University of Alberta

THE EXPERIENCE OF CAREGIVERS OF PEOPLE WITH DISABILITIES IN A PROJECT THAT USED SMS AS A TOOL TO IMPROVE INFORMATION ACCESS AND SOCIAL INTERACTION IN AN UNDER-RESOURCED COLOMBIAN COMMUNITY

by

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A thesis submitted to the Faculty of Graduate Studies and Research
in partial fulfillment of the requirements for the degree of

Master of Science
in
Rehabilitation Medicine - Occupational Therapy

Department of Rehabilitation Science

Fall 2013
Edmonton, Alberta

Abstract

The community of El Codito, an under-resourced Bogota community, has a high population density with the majority living under the poverty line. People with disabilities (PWD) and their caregivers in El Codito experience a lack of access to health information and are socially isolated. This community-based research project used SMS, on basic mobile phones, as a tool for information access and social interaction with 8 caregivers of PWD in El Codito. Using primarily qualitative methods, the research explored: 1) the experience of caregivers in the project, 2) the opinions and use of mobile phones and 3) sustainability considerations and constraints. Caregivers experienced the project as a window to possibility; the possibility of a social support network, the possibility of community participation and the possibility of change. The presence of mobile phone use in El Codito, and many under resourced communities, provides a feasible method for reducing the exclusion of PWD and caregivers.

Acknowledgement

I would like to express my gratitude to my supervisor, Dr. Kim Adams, whose expertise, guidance and patience contributed to a meaningful graduate experience. I would also like to thank members of my committee, Dr. Albert Cook and Dr. Gordon Gow for their assistance and support through all phases of this research.

A very special thank you to Monica Mendoza Molina, Francene Rodriguez Diaz, Patricia Puentes Bernal and the Universidad del Rosario's Social Action Institute (SERES). Without your support and countless hours of work this project would not have been possible.

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Chapter One – Introduction

Introduction

Chronic violence and unrest plagued Colombia throughout the latter half of the 20th century, particularly in the rural areas. Many Colombians who were displaced from their homes by violence or socio-economic factors settled in the mountainside on the perimeter of the capital city, Bogota (Blanco, 2012). These communities are characterized by low socio-economic status, limited access to municipal services such as electricity and sewage, and high crime rates. Citizens in these communities, including a high proportion of people with disabilities (PWD), also experience a lack of access to fundamental health services such as rehabilitation services (e.g. occupational & physical therapies, access to assistive technologies), health education and health promotion strategies. One of these mountainside communities is named El Codito, located in the northernmost region of Bogota. Community projects in El Codito do not have a reliable method for sharing information with the community. However, a high proportion of households have basic mobile phones, which may be a useful tool to support community projects.

This community-based research project, which was the basis for this thesis research, is in collaboration with the University of Rosario (UR) in Bogota, Colombia, and the community of El Codito. The UR's Social Action Institute (SERES) has been actively involved in the community of El Codito since 2007. SERES has interdisciplinary involvement from the UR departments of Sociology,

Political Science, Law, Rehabilitation, and Occupational Therapy. SERES is dedicated to research and social action work with vulnerable populations. Their goals include: the reduction of poverty, hunger and homelessness; the reduction of inequity and social injustice; and the promotion of community participation (SERES, 2013). One way that SERES approaches these development goals is by engaging vulnerable populations, such as people with disabilities (PWD), and providing these populations with the opportunity to play an active role in development projects.

Disability & Poverty

The World Health Organization (WHO) has indicated that approximately 15% of the world population experiences personal disability (World Health Organization, 2012) and 80% of those individuals live in lower-income countries (WHO, 2011). The WHO's International Classification of Function (ICF) and the UN's Convention on the Rights of Persons with Disabilities describe disability as an interaction between impairment and context specific factors (UN General Assembly, 2007; WHO, 2001). The ICF states that disability is the result of a complex interaction between impairments of body structure/function (e.g. spinal cord injury), activity limitations (e.g. difficulty leaving the house), participation restrictions (e.g. inability to interact with others in the community), and contextual and environmental factors (e.g. poverty, physical environment) (WHO, 2001). Similarly, the UN Convention on the Rights of Persons with Disabilities

describes disability as an evolving concept that "results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others" (UN General Assembly, 2007, p. 2).

The WHO (2010) states that there is a disproportionate number of people with disabilities in lower-income countries in comparison to higher-income countries. Poverty may magnify the interaction between impairment and contextual factors, increasing the individual's disability. For example a PWD who is unable to purchase a wheelchair and *cannot* leave their home experiences greater disability than someone with a similar impairment, but has a wheelchair and *can* leave their home. Poverty can be viewed as both a "cause and a consequence of disability" (WHO, 2010, p. 18). Individuals unable to afford medical services may experience poverty as a cause of disability, whereas the individual's loss of income would be viewed as a consequence of disability. Households with a PWD also spend more on healthcare, have few assets and have worse living conditions compared to households without a PWD (WHO, 2011).

Community-Based Research

Community projects often use a community-based research (CBR) approach, which is characterized by "research that is conducted by, with, or for communities" (Sclove, Scammell & Holland, 1998). This collaborative method acknowledges the expertise that community members and community

organizations can contribute to the project and involves them in the research process from the beginning (Hills & Mullett, 2000). The goal of CBR is to address a community issue or create a positive change in the community (Hills & Mullett, 2000). CBR has also been effective at improving health outcomes (Minkler & Wallerstein, 2008). Sclove et al. (1998) states that, "community-based research is intended to empower communities and to give everyday people influence over the direction of research and enable them to be a part of decision making processes affecting them" (p. 1). A CBR approach places an emphasis on promoting community involvement in all phases of research and encourages the long-term sustainability of projects (WHO, 2010; Minkler & Wallerstein, 2008). A CBR approach contributes to this sustainability by engaging the community in a project that they contribute to and serves a useful purpose for the community (Sclove et al., 1998; Talyarkhan et al., 2005).

Information and Communication Technology for Development (ICT4D)

ICT4D is an expanding field of study, which uses Information and Communication Technologies (ICTs), such as mobile and fixed-wire telephones, computers, tablets, radio, television, and Internet, as tools to address community development goals (Unwin, 2009). Mobile phones have become the preferred technology for ICT4D projects because of their widespread adoption in lower-

income countries (Dearden, Light, Kanagwa, & Rai, 2010). Projects and research that utilize mobile phones for the purposes of community development are generally referred to as *mobile for development* or *M4D* (Donner, Verclas, & Toyama, 2008). M4D has grown over the last 10 years into a practice community, utilizing the basic connectivity of mobile phones, i.e. voice and Short Message Service (SMS) (Donner, 2010). SMS messages, commonly referred to as text messages, are messages (160 character maximum) that can be sent from one mobile phone to another mobile phone. Over 80% of mobile phone users world-wide send SMS messages (International Telecommunications Union, 2010). ICT4D and M4D projects have ranged in focus from social action, commerce & marketplace communication, agriculture, emergency response systems, and some limited health service delivery (Donner, Verclas & Toyama, 2008).

ICTs in Lower-Income Countries

ICTs such as computers, the Internet and mobile phones are the primary mode of information sharing and knowledge transfer in developed countries (Barja & Gigler, 2007). Rates of computer and Internet use differ drastically between low/middle and high-income countries (what the ITU calls developed and developing countries). In high-income countries, 74% of households have a personal computer compared to 25% in lower-income countries (International Telecommunications Union, 2011); and 78% of households have broadband internet compared to 28% in lower-income countries (International

Telecommunications Union, 2013). These differences contribute to the *digital divide*, which is the separation between those who have access to digital information and those who do not (Unwin, 2009). In contrast to the lack of computer and Internet access, global statistics indicate that 89% of people in developing countries have a mobile phone subscription (International Telecommunications Union, 2011).

Global ICT statistics for developing countries are consistent with ICT use in Colombia. According to the 2012 International Telecommunications Union ICT Core Indicators, 29.9% of Colombian households have a computer, and 23.4% of households have Internet access. However, there are 103.19 mobile phone subscriptions for every 100 people in Colombia (International Telecommunications Union, 2012). The goal of ICT4D is not the proliferation of ICTs, but rather the promotion of development outcomes using ICTs as a tool (Anderson, 2012). This project used the presence of mobile phones to address the development needs of PWD in the community of El Codito.

Development

While no universally accepted view of development exists, development generally refers to the act of progress and growth in an impoverished community, region or country (Unwin, 2009). Two of the most prevalent views on development are held by two economists with contrasting views, Jeffrey Sachs and Amartya Sen. Sachs takes an economic view of development, ascertaining that poverty can be

eliminated with a focus on economic growth in developing countries (Unwin, 2007). Whereas, according to Sen (2000), development "must look at impoverished lives and not just at depleted wallets" (p. 3). Sen emphasizes a multi-dimensional approach, where poverty results from the restriction of freedoms (political freedom, economic facilities, social opportunities, transparency, and security) and is perpetuated by social exclusion (Sen, 1999; Sen 2000). Sen suggests that human freedoms are both the means to development *and* the end goal of development (Sen, 1999). Given the complex interaction between disability and poverty, a multidimensional approach is more appropriate than a strictly economic view of development. This project, which sought to improve access to health information and opportunities for social interaction, is consistent with Sen's development paradigm.

Social Exclusion

Sen (2000) suggests that poverty and marginalization of people and communities is the result of social exclusion. Social exclusion is a process where individuals, households, groups, or communities are prevented from participating in their community or society (Popay et al., 2008). Social exclusion was first introduced in 1974 by Lenoir, when he described various "excluded" members of society, which included: mentally and physically impaired, single parents, abused children, and, in Lenoir's words, "other social misfits" (Lenoir, 1974). Social exclusion adds a broader framework to the economic view of poverty, because it

acknowledges the contribution of multiple factors to the "cumulative disadvantage" of the socially excluded (Beland, 2007). The United Nations (UN) Development Programme (2011) outlined a theoretical framework for social exclusion in order to examine the multi-dimensional process that leads to exclusion. The three main dimensions of social exclusion include (UN Development Programme, 2011):

- *Exclusion from Economic Life* – Inequities in income, employment, housing, land and other assets.
- *Exclusion from Public Services* - Unequal access to education, health care, housing, public utilities, sanitation, physical access to the community, transportation, and social protection.
- *Exclusion from Civic and Social Life* - Inequalities in political, cultural and civic opportunities participation. Limited acceptance and respect for diversity, resulting in stigma and discrimination. Reduced social interaction and relationships (e.g. friendship, family, neighborhood, community), resulting in a reduced sense of belonging.

Social Exclusion, Health & Disability

PWD are an example of an excluded population that is particularly neglected and excluded from mainstream health development initiatives (WHO, 2010). Social exclusion is one of the social determinants of health, drastically impacting health

outcomes and instances of chronic disease and disability (Mikkonen et al., 2010). The social exclusion of PWD in under-resourced communities results in chronic poverty, isolation and poor health compared to the general population (WHO, 2010). This project addressed some of the exclusions experienced by PWD (health information and social interaction) and may have the potential to improve long-term health outcomes.

PWD are believed to be one of the most (if not *the* most) vulnerable and excluded members of society, particularly in under-resourced communities (Talyarkhan, Grimshaw, & Lowe, 2004; Maxwell, Belser & David, 2007). Shilderman (2002) states that development research should avoid focusing on the most active members of a community, since this broadens the gap of social exclusion; rather, focus on the needs of females, young people and PWD. Development practice suggests that interventions that target vulnerable members of society, such as PWD, often result in positive outcomes and cohesive communities (Talyarkhan et al., 2004). John Wolfensohn, former president of the World Bank stated that there must be a focus on the needs of PWD in order to achieve broader community development goals (WHO, 2010). This project specifically targeted the needs of PWD and their families.

Community of Interest – The Case of El Codito

El Codito has a high population density with the majority (if not all) living under the poverty line (Mendoza & Guevara, 2012). El Codito, has a mountainous environment that makes it very difficult for PWD and their families to leave their

homes or access their community, leaving them both physically and socially isolated. According to SERES, many PWD have not left their homes in over 5 years. While no official numbers are available, the community of El Codito is believed to have a high population of PWD. With a population of over 32,000 (Mendoza & Guevara, 2012), El Codito could have over 4000 people with some form of disability if using the WHO global proportion of disability (15%).

In August 2011, a UofA professor and a group of students (including me) visited Bogota, Colombia, and the community of El Codito to begin preliminary discussions about health related issues experienced by PWD and how to address them.. Discussions were held with key stakeholders, including SERES, community leaders, clinicians, PWD and their families. In these discussions, two key issues arose: PWD have limited access to health information and limited opportunities for social interaction. PWD and their families desired access to health information and to interact with others in their community, but lacked a reliable information and communication method.

In El Codito there is in an information disconnect; knowledge, services, and resources exist for PWD, but one of the most critical issues faced by PWD is the lack of access to this information. For example, a group of Colombian researchers developed an extensive database of assistive technology (AT) available in Bogota, Colombia (Rios, Vargas, Laserna, & Melo, 2007). However this 5000 item database could not be shared with the general public because there was no viable information distribution system; the majority of the population do not have computers and print media would be too costly.

Having limited access to information and limited social interaction contribute to social exclusion. Limited access to health information contributes specifically to exclusion from public services. The Convention on the Rights of Persons with Disabilities, Articles 9, 21 and 25 emphasize the rights of PWD to have access to information, including health information, and the option of accessing this information using ICTs (UN General Assembly, 2007). Limited information access has been associated with poor health outcomes and is an area of concern in developing countries (World Health Organization, 2003; World Bank, 1998).

Limited social interaction contributes specifically to exclusion from social life. Social isolation has been associated with poor health outcomes and is an area of concern in lower-income countries (World Health Organization, 2003; World Bank, 1998). The Convention on the Rights of Persons with Disabilities emphasizes the importance of social participation of PWD in their community (UN General Assembly, 2007). Social isolation not only impacts PWD, but their family members have also become isolated as they must remain in the home to take care of the PWD. It is believed that the family members who are most impacted by this social isolation are women; women are most likely to act as informal caregivers for PWD in Colombia/developing countries (Ogden, Esim, & Grown, 2006). These caregivers may experience similar social exclusion as the PWD. Decreased social interaction also contributes to decreased access to information since they are not able to benefit from 'word of mouth' advice from others in the community.

In Colombia and the community of El Codito in particular, limited access to information and limited social interaction have contributed to the social exclusion of PWD. SERES and a local community leader reported that PWD are excluded in all dimensions of social exclusion as follows:

- *Exclusion from Economic Life* – PWD are unlikely to have a form of employment and rarely leave their homes. Given that one family member often remains at home with the PWD, there may be decreased earning potential for the family along with increased financial burden of caring for a PWD. PWD may also experience stigma and discrimination, which reduces their ability to find employment.
- *Exclusion from Public Services* - PWD in El Codito have limited access to the health care and education. Similar to other members of the community, PWD have limited access to water, power, transportation and sanitation, and have varying degrees of access to food and adequate shelter. PWD are excluded by physical access to their community, primarily due to the mountainous environment.
- *Exclusion from Civic and Social Life* – SERES stated that PWD in El Codito are often limited to interacting only with members of their household since they are rarely able to leave their homes. Thus, PWD are excluded from forming friendships or a sense of community and they do not have the opportunity to participate in public life or political discussions. SERES believes that negative attitudes and perceptions of

disability may contribute to the exclusion experienced by PWD. These attitudes towards disability lead to stigmatization and discrimination of PWD in the community. This discrimination has resulted in PWD being hidden within the community. This is a common occurrence for the socially excluded PWD (Maxwell, et al., 2007).

