs. Native, Tested. Proud.	"The first line, getting tested for what?"	Getting tested for STDs is as easy as peeing into a cup. Urine tests can check for the most common STDs.
Have questions about ur relationship? Check out:		This message was removed because there was no immediate take home message for those who could not access

mozeo.me/cUPC the link

How many times have "I like the part How many times have you had sex in you had sex in the last 3 saying 'private' but the last 3 months? Text back NONE, ONCE, or MORE - Remember all months? Text back could also include "NONE, ONCE, or 'anonymous' saying: answers are kept private. MORE' - Remember all 'Remember all answers are kept answers are kept private. private & anonymous'" Thanks for your time. We'll text you your gift card soon. And to protect the privacy of your responses, delete our messages from your phone. Have you ever been Say 'private & Have you ever been tested for HIV or tested for HIV or STDs? anonymous' STDs? Text back 'NEVER, ONCE, or Text back 'NEVER, MORE' - Remember all answers are ONCE, or MORE' kept private. Remember all answers are kept private. Responded 'yes' to Thanks for your time. We'll text you participation only if your gift card soon. And to protect the privacy of your responses, delete our it says 'anonymous' messages from your phone. Happy Halloween! If "Eh, I don't know." Feeling lucky? Don't be so sure. You you don't get lucky CAN'T tell by looking if you or tonight don't get someone else has an STD. Many STDs tricked... treat yourself don't have any signs or symptoms. to a condom. "Hilarious!!! Love (Sent on St. Patrick's Day) it! Humor helps and sparks interest!"

#### Youth Feedback

Multiple respondents encouraged correct spelling and grammar in the intervention messages, capitalization of survey answer choices, and were critical of abbreviated spellings and improper grammar. Participants identified messages that lacked sufficient information. They also identified messages that failed to provide a take-home message for those who could not access supplemental web links. Privacy and anonymity were important to AI/AN young adults, as was humor when used in the proper context. Participants agreed that getting sexual health messages twice a week was an acceptable frequency.

#### Software pilot test

The University advisory group provided the most in-depth feedback on the study's design, testing its feasibility and functionality in a real world setting. The students had a variety of cell phone models (I-phone 5 and 5s, Android RSR Maxx and HTC) and carriers (AT&T, T-Mobile, Sprint, and Cricket). Using their phones to test message-delivery helped identify barriers to study participation. Some carriers do not allow text messages from short codes2. Delivery times varied between carriers, and in some cases, did not arrive at all during the testing period. This step helped verify our data collection procedures and participants' preferred message sequence.

#### **Discussion**

The formative research process successfully guided the design of an SMS intervention, and the content of text messages to address the sexual health questions and concerns of AI/AN youth. While reviewing draft messages, the most persistent comments related to grammar, spelling and format. As a credible health resource, We R Native was expected to use correct spelling and

 $<sup>^2</sup>$  Five or six digit numbers, known as short codes, are used to send and receive text messages from mobile phones (Twilio Help Center, 2015)

grammar. Abbreviations (4 = for, ur = your, u r = you are) were not highly regarded. Not all abbreviations were eliminated due to character limitations in text messaging, to maximize informational content, but messages were reworded to better reflect a trustworthy source. This feedback contrasted with findings from an Australian study, which found that informal SMS language resonated with their intervention audience (Bryant, Sanders-Jackson and Smallwood, 2006; Gold *et al.*, 2010; Lenhart, 2012).

Multiple comments also addressed message content or clarity. Relying on a link to connect users to more information was found to be inadequate, as not everyone had a smartphone or Internet access. Messages were revised to make sure that even those with links conveyed useful information. Messages referencing holidays or current events received mixed reviews. Some found them to be awkward while others loved the humor. Since there were more positive comments than negative, one message about STI testing on St. Patrick's Day was included in the series. All caps were also used to clearly distinguish possible survey response options.

The LGBT2S support group provided unique insights that improved the inclusivity of the SMS intervention. They felt the draft messages were respectful, but expressed their own distinct sexual health questions and concerns. Their feedback helped ensure the intervention messages were relevant to youth of different sexual orientations.

Privacy and confidentiality were a particular concern expressed by study participants.

The need to reassure participants that all responses were private, confidential and anonymous was important. Ultimately we did not include the suggested word "anonymous," because participants would be providing their cell phone number in order to participate. To alleviate their concerns, we added content to the recruitment messages, reminded participants to delete intervention messages from their phones, and sent frequent reminders to delete survey responses from their history.

Overall, the youth who provided feedback on the study were receptive to the messaging plan and enthusiastic about the purpose of the project. Participants agreed that getting sexual health messages twice a week was an acceptable frequency. Open-ended questions gave the research team the opportunity to confirm that the intervention messages addressed their most pressing sexual health questions.

# Limitations

One of the biggest challenges in the planning and execution of the study was to limit all messages for recruitment, consent, intervention, and survey evaluation to 160 characters (the maximum limit for a text message), and to design survey questions that included unique short-code options needed to capture participant responses.

We recognize that youth who participated in this formative research may not have been representative of all AI/AN youth, having been recruited at Native youth leadership camps and conferences. However, we sought to overcome this limitation by recruiting participants at several venues across the U.S, purposefully including youth from urban and rural locations, across the intended age range (15-24 years). We believe this cohort of students is representative, however, of youth who would ultimately enroll in the We R Native text messaging services.

The study was strengthened by the longstanding partnership between the Northwest Portland Area Indian Health Board and OHSU, and its use of We R Native – a multimedia health resource that was already known and trusted by AI/AN youth.

#### **Conclusions**

This study was the first of its kind to explore the potential of text messaging to promote health among AI/AN youth. Advisory groups, surveys, and software pilot tests helped determine the functionality of the text messaging software, and the acceptability of the intervention implementation plan. Privacy and confidentiality were found to be important concerns that could

deter participation during the recruitment and surveying phases of the study. New messages were added to assure participants that their responses would be kept private and should be deleted from their phones.

We found that AI/AN youth expect a trustworthy entity to deliver messages with proper grammar and spelling, to reflect the entity's credibility. Humor was appreciated by most formative research participants, but not overly employed in the study. Finally, questions posed by participants supported the topics addressed by the intervention, and strongly suggested that text messaging is an appropriate mode to deliver sensitive health information to AI/AN youth.

Since texting has become a daily, commonplace activity, it might be perceived as a trivial communication tool. Given that more than 80% of adolescents own a cell phone, that more than 90% of all SMS messages are read within three minutes of receipt (Collin, 2015), and that the average attention span is eight seconds (Statistic Brain Research Institute, no date), texting may be the most effective and efficient communication tool available today to convey important health information to teens and young adults.

Employing formative research strategies to tailor text messaging programs (or any health program) ensures that cultural relevance and sensitivity are achieved. After iterative rounds of review, the final messages and questions reflected the sexual health needs of AI/AN youth of varying genders, ages, and sexual orientations, while maintaining cultural relevance and sensitivity. This study extends the small but growing body of research by Allison (Allison *et al.*, 2012), Bull (Bull *et al.*, 2012), Rushing (Rushing and Stephens, 2012), Devine (Devine *et al.*, 2014), and Sheoran *et al.* (Sheoran *et al.*, 2014), using SMS to promote adolescent sexual health.

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# Chapter 4: Texting 4 Sexual Health: Improving Attitudes, Intention, and Behavior among American Indian and Alaska Native Youth

## **Abstract**

**Objective**: To explore the effectiveness of a text messaging intervention designed to promote condom use and STI/HIV testing among American Indian and Alaska Native youth

**Methods**: Participants were recruited, consented, surveyed, sent intervention messages, and incentivized through text messaging over a ten-month study period in a before-after study. Data were collected through text messaging keywords. Changes in sexual health knowledge, attitude, self-efficacy, intention and behavior were assessed. A mixed effects logistic regression model was used to analyze before-after change in responses.

**Results**: Participants' condom use attitude, condom use behavior, and STI/HIV testing intention improved after the intervention (P<0.05). With STI/HIV testing behavior, we observed that more than 40% (11/26) of those who had been tested beyond six months at baseline, had retested to be within six months when surveyed three months after the intervention.

**Conclusions:** Given the widespread use of cell phones, a mobile text-based intervention offers an effective and feasible method for promoting condom use and STI/HIV testing.

**Keywords:** Mobile health, text-messaging intervention, health behavior change, sexual health, adolescent, before-after design.

