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Project Cell & Tell—mHealth in the Urban American Indian and Alaska Native Clinical Setting

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Project Cell & Tell—mHealth
in the Urban American Indian and Alaska Native Clinical Setting

by

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A thesis submitted to the
Faculty of the Graduate School of the
University of Colorado Boulder in partial fulfillment
of the requirement for the degree of

Doctor of Philosophy ATLAS Institute
2016
This thesis entitled:
Project Cell & Tell—mHealth
in the Urban American Indian and Alaska Native Clinical Setting
has been approved for the ATLAS Institute

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Douglas Novins, MD

_________________________
Sarah Hug, Ph.D.

_________________________
Mark Gross, Ph.D.

Date ___________________

The final copy of this thesis has been examined by the signatories, and we Find that both the content and the form meet acceptable presentation standards Of scholarly work in the above mentioned discipline.

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ABSTRACT

Morse, Bradley Dean  
(Ph.D., Technology, Media, and Society; ATLAS Institute)

Project Cell & Tell—mHealth in the Urban American Indian and Alaska Native Clinical Setting  
Thesis directed by Professor Clayton Lewis and Professor Sheana Bull

Background and Significance: Project Cell & Tell (C&T) was a mobile health (mHealth) pilot intervention delivered in collaboration with the Denver Indian Health and Family Services (DIHFS) urban clinic. Content for the mHealth project was adapted from a classroom-based health education curriculum called Honoring the Gift of Heart Health (HGHH) and designed to be a standalone mHealth intervention. Short Message Service (SMS; text only) and Multimedia Messaging Service (MMS; text with images) were used to deliver health information over a five week period using three types of messages: information, quiz, and homework. Each participant received two informational SMSs, two quizzes, and a single homework message per week. The research questions were:

1. To what extent is the cell phone, as used in C&T, a feasible dissemination tool to increase knowledge of cardiovascular disease (CVD) risk factors in an urban American Indian Alaska Native (AI/AN) population?

2. In an urban AI/AN population, to what extent, if any, does the inclusion of text with photo elicitation (MMS) increase health knowledge and motivation more than text messaging (SMS)?

3. How applicable were the social science ideas about organic intellectuals and counterhegemonic discourse in shaping the intervention?
Methods: Sixteen people received the SMS intervention and 16 people received the MMS intervention. Following the delivery of messages, SMS participants (4, 25%) attended focus groups, and those in the MMS condition (6, 37%) participated in digital photovoice sessions. Baseline and post-intervention health knowledge surveys were collected from participants.

Results: Quantitative analysis suggested a positive trend in health knowledge for both the SMS and MMS conditions. Four specific types of health knowledge constructs were analyzed: heart attack knowledge, heart health knowledge, physical activity knowledge, and nutritional knowledge. Statistically significant increases were found in heart attack knowledge (F(1,21)=8.92, p<.01); both conditions increased knowledge from baseline (SMS = 41.16; MMS = 39.81) to post-intervention assessment (SMS= 43.08; MMS= 43.63). Varying degrees of participant response rates occurred in both conditions. Positive feedback, in focus groups and photovoice sessions, to the C&T messages and delivery system supported the findings that C&T is a feasible approach within an urban AI/AN clinic. Qualitative evidence from the focus groups, photovoice sessions, and received messages during the intervention supports blending social theory and health models for adoption and dissemination of the C&T strategy in an AI/AN clinic.

Conclusions: This dissertation project showed that using SMS and MMS cell phone functions to increase health knowledge of cardio vascular disease (CVD) in an urban AI/AN clinic was feasible, that participants who used MMS with photo elicitation gained more health knowledge than those using SMS capabilities, an increase in knowledge regarding signs and symptoms of heart attack by means of mHealth was possible, and blended social theory and behavioral health models could contribute to the cultural adaptation of mHealth strategies to engage underserved AI/ANs.
Keywords: American Indian, Alaska Native, mHealth, Cardiovascular Disease, SMS, MMS, Urban Clinic, photovoice
Acknowledgments

Thank you to my loving wife and best friend, Erica, who has supported me since day one; so glad to have rode this wave together. Olive, thank you for making me a progress chart – it was very helpful – and for telling me to keep my fizzy bubbles open (glad baby sister was with us for the defense 😊). Lisa, thank you for your support, and the good deal on rent as I pursued my Masters’ degree, your friendship means the world to me. Thanks for your insightful questions at the defense, Evan. Ma and Pa, there are no words to express my gratefulness for all your love and support – I hope I am half the parent you two have been and continue to be. A huge debt of gratitude to staff at Denver Indian Health and Family Services, as well as the Centers for American Indian and Alaska Native Health. To my chair, Clayton, your support and guidance have been greatly appreciated; thank you for your unwavering commitment and support. To Sheana, Doug, Sarah, and Mark: looking forward to years of collaboration!
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Chapter 1: Introduction

1.1. Statement of the problem: CVD in the urban AI/AN population

The Centers for Disease Control and Prevention (CDC) estimates that approximately 600,000 people die each year of cardiovascular disease (CVD) in the United States. Cardiovascular disease is responsible for one out of every four deaths (Heart Disease Facts-CDC, 2013). In the American Indian and Alaska Native (AI/AN) population, CVD is the second leading cause of death behind cancer. In 2008, heart disease represented 18% of the deaths among all AI/ANs (Heart Disease Facts-CDC, 2013). AI/ANs die from heart diseases at younger ages than other racial and ethnic groups in the United States; 36% of AI/ANs who die of heart disease die before age 65, compared to 6% in the general population. The median percentages of AI/ANs, age 18 and older that report no leisure-time physical activity in the last 30 days, is 37.2%. As a comparison, only 25% of 18 and older in the general population reported no leisure-time physical activity (Moore et al., 2012). Among AI/ANs age 45-74, 16.8% of men and 19.6% of women report no physical activity during the past year (American Indian and Alaska Native Heart Disease and Stroke Fact Sheet). A total of 15,565 deaths occurred in the AI/AN population in 2010, and 2,793, or 18%, were attributed to heart disease (National Vital Statistics Reports, 2013). Eighteen percent of deaths in 2010 are consistent with the percentage reported in 2008. Cardiovascular disease prevention services are needed to address the morbidity in the AI/AN population.

The importance of influencing knowledge and awareness of CVD is illustrated by an American Heart Association (AHA) effort in 2012, in a survey that sought to understand the connection between women’s knowledge and awareness of CVD risks and the established CVD risk among women as their number one killer. The results showed that only one in three women
were able to identify CVD as the leading cause of death among all women (Mosca, et al., 2013). If one does not know the signs and symptoms of heart attack or stroke, the person is less likely to respond in a time that will allow for emergency intervention (Jones et al., 2009). Knowledge and awareness is therefore paramount for survival.

The Mosca study showed that over the last 15 years, there has been an increase of awareness around CVD, but there is a population gap that emerged, in which racial and ethnic minorities were still unable to identify CVD as their leading cause of death.

Many AI/ANs moved to urban areas in the last half of the 20th century. “By 1977, 50% of all American Indians lived off the reservation” (Kramer, 1992, p. 281). Most recent census data shows the majority of AI/AN reside in urban areas (Wickramasinghe, et al., 2011). This represents a major change in lifestyle from predominantly remote rural and country areas to metropolitan and urban settings. Many AI/ANs moved to urban settings for work and other resources not readily available in reservation communities. Despite this residential shift, access to clinical services remained difficult to secure, including CVD prevention. Most services provided by the Indian Health Services (I.H.S.) are offered on or near reservation communities. Approximately 1% of the I.H.S. budget is used to provide services to AI/ANs living in urban areas (Robinson , 2007). Limited funding has made it difficult to provide prevention services in urban clinics. New, novel and innovative strategies are needed to address the CVD morbidity.

Mobile health (mHealth) is at the intersection of Electronic Health (eHealth) and cellular communication technology. eHealth is a term that was coined in the 1990s and refers to healthcare activities supported by any communication system or electronic process. mHealth, then, is any eHealth practice designed for and accessed by mobile technology (Adibi, 2015).
Despite an abundance of research on mHealth strategies in recent years, no studies look specifically at mHealth and CVD prevention, or any other health focus, in any AI/AN population, including an urban AI/AN population. Yet the urban AI/AN population could potentially benefit from such an intervention because of the lack of resources dedicated to the urban AI/AN population for public health prevention work.

This dissertation evaluates mHealth as a means of CVD prevention in an urban AI/AN population. It also explores ways of blending social theory and behavioral health models to aid the cultural adaptation of an evidence-based curriculum to be used as an mHealth strategy in the urban AI/AN population to increase knowledge and awareness around CVD.

1.2. Rationale for this study

Conditions that create deficiencies in health knowledge in lower socioeconomic status (SES) populations, including the AI/AN, include disparities in income (Zuckerman et al., 2004) and disparities in education (Marin et al., 1994) that lead to decreased access levels and operational knowledge of information and communication technology (ICT). These disparities may potentially lead to reduced consumption of public health media campaigns (Marin et al., 1994). The rationale for implementing an mHealth project stemmed from these reasons. The rationale also drew on observations from previous programs/interventions that were not successful due to difficult recruitment and enrollment, participant burden, and stigmatization of being affiliated with such programs.

Another motivating factor is the fact that some older AI/AN have stress related to the boarding school experiences (Littlemoon, 2009) that makes conventional classroom experiences difficult; mHealth provides a potential alternative. In his book, *They Called Me Uncivilized: The Memoir of an Everyday Lakota Man from Wounded Knee*, Littlemoon (2009) shone a light on the
impact federal Indian policies had on an entire generation of AI/AN boys and girls as they were forced to leave the security of their homes and attend boarding schools. Once at the boarding schools, AI/AN youth were not allowed to use their traditional languages or wear traditional clothing. These policies had a major impact on the way an entire generation feels about education, attending school, and learning in general.

A feasibility study was needed to assess if an mHealth approach for increasing health knowledge and awareness was appropriate in an AI/AN population. This assessment is needed before any amount of funding is directed to implementing mHealth initiatives within the national network of AI/AN urban clinics. If mHealth is not appropriate, the chance of modifying behavior in subsequent mHealth interventions designed to do more than increase knowledge and awareness of any health priority would be ineffective. Influencing healthy decisions and behaviors is more difficult than increasing health knowledge. For these reasons, the current study aimed to produce a breadth of foundational knowledge from general feasibility to whether people could increase knowledge and awareness by receiving health-related Short Message Service (SMS) on their cell phones.

1.3. What has been done to date for CVD prevention in the urban AI/AN population?

Urban AI/AN have historically been known as an invisible population (UIHI, 2011). This reputation is based on the last three decades, when AI/ANs moved from predominately rural areas where many reservation communities are located, to major urban centers throughout the country. Once in the urban centers, AI/ANs have not moved to centralized ethnic enclaves with other AI/ANs, but have spread out over the metropolitan areas, and become unseen by the rest of the urban population (UIHI, 2011). This urban-based migratory pattern is unique to the AI/AN
population and has created difficult issues in terms of creating and maintaining geographically-centered cultural communities.

In 2000, the Urban Indian Health Institute (UIHI) was created to research the health disparities affecting the growing urban AI/AN population. The UIHI worked directly with a network of urban Indian health organizations. These Indian health organizations were created by Congress by the Title V legislation of the Indian Health Care Improvement Act of 1976. Congress, in 2010, permanently re-authorized these important health organizations to ensure that the health needs of urban AI/ANs would not go unaddressed.

UIHI, and the 34 urban clinics that developed from this legislation, were predominately responsible for the bulk of CVD prevention work in urban communities in the last two decades. In 2010, UIHI launched the Health Equity Project. The focus of the Health Equity Project is CVD, depression, and a community-identified health focus or disease priority. The main aim of the Health Equity Project was to reduce morbidity and mortality in the urban AI/AN population by using culturally-targeted programs to achieve Healthy People 2020 goals (UIHI, 2013).

An emphasis on culture was intentionally employed by the Health Equity Project. Focus on culture was based on the notion that each population has a set of unique features that may place that population at risk for certain diseases. Not only does a focus on culture place an emphasis on unique characteristics of the population, but this approach also acknowledges that culturally sensitive and relevant health perspectives and communication styles are beneficial. The UIHI argues that incorporating a cultural approach to prevention work empowers people to make culturally specific decision-making health choices. For example, the extended family is an important cultural element of some AI/AN tribal groups of the Northern Plains (Whitesell et al.,
Therefore, individuals from tribes in the Northern Plains like to include their extended family network in the health decision-making process.

Based on the development and focus of the UIHI, this organization was uniquely situated to do a thorough and extensive review of research, awareness building, and prevention occurring in urban areas to address CVD in the AI/AN population. The UIHI leveraged intimate knowledge of the 34 clinics in the national network to gain insight on CVD work completed throughout the country. This exploratory research to canvas and document CVD related activities was conducted between 2010 and 2011.

A broad range of CVD prevention related programs or activities were found to be occurring throughout the nation to address CVD among AI/ANs. In all, 17 distinct programs or activities were identified, and these were categorized in five different initiative types: research (5), national initiatives (3), efforts to increase awareness (3), health education curricula (3), and other programs (3).

The UIHI report (2011) represents the totality of the response to the problem of CVD in the urban and reservation setting since 1995. Before 1995, there was little recognition of the urban AI/AN population health, but the 1990s brought an increased awareness of the failed federal policies of termination and relocation, with increased interest in this growing population and its related health (Rosenthal, 2012). Table 1.1 names and categorizes each of the 17 different responses to CVD, provides a brief description of the program, indicates whether the program included any evaluation, and indicates if the health education component, if the program included an educational component to address knowledge and increase awareness, was evidence-based.
Table 1.1: Urban clinic responses to CVD

<table>
<thead>
<tr>
<th>Program Name / Category</th>
<th>Brief Description</th>
<th>Included Evaluation?</th>
<th>Health education component supported by evidence base?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Building Healthy Hearts for American Indians and Alaska Natives – Research</td>
<td>Background report on disparities in CVD in AI/AN communities</td>
<td>Yes</td>
<td>NA</td>
</tr>
<tr>
<td>Strong Heart Study – Research</td>
<td>The largest epidemiological study of CVD risk factors in American Indians</td>
<td>Yes</td>
<td>NA</td>
</tr>
<tr>
<td>Native American Time to Treatment Intervention Evaluation – Research</td>
<td>Investigated barriers to timely treatment for heart attack in AI/AN communities</td>
<td>Yes</td>
<td>NA</td>
</tr>
<tr>
<td>Childhood Project – Research</td>
<td>Seeks to identify risk factors for obesity in a Tulsa, OK, community</td>
<td>Yes</td>
<td>NA</td>
</tr>
<tr>
<td>Inter-Tribal Heart Project – Research</td>
<td>Study identified CVD risk factor in Minnesota and Wisconsin tribes</td>
<td>Yes</td>
<td>NA</td>
</tr>
<tr>
<td>Racial and Ethnic Approaches to Community Health Across the United States – National Initiative</td>
<td>Programs designed to utilize community based participatory approaches in addressing health disparities in communities</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Healthy Heart Demonstration Projects – National Initiative</td>
<td>Focuses on the reduction of CVD risk factors in AI/ANs diagnosed with diabetes</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Well Integrated Screening and Evaluation for Women Across the Nation – National Initiative</td>
<td>Provides screening, referrals, and services and lifestyle interventions</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Pow Wow for the Heart – Effort to Increase Awareness</td>
<td>Sponsored pow wow to emphasize heart health</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Blackfeet Reservation Media Campaign – Efforts to Increase Awareness</td>
<td>Media campaign to encourage people to call 911 in the event of a heart attack on the Blackfeet Reservation</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Go Red for Women-</td>
<td>Uses storytelling from AI/AN to</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Storytellers Program – Efforts to Increase Awareness</td>
<td>inform others about the risks of CVD</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pathways – Health Education Curricula</td>
<td>School-based physical activity and nutrition curriculum</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Physical Activity Kit – Health Education Curricula</td>
<td>Utilizes a lifespan approach to promote culturally appropriate activities for all ages</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Honoring the Gift of Heart Health – Health Education Curricula</td>
<td>10-week curriculum that focuses on nutrition, tobacco cessation, physical activity, and traditional recipes to combat CVD</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Traditional Knowledge Camps – Other Programs</td>
<td>Restores and disseminates traditional cultural practices to reduce CVD</td>
<td>Yes</td>
<td>No</td>
</tr>
<tr>
<td>Wisdom Steps – Other Programs</td>
<td>Focuses on little changes elders in AI/AN communities can make to improve heart health</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Native American Cardiology Program – Other Programs</td>
<td>Program designed to eliminate health disparities by reducing by telehealth a barrier of access – distance</td>
<td>No</td>
<td>No</td>
</tr>
</tbody>
</table>

Twelve of the 17 programs had some evaluation components, but only three of the programs used evidence-based health education components to address knowledge. Two of the three programs using evidence-based educational components used *Honoring the Gift of Heart Health* (HGHH), which was used in this dissertation as source material.

The seventeen different programs or activities identified by the 2011 UIHI report represented a substantial effort to prevent CVD and increase knowledge and awareness about the condition. However, there is still a CVD problem in the urban AI/AN population and more needs to be done to curtail the high rates of CVD in this population.

None of the activities or programs reviewed above used social media or SMS to address CVD knowledge and awareness messaging. This gap in the literature further supports the
rationale of this dissertation. mHealth has particular qualities and characteristics that make using technology for knowledge acquisition and increased awareness potentially beneficial.

1.4. eHealth and mHealth: tools with potential

The definition of eHealth is not simple, due to the large number of electronic tools the term covers. A systematic review (Oh et al., 2005) included 1,209 abstracts and 420 citations that yielded 51 unique definitions for eHealth. The following resources were searched for eHealth definitions: Medline and Premedline (1966-June 2004), EMBASE (1980-May 2004), International Pharmaceutical Abstracts (1970-May 2004), Web of Science (all years), Information Sciences Abstracts (1966-May 2004), Library Information Sciences Abstracts (1969-May 2004), and Wilson Business Abstracts (1982-March 2004). In these searches, the inclusion criteria for eHealth definitions stated that the definition needed to be in print format or on the Internet, available in English, and contain text that attempts to explicitly define the term eHealth. A strategy called constant comparative method (Strauss and Corbin, 1998) was used in the qualitative analysis of the definition search. This method is an iterative process of analyzing data. Words, phrases, sentences, and paragraphs are coded and grouped until no new definitions emerge.

Oh et al. concluded that their 51 definitions, at the highest level, all included disparate concepts that span the range from health to technology to commerce. Health, in these 51 definitions, almost exclusively referred to health as a process instead of an outcome. The main characteristics of the definitions of technology included technology as a tool to support and extend the process/function/service of healthcare and also to support prevention. Overall, the Oh research team stated that the outlook embedded within the definitions of eHealth were generally positive and optimistic.
1.4.1. Definition of mHealth

The definition of mHealth is important because key attributes of the definition highlight reasons why mHealth might be a potentially beneficial approach to heart health knowledge and increased awareness in the urban AI/AN population. The definition provided here is a pragmatic definition that is applicable to a feasibility study to assess whether mHealth is an approach worth pursuing in the urban AI/AN clinic setting to improve CVD knowledge acquisition and increased awareness.

As previously stated, mHealth is any eHealth practice designed for and accessed by mobile technology (Adibi, 2015). The main difference between eHealth and mHealth is how health data are created, stored, retrieved, and transmitted (Akter et al., 2010). mHealth relies on devices that are mobile and accessible for most people, unlike desktop computers, because of the relatively low cost to purchase and maintain mobile devices.

Key attributes associated with the definition of mHealth include: easy accessibility, personalized solution, and location-based services (Akter et al., 2010). Additionally, mobile phones are relatively intuitive and do not require that the user have a sophisticated understanding of electronics to operate. These key attributes are also closely associated with Bull’s unique and beneficial rubric (2011). This rubric defines why technology-based health promotion is unique and potentially beneficial when compared to conventional healthcare and health promotion. This rubric is explored in greater detail in Chapter 2.

1.4.2. Potential benefits mHealth as an intervention for the urban AI/AN population

The circumstances of the AI/AN population made mHealth a potential approach to increasing CVD awareness. As mentioned previously, many AI/ANs have moved to urban areas (Kramer, 1992; Wickramasinghe, et al., 2011). Bull defines key mHealth characteristics in the unique and
beneficial rubric: autonomy, standardized information, interactivity, portability, and lower program costs (Bull 2011). These elements will be detailed more thoroughly in Chapter 2. However, for the time being, it is important to match these mHealth concepts with corresponding characteristics of the urban AI/AN population in Denver, Colorado.

The AI/AN population in Denver is dispersed throughout the metro area. mHealth has the ability to reach autonomous individuals throughout the community who can choose how much to interact with the content based on their individual need. Indeed, the geographical barrier introduced by the fact that there is not a centralized location, community, or enclave where most of the AI/AN preside makes connecting with people easier through electronic means instead of by place-dependent approaches.

The standardized information that is delivered by mHealth is important because of the relatively low SES of urban AI/ANs. According to the U.S. Department of Health and Human Services Office of Minority Health the median household income for American Indian and Alaska Natives is $37,353, as compared to $56,565 for non-Hispanic Whites. Twenty-nine percent of AI/AN age 16 and over work in management and professional occupations, in comparison to 40% of Whites. Additionally, 26% of the AI/AN cultural group live at the poverty level, as compared to 11% of non-Hispanic Whites (“http://minorityhealth.hhs.gov/omh,” n.d.). It is reasonable to assume that the health literacy of a population that is in an economically disadvantaged position will be lower than the general population.

Standardized information delivery can potentially help increase the general heart health knowledge of this population. Delivery of standardized information is critical because it guarantees the receipt of important information that all participants need to improve their
knowledge of heart health. As stated previously, in the instance of a heart attack or stroke, if the victim is not knowledgeable and aware of the signs and symptoms of a heart attack or stroke, or CVD in general, they will be less likely to call for emergency intervention. It is also true that if people are not generally aware of CVD, they will likely perpetuate unhealthy lifestyles. Ideally, standardized information is based in evidence and can ensure that program participants receive material that retains fidelity of the evidence base.

Interactivity in mHealth is an important characteristic for the urban AI/AN population because it creates a line of communication between individuals and healthcare providers. Transportation is expensive in urban communities and the urban AI/AN population is generally economically disadvantaged. Using electronic means to communicate health related information circumvents the need for individuals to be on time to appointments or interventions in which heart health-related information is provided. Furthermore, interaction by way of mHealth allows for retrieval of health-related information when needed if the information is saved or archived on a device.

Many of the reasons that mHealth is potentially beneficial in the urban AI/AN population are related to economic disadvantages, and portability is no exception. Portability is related to receiving information in real time no matter the geographical location of the mHealth recipient. There is a high degree of transition of residency for the urban AI/AN population, both back-and-forth from reservation communities, and within the urban context itself.

Lower program costs are also a key characteristic of mHealth initiatives. Because of the lack of funding in urban clinics, the low cost of mHealth is attractive when compared to traditional face-to-face interventions.
1.4.3. Texting as an mHealth intervention

Texting uses the ability of mobile phones to send and receive short messages, consisting of up to 160 characters. Fogg and Allen (2009) framed recommendations within technology-based health promotions for this specific modality. Their paper, *10 Uses of Texting to Improve Health*, and subsequent book, *Texting 4 Health: A Simple, Powerful Way to Change Lives* (2009), focused on how text messages could be used to motivate, persuade, and influence people’s health behaviors, as summarized in Table No. 1.2.

*Table 1.2: Texting strategies and potential outcomes*

<table>
<thead>
<tr>
<th>Strategy:</th>
<th>Potential outcome:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sending Information to the User</td>
<td>Educating People</td>
</tr>
<tr>
<td></td>
<td>Notifying People</td>
</tr>
<tr>
<td></td>
<td>Reminding People</td>
</tr>
<tr>
<td>Gathering Information from Users</td>
<td>Collecting data from People</td>
</tr>
<tr>
<td></td>
<td>Journaling by Individuals</td>
</tr>
<tr>
<td>User Questions &amp; Expert Response</td>
<td>Getting Answers from a Database</td>
</tr>
<tr>
<td></td>
<td>Getting Answers from a Person</td>
</tr>
<tr>
<td>People-to-People Connection</td>
<td>Connecting Individuals</td>
</tr>
<tr>
<td></td>
<td>Connecting Groups</td>
</tr>
<tr>
<td>Transactions</td>
<td>Getting things done</td>
</tr>
</tbody>
</table>


It can readily be seen how these strategies and outcomes are of potential value in health interventions.

Fogg and Allen were not investigating texting as a modality for minority populations. One might wonder whether the technology is widely available to these groups. In fact, there is reason to think that text messaging is a preferred communication method. As
Table 1.3 shows, messages now outnumber voice calls as the preferred modality of communication when using a cell phone. The Nielsen Company employed a large-scale study of cell phone use to provide this evidence (Nielsen, 2008). These numbers provide evidence that cell phone users are comfortable with SMS technology, and in most cases, SMS is preferred to voice calls. This preference is associated with lower costs of SMSs compared to voice and the ease of using SMS to communicate. The inference is that people of lower SES will use the technology because it costs less than voice minutes.

Table 1.3: SMS overtaking voice calls

<table>
<thead>
<tr>
<th>Time Period</th>
<th>Average # of Monthly Calls*</th>
<th>Average # of Monthly Text Messages*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Qtr 1, 2006</td>
<td>198</td>
<td>65</td>
</tr>
<tr>
<td>Qtr 2, 2006</td>
<td>216</td>
<td>79</td>
</tr>
<tr>
<td>Qtr 3, 2006</td>
<td>221</td>
<td>85</td>
</tr>
<tr>
<td>Qtr 4, 2006</td>
<td>213</td>
<td>108</td>
</tr>
<tr>
<td>Qtr 1, 2007</td>
<td>208</td>
<td>129</td>
</tr>
<tr>
<td>Qtr 2, 2007</td>
<td>228</td>
<td>172</td>
</tr>
<tr>
<td>Qtr 3, 2007</td>
<td>226</td>
<td>193</td>
</tr>
<tr>
<td>Qtr 4, 2007</td>
<td>213</td>
<td>218</td>
</tr>
<tr>
<td>Qtr 1, 2008</td>
<td>207</td>
<td>288</td>
</tr>
<tr>
<td>Qtr 2, 2008</td>
<td>204</td>
<td>357</td>
</tr>
</tbody>
</table>

Note. From The Nielsen Company (January 1, 2006 to June 30, 2008)
Note. Data includes U.S. wireless subscribers only.
Some data show minorities own mobile technology and use mobile capabilities more often than their white counterparts, according to the Pew Research Center (“Mobile Technology Fact Sheet-2014,” January 2014). This recent Pew survey (Table 1.4) described cell phone ownership within several major minority populations:

Table 1.4: Cell owners in 2014

<table>
<thead>
<tr>
<th></th>
<th>Have a cell phone – 90%</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>All adults</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Sex</strong></td>
<td></td>
</tr>
<tr>
<td>Men</td>
<td>93</td>
</tr>
<tr>
<td>Women</td>
<td>88</td>
</tr>
<tr>
<td><strong>Race/ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>90</td>
</tr>
<tr>
<td>African-American</td>
<td>90</td>
</tr>
<tr>
<td>Hispanic</td>
<td>92</td>
</tr>
<tr>
<td><strong>Community Type</strong></td>
<td></td>
</tr>
<tr>
<td>Urban</td>
<td>88</td>
</tr>
<tr>
<td>Suburban</td>
<td>92</td>
</tr>
<tr>
<td>Rural</td>
<td>88</td>
</tr>
</tbody>
</table>

*Note.* From Pew Research Center, “Mobile Technology Fact Sheet-2014,” January 2014

African-Americans and English-speaking Latinos continue to be among the most active users of mobile technologies. Cell phone ownership is higher among Hispanics (92%) than among whites (90%) and African Americans (90%). Similarly, minority groups are more likely to use text than their white counterparts (Lenhart, 2010). Whether the AI/AN population usage mirrors that of their African-American and Latino counterparts is uncertain, but it is plausible that it does.
1.5. Previous studies of mHealth

Positioning this project in the larger mHealth landscape is challenging because of the lack of previous research on the AI/AN population and mHealth. A special issue of the Wicazo Sa Review (1998), a journal of Native American studies, addressed AI/AN and modern technology and linked traditional culture with present day concerns, including health related concerns, but not mHealth; mHealth had not been formulated as a concept in 1998. Searches on Google Scholar, JSTOR, PubMed, and EBSCO yielded zero matches for evaluation of mHealth strategies and the AI/AN population. Search terms for relevant literature for this population included: American Indian, Native American, Native, Indian, AI/AN, and urban. Technology search terms included: mHealth, mobile health, texting, text message, SMS, and MMS (Multimedia Messaging Service). These terms were used in various configurations of population and technology to search for evaluated mHealth projects in the AI/AN urban population, with no result.