Community members indicated that mobile phones could be a feasible method to improve information access and social interaction in El Codito as most households in the community have a mobile phone. Mobile phones and SMS could be an affordable method for this community; all incoming SMS messages are free and outgoing SMS messages cost between $0.04 and $0.10 per message (Canadian dollar equivalent) (Tigo, 2011).

Purpose Statement & Research Questions

This community-based research project, titled *El Enlace* (Spanish for *The Link*) provided caregivers of PWD in El Codito with access to health information and a method of social interaction using technology they already own, mobile phones. The purpose of the study was to evaluate the experience of using a mobile phone, text messaging system for health information access and social interaction for caregivers of PWD in El Codito.

Research Questions

The following research questions guided the project.

1. What is the experience of caregivers participating in the project for accessing health information and social interaction?

2. What are the opinions of caregivers and coordinators about using the technology in the project?

3. What effect does participating in the project have on self-perceived health?

4. What are the key considerations and constraints in developing a sustainability strategy for the project?

Impact

This project had the potential to provide a vulnerable population in El Codito, PWD and their families, with affordable and sustainable access to health information and the opportunity to interact with others in the community.

This project supports the UN's Convention on the Rights of Persons with Disabilities (CRPD), which was developed in order to promote, protect and ensure the rights and dignity of PWD (UN General Assembly, 2007). Specifically, it supports articles 4, 9, 19 and 25.

- Article 4, which recommends research which promotes the use of new technologies such as information and communications technologies (UN General Assembly, 2007).
- Article 9, which reinforces the need for accessible technology, including promoting contextually relevant access to information and communication technologies (UN General Assembly, 2007).
- Article 19, which recommends improving awareness of existing community services and including PWD in existing community activities (UN General Assembly, 2007).
- Article 25, which recommends improving health information access and providing disability-specific information for PWD and their families (UN General Assembly, 2007).

Chapter Two - Literature Review

This review first focuses on literature about ICT4D in general and then literature pertaining to the use of mobile phones for information access, social interaction and disability. It concludes with an overview of some guiding principles for the implementation of ICT4D projects.

Information and Communication Technology for Development (ICT4D)

Information and communication technology for development (ICT4D) is a field of study that uses ICTs as tools to achieve development goals (Unwin, 2009). Starting in the early 2000s, international groups began trying to capitalize on the use of ICTs to meet development goals (Talyarkhan et al., 2004). The initial approach assumed that improving access to ICTs in developing countries would improve livelihoods and lead to economic development (Unwin, 2009). This approach was often termed, reaching the *last mile*, which focused on expanding mainstream ICTs (such fixed-wire communication systems) to remote areas using similar strategies that were used in higher-income countries (Talyarkhan et al., 2004). This approach has been re-conceptualized to connecting the *first mile*, focusing on the strengths and context specific needs of under-resourced communities and developing projects using local resources (McMahon et al.,

2011; Talyarkhan et al., 2004). Connecting the first mile goes beyond simply providing access to ICTs since it requires a contextual understanding of the community and how information and communication can help meet community specific development needs (McMahon et al., 2011; Talyarkhan et al., 2004). Connecting the first mile goes beyond traditional economic views of development, and is more in line with Sen's multidimensional view of development (Anderson, Gronlund & Wicander, 2012).

Researchers suggest that ICT4D has not yet revealed substantial development outcomes, either due to a lack of sustainability, relative infancy as a field of study, or simply because it lacks substantive research (Unwin, 2009; Meera, Khamtani & Rao, 2004). Although numerous projects have been developed, a very small number have been published in peer-reviewed journals (Deglise, Suggs & Odermatt, 2012). Authors encourage the use of exploratory and social science research in order to better guide future projects (Mapham, 2008).

ICT advancement in developed countries has played a significant role in the globalization of information, the rapid uptake of this information and the development of an information society (Kleine & Unwin, 2009). There is a digital divide between those who have access to digital information and those who do not and an even greater divide within under-resourced countries where ICTs and Internet connectivity may be high in the city, but non-existent in rural areas (Unwin, 2009). The Internet is a potentially powerful means of accessing information, but Unwin (2009) identifies three conditions for this to occur: people must have devices that can access the Internet, relevant information must exist on

Internet servers, and search engines must lead people to the right information. If any one of these conditions is not met, a digital divide is likely to exist (Unwin, 2009). ICT4D projects often aim to reduce the impact of the digital divide (Unwin, 2009).

ICT4D differentiates between information sharing and knowledge sharing. Information is data that is capable of answering 'who', 'what', 'when' and 'why' questions, but does not have contextual relevance (Bellinger et al., 2004). Knowledge is internalized, contextually relevant information that can be incorporated into lived experiences (Talyarkhan et al., 2004). ICT4D projects that share local, contextually relevant information are most likely to translate into knowledge sharing (Chapman, Slaymaker, & Yount, 2003). This translation of information to knowledge can be improved with the use of infomediaries (Lloyd Laney, 2003). Infomediaries are individuals who work between the information, the ICT and the community (Lloyd Laney, 2003). Contextually relevant information that is passed through an infomediary is most likely to result in knowledge sharing (Talyarkhan et al., 2004). The promotion and preservation of local, indigenous knowledge is important in ICT4D projects, but if new information is to be introduced, infomediaries are most likely to produce successful outcomes (Cecchini & Scott, 2003). An ICT4D project in Peru, which established community info-centres, attributed much of its difficulties to the inability to find infomediaries (Talyarkhan et al., 2004). Even if knowledge sharing does not occur in a project, improving access to relevant information can

still bring about positive change, advance development outcomes and enhance human freedoms (Galperin & Mariscal, 2007).

ICT4D - Information Distribution

A substantial amount of ICT4D research has been completed in the area of economics, microfinance, and agriculture (Dearden et al., 2010). Many of these projects utilize mobile phones for the purpose of information distribution and knowledge sharing, resulting in improved farming practice, improved market price communication and increased earning potential for farmers (Furuholt & Matotay, 2011). The information shared in these projects was contextually relevant, which motivated participants to engage in the project and successfully resulted in knowledge sharing and development outcomes (Furuholt & Matotay, 2011).

More pertinent to this project, a number of ICT4D projects have utilized mobile phones and SMS for distribution of health information. The use of mobile technologies to support healthcare initiatives is also referred to as mobile health or mHealth (Kahn et al., 2010). While a substantial number of projects have used SMS for health promotion and information sharing in lower-income countries, a limited number of them have reported results or evaluated their projects (Deglise, Suggs & Odermatt, 2012). Of thirty-four recent SMS-based projects identified by Deglise, Suggs and Odermatt (2012), only five were evaluated and/or reported by their initial project team. Twenty-nine of the thirty-four projects were simply

implemented, with no evaluative component or reported findings or outcomes (Deglise, Suggs & Odermatt, 2012). The projects that were evaluated found that using SMS to distribute health resources resulted in improved health outcomes and has potential in lower income countries (Deglise, Suggs & Odermatt, 2012). Lester et al. (2010) found that using SMS messages for patient monitoring and medication reminders significantly improved antiretroviral medication adherence and health outcomes for patients with HIV in Nairobi. This study concluded that mobile phones and SMS messages are an effective tool in healthcare delivery, especially in under-resourced countries (Lester et al., 2010). Nchise (2012) recently found mobile phones and SMS to be effective for the distribution of health information and for patient monitoring, especially in remote areas in Uganda. The use of edutainment, SMS quizzes with rewards, was believed to result in greater engagement with the information (Nchise, 2012). Using SMS for distributing information has been found to increase health-seeking behavior and improved participation in health care activities for HIV patients in under-resourced communities in developing countries (Mapham, 2008; Family Health International, 2009).

A feasibility study found that SMS was an appropriate method for improving access to health information and was accepted by under-resourced communities (L'Engle and Vadhat, 2009). In this study, 40 patients in various family planning clinics in Tanzania, Nairobi and Kenya were interviewed regarding the use of text messaging for a mobile reproductive health project (L'Engle and Vadhat, 2009). Participants increased their awareness of

contraceptive methods and reported positive behavior change (Family Health International, 2009). This feasibility study informed the 2010 implementation of further projects in Tanzania and Kenya, both are still in operation but have not been further evaluated or reported (Family Health International, 2009).

Cole-Lewis & Kershaw (2010) identified twelve projects that used SMS to communicate specific health information to at-risk populations. Topics included diabetes management, asthma management, physical fitness, smoking cessation and weight-loss (Cole-Lewis & Kershaw, 2010). Of the twelve projects, eight projects reported positive health outcomes. These projects were located in developed countries, limiting their relevance to the context of this project.

ICT4D – Social Interaction

Research has found that the use of SMS messages in ICT4D projects has created a distinct new form of communication in under-resourced countries (Taylor and Harper, 2003). This new form of communication has resulted in new networks of social support (MobileActive, 2007). The SHM Foundation, (2012), a charitable foundation that conducts social action, mHealth and arts/culture projects using mobile phones and social media, completed three projects. The findings of these projects have not been extensively reported in the academic literature, but were reported in an evaluation report on their website (www.shmfoundation.org). First, the Zumbido Project in Mexico gave mobile phones with unlimited SMS to 40 socially isolated, HIV positive individuals in order to establish an SMS-based

social network (Mapham, 2008). Participants developed meaningful relationships with each other, exchanged messages of support, exchanged information at times and even referred to each other as family (MobileActive, 2007). These participants reported feeling less isolated, having greater support networks and improved relationships (MobileActive, 2007). An overwhelming 25,000 messages were sent over a three-month period (MobileActive, 2007). Second, a similar project called Parents Aloud piloted an SMS support network for parents of HIV-positive children (The SHM Foundation, 2012). The project included 15 socially isolated parents, mainly mothers, across Africa and the UK: Uganda (6), Zambia (2), Ghana (2), Nigeria (1), Angola (1) and the UK (3) (The SHM Foundation, 2012). Parents Aloud found that participants developed a sense of belonging and a safety net that provided emotional relief (The SHM Foundation, 2012). Interestingly, there was not a high volume of SMS messages in this project, yet a sense of belonging and safety net resulted; simply the availability of social supports was enough to feel connected (The SHM Foundation, 2012). Unintentional byproducts of the project were healthy eating and information exchange about medications (The SHM Foundation, 2012). Third, in partnership with the Yale School of Medicine and the University of Pretoria, The SHM Foundation (2012) developed a social support program for HIV-positive mothers in South Africa, which aimed to prevent mother-to-child transmission of HIV. No outcomes from this project have been reported. These three studies highlight the potential for using text messaging as a method of social interaction and how social

isolation, social interaction, health issues and the need for health information are interconnected.

A 2009 study explored the role of mobile Internet in addressing economic, political and social participation in South Africa, concluding that mobile Internet had the greatest impact on social participation (Chigona, Beukes, Vally, & Tanner, 2009). This study also reported that mobile phones have the potential to reduce social exclusion of marginalized populations (Chigona, Beukes, Vally, & Tanner, 2009). Similarly, another descriptive study examined the contribution of mobile phones to rural livelihoods in Tanzania (Sife, Kiondo, & Lyimo-Macha, 2010). The study identified that mobile phones and SMS were most useful for social interaction compared to other aspects of livelihood such as efficiency of daily activities, emergencies, transport, business activities, market information and agriculture, banking, and household income (Sife, Kiondo, & Lyimo-Macha, 2010). Mobile phones were found to be useful for developing social networks and decreasing feelings of isolation among socially excluded populations in Tanzania (Sife, Kiondo, & Lyimo-Macha, 2010). Simply the presence of mobile phones in a community, even without any development strategy, can improve communication in under-resourced communities (Unwin, 2009).

While not using mobile phones, research completed in Pakistan showed that some communities in developing countries did not initially want to interact using ICTs (Ellahi & Mushtaq, 2011). However, prior to the study, participants did not report any issues of social isolation or a desire to improve their social

interactions. These researchers warn that social interaction may not be an issue that is always appropriate for ICTs to address (Ellahi & Mushtaq, 2011).

ICT4D - Disability

No ICT4D research was found that specifically used mobile phones to target the needs of people with disabilities (PWD) within a community. The literature suggests that mobile phones pose a *potential* method for reducing physical and social barriers experienced by PWD in developing countries (Chigona, Beukes, Vally, & Tanner, 2009). While not focusing on the use of mobile phones, a study by Guo, Bricout, & Huang (2005) identified that computer and Internet-based social media provided an avenue for increased social interaction for people with visual impairments in China.

The use of ICTs for PWD can be complicated since many PWD have physical, visual or cognitive impairments that make it difficult or impossible to use mainstream ICTs (Cook, 2009). Granholm, Ben-Zeev, Link, Bradshaw and Holden (2012) implemented a project that used basic mobile phones and SMS for the assessment and treatment of schizophrenia. They highlighted that lower functioning participants had some difficulty using the mobile phone, for example they had difficulty navigating menus or not recognizing when there were unanswered messages in their inbox (Granholm, Ben-Zeev, Link, Bradshaw & Holden, 2012). This study, not conducted in a lower-income country, proposed that participants had more difficulty using SMS on low-cost basic mobile phones

than they would with touchscreen smartphones that have a more intuitive user interface (Granholm, Ben-Zeev, Link, Bradshaw & Holden, 2012). I do not anticipate participants in my thesis research to have similar difficulty with SMS on basic mobile phones since they do not have cognitive impairments and are familiar with using the technology.

Rather than focusing on disability, the majority of health-related ICT4D projects in lower-income countries have focused primarily on infectious diseases (Deglise, Suggs & Odermatt, 2012). However, the Global Burden of Disease Study 2010 identified that non-communicable diseases and resulting disability is becoming more prevalent than infectious disease (Murray et al., 2012). The WHO (2011) states that in lower-income countries, infectious diseases account for 9% of the years lived with disability (YLD), whereas non-communicable chronic diseases account for 66.5% of YLD. YLD is a measure used by the WHO (2011) as an alternative to prevalence rates that do not capture the full impact of long-term, chronic disability. The literature is not clear about why there is a disproportionate number of projects that focus on infectious diseases, however, there is a gap in the literature regarding projects and research that address the needs of people with non-communicable diseases and resulting disabilities.

Principles in ICT4D

The following section identifies a number of guiding principles drawn from the literature for the implementation of ICT4D projects. These were applied in this project whenever applicable or possible.

Participatory Solutions

The ICT4D literature compares and contrasts participatory solutions with top-down solutions (Talyarkhan et al., 2004). Top-down solutions, also referred to as supply-led, are solutions where organizations outside of the community determine the development goals and the intervention strategy (Talyarkhan et al., 2004). Top-down solutions often reflect unequal power dynamics where the experts enter a community to help the under privileged (Unwin, 2009). These solutions are often the result of donor agendas, which may be overly ambitious and complex (Talyarkhan et al., 2004) and "undermine rich and effective existing information networks" (Chapman et al., 2003, p. vii). Top-down ICT4D projects fail to bring lasting benefits or achieve local ownership (Kleine & Unwin, 2009). For example, all 40 participants in the Zumbido Project in Mexico were given mobile phones at the beginning of the project, but all phones were taken away after 3 months, as costs were too high for the project (MobileActive, 2007). While this project demonstrated effectiveness during the intervention, there was not a focus on

building local partnerships and there were no lasting benefits to the participants in the study (MobileActive, 2007).

Alternately, participatory solutions, also referred to as bottom-up or demand-driven, are community-based solutions that address community identified needs (Talyarkhan et al., 2004). Active involvement from the community and strong partnerships with stakeholders improves participation in the ICT4D project (Grönlund et al., 2008) and results in greater sustainability (Kleine & Unwin, 2009). For example, the Grameen Village Phone Program in Bangladesh is a participatory solution where women in remote villages were given the opportunity to become mobile phone service providers in their community, and they became more engaged in their community and earned an income (Donner, 2010).