#### Introduction

Despite being one of the smallest ethnic and racial groups in the United States, American Indian and Alaska Native (AI/AN) youth experience persistent disparities related to teen pregnancy(Glanz, Rimer and Viswanath, 2008; Centers for Disease Control and Health Service, 2014; National Coalition for Sexual Health, 2015) and sexually transmitted infections (STIs), including human immunodeficiency virus (HIV).(National Center for Health Statistics, 2013; Centers for Disease Control and Health Service, 2014; National Coalition for Sexual Health, 2015; Yao *et al.*, 2015) Demographically, about 400,000 AI/ANs are 14-24 years old.(Glanz,

Rimer and Viswanath, 2008; National Center for Health Statistics, 2013; Centers for Disease Control and Health Service, 2014; National Coalition for Sexual Health, 2015) Although pregnancy rates fell for teens and young adults in the United States overall between 2011 to 2012, AI/AN teens (15-19 years) experienced the lowest decrease in birth rates.(National Center for Health Statistics, 2013; Centers for Disease Control and Health Service, 2014; National Coalition for Sexual Health, 2015; Yao et al., 2015; CDC - About Teen Pregnancy - Teen Pregnancy - Reproductive Health, no date) And despite the decline, AI/AN teen birth rates remained almost twice the rate of white teen birth rates,(National Center for HIV/AIDS Viral Hepatitis STD and Prevention, 2014; CDC - About Teen Pregnancy - Teen Pregnancy - Reproductive Health, no date) and experienced the second highest rates of chlamydia, and gonorrhea among all racial/ethnic groups, increasing their susceptibility to HIV infection.(Rights, 2004; National Center for HIV/AIDS Viral Hepatitis STD and Prevention, 2014)

A variety of structural and cultural factors have contributed to these disparities. Distrust of the federal government with their attempts to annihilate the Native population, lack of adequate funding for health services, and inability to access health services(Rights, 2004; Rushing and Stephens, 2012; Guse *et al.*, 2012) have all posed challenges to the Native community. Contemporary messages that have been successful in improving sexual health outcomes for teens and young adults in the general population conflict with AI/AN beliefs. (Norris, Vines and Hoeffel, 2012; Rushing and Stephens, 2012; Guse *et al.*, 2012) AI/AN culture encompasses a more holistic approach to adolescent health, embracing emotional, physical, social and spiritual facets that conventional practices do not include. Teen births are also not stigmatized in the AI/AN culture as they are in other societies. Since mainstream messages could cause confusion, tailored messages are needed to better meet the needs of AI/AN youth.(Patrick, Raab and Adams, 2009; Rushing and Stephens, 2012)

Text messaging has already been successfully utilized to improve help seeking behaviors and health outcomes for a variety of topics, including mDiet (Fogg and Adler, 2009; Patrick, Raab and Adams, 2009) (a personalized approach to weight management,) STOMP (Stop Smoking Over Mobile Phone – an interactive text messaging service that supports smoking cessation,) (Levine *et al.*, 2008; Fogg and Adler, 2009) and SEXInfo (Bryant, Sanders-Jackson and Smallwood, 2006; Levine *et al.*, 2008; Lenhart, 2010) (which used text messaging to provide sexual health and clinic referrals). As cell phones have become ubiquitous among teens, text messaging has become a promising avenue to promote adolescent sexual health.(Bryant, Sanders-Jackson and Smallwood, 2006; Lenhart, 2010; Guse *et al.*, 2012; Shegog *et al.*, 2013)

Text messages can be easily disseminated across large geographic regions with ease, maintaining intervention fidelity.(Bryant, Sanders-Jackson and Smallwood, 2006; Guse *et al.*, 2012; Shegog *et al.*, 2013; NPAIHB, no date) Given the successes demonstrated by previous studies, a short message service (SMS) intervention tailored to the unique needs and culture of AI/AN youth has the potential to improve sexual health outcomes for AI/AN youth. Therefore, the aim of the study was to determine whether a series of text messages could improve sexual health knowledge, attitude, self-efficacy, and intention among AI/AN teens and young adults, with the overall goal of improving sexual health behaviours related to condom use and STI/HIV testing.

## **Methods**

The study – *Texting 4 Sexual Health* – was conducted in partnership with the Northwest Portland Area Indian Health Board (NPAIHB) and Oregon Health & Science University (OHSU), using *We R Native*, a multimedia health resource for Native teens and young adults. Established in 2012 by the NPAIHB, the service includes an interactive website (www.weRnative.org), a text messaging service (Text NATIVE to 24587, with over 2,000 subscribers nationwide), a Facebook page, and a YouTube channel. *We R Native* offers over 350 health and wellness webpages

covering a variety of topics important to Native youth, including sexual health.(Glanz, Rimer and Viswanath, 2008; NPAIHB, no date) Through these platforms, *We R Native* had an existing relationship with Native teens and a working short message service (SMS) that could be used to recruit study participants and carry out intervention activities.

The intervention in this study was a series of text messages developed to improve sexual health among AI/AN teens and young adults (ages 15-24) using an iterative review process with the target audience. To enhance their effectiveness, the messages addressed multiple factors that affect health behavior: knowledge, attitude, self-efficacy, and intention based on the published literature. The conceptual frameworks blended insights from the health behavior model, social cognitive theory, and the theory of planned behavior(Glanz, Rimer and Viswanath, 2008; National Center for Health Statistics, 2013; National Center for HIV/AIDS Viral Hepatitis STD and Prevention, 2014; Centers for Disease Control and Health Service, 2014; National Coalition for Sexual Health, 2015; CDC - About Teen Pregnancy - Teen Pregnancy - Reproductive Health, no date), which formed the foundation for the text messages used in the study. (Rights, 2004; National Center for Health Statistics, 2013; National Center for HIV/AIDS Viral Hepatitis STD and Prevention, 2014; Centers for Disease Control and Health Service, 2014; National Coalition for Sexual Health, 2015; Yao et al., 2015; CDC - About Teen Pregnancy - Teen Pregnancy - Teen Pregnancy - Reproductive Health, no date)

Similar formative research activities were used to design a series of survey questions to evaluate the efficacy of the SMS intervention. Six survey questions were developed to assess condom use and another six questions were developed to assess STI/HIV testing, which were originally derived from validated survey tools (Table 1). ). The questions were sequenced such that with a given response to question one, question two was triggered, and so on. If a positive response was given to question five (sexually active or having been tested for STI/HIV), then

question six followed. For that reason, the sample size for question 6 in each survey is much smaller in total number responses.

Question	Behavioral	Condom Use Questions
,	Construct	1st a question about condoms. True or False? A condom should be put on the penis only if the penis is fully
1	Knowledge	erect or stiff. Text back 'TRUE or FALSE'
2	Attitude	Agree or disagree? Condoms should always be used if a person has sex, even if the 2 people have known each other a long time. Text back 'AGREE or DISAGREE'
3	Intention	If you decided to have sex, how likely is it that you'd get your partner to use a condom? Text back 'DEFINITELY, POSSIBLY, or UNLIKELY' changed to Definitely or Unlikely (Possibly+Unlikely)
4	Intention	If you decided to have sex, how sure are you that you would use a condom EVERY time, to protect yourself from getting an STD or HIV? Text back 'SURE or UNSURE'
5	Behavior	How many times have you had sex in the last 3 months? Text back 'NONE, ONCE, or MORE' changed to Didyou have sex in the last 3 months? Yes/ No
6	Behavior	How often did you use a condom? Text back 'NEVER, SOMETIMES, or ALWAYS' changed to Always or Never (Sometimes+Never)
Question	Behavioral Construct	STI/HIV Testing Questions
1	Self-efficacy	True or False? I am able to make an appointment to get tested for STDs. Text back 'TRUE or FALSE'
2	Self-efficacy	How sure are you that you could talk to your healthcare provider about your sexual behavior? Text back 'SURE or UNSURE'
3	Attitude	Agree or disagree? It would be a big hassle to use a condom & get tested for STDs to completely protect myself from getting a STD. Text back 'AGREE or DISAGREE'
4	Intention	How likely are you to get tested for STDs the next time you change partners? Text back 'DEFINITELY, POSSIBLY, or UNLIKELY' changed to DEFINITELY or UNLIKELY (Possibly+Unlikely)
5	Behavior	Have you ever been tested for HIV or STDs? Text back 'NEVER, ONCE, or MORE' - Remember all answers are kept private. Changed to Yes (Once +More) or Never
6	Behavior	When did you last get tested? Text back TIME followed by how long ago you were tested. Like 'TIME 2 months ago or TIME 1 year' changed to >6 months or <= 6 months

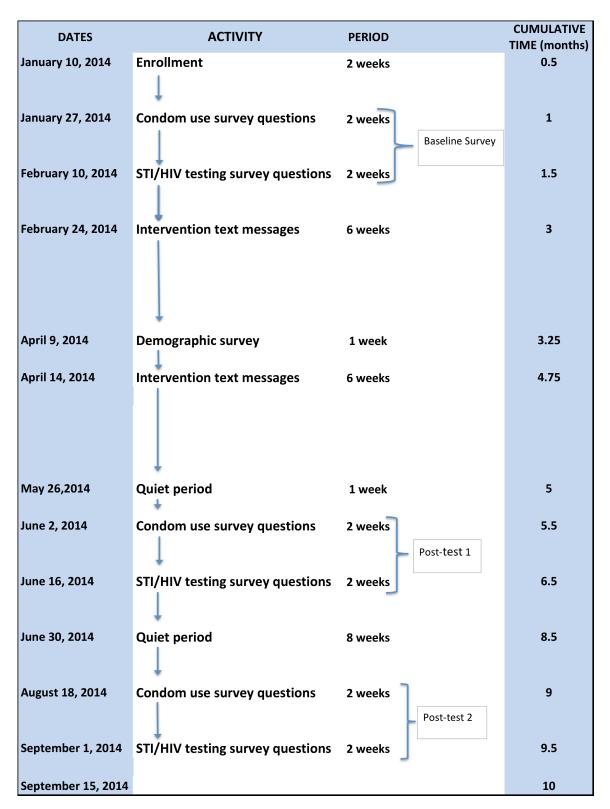
Table 4: Condom Use and STI/HIV Survey Questions

#### Protocol

The research protocol received Institutional Review Board (IRB) approval from both OHSU and the Portland Area Indian Health Service IRB. The study received a waiver for parental consent, allowing teens 15-18 years of age to participate without parental permission. Teens and young adults who had submitted their cell number to *We R Native* were invited and consented through text message, and an online survey with a more detailed consent form was made available. Inclusion criteria were: 1) American Indian/Alaska Natives, and 2) aged 15-24 years, with cell

phones having texting capability. All communications related to recruitment, consent, intervention, testing, incentives and data collection were conducted through SMS. Exclusion criteria were participants outside of the 15-24 year age group. If a participant reported being 25 at the time of the demographic survey, we accepted them since they could have been 24 years of age at the start of the study.