Given this lack of relevant studies, the development of this study drew on literature that addresses different, but potentially related technologies and/or populations, as applied to a range of health issues that may share characteristics with heart health.

1.5.1. mHealth as a strategy in chronic disease and self-management

Some authors argue that in this age, populations have aged, and unhealthy lifestyles have become routine, leading to the proliferation of chronic diseases, including CVD, and have become epidemic globally (Wang et al., 2015; Mirza et al., 2008). The pervasive nature of cell phones might be a critical attribute in how patients receive public information and awareness campaigns. Widespread adoption of mHealth strategies hinges on perspectives that are social, technical, economic, and organizational (Mirza et al., 2008). Social barriers include user
perspectives on less face-to-face interactions with healthcare providers, while technical skills are required to use technology that might be unaffordable to all users, and healthcare providers must buy in to mHealth as a strategy and endorse these strategies in their organizations.

If these barriers can be transcended, cell phones can be used in a manner that assists the management of chronic diseases. For example, people with chronic diseases are susceptible to secondary complications if self-management is not followed as directed by healthcare providers. Secondary complications can be minimized if patients have access to easily retrievable and understandable protocols (Parmanto et al., 2013).

Despite the barriers listed above, there is great potential for mHealth strategies to assist in the self-management of chronic diseases. Changes in clinical knowledge and awareness of risk factors are objective outcomes that can be measured (Free et al., 2010). However, enrolling participants into mHealth programs is not as simple as finding participants that have access to cell phones. The mHealth approach also requires that effort and resources are applied to other components of the program including curricula, support staff, patients, and the organization that is supporting the initiative (Free et al., 2010).

Adherence, in the case of chronic disease, is paramount. Short message service is the most commonly used tool for adherence in relationship to chronic diseases (Hamine et al., 2015). Appointment reminders are an example of how some healthcare providers increase adherence for a broad range of health priorities, from CVD to diabetes.

Evaluation of mHealth has produced enough literature to support research syntheses and meta-analyses focused on chronic disease self-management for a variety of health issues. mHealth has shown value for a number of challenges, including smoking cessation (Rodgers et al., 2005; Fjeldsoe, Marshall, & Miller, 2009; Whittaker et al., 2009); diabetes management
Rodgers et al. first studied smoking cessation via mHealth using SMS in a randomized controlled trial, with 1,700 participants. In the experimental condition participants received smoking cessation advice, support, and distraction via SMS, while participants in the control received only occasional thank-you messages. Rodgers’s team found that at six weeks, 28% of the experiment condition reported non-smoking compared to 13% of the control condition. This advantage held up at 12 weeks, but by 26 weeks an increase in nonsmoking among the control participants reduced the effect. Rodgers et al. concluded that SMS was helpful because it was affordable, personalized, age appropriate, and not location dependent.

The generally positive findings by Rodgers et al. are representative of the general pattern of results reported in reviews of the literature. Wei et al. (2011) reviewed the use of SMS for providing emotional support and health education to manage chronic conditions, using an electronic search in December 2009, keywords relating to SMS and health interventions were used as search terms. The review included 24 articles: seven on medication adherence, eight on clinical management, and nine on health-related behavior modification. Sixteen of the studies were randomized controlled trials (RCT); 10 of the 16 RCTs reported significant improvements as a result of the intervention, and the remaining six reported positive trends, but were not appropriately powered to claim more than this possibility or significant improvements.

Lewis and Kershaw (2010) conducted a systematic review to provide an overview for disease management using SMS. Studies including in the systematic review included RCTs and quasi-experimental controlled trials that appeared in the literature before June 2009. To be included in the systematic review, only research studies that used SMS as the primary channel of
communication between research and participant were used. Sources searched for relevant studies included: EDLINE, Cochrane Library, Google Scholar, PsychINFO, and PubMed. There were no time parameters placed on the search because of the novelty of an SMS approach in 2009 and earlier. Not all of the studies were focused on disease management; of the 12 studies included, five of the studies focused on disease prevention, while the other seven studies focused on disease management.

Only nine of the 12 studies were sufficiently powered, and eight of the nine studies found that SMS was a useful tool in the prevention or management of chronic diseases. Characteristics that were common among the eight research projects that show success for managing chronic disease included: interactivity, tailoring, and all of the projects ranged in length from 3 to 12 months. None of the studies had long-term follow up with research participants. Examples of positive health outcomes included significant behavior change in reduced smoking and greater frequency of blood glucose monitoring. Significant clinical outcomes included greater weight lose by obese adults at four and 12 weeks and greater decrease in hemoglobin A1c levels in both obese youth and adults.

This systematic review calls for a greater emphasis on how messages are framed because there is some evidence that framing can help people be more receptive to change (Rothman et al., 1993). The authors also mention that a limitation of the study is that because there was heterogeneity of topics addressed, which did not allow a presentation of pooled results. Framing is a key issue for how messages can influence health knowledge.

1.5.2. mHealth and minority populations

mHealth is a potential solution for lower socio-economic status (SES) ethnic minorities. The use of mHealth in the low SES working population of Singapore has been envisioned as a
potential tool to increase knowledge and awareness of CVD (Wang et al., 2015). The research team’s idea was that teaching the working population about healthier lifestyles would decrease incidences of CVD. An mHealth approach has become a reasonable strategy because of the sharp increase in smartphone usage, so much so that the authors claim that the smartphone is a device that most people can afford to own in Singapore, including the working class. However, established mHealth approaches to increase knowledge and awareness of CVD in Singapore do not speak to the unique cultural perspectives and experiences of the Singapore people. For example, Singaporeans have a different diet and work longer hours than their western counterparts. As a result, the research team sought to develop a culturally inclusive mHealth strategy that would meet the needs of the end users. The same need applies the AI/AN population in the Denver Metro area, as discussed below.

1.5.2.1. Studies of texting as a health intervention in minority populations

While increased knowledge and awareness via texting as a health intervention has not been evaluated in an AI/AN population, there have been studies using other minority groups. Gerber et al. (2009) carried out a weight loss program for African American women in which participants completed a six-month weight loss class/program. The study sampled participants in an ongoing clinical trial for weight loss and delivered SMSs to those in the sample population. The sample included 95 women who self-identified as African American, between the ages of 35-60, and who had a body mass index of 30-50, indicating obesity. Messages delivered by SMS were used to create a maintenance program over the six-month length of the study, with an average of three messages sent to each participant per week.

Gerber et al. used two kinds of messages, a pool of 230 generic, theme-based messages, and a collection of 165 messages created by the participants in a workshop of study participants.
The message delivery system used in the study allowed participants to request particular messages to be delivered at particular times. For example, one participant elected to receive messages as a reminder to eat breakfast each day and requested a precise time to receive these messages to encourage breakfast eating behavior, reinforcing knowledge around nutrition.

Gerber et al. report generally favorable response to the messages, with 70 of 73, or 96%, of participants reporting that they read the messages. Of the participants that indicated they received and read the messages, 54 of 68, or 79% of participants, self-reported that the messages helped them toward their weight loss goals. The study did not collect data on actual behavior change or weight loss/gain, and was designed as an early feasibility study investigating health behavior maintenance via SMS.

Unfortunately, Gerber et al. do not report on the impact of message type on participants’ responses. It would be helpful to know, in particular, whether the messages created by the participants were seen differently from the generic themed messages.

Despite this limitation, the Gerber study inspired aspects of the design of the current study, as discussed further in Chapter 3, in particular, the use of participant-created content.

Lin et al. (2015) also carried out mHealth evaluation work in an African-American population to address weight issues and obesity. In an RCT conducted with 124 adults, the Lin research team investigated whether a behavioral theory-based mHealth intervention could increase weight loss when added to conventional care. The primary outcome of this intervention was weight change, which compared a baseline measurement to a post-intervention measurement. Short Message Service messages were sent in a chronological order that reflected the goals of the intervention: preparation, reinforcement of participant nutrition and exercise knowledge, reflection, goal integration, weight loss methods, and maintenance. Sixty-three
participants were randomized to the mHealth condition and 61 to control condition. Weights were collected for 45 participants (36.3%) at three months and 51 participants (41.1%) at six months. At three months, the mean weight loss was 2.5 kg greater in the intervention group compared to standard care (95% CI, -4.3 to -0.6; p<0.001). At six months, the mean weight loss was 3.4 kg greater (95% CI, -5.2 to -1.7; p=0.001). Further, weight loss was correlated with the degree of engagement with messages.

Broom et al. (2015) investigated the feasibility of sending private supportive SMSs to a low SES minority population. Mothers who were at-risk for postpartum depression received SMS four times weekly for six months. Evaluation of the message protocol and perceptions of receiving the messages was done by a Likert scale questionnaire and an open-ended qualitative survey. Results were broadly positive; more than 80% of the mothers felt that messages were easily received and read and personally relevant.

Other mHealth studies of at-risk have been conducted outside the United States. Internationally, mobile technology clearly has decreased the barrier access issue described by the digital divide (Bull 2012), since mobile technology in some foreign countries appears on a massive scale. For example, according to a study based in rural clinics in India (Shet et al., 2010), 73% of people stated that they owned cell phones, and 26% of people stated that they shared ownership of a cell phone; astonishingly, 99% have access. Of the same respondents, 66% stated that they felt cell phones were a good option and had called the clinic for health-related information. On the other hand, cell phone penetration in Africa is low, compared to developed countries. In Africa, prepaid cards and sharing of cell phones affect access (Kaplan, 2006).
Text4Baby served low SES minority at-risk women (Poorman et al., 2012; Evans, Wallace, and Snider, 2012; Evans, 2014). It provided a free service for low-income women during pregnancy and the first year of their child’s life. It was designed and implemented by the nonprofit National Healthy Mothers, Healthy Babies Coalition (HMHB) using the principles of social cognitive theory (Bandura, 2004), the health behavior model (Ajzen, 1991), and the Transtheoretical Model (Prochaska et al., 1992). Participants who opted into the service received three free text messages a week. Topics included: labor signs and symptoms, prenatal care, urgent alerts, developmental milestones, immunizations, nutrition, birth defect prevention, safe sleep, and safety. The messages were timed relative to the expected birth date of the baby, so that messages on a given topic were received when that topic was most relevant.

A randomized study of Text4Baby showed significant differences in mothers’ beliefs and knowledge compared to care as usual (Poorman et al., 2012). In a second study Evans, Wallace, and Snider (2012) examined the impacts of the prenatal component of Text4baby on attitudes (such as the importance of eating five or more fruits and vegetables for the health of the baby) and behaviors (smoking during pregnancy) using a randomized-controlled pre-post study design. Eighty-six of 123 Text4Baby participants completed a follow-up interview approximately 28 weeks postpartum (48 participants in the Text4Baby condition, 28 in the care as usual condition). Bivariate analyses showed no significant changes in any of 13 attitudes or behaviors. However, when controlling for educational status in a multiple logistic regression model, Text4Baby participants were significantly more likely to endorse the statement, “I am prepared to be a new mother,” compared to those who received care as normal.

These results from studies of Text4Baby were relevant for the current study in three respects. First, they suggested that a high-risk population can be enrolled in a randomized study
of text messaging. Second, the investigators’ emphasis on theory-based development of text messaging interventions advanced an area that has typically taken a more pragmatic approach to content development (Evans et al., 2011). Finally, the study suggested that modest changes in overall attitudes are possible with this low-cost addition to usual care, but that changes in specific attitudes and all behaviors may be beyond the reach of this type of intervention.

The 2012 study (Evans, Wallace, and Snider, 2012) had a high attrition rate and a small sample size (with the authors acknowledging that the study was underpowered), so definitive conclusions about the true potential of this intervention were difficult to make. Evans (2014), reported further work, showing statistically significant increases for daily fruit and vegetable consumption, seeking health information online, reductions in reported smoking in the past 30 days, and taking pre-natal vitamins among Text4Baby participants compared to control participants (Evans 2014).

The authors noted an important challenge for evaluation work in the domain of mHealth. The ubiquitous nature of technology made it difficult to have a pure control condition within the study. Not sending messages to one condition does not necessarily mean those participants cannot seek related information on their own, thereby introducing unintentional contamination into the inquiry.

1.5.2.2. mHealth in the AI/AN population: unevaluated programs

As mentioned earlier, searches for reports of evaluations of mHealth programs for AI/AN participants were unsuccessful. However, there are some unevaluated mHealth programs for this population that are of interest for the design of the current study.

Project Red Talon (“http://www.npaihb.org/epicenter/project/project_red_talon,” n.d.) was implemented at the Northwest Portland Area Indian Health Board (NPAIHB) with an initial
focus on HIV/AIDS among AI/AN youth. Over time, the project expanded to include a wider range of content on social and health issues, delivered by a messaging system called WERNATIVE (as well as a Web site and other online resources.) For marketing and branding reasons, the “R” in the WERNATIVE title is red to make the word more readable.

WERNATIVE delivered messages regarding: the teachings from Native leaders; wellness and life balance; family relationships; mental health; tobacco; drugs and alcohol; violence and bullying; peer pressure; sexual health; healthy relationships; school pressures; community resources on where to get help from trusted adults; quizzes, polls, and discussions; and scholarships, conferences, and internship opportunities.

Of special importance for the design of the current study is the way in which WERNATIVE drew on the work of Fogg and Allen, discussed earlier. The use of ideas from Fogg and Allen by WERNATIVE is summarized in Table 1.5. As discussed further in Chapter 4, the current study adapted ideas from the WERNATIVE approach, including careful attention to branding, as illustrated in the business card used for recruiting for WERNATIVE (see Figure 1.1)
Table 1.5: WERNATIVE values matched with Fogg and Allen strategies

<table>
<thead>
<tr>
<th>WERNATIVE Values:</th>
<th>Corresponding Fogg and Allen Strategy:</th>
</tr>
</thead>
<tbody>
<tr>
<td>I am Strong, in mind and spirit. By sharing with one another, we can teach each other lessons about courage, pride, self-esteem, and how to find emotional and spiritual health.</td>
<td>Sending Information to the User</td>
</tr>
<tr>
<td></td>
<td>Sending Information from Users</td>
</tr>
<tr>
<td></td>
<td>People-to-People Connection</td>
</tr>
<tr>
<td>I control My Body. My body is mine and mine alone. I have control over my physical and sexual health.</td>
<td>Transactions</td>
</tr>
<tr>
<td>We are Native. We are members of diverse and vibrant communities. Learn more about your culture, history, and traditional teachings.</td>
<td>Gathering Information from Users</td>
</tr>
<tr>
<td></td>
<td>User Questions &amp; Expert Response</td>
</tr>
<tr>
<td>We are Not Alone. Regardless of the issue, there are other Native teens and young adults going through the same life challenges...hear their stories and share your own. Together we can support one another through tough times and come out stronger in the end.</td>
<td>People-to-People Connection</td>
</tr>
<tr>
<td>We can Change our World. Community involvement is something that can start small and make a big impact. We have the tools you need to get started shaping your community in positive ways.</td>
<td>Sending Information to the User</td>
</tr>
<tr>
<td></td>
<td>Gathering Information from Users</td>
</tr>
<tr>
<td></td>
<td>User Questions &amp; Expert Response</td>
</tr>
<tr>
<td></td>
<td>People-to-People Connection</td>
</tr>
<tr>
<td></td>
<td>Transactions</td>
</tr>
</tbody>
</table>
Unfortunately, neither WERNATIVE nor other aspects of Project Red Talon have been evaluated for knowledge or increased health awareness. Additionally, none of the efforts included in Project Red Talon or the WERNATIVE SMS program have been evaluated for increasing heart health knowledge or awareness.

Karasz and Bogan (2012) developed mHealth strategies for the King County department of Public Health in Seattle, Washington. In their formative work, Karasz and Bogan developed four distinct personas, representing four types of texters, to frame their consideration of ways to reach AI youth, ages 18-29, from both cities and reservations. Details on these four texting personas categories can be found in Appendix A. While the Karasz and Bogan work has not been evaluated, they have suggested guidelines for texting practices, summarized in Table 1.6.
Table 1.6: Texting etiquette

<table>
<thead>
<tr>
<th>Grammar and “Netiquette”:</th>
<th>Most people feel that organizations should not use abbreviations in text messages.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Willingness:</td>
<td>Most people interviewed (83%) want to receive text messages about emergencies and disasters. Most people want personalized text – 84% of parents opted-in to receive a text message reminder for their child’s second dose of flu vaccine.</td>
</tr>
<tr>
<td>Cost:</td>
<td>Most people said the cost of receiving text messages is not a concern, as long as they don’t receive a lot of messages.</td>
</tr>
<tr>
<td>Accessibility:</td>
<td>Most people have their phone with them and turned on all the time – especially useful in case of emergencies.</td>
</tr>
<tr>
<td>Trust:</td>
<td>Most people trust the Health Department and messages from the Health Department – may be the same for other tribal and governmental organizations.</td>
</tr>
</tbody>
</table>

*Note: From Public Health – Seattle and King County, n.d.*

They added further recommendations, as follows:

- Don’t waste scarce texting campaign resources on trying to recruit *non-texters* into a texting program. Go for those who already text; they want texting and they’ll sign up. Those who don’t text won’t.
- Don’t send “spam” or non-emergency messages unless individuals specifically request them.
- Text messaging needs to be timely to be valuable.
- Messages should be tailored and pertinent to the needs of the audience.

Although the Karasz and Bogan work, like the WERNATIVE work, has not been evaluated, their guidance was developed when working with an AI/AN youth population, which makes the guidance of potential value for the design of the current study.
1.6. Organizational context: DIHFS

Since the current work was inspired by observations of FitHealth, at Denver Indian Health and Family Services (DIHFS), it was natural to base the project there as well. DIHFS was a good fit to the needs of the project for access to the AI/AN population to test the research questions, and for a setting that offered a rich cultural context to explore possibilities with mHealth strategies. Finding the correct location for a feasibility pilot intervention was critical to test the research questions, but using a system that operates efficiently and reliably in the organizational context was also important. Further, the research objective for the current work is the beginning of a research trajectory and a long-term commitment to not only the DIHFS clinic, but also to the national network of urban clinics.

DIHFS was a member of the Urban Indian Health Programs (UIHP), a network of 32 non-profit 501 (c)(3) clinics that were located in major urban centers throughout the country. These clinical care providers were funded through grants and contracts from the I.H.S., under Title V of the Indian Health Care Improvement Act, PL 94-437. In the Omnibus Reconciliation Act (OBRA) of 1993, Title V, hundreds of tribal programs and clinics were added to the list of specific programs automatically eligible for federally qualified health center designation. The I.H.S./urban grant program fund numerous contract programs, including: information, outreach and referral, dental services, comprehensive primary care services, limited primary care services, community health, substance abuse (outpatient and inpatient services), behavioral health services, immunizations, HIV activities, health promotion, and disease prevention.

The DIHFS clinic was considered an appropriate location to carry out the intervention because it serves as a cultural hub of urban AI/AN interaction, activity, and health services. The DIHFS website described the Denver Indian community that it serves as a young population with
a median age of 30.2, as compared to 34.5 for all other races in Denver, Colorado. The average income reported by DIHFS patients was $621 per month, or $7,452 per year. Most services at DIHFS were available for Native people at no cost, with the exception of some services, like certain dental procedures.

People often came to DIHFS for reasons other than health concerns, services, or treatments. For example, some came to DIHFS to sell or buy jewelry or traditional foods at the clinic and many people stay long after their appointments to network and socialize in the lobby space. The DIHFS clinic also served these valuable roles for local community members with services that are unlikely to be offered at other healthcare providers (adapted from the DIHFS website at www.dihfs.info):

- DIHFS provides health and family services and works closely with their partners--the Denver Indian Center and the Denver Indian Family Resources Center.
- DIHFS can verify Certificate of Degree of Indian Blood (CDIB). If patients don't have a CDIB, DIHFS will ask potential patients to bring in a Tribal ID card or Bureau of Indian Affairs form. Children under 18 may use parental documentation along with their birth certificates.
- DIHFS’s staff checks every client for health coverage eligibility, like I.H.S./Medicare/Medicaid/private insurance. Coverage helps DIHFS to coordinate specialty/advanced care for their clients and helps them to recover costs.

In addition to these opportunities and services, academic research studies in the clinic setting are ordinary occurrences. The clinic population was large enough for sufficient recruitment to
satisfy the research design and successful retention was thought to be an achievable objective.

Figure 1.2 was an image captured from the “Research” page from the DIHFS website; it highlighted the current study near the bottom of the page. At the bottom of the webpage, the banner reads, “Health Research = Bridging Tradition with Science.” Culture was a top priority in the clinic and researchers working in the clinic were expected to understand and honor culture in a professional manner.

Figure 1.2: DIHFS research page

While DIHFS has welcomed research into their clinic, some historical tension between researchers and the AI/AN population remains (Deloria, Jr., 1969). Vine Deloria, Jr., famously
described anthropologists’ annual excursions to Indian reservations to collect data and then quickly leave field sites after their work was completed. Enough data was captured to write academic papers and/or full-length books about the topic. This approach to AI/AN research has been dubbed “helicopter research” for the efficiency that the researcher swoops in and takes what is needed in terms of data without making a commitment to address issues confronting the community. The problem of helicopter research was exacerbated by the relatively small AI/AN population throughout the country because many AI/AN often feel overly scrutinized by researchers who only want to work with communities to achieve their own ends.

Other research practices have unfortunately led to mistrust within AI/AN communities of research projects (“Federal Data Collection in American Indian/Alaska Native Communities,” n.d.). Data has been misused in the past for purposes not communicated to tribal members during consent processes, and the issue of data ownership is important because of these issues (Couzin-Frankel, 2010). These events have forced the AI/AN population to be leery of research, and that included the local Denver AI/AN population.

Working collaboratively with the DIHFS clinic allowed the researcher to build trust with potential participants because the participants were aware that the research was approved by the DIHFS executive committee. There are relatively few research projects that are approved by the DIHFS executive board. Allowing a limited number of research projects to have access to the clinic patient population curbs research fatigue and burden for patients.

The executive board at DIHFS was excited to move into the mHealth arena and have an mHealth intervention available to their patient population. However, the board was concerned about the safety of texting, specifically texting while driving; therefore, the DIHFS executive board requested that the current study made it mandatory that each participant sign an agreement
that stated they would not text and drive during the study (Appendix B). All 32 participants signed this agreement.

The DIHFS clinic had a specific role in this research. A Memorandum of Agreement (MOU) was signed by the researcher and the clinic before the research started. The full terms of the agreement can be seen in Appendix C. In short, this document was drafted with the aid of the University of Colorado legal office. The obligations of DIHFS included access to the client population the clinic serves, allowing the researcher to hang posters and flyers advertising the intervention, advertising of the DIHFS Facebook page, and providing space for the research activities to transpire. The obligation of the University of Colorado included providing the means and support for the completion of the self-report surveys, ensuring all HIPAA regulations are enforced, protecting patient specific research data, compensating DIHFS for physical space for the research activities to occur, and to acquire human subjects approval from the Colorado Multiple Institution Review Board (COMIRB) and from the I.H.S.

Establishing buy-in and trust from DIHFS was critical to the success of this project. Institutional buy-in for pilot projects can make or break a project’s implementation, especially when the project expands into new territory like mHealth. DIHFS had an executive board that governed research projects implemented at the clinic. The current study was presented to the executive board for implementation approval. There were some concerns raised by the board members. One such concern was texting while driving. Requiring such consent might have discouraged participation in the study. However, the inclusion of the no texting while driving pledge is an example of taking the communities’ perspective seriously and integrating it into health-related research. Additionally, the pledge constituted another public health message that the participants received.
1.7. Heart health education in the national AI/AN urban clinic network

_Honoring the Gift of Heart Health_ (HGHH) was not an mHealth intervention, unlike the studies described above, but was a classroom-based educational program developed by the I.H.S. in partnership with the National Heart, Lung, and Blood Institute (NHLBI). HGHH uses an evidence-based manual (see www.nhlbi.nih.gov) created in 2003.

The first national training that focused on the HGHH manual occurred in 2003, with six further regional trainings from 2004-2006. These efforts led to a national campaign to deploy the evidence-based approach in reservation-based communities, including a major emphasis on identifying local level expertise to deliver the heart health content. Federally funded HGHH training efforts lasted through 2010.

The collaborative approach to the development and national dissemination of HGHH was well received by many rural and urban tribal communities, and the program has been used widely across Indian Country. Two case studies at service units in New Mexico and South Carolina have verified the ease of implementation and flexibility of the curricula (“The NHLBI and the Indian Health Service Develop Honoring the Gift of Heart Health,” n.d.).

One study demonstrated increased knowledge and awareness as a result of delivering the HGHH curricula (Brega et al, 2013). This study showed that AI/ANs have a high level of CVD understanding, but lacked awareness of heart attack signs. This lack of awareness was concerning because of the high prevalence of CVD in the population. “Although HGHH participants improved in recognition of heart attack and stroke symptoms, the percentage of respondents with optimal knowledge remained low” (Brega et al., 2013). The study findings showed that the curriculum improved health knowledge, and participants with low health literacy skills benefited as much as more health literate participants.
During a research project, Centers for Excellence in Eliminating Disparities (CEED), in 2011, the Centers for American Indian and Alaska Native Health (CAIANH) surveyed the network of 32 urban Indian clinics throughout the country to gauge interest in social media and mHealth. Data collected came from a convenience sample, relying heavily on the relationships forged by CEED through national collaborations with and between multiple urban AI/AN clinics on health issues in the urban AI/AN population.