Local Solutions

In the early years of ICT4D, projects sought after far-reaching, global solutions in order to impact a wide range of people and tap into the global pool of information (Talyarkhan et al., 2004). Global solutions were often supply-led, offering generic solutions that do not work with context specific issues (Talyarkhan et al., 2004). These initiatives, often based on western ideology and strictly focused on economic development, fail to contextualize the information and attempt to apply the same strategy in multiple different contexts (Unwin, 2009; Talyarkhan et al., 2004). A global view often assumes that everyone sees life in a similar way and wants similar information; this view has had limited success (Unwin, 2009).

Local solutions, often at a much smaller scale, have had a greater degree of success and are more likely to result in valuable knowledge sharing (Klein & Unwin, 2009). ICT4D projects should improve existing practices and local knowledge sharing rather than introducing new practices (Donner, Varclas & Toyama, 2008). Nchise et al. (2012) identify that contextually relevant information is necessary in ICT4D. Their ICT4D project in Uganda that used SMS for distribution of HIV/AIDS information found that there was a negative response when participants received generic information, especially when the information was in English (Nchise et al., 2012). The Grameen Village Phone Program in Bangladesh is an example of a solution that was locally developed and context specific (Donner, 2010). The Grameen Village Phone Program successfully introduced new, mobile technologies into isolated villages using a community-based, participatory approach (Donner, 2010). This program utilized local community members as equal partners in program development. Local, community-based development strategies are believed to have been of principle importance to the success of the project (Donner, 2010).

Technology as a Development Tool

The ICT4D literature cautions researchers not to focus too much on the technology when developing a project (Donner, Varclas & Toyama, 2008). ICT4D projects have historically been overly optimistic about the contribution ICTs can make to development (Talyarkhan et al., 2004). Projects that over-emphasize the role of the technology often view complex development issues as

technical issues that simply need the right ICT in order to be solved (Talyarkhan et al., 2004). This focus views new and emerging technologies as the magic solution for development (Kleine & Unwin, 2009). However, technology and ICTs are cultural and ideological artifacts that carry a complicated history (Kleine & Unwin, 2009). Cultural artifacts are anything created by people that give information about the originating culture (Unwin, 2009). ICTs were born in the United States and are intimately connected with economic progress, capitalism and the globalization of information (Kleine & Unwin, 2009). Those with power have historically been the drivers of ICTs, have the best access to ICTs and control the majority of information (Unwin, 2009). Underlying inequities in power and opposition or hesitancy towards western ideology may impact the effectiveness of ICTs for development (Unwin, 2009). There is a substantial difference between the context in which the ICT was created and the context of its use in ICT4D (Heeks, 2002).

Alternately, ICT4D projects that focus on development will first identify the contextual needs of the community, and then select an appropriate technology (Unwin, 2009). If possible, projects should utilize an ICT that already exists in the community and that requires basic skills rather than additional technical knowledge (Donner, Varclas, & Toyama, 2008). No training is required with an existing technology, which allows local communities to focus on development goals rather than on the technology (Donner, 2010). Due to increasing prevalence, mobile phones are often one of the most common and accepted ICTs in under-resourced communities (Donner, 2010). An example is the use of mobile phones

to support local fishing practice in Kerala, India (Jensen, 2007). No outside organization introduced technology to the community, fisherman were interested in improving their access to market prices and improving efficiency; they began using mobile phones and text messaging to support this goal (Jensen, 2007). Donner (2010) reminds researchers of the "intentionality" of ICT4D research and that the "4D" is the most important component.

Conclusion

This thesis research, situated within the field of ICT4D, sought to further the current evidence base in the field, particularly regarding disability. ICT4D projects highlighted in this literature review have had success using SMS messaging for information distribution, supporting the decision to use SMS messaging for this purpose in the project. While there is not a substantial amount of peer-reviewed literature supporting the use of SMS for social interaction in ICT4D projects, there is an indication that this may be a potential benefit. The use of SMS for social interaction in this thesis research will contribute to the knowledge base in this area. Most notably, this project fills a gap in the literature regarding the use of SMS messaging to address the information and communication needs of PWD in lower-income countries. Incorporating principles learned in ICT4D and building upon the current body of literature, this project sought to use SMS as a tool for information access and social interaction with a population of people with disabilities and their caregivers.

Chapter Three – Methods

Researcher Perspective

This research used primarily qualitative methods, specifically a focused ethnography. One criticism of qualitative research is its subjectivity, which is often viewed as a bias or a drawback of the research. I however, in agreement with Mayan (2009), view subjectivity neither as a drawback nor strength in qualitative research, rather something that is unavoidable and always present. Reflexivity is one way of acknowledging researcher subjectivity and identifying one's personal views and their potential influence on the research (Morrow, 2005). Reflexivity is not the act of apologizing for one's subjectivity, rather it is defined as "thoughtful, conscious self-awareness" as it relates to research activities (Finlay, 2002, p. 532).

First and foremost, I am an occupational therapist; most of my experience has been in the community health setting. The central paradigm of occupational therapy is the view that humans are occupational beings and that occupations (or activities) give meaning to life (Townsend & Polatoajko, 2007). Moreover, I believe that individuals have a unique story and a unique experience that contributes to who they are and how they view the world. At the root of my occupational paradigm is the importance of individual experience. As an occupational therapist, I want to enable my clients to explore their own unique

experience, regardless of their disability, impairment, social circumstance or other characteristic.

My occupational perspective, within the context of this research, is referred to as occupational justice. Occupational justice, initially developed by Townsend and Wilcock (2004), is the promotion of occupational engagement that brings social transformation and change, particularly with marginalized populations.

Occupational therapy, when promoting occupational justice, is more likely to be practiced in non-traditional, less medical settings. Occupational therapy, as a health profession, is most commonly practiced within healthcare settings such as hospitals or clinics. However, there is a growing trend towards practicing occupational therapy outside of the traditional healthcare settings in collaboration with non-medical interdisciplinary teams. This movement towards non-traditional practice settings is referred to as role-emerging occupational therapy (Thew, Edwards, Baptiste & Molineux, 2011). I identify as a role-emerging occupational therapist, interested in promoting occupational justice.

When reflecting on my epistemological perspective, how we can know about the world, I realized that I do not hold firmly to any particular orientation. In fact, I do not necessarily believe that any one particular epistemological perspective is more authoritative than another. Be it, constructivist, structuralist, interpretivist, etc., none are necessarily more equipped than the other to explain the world, yet each could be useful at explaining a phenomenon. Curiously enough, my view is consistent with the epistemological perspective of epistemic

relativism. Epistemic relativism asserts that no authoritative standard exists (subjectivist relativism) or there are many authoritative standards (pluralist relativism), and that there is "no neutral way of choosing among them" (Luper, 2004, p. 274). In community-based research (CBR), collaborative methods are emphasized, with knowledge being co-generated by multiple researchers and participants. There is a high probability that CBR partners will each hold varying epistemological views. An epistemic relativist perspective makes it possible for me to accept multiple perspectives.

In terms of theoretical position, I orient myself towards the viewpoint of Rosi Braidotti's nomadic theory. Nomadic theory, as an extension of critical theory, focuses on unequal power relations yet is decidedly positive (Braidotti, 2011). Where critical theory focuses on the social inequities, nomadic theory focuses on the possibility for transformation and change (Braidotti, 2011). In nomadic theory, marginalized populations "are the privileged starting point for active and empowering processes of becoming" (Braidotti, 2011, p. 29). In nomadic theory, the perpetual process of 'becoming' is deeply rooted in the dignity and transformational potential of marginalized populations. It was my hope that this project would encourage this transformational potential of PWD and caregivers in the community of El Codito.

Focused Ethnography

Ethnography is the exploration and description of a community or culture (Hammersley & Atkinson, 2007). Ethnographers seek to understand the experience of a particular culture from the point of view of those who are a part of the culture (Mayan, 2009). While the epistemology of ethnography is variable (Whitehead, 2005), this research takes a constructivist perspective. In this view, reality is subjective and cannot be definitively measured; rather it is co-constructed at a particular point in time by the members of a culture together with the researchers (Whitehead, 2005).

Focused ethnography is a type of ethnography and targets a specific part of a culture (Knoblauch, 2005; Mayan, 2009). Focused ethnography features short-term field visits and targeted activities to understand a particular aspect of the culture (Knoblauch, 2005). This CBR project used a focused ethnographic method, targeting the culture of the participants in the El Enlace project, a specific segment of the culture in El Codito. I did three intensive field visits to Bogota, Colombia, two before and one after the intervention, totaling six weeks. I was immersed in the text messaging culture remotely from Canada during the 3-month intervention. Other members of the local research team (identified in the Partnership Development section below) were immersed in the community for the entire duration of the project.

Action Research

Project phases were guided by an action research cycle. CBR often incorporates action research methods to guide the iterative development of a project (Roche, 2008). Action research aims to not only understand the problem; it also aims to encourage change through the development of planned, actionable outcomes (Hearn & Foth, 2004). An action research cycle guides a project through an iterative process of: plan, act, observe and reflect (Kemmis & McTaggart, 2005). See figure 3.1 below for a visual representation of the action research cycle.

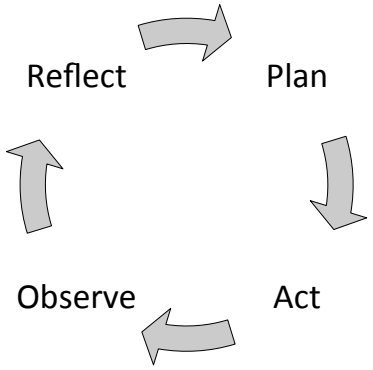


Figure 3.1 – Based on Kemmis & McTaggart's (2005) Action Research Cycle

The following table 3.1 outlines each phase of the action research cycle in this study and the corresponding research activities. See Appendix A for a timelines of these research phases and activities.

Table 3.1 – Action research phases and related activities

Action Research Phase	Activities	Data Collection Activity
Plan Phase	Partnership Development Technology Development Content Development Pre-Intervention Activities Baseline Data Collection • Measurement of Digital Poverty • Multidimensional Social Exclusion Index • Self-Perceived Health	 ✓ ✓ ✓
Act Phase	Intervention	
Observe Phase	Monitoring • Daily • Bi-weekly • Mid-Intervention Telephone Follow-up Collection of Message Data	 ✓
Reflect Phase	Focus Group Coordinator Questionnaire Transcription & Translation Co-Analysis of Focus Group Data Validation of Findings	✓ ✓

Plan Phase

Partnership development

As mentioned in the introduction and The Case of El Codito, partnership development began in August 2011. According to CBR and ICT4D recommendations, partnerships should be established with key stakeholders. Members of stakeholder groups in El Codito were considered and consulted while determining the project's use of mobile phones to provide access to health information and social interaction for PWD. The following partners were involved in the development, implementation and evaluation of this CBR project:

- *Social Action Institute (SERES)* – a UR affiliated institute that conducts social action work and research in vulnerable Bogota communities. SERES employs and has consultants in Sociology, Political Science, Law and Occupational Therapy.
- *Community Leader* – an individual from El Codito who volunteers as a community representative. This community leader is involved in various social action, healthcare and community development initiatives and is actively involved with PWD and their families in the community; she is also a caregiver of a PWD. She became employed by SERES during the course of this research and contributed to the project.

- *Community Clinician* – an occupational therapist that worked in El Codito through a Bogota hospital. She became employed by SERES during the course of this research and contributed to the project.
- *People with disabilities and families in El Codito* – this group was not directly represented in our project partners, but the community leaders consulted with and represented this population in the project development and implementation.

Technology Development

Materials: The software used for this project was FrontlineSMS, an open-source text message delivery program developed for international development (FrontlineSMS, 2011). The system requires one computer running FrontlineSMS connected to one mobile phone, no Internet is required. This computer, with a connected mobile phone, acts as a two-way text-messaging hub. A two-way messaging hub can send and receive SMS messages from groups of people, facilitating the sharing of information and interactive communication. In FrontlineSMS, keywords, which correspond with various actions in the software, can be used to facilitate this two-way messaging. Customizable keywords can be setup to perform the following actions:

- *Add to group:* FrontlineSMS automatically adds the sender to a specific contact group. E.g. the keyword "Subscribe" could add someone to the "Community Members" contact group.

- *Remove from group:* FrontlineSMS automatically removes the sender from a specific contact group. E.g. the keyword "Unsubscribe" could remove someone from the "Community Members" contact group.
- *Auto-reply:* FrontlineSMS automatically replies to an incoming message with a predetermined automatic reply message. E.g. "Thank you for subscribing to our information service"
- *Auto-forward:* FrontlineSMS automatically forwards a message to a contact(s) or contact group(s). E.g. a social interaction message can be forwarded to all individuals in the "Community Members" contact group.

See Appendix B for more information related to FrontlineSMS.

For this research, a GSM modem (Sierra Compass 885) containing a SIM card was connected to an HP Laptop. The SIM card used in the technology development was registered with Bell Mobility and had a local and international text-messaging plan. The laptop was running FrontlineSMS version 1.6. Settings were changed on the laptop to disable all automatic updates and system processes that restart or put the computer to sleep.

Technology trials: Three trials were completed using FrontlineSMS. The first trial was completed at the University of Alberta with a group of 8 students, faculty and clinicians. The second trial was completed remotely with a group of 6 members of SERES in Bogota. The third trial was also completed remotely with a group of 10 SERES members, community leaders and the community clinician in

Bogota. For all three trials, the SMS messaging hub was located in Edmonton, Canada. The objectives of the trials were to:

1) Test the technology, including all functions of FrontlineSMS on both Canadian and Colombian mobile networks
2) Test the usability of the system
3) Introduce the technology to the SERES, community leaders and clinicians
4) Test FrontlineSMS for information distribution
5) Test FrontlineSMS for social interaction

The technology worked as expected. The users found the system as easy to use as sending a basic text message. The information distribution and social interaction functions operated as expected and it was expected that they could be scaled up for the implementation phase. SERES indicated that they felt the system would be functional for the project in El Codito. The results from these trials highlighted the need to establish common terminology and common language when sending messages and interacting with the system. Hence, it was critical to have the involvement of SERES and community leaders when determining language and terminology that was appropriate for the community of El Codito. A detailed description of these trials can be found in Appendix C.

Content Development

It was initially proposed that one content area would be selected in collaboration (via Skype and email) with SERES, the community leader and community

clinician. This content would then be used for the Implementation Phase. During multiple conversations in July 2012, partners discussed whether existing program materials were available, possibly targeting a specific population. The use of existing material promotes local, contextually relevant knowledge sharing (Talyarkhan et al., 2004). However, it was determined that no collection of materials or curriculum was available that was relevant for people who have disabilities in El Codito. Project partners decided that the community clinician and community leader would research current, relevant general information throughout the implementation and generate content on a weekly basis. Initial information included: information on accessing health services for PWD and their families in El Codito (e.g. child vaccinations, a local disability registration event and information for parents on accessing mental health support) and community events for PWD (e.g. a local resource fair for PWD). This permitted greater flexibility in selecting participants for the project. The community clinician and community leader used the following criteria when selecting content to share with participants:

1) The content is relevant to PWD or family members in El Codito.
2) The community clinician and/or community leader must be familiar with the content to be able to answer questions from participants.
3) The content must be amenable to being broken down into small portions of information without losing its meaning (i.e., avoid overly complex content).