A before-after study design was used to assess the impact of text messaging on sexual health behavior – specifically condom use and STI/HIV testing behavior. Over a four-week period, the 12 survey questions - six questions per survey, were sent through two text message sequences to establish baseline responses, followed by intervention messages twice a week for 12 weeks. After a one-week quiet period, the survey questions were sent out again, to measure the immediate impact of the text message intervention. Another eight week quiet period followed, with the survey questions issued for a final time (see Figure 1). A demographic survey was issued midway through the 12-week intervention, which collected information on participant gender, age and sexual orientation. After each survey, \$5 Amazon gift codes were sent to respondents in appreciation for their time and participation, which increased to \$10 for the final round of surveys.



**Figure 1: Text Messaging Timeline** 

#### Measures and variables

Responses to questions could be binary (e.g., yes or no, agree or disagree, sure or unsure), or have three categories. For the purpose of this study, all questions were analyzed dichotomously. Questions with three response categories were collapsed to form dichotomous categories. For example, one question offered responses of definitely, possibly, or unlikely, and 'possibly' and 'unlikely' were combined. When responses were never (or none), once, or more, the 'once' and 'more' responses were combined. Lastly, in the case of responses with never, sometimes, or always, 'never' and 'sometimes' were combined.

The primary independent variable was the texting intervention, represented by post-surveys 1 and 2. Information was also collected on three demographic variables – age, gender, and sexual preference. The data on these variables were collected midway through the texting intervention.

## **Analysis**

Participant characteristics and responses at baseline and two post-intervention time points were summarized using descriptive statistics. A mixed effects logistic regression model was used to assess the differences in binary outcome variables before vs. after intervention while adjusting for participant characteristics (fixed effects). The identification variable for each participant entered the model as a random effect to take the correlation among repeated measures with the same participant into account. Some of the survey questions also served as independent variables in the analysis, in line with health behavior theories. Constructs such as attitude and self-efficacy are predictors for intention, so in assessing intention, the two constructs were included in the initial full model analysis if they were found to be significant in univariate analysis.

Pre- and post-survey responses were analyzed using frequencies. Only those who completed the demographic surveys were included in the overall analysis. Univariate analysis was used for each question except for question 5, which provided the context for question 6.

Univariate analysis for each questions contributed towards the selection of variables for multivariate analysis, but was omitted for question 5, which provided the context for question 6. Pre- and post-survey responses were analyzed using frequencies. Only those who completed the demographic surveys were included in the overall analysis.

In the logistic regression analysis, for each outcome, univariate analysis was first conducted on demographic variables, applicable behavior constructs and the intervention variable (noted as time points 1 and 2, representing post-survey 1 and 2). Demographic variables with a P value ≤0.25 and the intervention variable were then analyzed in a full model. Variables were selected in a backward elimination manner; those variables that were not significant in the model were removed with the least significant one removed first. Although the intervention variable was retained in the model regardless of significance level, other variables that were not significant were dropped. A preliminary parsimonious final model was built for each outcome including the intervention variable and other significant variables. To facilitate interpretation, a common final model was built for condom use and STI/HIV testing behavior, separately, by including demographic variables that were significant from any of the outcomes in each category.

All analyses were conducted using Stata/IC11.0 (StataCorp LP, College Station, TX).

# **Results**

Among those enrolled in the *We R Native* text-messaging service (1,300 at the time of the study), 408 youth consented to participate. However, demographic data was collected for only 192 of those participants. Based on their cell phone area codes, it appeared participants were well distributed across the United States. In general, there were approximately ~3:1 ratio of females to males, ~3:2 ratio of 19-24 year olds to 15-18 year olds, and ~4:1 ratio of straight to LGBT2Spirit participants. (Table 2)

	Characteristics	Frequency	Percent	Total
Gender	Males	44	23%	192
Gender	Females	148	77%	192
Age Group	15-18 year olds	79	41%	192
Age Group	19-24 year olds	113	59%	192
Sexual	Straight	158	82%	192
Orientation	LGBT2S	34	18%	192
Net use	No	25	13%	192
ivet use	Yes	167	87%	132

**Table 3: Demographic Characteristics** 

## Condom Use

Question	Dependent Variable	Response	Independent Variable	Comparison	Crude Proportion @ Baseline	Crude Proportion @ Post-tests	OR	959	% CI	P-value	Testparm P value
1	Condom Use Knowledge	TRUE TRUE Yes	Post-test1 Post-test2 Sexual activity	vs. Pre-test vs. Pre-test Yes vs. No	183/254 (72%) 183/254 (72%)	146/208 (70%) 141/188 (75%)	1.15 1.30 2.64	0.57 0.62 1.12	2.31 2.71 6.45	0.70 0.48 0.03	0.7795
2	Condom Use Attitude	Agree Agree Yes	Post-test1 Post-test2 Sexual activity	vs. Pre-test vs. Pre-test Yes vs .No	229/276 (83%) 229/276 (83%)	152/165 (92%) 138/153 (90%)	3.25 3.93 0.29	1.44 1.66 0.11	7.35 9.34 0.78	0.005 0.002 0.014	0.0022
3	Condom Use Intention (Partner use)		Post-test1 Post-test2 Condom use attitude Sexual activity	vs. Pre-test vs. Pre-test vs. Pre-test Yes vs. No	168/272 (62%) 168/272 (62%)	111/167 (66%) 105/158 (66%)	1.33 1.07 3.07 0.34	0.77 0.61 1.37 0.18	2.29 1.86 6.91 0.65	0.307 0.825 0.007 0.001	0.5731
4	Condom Use Intention (Self-use)	Sure Sure Agree Yes	Post-test1 Post-test2 Condom use attitude Sexual activity	vs. Pre-test vs. Pre-test vs. Pre-test Yes vs. No	207/267 (78%) 207/267 (78%)	126/161 (78%) 114/149 (77%)	0.97 0.84 6.36 0.21	0.50 0.43 2.64 0.09	1.89 1.66 15.32 0.52	0.925 0.615 0.001 0.001	0.8694
5	Sexual Activity	Yes Yes	Post-test1 Post-test2	Yes vs. No Yes vs. No	210/292 (72%) 210/292 (72%)	117/168 (70%) 116/156 (74%)					
6	*Condom Use Behavior	Always Always Agree Sure	Post-test1 Post-test2 Condom use attitude Condom Intention (self-use)	vs. Pre-test vs. Pre-test vs. Pre-test vs. Pre-test	61/204 (30%) 61/204 (30%)	45/107 (42%) 43/107 (40%)	2.43 2.60 3.09 53.22	1.15 1.18 0.94 13.02	5.13 5.73 10.20 217.48	0.020 0.018 0.064 0.001	0.0264

**Table 4: Multivariate Models for Condom Use** 

# Condom Use Knowledge

Question 1, assessing condom use knowledge, asked, "True or False? A condom should be put on the penis only if the penis is fully erect or stiff." Responses suggested that 73% knew how to use a condom at baseline, and little change was observed after the text messaging intervention. (Table 3) After adjusting for all other variables in the model, the odds of knowing how to use a condom was 2.6 times higher (OR=2.64, P=0.03, 95% CI: 1.12-6.45) among those who were sexually active (having had sex "once or more" in the last 3 months) compared to those who were not.

#### Condom Use Attitude

Question 2, used to assess condom use attitudes, asked, "Agree or disagree? Condoms should always be used if a person has sex, even if the 2 people have known each other a long time." After adjusting for all other variables in the model, the odds of agreeing that condoms should always be used was more than 3 times higher (OR 3.25; P=0.005, 95% CI: 1.44-7.35) one week after and almost 4 times higher (OR 3.93; P=0.002, 95% CI: 1.66-9.34) three months after the text messaging intervention, compared to before the text messaging intervention. The difference in the responses between the two post-surveys was not statistically significant, indicating that the effects of the text messaging were maintained three months after the intervention. (Table 3)

After adjusting for all other variables in the model, the odds of agreeing that "condoms should always be used" if one was sexually active was 0.71 times higher (OR=0.29, P=0.014, 95% CI: 0.11-0.78) compared to if the individual was not sexually active. (Table 3)

#### Condom Use Intention

Question 3, one of two questions used to assess participants' intention to get a partner to use a condom, asked, "If you decided to have sex, how likely is it that you'd get your partner to use a condom? Text back 'DEFINITELY, POSSIBLY, or UNLIKELY'." For analytic purposes, responses were dichotomized to "Definitely or Unlikely" ("possibly" and "unlikely" were grouped together). A proportion of 64% of respondents answered 'Definitely' at baseline, and very little change was observed after the text messaging intervention. (Table 3)

Question 4, the second question used to assess participants' intention to self-use a condom, asked, "If you decided to have sex, how sure are you that you would use a condom EVERY time, to protect yourself from getting an STD or HIV? Text back 'SURE or UNSURE'." At baseline, 75% of respondents answered 'Sure,' and very little change was observed after the text messaging intervention. (Table 3)

### Context for Condom Use Behavior - Frequency of Sexual Activity

Question 5 asked, "How many times have you had sex in the last 3 months? Text back 'NONE, ONCE, or MORE'." Responses were dichotomized to "Not sexually active" (from 'none') or "Sexually active" (from 'once' or 'more'). This question was used to give context to question six, which asked how often condoms were used. Sexual activity was found to be a significant independent variable in univariate analysis for some of the behavioral constructs explored, but was not expected to be affected by the text messaging intervention.