As recently as 2011, urban clinics throughout the country had not been utilizing social media and mHealth. The CEED social media research is unpublished, but provided insight on the lack of mHealth initiatives occurring in the national urban clinic network, while responses indicated an interest in the mHealth approach. The response rate for the CEED social media survey was 31% (10 of the 32 clinics). In answer to the question, “What specific results or impacts do you want from your social media efforts?” CAIANH received the following responses:

- “Build awareness in our community, health issues, etc.”
- “I have no plans to use social media in that very few NA have computers at this time.”
- “No one is currently sharing anything about social media.”
- “If we were using social media I would want the efforts to result in increased participation in our programs and to increase access to NA specific health promotion disease prevention education.”
- “People’s phones are more important than their rent so they are always connected.”
Acknowledgement from the clinics that awareness is an important health-related concern, as the first bullet suggests, was interpreted as an endorsement that the clinics could stand to benefit from new and novel approaches to increase knowledge and awareness.

The last quotation on this list is also illuminating, especially when read together with the second. Historically, clinics have not used social media because there is a perceived lack of technology accessibility. Cell phones, on the other hand, are accessible and easy to use, so much so, that people tend to pay for cell phone services before rent. Undoubtedly, many in the AI/AN population value the access and connectivity that cell phones provide.

Face-to-face HGHH courses have been taught in the DIHFS clinic, and the researcher served as an instructor. This experience provided an opportunity to see participants interact with the HGHH curriculum. In the seminar style classes, participants shared their understandings of the material and how the material affected their lives. Lively conversations during the classes indicated that the material was culturally relevant, and DIHFS clientele were interested in improving their heart health knowledge.

A formal assessment was not implemented during the time the face-to-face classes were taught at DIHFS. However, observations of participants were made that indicated potential success in terms of how promising an mHealth project would be in this particular clinic population. Casually observing HGHH participants using their phones was a good sign of technological familiarity. Although few people who attended the face-to-face HGHH classes were younger than 30, notably, many of the HGHH participants used cell phones to send and receive SMSs while in class.

If, in fact, the AI/AN population have access, then it may be possible to use cell phones as targeted personal health assistants in the AI/AN population. Targeted mHealth programs for
the AI/AN population would be similar to what Derbyshire and Dancey’s (2013) call for in women’s health. These authors acknowledged that mHealth solutions have some merit, but tailored solutions to a cultural audience or a specific gender will likely be more successful. Based on their feedback analysis, women seek mHealth solutions that are trustworthy and evidence-based, but more importantly, speak to their needs as women. The same is true for the AI/AN populations; mHealth solutions must acknowledge the cultural needs of the population.

1.8. Overview of the dissertation

There are four remaining chapters. Chapter 2 describes the theoretical approach to the research project described in this dissertation and provides more detail on how the research questions are related to the theoretical approach.

Chapter 3 describes the mHealth system design and provides a rationale for the technical decisions made in its development, presents the study design, and what measure were used and how the measures relate to the theoretical framework.

Chapter 4, Results, presents demographic data and outcome data in the form of memoing, survey data, response rates, participant SMS/MMS response content, exit surveys, focus group responses, and photovoice narrative analysis.

Chapter 5 presents a table that summarizes answers to the three research questions. A discussion follows that relates the answers to the literature of other mHealth pilot/feasibility projects discussed in Chapter 1. The conclusion synthesizes the research questions and findings, and relates them to the literature presented in the Scientific Background section. This discussion then leads into a description of planned future work.
Chapter 2: Behavioral Health Model and Critical Social Theory

2.1. Cell & Tell: a response to the background

Chapter 1 – Introduction provides the background that establishes mHealth and texting as a potential strategy for supporting cardiovascular (CV) health in AI/AN populations. The current study describes the design and implementation of Cell & Tell (C&T), an mHealth strategy designed specifically for the urban AI/AN population to increase knowledge and awareness of CVD. C&T delivered heart health messages to participants for a five week period, after which participants were invited to share their opinions in focus groups or create group-level photovoice documents. The design of C&T is shaped by the theoretical background discussed in this chapter.

2.2. Theoretical components

This chapter is organized in a manner to orient the reader to a theoretical framework that combines a behavioral health model with social theory. In particular, C&T draws on three bodies of theory: the Information-Motivation-Behavioral Skill (IMB) model of behavior change (Fisher & Fisher, 1992), Bull’s analysis of key attributes of mHealth interventions (Bull, 2011), and the social theory of counterhegemonic discourse (Gramsci, 1971; see also Carroll, 2009 and Crehan, 2002).

2.2.1. Information, motivation, behavioral skills (IMB)

Information-Motivation-Behavioral Skill (Fisher and Fisher, 1992) focuses on three aspects of a health intervention. The first, information, is the knowledge about a certain health priority that a person receives when participating in an intervention. The second IMB factor, motivation, reflects attitudes towards personal adherence to a certain type of behavior. Does the person want to engage in the behavior, or not? The third IMB factor, behavioral skills, is the
possession of certain skills needed to carry out a new behavior. The three aspects create a system where “information and motivation are thought to activate behavioral skills that result in risk-reduction behavioral change and maintenance of change” (Fisher and Fisher, 1992, p. 464). Recently, a number of projects have demonstrated that IMB is an effective theoretical foundation to modify risky sexual behavior in at-risk populations, including women in low-income housing (Anderson et al., 2006), truck drivers (Comman et al., 2007), and men who have sex with men (Knuaz et al., 2007). IMB is also being used in minority populations within technology-based health promotions for diabetes self-management (Lynch et al., 2016) and breast cancer screening (Talley et al., 2016).

IMB asserts that information, motivation, and behavioral skills are relevant to behavior change and are prerequisites to the change (Kodiath et al., 2005). In this model, informative messages are the key components in helping people know why modifying behaviors can eliminate poor health outcomes. Motivation is also crucial. As Bazargan et al. have argued, “the IMB model views health-behavior modification as a process of providing relevant detailed information while understanding cultural practices and norms in order to carefully create an atmosphere conducive to the consideration of an alternative practice [behavior skill].” Note the emphasis on cultural practices and norms: this point is critical. As will be discussed later in this chapter, it provides the basis for important aspects of the design of C&T, encouraging participants to re-express information provided by C&T in their own terms. Behavioral skills in the application of IMB in the current study are represented by interactions in the C&T intervention through sending text messages, read text messages, and sending photos via MMS.

The IMB framework was used in two ways in the course of the C&T project. First, IMB was used to analyze the potential impact of C&T on participants’ health enhancing behavior.
Here “I” is information supporting healthy behaviors, “M” is the motivation to engage in such behavior, and “B” is the behavioral skills that one must enact to change behavior. In this initial study of C&T, “B” was not assessed, but how well the “I” was transmitted was assessed by tests of health knowledge. The “M,” how the participants felt about the messages used to transmit “I,” was assessed by analyzing participant responses. Second, IMB was used to design and assess the mechanics of the C&T intervention itself, where the “I” is the health information participants need to participate in C&T, the “M” is motivation to participate, and the “B” is applying the skills of interacting, i.e. responding to C&T messages by texting or sending photos, in an mHealth SMS strategy. Here “B” was assessed from response rates of participants, as well as from observations of difficulties participants had or did not have. The behavioral skills needed to participate, reading and sending SMS or MMS, were already accessible in the C&T population. The nature of the question C&T asks in relationship to behavioral skills is a question of feasibility, whether these behavioral skills would be applied to a CVD prevention program.

2.2.2. Bull’s unique and beneficial rubric of technology-based health promotion

Bull’s unique and beneficial rubric (introduced in the previous chapter) was used as a description of what is needed to create a minimally viable product (MVP) (Ries, 2011) for an mHealth intervention. An MVP is a first step in an iterative development process, a version of a product of some sort that has sufficient, if not bare bones, features, to the degree that the features might be acceptable to early adapters of new technology. In the case of mHealth, an MVP allows the testing of a system concept, such as the C&T message delivery model, while limiting the time, money, and other resources needed for development. An MVP makes sense in the framework of a feasibility test: if the basic approach of getting health information via SMS over
mobile cell phones is not appropriate for the intended audience, it is good to know this before resources are used on building a sophisticated system.

Bull’s unique and beneficial mHealth attributes (2011) are a selection of five key theoretical features, from a larger list of technology-based health promotions characteristics, which make mHealth potentially beneficial. As discussed in the previous chapter, these attributes seem well adapted to the needs of the urban AI/AN population addressed by C&T. The attributes shaped the development and implementation of C&T as follows.

To realize Bull’s autonomy attribute, the C&T intervention allowed participants to select information in the intervention that was interesting and relevant to them while ignoring other information. Further, participants could determine how much or little they wished to engage. Thus participants could create and manage an identity within the framework of the intervention, and could express their values either actively through communication, or passively by not engaging with the information or responding to health messages. Face-to-face interventions do not allow the expression of identity as fluidly. The researcher taught a CVD prevention curriculum at the DIHFS clinic. Identity was expressed in person through attendance and engagement only. C&T allows for engagement mediated by the cell phone without in-person attendance.

Bull’s standardized information was realized in C&T by using content from the evidence-based HGHH curriculum, as discussed in the previous chapter. Thus all C&T participants received the same, high quality, information.

Bull’s interactivity attribute motivated two-way communication in C&T. When C&T was developed in 2010, the human-mediated interaction was modeled after texting programs that allowed for interaction with a live therapist, albeit in an asynchronous manner (Hazelwood,
C&T allowed easy and confidential back-and-forth communication with participants, instead of only pushing information to participants (Gerber et al., 2009) without their ability to follow up with questions or comments. Instead, C&T interaction incorporated a response from a human mediator, as in the Hazelwood program (2008), thereby using technology to replicate successful traditional programs in-person interactivity mediated by SMS and MMS.

Bull’s *portability* attribute follows directly from the use of a mobile platform, a key commitment in the basic conception of C&T. As discussed in Chapter 1 this is potentially a key feature for the highly mobile target population for whom C&T was designed.

Finally, Bull’s *lower program costs* attribute shaped the early technical decisions in the design of C&T. As described more fully in Chapter 3 - Methods, C&T is based on free software that could be configured and administered by a sole investigator. This means that a similar program could be implemented elsewhere inexpensively. Since it uses phones that participants already have, costs to participants, as well as to providers, are very low. Further, relative to face-to-face delivery of HGHH, there are savings for participants in the form of gas money, bus tokens, baby sitters, and time spent commuting.

### 2.2.3. Social science of counterhegemonic discourse

Recall the argument by Bazargan et al., discussed earlier, that, to be effective, the “I” in IMB must be presented in a way consistent with “cultural practices and norms in order to carefully create an atmosphere conducive to the consideration of an alternative practice.” Unpacking this claim, it rests on two points. First, participants may already know why their health decision-making and efforts might be thwarted, better than those attempting to influence them. Thus communication that respects this participant knowledge, and takes advantage of it, may be more effective than communication based on the knowledge of outsiders. This line of
thought is developed in the work of Gramsci. Second, some groups in society, including AI/AN, have experienced oppression, including from well-intentioned people aiming to “help” them. In response they have developed resistance to messages from more powerful agencies (Golds et al., 2008; Ivers, 2003; Hunter, 2002; Panford, 2001; Barnes, 2000). Communicating effectively in the presence of such resistance may be helped by creating what social scientists call counterhegemonic discourse. Gramsci’s ideas, and the concept of counterhegemonic discourse, are discussed below.

2.2.4. Gramsci’s organic intellectual

A unique perspective on hegemony, the power one group wields over another, is provided by Gramsci (1971; see also Crehan, 2002). Gramsci points out the domination of some groups by others, and sees intellectuals as playing important roles in the conflict. Traditional intellectuals are producers and disseminators of knowledge for the dominating class. Organic intellectuals, in Gramsci’s terms, are intellectuals who produce and disseminate knowledge for the dominated class. Organic intellectuals often know the source of their problems, and potentially even know a solution, but lack the resources to carry out the solution (Crehan, 2002).

All individuals, according to Gramsci, have the potential to emerge as organic intellectuals. Certain organic intellectuals can be defined as community champions, in that they speak on behalf of their communities because they understand and communicate the struggles of the communities. Often knowledge of these struggles comes from lived experience. Supporting these individuals, and enlisting their involvement, can improve communication of health knowledge and awareness within a dominated class.

C&T was designed to cultivate organic intellectuals in two ways. First, the interactive nature of C&T, with participants able to respond to messages rather than simply consuming
them, was intended to encourage participants to recast the HGHH content in ways appropriate to
participants’ settings, and reflective of their knowledge. Second, focus groups and photovoice
sessions, scheduled after the main intervention, were intended as opportunities for contributions
by organic intellectuals.

2.2.5. Promoting co-learning and empowerment by supporting counterhegemonic
narratives

Michel Foucault advanced the idea that those who produce and control knowledge are
endowed with the ability to define truth (Fillingham, 1993). New kinds of media present new
opportunities for the production and control of knowledge, thereby giving the ability to impose
defined truths on underrepresented populations. Power, as conceptualized by Foucault, is a fluid
entity with the ability to promote some behaviors, both by individuals and by groups, while
simultaneously inhibiting other kinds of individual and group behavior (Barrett 2002).
Foucauldian thought focuses on the power conferred by the production of media, not on the
content of the media (Roseberry, 1988). Some media scholars call this media imperialism
(Boyd-Barrett, 1998; Browne, 1996): wealthy northern cultures exported their media so that the
belief the values expressed in the media would convert, create, or condition favorable feelings
towards the media exporters’ views of the world. This, in turn, created cultural hegemony in the
media and mainstream culture, that is, the domination of a culturally diverse population, such as
AI/AN, by the ruling class, or mainstream society (Bullock and Trombley, 1999). The ruling
class worldview overcomes the worldview of the cultural minority, and the ideas, perceptions,
and values of the dominant are imposed as the norm for the dominated group.

Paulo Freire’s work (1968) provides an argument for “whose knowledge counts.” Freire
argued that humans have a unique ability to change their reality because of their ability to think
and eventually to understand the things that are oppressing them. He explained this ability through the concept of conscientization: “the process by which the capacity for critical thinking by the oppressed … of themselves and the community and, ultimately, the society they live in” is enhanced (Blackburn, 2000, p.7).

Conscientization can be promoted by counterhegemonic movements and the counter-narratives they produce, providing resistance to truths constructed by the ruling class and top-down approaches to intervention work. Counter-narratives are critical for underrepresented groups in society, such as the AI/AN population (Solórzano and Yosso, 2002). When underrepresented groups in society experience technological empowerment, a change in the way mass media are consumed is possible. A shift in the power relationship between the conventional media creator and consumer occurs, since the consumer can create and share culturally relevant knowledge (Meadows, 1994).

New technologies that allow for Internet and cell phone users to create and share content, give the dominated cultural group the potential to change the way mass media is perceived, trusted, and consumed. The lack of mainstream media coverage of AI/AN issues creates additional opportunity for counterhegemonic narratives to create discourse that challenges the hegemonic status quo. This discourse provides an alternative view of the world that privileges underrepresented segments of society and champions the experience of the underrepresented. In other words, new technology and being underrepresented provides an opportunity for the creation of counterhegemonic narratives.

The interactive nature of the C&T intervention was aimed at this issue. C&T used the technology of the cell phone to allow participants to respond to messages in and on their own terms, as described earlier, rather than simply accepting them. The focus groups and photovoice
sessions, also mentioned earlier, were also intended as a setting for the development of participants’ own communications. Thus participants could embed HGH content in their own narratives, narratives that are counterhegemonic, in that they originate from the participants, not from powerful outsiders or from top-down health interventions.

2.2.6. SMS and MMS: a manipulation for richer counterhegemonic narrative

Returning to the critical point made by Bazargan et al, C&T attempted to create an atmosphere that was respectful of AI/AN cultural norms. In doing so, C&T invited participants to share their health knowledge of CVD in the intervention, rather than just receiving heart health information from the C&T facilitator. Health knowledge participants shared was in turn used as a vehicle to further participant’s overall health knowledge by building on what each participant individually brought to the intervention through content interaction and questions.

There are different channels for sharing knowledge that are supported by mobile phones. Participants could respond with text messages, but they could also respond by sharing photographs, using the MMS supported by many phones. Would MMS sharing offer advantages over text? C&T explored this question, by including an MMS condition that asked participants to share pictures that were related to the C&T content. The purpose of this request was to enrich the counterhegemonic narrative through visuals rooted in participants’ everyday lives. Photo elicitation is a different style of content interaction, going beyond simply texting the facilitator answers to questions or examples of health knowledge. The hypothesis is that photo elicitation is a more involved interaction with content. Interacting with heart health knowledge in a deeper manner is hypothesized to yield higher health knowledge scores in the post-intervention survey analysis.
2.2.7. Depth of processing: an additional potential benefit of the C&T approach

To be effective, the information conveyed in an mHealth intervention usually must be remembered. An occasional piece of information might support an immediate action, like a visit to a doctor, but more commonly the information has to be referred to over time, guiding decisions about diet or exercise in the long term. Psychologists have long known that memory for information is strongly influenced by how the recipient processes the information (see e.g. Craik and Lockhart, 1972). If someone simply reads a message, without thinking much about it, retention will be poor. The more complex, or “deeper”, processing the recipient performs, the better will retention be, an effect called depth of processing. Thus the interaction supported by C&T, in which participants respond to HGH content by expressing it in their own words, or by sending a photo that relates to the health education content, may produce superior retention, relative to an intervention in which messages are simply read.

2.2.8. Participatory research

Ideally, participatory research is a process in which researchers and community members collectively move through successive stages of reflection and action. In this approach, the host community shapes the research agenda. By shaping the research agenda, the host community becomes a collection of agents orchestrating the research, instead of subjects upon whom the research acts (Stoecker 2003; Themba and Minkler 2003; Cornwall and Jewkes, 1995).

C&T did not engage community members to shape the research agenda or to develop content delivered by C&T. As a result, C&T cannot be called Community Based Participatory Research (CBPR). However, C&T sought to honor participants by seeking their knowledge, opinions, and perspectives in regard to heart health knowledge as a baseline from which to start a dialog about heart health.
Research can be, and often is, something “done to” research “subjects,” not something “done with” research “participants.” And as just discussed, dominated groups often resist activities, including research activities and public health programs that are perceived as hegemonic and not representing the culture of the intended audience. C&T is a response to this situation.

Creating opportunities in which people can be empowered is a critical step in the process of restoring, or building confidence, and that is what C&T strived to accomplish. One potential activity to build confidence is by engaging in a process through which participants can identify and confront problems (Cornwall and Jewkes, 1995). C&T facilitated the identification and confrontation of health problems related to CVD.

Failed top-down research projects in AI/AN communities and instances of abuse of research practices have historically occurred, for example, the infamous Havasupai genetic testing incident (http://genetics.ncai.org/case-study/havasupai-Tribe.cfm). Working in the tribal or AI/AN context should be thought of as an agreement between the research group and the community, and the research should in some way benefit the community (Isreal, 2001). While not fully participatory, C&T did aim to bring the experiences and knowledge of the local community members to the surface, to the benefit of the community.

2.3. Research questions

The primary aim of this dissertation is testing feasibility of using mHealth strategies in the urban AI/AN clinical setting. The C&T intervention provided CVD prevention messages to increase heart health knowledge in an urban AI/AN population, using SMS and/or MMS messages. To evaluate the potential impact of C&T, an experimental, randomized, pre-post, without control, study design was implemented. The research questions addressed were:
(1.) To what extent is the cell phone, as used in C&T, a feasible dissemination tool to increase knowledge of cardiovascular disease (CVD) risk factors in an urban American Indian Alaska Native (AI/AN) population?

(2.) In an urban AI/AN population, to what extent, if any, does the inclusion of text with photo elicitation (MMS) increase health knowledge and motivation more than text messaging (SMS)?

(3.) How applicable were the social science ideas about organic intellectuals and counterhegemonic discourse in shaping the intervention?

To answer these three questions, data were collected from survey questions at baseline and post-intervention to provide quantitative health knowledge evaluation, and from focus groups, photovoice sessions (photovoice is described in detail in Chapter 3 – Methods), and exit surveys to provide qualitative contextual data.

Research Question 1 aimed to describe the perceptions and experiences of participants that enrolled in C&T. This question was answered with qualitative data produced by text responses produced by participants, by two focus groups and one photovoice session, and a short exit survey, along with text response frequency analysis at the individual and group level describing interaction patterns.

Research Questions 2, a quantitative question, was answered using the study’s health knowledge acquisition data. Question 2 compared the SMS and MMS conditions with respect to heart health knowledge.

Research Question 3, an exploratory qualitative research question, had broader aims. There is great need to understand how to engage the AI/AN population in research using technology and social media in a meaningful, equitable manner. In addressing Question, 3 the
dissertation considers how to address the cultural diversity of the AI/AN community, and to reflect the diverse perspectives of the study participants, rather than simply disseminating content created by the investigator for the consumption by intervention participants.
Chapter 3: Methods

3.1. Finding the right technology for the DIHFS population

The clients at the DIHFS clinic were often living below the poverty line. Many had only recently begun receiving health insurance through universal health care, and some still did not have health insurance. These individuals resided in an urban setting where there were few opportunities to receive health services through the I.H.S. This was not the case in many reservation communities where a great majority of the funding is directed. Circumstances confronting individuals who obtained services at DIHFS were often the same as other underserved communities in urban locations. DIHFS patients often resided in geographical areas where access to fresh fruits and vegetables or high-quality foods was limited. Areas that lacked access to quality food are commonly known as food deserts (Wrigley et al., 2002). Inner-city travel was also difficult; many times DIHFS clients needed to ride three to four buses to get to the clinic. This logistical constraint represented both a financial and a time burden.

The researcher made the determination to use non-smartphones based on knowledge that members of the AI/AN population have higher access to simple phones with SMS/MMS capabilities than to smartphones, as mentioned earlier. As mobile technology advances, so do the possibilities for mHealth. Specifically, the advent of smartphones, that is, phones with Internet capabilities, clearly creates new opportunities to present information and interactive applications. However, at the time of the study, the penetration level of smartphones was relatively low within the C&T target population in Denver, Colorado. Sixty-three percent of AI/AN who use DIHFS have smartphones, compared to 90% who have cell phones without Internet capabilities (Brega, 2013). As the market for Internet enabled phones grows and demand climbs, the price will fall and become more affordable (Kirk et al., 2013). Smartphone
technology will likely more deeply penetrate, based on lowering costs, the urban AI/AN population and future research projects might benefit from them. Given conditions at the time of this study, though, C&T uses only basic mobile phone capabilities.

As just mentioned, 90% of AI/AN who use DIHFS have cellphones. But what phone capabilities are being used? While specific data are not available, general trends strongly suggest that not only voice communication is being used, but text messaging as well.

In addition to the published data cited earlier, there were unpublished local data for the clients of Denver Indian Health and Family services, shown in Table 3.1. These cell phone access data came from a data collection effort in 2012 managed and executed by the CEED project and founded by the Centers for Disease Control (CDC) through the REACH initiative.

Table 3.1: Penetration of cell phones at Denver Indian Health and Family Services

<table>
<thead>
<tr>
<th></th>
<th>Yes, I have access.</th>
<th>No, I don't have access.</th>
<th>Not Sure</th>
<th>Missing Data Points</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you have a cell phone?</td>
<td>87.20%</td>
<td>12.80%</td>
<td>0</td>
<td>0</td>
<td>188</td>
</tr>
<tr>
<td>Are you able to send and receive text messages using your cell phone?</td>
<td>89.60%</td>
<td>10.40%</td>
<td>0</td>
<td>24</td>
<td>164</td>
</tr>
<tr>
<td>Is your phone able to connect to the Internet?</td>
<td>62.60%</td>
<td>31.90%</td>
<td>5.50%</td>
<td>25</td>
<td>163</td>
</tr>
</tbody>
</table>

3.2. Program development

Recall that Fogg and Allen identified five strategies in their review that were described in the *Why mHealth Might Help* section of Chapter 1 – Background: sending information to the user, gathering information from users, user questions and export responses, person-to-person
connection, and transactions (Fogg and Allen, 2009). C&T incorporated all of the strategies listed by Fogg and Allen.

C&T sent culturally sensitive information from the HGHH curriculum to educate participants about heart health, as discussed further below. Additionally, when sending information to participants, the C&T intervention gathered information from participants using the open communication model via SMS and MMS. Sometimes this information was gathered in the form of expert responses, as participants in C&T are considered organic intellectuals (a theoretical concept described in the previous chapter). The deployment of C&T also created a person-to-person connection, i.e., between participant and researcher. Finally, the C&T researcher used SMS to confirm appointments for survey data collection, a transaction, by definition from Fogg and Allen, in the spirit of getting research activities accomplished.

The core of the C&T intervention was sending heart health messages to participants. These messages are thoroughly detailed in a later section of this chapter, Materials. A five-week overall schedule of C&T messages, one message per day Monday-Friday, were sent to all individuals, and tailored messages were sent to specific participants when they asked questions about the content of the C&T messages. Participants in the SMS condition replied with text-based messages only; participants in the MMS condition replied with text-based messages and also multimedia images captured with the in-cell phone camera.

3.2.1. The messaging platform

The messages were delivered using a system for sending SMS messages that could be used easily and adopted by an urban AI/AN clinic. A free technology provided by many cell phone carriers called SMS gateway was adopted instead of using a commercial option for
scheduling and sending out messages. This design decision was based on creating a system that underfunded urban AI/AN clinics could afford if the C&T intervention was shown to be feasible. Utilizing the SMS gateway, messages are sent as email, from an email platform (C&T used Microsoft Office Outlook), but delivered to recipients’ phones as text messages. To send a message this way, the sender must know the recipients’ cell phone carriers’ SMS gateway. For example, to send a SMS to someone who has cell phone services provided through Cricket and has the telephone number (123) 456-7890, the SMS message would be addressed as follows: 1234567890@sms.mycricket.com.

This message-addressing format works internationally and is free; however, the SMS content must be less than 160 characters long. If the text exceeds 160 characters, the SMS gateway breaks the message into multiple messages, which is a problem. The multiple messages may lose the attention of the recipient, and often a second portion of a message is delivered before the first, which is obviously confusing. When a texting service app such as WhatsApp and Snapchat are used, character limits are less of an issue because the app reassembles multiple message parts into one delivery. But these apps require an Internet connection and a smartphone and were not a viable option for C&T due to the increased level of technology needed by participants. Using SMS technology was advantageous because the technology could be used to remind participants about surveys, focus groups, and photovoice sessions.

The email system used for sending the C&T messages via the gateway provided useful organizational tools. A copy of each outgoing message was saved in a sent folder, allowing the message to be viewed and reviewed, so the researcher could look back at the messages sent to each of the intervention participants. This was also good for program fidelity, since by
reviewing the sent folder the researcher could check that all participants received all the messages that the intervention offered.

The email system also allowed the researcher to set up individual folders in the inbox associated with each participant. Correspondence from participants was moved into these individualized folders, allowing the researcher to have quick access to all the incoming SMS that the participants sent. This feature was convenient when it was necessary to look back on correspondence associated with particular heart health conversations that stemmed from SMS that the participants found particularly relevant or interesting.

Figure 3.1: Screen shot of unique C&T participant de-identified folders

These folders were reviewed during the intervention to monitor all participants’ involvement or problems experienced with the system, and they also were reviewed during the analysis phase of the project. During analysis, messages were flagged that were particularly relevant to any of the three research questions.

The Microsoft Outlook system used by C&T was supported the University of Colorado Anschutz Medical Campus. This maintained appropriate ownership of data, though public institutional email is open to Freedom of Information Act inquiries (“http://www.foia.gov/,” n.d.). Participants were informed that the researcher would protect the confidentiality of the C&T SMS/MMS correspondence. However, there are situations when confidentiality could be
lost because of a request through the Freedom of Information Act because the University of Colorado Anschutz Medical Campus is a public institution. These issues were raised during the enrollment process at the beginning of the project for each participant. However, each participant was informed that the C&T SMS would not request any personal health information (PHI). Content of the C&T messages was also described to the participant so that the participant would expect to receive benign health messages intended for wellness.