Pre-Intervention Activities

From August 10-31, 2012, I traveled to Bogota for three weeks to prepare for and launch the intervention. A detailed workplan was confirmed in collaboration with SERES, the community leader and community clinician identifying the tasks that were to be completed during this trip (see Appendix D). Partners that were identified in the Plan Phase (as noted in the above Partnership Development) became part of the project coordination team, which was responsible for carrying out activities related to the project. The project coordination team was comprised of the following roles:

- *Research Coordinator* – me
    - Oversee all technical aspects of the intervention and remotely access FrontlineSMS as needed.
    - Monitor all incoming and outgoing messages.
    - Provide guidance on research methods.
- *UR Project Coordinator* – SERES researcher (sociologist)
    - Locally monitor FrontlineSMS, consult with the Research co-ordinator and make changes as needed.
    - Review all incoming messages, respond to urgent messages and deal with health/safety risks.
- *Information and Resource Coordinator* – the community clinician (occupational therapist)
    - Responsible for researching and distributing information and resources as per the content development phase.

        - Receive and respond to all incoming messages and questions.
        - If the incoming message was determined to have a health/safety risk, contact the UR Project Coordinators .
    - *One Community Coordinator* – the community leader
        - Liaise between UR coordinator and information and resource coordinator and the community.
        - Communicate necessary information to community participants regarding project participation.
        - Be available for participants if they have questions or concerns about the project.

The project coordination team was trained on the use of FrontlineSMS and other technical aspects of the intervention. See Appendix E for instructions that were left with the coordination team. Once the training was completed, the coordination team collaborated on keyword and message distribution protocols in FrontlineSMS (see Appendix F), development of instruction sheets for the participants (see Appendix G) and setup the SMS messaging hub. The keywords created by the coordination team facilitated information sharing and social interaction. See below for a list of all keywords used in the project and their corresponding actions:

Participant Keywords: keywords used by participants in the project

CUIDADORES (Spanish for CAREGIVERS)

- Whenever this keyword was used, the participant's message was forwarded to all other participants as well as to the coordination team.
- Example of a participant named Juliana sending a message: "cuidadores hola todos, como esta?" (Spanish for CAREGIVERS hello everyone, how are you?). This message would be received like this: "De Juliana: hola todos, como esta?"
- See Figure 3.2 for a diagram of the function of this keyword.

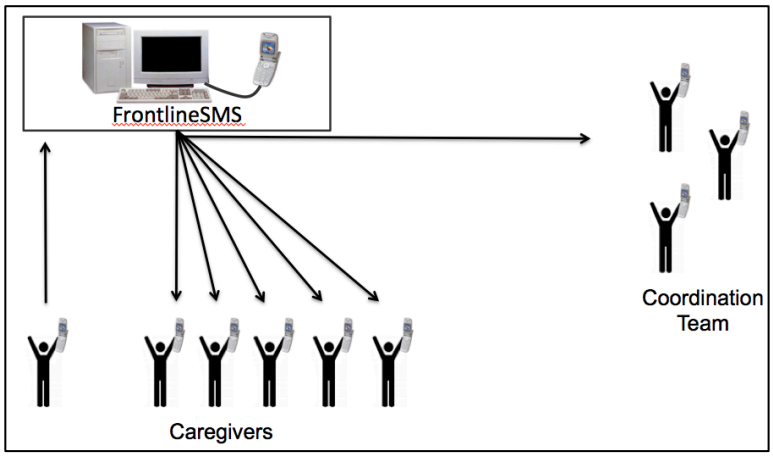


Figure 3.2 – The use of the keyword "CUIDADORES"

PREGUNTA (Spanish for QUESTION)

- Whenever this keyword was used, the participant's question was forwarded only to the coordination team. The participant also received a confirmation message thanking them for their question.

- Example of a participant named Juliana sending a question: “pregunta qué hora es la reunión?”. This question was received by coordinators like this: “Pregunta De Juliana: qué hora es la reunión?”
- See Figure 3.3 for a diagram of the function of this keyword.

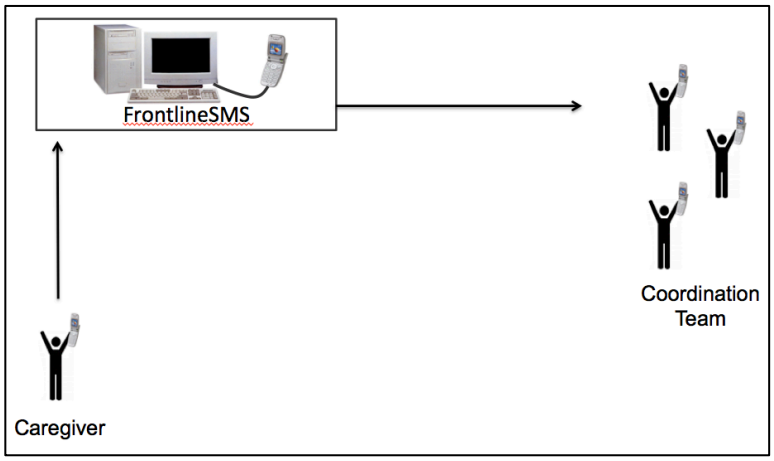


Figure 3.3 – The use of the keyword “PREGUNTA”

CANCELAR

- This keyword removed the participant from the project contact list, withdrawing them from the project.

NO KEYWORD

- Whenever no keyword was used or there was a formatting error (e.g. spelling error), the participant received the following two automatic replies (translated to English):

  Auto-reply one: “Sorry, the keyword is incorrect. Please use the keywords as stated on the instruction sheet. For example “Cuidadores” or “Pregunta”. Thank you.”

Auto-reply two: “Remember to put a space after the keyword to send the message correctly.”

Coordinator Keywords: keywords used by coordinators in the project

INFO

- Whenever the keyword was used, the message was forwarded to all participants as well as to the coordination team. This keyword was used by the information and resource coordinator when sending information messages from her mobile phone.
- See Figure 3.4 for a diagram of the function of this keyword.

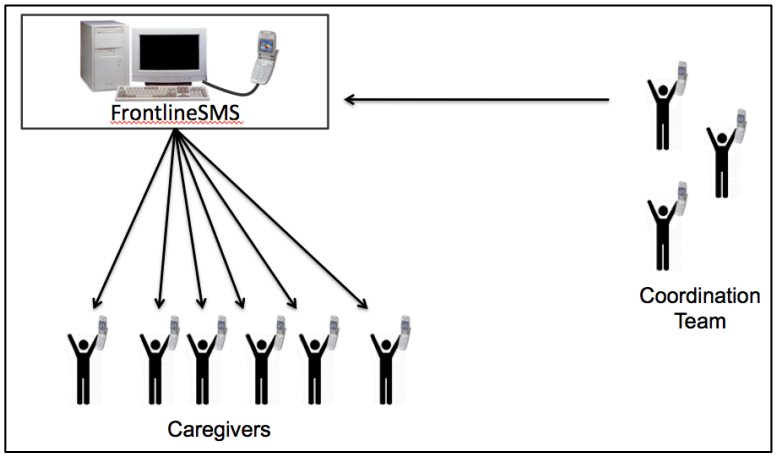


Figure 3.4 – The use of the keyword “INFO”

ENVIAR (followed by an individual’s name) – e.g. ENVIAR JULIANA

- This keyword forwarded a message directly to an individual.

HOLA EL ENLACE

- This keyword was used only to test the system.

- The sender received an automatic reply indicating that the system was fully functional.

The same SMS messaging hub as in the previous technology trials was used with the exception of the use of a local SIM card. A SIM card was purchased through the mobile provider Claro with a text-messaging plan. The coordination team believed it was necessary for the project to cover all participants' costs associated with sending messages during the project. SMS packages were purchased for participants on a monthly basis. Participant SMS packages allowed participants to send up to 30 SMS messages per month during the project. In Colombia, it is free for individuals to receive SMS messages.

Participant recruitment

The community coordinator was involved in a 2010 census of two neighborhoods of El Codito, revealing over 200 PWD. She drew from those PWD identified, along with others in similar surrounding neighborhoods, when recruiting for this project. The community coordinator, who is also a caregiver of a PWD, has developed a trusting relationship with PWD in El Codito. Participants in this initial implementation were caregivers, not PWD. The community leader believed that caregivers would be the most appropriate population for this initial implementation for the following reasons:

- Greater familiarity using mobile phones

- Greater awareness of their isolation and limited access to information
- Desire to be involved in a project focused on disability
- Fewer confounding variables that may limit their participation in the project

We selected a purposeful sample of 8 caregivers (7 mothers, 1 father) who wished to participate in this project. A purposeful sampling technique is one that identifies participants who can provide the best information for the phenomenon being studied (Mayan, 2009). In terms of a focused ethnography, sample size is determined by the number of individuals available who are characteristic of the phenomenon and tends to be small (Morse, 1991). Apart from their desire to participate in the project, participants met the following inclusion criteria:

1. Is a caregiver of a person who has a disability.
2. Their household has at least one mobile phone subscription.
3. The caregiver is able to successfully demonstrate sending a text message on their mobile phone independently (or with minimal assistance from a family member). This was required because the project did not include any training and/or education on the use of mobile phones; rather, it built on existing capabilities.

Participants signed informed consent forms (see Appendix H). A demographic information form was completed (see Appendix I) from August 15-21, 2012.

While recruiting participants, one adult PWD expressed a desire to participate along with her mother. This adult PWD had experience with text messaging, in

fact more experience than her mother. See table 3.2 below for demographic information.

Table 3.2 – General participant information

Caregiver	Caregiver Role	Age	PWD: Disability	PWD: Age
C1	Mother	38	Developmental disability, blind, hyperactivity	9
C2	Mother	54	Developmental disability, cognitive impairment	25
C3	Mother	41	Developmental disability, blind, hydrocephalus	19
C4	Mother	27	Cerebral palsy, cognitive impairment, visual impairment (myopia)	8
C5	Mother	35	Encephalitis, brain damage, upper extremity paralysis	7
C6	Mother	44	Hearing impairment	20
C7	Father	37	Down Syndrome	16
C8	Mother	54	* Cerebral palsy, spastic-quad	32

** This PWD participated along with her mother in the project.*

Baseline Descriptive Data

Measurement of Digital Poverty

ICT prevalence and use was measured using Barrantes' (2007) measurement of digital poverty (MDP) (see Appendix J). This tool identifies and classifies households according to their ICT use. It was adapted in order to gather more detailed information on mobile phone use. Households fall into one of the following categories of digital poverty:

- *Extremely Digitally Poor:* at most, owns a radio and/or a television
- *Digitally Poor:* owns a radio, television and telephone
- *Connected Household:* owns a radio, television, telephone and uses the internet using telecentres
- *Digitally Wealthy:* owns a radio, television, telephone and uses the internet on a computer in their home

When completing the MDP, additional information was gathered specifically regarding mobile phone use. One of the MDP items is: *owns a telephone*, but does not specify any further details. The supplementary information gathered included:

- Uses a fixed-wire phone
- Owns a mobile phone
- Uses mobile for voice calls
- Uses mobile for text messaging
- Uses mobile for email
- Uses mobile for internet
- Other mobile phone uses

Multidimensional Social Exclusion Index

Social exclusion was measured using the Multidimensional Social Exclusion Index (MDSEI) (see Appendix K). This index was developed by the United Nations Development Programme (2011) and assesses the degree that households

are excluded from the three dimensions of social exclusion (economic life, social services and civic and social life). The MDSEI was developed in order to identify social exclusion at the national, municipal and community level, but is not believed to be sensitive enough to identify small changes in exclusion (United Nations Development Programme, 2011). This index was useful in describing the exclusion of the population of participants, but not for evaluating the outcomes at the individual level. Therefore the MDSEI was used strictly as a descriptive measure in this research. The MDSEI is comprised of 24 deprivations (i.e. indicators of exclusion), broken down into the three dimensions of social exclusion. For a household to score as socially excluded on the MDSEI, they must experience a minimum 9 of 24 deprivations.

Self-Perceived Health

Participants answered a self-perceived health question both pre and post-intervention. The pre-intervention question was asked by the UR coordinator during the initial home visit and a UR research assistant asked the post-intervention question over the telephone.

Improved access to health information and improved social interaction are both linked to positive health outcomes. This measure may identify whether the 3-month intervention had an impact on general health. The self-perceived health question was created using the guidelines for Single-Item Health Indicators (McDowell, 2006). Single-item scales are found to be both reliable and valid measurement tools for evaluation of general health. The single-item scale used a

Delighted-Terrible Scale, using the question: *how do you feel about your health?* (McDowell, 2006). Participants responded using the 7-point scale below:

7	*6*	*5*	*4*	*3*	*2*	*1*
Delighted	*Pleased*	*Mostly Satisfied*	*Mixed (equally satisfied & dissatisfied)*	*Mostly Dissatisfied*	*Unhappy*	*Terrible*

Act Phase

Intervention

During the 3-month intervention, participants were provided with access to health information and resources using SMS messages. It was predetermined that participants would receive information messages a minimum of two times per week from the information and resource coordinator. Participants had the opportunity to ask questions about general health, disability, or service delivery. No limitations were set in terms of what questions could be asked.

During the 3-month intervention, a method of social interaction was available using the system. Participants determined what types of messages they wanted to send (e.g., ask each other questions, share their story and interact with one another). The social interaction component was conducted in a similar way to the Zumbido Project in Mexico, where an isolated population was given the

opportunity to interact with one another using text messaging (MobileActive, 2007).

Monthly SMS messages were sent to participants reminding them how to use keywords to ask questions and interact with others. Sample social interaction messages were sent occasionally during the intervention in order to encourage participation. Participants had the opportunity to request technical assistance throughout the intervention.

Observe Phase

Monitoring

Daily monitoring: As the research coordinator, I monitored the SMS hub at the end of each day using a remote desktop called Splashtop Remote Desktop. This was done to ensure proper functioning of the system. FrontlineSMS was configured to forward all incoming messages to the coordination team. However, during the first week of the intervention, the coordination team identified that it was difficult to keep track of the incoming messages from participants on their mobile phones. As a result, when monitoring the system each day, I wrote a summary email to the coordination team. This email listed all incoming and outgoing messages from the particular day as well as any outstanding, unanswered questions. An example of this daily email update can be found in Appendix L.

Bi-weekly monitoring: It was determined prior to the intervention that members of the coordination team would meet via Skype on a bi-weekly basis to discuss the intervention successes, challenges and any necessary changes/iterations.

Mid-Intervention Telephone Follow-up: Approximately six weeks into the intervention, the Information and Resource Coordinator contacted all participants by telephone to gather general feedback on the intervention. Participants were asked particularly about message content, whether message formatting was easy to understand and whether content was relevant. As a result of these telephone conversations, two changes were made to how the messages were sent.

1. Participants were no longer sent multi-part messages. Prior to these telephone conversations, longer messages were broken up into multi-part messages. E.g. "Message 1 of 2: …" followed by "Message 2 of 2: …". This was confusing for many participants.
2. Participants were no longer sent messages about the Convention on the Rights of Persons with Disabilities. Prior to these telephone conversations, participants were sent messages about the convention in order to increase their awareness of the rights of PWD in Colombia. However, participants found this information confusing and did not understand how to apply this information to their lives in El Codito.