#### Condom Use Behavior

Question 6, used to assess condom use behavior, asked, "How often did you use a condom? Text back 'NEVER, SOMETIMES, or ALWAYS', and the responses of 'Never and Sometimes' were grouped as one category. After adjusting for all other variables in the model, the odds of having used a condom was 2.4 times higher (OR=2.43; P=0.020, 95% CI: 1.15-5.13) one week after the intervention and 2.6 times higher (OR=2.60, p=0.018, 95% CI: 1.18-5.73) three months after the intervention, compared to rates reported at baseline. (Table 3)

### STI/HIV Testing

Question	Dependent Variable	Response	Independent Variable	Comparison	Crude Proportion @ Baseline	Crude Proportion @ Post-tests	OR	95%	CI	P-value	Testparm
1	STI/HIV Testing Self-efficacy (Make an appointment)	TRUE	Post-test1	vs. Pre-test	250/261 (96%)	174/178 (98%)	1.63	0.40	6.64	0.498	0.2515
		TRUE 15-18	Post-test2 Age group	vs. Pre-test 15-18 vs. 19-24	250/261 (96%)	161/162 (99%)	6.77 1.96	0.69 0.40	66.38 9.70	0.101 0.41	
2	STI/HIV Testing Self-efficacy (Speak to healthcare provider)	Sure	Post-test1	vs.Pre-test	208/252 (83%)	141/170 (83%)	1.01	0.51	1.99	0.986	0.879
		Sure 15-18	Post-test2 Age group	vs. Pre-test 15-18 vs. 29-24	208/252 (83%)	131/157 (83%)	1.12 0.73	0.55 0.32	2.29 1.67	0.747 0.459	
3	STI/HIV Testing Attitude	Disagree Disagree 15-18	Post-test1 Post-test2 Age group	vs. Pre-test vs. Pre-test 15-18 vs. 19-24	208/245 85%) 208/245 (85%)	151/168 (90%) 129/150 (86%)	1.11 0.56 1.54	0.49 0.25 0.63	2.51 1.24 3.77	0.808 0.151 0.344	0.8837
4	STI/HIV Testing Intention	Definitely Definitely 15-18 Disagree Sure	Post-test1 Post-test2 Age group Attitude Self-efficacy	vs. Pre-test vs. Pre-test 15-18 vs 19-24 vs. Pre-test vs. Pre-test	110/241 (46%) 110/241 (46%)	95/163 (58%) 92/150 (61%)	2.46 2.64 2.09 2.36 3.80	1.42 1.49 1.17 1.11 1.94	4.26 4.68 3.74 5.02 7.43	0.001 0.001 0.013 0.026 0.000	0.0006
5	STI/HIV Testing Behavior		Post-test1 Post-test2	Yes vs. No Yes vs. No	152/236 (64%) 152/236 (64%)	111/161 (69%) 90/146 (62%)					
6	*STI/HIV Testing Behavior	>6 months >6 months	Post-test1 Post-test2	>6 mos vs. ≤6 mos >6 months ≤6 mos	**42/73 (58%) **26/48 (54%)	***9/42 (21%) ***11/26 (42%)	-	-	-	-	
	*All responses based on Yes for Q5  ** These are the people who tested more than 6 months earlier, at baseline, out of total number who tested.  *** These are the people who retested within six months of post-test, out of those who tested more than six months at baseline.										

Table 5: Multivariate Models for STI\HIV Testing

## STI/HIV Testing Self-efficacy

Questions 1 and 2, designed to assess testing self-efficacy, asked, "True or False? I am able to make an appointment to get tested for STDs" and "How sure are you that you could talk to your healthcare provider about your sexual behavior? Text back SURE or UNSURE." Respondents felt confident in their ability to make an appointment to get tested for STDs/HIV (96% at baseline), and to speak with a health care provider about their sexual behavior (79% at baseline.) After the text messaging intervention the numbers improved, but not significantly.

Having a strong sense of STI/HIV testing self-efficacy (captured as a "sure" response) increased the odds of *intending* to get tested for STI/HIV by 3.8 times (OR=3.80, P<0.001, 95% CI: 1.94-7.43), compared to those reporting low self-efficacy. Having a positive attitude toward STI/HIV testing (as measured by a "disagree" response) also increased the odds of intending to get tested by 2.3 times (OR=2.36, p=0.026, 95% CI: 1.11-5.02), compared to those who reported negative attitudes toward testing. Younger participants (15-18 years old) reported twice the odds

of intending to get tested for STI/HIV (OR=2.09, P=0.013, 95% CI: 1.17-3.74), compared to those who were slightly older (19-24 years old.)

## STI/HIV Testing Attitude

Question 3, used to assess participants' attitude toward STI/HIV testing, stated, "It would be a big hassle to use a condom & get tested for STDs to completely protect myself from getting a STD.

Text back 'AGREE or DISAGREE'." At baseline, 88% disagreed with the statement, and the small changes observed after the intervention were not significant.

#### STI/HIV Testing Intention

Question 4 regarding intention asked, "How likely are you to get tested for STDs the next time you change partners? Text back 'DEFINITELY, POSSIBLY, or NOT LIKELY'." The responses were modified for analysis whereby 'Possibly and Not Likely' were merged into one group. After adjusting for all other variables in the model, the odds of intending to get tested was 2.4 times higher (OR=2.46, P=0.001, 95% CI: 1.42-4.26) one-week after the intervention, and 2.6 times higher (OR=2.6, P=0.001, 95% CI: 1.49-4.68) three months after the intervention, compared to rates reported prior to the intervention. The difference in the responses between the two post-surveys after the intervention was not statistically significant, suggesting that the effects of the intervention were maintained three months after the intervention ended. (Table 4)

Having a strong sense of STI/HIV testing self-efficacy (captured as a "sure" response) increased the odds of *intending* to get tested for STI/HIV by 3.8 times the odds (OR=3.80, P<0.001, 95% CI: 1.94-7.43), compared to those reporting low self-efficacy. Having a positive attitude toward STI/HIV testing (as measured by a "disagree" response) also increased the odds of intending to get tested by 2.3 times the odds (OR=2.36, p=0.026, 95% CI: 1.11-5.02), compared to those who reported negative attitudes toward testing. Younger participants (15-18 years old) reported twice the odds of intending to get tested for STI/HIV (OR=2.09, P=0.013, 95% CI: 1.17-3.74), compared to those who were slightly older (19-24 years old.) (Table 4)

### STI/HIV Testing – Context for Time of Last Test

Question 5 asked, "Have you ever been tested for STI or HIV? Text back 'NEVER, ONCE, or MORE'." Responses were dichotomized to "Yes" (from 'once' or 'more') and "No" (from 'never'). This question was used to give context to question six, which asked how long ago the last test was conducted. (Table 4)

#### STI/HIV Testing Behavior

STI/HIV Testing behavior (question 6) was analyzed differently from the other questions. Among those who responded at baseline, 44% had been tested in the last six months, and 56% had been tested more than 6 months ago (i.e. reporting "infrequent" testing). After the text messaging intervention, among those who had reported infrequent testing at baseline, 21% had been retested within the last six months. And by three months post intervention, among those who had reported infrequent testing at baseline, 42% had been retested within the last six months. (Table 4)

#### **Discussion**

To our knowledge, no previous studies have conducted an entire study, involving recruitment, consent, incentivizing, intervention messages, and data collection - all via text message. Similarly, no previous studies have evaluated text messaging as a sexual health promotion strategy among AI/AN teens and young adults. For all questions, responders and non-responders were similar in proportion with respect to gender, age and sexual orientation, suggesting that any differences in responses could not be attributed to such subject characteristics.

The responses to the condom use knowledge questions suggested that many AI/AN youth know how to use a condom. The text messaging intervention had a greater impact on condom use attitudes, with more people expressing positive attitudes towards condom use after the intervention. However, the intention to get their partner to use a condom did not improve significantly, remaining close to the pre-intervention rate of 64% after the intervention. In the future, messages promoting partner condom use should be strengthened. In contrast, the

participants showed a strong attitude towards using a condom to protect themselves from getting an STI/HIV. Condom use behavior also improved after the intervention, suggesting that the survey messages were effective.

A parsimonious model for condom use suggests that sexual activity and age (15-18 years) are the strongest predictors for condom use. This is a positive indicator for early intervention for sexual health, because we can assume that most 15-18 year olds will have less sexual experience than 19-24 year olds. Thus the intervention may seed more healthy attitudes toward condom use, if the intervention were to take place at a younger age. We can also assume that 19-24 year olds may be in longer-term relationships, whereby condom use may not be considered necessary in a monogamous relationship when there are other options for birth control (i.e. oral contraception.)