3.2.2. Branding

C&T used the email address cell.tell@ucdenver.edu. The account name was an important part of branding for the project. Once participants received one or two messages from the project, they were able to easily recognize the source. Spam mail has not yet become a prevalent or significant issue facing users of SMS technology, but it is still important to brand public health initiatives so participants feel comfortable receiving and interacting with the messages, as indicated by Karasz and Bogan’s work in King County (2012). The “tell” part of the cell.tell email was meant to encourage participants to “tell” or share with the researcher their opinions and feelings about the content they received and how that content was, or was not, applicable and/or relevant in their local environment.

The ucdenver email suffix stands for University of Colorado at Denver, a trusted regional institution and is well known in the Denver Metro area. The University of Colorado-CAIANH has conducted multiple research programs at the DIHFS clinic. Using the suffix helped to create a brand that was recognizable and backed up by the reputation of the university and past efforts of the university in the clinic.
More generally, project branding was aimed at solidifying the C&T project as a reliable source of health information, which was honest and trustworthy. The C&T logo in Figure 3.3 was used on recruitment materials and literature. The logo conveyed several ideas that would eventually become identifiable to the participants in the study. The cell phone at the top of the logo conveyed the idea that C&T is a project that uses cell phones. The depiction of the Rocky Mountains and the skyscrapers in the downtown Denver area conveyed a local aspect, which is how C&T grounded the intervention in the Denver Metro area. This localization differentiated C&T from other public health campaigns and outreach projects that are national in scope and not tailored to a specific local community. Similarly, the Rocky Mountain and skyscraper motif is also shown on the DIHFS webpage, providing a link between C&T and DIHFS. In fact, the C&T logo shows the specific view of downtown Denver and the Rocky Mountains that clients at DIHFS would see if they crossed the street at the clinic and went to Denver City Park. City Park is often used by the DIHFS clinic as a site for physical activity in health and wellness programs offered by the clinic.
The logo also refers visually to the talking circle, a popular counseling format sometimes used in AI/AN communities, including DIHFS and the Denver Indian Center (DIC). AI/AN clinics throughout the country would be able to adapt the C&T logo by simply taking a picture of their local surroundings or a local landmark and modifying it in Adobe Photoshop, as was done for the C&T logo.

3.2.3. Beta testing

Beta testing is a preliminary trial of an electronic system, in this case an mHealth system, to check that it functions as intended. A trial of this nature is especially important in a research project and is carried out before participants are enrolled. If beta testing is not completed, the researcher risks wasting valuable time and resources, not to mention the attention and trust of prospective participants.
During the beta testing phase of C&T, five casual volunteers, including professional colleagues at the CAIANH and family members, were recruited and agreed to receive C&T intervention heart health messages over a five week testing period. These volunteers were not compensated for their time or the message charges they may have incurred by receiving the heart health messages.

Beta testers were recruited who subscribed to different cell phone carriers. This approach allowed testing the different SMS gateways that would be encountered when the intervention was implemented. In particular, two participants used Cricket as their carrier; DIHFS advised that many of the clinic patients used Cricket, possibly due to the carriers’ flexible pricing and the presence of a brick and mortar Cricket store within walking distance of the DIHFS clinic.

One major functionality issue was revealed in the beta test. If all the desired message recipients were included in the “To” line of an email intended to be sent via the SMS gateway, any responses generated by the recipients would go to all the recipients that received the original message (or those who were originally included in the “To” line) as a group message. This functionality might be helpful in another study, but C&T was designed to host one-to-one correspondence between participants and the researcher, exclusively. Use of the “To” line was therefore abandoned for the C&T deployment.

The beta test included the capability of the Outlook mail system to schedule messages for delivery at a pre-programmed later time. Unfortunately, this proved not to work well in the C&T setting. Timing was disrupted by overnight university computer network backups and required that the email system be kept open until the messages were sent. The C&T deployment therefore did not use this feature, though this limitation could be overcome with different online commercial software tools.
With the adjustments noted, the beta test showed that the C&T technology allowed heart health messages to be sent reliably. The system was technologically simple, and used only tools and resources that were confirmed to be available in the DIHFS clinic. Additionally, the technological simple design of the C&T system could be used with a commercial email system. Email services such as Gmail, Hotmail, or Live email could be used to send the heart health messages. Using these commercial products, however, would complicate the ownership of the data and the ability to protect it when the data resided on a commercial server or cloud. C&T could therefore be replicated with tools that are available to most urban Title V AI/AN clinics throughout the country, depending on how the clinic viewed the sensitivity of the content in the messages and the location of where the data would be stored.

3.3. Study methods

C&T was designed as a RCT. The research design was a two arm pre-post experimental study. It used random assignment to place all enrolled participants into one of two conditions: SMS or MMS. Study participants were randomly assigned to one of the intervention conditions and were not informed about the details of the other condition(s). Random assignment happened after participants fulfilled all eligibility requirements, and were successfully enrolled in the study, before the intervention began. Conceptually, the process is based on “the luck of the draw.” This approach is the best way to avoid allocation bias to achieve random groups of participants in each of the conditions so a proper comparison between the conditions can be drawn (Chalmers et al., 1981) and the condition that influences knowledge and awareness the most can be identified. The C&T process of randomization took place after all participants were enrolled in Wave 1 or Wave 2 (waves are described in detail below).
The C&T intervention and its conditions were designed to deliver the same amount of heart health content to each participant in an attempt to control for information dosage. With dosage controlled, outcomes could be compared statistically by the Paired Sample \( t \)-test (described further in below) to see if one condition outperformed the other condition in terms of health knowledge acquisition.

### 3.3.1. Recruitment

Recruitment flyers were hung throughout the clinic so all incoming patients had an opportunity to see the advertisement. Flyers were also positioned near stairwells and elevators on bulletin boards were other community activities and resources were hung. Unfortunately this passive approach was not helpful in enrolling participants.

An alternate recruitment strategy was more helpful. Instead of relying on flyers in the clinic, C&T project staff approached patients in the waiting room to encourage patients to enroll in the mHealth study. A recruitment desk was set up by the researcher several times a week to conduct face-to-face recruitment. This approach allowed potential participants the ability to ask questions concerning involvement in the study. Furthermore, DIHFS receptionists helped by communicating how many appointments were scheduled on particular days, so that the researcher could plan to come and set up the recruitment table during timeframes when the clinic expected high volume traffic. All participants were enrolled in person at the DIHFS clinic.

When enrollment concluded for each participant, the only difference between conditions was assignment to a focus group for SMS participants (who responded to heart health messages sent by the researcher by SMS text only) and to photovoice sessions for MMS participants (who responded by SMS text and MMS picture attachments when prompted for photo elicitation). This meant that participants in each of the conditions would receive the same heart health
messages – only their responses would differ in terms format: text only vs. text with an accompanying photo. The evaluation specifically focused on the way each condition responded to the heart health messaging and aimed to indicate whether plain text was as memorable and promising as responding to messages, by including photos as visual evidence, for health knowledge acquisition.

### 3.3.2 Participants

There were four distinct eligibility requirements to join the C&T intervention:

1. The participant was between 30-70 years old.
2. The participant had a cell phone capable of sending and receiving both SMS and MMS.
3. The participant had received services from the DIHFS clinic in the last 12 months.
4. The participant could not have received the HGHH curriculum before enrolling in the C&T project.

The requirements for participation were put in place for several reasons. The first requirement defined the sample targeted at DIHFS. The second requirement was included to assess whether people have SMS/MMS technology readily available and also to see if using photo elicitation could increase health knowledge acquisition. The eligibility requirement of phone technology helped maintain the study’s integrity. This eligibility requirement stated that participants needed to have cell phones capable of sending and receiving both SMS and MMS, and both conditions required phones with an in-cell camera, thereby maintaining the random allotment of condition. The third requirement was included to confirm participants receiving the intervention were accessing healthcare through an urban AI/AN clinic. To obtain services at
DIHFS, individuals must present their Certificate of Degree of Indian Blood or tribal enrollment ID, which confirmed all of the participants were in fact AI/AN. If SMS/MMS interventions are determined to be feasible and potentially beneficial for the urban AI/AN population, many other health priorities could be addressed with this delivery model.

Two people who wanted to be in the study, and who completed a consent form, could not make the texting application on their cell phones receive the health content from the SMS gateway (the system used to send health messages). These participants were therefore excluded from the study based on eligibility requirement 2.

None of the 32 participants had received any of the HGHH curriculums content in previous research projects or community health outreach projects, including the FitHealth study where HGHH was taught face-to-face in the DIHFS clinic.

Participants received compensation for taking part in the study. Each participant received $40 for the baseline survey and an additional $40 for the post-intervention survey. Participants, who attended the photovoice portion of the intervention or the focus group, an activity that lasted approximately two to three hours, received an additional $50. Respondent compensation was in the form of Walmart gift cards.

3.3.3. Study flow

To answer Research question 2, C&T compared two message conditions, SMS and MMS. Participants in the SMS condition received a baseline survey, five weeks of health education messaging, consisting of one message per day on the five business days of the week, and a follow-up survey, and then were asked to participate in a focus group, followed by a final survey. The focus group guide is included here as Appendix D. Participants in the MMS condition received the same baseline survey and five weeks of health education messaging. The
messages were the same as in the SMS condition, except for the last messages of the week that asked for a response. The SMS condition responded to the request by text. The MMS condition responded with a photo and text.

After the five week messaging period the MMS participants were given the follow-up survey, and asked to attend a photovoice group session, in which they used the photos they took in response to the photo elicitations to produce a group-level media-rich document that gave insight into AI/AN community heart health. The photovoice activity is described in more detail below. After the photovoice activity participants received a final survey. The CONSORT diagram, Figure 3.4, depicts the flow of the study.
The seven-week C&T intervention was conducted at DIHFS at two different times, defined as Wave 1 and Wave 2 – once in the fall of 2013 and once in the spring of 2014. An intervention wave format was introduced because of initial difficulty in recruitment; rather than delay data collection until the sample was complete, the study was started with the first group of recruits and repeated with a second group. The participants enrolled in Wave 1 of the intervention did not receive their condition allocation until all participants for Wave 1 were
enrolled, and they each received a condition assignment at the same time. The condition assignment was the same for Wave 1 and Wave 2, which avoided possible bias in the process of assigning conditions as the participants enrolled.

3.4. Materials

As discussed in the last chapter, the inspiration for adapting HGHH to use cell phone technology came from a project called FitHealth (Jan Beals, PI) that presented the HGHH curriculum face-to-face to 30 participants at DIHFS. The author of this dissertation participated as an instructor, and observed that each HGHH session had potentially powerful take-home messages. If participants left each class with one take-home message they could put into practice, those individuals could potentially be successful in increasing knowledge about heart health. This raised the question, could mHealth technology be used to deliver these key messages in a way that would be more accessible and reliable than face to face classes?

Accordingly, the messages received by participants during C&T were adapted from the HGHH curriculum, described earlier in Chapter 1 – Background. To create the messages used in C&T, the sessions in the HGHH curriculum were condensed to one or two take home points per session, that when learned, could have an influence on heart health knowledge. These take home points were then written as messages, in such a way that five messages would cover the essence of two HGHH sessions. This permitted C&T to cover all ten HGHH sessions in five weeks of messages, one delivered each weekday. The 25 messages are listed in Appendix E.

Two sets of two informational messages were delivered each week that focused on one of ten categorical themes in the HGHH curriculum. The fourth message each week was a quiz covering the material presented in messages earlier in the week. Participants in the SMS condition were expected to respond with text only to the quiz questions. Participants in the
MMS condition also were expected to respond by text only to the quiz. The only time the MMS condition participants responded with visual data is when they were asked to send a photo of something in their local environment that either helped or hindered their ability to enact healthy lifestyle choices with respect to one of the ten categorical themes in the HGHH curriculum. As already mentioned, the fifth, and last message each week, was a homework message that requested a response. The response for the SMS condition was to text a description of someone, something, or a place that would, for example, help prevent a heart attack while the MMS condition was asked to text a picture of the same content.

3.5. Measures

In all, there were seven measures collected: memoing, survey data, response rates, participant SMS/MMS response content, exit surveys, focus group responses, and photovoice narrative analysis. These measures generated the data to answer the three research questions. Each measure is described in turn and research questions each specific measure addressed are identified.

3.5.1. Memoing

One strategy to record qualitative process data was memoing (Paton, 2001). In this qualitative research method (Paton, 2001) documentation was created that records what is going on during conceptualization, development, testing, and implementation. In the case of C&T, the researcher memoed on a weekly basis and made sure to touch on all of the elements in Bull’s unique and beneficial rubric to assure that the intervention did not stray from these critical elements that foster a well-balanced and potentially successful intervention.

Specifically, the memoing process asked these questions (Patton, 2001, p. 160):

1. What are the things people experience that make this program what it is?
(2.) How does what people do differ from what they are trying to do?

(3.) What are the strengths and weaknesses of the program?

(4.) What is the nature of staff-participant interactions?

The data from this method was used to address research question 1.

3.5.2. Survey data

The survey for this intervention was chosen based on its use in a previous project conducted at the CAIANH using HGHH content. The same survey was administered at baseline and post-intervention. All survey questions were health knowledge or attitude/opinion questions about heart health, diet, cholesterol, fat, nutrition, exercise, and smoking, CVD risk factors, both changeable and predisposed factors, and questions about what to do in the event of a heart attack. Some questions explored what people thought they could change that would affect heart health and to assess how difficult the change would be. A copy of the survey is included here as Appendix F.

Scores on this assessment directly measured information, or the “I,” in the second use of the IMB framework, described above in Chapter 2 – Theory. Further, differences in scores between the SMS and MMS conditions showed whether the enhanced roles of participants in the MMS condition resulted in increased health knowledge, as suggested by the CPBR framework. This data was used to address research questions 1 and 2.

3.5.3. Response rates

Response rates were indicative of the level of participant engagement with the intervention. High levels of engagement would be supportive of an assessment that the intervention is feasible, which is the subject of research question 1. Low response rate would indicate that participants were not engaged and that this approach may not be feasible. Low
response rate is defined as only responding to a third or less of the messages, while high response rate is defined as responding to two thirds or more messages.

3.5.4. Content of participant SMS/MMS responses

These responses indicated the success, if any, of the intervention in supporting counter hegemonic discourse. This data was used to address research question 3. Participant content was saved in Microsoft Outlook in folders as described earlier in this chapter. All content received by the researcher was transferred to a secure University of Colorado Anschutz Medical Campus server and coded. Codes included “answer” (to the question asked in the health message), “acknowledgement” (of the content as helpful or unhelpful), “contextualization” (content from the health message was placed in general context of wellness as seen by the participant), “personalization” (content was associated with the participant’s lived experience), “remix” (the heart health content was reorganized or re-conceptualized in the participant’s own voice, but the meaning of the original message was not changed, but confirmed), and scaffolding (the heart health content was used as a spring board into other health priorities related heart health deemed important by the participant).

3.5.5. Exit surveys

Exit surveys were conducted after the last survey each participant took, which was either the follow-up survey after the intervention or the survey after the focus group or photovoice exercise. Exit survey responses were intended to suggest whether (1) C&T’s use of CBPR succeeded in supporting the development of counter-hegemonic narratives, and (2) general feasibility of C&T as an mHealth approach. The exit survey consisted of two questions: “How did your participation contribute to experiencing the intervention” and “overall, what did you think about the C&T program?” The questions were asked in an intentionally vague manner to
allow the participant to expound on whatever facet of the intervention the participant especially liked or disliked. The data collected from exit surveys addressed research question 1.

3.5.6. Focus group responses

Participants’ responses were coded with a priori codes established from Bull’s unique and beneficial rubric. These codes indicated the extent to which the attributes in Bull’s rubric influenced participants’ opinions of the intervention. Again, these codes included: autonomy, standardizing information, interactivity, lower program costs, and portability. This data was used to address research question 1.

3.5.7. Photovoice narrative analysis

Caroline C. Wang and Mary Ann Burris developed photovoice in a project based in China, where they used photos and group-level narratives describing those photos to empower rural women on different policies that affected their lives and to inform them about different programs that could possibly enrich their lives (Wang and Burris, 1994; Wang, 1997). The photovoice method asks research participants to be critical in examining subjects that are topics of inquiry for that community. The participants then express their points of view by taking photographs that in some manner address the questions asked by the research project. The photos taken by the individuals are brought before a group and discussed. These discussions yield narratives for each photo; when the photos and narratives are pulled together, the resulting photovoice documents provide community-based perspectives. Often these perspectives lead to greater insight on the research questions and the resulting information can be used for community action or outreach programs.

Photovoice is often used when working with populations that are subject to some form of disparity (Oden, 2013; Skovdal, 2011). Photovoice integrates Freire’s pedagogy of focusing on
people sharing and speaking in a manner that communicates their perspective from their unique position in the world (Wang, Cash, and Powers, 2000). In a sense, photovoice is a form of community consultation and provides a tangible approach to collecting and organizing perspectives from large groups of disenfranchised people. This approach attempts to reconcile the perspectives and understanding of people who do not have the means to shape the reality that surrounds them with the perspectives of those people who are responsible for policy (Ruby, 1992).

Community consultation through photovoice allows the researcher to elicit perspectives from community members. This happens when participants share images taken with their cell phones. Community member’s interactions produce a shared document and the narrative becomes reflective of their community.

In C&T, the content of the photovoice documents was examined to assess the degree of success in supporting the organic intellectual role and counter hegemonic discourse. The photos used, and the story told with the photos, are examples of how participants imagined solutions to the prevention of CVD. These solutions may be more relevant and likely to work because they originated from the organic intellectual. Indications of in-depth knowledge of CVD are examples of Freire’s conscientization. The data collected from this measure was used to address research question 3.

3.6. Data collection

As described earlier, the survey was administered three times, at baseline, after the five week messaging period, and after the focus group or photovoice activity. Because participation in the focus group and photovoice activities was too low to support statistical analysis, the final set of surveys was not analyzed.
As mentioned earlier, the final message in each week requested a reply or answer to the homework message, and participants were encouraged to send messages containing questions or comments. Counts of these messages were collected. Discussion during the focus group was recorded for later coding and analysis. The focus group discussions were recorded with a digital audio recorder. Table 3.2 summarizes these aspects of data collection in the study.

*Table 3.2: Data collection notation*

<table>
<thead>
<tr>
<th>Time</th>
<th>Randomization:</th>
<th>Baseline Survey</th>
<th>Intervention</th>
<th>Post-Intervention – Survey Data:</th>
<th>Qualitative Data Collection, post-survey, and exit survey</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>R (16)</td>
<td>O1</td>
<td>SMS</td>
<td>O2</td>
<td>Focus Group (5)</td>
</tr>
<tr>
<td></td>
<td>O1</td>
<td>MMS</td>
<td>O2</td>
<td></td>
<td>O3</td>
</tr>
</tbody>
</table>

*Note: O = Observation, data collection time point*

In all, six photovoice participants completed the photovoice exercise. Minimal instructions were given during this component of the study. The researcher gave a short introduction to using Apple’s iMovie at the beginning of the photovoice sessions. Both groups then worked together to make their group-level narratives. Only one photovoice document was analyzed for the purpose of this dissertation.

As discussed earlier, members of the AI/AN community may feel disempowered with respect to their health, so photovoice may be an appropriate way to support them in developing
their own, possibly counter-hegemonic ideas about health. C&T explored this possibility, using the photovoice guide that is included here as Appendix G.

3.7. Methods of data analysis

Quantitatively, participants’ health knowledge score (HKS) was analyzed using a paired sample $t$-test to determine condition specific HKS change. The HKS was comprised of answers from four different constructs: heart attack knowledge (HA), heart health knowledge (HH), physical activity knowledge (PA), and nutritional knowledge (NUT). Each construct was also independently analyzed using ANOVA to assess change of health knowledge within each construct. The heart attack construct questions were based on Behavioral Risk Factor Surveillance System (BRFSS) questionnaires. The heart health knowledge construct questions were based directly on the materials delivered in the HGHH program. Tina Mitchell, Jan Beals, and Angela Brega developed physical activity and nutritional knowledge construct questions for the FitHealth project survey instrument. The intent was to use the same constructs, so secondary analysis could determine how participants in the face-to-face HGHH program compared to participants in the mHealth strategy.

The C&T photovoice product was analyzed using narrative analysis, a form of qualitative analysis in which the analyst focused on how respondents imposed order on the flow of experience in their lives and made sense of events (the intervention) and actions (receiving/sending SMS/MMS) in which they participated.

Process data from the memoing process described above were analyzed using the Process/Outcomes Matrix popularized by Campbell (1983), Table 3.3. The matrix helped to shape the creation of codes used in evaluating the focus group and the community-level photovoice.
Table 3.3: Process/outcomes matrix

<table>
<thead>
<tr>
<th>Program Process or Implementation Components</th>
<th>Types or Levels of Program Outcomes</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>A</td>
</tr>
<tr>
<td></td>
<td>B</td>
</tr>
<tr>
<td></td>
<td>C</td>
</tr>
<tr>
<td></td>
<td>D</td>
</tr>
<tr>
<td>1</td>
<td>LINKAGES EXPRESSED AS THEMES, PATTERNS, QUOTATIONS, PROGRAM</td>
</tr>
<tr>
<td>2</td>
<td>CONTENT OR ACTUAL ACTIVITIES</td>
</tr>
</tbody>
</table>

Note: From Patton 2001.

The Process/Outcomes Matrix allowed qualitative data collection to be organized and categorized so that themes emerged to indicate what was successful and what failed during the implementation. The emergent themes about dissemination and program impacts also allowed for analysis to be focused on content within the focus groups, providing relevant codes to be used in that analysis (Cassell and Tversky, 2005; Strauss and Corbin 1988).

Bull’s unique and beneficial characteristics were also used to inform the coding structure for analysis of focus groups and to evaluate if C&T embodied these theoretical characteristics. The codes from that rubric included: autonomy, interactivity, portability, and lower program costs.
Chapter 4: Results

4.1. Demographic and study coverage data

Study coverage data included the number of users observed (32), the number of questionnaires collected (65), the number of participants in focus groups (4), and the number of participants in photovoice (6). As mentioned earlier, all of the participants were between the ages of 30-70, each had received services at DIHFS in the last 12 months from the date of enrollment, all had exclusive access to a cell phone that had the capability to send and receive both SMS and MMS, and the participants did not receive the HGHH curriculum in any form before enrolling in the C&T project. Of the participants, 24 were women and 8 were men. Their average age was 43. All participants were American Indian and/or Alaska Native, a criterion for receiving services at DIHFS.

Participants were given the ability to opt-out of the study when no longer interested; however, no participants selected this option and all 32 participants stayed enrolled in the intervention. The opt-out option was designed to be easy and memorable for the participants. The participants needed only to respond to a received text message and communicate that they no longer wanted to receive the heart health messages.

4.2. Study findings and outcome data

The findings will be presented in the following order: memoing, survey data, response rate results, participant SMS/MMS response content, exit surveys, focus group responses, and photovoice narrative analysis.
4.2.1. Memoing

A qualitative aspect of the study, as mentioned in Chapter 4 – Results, was memoing, which was done in four main timeframes during the research project, i.e., conceptualization, development, testing, and implementation.

Memoing was a key element in the development of the qualitative codes reviewed later in this chapter, in addition to keeping track of the design and implementation process. Memoing during conceptualization was designed to keep track of Bull’s unique and beneficial features of mHealth during the design of C&T. Throughout the project, memoing allowed the researcher to notice if any issues were emerging that could potentially be deemed positive or negative for the feasibility of the project. The full array of memos for conceptualization, development, and testing phases are located in Appendix H.

4.2.2. Survey results

Twelve participants in the SMS condition completed both a baseline survey and post-intervention survey, and 11 participants completed the same measures for the MMS condition (overall, a 72% completion rate of baseline and post-intervention survey). The remaining 10 participants (28%) were lost to follow up because of scheduling constraints, lack of interest, or too much time passed after the intervention was completed to collect meaningful comparative surveys. Time between the two surveys was seven weeks, five weeks of receiving SMS or MMS health message content and another two weeks to schedule the follow-up survey at the DIHFS clinic.

The health knowledge survey discussed in Chapter 3 – Methods included a total of 51 health knowledge questions, asked at baseline and again at post-intervention. The questions spanned four constructs of health knowledge: heart attack knowledge (HA); heart health
knowledge (HH); physical activity knowledge (PA); and nutrition knowledge (NUT). Responses reflecting an individual’s awareness of his or her health status were scored 1, and responses reflecting a lack of awareness were scored 0. Item scores were summed to form construct scores for HA, HH, PA, and NUT; each question was worth one point in the overall health knowledge index. These health points were then compared across baseline and post-intervention within each of the conditions (SMS and MMS) using paired sample \( t \)-tests, and ANOVA, as shown in Table 4.1

Table 4.1 shows the change in the mean for the four constructs in both the SMS and MMS conditions. As shown by the paired sample \( t \)-tests, no significant pre-post difference was found for any of the conditions and constructs, but the raw means show average increase. However, an ANOVA that pools SMS and MMS data, does show a significant improvement for heart attack knowledge (HA), with \( p < .01 \). Corresponding ANOVA for the other three constructs did not produce significant results. A further ANOVA, testing the interaction of conditions and time (pre vs post) found a significant contrast for nutrition knowledge, reflecting the fact that tested nutrition knowledge actually decreased in the SMS condition. Apart from this case, it can be seen that post-intervention knowledge as tested was always higher than baseline, for both conditions and all other constructs.
### Table 4.1: Comparison of baseline and follow-up health awareness scores, by construct

<table>
<thead>
<tr>
<th>Paired Sample t-test</th>
<th>Baseline</th>
<th>Post-Intervention</th>
<th>95% Confidence Interval of Difference</th>
<th>Analysis of Variance</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>N</td>
<td>Mean</td>
<td>Mean</td>
<td>Time - F (1,21)</td>
</tr>
<tr>
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*p < .01, **p < .05

The differences in the means in Table 4.1 are promising, and suggest that a larger study, which goes beyond testing feasibility, with more power, is warranted to determine whether the apparent increases in knowledge holds true.

#### 4.2.3. Response rate results

During Wave 1 and Wave 2, a total of 800 messages were sent to the 32 participants.

C&T received 244 responses to the 800 messages, a 31% response rate. Not all of the messages
were designed to elicit a response. Of the 320 messages that asked for a response, C&T received 75 responses, a 23% response rate. Of the 480 messages that did not ask for a response, C&T received 169 responses, a 35% response rate. It is not surprising that participants often responded to messages that did not ask for a response. Participants were instructed and invited to respond anytime the material in the messages was interesting, and they wanted to engage to discuss the topic of the message further. But it is interesting that they were less likely to respond to messages that asked them to respond.

Figure 4.1 summarizes the number of times the individual participants responded, showing that rate of responding varied widely. Sixteen participants (50%) responded five or fewer times (and four of those did not respond at all.) Four people (12.5%) responded between 16 and 20 times.