Reflect Phase

Data Collection

Placing the greatest emphasis on qualitative methods, the primary data collection method was a focus group. Given that this CBR project used a focused ethnographic method, a focus group is an appropriate and recommended data collection method that helps researchers understand the shared experience of those who participate in projects (Mayan, 2009; Knoblauch, 2005). A focus group also supports the co-creation of knowledge that is critical in CBR (Israel, 1998). Most importantly, this type of data collection has been used successful in the community of El Codito in other instances of community-based research conducted by SERES. They have found that focus groups and group interviews are an effective method to gather information and get a detailed understanding of the experience of this community.

Secondary quantitative data, such as message data, was also gathered to compliment the qualitative data. Baseline data mentioned in the Plan Phase is also considered quantitative data and was considered in the analysis.

Focus Group

The focus group was held on November 15, 2012, following the 3-month intervention. Not all of the participants were able to attend this focus group; in the

two instances where participants could not attend, another family member familiar with the project attended (in one instance a grandmother, in another a father).

The UR project coordinator, community coordinator and information and resource coordinator jointly facilitated the focus group. These facilitators attempted to draw out the richness of participants' experience in the project and ensure that each participant had the opportunity to share (Mayan, 2009). A focus group guide was developed collaboratively with the coordination team and included a set of questions and prompts for facilitators to use (see Appendix M). The most important feature of a focus group is the interaction between participants and the analysis of this interaction (Kitzinger, 1994). The facilitators desire to find a balance between encouraging discussion and being silent and letting the participants interact with each other. The UR provided free transportation to the focus group event. The UofA provided refreshments and snacks for the focus group.

Coordinator Questionnaire

A short questionnaire was sent to members of the coordination team in order to gather their feedback on the project. The questionnaire asked about coordinators' general opinions on the project, the use of SMS, the usability of the technology and sustainability considerations and constraints. The questionnaire can found in appendix N.

Message Data

The evaluation of the project also included data on the messages sent and received during the intervention. Message data included the number of information messages sent to participants, number of social interaction messages from participants and number of health questions from participants to administrators. The analysis of message data included observations on the use of keywords by participants, including any errors or challenges observed during the intervention.

Data Analysis

Transcription & Translation

The focus group was conducted in Spanish, therefore the audio recording had to be initially transcribed and then translated to English. A graduate student at the UR who attended the focus group transcribed the recording. A bilingual (Spanish and English) researcher who is familiar with the cultural nuances of El Codito and has spent over 3 years working closely with the community completed the translation of the transcription. With this process, our hope was that the cultural meaning in the text would be preserved as recommended by Tsai et al. (2008).

During the initial stages of the translation, a verbatim translation method was used. A verbatim translation is a direct translation of the words and phrases from source language to the target language (Regmi et al., 2010). However, I had difficulty understanding the verbatim translation. As a result, two new translation concepts were introduced: *content equivalence* and *comparative equivalence*.

Content Equivalence Translation: when concepts have similar or exact meaning in two different cultures or languages (Regmi et al., 2010). In order to achieve content equivalence, Esposito (2001) suggests that the translator first conceptualize the meaning of the source text, then understand the meaning, and lastly re-express the meaning in the target language.

Comparative Equivalence Translation: when a concept in one language does not have a similar meaning in another language. A comparative equivalence translation (also known as transliteration) is the "process of replacing or complementing the words or meanings of one language with meanings of another as sometimes the exact equivalence or exact meaning might not exist" (Regmi et al., 2010, p. 18). Some meaning may naturally be lost in translation, but transliteration replaces or complements the translation with text that helps create a new meaning that is close to the meaning of the original (Regmi et al., 2010).

Content equivalence and comparative equivalence are both important to preserve the cultural meaning of the original text.

Backwards Translating: To ensure a rigorous translation, backwards translating should be used in order to identify potential bias that was introduced in the translation process (Espisito, 2001). It is recommended that someone other than the translator compare the source language transcript with the translation for

readability and equivalence (Esposito, 2001; Regmi et al., 2010). Therefore, once the focus group translations were completed, they were sent to the UR coordinator, she read the new English translation alongside the original transcript. The UR coordinator reviewed the translation for content and comparative equivalence.

Translation of Coordinator Questionnaires

Coordinator questionnaires were also translated using content equivalence and comparative equivalence translation. These questionnaires were not back translated.

Translation of Message Data

The message data was initially translated using Google Translate then reviewed by the abovementioned translator for necessary revisions only. I was interested in maintaining the grammar and structure of the original SMS messages.

Co-Analysis

Once the translation was completed and validated, a co-analysis occurred in English and in Spanish. I conducted the analysis from the English translation while the information and resource coordinator (in Bogota) conducted the analysis from the Spanish transcript. In alignment with a focused ethnographic methodology, focus group data was analyzed using a content analysis. The

content analysis was completed according to six phases of thematic analysis proposed by Braun & Clarke (2006) in conjunction with the content analysis outlined by Mayan (2009). There is some flexibility within Braun & Clarke's (2006) thematic analysis as the researcher may conduct a manifest analysis (focuses on frequency of words or ideas) or latent analysis (focuses on patterns and relationships within the data) (Braun & Clarke, 2006). While content analysis and thematic analysis are not the same thing, a latent thematic analysis is similar to latent content analysis since it focuses on patterns and meaning rather than frequency of terms (Mayan, 2009). Braun & Clarke's (2006) six-phase thematic analysis was used by Chigona et al. (2009) in their mobile phone research in South Africa.

The first phase begins with familiarizing oneself with the data, which occurs during the transcription process and by reading the transcription without making any notes. The second phase is the generation of initial codes, identifying interesting content and highlighting this content directly in the text. The third phase is searching for categories, carefully reviewing previously coded content and considering the relationship between codes, categories, and overarching themes. The fourth phase is reviewing categories and themes; this involves refining previously identified categories, striving for an accurate representation of the data as a whole. The fifth phase is to define and name categories and themes, identifying the 'story' that each theme tells. The sixth phase is the final analysis and report. After each phase of the analysis, the information and resource

coordinator and I met over Skype to discuss to compare our findings. Details of Braun & Clarke's thematic analysis can be found in Appendix O.

Member Checking: Upon completion of the co-analysis and reaching a consensus on the overarching themes and sub-themes, the results were then reviewed with project participants for final validation. This process is also referred to as member checking. For this step, I travelled to Bogota, Colombia and met with participants in order to discuss the results of the analysis and confirm our findings.

Validation of Content Analysis: Upon completion of the content analysis and validation with project participants, I met with a qualitative research advisor at the Rehabilitation Research Centre in the Faculty of Rehabilitation Medicine. This advisor completed a thorough review of the content analysis, validating the method of analysis.

Quantitative Data

Participant responses to the measurement of digital poverty, multidimensional social exclusion index and self-perceived health question were compared against each other, looking for trends in responses. Message data was tabulated using proportions and percentages.

Trustworthiness of the Data Collection and Analysis

There is considerable debate in the CBR literature about whether rigor is important or if meaningfulness to the community is all that matters (Horowitz, Robinson & Seifer, 2009). In order to address the issue of rigor in this study, I utilized Lincoln & Guba's (1985) trustworthiness instead of rigor, which includes the criteria of: credibility, transferability, dependability and confirmability. The following table 3.3 shows how the above methods and data collection applied to each of these criteria.

Table 3.3 – Methods used for achieving trustworthiness

Trustworthiness Criteria	Method Used to Achieve Criteria
Credibility	• Translation using Content Equivalence & Comparative Equivalence • Methods Triangulation (comparing qualitative and quantitative findings) • Analyst Triangulation (co-analysis in English and Spanish) • Member checking
Transferability	• Thorough description of the participant experience
Dependability	• Careful documentation (including a research journal) • Reflexivity (through self-reflection and keeping a research journal)
Confirmability	• Careful documentation (including a research journal) • Validation of content analysis with a research advisor at the UofA's Rehabilitation Research Centre

Sustainability

Sustainability in this research will be viewed in terms of economic sustainability, social sustainability, and institutional sustainability (Batchelor, Norrish, Scott &

Webb, 2003). Economic sustainability is achieved with the ability to maintain a particular level of expenses over time; social sustainability is achieved through improved social opportunities and participation; and institutional sustainability is achieved when structures and processes can continue their function in the long term (Talyarkhan et al, 2004). Sustainability was addressed and discussed throughout the project phases. The development of a sustainability strategy began in the early stages of the El Enlace. The coordination team met (during the Pre-Intervention) in August 2012 in order to discuss issues regarding economic, social and institutional sustainability, identifying potential considerations and constraints. Sustainability was discussed during a mid-intervention Skype meeting with the coordination team and again at the conclusion of the intervention. During the focus group, participants were asked regarding aspects the sustainability of the El Enlace project. After completing the data collection and analysis, a final sustainability meeting occurred with members of SERES. During this final meeting, a sustainability strategy was discussed, confirming key considerations and constraints.

Ethical Considerations, Bias and Limitations

Ethical Considerations

Prior to undertaking this research, I received ethical approval from the Research Ethics Board at the UofA. Because of the partnership that exists between SERES and the community of El Codito for ongoing CBR, there was no required or

recommended ethics review in Colombia. Informed consent was obtained from each of the research participants. All SMS messages sent and received by El Enlace were stored on a password-protected computer that was located in a locked office at the UR. Participant phone numbers and messages were stored on this password-protected computer. FrontlineSMS was configured not to share any identifiable information in outgoing SMS messages, ensuring the privacy and confidentiality of participants. Participants did give consent to their first names being used in the social interaction messages. For example, when a participant sent a message to others in the group, it would be received like this: "*From Maria: Hello everyone, have a great afternoon*". Participants were reminded of the risks of sharing personal information with other participants in the project.

There was potential for inappropriate use of SMS messaging using El Enlace. The UR coordinator, information and resource coordinator and I monitored and reviewed all messages on a daily basis. If a participant had sent inappropriate content, on the first occurrence they would have been warned, but on the second occurrence the participant would have been blocked from sending additional messages to the group. Depending on the nature of the inappropriate message, the coordination team would determine whether this participant would still be permitted to receive messages as part of the project. If instances of illegal activity were revealed in the form of an SMS message, the coordination team would have reviewed these occurrences and dealt with them according to legal requirements. The coordination team reviewed messages for clinical accuracy and ensured that any inaccurate information was identified and corrected.

Potential Bias'

It was initially thought that I would not be present during the initial data collection, data collection or the validation meeting in order to minimize bias. There may have been a potential for desirability bias. Desirability bias is when participants report an impact (either positive or negative) in a way that is viewed favorably by others, regardless of actual impact. It has been found that if a foreign researcher is present during data collection, participants are twice as likely to report positive outcomes to a technology-based intervention (Dell et al., 2012). Since this project involved a marginalized population in El Codito, there was a chance that participants would falsely report a positive impact in hopes that they would receive additional help in the future. However, since this project used a CBR approach, relying on collaboration and equitable partnerships, it was decided that I would be involved in the data collection and validation. That being said, I was not a part of the mid-intervention telephone call and the final focus group because I was not in Colombia at the time.

Given that numerous Non Government Organizations (NGOs) are present in El Codito, it was possible that other community interventions would have occured at the same time as El Enlace, creating the possibility of a history bias. SERES is very involved in El Codito and was able to identify that no other interventions occurred with this population during the time of the project.

Chapter Four - Results

Quantitative Results

The quantitative results are comprised of the baseline data collection (measurement of digital poverty & multidimensional social exclusion index), ratings of self-perceived health, and a breakdown of the project message data.

Table 4.1 shows the participant measurement of digital poverty (MDP) scores along with additional details of their mobile phone use.

Table 4.1 – Measurement of digital poverty scores and mobile phone use profiles

Caregiver	Level of Digital Poverty	Has fixed-wire phone	Mobile phone use				
			Talking	SMS	Email	Internet	Other
C1	Digitally Wealthy	-	✓	✓	-	-	-
C2	Digitally Wealthy	-	✓	✓	-	-	games
C3	Digitally Wealthy	✓	✓	✓	-	-	radio
C4	Connected Household	-	✓	✓	-	-	-
C5	Connected Household	✓	✓	-	-	-	-
C6	Digitally Poor	-	✓	-	-	-	-
C7	Digitally Wealthy	✓	✓	✓	✓	✓	-
*C8	Connected Household	-	✓	✓	-	-	games, music

** The PWD participated along with this caregiver*

The following table 4.2 shows the participant multidimensional social exclusion index scores.

Table 4.2 – Multidimensional social exclusion index scores

	Multidimensional Social Exclusion Index	
Caregiver	***Score***	***Classification***
C1	14/24	Socially Excluded
C2	12/24	Socially Excluded
C3	12/24	Socially Excluded
C4	15/24	Socially Excluded
C5	11/24	Socially Excluded
C6	10/24	Socially Excluded
C7	3/12	***NOT Socially Excluded***
C8	12/24	Socially Excluded

The following table 4.3 shows the pre and post ratings of self-perceived health (SPH) scores. Self-perceived health was rated on a 7-point scale, 7 indicated feeling the best about their health whereas 1 indicates feeling the worst about their health.

Table 4.3 – Pre and post-intervention ratings of self-perceived health

Caregiver	SPH Pre-Intervention	SPH (of PWD) Pre-Intervention	SPH Post-Intervention	SPH (of PWD) Post-Intervention
C1	3	-	5	-
C2	5	-	-	-
C3	5	-	3	-
C4	2	-	3	-
C5	5	-	-	-
C6	6	-	7	-
C7	6	-	-	-
*C8	6	2	5	5

** This PWD participated along with her mother in the project.*

Message Data

The message data from the project was broken down into the following categories:

1. *Information messages sent to all participants*
2. *Questions from participants* (the use of the 'question' keyword)
3. *Information messages sent to specific participants*
4. *Social Interaction messages from participants* (the use of the 'caregivers' keyword)
5. *Formatting errors (incorrect use of keywords) by participants*

Information messages sent to all participants

During the 3-month intervention, a total of 56 information messages were sent to participants, 45 of these were sent by the information & resource coordinator and 11 were sent by the community coordinator. The majority of messages were sent remotely using the "Info" keyword. An example of an information message is:

> *"Info: Vaccinations for children under 10 will be available tomorrow from 8-12 in the Codito sector"*

Questions from participants

Participants used the "Question" keyword 20 times. Of these 20 occasions, 7 were health-related questions (e.g., one of the participants asked a question about a specific bacterial infection), 6 were expressions of gratitude (e.g. "Thank you very much for the useful information"), 4 were general clarification questions (e.g. "what is the address for the event mentioned in the last message") and 3 messages had no meaningful content (e.g. a blank message).

Information messages sent to specific participants

Over the course of the 3-month intervention, the information & resource coordinator sent 7 messages to specific individuals (as opposed to the whole group). For example, one of the participants, an adult PWD, expressed interest in receiving information about potential employment. Messages were sent to her pertaining to job banks and career fairs. Other messages were sent in response to

questions from participants. For example, when the participant asked about a bacterial infection, the information & resource coordinator sent a response and also directed her to speak with a physician for further information.