With regard to the STI/HIV testing, most participants felt confident enough at the onset of the study to make an appointment to get tested and to speak to their healthcare provider about their sexual behavior. Most also disagreed at baseline, that condom use and STD testing "would be a big hassle." Consequently, the text messaging intervention did not significantly change participants' self-efficacy or attitudes towards STI/HIV testing. However, the text messaging intervention did improve participants' intention to get tested for STI/HIV with a change in sexual partners. Fifteen percent more people stated that they had the intention to get tested compared to before the intervention. Among those who had been tested more than six months at baseline, 42% (11/26) responded three months after the intervention with more recent testing dates (within the last six months.)

This study suggested that the text messaging intervention, attitude (disagree), self-efficacy (sure), and age (15-18 years) were associated with STI/HIV testing intention. Among those who reported infrequent testing at baseline, testing increased from 0 to 42% three months post-intervention. The text messages likely served as a reminder to get tested.

#### Limitations

This study did have several limitations. Only 192 people had associated demographic data and not all of them fully participated in all six surveys. Future studies would benefit from a larger sample size. Participants were not randomly selected, and therefore, cannot be considered representative of all American Indian and Alaska Native youth. However, this sample is unlikely to differ in meaningful ways from the larger population of AI/AN youth aged 15-24 years who attend school. We recruited participants at several venues across the U.S, purposefully including youth from urban and rural locations, with different sexual orientations, across the intended age range (15-24 years). The study was strengthened by the longstanding partnership between the Northwest Portland Area Indian Health Board and OHSU, and its use of *We R Native* – a multimedia health resource that is known and trusted by AI/AN youth.

#### Conclusion

Overall, *Texting 4 Sexual Health* provided very encouraging results for improving AI/AN youths' attitudes and behavior towards condom use. Intention to get tested for STI/HIV improved after the intervention, and an increase in STI/HIV testing behavior 3 months after the intervention was observed among those who reported infrequent testing at baseline. With the widespread use of cell phones among AI/AN youth, a mobile text-based intervention proved to be an effective and feasible method for promoting condom use and STI/HIV testing.

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# Chapter 5: Delivering Digital Sex Ed: lessons learned during the Texting 4 Sexual Health study

## **Abstract**

**Objective:** To share lessons learned while implementing Texting 4 Sexual Health, a national study that delivered sexual health text messages to American Indian and Alaska Native teens and young adults.

**Materials and Methods:** Study participants were recruited, consented, surveyed, sent intervention messages and incentivized via text message over a six-month study period, in a before-after study design. Messages were scheduled and delivered using a short messaging service (SMS) provider, and data were collected using keyword responses.

**Results:** Three primary lessons emerged related to: 1) participant recruitment, 2) crafting suitable SMS messages, and 3) the logistics of conducting all phases of the study via SMS. This paper offers insights to the design and implementation of a text-based intervention, methodological challenges, and lessons learned.

**Conclusions:** Findings from the Texting 4 Sexual Health study provide insights to others interested in designing and delivering SMS digital health programs.

# **Background**

In health, text messaging is increasingly being used to communicate with patients and caregivers, offering a viable option for information exchange, health promotion, and health research. The compelling power of text messaging lies in the fact that cell phones are more accessible than the Internet on a global level, and that text messages are available to anyone, anytime, and anywhere.(Collin, 2015)

Numerous challenges remain, however, for organizations wanting to harness the power of text messaging to promote health and – perhaps most importantly – to measure the impact of their text-based interventions. Many organizations have limited resources or lack the available expertise to put forward such an endeavor. Implementing a text-based intervention is not as straightforward as it may seem.

The Texting 4 Sexual Health study was designed to improve sexual health outcomes among American Indian and Alaska Native (AI/AN) youth (15-24 years old), who suffer disproportionate rates of sexually transmitted infections (STI) and teen pregnancy. To design culturally-sensitive intervention messages and pre-post survey questions, the research team carried out iterative formative research activities with 60 AI/AN youth across the U.S. (in press).

The study was designed in partnership with Oregon Health & Science University (OHSU) and *We R Native*, a multimedia health resource for Native teens and young adults, run by the Northwest Portland Area Indian Health Board (NPAIHB). *We R Native's* text messaging service provides weekly health promotion messages and life advice to service subscribers across the U.S. At the time of the study, over 1,300 AI/AN youth subscribed to the service.

#### Methods

We R Native scheduled and sent text messages using Mozeo, a short messaging service (SMS) provider based in New York State. The research protocol received Institutional Review Board

(IRB) approval from both OHSU and the Portland Area Indian Health Service (PA IHS) IRB (#476310 – Formative Research to Design Sexual Health Text Messages for AI/AN Teens and Young Adults). The study occurred over a period of nine months, from recruitment to the final distribution of incentives. AI/AN teens and young adults between the ages of 15-24 years of age, equipped with cell phones with texting capability, were invited to join.

#### Results

## Participant Recruitment

We R Native leveraged several of its communication channels to solicit participation, including its short message services (SMS), Facebook, Twitter and the We R Native website (www.weRnative.org), taking advantage of its existing relationship with Native teens and young adults.

To our knowledge, only one other adolescent sexual health study (Lim, Wright, & Hellard, 2014) has successfully used text messaging for participant recruitment, using an opt-in approach via text message. Our study employed similar methods. Subscription numbers were bolstered prior to the invitation, by marketing the text messaging service in the months leading up to the study (E.g. Facebook posts, Twitter tweets, and text messages that read, "PLEASE FWD ONTO YOUR FRIENDS: We R Native is a free txt service 4 N8V youth, by N8V youth. Join by texting NATIVE to 24587.").

Recruitment began in early January 2014 for a period of two weeks, during which over 408 individuals signed up to participate through SMS, phone calls, and an online consent form (using Survey Monkey®).

We R Native's 1,300 text message subscribers were notified of the upcoming study – Texting 4 Sexual Health. (Table 6)

Table 6: Example messages sequenced by sexual experience

Message 1 sent to N=1586

We R Native is doing a research study: Texting 4 Sexual Health. The goal is to reduce STD/HIV rates among Native teens and young adults.

Message 2 sent to N=1584

You must be AI/AN & 15-24 yrs. You will get 2 sexual health msgs per week for 3 months. All texts are private. Earn \$40 for answering 40 Q's over 6 months.

Message 3 sent to N=1574

We won't collect your name, just cell # to analyze results. To protect your privacy, you can delete our messages from your phone.

Message 4 sent to N=1566

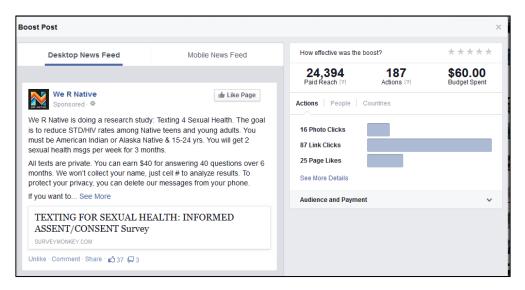
Reply "AGREE" if you want to join. Reply "LEAVE" to quit anytime. Go to http://mozeo.me/WoGe to learn more about the study and your rights.

A similar message was tweeted to approximately 1100 Twitter followers (Figure 2):



Figure 2: Twitter Invitation

A more detailed message was posted to Facebook, which was viewed by over 24,000 AI/AN youth, achieved by "boosting" the post to our desired target audience (Figure 3).



**Figure 3: Facebook Invitation** 

For a fee, boosted posts appear higher on the target audience's News Feeds.(Sorokina, n.d.) The cost depends on the number of people targeted, the duration of time, and the number of times the post is shown (impressions), regardless of whether it is clicked on or not.(Help Center, n.d.) A post encouraging enrollment in the text messaging service was boosted once before the study, and three study recruitment messages were boosted during the recruitment period, for a total of \$610 in paid advertising. (Figure 4)



Figure 4: Facebook Boost

By leveraging its social media networks, an additional 171 people joined *We R Native's* text messaging service in the 10 days prior to study recruitment. During the actual recruitment period, another 243 subscribers joined the text messaging service, texting the keyword "NATIVE" to 24587 from January 10-20, 2014.

## **Informed Consent**

To protect the rights and welfare of study participants, it is critical that informed consent be obtained before the onset of the study. This study was unique in that consent was obtained via short message service (SMS). One of the driving forces behind this decision was that our target audience included youth who lived on reservations where in many cases, cell phones and mobile communications are more convenient than computers with Internet access.(G. Smith, 2012) Recognizing this context fostered efforts to obtain informed consent directly via text message, without the added burden of printing, scanning, or faxing consent forms.

We requested and received IRB permission to waive parental consent for participants 15-18 years old, given that the subject matter posed no more than minimal risk to participants, and that youth 15 years and older may legally obtain sexual health services without parental consent. Otherwise, teens were unlikely to approach their parents for permission to participate.(Boonstra & Nash, 2000; Tigges, 2003; Toner & Schwartz, 2003)

The invitation to join the study included key elements necessary for informed consent, communicated through a sequence of text messages. (Table 7)

"We R Native is doing a research study: Texting 4 Sexual Health. The goal is to reduce STD/HIV rates among Native teens and young adults."

"You must be AI/AN & 15-24 yrs. You will get 2 sexual health msgs per week for 3 months. All texts are private. Earn \$40 for answering 40 Q's over 6 months."