*Figure 4.1: Individual participant responses*

![Graph showing number of participants responding to different number of messages.](image)

Figure 4.2 shows the distribution of responses over days during the five-week intervention. The SMS and MMS conditions show the same pattern in terms of the flow of participant responses; that is, the conditions have the same peaks and valleys in response rate. Response activity ramped up at the end of the week when the quiz and homework messages (indicated by the blue vertical lines at 5, 10, 15, 20, and 25 days) were delivered and participants were asked to identify something in the local environment that was either a benefit or barrier in making health choices.
and decisions (as discussed earlier, those in SMS condition were asked to send in a text description of the benefit or barrier; whereas, the MMS condition participants were asked to send in a picture text or MMS as evidence of the benefit or barrier). The figure also shows that the rate of response was consistently higher for SMS than for MMS.

Figure 4.2: Flow of responses by intervention day

The topic of the messages sent each week varied, as shown in the following bullets. Figure 4.3 shows responses received by week/topic.

- **Week 1:** Are you at-risk for heart disease and act in time for heart attack?
- **Week 2:** Be more physically active and maintain a healthy weight.
- **Week 3:** What you need to know about high blood pressure, salt and sodium, and what you need to know about high blood cholesterol
- **Week 4:** Make heart healthy eating a family affair and eat in a heart healthy way even when money is tight.
- **Week 5:** Enjoy living smoke free and review
Figure 4.3: Response rate according to topic

Most responses for the SMS group were related to the heart disease/heart attack and smoking messages, weeks 1 and 5 respectively, and the most responses for the MMS group was related to physical activity and smoking. The MMS group also responded frequently to the topic of heart attack and smoking.

Figure 4.4 represents the overall number of solicited vs unsolicited messages received, the number of solicited vs unsolicited received messages for the SMS condition, and the number of solicited vs unsolicited received messages in the MMS condition.
4.2.4. Participants’ SMS/MMS response content

The C&T intervention aimed to provide an open communication channel between the researcher and the participant. The messages that the researcher received were usually in an acknowledgement or question format. For example, the participant would pose a question based on the information they received in the informative health messages. The other prominent type of participant response repackaged the health information that had been sent to the participant in a manner that made sense to them, thereby personalizing the information.

Overall, as mentioned previously, there were 244 different responses, which were coded and quantified. Six codes emerged in this analysis: answer, acknowledgement, contextualization, personalization, rephrase, and scaffolding. These codes are not mutually exclusive. In fact, some responses could have elements from all six different codes. For solicited responses, the answer code marks an answer to a direct question from the SMS participants received. The acknowledgement code is applied when the participant acknowledges
the heart health information in the SMS as true or accurate or simply acknowledges receiving the SMS. The contextualization code was applied when the participant placed the heart health information from the SMS into a general context of their own development. Personalization was applied as a code when the participant used the information in the heart health messages as a way to identify with their own health, a personally specific context of their own development. Rephrase was applied when the participant took the information from the heart health message and rephrased the information and sent it back to the researcher. Finally, scaffolding, the rarest of the codes, was used when the participant used the information in the SMS as way to explore other health phenomena, or scaffold new topics of health information around the information that was received through the intervention, related to the information in the SMS, or put the knowledge into action.

Table 4.2 lists each of the codes and the number of SMS/MMS that were analyzed to fit the definition of each of the six different codes. There were a total of 465 codes applied to the 244 messages. In this treatment, the same codes were applied to messages that solicited a response and those that did not solicit a response. The answer code could be used for both solicited and unsolicited response because a question could have emerged in the resulting messages after the root C&T message.

Table 4.2: Coded individual responses

<table>
<thead>
<tr>
<th>Code</th>
<th>Answer</th>
<th>Acknowledgment</th>
<th>Contextualization</th>
<th>Personalization</th>
<th>Rephrase</th>
<th>Scaffolding</th>
</tr>
</thead>
<tbody>
<tr>
<td>Quantity</td>
<td>158</td>
<td>83</td>
<td>82</td>
<td>87</td>
<td>29</td>
<td>26</td>
</tr>
</tbody>
</table>

The list below shows the 25 health messages that were delivered to participants, indicated by the numerals 1-25, with an example of one response per day of the intervention, marked “r”
for “response”. The associated code is in bold font after the PID, a unique identifier for the response. Four of the responses, in the MMS condition, included pictures that are shown as accompanying figures.

1. Risk factors for heart disease include high blood pressure, high blood cholesterol, being overweight or obese, smoking, diabetes or lack of physical activity.

r: Trying to stop smoking (PID 012013090403-Wave 1) personalization

2. Delay is deadly. If you think a heart attack is taking place the most important thing to remember is call 9-1-1 in 5 minutes of less. Do not wait too long.

r: True. Asap is best. My friend had a heart attack in front of me & refused my help. I called anyway. She wouldn't believe me & sure enough she had one. This was this past Friday!!!! (PID 022014011603-Wave 2) acknowledgment/personalization

3. Family and friends might have one, several or all risk factors for heart disease. Make sure everyone knows what to do and who to call in case of heart attack.

r: Call 911 is what I tell my kids. (PID 012013090401-Wave 1) answer/personalization

4. What should you do in time of heart attack? a) Call a family member, b) Call 911, c) Drive to the hospital, d) Wait 20 minutes to see if you feel better

r: B) Call 911 (PID 022014011502-Wave 2) answer

5. Over the weekend take a picture of something, someone or a place that will help you in time of a heart attack and text me a description!

r: A sign of truth don't second guess a heart attack. Listen to your heart in time of need (see Figure 4.5). (PID 022014012904-Wave 2) answer/contextualization
6. Physical activity makes your heart and lungs strong. Do 30 minutes of physical activity most days. Break up 30 minutes of exercise into ten minute sessions.

r: I do that every day (PID 012013090403-Wave 1) personalization

7. Being overweight increases your risk of heart disease. To lose weight, cut down on portion size and be more active. Trim visible fat from meat before cooking.

r: Oh god cleaning the house is tough. My wife makes us do it like daily. And I even get tired from shaking the big rugs. She's a cleaning freak. Don't tell her I said that..... lol have a good night (PID 012013090401-Wave 1) acknowledgement/personalization

8. Exercise is always easier with a partner. Traditional activities like dancing to increase physical activity. Activities like cleaning the house get us moving.
r: Dancing increases physical activity. Housework gets us moving. I don't Traditional Dance but I do dance. (PID 022014011601-Wave 2) acknowledgement/personalization/rephrase

9. How do you make physical activity fun and family oriented? What is an activity almost anyone can do in any location?

r: You can play games like kickball or dancing with your family. Any activity you can do anywhere is walking or running (PID 012013082802-Wave 1) answer/contextualization

10. Over the weekend take a picture of something, someone or a place that will help you be more active and maintain a healthy weight and text me a description!

r: about 2 yrs ago i invested in my own heavybag because theres days i cant make it to the gym i try to run 3 miles 4-5 times a week along with working out daily (see Figure 4.6) (PID 022014011505-Wave 2) answer/personalization

*Figure 4.6: Home gym*
11. A blood pressure reading of 140/90 mmHg or greater is high. Hypertension is another
term for high blood pressure. Use herbs and spices instead of salt.

r: True. Use no salt if possible. Sauces, canned veggies, or any processed food has a lot of salt
also. (PID 022014011603-Wave 2) acknowledgment/contextualization

12. Cholesterol clogs your arteries and cause a heart attack or stroke. High blood cholesterol
is 240 mg/dL or higher. Trim visible fat from meat before cooking.

r: All true until next time (PID 022014012901-Wave 2) acknowledgment

13. Eating a heart healthy diet low in saturated fat, trans fat, and cholesterol lowers blood
cholesterol. Eat more vegetables each day. Have a salad with low fat dressing for lunch.

r: You can get your BP checked at most pharmacies and your primary care physician.
Foods that are low in sodium and fat are fruits and veggies. (PID 012013090601-Wave 2) acknowledgement/rephrase

14. Where can you get your blood pressure checked? What types of food are low in sodium
and fat?

r: Pharmacy, free clinics. Fresh vegetables, fruits, fresh fish (PID 022014011606-Wave 2) answer

15. Over the weekend take a picture of something, someone or a place that will help you
lower you blood pressure and cholesterol and text me a description!

r: My son “---” is the person who I am getting fit for. “---” has Asperger’s and needs motivation
to stay fit. So we are trying out a new rule right now. "If I can do it so can he". I could not get a
picture of him since he hates pictures. (PID 012013090501-Wave 1) answer/rephrase

16. Teach your family how to grocery shop. Include your family in preparing meals and
cleaning up. Plan weekly meals based on your family’s schedule.
r: I am an elder so I live by myself. When my kids were young they helped. Now teaching my grandchildren! (PID 022014011601-Wave 2) acknowledgment/personalization

17. Make a shopping list based on your meal plan. Check the food sale ads. Use coupons.

Make fresh foods at home instead of using canned or frozen prepared items.

r: I just brought lettuce, tomatoes, cucumber and celery and decided 2 have baked chicken (PID 022014012902-Wave 2) acknowledgment/scaffolding

18. Save food dollars, plan weekly menus. Shop with a list! Have your family help in the kitchen, and the kids too. Cook more and freeze for later to save time.

r: Sounds easy (PID 022014012902-Wave 2) acknowledgment

19. Some American Indians have adopted cooking and eating habits that can lead to health problems like heart disease. What are some examples of these habits?

r: I think using that old lard, fast food 2 much, not enough fruit vegs (PID 022014012903-Wave 2) answer/contextualization

20. Over the weekend take a picture of something, someone or a place that will help you eat right even when money is tight and text me a description!

r: Sharing is caring at a church pot luck. A good way for families to have good meal if cash is tight (see Figure 4.7). (PID 022014012904-Wave 2) answer/contextualization
21. One year after a person stops smoking the risk of heart attack will drop by more than half. Children who grow up in homes with smokers are more likely to smoke.

r: Hopefully this factoid does not apply to all native american youth. Yes, there is a scathing need for more health minded programs and extra-curricular activities for native american youth. This might include information blitzes from community members and programs designed to help natives stop smoking! (PID 022014013001-Wav2)

22. American Indian youth start smoking at much younger ages than other youth, and the source of tobacco is from family and friends.

r: [a message dated 2.13.2014] Cool. I'm gonna quit smoking Feb. 27 wish me luck.

[Then, a message in response to #22, dated 3.10.2014] I quit smoking Feb 26th

23. What’s the difference between ceremonial smoking and commercial smoking, and how does each affect your health?
r: Spiritual Smoking is non-harmful and way different tobacco but commercial smoking is really bad as it has killer ingredients (PID 022014011504-Wave2) answer/contextualization

24. What week of messages was your favorite/most helpful: 1) 911/heart attack 2) physical activity 3) cholesterol/blood pressure 4) nutrition 5) smoking, and why?
   r: Most helpful, cholesterol, because idk if i have it. And exercise, favorite, because i do it. (PID 012013082801-Wave 1) answer/personalization

25. Over the weekend take a picture of something, someone or a place that will help you live a healthier lifestyle and text me a description!
   r: this is a picture of mount falcon where i run in the mountains. its quiet and peaceful thinking of this place would help to relax (see Figure 4.8) (PID 022014011505-Wave2) answer/personalization

Figure 4.8: Falcon Mountain

As can be seen, the responses vary over a wide range. More information and details are in the next chapter, Chapter 5 – Discussion and Conclusion.
4.2.5. Exit survey

After the focus group or the photovoice session each participant completed the third survey, and was then asked, “How do you think of Cell & Tell after having completed the intervention?” Thirteen of 23 participants responded, with 11 comments being positive (85%), and two negative (15%). Here are the responses:

Positive Responses:

1. I learned a lot; more than I expected. (PID 012013082201)
2. I liked it, it helps you keep motivated. (PID 012013090501)
3. It was fun, I liked it a lot. (PID 012013090601)
4. I enjoyed it. (PID 022014011603)
5. I asked my friend if she bought salad this week because, "he [C&T] is really on salad now." And she lost three pounds. (PID 022014011603)
6. Really liked going out and looking for pictures. (PID 022014011606)
7. I learned from this program to call 911. I was in the hospital because my son's partner was in my house. She came to stay one night and ended up staying a week. I had chest pains, shallow breath, and my arm hurt due to the stress of having someone stay with me in my small house. It was stress related, but my blood pressure was 170/100. They put a surgery bracelet on me because they were prepping for surgery. I called 911 because of Cell & Tell. (PID 022014012902)
8. Pretty interesting. (PID 022014012903)
9. You made [me] more conscious about texting and driving. (PID 022014013001)
10. When my minutes run out at the end of the month, I can't get text until the beginning of the next month. I think the intervention is good because people are not aware of their
bodies. I believe that anything in prevention is a key step to helping people. So many people don't consider their ailments as problems, but prevention is a key step, and that people bring up their ailments as a first sign. (PID 022014011605)

11. Really liked the question about ceremonial tobacco. Sometimes a pain. (PID 012013090502)

Negative Responses:

12. Well, just that early morning Sunday time, I think, weekend times were not good. (PID 012013090502)

13. I enjoy the Cell and Tell. I think more health issues would have been better too. Because I mean more facts on it. Because I did try to read it and then what I did was I erased it because I was getting too many texts in. And so, I was losing a lot of room. (PID 022014011603)

Some of these comments suggest that there was a wide spectrum of program attributes that pulled people in and made them interested in learning about their health and how to make healthy decisions to prevent CVD, such as comments one, two, four, and five. Furthermore, the participants who provided comment number five and seven experienced major life events during the implementation of the C&T intervention. Comment five demonstrates, at least for this one participant, that weight loss could be achieved by implementing the lifestyle changes suggested in the HGHH curriculum. Eating salad is a good first step in changing dietary habits. Comment seven is related to a major theme in the HGHH curriculum, teaching people to use the resources they have at their disposal, such as 911. Despite the outcome of this event, the participant was made to feel more comfortable in calling 911 and used the service when they needed it the most.
Comment 9 suggests an indirect benefit of the research study being implemented at DIHFS. Denver Indian Health and Family Services requested that the researcher make a statement during enrollment and consent about the dangers of texting and driving. More details about DIHFS involvement are provided later in this chapter.

Negative comments about the intervention tended to fall into three different areas: timing of the messages (11 and 12), lack of depth or complex messages (13), and participants feeling they were getting too many messages (13). These comments clearly indicated C&T was not a perfect project, with perfect messages, sent at the perfect time. Tailored messages, the complexity/depth of the messages, and the delivery timing are all interesting arenas for further exploration.

The benefits suggested in the positive comments are what make mHealth a fascinating strategy for this space. Evidently, some participants liked communicating and connecting about their health, and technology allowed us to reach more people than we could with traditional outreach models. People who are more likely to call 911 or eat salad because they received several helpful SMS were representative of mHealth as a potentially powerful tool for the urban clinics throughout the country.

4.2.6. Focus groups coded by Bull’s rubric

As discussed in the previous chapter, the content of the focus group discussions for the SMS participants were analyzed using codes based on Bull’s (2011) unique and beneficial mHealth attributes: autonomy; standardizing information; interactivity; portability; and lower program costs.

Bull’s attributes were originally described in the book *Technology-Based Health Promotions* (Bull 2010) as a short set of concepts that differentiated conventional approach to
public health from mHealth approaches. The characteristics were organized as a list of attributes with brief descriptions. Therefore, the concepts were adapted to make sense in the context of providing public health prevention messages in the urban AI/AN context.

For example, in Bull’s description of lower program costs, the description only mentions the savings that are realized on the behalf of the researching organization. However, program costs are a concern for participants as well. Participants need to make time to be involved in research; their time is a commodity. Participants often cannot bring their children along to research functions, necessitating child care; child care is a commodity. In actuality, these resources cut both ways and it is important to acknowledge the expense of participant on the behalf of the research sample.

More generally, the application of Bull’s unique and beneficial attributes as qualitative codes here is rooted in the original description provided by Bull, but also looks to extend the original framework. Below are excerpts from the focus groups coded by their reference to these elements. Following each excerpt are thoughts on what each passage suggests, positively or negatively, about the intervention, as often done in qualitative manuscripts (Whitten, 2000; Caiata-Zufferey and Schulz, 2012).

*Autonomy.*

Bull defined autonomy as “participants in technology-based programs can have the option of choosing program elements that are relevant and appealing to them. Traditional programs may often require users to complete elements in a particular order” and “technology-based programs are always on, allowing access at any time of day or on any day of the week that is convenient to the user” (Bull, 2011, p. 6). Autonomy refers to the participants’ ability to respond to C&T in their own way in terms of regularity, timing, and volume. Here is a relevant excerpt:
Because, you know, I really – and I know sometimes I did forget and I did have a response but then I got too busy to sit and type it in. So, it wasn’t that it wasn’t important to me or that I didn’t want to participate it was just that maybe I totally forgot (PID 012013082801).

This participant values their participation, but nevertheless did not always respond. Allowing them to continue without forcing a response was appropriate, since it allowed them to continue to participate.

If you’ve had your mom or dad or grandparents have issues with coronary heart disease then that’s – I would think that would be a sign of – to keep yourself healthy. (PID 012013082801).

This participant related a C&T message to their own family situation. The C&T message was not personalized; the same message was delivered to all participants. The participant responded to the message because they found it relevant to their situation.

I personally said I’m going to go back to my old reservation ways. The way my grandmother did because I have great-great grandmothers who are medicine women. And I know that their ways of cooking, the ways of how I was taught to eat, and how I know food was prepared. I know that the men they always gave them buffalo jerky. Dried deer meat to keep with them. And that’s sustained you because you’re sucking on this and drawing nutrients from it. Or the fruits and berries off the trees as you’re going or eating roots and vegetables as you’re going along. So, I said, “Okay. I’m going to follow my own reservation diet” (PID 022014011502).

This comment shows another situation where the participant identified with program information that was considered relevant. In working with the information, the participant made the
information more relevant by personalizing their relationship to the message. A more constraining intervention would not have given the participant the autonomy to do this. Nutritional content from HGHH was more mainstream or commonplace than what some participants may have liked, enjoyed, or expected. However, the intervention did not place a value judgment on taking a traditional or western approach to diet and healthy living. This afforded participants the opportunity to convey their own autonomy, values, and identities.

*Standardized information.*

Bull defined standardized information as “technology-based programs’ content is delivered in exactly the same way each time to every user” and “technology-based programs aren’t dependent on the personality or charisma of one individual to deliver content” (Bull, 2011, p. 4). Standardized information, in Bull’s sense, is standardized for the sake of program fidelity. Program fidelity is important so that all participants get program content that is important to being involved in the intervention. User comments did not shed light on standardized information as an aspect of C&T. There were comments that indicate that the information delivered did have impact, however. Here are comments that reflect participants receiving such information.

> I think I’m okay in the heart health area. I did have a cholesterol test not too long ago, which I hadn’t heard the results about yet, so I need to follow-up on that. I had them checked at the beginning of this study (PID 012013090502).

While this participant had already begun looking at their cholesterol, C&T reinforced the importance of doing so by sending standardized information, critical to the evidence-based curriculum, which prompted the participant to action.
I think—with the help of the study—and that was my invite to come here because the high blood pressure. I knew that I was holding things internally. (PID 012013082801). This comment is another good example of how standardized information for an mHealth intervention can be helpful. Because C&T used information from the HGHH curriculum, all of the most important risk factors for CVD were covered, including high blood pressure. This participant received the health messages and found that it might be important (as indicated by the “my invite” comment) to come to the clinic and talk to someone about how to control high blood pressure. Therefore, the health messages provided through C&T were a call to action.

But I liked the daily – I liked the reminders and some of the – I had heard a lot of the information before but it’s always good to be reminded of it, like, the nausea for women thing, I’m sure I knew that at one time but then, you know, you forget and think about just the left arm kind of thing or the crushing pain (PID 012013082801).

This participant highlighted that, whereas a piece of information e.g., heart attack symptoms for women might be known, the re-experience of this information as a reminder while enrolled in the intervention was beneficial. Had this participant not interacted in the intervention, there would be critical information missing from the participant’s knowledge base about the signs and symptoms of heart attack.

**Interactivity.**

Bull defined interactivity as “technology-based programs allow for users to get instant feedback and interact with a computer. While traditional programs allow for interaction with other people, technology based programs allow for interaction with computers and people simultaneously” (Bull 2011, p. 4). Interactivity is the line of communication that is created between the research participant and the researcher which allows for feedback to the participant.
C&T did not simply push information to the participant, but, instead, welcomed and encouraged a dialectical relationship that would allow the participant to increase health knowledge regarding heart health and CVD. Here are comments from participants on this aspect of C&T.

I liked it [C&T]. The only thing that I felt that was hard was to respond sometimes because I would read it, it depends on what I was doing too at the moment, but I would read it and I would think about it and I kind of formulate a response in my mind but sometimes I didn’t actually get to the point of texting you back (PID 012013082801).

In this case, the participant thought about the messages, but did not text back. Sometimes participants will not be in a position where they can respond. This comment spoke to all distractions people have on a daily basis that can possibly limit interaction. However, it also mattered that the participant was consuming and thinking about the health messages despite not having the ability to respond to all messages that solicited a response.

The tough part was replying…depending on what you were doing at the moment when you received the text and then you kind of think of what you’re going to respond or what your response is going to be and then responding, I think, responding was the toughest thing because if it was something that you knew right off the bat that you really didn’t have to think about and process, so just depending on the text, but I enjoyed like all the SMSs, they were good reminders, good messages that always kept heart health on your mind (PID 012013090502).

This comment spoke to the difficulty of responding and interacting. The participant identified breadth of the heart health information, as well as the lack of depth, at times, of the information in the intervention. In the messages that asked for a response, the participant mentioned that sometimes the answer was immediately clear and obvious, something that did not require a lot of
thought. Despite the depth of the information that did not require a lot of thought, this participant enjoyed the interaction with the health information because it was a constant reminder to think about heart health.

I think initially I was a little confused because I would get the information and then I would be like, was I supposed to respond to this information? And I finally caught on, like, take the information and wait for the question and then respond and so I caught on it. But at first I was confused, like, do I respond, what am I supposed to respond (PID (012013090502)?

A major piece of the intervention was not communicated well to this participant. At the time of consent, the project should have been described more thoroughly so the participant would not be confused and wondering about how, when, and what to respond.

Interactivity, based on the participant comments above can be interpreted as a weakness of C&T. Time is an issue for responding. Often, other things in participant’s lives were difficult and took priority. This is an important finding. The Recommendation section in the next chapter takes this negative feedback from participant’s and incorporates it into theory development.

Portability.

Bull defined portability as “technology-based programs can be ubiquitous and portable if available on a laptop or mobile phone” (Bull 2011, p. 6). Portability is related to receiving information in real time no matter the geographical location of the mHealth recipient, and can make health information ubiquitous and portable. Here are comments from participants on this aspect of C&T.

I think the technology is there because people all have phones whether you’re here or on the reservation (PID 022014013001).
The comment above highlighted that the technology was available, accessible and portable. Mobile technology was useful because it penetrated both rural and urban locations. Several of the participants traveled to and from reservation communities during the intervention implementation.

And just with today being in a different area and in urban setting and more, like, everything from a western perspective you sort of have to draw from both [the reservation and urban settings] (PID 012013090502).

There is a great deal of transience in the Denver Metro, and regional, AI/AN population. Many AI/AN people move freely from the urban to the reservation context. Several participants were traveling during the intervention. The mobility of C&T could allow traveling participants to continue being involved. Many AI/AN travel freely from urban areas to reservation communities based on the need to find work, housing, or medical attention (Pickering, 2004).

mHealth strategies are uniquely suited to reach participants even when they are mobile and moving between different residential areas. A face-to-face intervention may not have worked for this participant because of movement between locations, and the portability of the CVD messages could have been beneficial. Participants’ substantial knowledge of both urban- and reservation-based living was obvious.

Yeah. That’s going to be an issue with me too because I just now got a truck from John Elway. Now everything that can go wrong—I should say I bought a lemon and they’re not defending what they sold me. So now I’m going to be bussing it. And that was never an issue before…transportation is definitely going to be an issue (PID 022014011502).

Face-to-face interventions can be a barrier for participants that do not have reliable access to transportation. However, the ubiquitous nature of mHealth on cell phones circumvents this
barrier. Ideally, little to no cost should be associated with involvement in an mHealth intervention on the behalf of the participant. People of low SES face many barriers and could potentially take advantage of interventions that are portable.

*Lower Program Costs.*

Bull defined lower program costs as “if technology-based programs reach greater numbers of people, can be standardized, and can be delivered at any time in diverse locations, we have potential to lower program costs associated with delivering health promotion” (Bull 2011, p. 6). As discussed earlier, lower program costs refer only to the organization that is delivering the intervention and not to intervention participants. What participants had to say about cost did not necessarily take into consideration the cost of the participant, but the cost to the participant as the end user. This population is sensitive to the cost of participating in health interventions. Here is a participant comment on this topic.

This was a really short program. I wouldn’t mind a longer program. Just so long as I can afford my cell. I wouldn’t mind it one bit at all (PID 012013082801).

Lower program costs allow interventionists to deliver longer programs. In the case of this participant, a longer program was desired and the participant wanted to continue getting messages as long as the cell phone remained affordable. Because the intervention was completed by means of mHealth, the participant did not have costs associated with logistics to get to the clinic and could use resources at their disposal to keep a cell phone on which to receive intervention messages.

*Additional topics in the focus groups: incentives.*
One additional important topic emerged in the focus group sessions that was related to Bull’s concept of lower program costs, but not directly. The topic of incentives was identified by three participants.

But then you also have to look at too at the fact that income does play into it a lot for those people that are on the reservation and people that are off the reservation. People off the reservation have to pay rent. People on the reservation don’t rent. They still get commodities. They got to make use of those commodities. And off the reservation rent, utilities, bills, have to be done. So, you have to buy what you can from wherever you can (PID 022014011502).

This comment highlighted the benefits and drawbacks of living in a metro or a rural area. Lower program costs are important for AI/AN in both the rural reservation setting and also, if not more so, in the urban setting. As the participant suggests, there are a lot of expenses that are associated with living in the urban setting. Participating in a mHealth intervention should not be an added expense that participants have to make difficult decisions over getting involved or not getting involved to save money.

Sometimes it’s hard to get our community interested in actually doing stuff that’s good for them. So, if it could be presented in a way that they could see the benefits. And the cards [gift cards for participant compensation] really help, for me, you know. I’m really interested in helping our community and so it was important for me to make it here. (PID 012013090502).

Because mHealth strategies can be implemented at lower cost, resources can be saved for compensating participants. This comment asserted that there needs to be an incentive, a reason, to be involved in an intervention other than the inherent benefits of enrolling into a prevention
mHealth allows project budgets to include perks like bus passes because there are fewer costs associated with a face-to-face intervention. The comment requested an incentive option to build into mHealth interventions and also emphasized why the remote nature of mHealth is advantageous. Bus passes could be possible because of lower program costs that are inherent of mHealth interventions. Face-to-face classes are good to build rapport and networking opportunities among participants. However, attending conventional classes is expensive for some, and many of the urban dwellers enrolled in the C&T intervention needed bus passes to enroll in the project and complete post-intervention surveys.

### 4.2.7. Photovoice and narrative analysis

Participants in the MMS condition created digital photovoice essays. One photovoice essay generated from the research design was analyzed using narrative analysis, a form of qualitative analysis focusing on how respondents impose order on the flow of experience in their lives and make sense of events (the intervention) and actions (receiving/sending SMS/MMS) in which they have participated (Riessman, 1993). The photovoice document analyzed here was from Wave 1. The document from Wave 2 was structurally similar and the analysis of that document proved not to add any new and valuable insights.