Social interaction messages from participants

Participants used the "Caregivers" keyword 30 times. This keyword sent a message to the other participants in the project, as well as to the coordination team. The use of this keyword does not necessarily mean that an interaction where one participant responded to another occurred. There were a combination of greetings, prayers and encouragements shared between participants. The following are some notable messages from participants:

> *"From Astrid: good day, our special people always carry an angel inside and are an example of quality of life and peace as they please our heavenly father"*
>
> *"From Juliana: I want to share with everyone the following prayer I thank our father who blessed us with an angel that requires special attention you have given us an invaluable treasure but on the occasion that we are filled with physical fatigue and we feel suffocated I ask that at this moment we feel you and that we are not alone q q q hold us and share your strength and have your love cover us and heal us give us grace to allow us to do all things that our special treasure requires because of this simple and fragile human being we learn the meaning of pure*

unconditional love and bless us x the mothers of special children and responsible for other tasks at home wife and mother of other children love good night everyone happy dreams"

The following is an example of an interaction where one participant responded to another participant:

"From Olga: good evening I would like to know what is good for a sore throat thank you very much"

In response to Olga's message - *"From Lucia: for sore throat gargle boiled water with lemon juice and salt then melt a little butter with orange juice and a tablespoon of honey take three times a day as hot as you resist is a home remedy is very effective hope you are better soon. If there is a fever go to the medical center"*

After one of the information messages about a community event was sent by the information and resource coordinator, one of the participants sent this message encouraging others to attend the event:

"From Laura: we are enjoying the carnival parades and there is still much more music and still time to get here ok come and my daughter and I are still here and this national army band will be soon for us to enjoy"

Lastly, an advertisement was sent by a participant, sharing her vocational skills with the other participants:

> *"From Theresa: I have a small sewing shop and am looking to make jumpers and will work from my house thanks"*

Formatting Errors

Throughout the 3-month intervention, participants made formatting errors 24 times. These were a combination of misspelled keywords and not leaving a space after the keyword (17 times) or not using a keyword at all (7 times). Each time a keyword error occurred, the participant received an automatic reply to remind them of the correct way to use keywords and their spelling. Every participant who made a keyword error eventually used the keyword correctly and sent the desired message. On one occasion, a participant incorrectly spelled a keyword 4 times before spelling it correctly and sending the message. The following table 4.4 shows the percentage of total messages sent which contained formatting errors in the first and second half of the intervention.

Table 4.4 – Comparison of the percentage of messages with formatting errors in the first half and second half of the intervention

1st half of intervention	*2nd half of intervention*	*Combined*
47.4%	*21.1%*	*34.2%*

Total messages

The following table 4.5 shows the number of messages, as well as formatting errors, sent by each participant.

Table 4.5 – Distribution of messages sent by participants

Caregiver	Question Messages Sent	Social Interaction Messages Sent	Total Sent Messages	*Formatting Errors*
C1	3	1	4	*1*
C2	12	8	20	*3*
C3	2	5	7	*2*
C4	2	2	4	*1*
C5	0	1	1	*1*
C6	0	8	8	*7*
C7	0	0	0	*1*
C8	1	5	6	*8*
TOTAL	***20***	***30***	***50***	***24***

The total number of messages, by the time FrontlineSMS distributed the messages to all participants and administrators as appropriate, was 900 SMS messages.

Qualitative Results

The following categories and themes are based on a content analysis of the focus group transcript, questionnaire given to coordinators and mid-intervention telephone feedback in conjunction with my own experience and observations throughout the project. These categories and themes are not necessarily the views

of any one participant; rather they are general results that emerged from the participants and coordinators as a collective.

My analysis, using a conventional content analysis, of participant experience (research Q1) included categories, sub-categories and an overarching theme. My analysis of the opinions about the technology (research Q2) also used a conventional content analysis, but only for identifying general categories. My analysis pertaining to sustainability (research Q4) used a directed content analysis and only contained categories that were in alignment with Batchelor, Norrish, Scott & Webb's (2003) view of sustainability. The following figure 4.1 shows the categories and overarching theme identified in relation to research question 1 about the experience of participants. The overarching theme of the data is indicated at the top of the figure and groupings of prominent categories are below.

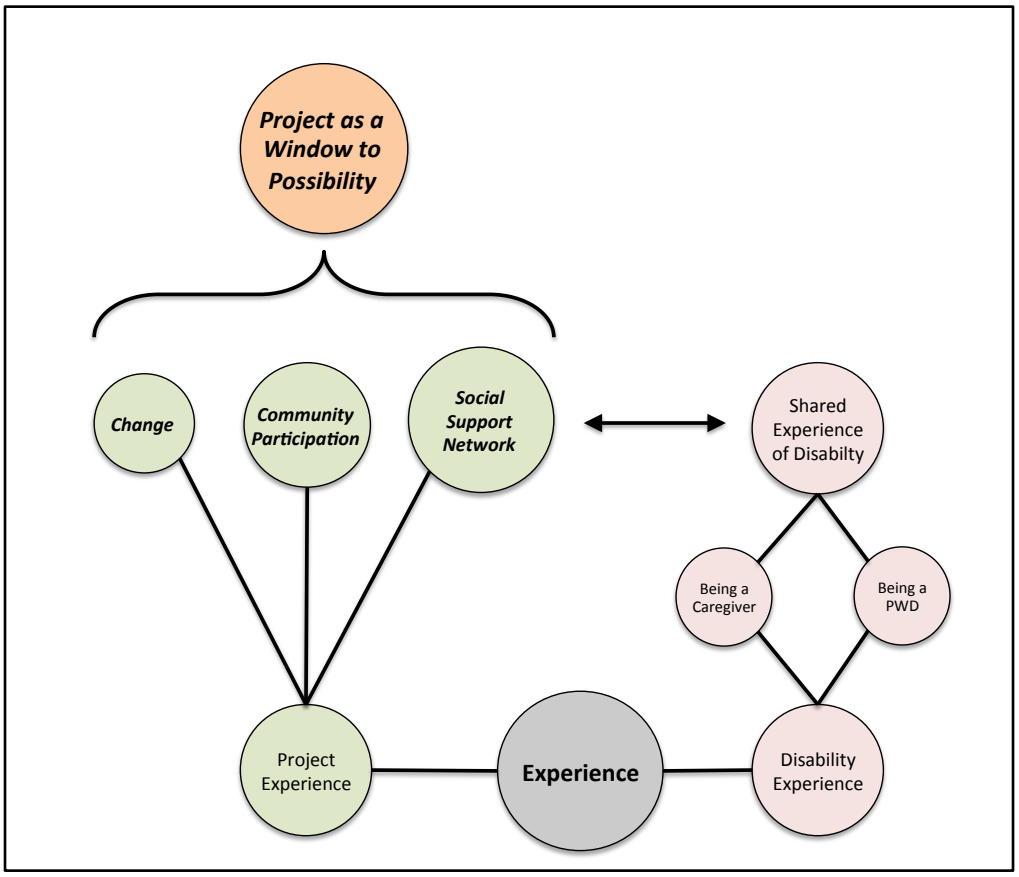


Figure 4.1 – Categories and overarching theme of the experience of participant

Parallel Experiences – Disability Experience and Project Experience

Although not a part of the original research questions, participants revealed a substantial amount of information about their experience with disability. The experience of disability was present throughout the narrative and could not be separated from the experience of the project. Similarly, the experience of the project could not be separated from their experience of disability.

Disability Experience

Shared Experience of Disability

Caregivers appear to have a similar experience of disability as the PWD. Caregivers referred to the experience of their loved ones and identifed with their experience. At one point, a caregiver stated "no one cares about *us, the persons with disability*". Because there appeared to be an alignment between the PWD's experience and the caregiver experience, our research team agreed to refer to this as the shared experience of disability.

The caregiver's experience of disability is one that is lonely and isolating. They described being alone in their homes, without contact with others outside their family.

> *"no one has ever acknowledged that we are always there alone in our homes, without knowing anything or any help…"*
>
> *"no one calls us or says anything to us"*
>
> *"in the neighborhood, I feel like I am alone with my son"*

The child's disabilities also limited caregivers' ability to attend events in the community.

> *"I could not attend (an event) because of my son's mobility…it is very difficult to use the bus with a wheelchair… if there was another form of*

transportation for my son and I, we would go. If not, I will not go…I cannot be calm knowing that he is alone at home."

The disability experience also limits both caregivers' and PWD's ability to be employed and have a vocation.

Caregiver: "I tried to continue working, but I found that my daughter [a person with a disability] demands a lot of time, permanently taking care of her"

PWD: "society sees us like little weird bugs that cannot work or have a decent position"

"[employers] say: "so you have a disability, then you cannot work for us""

The disability experience brings feelings of worthlessness.

"on such few occasions do we feel accepted"

"in society, no one cares about us"

Another characteristic common among participants is that life is "truncated", cut short or not full of experiences.

"I felt sad for my daughter for all the time wasted…"

PWD: *"my life is truncated and also [my mother's] life too"*

This truncated life is mundane, boring and the same routine everyday. Caregivers lack a sense of meaning in their day-to-day activities.

> *"What do you do when everything you have to do is done…one gets bored…every day the same routine."*
>
> *"…the everyday routine of being at home"*

Experience of Being a Caregiver

Caregivers identified some characteristics that specifically related to their roles as caregivers. They expressed that being a caregiver is stressful and challenging, to the point that it is almost too difficult.

> *"one feels tired and not wanting to continue"*
>
> *"sometimes one would like to leave everything behind"*
>
> *"having a child with a disability is very stressful, but life should not be this way, in this confinement"*

Project as a *Window to Possibility*

The primary overarching theme was that the project was a window to possibility. Participants experienced a window to the possibility of a different experience than their previous shared experience of disability. The project was a window that opens away from loneliness, isolation, limited participation and worthlessness. This section will explore the project as a window to three possibilities:

1) Possibility of a social support network
2) Possibility of community participation
3) Possibility that things could change

Possibility of a Social Support Network

The project was a window to the possibility of a social support network. Participants experienced a life that was lonely and isolating, but with the project they were no longer alone in their disability experience. Participants had not had the opportunity to meet others with similar struggles before.

> *"It is like we share a particular experience of our lives with others in the project"*
>
> *"I was able to meet people that share one's own situation"*
>
> *"project was a blessing because wonderful people like you have become closer to my life"*
>
> *"one no longer feels loneliness"*

Connecting with others who have similar struggles in this project also helped build trust.

> *"We have more trust in each other. We know we are sharing the same gift and a common experiences*

Participants were presented with an opportunity to be a support to one another and find strength in their shared experience. Even participants who did not send many

messages felt supported and enjoyed the project. Life for these participants is stressful, but the project gave them strength.

> *"I liked (her) messages, because those messages gave me strength"*
>
> *"It was nice to receive messages from other caregivers, when one is stressed, one receives the messages"*

They found the information messages to be supportive. Participants have not had the opportunity to participate in anything like this project before, so there was a sense of support simply because they were receiving messages.

> *"the messages arrived when one is depressed or worried, but also when one is happy. That's why for me the project was a way of accompaniment that was very important and interesting."*

Being involved as a participant in this project also helped them feel valuable and valued.

> *"I thank God and you all because in my child's ten years of living, this is the first time that we feel that someone cares about us."*
>
> *"We really feel like we are value."*
>
> *"I felt very important"*

Lastly, the project was a window to the possibility of becoming a collective rather than isolated individuals. The next statement exemplifies how a participant transformed from saying 'I' to "WE'.

"in the neighborhood I feel like I am alone with my son because I do not know if there are more children with disabilities. We, the parents, should join together and make a committee, a meeting or something like that. We should take advantage of the spaces we know with our children. In the community hall we can make an event, a meeting and then we can accomplish the integration with other neighbors, because perhaps they can come… and get information about us."

Possibility of Community Participation

This project was a window to the possibility of community participation. Many of the messages sent to participants during the project included information about community events. Five participants mentioned during the focus group that they attended a community event after receiving one of the project text messages. One participant stated that these events were the only events that they attended in the community for the past year. Coordinators did not necessarily believe that occasional attendance of community events suggested community participation, but they did think that the project was a window towards the possibility of community participation.

"(we) had the opportunity to attend various events according to the information provided in the messages"

"my daughter and I were there, listening to the orchestra. We were listening the orchestra made up of children with disabilities playing the

saxophone, the drums, everything was really exciting, the crowd cheering loudly"

"In reality, this was the first time that we have been invited to an activity like this."

"No word of a lie, this year I have only been at this lunch and one community activity organized by the Usaquen mayor…and I found out about that through the text messages."

Attendance at community events also occurred due to receiving messages from other participants. One of the participants, while at a community event, sent out a message to other participants to invite them to come to the event.

"When I was in the event, I sent a text message: come, this is very good…come you still have time."

Even when participants were unable to attend an event, they expressed an interest in participating in the events. Below is a statement from the adult PWD who participated in the project.

"One [event] on sexuality, I really wanted to go but I could not, but I have hopes of going to another…very interesting."

Participants acknowledged that they were not always aware of things that are happening in their community or what they are missing out on. The project increased their awareness of the possibilities for participation that exists in the community.

"...sometimes one is blind to the projects that are being made for people with disabilities"

"Probably there are some unknown spaces or places [for participation]."

Possibility of Change

This project was a window to the possibility that things could change. Their "truncated", boring lives have the potential to change. First, there is the possibility of forming relationships with people outside their family.

"...the important thing is the possibility of interacting with other people outside one's family"

The project highlighted the possibility that there could be new meaning in their daily activities.

"...you help us to have dreams."

The project also changed the adult PWD's perspective on disability. Previously, she believed that disability must be isolating, that there are no other options for someone with a disability. But a change occurred, she now believes that disability does not automatically isolate you. The project helped her see that PWD have the right to participate the community.

"With you, I was able to learn that disability is not a disease that isolates you. I learned that a person with disability has the same rights as a person who does not have a disability."

Technical Observations

The following three technical issues occurred during the project:

1. August 24, 2012 - Computer became unplugged overnight, the battery drained and the system was unresponsive for the day. The UR Coordinator plugged the computer back in at 5pm and restarted FrontlineSMS.
2. September 7-10, 2012 – When I was logged onto the project computer remotely to send an information message, I accidentally sent a duplicate message. In an attempt to cancel the duplicate message, I closed and reopened FrontlineSMS. The program no longer recognized the GSM modem, therefore the system was no longer functional. The issue could have been remedied by removing the GSM modem, closing the program and then reinserting the GSM modem, however there was no one present to do this for me. I attempted to remedy the situation by restarting the computer, but the computer was no longer remotely accessible after the restart. The computer system was off for the weekend, from September 7 to September 10. The UR Coordinator reset the computer on the morning of September 10. Two messages that were sent by participants over the weekend were received at this time. The UR Coordinator sent a message to participants to let them know about the technical difficulties encountered over the weekend.

3. September 11-12, 2012 – Computer became unplugged during the day and the battery died at approximately 6:30pm. I had been remotely logged onto the system at 5:30pm and saw that the battery was low, but there was no one in the UR office at the time that could plug it in. The UR Coordinator plugged in the computer in the morning of September 12 and restarted FrontlineSMS. A sign was taped to the computer and plugin reminding others in the office not to unplug the computer.

Analysis of Technical Considerations

A conventional content analysis was used to identify general categories for opinions of participants and coordinators about using the technology (research question 2). Figure 4.2 shows the categories identified in relation to the technical considerations for the project.

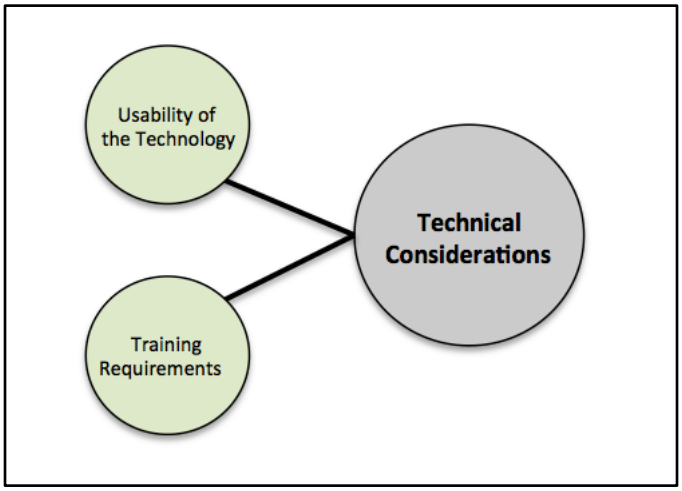


Figure 4.2 – Categories related to technical considerations

Usability of the technology

The majority of participants expressed having some difficulty using the system; in particular they had difficulty sending messages using keywords. During the focus group, participants reflected on times when they attempted to send messages, but received an auto-reply.