"We won't collect your name, just cell # to analyze results. To protect your privacy, you can delete our messages from your phone."

"Reply "AGREE" if you want to join. Reply "LEAVE" to quit anytime. Go to <a href="http://mozeo.me/WoGe">http://mozeo.me/WoGe</a> to learn more about the study and your rights."

Table 7: Sequenced messages for informed consent

The link sent users to the complete consent form, posted as a Survey Monkey document. (Flicker & Guta, 2008; Holder, 2008; Holder & Veatch, 1981) From Survey Monkey, participants could consent to the study's terms and conditions by validating their cell phone number.

At least one "active" step was thus required to participate in the study. Participants had to either reply with the short code "AGREE," or enter their cell phone number at the end of the online consent form. This dual process was recommended by the PA IHS IRB to establish informed consent.

Study enrollment was confirmed with the following message:

"Thanks for joining! Incentives will require Internet access. You will be given a code that will not expire until used. Text "LOST" for lost codes. "

At any point during the study, participants were able to leave the study by replying "LEAVE" or texting the word "STOP" to unsubscribe from the text messaging service. If a participant chose to withdraw from the study, the following message was sent:

"Thanks for your time... participation is always voluntary. We appreciate your input!"

### Crafting Suitable SMS Messages

The text messages were the core of this study, encompassing recruitment, consent, intervention, evaluation, and incentive delivery. Accordingly, the research team consulted the published literature to design a series of text messages aiming to improve sexual health among AI/AN teens and young adults (ages 15-24). (Gold, Lim, Hocking, & Keogh, 2010b),(Gold et al., 2010a),(Levine, McCright, Dobkin, Woodruff, & Klausner, 2008).

Text messages can only be 160 characters long. To enhance their effectiveness, the messages were designed to address factors known to affect sexual health: knowledge, attitude, self-efficacy, intention and behavior. The conceptual frameworks blended insights from the health behavior model, social cognitive theory, and the theory of planned behavior (Glanz, Rimer, & Viswanath, 2008). Once the messages were crafted, they were sequenced to begin with tips for youth who were not yet sexually active, including tips for those who might be questioning their sexual orientation (Table 3).

Think everyone's doing it? Be your own person. It's ok to say no to sex.

Thinking about having sex? It's an important decision. Discuss it with your partner & someone you trust: *We R Native* link

Awkward or Not? Take this quiz to find out how ready your parents are to talk to you about sex: *AwkwardOrNotApp.org* (this link is no longer active)

Healthy relationships are based on equality and respect. Part of that is having good communication: Stop, think, talk, listen.

It's common for people to feel unsure about their sexual orientation. It's complicated! Learn more at: *We R Native* link

**Table 8: Text messages sequenced by sexual experience** 

Similar to the intervention messages, a series of survey questions were sent before and after the texting intervention measuring changes in knowledge, attitude, self-efficacy, intention and behaviour related to condom use and STD/HIV testing, to evaluate the efficacy of the SMS intervention (Tables 9 and 10)

A condom should be put on the penis only if the penis is fully erect or stiff. Text back 'TRUE or FALSE'

Condoms should always be used if a person has sex, even if the 2 people have known each other a long time. Text back 'AGREE or DISAGREE'

If you decided to have sex, how likely is it that you'd get your partner to use a condom? 'DEFINITELY or UNLIKELY'

If you decided to have sex, how sure are you that you would use a condom EVERY time, to protect yourself from getting an STD or HIV? Text back 'SURE or UNSURE'

How many times have you had sex in the last 3 months? Text back 'Yes or No' - Remember all answers are kept private

How often did you use a condom? Text back 'NEVER or ALWAYS'

**Table 9: Condom Use Survey Questions** 

True or False? I am able to make an appointment to get tested for STDs.

How sure are you that you could talk to your healthcare provider about your sexual behavior? Text back 'SURE or UNSURE'

Agree or disagree? It would be a big hassle to use a condom & get tested for STDs to completely protect myself from getting a STD.

How likely are you to get tested for STDs the next time you change partners? Text back Definitely or Not Likely

Have you ever been tested for HIV or STDs? Text back 'Yes or NO

When did you last get tested? >6 months or  $\le 6$  months

**Table 10: STI/HIV Testing Survey Questions** 

## **SMS Delivery Platforms**

Any system used to deliver bulk text messages has features that can impact service delivery and data collection. These features vary from vendor to vendor, unless an in-house system is available. Third party vendors have many clients and accordingly, there are service limitations – functionality will essentially be

a reflection of how much is paid. Texting 4 Sexual Health was designed to operate within the parameters of its SMS vendor, including the following features:

One- or Two-way text messaging. Used for sending messages to a list of recipients, one-way text messaging is also known as text blasting or bulk messaging. Public health alerts are often sent this way, as are notices for parents from schools – it is a convenient mode of communication that allows one-to-many messaging. Many systems also allow for two-way text messaging, which is the capability of sending and receiving messages. For this study, two-way messaging was used. Participant responses were tracked to obtain consent, evaluation survey responses, demographic question responses, and at any time, to leave the study (LEAVE) or obtain lost incentive codes (LOST).

**Opt Out Service.** Another important feature for SMS programs is an opt out feature (that can be provided by texting "STOP"), providing subscribers a simple and convenient way to stop receiving messages.

**Short Codes.** Shorts codes are 5-6 digit codes that are used to send and receive text messages. They are usually used for text blasting or bulk messaging by organizations or companies, can reflect an easy-to-remember number, and can be purchased from the vendor. However, not all mobile calling plans accept short codes and this became an issue for the study. Mobile plans that do not accept short codes are usually discounted plans, and more economical for the consumer. In this study, there were five people who signed-up and conveyed that they were unable to receive messages from short codes. To accommodate these participants, the research team decided to use Gmail texting that was available from the Gmail application. It meant that each message, for testing and intervention purposes, had to be sent manually through Gmail to their cell phones. This worked for about 10 one-way messages, until the

Gmail system assumed we were spamming participants (because there were no responses to the sent messages) and locked us out of the feature. The only other feasible alternative was to use a personal cell phone to send out the text messages and test questions. The messages and questions were sent out individually to each cell number for privacy and confidentiality reasons. It was not an arduous task because there were only five participants who required this service, but for a much larger number, it would have been impractical. Of the five accounts, only two were consistent participants in the study. As of April 1, 2014, Google stopped providing SMS messages through Google Chat in Gmail. (support.google.com, n.d.)

Losing Participants. One of the main concerns in the study was loss of participants. Dropouts can occur because of possible errors on the part of the research team, the participant, or the SMS vendor. There are various levels of sophistication that a vendor can offer related to the technology. During this study, uploading numbers for follow-up would result in dropouts. We had no way to confirm active cell numbers because that area of the system was out of our domain and we were not permitted to contact participants directly. The SMS provider informed us that cell numbers not in use were automatically dropped. However, this is where an in-house system would be preferable. Troubleshooting a research study may not be a viable option when using an outside vendor, and as such, was not offered as a service to the client. From the participants' perspective, they could have lost their account or had it frozen, if their bill was not paid. This could have interfered with their receiving certain messages or surveys, and impacted data collection as a result.

There was also loss of participants with each question and with each round of survey questions. From question to question, we lost between 1-9 people, and between survey rounds, we lost between 10-30 people.

so most of the analysis was conducted manually by exporting the data to Microsoft Access and Excel, cleaning and formatting the data, then recoding for statistical analysis in STATA® (v11). The system was able to deliver a keyword report that could be defined by dates and would report the number of times a keyword was used. However, this report could include counts where a user may have responded multiple times, and would not include mistyped words or words that were very similar. To be accurate, all data was manually reviewed. A more sophisticated system could probably address all of these issues, provide more flexibility, and offer algorithms to respond to different types of responses.

Other systems might also have the ability to push the last unanswered question out but with this particular vendor, that option was not available. Depending on the system, as in this study, creating a new list of users fell upon the research team to create and pass to the vendor for upload. Making a request did not necessarily mean a timely response. Mozeo was an average provider with reasonable costs and services.

#### **SMS Intervention Logistics**

Timing deliveries, deciding incentives, and collecting data can be straightforward issues but there is more thought required when executing for maximum returns.

Timing. Coordinating the timing of the messages, frequency, and follow-up to the survey questions were all non-trivial tasks. Since the target population were students, consideration had to be made to accommodate general schedules (holidays and final exams), best time to send health messages that would not get lost among the many messages teens and young adults send to each other, and timing of survey questions to best garner the greatest response (in the morning or after school.) This study was also nationwide so the delivery had to be considerate of the various time zones.

Incentivizing Participation. In appreciation for their time and participation, study participants received a \$5 gift card at the end of each survey sequence, and \$10 for the final two surveys, for a total of \$45 over the course of the study. (The original amount of \$40 was increased to \$45 to accommodate the demographic survey. At the start of the survey, we were not sure if we would have enough funding to cover the demographic questions.)

As an element of the consent process, participants were informed that they may stop answering questions at any time, if they felt uncomfortable answering. Due to the short-code sequencing pattern, there was no way for participants to "skip" questions that they didn't feel comfortable answering. They simply stopped where they were in the question sequence. Consequently, participants were not required to complete all the questions in a series in order to receive the incentive.

Before the study began, an extensive search was carried out to locate gift codes that could be delivered to participants via SMS. The incentive had to be well known, available to non-smart phone users, desirable by participants, and with no time limitation on use. If there were incentives available by cell phone, it was not widespread enough to be used across the US, and it was from a vendor that was not well known.