Table 4.3 contains the transcribed narrative from the photovoice. Labov’s framework was used to identify key features of the narrative and to define in concrete terms the structure of the narrative (Wang, 1997). The codes [A], [O], [CA], [E], and [R] in the columns in the table
refer to the following attributes: [A] = provide an abstract for what follows, [O] = orient the
listener, [CA] = carry a complicating action, [E] = evaluate the complicating action’s meaning,
and [R] = resolve the complicating action. The right column of the table contains the core
narrative of the story, which makes it possible to break down a longer narrative into its
component parts.

Table 4.3: Narrative analysis

| Transcription | 001: Welcome to Cell and Tell [O], a study conducted by the University of Colorado to help educate us in heart health [A]. My name is Jenna [O]. | 006: Technology is not the only way to incorporate exercise into your lifestyle [CA]. Many sporting activities such as golf (Figure 4.9, below) can help you to stay fit [E]. Golf is a sport that allows you to get a full-body workout [E]. Playing different sports allows you to get your exercise in a fun way [E]. The picture is of a set of golf clubs. |
| 002: And my name is Ronald [O]. | 003: And we are here to share in what we learned in this study [A]. This picture is of the C&T logo. | 007: Healthy eating habits are beneficial not only to your heart but also to your overall health [CA]. Foods such as oatmeal can help to lower cholesterol [E]. Foods that contain flax can also help to lower blood pressure [E]. Olive oil and flax contain Omega-3 fatty acids that help reduce heart disease (Figure 4.10, below) [E]. The picture is of muffin mix and extra virgin olive oil. |
| 004: One of the best ways to get yourself active is to join a gym [CA]. A gym membership can help to motivate you to become healthy [E]. Gyms are for group exercising and personal exercising to fit your preferences [E]. The picture in the photovoice is a gym membership card. | 005: Another way to motivate you to exercise is to incorporate technology [CA]. This can be achieved by using video gaming systems such as the Wii, Xbox and Playstation [E]. Many of these gaming systems have fitness games that can be fun and interactive for yourself and/or family members [E]. The picture is of two boys playing the Nintendo Wii.
008: Eating fresh or frozen fruits and vegetables can also promote your overall health [CA]. Fruits and vegetables are a better food choice than eating processed foods or fried foods [E]. *The picture is of frozen vegetables and fruits.*

009: If you suspect that you are experiencing a heart attack [E], taking two aspirin can help to save your life [CA]. You should also call 911 even if you are unsure if you are having a heart attack [E]. Doing these two simple things can really save your life [E]. *The picture is of two aspirins in the palm of a hand and another picture of 911 dialed on a cell phone.*

010: Staying active and eating right can prevent heart disease and life threatening incidents related to your heart [R]. *This picture is of the C&T logo.*

**Complicating Action**

004 One of the best ways to get yourself active is to join a gym

005 Another way to motivate you to exercise is to incorporate technology

006 Technology is not the only way to incorporate exercise into your lifestyle

007 Healthy eating habits are beneficial not only to your heart but also to your overall health

008 Eating fresh or frozen fruits and vegetables can also promote your overall health

009 taking two aspirin can help to save your life

**Resolution**

010 Staying active and eating right can prevent heart disease and life threatening incidents related to your heart.

---

**Core Narrative of Wave 1 Photovoice**

**Abstract**

001 a study conducted by the University of Colorado to help educate us in heart health

003 And we are here to share in what we learned in this study

**Orientation**

001 Welcome to Cell and Tell
My name is Jenna

002 And my name is Ronald
The photovoice provides clear evidence that the participants re-stated some of the key messages from HGHH. The narrative directly links to the different information that was present in the different weeks throughout the intervention. But it re-presents the information using different examples.

For example, comments 004, 005, and 006 about physical activity link to the messages that were sent during the second week of the intervention when the focus was on physical activity. In the narrative, golf is used as an example, but golf was not mentioned in the messages the participants received. Although this information was not explicitly sent to participants, at least one of the photovoice participants saw value in their golf activities and added the photo to the photovoice to convey how they like to get their physical activity.

*Figure 4.9: Golf clubs from photovoice session*

Another example of how HGHH content was rephrased in the photovoice session is seen in this photo, Figure 4.10. In week five of the C&T intervention the participants received
messages on how to eat healthy even when their personal financial budget was tight. Some of this discussion focused on how to purchase meals in the supermarket to get the most nutrients for their dollar. For example, frozen foods are better for you than canned foods because frozen foods do not contain the syrups or liquids that contain added sugars. Figure 4.10 was received by the researcher during the same week as the information about frozen food was transmitted; the topic of that week was how to shop in a healthy manner. Figure 4.10 was a homework assignment that the participant in the MMS condition sent to the researcher and was used in the photovoice being analyzed here. In the photovoice session, the participants expanded on this idea to show a picture of household items that they commonly use because of the healthy benefits the foods provide. Both flax and olive oil were not explicitly discussed in the standardized messages that the researcher sent, but because the participants were thinking about healthy ingredients, identifying other healthy ingredients was not a problem and was in line with the topics that the C&T intervention covered.

Figure 4.10: Frozen foods instead of canned foods
Chapter 5: Discussion and conclusion

This chapter provides a critical interpretation and assessment of the study results. The research questions are reviewed and answers to each of the questions are provided. Then the relationship of the results to findings of similar studies is discussed. The remaining subsections in this chapter include strengths of the study, limitations of the study, recommendations that emerged as a result of conducting the research study, unanswered questions and emergent questions, unexpected observations, unexpected events, and implications for future work.

5.1. Answers to research questions

Here are answers to the questions asked at the beginning of this dissertation, based on the data presented in Chapter 4 – Results. At the end of this section, Table 5.1 organizes the research questions in a research question/answer/evidence table format.

5.1.1. Research question 1

The first research question was: to what extent is the cell phone, as used in C&T, a feasible dissemination tool to increase knowledge of cardiovascular disease (CVD) risk factors in an urban American Indian Alaska Native (AI/AN) population? The evidence produced to answer this question was collected in the form of memoing, survey data, response rates, exit surveys, and focus group responses.

As stated previously, memoing was a qualitative exercise put into place to keep track of the important mHealth characteristics that Bull advances. Memos were taken at critical junctures throughout the research process. Some memos highlight important decisions made based on the guidelines Bull’s characteristics provided. Decisions made that were based on Bull’s work were flagged as to track the inclusion of Bull’s important features.
As already mentioned, a total of 90 memos were collected during the study, 26 in conceptualization, 30 in development, 19 in testing, and 15 in implementation. It is not surprising that more memos were created during the conceptualization and development phases of C&T, because there was a good deal of critical thinking and planning associated with the development of the intervention. These memos allowed the researcher to revisit the decision-making process that was followed in the development of the intervention.

In regard to Research Question 1, an example of how Bull’s unique and beneficial attributes tracked feasibility is this memo, “Participants like the interaction that comes from attending the face-to-face classes.” Based on this memo, interaction was an element that was important in the conceptualization and development phase. Participants liked interacting when in an in-person group. Through the development of C&T, the researcher attempted to prioritize interaction through the message types, including quizzes and homework.

Other relevant memos were created when the researcher noticed something important about the participant’s experience of C&T. None of the memos indicated frustration or annoyance. One negative memo captured was that the survey was long for some respondents. Long surveys are a burden to research participants, and some participants in C&T were turned off by the time commitment needed to complete the surveys, but no participants declined the survey based on the time required for completion.

The survey results provide evidence for the general positive feasibility of the C&T intervention. The C&T model worked well for promoting heart health messaging over the cell phone. The four constructs analyzed in both the SMS and MMS conditions yielded only one decrease in knowledge from baseline to post-intervention. While it cannot be stated that the same results would be found in a larger RCT, these results do support the notion that a larger
project that utilizes the C&T design is worth pursuing to assess whether the intervention can influence health knowledge and increased awareness.

The response rates also suggest feasibility, based on the high number of overall responses (244 responses to the 800 messages sent overall, or 31%). There was a response rate of 23% to the 320 messages that explicitly asked for a response, and the consistency of response throughout the five-week intervention time period as depicted in Figure 4.3. Response rates did not decline in numbers over the course of the intervention weeks.

The exit survey data set suggests that participants generally viewed their experience in the mHealth setting positively. As previously stated, 13 of 23 participants responded, with 11 comments being positive (85%) and two negative (15%).

The two negative comments are really critical learning opportunities for the researcher, rather than suggesting serious problems. The first negative comment is a reaction to receiving messages early in the morning. There are steps the researcher can take to minimize frustration with message delivery time, such as tailoring messages to be delivered at the participant’s preferred time, or just avoiding a time that may be problematic for participants because mornings seem to be busy for most people. The second negative response described the participant’s desire to get deeper, more sophisticated, health knowledge. This issue can be addressed with more information geared towards different levels of health knowledge understanding. For example, a database containing three tiers of health information can be created to meet participants at a novice, intermediate, and expert level of health knowledge.
The positive comments are encouraging in terms of feasibility of mHealth in the urban AI/AN clinic context. Perhaps the most important example is of the participant that decided to call 911 because of stress induced chest pains. This participant stated that the call was placed because of C&T. The importance of this response cannot be overstated: the C&T intervention influenced someone to take responsibility for their own health, and take consequential action. There are many reasons that people who suffer from economic disadvantages and racism do not access healthcare. In at least this one case, C&T helped build knowledge and confidence on how to manage this health situation.

5.1.2. Research question 2

The second research question was as follows: in an urban AI/AN population, to what extent, if any, does the inclusion of text with photo elicitation (MMS) increase health knowledge and motivation more than text messaging (SMS)?

Survey data showed that participants in the MMS condition were able to identify signs and symptoms of heart attack more accurately at post-intervention than they did at baseline when compared to the SMS condition. Although there was not a large enough sample to assert that the intervention influenced health knowledge and awareness, the general trend in the four paired sample \( t \)-tests suggests a trend in the positive direction where more participants are answering survey questions correctly at post-intervention as compared to baseline.

5.1.3. Research question 3

The third research question was: how applicable were the social science ideas about organic intellectuals and counterhegemonic discourse in shaping the intervention? The evidence produced to answer this question was collected from the content of participant SMS/MMS responses and photovoice narrative analysis.
The author cannot argue that health hegemony was transformed in the context of the Urban AI/AN clinic, thereby creating a new health counter hegemony. To do so, a fundamental shift would have had to be observed in the social, political, and economic systems that govern participant’s abilities to make health choices. “So long as power-over is sustained through an effective blending of persuasion and coercion, [health] hegemony remains intact,” (Carroll, 2009). New health hegemony is an ideal to strive for, but not achieved in C&T. However, some participants created content by responding to health messages that may have influenced the individual’s opinions and understanding of heart health.

Not all the participants took action when presented with the opportunity to produce counterhegemonic discourse. Those who did take the opportunity crafted their own understanding of evidence-based curriculum materials. By doing so, these participants behaved in a manner that transformed the C&T material so that it came from them, not from C&T, and is an example of deep processing as mentioned in Chapter 2: Behavioral Health Model and Critical Social Theory. In this sense they reversed the traditional, top-down hegemonic relations.

A good example of this is PID 022014011603-Wave2. The message received was: “Delay is deadly. If you think a heart attack is taking place the most important thing to remember is call 9-1-1 in 5 minutes of less. Do not wait too long.” And the response from the participant was: “True. Asap is best. My friend had a heart attack in front of me & refused my help. I called anyway. She wouldn't believe me & sure enough she had one. This was this past Friday!!!!” The message sent back to the researcher acknowledged the message as being a key piece of heart health information. The message made the content personal and meaningful in the participant’s life. Therefore, the message was an instance of counter hegemonic discourse.
because it was produced by a participant in a manner that will be more memorable and important to the participant. The transformed content was not pushed onto the participant, but, by communicating through C&T, was produced by the participant.

The photos received through cues to action from participants are visual data for the photovoice narrative analysis. The approach allowed the participants to couch the health information they received via SMS in a local and personal context. As mentioned previously, when the information contained in the photovoice that was analyzed, it was clear that there was information delivered in the intervention that participants carried forward to the photovoice, although rephrased, and made more personal through the photos used in the document. The photovoice document is an example of the production of counterhegemonic narrative, produced by the participants and not delivered to them in the form of a top-down health intervention.

While the content is counterhegemonic, it does not constitute a shift in hegemony because the underlying material conditions in the system that is DIHFS did not change. In this example, participants were first provided evidence-based health information.

The content of health knowledge is mainly universal and not based on cultural or ethnic identity. Accordingly, health knowledge is often delivered in an impersonal manner. C&T provided an opportunity for participants to take ownership of impersonal health information, thereby creating a counterhegemonic narrative.

A narrative does not need to be “cultural” or “Native” in a stereotypical way to be counterhegemonic. The narrative of the photovoice is cultural because culture takes on many forms, and the participants in the photovoice exercise presented their personal AI/AN culture in terms of the words they chose and images they captured simply by being AI/AN themselves. This photovoice did not focus on cultural phenomena that are often associated with AI/AN
culture, such as living in tipis or hunting buffalo. These cultural elements are from another era, and to have the expectation that this type of visual data show up in the photovoice would be to freeze a culture in time and not allow it to develop over the course of the lived experience of these individuals. What is important is that the participants linked the information they received by SMS/MMS through participating in C&T with the realities of their own daily lives. The exercise of producing the document is the essence of counter hegemony.

The co-creation of shared narrative connected theoretical elements used in the development of C&T, namely, IMB, the organic intellectual, and Bull’s unique and beneficial characteristics. The connection between theory and method happened when the participants, in their own environment, received the MMS from the C&T researcher asking them to take pictures of something that was either a benefit or a barrier for enacting heart healthy choices. The participants, in taking their own individual pictures, acted on their own motivation and volition by selecting something they knew either helps or hinders heart health. Therefore, C&T truly relied on participation and worked because of the self-knowledge that each participant demonstrated through this activity, thus incorporating their own ideas and understandings of heart health.

Table 5.1 contains each research question and the answers to those questions, followed by a summary of the evidence supporting the answers arrived at after analyses.
<table>
<thead>
<tr>
<th>Research Question:</th>
<th>Answer:</th>
<th>Evidence:</th>
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<tbody>
<tr>
<td>1. To what extent is the cell phone, as used in C&amp;T, a feasible dissemination</td>
<td>Feasible</td>
<td>Answered with response frequency analysis at the individual and group levels describing participant interaction patterns and triangulated by qualitative analysis of focus group sessions using Bull’s unique and beneficial rubric.</td>
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<td>tool to increase knowledge of CVD risk factors in an urban AI/AN population?</td>
<td></td>
<td></td>
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<tr>
<td>2. To what extent, if any, does the inclusion of text with photo elicitation</td>
<td>A positive trend suggests MMS might increase knowledge and awareness</td>
<td>Answered by the paired sample t-test applied to the condition comparison.</td>
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<td>(MMS) increase health knowledge more than text (SMS) health knowledge messaging</td>
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<td>in an urban AI/AN population?</td>
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<tr>
<td>3. How applicable were the social science ideas about organic intellectuals and</td>
<td>By hosting the intervention through the DIHFS clinic and using a</td>
<td>Answered with participant responses to health messaging, qualitative analysis of focus groups which were geared towards understanding culture as a concept. A narrative analysis of the photovoice was also conducted.</td>
</tr>
<tr>
<td>counterhegemonic discourse in shaping the intervention?</td>
<td>curriculum aimed at AI/AN, a familiar context is used, and open</td>
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<td></td>
<td>channels of communication are created so participants can focus on</td>
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<td>improving health. This, in addition to using social and behavioral</td>
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<td>theory that seeks to attain opinions, perspectives, and thoughts from</td>
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<td>the AI/AN population make for deeper processing, higher level of</td>
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<td>engagement and opportunity to produce counter hegemonic discourse</td>
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<td>because the intervention meets the participants in a place that is</td>
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<td>familiar and privileges their opinions.</td>
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5.2. Results in relation to other studies

It is helpful to compare the results from the C&T program with the results of three similar studies touched on in the Scientific Background section. These comparisons help position the C&T work in the literature of mHealth feasibility studies.

A comparison with Gerber (2009) showed that small pilot interventions could provide insight on participant involvement in design and perceptions of acceptance for mHealth strategies. As stated before, Gerber was a critical piece used in developing the research protocol and system for C&T. Gerber’s research provided an example of how importance could be placed on making participants a critical and central piece of the intervention. In terms of a feasibility study, Gerber provided a blueprint on how to enter a population and assess whether the selected technology was appropriate for a population. Many of the same data types were captured, such as exiting reflections on the intervention and general acceptability of the technology used. Both Gerber and C&T uncovered generally positive attitudes about the technological modality. However, the real importance of these two studies was the reliance on the participants to be critical voices in how the messages should be received. Gerber was able to obtain this information through exit surveys. C&T collected the same data, but through the focus group format.

As with Wayne and Ritvo (2014), the mHealth approach of C&T showed positive influence on outcomes in lower SES populations within the urban community health setting. In terms of feasibility, Wayne and Ritvo was an initial mHealth project in a population where mHealth approaches were new and novel. As with the Gerber, the Wayne and Ritvo study helped to further support the feasibility of C&T in an urban clinic setting when working with participants that may be subject to lower SES. The majority of DIHFS clientele are single parent
heads of household. The average income reported by DIHFS patients is $621 per month or $7,452 per year. Seventy-three percent of DIHFS patients did not have health insurance before the 2010 Affordable Care Act passed. Wayne and Ritvo worked with lower SES participants and with smartphones that were provided by the project; because smartphones were used, this study was not described in the Scientific Background. The authors reported that many of the subjects in the study did not have previous experience with smartphones. The use of smartphones was interesting because the price tag for services and equipment will continue to decline to a level that will allow greater penetration in low SES communities. However, the findings suggested that the use of mHealth strategies in low SES urban settings was feasible and acceptable.

Moreover, similar findings between their research and C&T were interesting because Wayne and Ritvo looked specifically at managing type 2 diabetes, a highly prevalent disease in the AI/AN population, and this mHealth approach could be administered through the national AI/AN clinic network.

The comparison of C&T to Text4Baby (Evans, 2014) also yielded interesting observations, especially because Text4Baby had positive evaluation findings using the same technology. The results of the first evaluation study for Text4Baby revealed statistically significant increases in daily fruit and vegetable consumption and in seeking health information online. It also revealed reductions in reported smoking in the past 30 days among Text4Baby participants compared to control participants, and increases in beliefs about pre-natal prevention and health-promoting behaviors, such as smoking cessation and pre-natal vitamins (Evans 2014). Similarly, C&T found that health knowledge on signs and symptoms of heart attack could be increased through receiving health related messages via mHealth. These results were important because both studies highlighted a statistically significant change that was induced by simply
receiving and reviewing health messages on cell phones. Neither study assessed long-term behavior change, a necessary future step.

5.3. Lessons from DIHFS involvement

The DIHFS setting for C&T was of central importance. The experience of working with DIHFS produced some lessons that will be valuable for future mHealth interventions with AI/AN populations, that are not directly tied to the research questions for C&T. Denver Indian Health and Family Services clinic was highly involved in the conceptualization and implementation of C&T. C&T flowed from another research project implemented at the clinic and was viewed within the same research trajectory of the previous project, FIT Health. This research trajectory investigated how to get prevention messages and health education to clinic patients in a manner that would not suffer as much from poor attendance.

The DIHFS clinic was enthusiastic about the idea of bringing mHealth to their patient population. This enthusiasm was displayed in meetings that were held with stakeholders in the spring and summer of 2014. The diabetes care manager was eager to provide more outreach in a different modality. In an environment of funding constraints and shrinking budgets, mHealth represented a new approach to getting health information out to people in need of health education and CVD prevention messages.

Although there was a great deal of excitement about the potential of mHealth in the urban clinic setting, there was also some concern about this uncharted area of mHealth research for DIHFS. When the researcher met with the executive board in advance of implementing the intervention, questions were asked about how safe mHealth would be for the patients at the clinic that may not have used technology for health purposes. The questions centered on personal safety while engaging technological interfaces, but did not touch on issues of confidentiality or
privacy. Regardless, the researcher assured that the C&T intervention was not set up in a manner that would jeopardize personal confidentiality or privacy.

The DIHFS Executive Board is made up of professionals and community members, all of whom have a personal investment and stake in the success of the clinic. Some of the professionals work in the healthcare industry; others work in fields such as law and entrepreneurial business. Diverse professional backgrounds created a mixed reaction to the introduction of mHealth as a service provided to clinic patients. Some members of the board were immediate proponents, while others raised concerns about the liability to the clinic based on offering new prevention services.

Liability concerns were associated with clinic patients interacting with clinic-sponsored content while not at the clinic. For example, one board member raised the issue of someone interacting with a C&T health message while walking down the street. This interaction could be distracting and the participant might walk off a curb and sprain an ankle or walk into oncoming traffic. This example immediately led to a discussion about participants interacting with C&T messages while driving.

Texting and driving emerged as a serious issue that needed to be addressed before the Executive Board would allow the C&T intervention in the clinic. The researcher was open to ideas on how to prevent this dangerous behavior. The Executive Board suggested that participants had to pledge that they would not text and drive before enrolling into the research project. The researcher was tasked to find a strategy to produce documentation that stated the participant would not text and drive. The form in Appendix B was used to produce this documentation. Documentation was important to the law professional in the group who argued
that participants that signed this pledge could not find the clinic at fault if the participant happened to be in an accident, such as texting and driving.

The texting and driving agreement was outlined in a Memorandum of Understanding (MOU). The MOU is another document that represents a high degree of involvement in the process of bringing the C&T intervention to the clinic. The MOU was written and executed so that the researcher and the staff at DIHFS had a concrete understanding of what was expected from both parties.

C&T would not have been possible without the involvement and cooperation of the DIHFS Executive Board. It was encouraging that the clinic staff and Executive Board took such great care to make sure that the DIHFS patient population would be safe with regard to the C&T protocol. The texting and driving pledge form was approved by both COMIRB and the National I.H.S. (NIRB) human subjects review committees.

The clinic staff was not asked to do many tasks involved in the implementation, though front line staff was helpful in identifying patients that might be interested in C&T. The small support that DIHFS was asked to contribute is significant because it demonstrates that outreach prevention programs similar to C&T that use social media and mHealth methodology, can have good reach without large staff commitments.

The Executive Board’s high degree of involvement in the process to bring mHealth to the clinic was viewed as a great achievement. Careful consideration of the impact mHealth would have on the organization is time well spent for future mHealth programs in the DIHFS clinic. mHealth strategies can be adopted by DIHFS in the future because C&T has been established as a productive way to communicate health knowledge and awareness messages to the AI/AN population.
5.4. Strengths of the study

Strengths of the study included increased health knowledge, extended reach beyond the classroom-based health education strategy standard of care, and a high level of retention, as none of the participants dropped out of the research study. Other more general strengths included a high degree of interest and influence from the DIHFS clinic. Acceptance of mHealth as a strategy by the participants was high: no participants opted out of receiving the heart health messages, and of the 32 participants who enrolled, 23 participants (71%) completed the baseline and post-intervention surveys. Low attrition rates spoke to the success of the program and how non-invasive this strategy can be for low-income populations.

One completed photovoice essay shifted an individual level intervention on the Socio-Ecological Model to an interpersonal level intervention. The photovoice essay demonstrated a methodology for confirming that heart health messages were accurately received by the intervention participants and successfully grounded in participants’ own verbiage in the photovoice.

A secondary successful component of the C&T system design was that texting could be used for scheduling face-to-face meetings to collect survey results the investigator needed to meet with each participant face to face three times. It proved natural just to use text messages to schedule these meetings. This worked so well that it is a potential benefit of mHealth to keep in mind in future projects.

5.5. Limitations of the study

A number of factors limited what can be learned from the results of the C&T study. Here is a discussion of some of these limitations, along with suggestions on how these could be addressed in future work.
First, the sample size was small, limiting the power of the statistical comparisons. Only a few contrasts reached significance, such as the finding on the heart attack (HA) knowledge construct. Because the power of the comparisons was so limited, we simply cannot tell whether or not positive or negative results would be found in a larger study, or in an actual deployment. Obviously, a larger study would address this limitation.

Second, the study did not have formal mechanisms in place to follow up with participants that did not send responses back to the intervention facilitator. As previously stated, there were no instances of participants opting out of receiving the C&T messages, and it would have been easy for participants to opt out, had they wished to. However, it cannot be assumed that participants who were not responding actually paid attention to all the messages during the intervention. Relatedly, 32 participants were enrolled in the study, but only 23 (72%) completed a post-intervention survey. The study design did not include a way to gather information from the non-responders, or those who did not complete a post-intervention survey.

Information on these matters might help the researcher understand the causes of these behaviors, and possibly prevent them. For example, if the surveys were not collected because of scheduling issues, or other logistical barriers, these might not be difficult to address, but if participants simply tuned out the intervention because of lack of interest that could be more challenging.

It is not easy to collect data from non-responders, of course, but some approaches could be tried in future work. For example, in countries with socialized medicine, follow-up rates are extremely high (Højmark, 2016). This is due to the fact that citizens in these countries understand that if free services are going to be available, patients need to provide data to help the health infrastructure to continue being able to manage the resources needed to provide the
services. Despite the high rates of follow-up in these countries, researchers have piloted new strategies to get follow-up data from non-responders. One strategy is to schedule a structured phone interview to collect outcome measures, if possible, and also to collect reasons why patients did not respond. This is a simple, low-tech solution that can be easily added to future research protocols.

This limitation relates to a gap in our understanding of the impact of the intervention. While it seems likely that increased engagement with the intervention leads to more learning about heart health, we cannot be certain of that, from the data. That is, we cannot assess a dose effect for engagement, other than very crudely: we observed some engagement, and some learning, but cannot trace the connection between the two quantitatively. In future work, this limitation could be addressed by a larger sample, along with a quantitative measure of engagement that could be correlated with quantitative measures of learning. For example, the mHealth Technology Engagement Index (mTEI) could be used as a measure of engagement (Dewar et al., 2016). Connecting this point to the previous issue, post assessment data on non-responders would be very useful.

Finally, the C&T study did not assess long-term behavior change. Many mHealth researchers are calling for more rigorous studies that evaluate long-term behavior change, and such studies are certainly important. But establishing feasibility for an intervention, as has been done for C&T is a critical first step.

5.6. Recommendations

The recommendations that emerged from the C&T intervention are based on evidence that was produced through data collection and data analyses. These recommendations are meant to inform other researchers when conducting feasibility research in mHealth.
Two-way communication model is important to establish a health dialog. The first recommendation flows from the response rate data. There were many more unsolicited responses (169 responses, 69% of total responses) than solicited response (75 responses, 31% of total responses). The participants were encouraged during the enrollment process to respond to any of the messages that were found to be interesting. This data suggests that a two-way communication model is important in an intervention such as C&T. Creating opportunities for participants to discuss all of the content from the intervention increased engagement and dialog.

Targeting specific times different intervention participant receive messaging is important. The second recommendation flows from the focus group results and is based on several participants admissions that sometimes it was difficult to respond to the homework messages. This recommendation is naturally related to the first recommendation. Clearly responding was not too difficult when the researcher received 244 response messages from a total of 800 messages sent to 32 participants. However, some participants, including PID 012013082801, whose focus group comment is below to illustrate that timing is sometimes the greatest barrier to responding.