> *"One thing that they have written the message properly and it was not. One can make mistakes, especially the lack of space. That happened to me twice"*
>
> *"I receive the response that your message was not accepted because you did not leave a space, so I had to do it again."*
>
> *"Often when I sent a text message, I received a message that said "the message was not accepted because you must first introduce a space."*

Despite their incorrect use of keywords, every participant continued to try and use the keyword and was eventually successful.

> *"Often with I sent a text message, I received a message that said "the message was not accepted because you must use a space"…so I a saw how my other family member sent a message and that's how I learned how to send them."*

Participants did not become discouraged when they had difficulty sending messages. Multiple participants acknowledged that although it was challenging to use keywords, it became easier with practice.

> *"Let's say that is also something that will improve with practice"*

Challenges that participants had using the system may have been due to their lack of familiarity with mobile phones in general. Two of the participants did not have prior experience using text messaging, but had a family member who could help. As a result, at least one of these participants learned how to send text messages during the project.

> *"For my mother, she had never sent text messages. She has learned."*
>
> *"To be honest, I did not know how to send text messages."*

"I barely use the cell phone or in other words I do not know how to use it, particularly for text messaging."

Training requirements

Participants were given an instruction sheet during the initial home visit to refer to when sending messages in the project. During this initial home visit, a member of the coordination team reviewed the instruction sheet and offered them an opportunity to ask questions. Participants indicated that they used this instruction sheet when they were having difficulties.

"I had a little confusion to send messages. The response was that I used an incorrect keyword, so I had to look for the instructions sheet and read again what I wanted to do."

However, many of the participants indicated that they would have benefitted from more training prior to starting the intervention. Coordinators went over the instructions and also practiced sending a text message, but did not practice the use of keywords.

"Perhaps at the beginning you could have done training to send the text message with more skills"

"But what was really missed was the opportunity for us to ask more health questions, but that was because of the lack of training."

"I think a little bit more of explanation would be helpful"

Sustainability

Using a directed content analysis, sustainability considerations and constraints from the focus group transcript and administrator questionnaires were grouped according to Batchelor, Norrish, Scott and Webb's (2003) categories of sustainability: Economic, Institutional, Social and Contextual. Figure 4.3 shows the categories identified for research question 4 about sustainability.

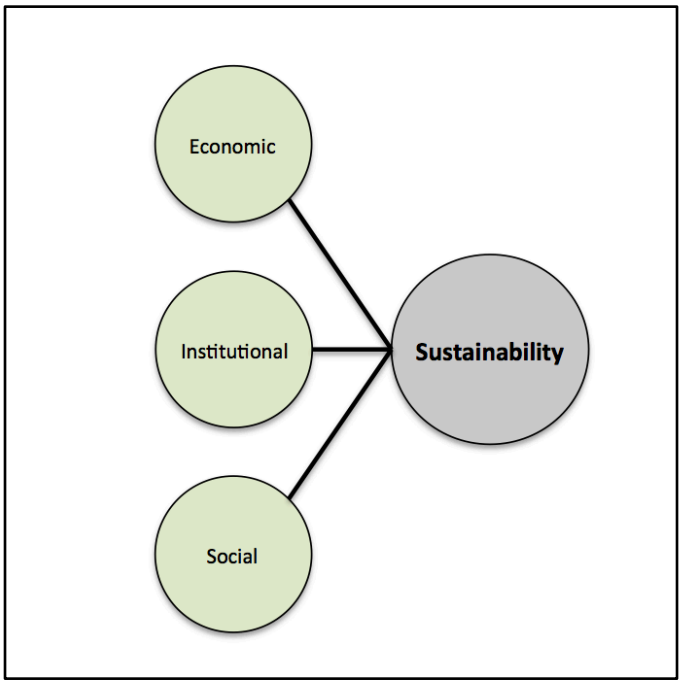


Figure 4.3 – Categories related to sustainability

Economic Sustainability

The primary project expense during the project was the cost of the technology, which included the SMS message cost, the computer and the GSM modem. The SMS message cost consisted of: participant SMS packages and project SMS

packages. Purchasing monthly SMS packages for participants was the most economical method for covering these costs. Project SMS packages were also required since all project messages were sent from an SMS hub located at the UR. When combining the participant and project SMS packages, it cost a total of 184,800 pesos ($100.47 Canadian dollar equivalent) for the project. See table 4.1 for a breakdown of the project SMS message costs.

Table 4.6 – Project SMS message costs

	Number of SMS messages per package/plan	Cost for SMS package	Number of packages per month	Cost per month	Cost for 3-month project
Participant SMS Packages	30	2900 pesos ($1.57 CAD)	8	23,200 pesos ($12.59 CAD)	69,600 pesos ($37.78 CAD)
Project SMS Packages	150	9600 pesos ($5.22 CAD)	4	38,400 pesos ($20.88 CAD)	115,200 pesos ($62.64 CAD)
TOTAL				61,600 pesos ($33.48 CAD)	184,800 pesos ($100.47 CAD)

Another resource required for the project was human resources. The Universidad del Rosario's Social Action Institute (SERES) offered in-kind contributions of human resources and office/meeting space. SERES permitted three paid staff to work on the project during their regular workday. Table 4.2 shows a breakdown of the hours worked by each member of the coordination team to launch the implementation. This breakdown does not include preparation and partnership development activities that occurred prior to August 2012 and does not include any evaluation or analysis activities.

Table 4.7 – Project human resource requirements

Team member	**Pre-implementation hours (Aug 13/14, 2012)**	**Participant recruitment & initial data collection hours (Aug 15-18, 2012)**	**Hours per week – Intervention**	**Total hours - Intervention (14 weeks)**	**TOTAL hours**
Research Coordinator	10	18	6	84	112
UR Project Coordinator	7	12	2	28	47
Information & Resource Coordinator	7	12	6	84	103
Community Coordinator	5	18	2	28	51
TOTAL HOURS	***29***	***60***	***16***	***224***	***313***

Participant comments reinforced that affordability of the text messages is critical. Participants stated that there is a significant financial burden being a caregiver of a PWD, primarily because of loss of income. Participants would only be willing to continue participation in this project if the cost of messages were covered. Despite the benefit associated with participating in the project, participants would not be able to cover the cost of sending messages. The UR coordinator indicated that a long-term project would need to secure funding to cover all message costs.

The team noted that an SMS message system could have potential cost and time savings. The community coordinator identified that SMS was a very efficient method for sharing information with a large group of people. Prior to the project,

if she wanted to share information with these caregivers, she would walk door to door. This was problematic when she had a limited amount of time and was not always able to visit everyone's home.

Institutional Sustainability

Project coordinators expressed their support for the project, but identified a number of institutional considerations that would impact the long-term implementation of the project. The three primary considerations were: economic, rising insecurity in the community and preference for face-to-face interaction.

The UR would be more likely to continue their involvement in the project if there was economic support. It became clear during the project that it required more human resources than simply having one person send a few messages every week. The coordinators identified that a long-term implementation, scaling up the project to a wider population of caregivers and PWD in El Codito, would require one full-time coordinator (or equivalent, e.g. two part-time) who would continue to work with the community coordinator. This full-time coordinator would manage all aspects of the research coordination, participant recruitment/training, message distribution and monitoring. Alternately, coordinators identified that aspects of this project could be used to support other projects, which would have a lower human resource requirement. Even so, the cost of SMS messaging must be covered for the UR to use it as a tool.

Rising insecurity in the community limits the development of a long-term implementation. Since the project was implemented in August 2011 there has been an increase in violent crime in El Codito. On September 7, 2012, the Information & Resource Coordinator was physically assaulted and robbed in El Codito. During this encounter, she was also threatened with a gun as a deterrent to her reporting the incident to the police. This coordinator remained on the coordination team for the intervention, but no longer entered the community. On October 7, 2012, when the UR had a group of professors and students in El Codito to gather data for another study, there was another incident. There was gunfire and a murder in close proximity to the UR professors and students, many of them witnessing the incident. After this incident, in conjunction with an increasing incidence of other violent incidents, the UR determined that no further research activities would be conducted in the community of El Codito. The El Enlace project was able to continue since it could operate without a researcher entering the community. These new restrictions would make it very difficult to scale up the project or have a long-term implementation in El Codito.

The last consideration regarding institutional sustainability is SERES' history of using face-to-face communication. The coordinator indicated that face-to-face interaction "generates trust and nearness" and it is her preferred method for communicating with community members. But, she did state that text messages are a good alternative, particularly when individuals are isolated. Similarly, the Information & Resource Coordinator identified that she would

prefer to see other forms of interaction used simultaneously with SMS such as phone calls and face-to-face meetings.

Social Sustainability

Participants expressed appreciation and fondness for the project, affirming the usefulness and relevance of the project. They stated that the project met a need and provided them an opportunity to participate in their community. Participants were consulted during the project, their feedback lead to iterative changes to the message distribution method. Most importantly, participants enjoyed participating in the project and genuinely felt valued through the project. During the focus group, participants stated they felt like equals with the research team, further contributing to their engagement in the project. Participants expressed a desire to continue with the project, including a desire to play a participatory role if the project were to continue.

Contextual factors in the community remain a primary constraint to sustainability. While the project shared relevant information about community events, the geographic and physical characteristics prevented participants from attending these community events. Many PWD in the project could not leave their homes due to limited accessibility in the community, steep roadways and lack of accessible housing. Accessibility of public transportation is also an issue as it is very difficult for caregivers to load a wheelchair onto an inaccessible and usually overcrowded bus.

Chapter 5 – Discussion

Quantitative Data

Quantitative data was used predominantly as baseline descriptive data, although some interesting findings did emerge in the data.

Measurement of Digital Poverty

The measurement of digital poverty revealed that 50% of participant households were considered digitally wealthy, which means they have a computer and Internet in their home. This proportion is higher than the national prevalence of computers and Internet access, which is 29.9% and 23.4% respectively. The inclusion criteria (i.e. requiring that participants have a mobile phone), in combination with a small sample size, most likely contributed to this difference. Community members who do not have a mobile phone were not able to participate in the research.

It could be said that a project that uses mobile phones may further exclude some of the most socially excluded individuals. According to Barrantes (2007), households that are extremely digitally poor are more likely to be excluded from public utilities such as electricity, running water and sewage. However, our choice to use mobile phones was motivated by the high prevalence of this technology in El Codito.

Of the 8 households, the most common use for the mobile phone was voice calling (8/8) and second most common use was SMS (6/8). Internet was the least common mobile phone use among participant households (1/8). For this group of participants, SMS was an appropriate mobile communication method.

The participant's MDP score did not appear to be associated with the number of messages sent by a participant. The most messages were sent by C2 (20 messages), who was digitally wealthy and the second most messages were sent by C8 (8 meassages), who was digitally poor. The MDP was useful as a descriptive tool only.

Multidimensional Social Exclusion Index (MDSEI)

In using the MDSEI, it was identified that 7 of the 8 participant households scored as socially excluded. Scoring as socially excluded did not appear to be associated with higher levels of digital poverty. In other words, having more ICTs was not associated with having less exclusion. While higher scores do not necessarily indicate greater exclusion, the only participant household that scored as digitally poor had a lower MDSEI score compared to other socially excluded participants.

The one caregiver whose household did not score as socially excluded, did not send any messages during the project. He also reported that the project was not useful to him and he does not feel socially isolated. He is employed (runs his own business), reports having numerous familial supports and his daughter (a 16 year old PWD) attends a community program five days per week. This caregiver

also stated that he and his wife have numerous friends in the community and did not report any limited community participation. Orr (2005) suggests a cautious approach when generalizing social exclusion across a community. Thus, it should not be generalized that all caregivers of PWD in El Codito are socially excluded, as was the case with this caregiver. All other participant households did score as socially excluded. These caregivers have limited financial resources and lack reliable employment, have less familial supports and the PWD is not involved in the community. One of the socially excluded PWD does attend a day program, but his caregiver reports that the day program did not provide enough support and she has difficulty managing her son's behaviors once he is at home.

Although social exclusion exists on a continuum and is not a binary value of "excluded" or "not excluded", this project was most beneficial for participants who scored as socially excluded. All participants who scored as socially excluded expressed some benefit from the project. For this group of participants, scoring as socially excluded was a good indicator that participants would benefit from this type of project. The MDSEI could be used as a screening tool for future projects.

Self-Perceived Health

It was initially proposed that self perceived health would be measured using a single-item scale pre and post-intervention (to address research question 3). Unfortunately, only 6/9 participants (including PWD participating with C8) were asked the question post-intervention and 2/9 participants were not asked the pre-

intervention question in a standardized way (e.g. the response options were not read to participant). In addition, the self perceived health question was based on North American literature and may not have had the same meaning in the Colombian context. Litwin (2006) found that there is a difference between self-perceived health in Western versus non-Western societies. The concept of general health in Western societies, which encompasses ideas of wellness and well being, may not be the same in the context of El Codito. The majority of participants (7/9) reported being "pleased" or "mostly satisfied" with their health, yet reported high levels of stress, one reported having recent mental breakdowns and another requested assistance in accessing psychological services. For these reasons, the self-perceived health question was not analyzed and not further reported here.

Message Data

Over the course of the 3-month intervention, 34.2% of messages sent by participants had formatting errors (26 of 76). This percentage is reflective of participant opinion in the focus group that the system was challenging to use. But, more importantly, none of the participants indicated that it was *too* difficult use. All participants, despite making errors using keywords, were able to learn and eventually had success using keywords. Participants did not become discouraged; rather they persevered despite making formatting errors. These findings regarding formatting errors are similar to what Danis et al. (2010) found in their use of SMS for health education in Uganda. In her project (an SMS quiz that required the use

of keywords sent to 10,000 untrained Ugandan participants) Danis et al. (2010) found that participants made formatting errors 36.4% of the time. She also found that formatting errors decreased with practice. Our study had similar results as 47.4% of the messages in the first half of the study had formatting errors, whereas there were only 21.1% in the last half of the study. Participants' accuracy using keywords improved over the course of the intervention.

Initially we thought that information shared during the project would focus on health information and service delivery. However, the project and system was not intended to be tightly controlled, participants and coordinators were free to use the system as they chose. Hence, not all of the information shared during the project was related to health information or health service delivery, with much of the information being about community events or an activity of some kind. In a way, some of the information shared in the project was intended to reduce social isolation. The information and resource coordinator, having an understanding of the context, sought to share information that brought participants out of their homes.

The social interaction component did not have many instances of interaction, yet participants felt supported by others when they sent messages. While I had initially thought that participants would have interactive conversations, this did not occur. Possible reason could be: participants' limited experience using the technology or participants do not view SMS as a conversational tool. This was not further explored in this research. Participants did however use the social interaction keyword, but primarily for broadcasting

messages to the group. The one interaction that occurred in the project, pertaining to a sore throat remedy, was also an information exchange. This demonstrated the potential for a system like this to be used a tool for exchange of indigenous information and knowledge.