Ultimately, Amazon® Gift codes were determined to be the best available option, available in quantities of \$5 or more, and allowed for immediate use or bankable for later use towards a variety of purchases. The downside of this feature was that there was no automated process; the sending of codes had to be conducted manually to each cell phone number. This became one of the most tedious aspects of the study, and given recent advancements in mobile banking, came as a surprise.

Through our SMS vendor, there was no automated way to deliver gift codes to a select number of cell phone users. It should be noted that this feature was probably not a difficult program to code BUT it was a service that needed to be provided by the vendor. Thus, one of the advantages of having an inhouse system is that coding such features may be more accessible.

**Data Collection.** Data collection was conducted using keywords. A keyword response is a feature that allows certain words to be used, which can then trigger a specific response if needed. Keywords are purchased from the vendor and can only be used by the purchaser; there is no sharing of keywords. As a result, not all the words desired for the study were available, as they had already been purchased. This would sometimes result in having to modify the outgoing message to accommodate a change in keywords. For example, the keywords Yes/No were not available for the study so True/False were used instead.

An automated response is a feature that pre-programs a response to an incoming text message. This feature was used with keyword responses to trigger the sequence of survey questions used for the study. Because these keywords triggered the next question in the sequence, the response option could not be repeated in a survey sequence, requiring unique answer choices for every question in the sequence. Table 11 demonstrates the pattern of messaging that was used for the condom-use pre-post survey questions.

Question	Texts	Keyword Options
Introduction	Welcome 2 Texting 4 Sexual Health! Questions coming your way about sexual health. Your texts are always PRIVATE & CONFIDENTIAL. Answer to get \$5!	
1	1st a question about condoms. True or False? A condom should be put on the penis only if the penis is fully erect or stiff. Text back 'TRUE or FALSE'	TRUE FALSE
2	Agree or disagree? Condoms should always be used if a person has sex, even if the 2 people have known each other a long time. Text back AGREE or DISAGREE	AGREE DISAGREE
3	If you decided to have sex, how likely is it that you 'd get your partner to use a condom? Text back DEFINITELY, POSSIBLY, OR UNLIKELY	DEFINITELY POSSIBLY UNLIKELY
4	If you decided to have sex, how sure are you that you would use a condom EVERY time, to protect yourself from getting an STD or HIV?  Text back SURE or UNSURE	SURE UNSURE

**Table 11: Keyword Response Examples** 

For example, the first question asks for a response of 'TRUE" or "FALSE." The next question got triggered only if the keyword was correctly spelled when submitted. There was a time limit for each set of questions (two weeks), during which the keywords would trigger the next question. After the period expired, the trigger words were turned off. In this way, responses were specific to the questions within a given time period.

During the study, responses were manually checked for errors, and active steps were taken to improve survey response rates. One method was to identify all the non-responders and those who did not receive a follow-up message due to keyword misspellings, and send them the last unanswered question as a prompt the following week. This allowed those who meant to respond but got distracted, or who submitted a misspelled keyword, to continue with the survey. Through our particular SMS vendor, this

process proved to be time-consuming, requiring a new list of numbers to be compiled for each drop off point, for each push.

The other option was to trigger the next question to the participant, which was a direct manual push. The direct manual push allowed a message to be pushed immediately – allowing the recipient to continue on with the survey. Ideally, those who have keyword spelling errors should be pushed the next message as soon as possible, to maintain survey continuity. However, there are challenges to this. If there are a large number of misspelled responses, a manual push would require attention to each individual number. For a large number of misspelled words, it might just be easier to collect all the numbers and push the question to all of them at once.

**Tracking Participants.** Another time consuming task related to the study was participant tracking. All cell numbers had to be tracked for responses, and with this vendor system, it required a screen copy of the cell numbers, pasting it into word, cleaning up the format, pasting into access, matching up the responses by number, and then moving the final dataset into excel. (Not everyone has Microsoft Access but most people have Microsoft Excel.) There was no automated download of numbers. All of this was necessary for each participant to receive a gift code/incentive.

Grouping respondents based on last question answered was conducted manually. Even with all the technology available, and the ability to program, some of the limitations of the vendor simply required basic, manual sorting and analysis for follow-up.

## **Discussion**

Participant recruitment was an important factor for this study. Leveraging all the multimedia tools available ensured a large following and provided an adequate cushion to accommodate the expected dropout participants. It is not enough to just have a presence in social media, but essential to also use the

various tools offered by the social media sites. Facebook's boost feature brought greater attention to the study and contributed towards increasing participant engagement.

Informed consent was delivered succinctly and effectively as a series of text messages, highlighting the important facts and offering a more descriptive online consent form. Offering a single step response (short code 'AGREE') was an active step in establishing informed consent. Given the sensitive nature of the study, the study team and IRB were particularly concerned about protecting the confidentiality of participants. To alleviate their concerns, we reminded participants to delete intervention messages from their phones, and sent frequent reminders to delete survey responses from their history. All caps were also used to clearly distinguish possible survey response options. The study was designed for anonymity, ensuring privacy and confidentiality of study participants, and investigators implemented a strategy to interact with participants after the study by informing participants of the findings of the study after preliminary analysis.

Intervention messages were carefully designed to enhance knowledge, attitude, self-efficacy, and intention, guided by the health behavior theories and published literature. These messages were then sequenced, starting with content requiring little or no sexual experience, and offered tips for those who might be questioning their sexual orientation. A similar process was employed in the design of the prepost survey questions used to measure change.

The technical aspects of the text messaging platform can offer the greatest challenges, because the extent of controlling issues is dependent on the provider of the services (in-house or third party vendor.) Be mindful when selecting an SMS vendor. Talk to the vendor ahead of time. Make sure they know what you are doing, and what to expect during the study. Be mindful of system issues that might cause an unnecessary loss of study participants. Also be aware that not all cell phone service providers accept short codes; low discount plans might block short code messaging.

The logistical aspects of a text-messaging intervention can both offer and demand opportunities for creativity. In hindsight, the incentive payment methodology used in the study could have impacted survey completion rates. In the first round of questions, if a participant had not completed all the questions but received an incentive, it was not difficult to figure out that one response earned the reward. And in future surveys, testing that idea would garner further rewards with little effort. Timing of messages was another interesting challenge. Possible deterrents to completing surveys (e.g. holidays and exams) were considered in timing deliveries, along with the time differences across the country.

Data collection was restricted to keywords within a given time period to relate to specific questions. This set the limits for the study, and perhaps with a more sophisticated system, would require less effort on the investigators' part. However, the responses were distinct and easy to ascertain even with misspellings. Texting itself is easy – the thought behind it requires much more planning and research.

## **Conclusion**

Text messaging is such a common facet of life these days (A. Smith, 2011) that the design and methodology of executing a texting intervention may be considered deceivingly minor. Employing SMS to recruit, consent, send intervention messages, incentivize, and collect data does require planning. The many considerations that are integral to a successful execution are as important as the planning of a traditional research study. Hopefully, these lessons and insights will encourage programs to take advantage of a simple but powerful tool that has a dominating presence in society today.

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## **Chapter 6: Discussion**

This dissertation addressed three aims with an additional chapter on lessons learned.

Aim 1: Design a series of text messages that improve sexual health knowledge, attitudes, self-efficacy, intention and behavior among AI/AN teens and young adults (ages 15-24), and a series of pre-post survey text messages that can be used to evaluate the text messaging service.

Health behavior theories guided the development of the text messages and provided insights to the knowledge, attitude, self-efficacy, and intention constructs, with the ultimate goal of measuring behavior change. Advisory groups, surveys, and software pilot tests helped determine the functionality of the text messaging software, and helped ensure the acceptability of the intervention implementation plan.

Aim 2. Ensure the messages speak to a range of perspectives and readiness levels, by pilot testing the messages with AI/AN youth of varying genders, ages, and sexual orientations.

Employing formative research strategies to tailor text messaging programs ensured that cultural relevance and sensitivity were respected, while empowering AI/AN youth to take an active role in their own health and wellbeing. AI/AN youth expect a trustworthy entity to deliver messages with proper grammar and spelling, to reflect the entity's credibility. Privacy and confidentiality were very important, along with anonymity, to assure respondents that their responses would be private. Humor was appreciated by most survey takers, but not overly employed in the study. Finally, questions posed by participants supported the topics addressed by the intervention, and strongly suggested that text messaging is an appropriate mode to deliver important, but sensitive information to AI/AN youth.

Aim 3. Quantify the effectiveness of a text messaging intervention, designed to promote condom use and STI/HIV testing, by measuring change in sexual health knowledge, attitude, self-efficacy, intention, and ultimately improve overall sexual health behavior.

The text messaging intervention improved condom use attitudes and condom use behavior, with past sexual activity and younger age (15-18 years) acting as the best predictors for condom use. Attitude (disagree), self-efficacy (sure), and young age (15-18 year) were predictors for intention to get tested and STI/HIV testing behavior. Condom use attitude and behavior, and STI/HIV testing intention and behavior all improved significantly after the intervention. Condom use knowledge and intention, and STI/HIV testing self-efficacy and attitudes were already strong among AI/AN youth, which is reassuring. The texting intervention served to support already strong levels of knowledge, and promote change for better sexual health.