Because, you know, I really – and I know sometimes I did forget and I did have a response but then I got too busy to sit and type it in. So, it wasn’t that it wasn’t important to me or that I didn’t want to participate it was just that maybe I totally forgot.

Many commercial SMS applications allow users to program the time a message is sent. Tailoring the delivery of messages could potentially increase engagement of participants. Delivering health messages at a defined time that is convenient for the participant is a good use of tailoring and may influence knowledge and increased awareness.
Encourage interaction and content creation from the participant to yield rich data that can be interpreted in multiple ways. This final recommendation is based on the coded responses received from the participants, discussed in the previous chapter, with a total of 465 codes applied to 244 messages. The spectrum of responses demonstrates that participants engaged with the content in various ways. The contextualization and personalization codes are noteworthy because in both cases the participant takes health information and repurposes it to make sense to the individual. Making sense of the information in contextualization means the participants frames the information in general context, while personalization makes the information relevant to the participant’s life.

5.7. Unanswered questions and emergent questions

One question that was not answered during C&T is why participants chose not to respond to messages. As stated previously, four respondents did not respond at all. In retrospect, an exit survey with these participants would have been beneficial to better understand why they did not respond to the health messages. It is possible these participants received the heart health messages and fully paid attention, but the researcher cannot know if this was the case because follow up with participants who were non-responsive was not built into the protocol. Each of these four participants provided a baseline survey, but they were lost to follow up. In future efforts, protocols will include an exit interview strategy for non-responsive participants to ascertain why response rates in the study were low or absent.

C&T generated new questions that can be explored in future research projects. Whereas in Research Question 2, “To what extent, if any, does the inclusion of text with photo elicitation (MMS) increase health knowledge more than text (SMS) health knowledge messaging in an urban AI/AN population?” the findings were not statistically significant, a trend did emerge that
suggested photo elicitation increased knowledge when compared to the SMS condition. A continued line of inquiry involving MMS is warranted according to this trend.

Future studies could look more precisely at the meaning of cues to action that request picture taking within a community when prompted by an mHealth intervention that focuses on a specific health priority. Such studies could capitalize on thinking about the ecological moment.

The ecological moment is a theoretical concept that places emphasis on the local context in which an intervention takes place. Bull advanced this concept in work associated with cell phones (Bull, 2012). In the SMS Truvada project, cell phone SMS helped facilitate adherence with the daily Truvada regimen for women at-risk of HIV infection. Essentially, the ecological moment capitalizes on the ubiquitous nature and mobility of cell phones. For example, in the Truvada case, SMSs were sent to confirm that medication has been taken, and participants with questions had the option of receiving a call from project staff. Because this project dealt with sexually transmitted infections (STI), just-in-time messages were sent to make sure participants protected themselves when engaged in sexual contact.

The C&T intervention sought to capitalize on the ecological moment and took it one-step further by creating a technological system that yielded a dialogue for CVD risk reduction between participants and C&T researchers. The ecological moment occurs when a text is received while participating in a health intervention and engaging in ongoing life activities, rather than interrupting recipients from what they are doing to look for email or to seek information on the Internet (Bull, 2012).

A question about the ecological moment for future research is how does time and location when a message is received influence immediate behavior? This question could be addressed by
using the GPS and mapping functions on the cell phone, coupled with a diary application to record behavior after receiving a message.

The narrative that emerged from the pictures taken when photos were elicited from the intervention researcher would be at the heart of this inquiry. The pictures taken by participants represent the ecological moment, or the environment the participant operates within and the context that surrounds all health-related decisions. Narrative analysis seeks to explain the lived experience and how individuals organize their thoughts on topics. This type of inquiry would also be a novel approach to making individual-level interventions on the Socio-Ecological Model in public health move into community-level interventions. When individuals gather, share their lived experiences, and ask to make sense of their own realities in relationship to the realities of other participants, a new form of knowledge is created through community collaboration. This type of approach is true to the CBPR principles used for the development and implementation of C&T.

Another question that emerged from C&T is how and whether knowledge influenced behavior. Future efforts could track a specific set of behavioral outcomes to address behavior change. For example, in relationship to physical activity, participants could receive pedometers to count daily steps taken, and before-and-after height and weight measurements could support the pedometer datum about BMI change. C&T has illuminated many areas for continued inquiry in the AI/AN population around mHealth strategies.

5.8. Unexpected observations

Unexpected observations included the decline in knowledge for the SMS condition within the nutritional knowledge construct, see table 5.1. This may be because the nutritional messages were more complex than other C&T subjects. They included numerical information
about cholesterol and fat and tended to be more complicated in terms of numerical literacy than the messages such as the ones on physical activity.

Additionally, because of the HGHH adaptation process that condensed this complicated information into two messages during week three of the intervention, it is possible that the content became more confusing to the participants because of the brevity. In future work, content that covers this topic should be reviewed by nutritional experts and also reviewed by lay people in focus groups before being added to the mHealth curriculum.

5.9. Unexpected events

Only one unexpected event occurred that needed reporting during the course of C&T. The protocol was approved by the COMIRB for 30 participants. However, 32 participants were enrolled. The C&T researcher made an appointment with the 30th participant for enrollment, and that person brought two friends. The researcher was not comfortable turning the two additional participants away; they were enrolled into the study. Therefore, C&T recruited 32 people instead of the COMIRB-approved 30. However, this event turned out to be fortuitous. The study researcher asked all participants if they were between 30-70 years of age, and all participants responded yes. However, two people self-reported that they were less than 30 years of age on the survey. Enrolling over the COMIRB approved number would not damage the study or place anyone in unnecessary danger. The nature of the protocol deviation created no increased likelihood of harm, risk, or danger to any participant. The COMIRB specialist concurred. Project staff closed the loop with COMIRB by submitting an amendment attached to the continuing review.
5.9.1. Technological failures

In addition to over enrollment matter just discussed, there were three technical problems during the study. First, one participant in the SMS condition did not get the daily messages at the end of one month because that participant used all the allotted texting credits on their cell phone for the specific month. In this case, although no hardware or software failed, the participant did not receive the intended messages. The researcher was made aware of this situation and because of the flexibility of the technology, the messages could be re-sent so the participant had access to the full array of health messages. Therefore, this was not a serious problem.

The second technology failure for some participants was inability to save the messages they received from C&T, because storage capacity on some cell phones limited the ability to save messages. This may have led to lower participant response rates to C&T messaging.

The third technological failure was that one participant in the MMS condition could not send any pictures for the homework assignments. On the surface, this did not seem notable, because there were multiple participants not sending pictures. However, this participant was very engaged in the study and sent 11 MMS in response to the homework assignments, according to the record on the participant’s phone. The participant’s device was simply not sending the photos and not giving any feedback to the participant that delivery failed. The participant showed the researcher how she was sending the photos on her phone, and by all accounts, it seems as if these photos should have been delivered.

5.9.2. Recommendations based on technological failure

Two of the technology failure situations involved participants who were using Cricket data plans or pay-as-you-go Cricket data plans, while one of these two situations involved devices that were not able to send and receive MMS with the associated data plan. As a carrier,
Cricket makes their plans affordable and flexible. Often, individuals who use Cricket are doing so because other data plans that would allow sending and receiving MMS are too expensive. These individuals could have been in the study if they were randomized to the SMS condition, but the inability to send and receive MMS violated an eligibility requirement.

With these two instances of technological failure, there is little to recommend as a correction because the individuals were using the data plans and devices that were available and accessible. mHealth programs, however, can be designed to have a low-tech version of the content that is offered to individuals who do not have the technology needed for more sophisticated interventions. Often these low-tech versions are called Minimum Viable Product, or MVP. This approach can be adapted by mHealth from the tech industry that often prototypes software or hardware quickly to get a product out into the marketplace even when all the bugs have not been corrected (Moogk, 2012). Adopting this approach will allow more people to be involved in an intervention than might be the case otherwise due to technology access.

The third technological failure was unfortunate because the participant was highly engaged, but the research was unaware of the engagement due to MMS delivery failure. A simple protocol change can make this a less common technological failure. In future interventions that require feedback from the participant, the researcher suggests that when there is little to no interaction, a check-in call or text can be placed to assess whether the lack of interaction is due to a technological barrier or non-interest on the behalf of the participant. If the lack of interaction is due to technology that is not performing as expected, the researcher can help the participant trouble shoot the problem or, if the protocol allows, develop a work around solution.
Optimally, technology should not be a barrier to participation in mHealth programs. However, barriers often emerge that require the attention of the research staff. The best approach is to write a protocol that allows contact with participants who seem to be disengaged, and having tools developed to assess why there is a lack of interest on the behalf of the participant.

5.10. Implications for future work

The three research questions on which this dissertation project was based all have a common theme: whether mHealth is feasible in the AI/AN urban clinic setting, and to what extent. Answers to these questions are needed because of a mass movement of people from reservation communities to urban centers, especially in the western states. Lack of funding for urban clinics requires that new strategies are needed to provide heart health risk prevention.

This dissertation project showed that using SMS and MMS cell phone functions to increase health knowledge of CVD in an urban AI/AN clinic is feasible, that participants who used MMS with photo elicitation gained more health knowledge than those using SMS capabilities, that an increase in knowledge regarding signs and symptoms of heart attack by means of mHealth was possible, and that blending social theory and behavioral health models could contribute to the cultural adaptation of an mHealth strategy.

Despite the lack of sufficient quantitative data to declare an explicit answer to Research Question 2, the feasibility portion and the blending of social and behavioral theory of this project can be positively endorsed. C&T will be a springboard into more explorations on the topics of health, culture, and technology. C&T has opened new doors, including the possibility of conducting a scaled-up version of C&T as a RCT randomized controlled trial on a national level within the national structure of AI/AN urban clinic.
In all the collected, qualitative data, one comment stood out as meaningful and critical for the future work. This particular comment was captured in an exit survey: “I have to watch what I eat. It is just so important. I think it is a good thing you are trying to get services to Native Americans,” (PID 022014013002). This notion of getting services to Native Americans is not new, novel, or earthshattering on the surface. However, in recent experiences in public health, funding agencies are endorsing evidence-based programs and projects that rely on evidence-based curricula or material, which are more likely to receive positive reviews and ultimately to be funded. Unfortunately, few evidence-based curricula have been developed for the AI/AN population, despite abundant health disparities and the clear need.

An interesting phenomenon, not yet explored in the literature for AI/AN people, is that people who do not identify as White or Caucasian may feel cultural tension in pursuing goals endorsed by majority culture. For example, Fordham and Ogbu (1988), argue that one reason Black students do poorly in school is that they experience inordinate ambivalence and affective dissonance with regard to academic effort and success. The authors argue that this problem arises partly because White Americans traditionally refused to acknowledge that Black Americans were capable of intellectual achievement and partly because Black Americans began to define academic success as the White person's prerogative, and to discourage peers from emulating White people by seeking academic success—acting White.

Oyserman and colleagues (2007) have reported that similar conflicts can arise for healthy behavior. In a research agenda that included seven different research projects, the author showed the effect of identity-based motivation on health and healthy living. In all seven studies it was show that racial-ethnic minorities classify health promotion behaviors as a White middle class
endeavor, while unhealthy behaviors were classified as in-group definitions of either the racial or ethnic population.

The parallel can be made that AI/AN may suffer the same ambivalence and affective dissonance, accepting White beliefs that they are incapable of self-care, doubting their own abilities, and seeing eating right and getting exercise as majority values to be imposed on them. This idea is ripe for exploration. Just as participant PID 022014013002 feels that it is good for services to be delivered to Native Americans, one can extrapolate that it would be even better that services are offered that originate from a curriculum produced by AI/AN people, and that the intervention is being delivered from an urban Indian clinic. When this happens, implementing changes will not feel so uncomfortable because the changes are couched in authentic culture.

The Oyserman theoretical positioning allows the conception of a future C&T that introduces the concepts of tailoring messages, tailoring the complexity/depth of the messages, and tailoring the timing of delivery. This approach would capitalize on the authentic materials produced in HGH and add a personal touch that could be extremely beneficial. This second-phase RCT would need a slightly different design. The vision is to compare the SMS/MMS condition, or a hybrid, with a standard of a care condition in which health educators in urban clinics would teach the HGH material. This design would truly test if the mHealth approach is any different than the face-to-face approach.
References


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Texting personas (Katasz and Bogan, 2012)

<table>
<thead>
<tr>
<th>Role</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Casual Texter</td>
<td>Jody is a 27-year-old stay-at-home mom. She sends 50 texts a week, mostly back and forth conversations with friends and family. She sees texting as a practical communication tool, and a good way to have light-hearted communication about trivial topics. Texting fits seamlessly into her daily life - it’s quick and easy. She really appreciates that texting doesn’t interrupt others like calling does, and she doesn’t like getting trapped into long phone conversations. She also likes that texting allows her to keep conversations private from her parents and kids.</td>
</tr>
<tr>
<td>Convenience Texter</td>
<td>John is 21 years old and works at a preschool. He has an unlimited texting plan, and sends more than 15 text messages per day. He sends messages to family, friends, and coworkers. He is a very busy person, and uses texting to get information and to confirm plans. He feels that texting can limit social interaction, which is good and bad. He prefers in-person conversations, but John doesn’t like to gossip. Texting allows him to avoid personal drama that occurs with phone calls.</td>
</tr>
<tr>
<td>Connector Texter</td>
<td>Matt is a 20-year-old student. He sends more than 15 texts every day, and he loves the back-and-forth nature of texting. He has text conversations with friends, family, and distant relatives, sometimes lasting for hours. Oftentimes, he texts just to pass the time. He texts more than he talks on the phone, and he feels that texting is fun and addictive. Matt uses texting as a way to maintain social connections, and to feel closer to family.</td>
</tr>
<tr>
<td>Responsible Texter</td>
<td>Sarah is a 21-year-old student who sends about 15 texts per day. She uses texting to multitask with her family. With texting, she is available to family in case of emergencies, she can provide support and update plans, and she can check in on family and friends who rely on her. Sarah does not see texting as a social medium. Instead, she sees it as an impersonal and very practical planning tool.</td>
</tr>
</tbody>
</table>
### Appendix B

Example personal text messages created by subjects (Gerber et al., 2009)

<table>
<thead>
<tr>
<th>Category</th>
<th>Example messages</th>
</tr>
</thead>
</table>
| Healthy eating         | Don’t 4-get to eat breakfast!  
                          | STOP! Are you really hungry?                                                     |
| Pack your lunch        | Don’t eat junk food … cook dinner!                                               |
| Physical activity      | Make sure you get your walk in today.  
                          | Do your total gym workout.                                                       |
|                        | Walk up those stairs.                                                             |
|                        | Did you walk today?                                                              |
| Encouragement          | One step = to one less pound.                                                    |
|                        | Don’t give up!                                                                   |
|                        | Remember your goal!                                                              |
|                        | The more pounds you lose, the less you carry.                                    |
| Drinking water         | Water, water, water.                                                             |
|                        | Drink some water girl!                                                           |
|                        | How much water have you had today?                                               |
| Personal reminders     | Get out of bed!                                                                  |
|                        | Don’t forget your calcium.                                                       |
Appendix C

Memorandum of understanding

THIS MEMORANDUM OF UNDERSTANDING (“MOU”) is between Denver Indian Health and Family Services (“DIHFS”), the Regents of the University of Colorado, a body corporate, for and on behalf of the University of Colorado Denver Centers for American Indian and Alaska Native Health (“University”), and Brad Morse. Hereafter, collectively referred to as the “Parties,” or individually as a “Party.”

WHEREAS, the University desires to conduct research within the American Indian population, under the auspices of the Centers for American Indian and Alaska Native Health at the University of Colorado Anschutz Medical Campus, to be conducted by Brad Morse in order to complete requirements for a doctoral degree in Technology, Media, and Society from The University of Colorado Boulder ATLAS Department and Computer Science Department. The research aims to increase health knowledge on cardiovascular disease and incorporates a community perspective through group community assessment by means of mobile phones and photo elicitation.

WHEREAS, University desires to obtain access to DIHFS’s client population for the purpose of enrolling participants in its study.

WHEREAS, DIHFS desires to provide University access to its client population for the purpose of enrolling clients in the University’s research study.

NOW, THEREFORE, in consideration of the covenants and agreements hereinafter set forth the Parties agree as follows.

I. OBLIGATIONS OF DIHFS

DIHFS agrees to:

A. Provide University access to its client population for recruitment by allowing the University to place flyers and information material at its clinic site regarding participation in the study and allow recruitment via the DIHFS Facebook page.

B. Provide office space for the purpose of allowing University to meet with research participants and conduct surveys.

II. OBLIGATIONS OF UNIVERSITY

University agrees to:
A. Provide the means and support for completion of the self-report surveys.
   The studies will be computer administered.

B. Ensure that all HIPAA regulations and compliance are maintained and enforced for the
duration of the research study.

C. Ensure patient specific data is physically maintained in a confidential and limited access
manner.

D. Compensate DIHFS for use of the meeting room space as set forth in Section IV., below.

E. To ensure that appropriate Institutional Review Board (IRB) approvals are in
place and that said approvals has been accepted by the Colorado Multiple Institutional Review
Board and National IRB of the Indian Health Service.

III. TERM and TERMINATION

   This MOU is effective as of the date of the last signature hereto and shall terminate on
December 31, 2013 (the “Initial Term”). This Agreement may be extended beyond the Initial
Term by the written mutual agreement of both parties.

   Either Party may terminate this MOU at any time by giving the other party written notice
of not less than thirty (30) days. In the event of termination prior to the expiration of the Initial
Term, payments will be made to DIHFS for all services provided up to and including the date of
termination.

IV. COMPENSATION

   Brad Morse shall compensate DIHFS $600 for sporadic use of office space for the
duration of the University project.

V. PAYMENT

   Payment shall be made to DIHFS within thirty (30) days of receiving an invoice. Invoices
shall be sent to the following address:

   Bradley Morse
   MS F800
   13055 East 17th Ave.
   Nighthorse Campbell Native Health Building
   Aurora, CO 80045

   Payments will be sent within 30 days of invoice receipt, payable to DIHFS, and sent to
the following address:
VI. OWNERSHIP OF DATA

All data collected by University from DIHFS clients shall belong to University. All research methods, tools, and previously existing Intellectual Property and or data used by University throughout its research related to this project shall be owned by the University. All resulting data sets, reports, studies, or other documents prepared by the University in the performance of its obligations under the Agreement shall be owned by the University. The University agrees to share its research results with DIHFS and shall provide DIHFS with a copy of its final report and research findings. Additionally, Bradley Morse is willing to perform targeted analyses as requested by DIHFS as mutually agreed upon between the parties.

VII. PARTY REPRESENTATIVES

Each party to this MOU will assign a representative to interact and communicate with the representative of the other party concerning all matters arising under this MOU. The contact information for the designated representative of each party to this Agreement is set forth below:

For University:

Name:
Title:
Address:
Phone Number:
E-Mail Address:

For DIHFS:

Name:
Title:
Address:
Phone Number:
E-Mail Address:

For Brad Morse:

Name:
Title:
Address:
Phone Number:
E-Mail Address:
VIII. LIABILITY AND INSURANCE

A. Each party hereto agrees to be responsible and assume liability for its own wrongful or negligent acts of omissions, or those of its officers, agents or employees to the full extent allowed by law.

B. It is specifically understood and agreed that nothing contained in this paragraph or elsewhere in this Agreement will be construed as: an express or implied waiver by University of its governmental immunity or of the governmental immunity of the State of Colorado; an express or implied acceptance by University of liabilities arising as a result of actions which lie in tort or could lie in tort in excess of the liabilities allowable under the Colorado Governmental Immunity Act, C.R.S. §24-10-101 et seq.; or, as the assumption by University of a debt, Agreement, or liability of DIHFS in violation of Article XI, Section 1 of the Constitution of Colorado.

C. No liability hereunder shall result to either Party by reason of delay in performance caused by force majeure -- that is circumstances beyond the reasonable control of the Parties, including, without limitation, acts of God, fire, flood, war, civil unrest, or shortage of or inability to obtain material and equipment.

IX. RELATIONSHIP OF THE PARTIES

Nothing contained in this MOU shall be deemed to create or constitute a partnership, joint venture, or relationship of principal and agent between the Parties. DIHFS will not be engaged in research by performance of its obligations under the terms of this MOU.

X. ASSIGNMENT

Neither Party shall assign its rights or obligations hereunder without the prior written consent of the other party and any purported assignment without such prior written consent shall be null and void.

XI. SEVERABILITY

In the event that any clause or provision of this Agreement (or the application of such clause or provision to a particular set of circumstances) is declared by a court or other competent authority to be invalid, illegal, or unenforceable, such holding or declaration shall not in any way effect the validity or enforceability of any other clause or provision of this Agreement.

XII. GOVERNING LAW

The construction, interpretation, and enforcement of this Agreement are governed by the laws of the State of Colorado.

XIV. AMENDMENTS
Any amendments hereto shall be in writing and signed by authorized representatives of the Parties.

XV. ENTIRE AGREEMENT

This Agreement sets forth the entire understanding and agreement of the parties and supersedes any and all oral or written communications or understandings between the Parties as to the subject matter of this Agreement and may not be changed, modified, or discharged, in whole or in part, except by a writing signed by both parties.

IN WITNESS WHEREOF, the parties hereto have caused this MOU to be executed as of the date set forth herein by their duly authorized representatives.

Regents of the University of Colorado, a body corporate, for and on behalf of the University of Colorado Denver, Centers for American Indian and Alaska Native Health

By: ___________________________  By: ___________________________
Name: __________________________ Name: __________________________
Title: __________________________ Title: __________________________
Date: __________________________ Date: __________________________

Denver Indian Health and Family Services

Brad Morse

By: ___________________________
Name: __________________________
Title: __________________________
Date: __________________________
Appendix D

Focus group guide

Introduction:

Hello everyone! Welcome, and thank you for agreeing to be part of the focus group today. Let me reintroduce myself. My name is Brad Morse and I will be facilitating the discussion. I work at the Centers for American Indian and Alaska Native Health. This focus group is a part of the work I am doing for my dissertation.

The purpose of this interview is to learn your opinion on the health related messages you received via text on your mobile phone. The messages are based on information adapted from the Honoring the Gift of Heart Health (HGGH) developed by the National Heart, Lung and Blood Institute. I am interested in your opinion on the application, usefulness, and cultural appropriateness of the Cell & Tell program in your community. Your opinion, among others in your community, will help me to determine whether this program would benefit your community, or other American Indian communities in both urban and rural settings.

This interview will take an hour to an hour and a half. Please keep in mind when we talk there are no “right” or “wrong” answers to any of the questions I may ask you- we are simply interested in learning your opinion on the Cell & Tell program in your community. All things you share with me today will be kept confidential, but I will be recording this interview, so that I won’t miss anything you say. After our interview, the recording of our conversation will be summarized and transcribed. However, no identifying names or identifying information will be included in the summary.

Can I confirm that you are ok talking and recording the conversation today?

Part A: Screening for heart health and community needs

In this first section, I am going to ask you about general questions about your heart health, your environment and how it relates to your heart health, and your community.

1. In your opinion, are you heart healthy and what about the heart health of your families and young children in your community?
   a. Probe: Why would you say this?

2. What are the indicators of a healthy heart?
   a. Probe: Examples?

3. What are signs of an unhealthy heart?
   a. Probe: Examples?

4. How would you define healthy signs of heart health for young children?
   a. Probe for clarity (explain by): types of disorders, characteristics, or examples?
5. Do you feel like you live in a healthy environment that is conducive to heart health?

6. What factors into your decision making that concerns your heart health? Do you have the ability to always making healthy choices?
   a. Probe: Why or Why not Give examples.

Part B: Project Cell & Tell
Now in this section I am going to ask you specific question about the Cell & Tell program. Please feel free to refer to the copies of the messages found on the table.

1. What do think overall about the Cell & Tell program?
   a. Probe: Why?

2. Does the Cell & Tell program make sense?
   a. Probe: All parts make sense? Which parts?

3. Are there any parts that do not make sense?
   a. Probe: Which parts? What specifically does not make sense?

4. Do you think the messages are culturally appropriate?
   a. Probe: Why or why not? Any particular parts?

5. Do you think the Program would do well in your community on a larger scale?
   a. Probe: Why? Why not?

6. Do you have any concerns about using this approach to heart health in your community?
   a. Probe: If yes, what are they?

Part C: Application and feasibility of Cell & Tell
In this last section, I am going to ask you specific questions related to barriers for implementing Cell & Tell in your community.

1. Do you think American Indian in both rural and urban settings would take time to be in Cell & Tell?
   Probe- Yes or No? Why?

2. Where do you think would be the most convenient setting to administer this instrument?

3. Are there any burdens to people who want to be involved in this type of ehealth?
   Probe- Why or why not?
4. Cell and Tell could be offered through twitter or Facebook. What format would you prefer?  
   Probe- Why that format?

5. Can you think of any potential barriers for you being able to complete the Cell and Tell program?  
   Probe- What barriers? Big impact or small impact? Any suggestions how to change that?

6. Before we end is there anything that I have not touched on that you think is important for me to know as far as how you liked or disliked Cell & Tell?

That concludes our interview. If you think of anything else that you would like to share with me please do not hesitate to contact me. Thank you so much for providing feedback for this project.

Turn off the recorder.

THINGS TO KEEP IN MIND:
- Start BROAD → NARROW questions
- Use OPEN ENDED QUESTIONS- use phrases like “how satisfied” and/or “to what extent” / KEEP PROBES OPENED ENDED TOO- AVOID- is there anything else? – can easily be answered no
- Common useful probes: “Would you explain ___ further”, “Can you provide an example”, or simply just pausing for 5 seconds to see if they provide more information
- AVOID stacked questions- ask one question at a time
- RANKING Questions are good

1. Is the cell phone an appropriate dissemination tool to increase knowledge and awareness of CVD risk factors?
2. Does community-level photovoice increase knowledge and awareness more than face-to-face focus groups covering CVD risk factors?
### Appendix E

**Honoring the Gift of Heart Health SMS/MMS text messages**

<table>
<thead>
<tr>
<th>Week One:</th>
<th>HGHH Sessions:</th>
<th>1st Message (corresponds to 1st of 2 paired sessions)</th>
<th>2nd Message (corresponds to 2nd of 2 paired sessions)</th>
<th>3rd Message (address both sessions)</th>
<th>4th Message: Question on Material presented in first two messages</th>
<th>5th Message: Picture Request (for research condition 2)</th>
</tr>
</thead>
<tbody>
<tr>
<td>S1 - Are you at Risk for Heart Disease</td>
<td>Risk factors for heart disease include high blood pressure, high blood cholesterol, being overweight or obese, smoking, diabetes or lack of physical activity. Delay is deadly. If you think a heart attack is taking place the most important thing to remember is call 9-1-1 in 5 minutes of less. Do not wait too long. Family and friends might have one, several, or all risk factors for heart disease. Make sure everyone knows what to do and who to call in case of heart attack. What should you do in time of heart attack? a) Call a family member, b) Call 911, c) Drive to the hospital, d) Wait 20 minutes to see if you feel better.</td>
<td>Over the weekend take a picture of something, someone or a place that will help you in time of a heart attack and text me a description!</td>
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<tr>
<td>S2 - Act in Time for Heart Attack</td>
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<tr>
<td>Week Two:</td>
<td>Physical activity makes your heart and lungs strong. Do 30 minutes of physical activity most days. Break up 30 minutes of exercise into ten minute sessions. Being overweight increases your risk of heart disease. To lose weight, cut down on portion size and be more active. Trim visible fat from meat before cooking. Exercise is always easier with a partner. Traditional activities like dancing increase physical activity. Activities like cleaning the house get us moving. How do you make physical activity fun and family oriented? What is an activity almost any one can do in any location?</td>
<td>Over the weekend take a picture of something, someone or a place that will help you be more active and maintain a healthy weight and text me a description!</td>
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<tr>
<td>S3 - Be More Physically Active</td>
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<td>S5 - Maintain a Healthy Weight</td>
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<td>Week Three:</td>
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<td>A blood pressure reading of 140/90 mmHg or greater is high. Hypertension is another term for high blood pressure. Use herbs and spices instead of salt. Cholesterol clogs your arteries and causes a heart attack or stroke. High blood cholesterol is 240 mg/dl, or higher. Trim visible fat from meat before cooking. Eating a heart healthy diet low in saturated fat, trans fat, and cholesterol lowers blood cholesterol. Eat more vegetables each day. Have a salad with low fat dressing for lunch. Where can you get your blood pressure checked? What types of food are low in sodium and fat?</td>
<td>Over the weekend take a picture of something, someone or a place that will help you lower your blood pressure and cholesterol and text me a description!</td>
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<tr>
<td>S4 - What you Need to Know about High Blood Pressure, Salt and Sodium</td>
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<tr>
<td>S5 - What you Need to Know about High blood Cholesterol</td>
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<td>Week Four:</td>
<td>Teach your family how to grocery shop, include your family in preparing meals and cleaning up. Plan weekly meals based on your family’s schedule. Make a shopping list based on your meal plan. Check the food sale ads. Use coupons. Make fresh foods at home instead of using canned or frozen prepared items. Save food dollars, plan weekly menus. Shop with a list! Have your family help in the kitchen, and the kids too. Cook more and freeze for later to save time. Some American Indians have adopted cooking and eating habits that can lead to health problems like heart disease. What are some examples of these habits?</td>
<td>Over the weekend take a picture of something, someone or a place that will help you eat right even when money is tight and text me a description!</td>
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<td>S7 - Make Heart Healthy Eating a Family Affair</td>
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<td>S8 - Eat in a Heart Health Way- Even when $ is Tight</td>
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<td>Week Five:</td>
<td>One year after a person stops smoking the risk of heart attack will drop by more than half. Children who grow up in homes with smokers are more likely to smoke. Tailored message based on participants involvement. Tailored message based on participants involvement. Tailored message based on participants involvement.</td>
<td>Over the weekend take a picture of something, someone or a place that will help you live a healthier lifestyle and text me a description!</td>
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<td>S9 - Enjoy Living Smoke Free</td>
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<td>S10 - Review</td>
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</table>
Appendix F

Survey

How old are you today? _____________________ PID: ________________________________

1. The last time you had your blood cholesterol checked, was it low, normal, or high?
   Normal or Low ☐
   High ☐
   Don't Know ☐
   I would like to skip this question. ☐

2. The last time you had your blood pressure checked, was it low, normal, or high?
   Normal or Low ☐
   High ☐
   Don't Know ☐
   I would like to skip this question. ☐

3. Are you currently taking medicine for your blood pressure?
   No ☐
   Yes ☐
   Don't Know ☐
   I would like to skip this question. ☐

4. Are you changing your eating habits to help lower or control your blood pressure?
   No ☐
   Yes ☐
   Don't Know ☐
   I would like to skip this question. ☐

5. Are you cutting down on salt to help lower or control your blood pressure?
   No ☐
   Yes ☐
   I do not use salt. ☐
6. Are you reducing alcohol use to help lower or control your blood pressure?
   No □
   Yes □
   I do not drink. □
   Don't Know □
   I would like to skip this question. □

7. Are you exercising to help lower or control your blood pressure?
   No □
   Yes □
   Don't Know □
   I would like to skip this question. □

8. Do you think pain or discomfort in the jaw, neck, or back are symptoms of a heart attack?
   No □
   Yes □
   Don't Know □
   I would like to skip this question. □

9. Do you think feelings weak, lightheaded, or faint are symptoms of a heart attack?
   No □
   Yes □
   Don't Know □
   I would like to skip this question. □

10. Do you think swelling of the feet and legs is a symptom of a heart attack?
    No □
    Yes □
11. Do you think chest pain or discomforts are symptoms of a heart attack?
   No □
   Yes □
   Don't Know □
   I would like to skip this question. □

12. Do you think sudden trouble seeing in one or both eyes is a symptom of a heart attack?
   No □
   Yes □
   Don't Know □
   I would like to skip this question. □

13. Do you think tingling in the fingers and toes is a symptom of a heart attack?
   No □
   Yes □
   Don't Know □
   I would like to skip this question. □

14. Do you think pain or discomfort in the arms or shoulder are symptoms of a heart attack?
   No □
   Yes □
   Don't Know □
   I would like to skip this question. □

15. If you thought someone was having a heart attack, what is the first thing you would do?
   1. Take them to the hospital □
   2. Tell them to call their doctor □
   3. Call 911 □
4. Call their spouse or a family member
5. Do something else
7. Don't Know
8. I would like to skip this question.

16. Now we have some questions about staying healthy. Can having a large waist increase your risk of heart disease?
   No
   Yes
   Don't Know
   I would like to skip this question.

17. Can eating foods that are high in sodium increase your risk for high blood pressure?
   No
   Yes
   Don't Know
   I would like to skip this question.

18. Can eating too much saturated fat and trans fat raise your bad cholesterol level?
   No
   Yes
   Don't Know
   I would like to skip this question.

19. Is a blood pressure of 140/90 mmHg considered high?
   No
   Yes
   Don't Know
   I would like to skip this question.

20. Can being overweight or obese put you at risk for developing high levels of bad cholesterol?
21. Is being physically active a way to reduce your risk for heart disease?
   No □
   Yes □
   Don't Know □
   I would like to skip this question. □

23. It would be easy for me to do more physical activity than I do now.
   1. Strongly disagree □
   2. Disagree □
   3. Neither agree nor disagree □
   4. Agree □
   5. Strongly agree □
   98. I would like to skip this question. □

24. Being physically active would make my heart healthier.
   1. Strongly disagree □
   2. Disagree □
   3. Neither agree nor disagree □
   4. Agree □
   5. Strongly agree □
   98. I would like to skip this question. □

25. I can make the effort to be more physically active.
   1. Strongly disagree □
   2. Disagree □
   3. Neither agree nor disagree □
4. Agree
5. Strongly agree
98. I would like to skip this question.

26. Regular physical activity would help me lose weight.
   1. Strongly disagree
   2. Disagree
   3. Neither agree nor disagree
   4. Agree
   5. Strongly agree
   98. I would like to skip this question.

27. I can do physical activity even if I’m tired or busy.
   1. Strongly disagree
   2. Disagree
   3. Neither agree nor disagree
   4. Agree
   5. Strongly agree
   98. I would like to skip this question.

28. I’ll feel better if I’m more physically active.
   1. Strongly disagree
   2. Disagree
   3. Neither agree nor disagree
   4. Agree
   5. Strongly agree
   98. I would like to skip this question.

29. It is hard for me to be as physically active as I should be.
   1. Strongly disagree
   2. Disagree
3. Neither agree nor disagree □
4. Agree □
5. Strongly agree □
98. I would like to skip this question. □

30. It’s too much trouble to be more physically active
   1. Strongly disagree □
   2. Disagree □
   3. Neither agree nor disagree □
   4. Agree □
   5. Strongly agree □
98. I would like to skip this question. □

31. If I am more physically active, I’ll just get hungry, eat more, and gain weight.
   1. Strongly disagree □
   2. Disagree □
   3. Neither agree nor disagree □
   4. Agree □
   5. Strongly agree □
98. I would like to skip this question. □

32. Being more active would be tough for me.
   1. Strongly disagree □
   2. Disagree □
   3. Neither agree nor disagree □
   4. Agree □
   5. Strongly agree □
98. I would like to skip this question. □

33. Doing more physical activity would mean less time with my family.
   1. Strongly disagree □
2. Disagree □
3. Neither agree nor disagree □
4. Agree □
5. Strongly agree □
98. I would like to skip this question. □

34. I don’t think I can get as much physical activity as I should.
   1. Strongly disagree □
   2. Disagree □
   3. Neither agree nor disagree □
   4. Agree □
   5. Strongly agree □
98. I would like to skip this question. □

35. Even if I do regular physical activity, my health won’t really improve.
   1. Strongly disagree □
   2. Disagree □
   3. Neither agree nor disagree □
   4. Agree □
   5. Strongly agree □
98. I would like to skip this question. □

36. I can’t find the time to be more physically active.
   1. Strongly disagree □
   2. Disagree □
   3. Neither agree nor disagree □
   4. Agree □
   5. Strongly agree □
98. I would like to skip this question. □
37. My family won’t be happy if I take the time to be more physically active.
   1. Strongly disagree
   2. Disagree
   3. Neither agree nor disagree
   4. Agree
   5. Strongly agree
   98. I would like to skip this question.

38. I can easily eat smaller portion sizes.
   1. Strongly disagree
   2. Disagree
   3. Neither agree nor disagree
   4. Agree
   5. Strongly agree
   98. I would like to skip this question.

39. A healthy diet would help me lose weight.
   1. Strongly disagree
   2. Disagree
   3. Neither agree nor disagree
   4. Agree
   5. Strongly agree
   98. I would like to skip this question.

40. It would be easy for me to eat fruit instead of candy or desserts.
   1. Strongly disagree
   2. Disagree
   3. Neither agree nor disagree
   4. Agree
   5. Strongly agree
41. Eating low-fat instead of regular dairy products would not be a problem for me.
   1. Strongly disagree
   2. Disagree
   3. Neither agree nor disagree
   4. Agree
   5. Strongly agree

42. I would lower my risk of having a heart attack if I ate healthy foods.
   1. Strongly disagree
   2. Disagree
   3. Neither agree nor disagree
   4. Agree
   5. Strongly agree

43. It would be easy to reduce the amount of cholesterol and fat that I eat.
   1. Strongly disagree
   2. Disagree
   3. Neither agree nor disagree
   4. Agree
   5. Strongly agree

44. A diet low in saturated fat would help to lower the level of my bad cholesterol.
   1. Strongly disagree
   2. Disagree
   3. Neither agree nor disagree
   4. Agree
5. Strongly agree □
98. I would like to skip this question. □

45. I don’t know how to find foods with less sodium.
   1. Strongly disagree□
   2. Disagree□
   3. Neither agree nor disagree□
   4. Agree□
   5. Strongly agree□
   98. I would like to skip this question. □

46. If I make healthy meals, the food won’t taste good.
   1. Strongly disagree□
   2. Disagree□
   3. Neither agree nor disagree□
   4. Agree□
   5. Strongly agree□
   98. I would like to skip this question. □

47. It would be hard for me to eat more whole grains.
   1. Strongly disagree□
   2. Disagree□
   3. Neither agree nor disagree□
   4. Agree□
   5. Strongly agree□
   98. I would like to skip this question. □

48. Preparing healthy meals takes too long.
   1. Strongly disagree□
   2. Disagree□
   3. Neither agree nor disagree□
4. Agree □
5. Strongly agree □
98. I would like to skip this question. □

49. I don’t think I can substitute baked or grilled foods for fried foods.
   1. Strongly disagree □
   2. Disagree □
   3. Neither agree nor disagree □
   4. Agree □
   5. Strongly agree □
98. I would like to skip this question. □

50. Healthy foods, such as fresh fruit and vegetables, are too expensive.
   1. Strongly disagree □
   2. Disagree □
   3. Neither agree nor disagree □
   4. Agree □
   5. Strongly agree □
98. I would like to skip this question. □

51. It would be hard to cut down on the amount of fast food I eat.
   1. Strongly disagree □
   2. Disagree □
   3. Neither agree nor disagree □
   4. Agree □
   5. Strongly agree □
98. I would like to skip this question. □

52. On a healthy diet, I can’t eat traditional foods.
   1. Strongly disagree □
   2. Disagree □
3. Neither agree nor disagree
4. Agree
5. Strongly agree
98. I would like to skip this question.

53. Are the following resources available in your community?
   1. Health classes
   2. Walking trails
   3. Farmers' markets
   4. Healthy cooking classes
   5. Low-cost exercise facilities
   6. Health fairs
   7. Safe places to exercise
   8. Low-cost fruits and vegetables
   98. I would like to skip this question.

54. Please tell us how often these things happen to you.
   How often are you able to get an appointment with a doctor or other health care provider when you need to?
   1. Rarely or never
   2. Some of the time
   3. Most of the time
   4. Always
   98. I would like to skip this question.

55. How often does it happen that you have to make an appointment a long time in advance to see a doctor or other health care provider?
   1. Rarely or never
   2. Some of the time
   3. Most of the time
   4. Always
98. I would like to skip this question.

56. When you go to the clinic, how often do you have to wait for a long time in the waiting room or exam room before seeing the doctor or other health care provider?
   1. Rarely or never
   2. Some of the time
   3. Most of the time
   4. Always

98. I would like to skip this question.

57. When you need to, how often are you able to get an appointment to see a doctor who specializes in certain things (like a diabetes doctor, heart doctor, skin doctor, arthritis doctor, or bone doctor)?
   1. Rarely or never
   2. Some of the time
   3. Most of the time
   4. Always

98. I would like to skip this question.

58. There is a particular doctor or care provider I usually see when I go to the clinic.
   1. False
   2. True

98. I would like to skip this question.

59. How often do you go to the emergency room at the hospital when you need health care?
   1. Rarely or never
   2. Some of the time
   3. Most of the time
   4. Always

98. I would like to skip this question.
60. Do you have a video game console that you hook up to your TV? By this we mean something like the Nintendo Wii, Microsoft Xbox, or Sony Playstation?
   0. No
   1. Yes
   98. I would like to skip this question.

61. When you play video games on your TV, how many hours do you play in a day?
   1. Less than 1
   2. 1-3 hours
   3. 4-6 hours
   4. More than 6 hours
   98. I would like to skip this question.

62. Have you used a computer before today?
   0. No
   1. Yes
   98. I would like to skip this question.

63. Do you have a personal computer in your home?
   0. No
   1. Yes
   98. I would like to skip this question.

64. On average, how often have you used a computer in the last 6 months?
   0. Not at all in the past 6 months
   1. Less than once a month
   2. Less than once a week
   3. Once a week
   4. Several times a week
   5. At least once a day
98. I would like to skip this question.

65. How confident are you in using a computer?
   1. Not at all confident
   2. Fairly confident
   3. Very confident
   98. I would like to skip this question.

66. Do you have access to the Internet at home?
   0. No
   1. Yes
   98. I would like to skip this question.

67. Do you have an e-mail account that you check regularly?
   0. No
   1. Yes
   98. I would like to skip this question.

68. Is your phone able to connect to the Internet?
   0. No
   1. Yes
   7. Don't Know
   98. I would like to skip this question.
Appendix G

Photovoice guide

iPad Basics

(Please see the iPad Quick Reference sheet to see where buttons and ports are located)

How to turn on the iPad
Press and hold the On/Off – Sleep/Wake button until the Apple icon appears (approximately 3 seconds), then let go.

Slide the “Slide to Unlock” arrow along the bottom of the screen.

Orientation
Personal Preference
Most instructions and examples are portrait.
You can use landscape, but some screens might look a little different.
How to Use the Touchscreen
Tap: Lightly touch an icon or onscreen item, and immediately let go
Press: Lightly touch an icon or onscreen item, and hold briefly
Swipe: Lightly touch the screen with one finger and move it to the side, then let go
Drag: Tap, hold, and move an icon or onscreen item, then let go
Pinch: Lightly touch the screen with two fingers, or finger and thumb.
Move them apart to make the item larger, or together to make the item smaller.

*You can also use a stylus on the touchscreen – please ask for one if you would like to try it!"
Icons
The icons on the home screen are apps/functions that come with the iPad
If you add apps, they go on a new screen
Swipe left to see the new screen
(Or, tap the dots near the bottom of the screen (middle = main screen, right = additional apps, left = search screen)

Keyboard
Onscreen keyboard only shows on screens that let you type
Example: Notes – tap the Notes icon

Keyboard appears – type a note
New keyboard screen with numbers and symbols (see below)
iPad Quick Reference

iPad Components

- Headphone
- Camera
- Microphone
- On/Off or Volume
- 30-pin connector
- Mute (or Lock)
Appendix H

C&T memoing

**Conceptualization**

1. Memoing from HGHH classes and the evaluation forms collected at the end of each class
   a. February 2011 HGHH Classes
      i. What did participants like best about today's class?
         1. They liked learning how to read labels
         2. Several participants said there was lots of good info tonight, different ideas about exercise & how to get into a busy day
         3. Some people found the topic on smoking is helpful for their family members who smoke
         4. Shopping tips/preparing food in advance
         5. The quiz regarding fast food
      ii. What did participants like least about today's class?
         1. Leaving to go for a walk
         2. That there were not as many participants (people felt that there needed to be more people in the class)
         3. Several people said that there wasn't anything about today's class that was bad. The information was quick and the physical activity was enjoyable.
         4. The nutritionist cancelled...participants were really disappointed
         5. Some people were upset about finding out how much or long they had to work out
      iii. Are there ways we could make this class better?
         1. Liked the earlier time.
         2. By keeping it cultural! I have taken classes before and I feel that I have learned much more from instructor because I can identify.
         3. Always keep a native teacher. Also: for the smoking, find an example of a lamb lung smoking and non-smoking

2. Meeting with staff at DIHFS went well and they are excited about the possibility of having a mHealth project to provide to their clients.
   a. The staff is very busy do there is little help besides access to patients that they can provide for the duration of the project.
   b. The beast approach to recruitment will be Facebook, posters, flyers, and face-to-face according to Adrienne Maddux
   c. October 18, 2012

3. The executive board meeting is scheduled for November 7, 2012. The board is asking for updates, human subjects approval, potential risks, and potential benefits.
   a. UPDATE FOR DIHFS BOARD: Project Cell and Tell
i. Short message service (SMS or text messaging) is a cell phone function that sends messages with up to 160 characters. In some cases, SMS interventions will lead to health knowledge and is a promising alternative to face-to-face health education. This study is an individual-level intervention that aims to increase health knowledge on cardiovascular disease (CVD) and incorporates a community perspective through group community assessment. A SMS and photovoice intervention in the urban American Indian population will be a contribution to public health and provide a foundation for future studies in urban-based American Indian populations.

ii. The SMS intervention will have three styles of SMS, 1) knowledge, 2) quiz, and 3) action. Groups will work together to create photovoice narratives to promote increased knowledge and awareness of CVD risk factors. These sessions will lead to discussions around community obstacles that can limit the enactment of good health choices, and also strategies to overcome these obstacles will emerge during group interaction.

iii. Creating good health is difficult. This intervention aims to promote increased knowledge and awareness about behavior and activities that can decrease CVD risk factors. These activities include: physical activity, smoking cessation, healthy food choices, and maintaining a healthy weight. These activities are known to decrease risk factors associated with CVD and are based on the health education class titled Honoring the Gift of Heart Health.

iv. The importance of this research is evaluating a new model to teach health education that is accessible and affordable within the urban environment.

b. Human Subject Approval:
   i. Colorado Multiple Intuitional Review Board (COMIRB) approval: April 10, 2012
   ii. Indian Health Services – National Institutional Review Board (NIRB) approval: August 29, 2012. There is some confusion at I.H.S and it took several months to get approval forms for the protocol.

c. Potential Risks:
   i. No sensitive data are being collected. The completion of the CVD risk survey, taking photos with cell phones or viewing images and developing a photovoice document does not increase the probability and magnitude of harm or discomfort than events ordinarily encountered in daily life or during the performance of routine physical or psychological exams.

d. Potential Benefits:
   i. People enrolled in the study may learn about CVD risks and also about strategies on how to decrease CVD risk.
1. Message Development
   a. These notes are taken from the researcher’s experience teaching HGHH in a classroom at the Denver Indian Health and Family Services
      i. Participants like the interaction that comes from attending the face-to-face classes.
      ii. Participant who attend class have a good idea about what obstacles they face when trying to make healthy choices.
      iii. There are often conversations about what resources are available in the community and most participants are willing to share strategies about these community resources.
      iv. The heart health information is made more interesting and relevant when there is a connection to one’s own health. Some participants seem willing to share this information with others freely. However, there are some participants who are much more unlikely to share personal stories with others. Need to find a way to encourage all people to share.
      v. Some of the material in the nutrition section is tricky and complicated. Cholesterol needs to be explained better so there is an understanding between good cholesterol and bad cholesterol.
   b. Photo Elicitation
      i. Participants who send in photos might be a good way to make the material more relevant.
      ii. Digital Photovoice might be a good way to organize and analyze the photos. How will you do the analysis?

2. Hosting Issue – On what system should the Cell & Tell messages be sent?
   a. There are a lot of commercial options for host Cell & Tell. What are the pros and cons of using a commercial product like EZTexting.com, Twilio, and Clickatell? (September 14, 2012)
   b. Pros:
      1. Commercial options allow for pre-programming text with date stamps.
      2. Commercial options can be programmed and each message does not need to be sent individually.
      3. Messages will reside on the provider’s servers (this may also be a con).
      4. Cell & Tell will enjoy the profile that the commercial provider has in terms of marketing. This may not matter to some or any of the participants.
   ii. Cons:
      1. The commercial provider will have all the program content as well as participant responses on their servers.
      2. IT IS expensive
      3. What happens to the data after I close the account?
      4. Are these platforms compatible with all the national cell phone providers? What about Cricket wireless?
5. I don’t have enough resources to purchase/lease a short code.

iii. Questions for SMS Commercial Providers (from the handbook *Text Messaging in Healthcare Toolkit* produced by The Center for Research in Implementation Science and Prevention (CRISP) *University of Colorado School of Medicine*, October 2013) NOTE-this toolkit was made available after Cell & Tell started data collection and the SMS gateway had already been selected. This list is provided here because it is through and complete. The list also underscores the memos taken above in the Pros and Cons sections.

1. What is the cost per message sent?
2. Are there any other costs?
3. What are the payment options?
4. What is the availability and cost of technical support services?
5. Is there a monthly minimum credit purchase requirement?
6. Is there an expiration period for credits purchased?
7. Can you test the system at no charge?
8. What is the quality of the SMS gateway’s network coverage?
9. Is the SMS gateway compatible with the application or interface you are using?
10. Where will the data be stored?
11. How are the accounts and availability of remaining credits managed?

Testing

1. Formal testing occurred between April and July 2013 – earlier memos are in the beginning of the list and date back to April 8, 2012.
   a. Started to send some test messages today from my regular UCD email address today (April 8, 2012)
      i. The first SMS to be sent by SMS gateway from my regular account did not go through and has this error message attached:
         1. Delivery has failed to these recipients or distribution lists: XXXXXXXXXXX@myvzw.com
            An error occurred while trying to deliver this message to the recipient's e-mail address. Microsoft Exchange will not try to redeliver this message for you. Please try resending this message, or provide the following diagnostic text to your system administrator.
         2. This is good information because I will know when my messages are not being sent and not being received by the recipient.
      ii. Sent another SMS on April 10, 2012 at 7:22 am
         1. This message was received and had this text: Got it.
iii. Sent another test SMS on April 10 and received the following message later on the same day:
   1. Delivery to these recipients or distribution lists is complete, but delivery notification was not sent by the destination:
      XXXXXXXXXXXX@messaging.sprintpcs.com

Subject:
2. This does not seem to be a big problem – however, I don’t want to receive notifications by the destination – if the message is sent and received, no notifications of any kind is how the system should work.

iv. Two MMS tests were sent today and both worked, November 8, 2013
b. Cell.Tell@ucdenver.edu was created and test on March 7, 2013 – will begin formal testing next month!
c. Per Adrienne Maddox – Many of the people who use the DIHFS services use Cricket Wireless for their phone needs and are on pay-as-you-go service plans. Find some Cricket users and make sure there is no problem with the system. This is IMPORTANT based on Adrianne’s guidance.
i. Test to Cricket users:
   1. A test SMS was sent to XXXXXXXXXXXX@mms.mycricket.com on 8.22.13 and was successfully received at 4:14 pm.
   2. A second test SMS was sent to XXXXXXXXXXXX@mms.mycricket.com on 8.22.13 and was successfully received at 4:16 pm.

d. Need to find up to five users that will not mind using receiving the Cell & Tell messages.
e. There needs to be a mix of service providers so I can tell if the messages will be carried on the different services.
f. Adrienne Maddux told me that there are a lot of people who use Cricket Wireless and use pay-as-you-go plans. Need to make sure someone who uses Cricket wireless is in the formal test.

Recruitment:
1. People are not responding to the DIHFS Facebook advertisement. So far, there have been no inquiries through this interface. August 20, 2013-Wave 1.
2. Potential participants seem to be more receptive to talking about the intervention face-to-face in the clinic than doing so on Facebook. August 22, 2013-Wave 1.
3. The most often asked question during the recruitment phase from the participants is how many messages they will receive and if it will cost them anything. September 1, 2013-Wave 1.
4. Two participants are unable to make their phones accept MMS through their carriers, which is Cricket Wireless. I tried to help by making several call, but I think the issue is that they are using a pay as you go program. September 7, 2013-Wave 1.
5. Participants are concerned about how much they will have to interact in a face-to-face manner during the winter months. I think this has to do with the difficulties with traveling to and from the DIHFS clinic. January 20, 2014-Wave 2.

Enrollment:
1. During enrollment, the most often asked question is when will I know if I need to send you a response? September 4, 2013-Wave 1.
2. Another interesting question today. A participant asked if their healthcare provider would know if they are enrolled in the program. September 10, 2013-Wave 1.
3. Today, a participant stated that it is a good thing that this intervention is being done in the Indian clinic. Often, these types of opportunities are not made available in organizations that serve the AI/AN population and the other programs make this participant feel like they are “acting white.” Not so much for being involved, but because what friends and relative say about the use of programs to help with health/wellness. January 22, 2014-Wave 2.

Intervention:
1. Today, I sent the first of 25 C&T messages out to the study population and received responses immediately! September 23, 2013-Wave 1.
2. The first homework messages went out today. Not a lot of response. Perhaps I need to send a reminder message before the weekend is over? September 27, 2013-Wave 1.
4. Participants are stating that it is hard to go outside and be physically active in the cold winter months, and gym memberships are too expensive. February 19, 2014-Wave 2.

Data Collection:
1. Some participants are taking a long time to complete surveys. One participant took 1.5 hours today. I asked if they needed help with reading the survey. The participant did not seem to be offended, but declined help. November 22, 2013-Wave 1.
2. The photovoice participants really got engaged and worked really well together. One participant had experience with the Apple OS, but the other did not. The knowledgeable participant offered to teach the other. After this was completed, the two photovoice session participants worked really well together and talked about how they wanted to convey their messages. They even went so far as to write out scripts for the oral piece of the photovoice! December 5, 2013-Wave 1.
3. Bus passes, as mentioned be a participant today, might be really helpful to get a better response to survey collection. Wanted to note this for the next iteration of C&T. April 24, 2014-Wave 2.