The first aim of creating messages that addressed knowledge, attitude, self-efficacy, intention and behavior was guided by literature reviews and behavior theories. Health behavior theory is an essential tool in designing and implementing health promotion programs, providing the theoretical direction for a given intervention.(Glanz, Rimer and Viswanath, 2008) Messages were tailored on key theoretical determinants - knowledge, attitude, self-efficacy, intention, and ultimately behavior. The theories informed the research and development of the messages, and the selection of the test questions used to measure change. Pellegrini et al. (Pellegrini et al., 2012) used health behavior theories to guide her study for weight loss using social networks. They hypothesized that using a theory-guided, technology-supported weight loss treatment program would result in clinically significant weight loss through preserved social support and mobile technology. Head et al conducted a meta-analysis on the efficacy of text messaging-based health promotion interventions and concluded that message tailoring and personalization were significantly associated with greater intervention efficacy. (Head et al., 2013) Following health behavior theories enhanced the relevance of the information (Hawkins et al., 2008) related to condom use and STI/HIV testing in this study.

The second aim employed formative research to pilot test the messages and test questions. This provided validation toward the proposed messages and test questions, creating opportunities to refine and better adapt the messages to AI/AN youth and young adults. One study used formative research with overweight men and women to collect feedback about dietary behaviors, phone, text, and picture

messaging habits, type and frequency of messaging (Patrick *et al.*, no date) – very similar to the issues we had with this sexual health study. Community based participatory research, one approach in formative research, has been very effective with indigenous communities in the United States. By engaging an insider's perspective to a given issue(Teufel-Shone *et al.*, 2006), community attitudes are identified and intervention effectiveness can be improved. Working with the target community also promotes a collaborative effort, involving them in a concerted effort towards resolving a community concern.

The third and final aim of this dissertation addressed the study itself. We recruited, consented, sent intervention messages, incentivized and collected data, all through text messaging. We experienced the same issues that any research study grapples with – loss of participants, technology limitations, and other unexpected issues. Despite all of that, the study findings were encouraging, suggesting that text messaging was a feasible and acceptable tool to promote a sensitive health topic. We were able to leverage a common communication tool – the cell phone, and employ a basic functionality – text messaging, and navigate data collection to realize some very promising findings. There have been numerous other studies that looked at appointment reminders (Sims et al., 2012), weight loss (Patrick et al., 2009; Pellegrini et al., 2012), and sexual health(Gold et al., 2010), with similar findings that support our conclusions. Texting for sexual health is a sustainable, economical and effective approach in promoting sexual health among AI/AN youth and young adults, respecting their privacy and confidentiality concerns, and providing a resource that may otherwise not be available.

Finally, this study also offered some noteworthy insights to the world of texting. Such a simple activity but when involved in a program to effect change, texting is no longer trivial. The messages need to be informative, understandable, timely, and more. Making use of social media to increase the profile of a study and to maximize recruitment is key. The lessons gathered from executing the study offer pointers from which future organizations can learn and benefit.

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## **Chapter 7: Conclusion**

The cell phone has grown beyond just a device for talking, and with its ability to employ tools for work and play, texting seems to pale in comparison. However, as basic as it is, texting has become the defacto tool for communication. To meet the specific needs of AI/AN youth, community-based participatory research helped to refine intervention text messages and evaluation survey messages, for greater cultural sensitivity. Collecting feedback from the target audience allowed AI/AN youth to actively contribute to message development, and confirmed the need for an intervention on sexual health. To our knowledge, no previous study has analyzed the efficacy of sexual health text messaging to AI/AN teens and young adults, with encouraging results, or evaluated constructs of knowledge, attitude, self-efficacy, intention or behavior of AI/AN youth using text messaging. This study also provided some valuable lessons in the execution of text messaging, ranging from limitations associated with some wireless carriers, engaging tools within social media for greater reach, and the art of texting with a particular theme. Overall, texting for sexual health was shown to be an effective tool for promoting healthy sexual behaviors among AI/AN youth, and the lessons learned through this study can be used as a template for other programs to follow.

# **APPENDICES**

## TEXTING FOR SEXUAL HEALTH: INFORMED ASSENT/CONSENT

Please read this form carefully. This form will give you important information about the TEXTING FOR SEXUAL HEALTH research project.

#### INVITATION TO TAKE PART

You are invited to take part in this research because you are an American Indian or Alaska Native youth, 15-24 years old. The research project will take place over 6 months.

The Principal Investigator (PI) is Stephanie Craig Rushing of the Northwest Portland Area Indian Health Board (NPAIHB), Tribal Epidemiology Center, Portland, OR. The PI is in charge of the research project. If you have any questions or concerns please contact Stephanie Craig Rushing by phone at (503) 228-4185 or by email at native@npaihb.org

## PURPOSE OF THE PROJECT

By participating in the study, the information you give will help us understand how Native teens and young adults use text messaging and how it affects their sexual health. The information collected may not help you directly, but what we learn from this study will be used to improve the quality of health information available to other Native teens and young adults.

#### **SURVEY METHODS**

Altogether, we will ask you to respond to 40 questions over 6 months using your cell phone: Twelve (12) questions at the start of the study, three to four (3-4) demographic questions mid-way through (age, gender, sexual orientation), twelve (12) questions after getting the sexual health text messages for three months, and the same twelve (12) questions three months later.

## CONFIDENTIALITY

- Your answers will not include your name or any other identifying data (tribe, birthdate, etc.), other than your cell phone number.
- Any personal answers from you will be kept private as required by law.
- Your phone number will not be linked to the study documents.
- Data from the computer system will be downloaded into a safe research library. This library is part of the NPAIHB computer system, and is only accessible to study personnel.

## **PRIVACY**

To protect the privacy of your survey responses, you should delete the messages from your phone immediately after sending them. If you do not delete them, your parents or friends may be able to read your answers to our questions.

Some phones also let you add a password to lock your phone. Be sure to add a password, if your phone allows you to do so.

## LOST OR STOLEN PHONES

If your phone is lost or stolen, take another look around and try to find your phone. (It's always the last place you look, right?). If you still can't locate it, let your cell phone carrier know right away and they'll suspend service to the phone. That way, no one else can use your phone.

#### COST OF JOINING THE PROJECT

If you are normally charged for receiving/sending text messages, this will still apply to the messages we send you, and to the responses you send us.

#### **INCENTIVES**

In appreciation for your time, you will receive a \$40 incentive (\$10 for completing the baseline survey + \$5 for the mid-point demographic survey + \$10 for the post-survey + \$15 for the 6-month follow-up survey = \$40).

#### **BENEFITS**

By participating, you will learn about sexual health and how to protect yourself from STDs and HIV. Additionally, your answers will help the research team create better sexual health information for Native teens and young adults.

## RISKS AND/OR DISCOMFORTS

There are very few risks from joining this study. Some of the questions asked may be embarrassing. You do not have to answer any questions, if it makes you feel uncomfortable.

If you do feel uncomfortable about any of the topics included in the study, you can find support services at:

- Dating violence support services: www.loveisrespect.org
- STD/HIV screening services: www.gytnow.org
- LGBT support services: http://amplifyyourvoice.org/youthresource
- We R Native: http://www.wernative.org/Resources.aspx?type=SexualHealth

#### JOINING AND LEAVING THE STUDY

- Your participation is voluntary. You may choose not to participate, you may stop responding at any time, or you may skip any questions that you do not want to answer.
- By replying with the keyword AGREE, this serves as your voluntary agreement to participate in this research project.
- You may choose to join now, but can change your mind and leave later if you want. Either way, you will be treated the same.
- To exit the study, text LEAVE to 24587. You can also email native@npaihb.org and ask us to remove you at any time.
- Saying "No" now will not change the services available to you, including the We R Native text message service.

## IN CASE OF INJURY

If you are harmed as a result of being in this project, we cannot pay you.

### RESEARCH CONTACTS

Questions about the purpose of the research can be directed to me, at 503-416-3290 or scraig@npaihb.org.

This study has been reviewed by the Portland Area Indian Health Services' Institutional Review Board, a tribal committee that is responsible for protecting the rights and welfare of research participants and NW tribal members.

If you have concerns or questions about your rights as a participant in this study, you may contact the Portland Area IHS IRB Chair, Dr. Weiser, at 877-664-0604 (toll free).

1. You've replied AGREE to participate in this research study, please confirm and enter your cell phone number

1. You've replied AGREE to participate in this research study, please confirm and enter your cell phone number

		1
		1

2. Do you agree to participate in the research study: Texting For Sexual Health
Do you agree to participate in the research study: Texting For Sexual Health Yes No

# **Additional Graphs and Tables**



Figure 4: Map of study participants across the United States

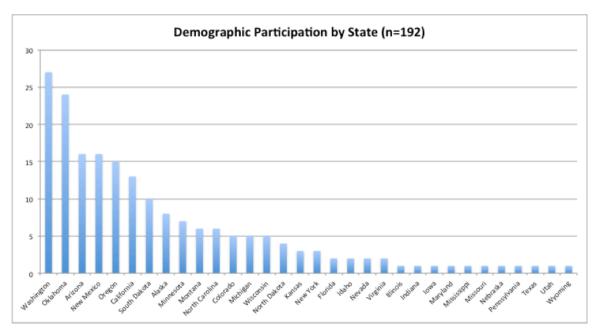


Figure 5: Demographic participation by state