Qualitative Results

The Experience of Caregivers (Research Question 1)

Disability Experience

The category of shared experience of disability (between caregivers and PWD) was not expected. It was initially believed by the project partners that caregivers would have similar experiences of isolation and reduced information access, but it was surprising to learn the extent to which caregivers experience parallels the PWD. Much of the social exclusion experienced by PWD and their caregivers can be attributed to their shared experience of disability. An aspect of the disability experience that was not discussed by the project partners prior to this study is the stigma, discrimination and feelings of worthlessness for both caregivers and PWD.

Project as a *Window to Possibility*

The theme "project as a window to possibility" came from one of the project coordinator's final questionnaires where she said "window to the world". In this quote, I interpreted 'world' to mean 'new horizons', or a 'new point of view'. The window metaphor can be viewed from two perspectives, either as opening away from something negative (e.g. loneliness, isolation, etc) or opening towards something positive (e.g. social support, community participation, etc). The analysis revealed a strong emphasis towards new perspectives rather than old perspectives, therefore we elected to take the positive approach and the project as a window to possibility. Although there was no indication that the project would be able to continue beyond the 3-month implementation, there was a sense of optimism in the data.

Possibility of a Social Support Network

The term social support network was identified early in the content analysis. It seemed to me that participants felt supported through the network that developed in this project. The information and resource coordinator validated the use of this term and eventually used it as a primary category. However we were not considering the theoretical understanding of these terms at the time of analysis.

The term social support network is a combination of two concepts in the literature: social support and social network. Social support is an important function of social relationships that can be broken down into four types of

supportive behaviors: emotional support (empathy, trust and caring), instrumental support (practical aid, service and assistance), informational support (advice, suggestion and information) and appraisal support (constructive feedback and affirmation) (Heaney & Israel, 2002). In this project, there was basic evidence of all four aspects of social support:

- Emotional support: participants felt empathy from others that had a shared experience, they felt cared for during the project and developed trust with one another.
- Instrumental support: practical aid and assistance was received from project coordinators.
- Informational support: advice was received in a limited way from other participants, and project coordinators provided additional advice and information.
- Appraisal support: on multiple occasions participants reported being encouraged and affirmed during the project, however instances of feedback are unknown.

Social networks are connections between people that may or may not involve social support (Heaney & Israel, 2002). One of the functions of social networks is to encourage the acquisition of social capital (Woolcock & Narayan, 2000; Heaney & Israel, 2002). Social capital is the view that family, friends and other associates make up an important asset, an asset that can be used by individuals when desired or when necessary (Woolcock & Narayan, 2000).

Social networks, in combination with social support, are likely to result in social cohesion, which is the social solidarity that results from development of shared values, common bonds and sense of community (Galabuzi & Teelucksingh, 2010). With social cohesion comes a sense of belonging (Stillman et al., 2009). In this project, there was some initial evidence of social cohesion in the group, primarily in the transformation from 'I' to 'WE' statements. Participants had a shared experience with people in similar situations, developing a sense of belonging.

Social capital along with social cohesion is believed to contribute to collective action, reduced marginalization and ultimately reduce social exclusion experienced by a population (Galabuzi & Teelucksingh, 2010). Through this project participants developed an interconnected social network, although it is not clear to what extent social capital was acquired or social cohesion occurred. However, a longer-term implementation of a social network is likely to result in increased social capital and social cohesion.

Given the above discussion, a social support network, as the term was used here, is a group of interconnected individuals that acquires social capital, demonstrates social cohesion and in turn demonstrates supportive behaviors. A social support network has the potential to decrease social exclusion. Continuation of this project, having the potential to develop into a social support network, also has the potential to reduce social exclusion.

Possibility of Community Participation

Community participation is the involvement of people in activities that serve the needs of the community (Wallerstein & Duran, 2006) or contributes to change in the community (Harvey, Baghri & Reed, 2002). Furthermore, community participation requires citizens' active involvement in seeking solutions (Zakus & Lysack, 1998). Community participation is not simply the attendance of events in the community. Thus, it cannot be said that community participation occurred in this research project.

There were two factors that contribute to the possibility of community participation of these participants in the future: 1) participants' increased community involvement and 2) development of social cohesion among participants. Participants became more involved in the community during the project, both through attending events in the community and through their involvement in the project itself. For some participants, this project was the first time they had ever been involved in a community activity. Through this involvement, participants became aware of possibilities they never knew existed. They became aware that there were places outside of their home where they could become involved. According to Zakus and Lysack (1998), involvement in community can be an initial step that leads toward community participation.

It is also through this involvement in the project and in community events that participants began to develop social cohesion. Participants built relationships with people who have a similar experience, beginning to form a common bond. Rolfe (2006) stated that social cohesion contributes to a group's sense of

community and ultimately to community participation. Social cohesion can also help marginalized populations overcome hesitancy and resistance to participation (Kronenberg, Algado & Pollard, 2005). Participants demonstrated an increased awareness of the exclusion experienced by PWD and caregivers, and the value of raising community awareness. This project created an environment that sparked the possibility of future community participation.

Possibility of Change

The possibility that things can change, is an optimistic possibility that is interconnected with the previous two possibilities. It reflects a potential transformation from the participants' previous disability experience towards something new. Stillman et al. (2009) identifies that social exclusion often results in hopelessness. Yet with optimism there is a potential for a renewed sense of purpose, motivation and reduced feelings of exclusion (Stillman et al., 2009). This optimism was most clearly represented by the focus group quote: "you help us to have dreams". Participating in the project helped participants to see beyond their exclusion. The possibility of change brings a new optimism that can help motivate participants towards having a participatory role in the improvement of their situation.

Project Possibilities & Social Exclusion

The project demonstrated potential value for the socially excluded participants, however not for the one participant who did not score as socially excluded, C7. This participant stated that the information might have been useful "a couple years before" when he was less connected with community programs. If the project is less useful for those who are less excluded, then perhaps projects like this should be considered most useful in the initial stages of addressing social exclusion.

Alternately, the perceived lack of usefulness of the project for C7 may be more of a reflection on the type of information than on the degree of social exclusion. This participant may have information and/or communication needs, but needs that are different from the socially excluded participants in this study. Perhaps the project would have been more useful to him if he was in a project with others who did not score as socially excluded or with other parents from his daughter's day program. Then, rather than receiving basic information, he could receive information related to the programs in which he and his daughter participate. In this case, rather than leading to basic community participation, it would enhance his existing participation.

To be consistent with this finding, projects that include participants who score as socially excluded should focus on basic information sharing and seek to encourage introductory levels of community participation, whereas projects for those who do not score as socially excluded should focus on enhancing existing programs. In projects where individuals are socially excluded, the SMS messages

may be the primary project component, whereas when individuals are less excluded, then the SMS messages may play a more supplementary role.

Opinions About Using the Technology (Research Question 2)

Technical Considerations, Usability & Training

Technical issues that occurred during the project were very minor and easily resolved. The combination of remote and on-site monitoring worked well as all issues were promptly identified and resolved. That being said, having the same (local) person doing all monitoring would simplify and expedite the resolution of technical issues. At the launch of this project, local coordinators said they would not be comfortable managing the technical aspects of the project, which necessitated my remote monitoring and technical oversight. However, after being exposed to the system for the 3-month intervention, coordinators have increased their comfort level with the software. Therefore, local coordinators could now manage the technical aspects of the project on their own with minimal training.

The ideal situation would be to identify a tech steward in the community. A tech steward is a community member with some technical ability who can be mentored by a project team to lead the technical component of the project (Wenger, White & Smith, 2009). The involvement of tech stewards also ensures the technology continues to meet the context specific needs over time (Wenger,

White & Smith, 2009). For this project, there were no individuals identified that could act as tech stewards. It was noted that numerous Internet cafes exist in the community, often run by young males. These individuals could be approached to act as tech stewards in the future if the opportunity arises.

Participants all stated that they would have liked to receive more training prior to the intervention. They found it particularly difficult to use the keywords even if they were familiar with using SMS. Participants did not identify difficulty sending SMS, rather only difficulty using keywords. Therefore, using keywords with SMS was not an equivalent level of difficulty as sending SMS. However, despite making formatting errors, every participant continued to try to use the keyword and was eventually successful. This perseverance was clearly represented in participants' improvement over the course of the intervention. Participants noted that if they had received more training they would have taken more advantage of the project, for example with more training they would have used the "Question" keyword more. It is not known whether additional training on the use of keywords at the beginning of the project would have increased participation in the project. Perhaps extensive training was not necessary, but some basic practice at sending keywords during the initial home visit is recommended.

Considerations and Constraints Regarding sustainability (Research Question 4)

Sustainability

The considerations and constraints identified in the analysis of the project could be used to help develop a sustainability strategy for a long-term implementation of the project. There are significant hurdles in the area of economic and institutional sustainability, and the two are inextricably linked. In order for the UR (and SERES) to continue or scale up the project, there must be funding. Without economic sustainability there will be no institutional sustainability. If there was funding that would support the human resource and message costs, SERES would be willing to continue their involvement. The participants desire to continue with the project, yet are only willing to do so if their message costs are covered. Presently, there is no funding available to support either the human resource costs or the cost of sending messages.

Social sustainability was a relative strength of the project. A CBR approach, addressing exclusions experienced by PWD and their families, placed social sustainability at the forefront. This group of caregivers expressed a desire to continue meeting together after the project concluded. As a result a spin-off project was developed by SERES (personal communication, May 7, 2013) that will further the development of a social support network and encourage community participation. So, although an SMS-based project is not currently sustainable, the project led to something that *was* sustainable.

Contextual factors in the community of El Codito, however, remain a primary constraint to overall sustainability. Two contextual factors were at the forefront throughout the project and its analysis: insecurity and inaccessibility. Insecurity in the community placed the project in jeopardy during the early stages of the intervention, even placing one of the coordinators in danger. Insecurity limits institutional sustainability as the UR has mandated that no further research activities can be conducted in the community of El Codito. Inaccessibility of the physical terrain prevented at least one caregiver from attending community events that were shared during the project. Insecurity and inaccessibility are contextual realities in the community of El Codito, and likely a reality in other similar communities in Bogota. However, in spite of these contextual factors, the use of SMS in this project made it possible to reach participants who are isolated by insecurity and inaccessibility.

Economic and contextual factors in under-resourced communities like El Codito make sustainability a challenge. Other similar projects, such as those conducted by the SHM Foundation (2012), were unable to continue because of challenges with economic sustainability. However, despite our project's inability to sustain an ongoing project using SMS messaging, a spin-off project will continue to build upon the foundation set by this research. So, El Enlace, focusing on the technology as a tool, made progress towards a sustainable reduction in social exclusion.

Community-Based Research

The community coordinator's involvement was critical to the project. Members of SERES frequently stated that while the project was titled El Enlace (Spanish for The Link), it was the community coordinator that truly was El Enlace. She was an important person in the community for issues regarding disability. People with disabilities and their families in the community outside the project participants seek her out when they have questions or need help. She was our initial link to the project participants. She became even more critical to the project once the UR could no longer enter the community. The community coordinator was a visible face for the project in the community. At the end of the project, she coordinated the final meeting and focus group, including the transportation of participants to the UR. The project could not have occurred without her involvement. Using a CBR approach, the community coordinator was not a volunteer, but an equal member of the research team. She was employed as a UR researcher; this project was one of her formal research activities. Consistent with the literature (Kelly, Mock & Tandon, 2001; Minkler, 2004), the involvement of a community liaison in this project improved community partnerships and the engagement of community in the research process. After the project, participants were eager to continue with ongoing activities with the UR. This is in agreement with Minkler (2004) and her assertion that a community-based approach can improve retention of participants in projects and lead to ongoing community involvement.

A CBR approach also helped identify participant's information needs during the project rather than relying solely on the needs identified prior to the

project. The information and resource coordinator and the community coordinator, as they became more aware of the participant's needs, adapted the information being shared. Rather than focusing strictly on health information, they began sharing more information that encouraged community involvement (e.g., community events).

Reflections as an Outside Researcher

I have reflected on my experience as a foreign, outside researcher in this project. I am a North American, educated, middle-class, white male. I believe that it is important to acknowledge my privilege and the role it played in the project. In the fall semester 2012 I attended a CBR class at the UofA (INT-D 500: Introduction to Community-Based Research and Evaluation). During one of the classes, our instructor led us in an activity based on Samuels' (2007) and McIntosh's (1989) work on privilege. Each member of the class was asked to stand in circle while the instructor asked us questions related to privilege in the literature, each individual taking one step into the circle for each positive response. At the end of the exercise I found myself at the center of the circle, in front of most of my classmates. The exercise demonstrated our relative self-perceived privilege in comparison to our peers. I felt quite humbled by the exercise. I am still not sure how to fully deconstruct my privilege, but I believe that the simple act of self-reflection was a valuable starting point.

One specific example of seeing the implications of my privilege comes to mind from this project in El Codito. I recall one initial home visit with a research participant in August 2012. When I walked into her home, I extended my hand to her, attempted to make eye contact and greeted her in my pre-rehearsed, broken Spanish. This woman extended her arm, limp wristed, only allowing me to grasp her wrist. She held her head down and did not make eye contact with me. For the next 2 hours, we sat around her kitchen table, sipping a cup of coffee and talking about her life and about having a child who has a disability. At the end of the meeting, she grasped my hand and looked me in the eyes. According to a Colombian project partner, this is a common response for a community member to give to white North Americans. White North Americans, particularly males, are perceived to be important, powerful and superior. But, by the end of my meeting with this participant, she felt comfortable enough to grasp my hand and make eye contact. This experience has stayed with me throughout the project and is something that I considered in each of my interactions.

There were probably drawbacks and strengths to my involvement in the project. The greatest potential drawback is the potential desirability bias. It seemed as though some of the enthusiasm and gratitude from participants was because I, a Canadian researcher, showed interest in their lives. Frequently, participants acknowledged the importance of having an outside researcher involved in their lives. One participant stated “we live here, but there are people like [Tim] that have some interest in our situation.” While another participant, referring to me, stated “one feels flattered or cared for by people we do not

know." On the other hand, there are potential strengths to having an outside researcher. I was able to bring outside technical expertise and develop local capacity for using SMS in a community-based project. My privilege was used in a positive way, reinforcing participants' value. The literature indicates that a balance between inside and outside researchers in CBR can have a positive impact (Wright et al., 2011). The insider brings contextual awareness, personal experience with the identified issues and knowledge of local systems and structures, whereas the outsider brings scientific knowledge, methodological and technical experience (Minkler, 2004; Story, Hinton & Wyatt, 2010; Caine, Salomons & Simmons, 2007). Both the insider and outsider share a valuable role in the research process and should not be minimized.

Limitations

In addition to the limitations of this study included in previous sections, I would like to draw attention to one of the procedural challenges in this research. Given that this research was completed in Colombia, in Spanish, I relied heavily on the work of my Colombian research partners who provided support for me throughout the research process. There is a risk that data was not collected as I intended. For example, after the focus group was completed, I realized that not all of the questions in the focus group guide were asked, particularly a question about participants opinions on using mobile phones for this project. Participants expressed gratitude and appreciation for the project, they stated that they enjoyed

the project and found it useful, but their opinions on using mobile phones and SMS was not fully explored. Had I been present at the focus group or had easier access to participants, I would have been able to more adequately address my second research question.

Implications for the Field

The project was not simply a window to possibility for participants; it opened a window to possibility for researchers and practitioners. This research has implications across a broad range of practice areas: ICT4D, community-based research, rehabilitation and occupational therapy. This is the first known ICT4D project using mobile phones to address the needs of PWD and their families.

SMS was a useful tool for sharing information and connecting isolated, marginalized or excluded populations, particularly when using a CBR approach with development objectives clearly at the center. Using SMS for information sharing and communication in a CBR project helped develop social cohesion and social capital with socially excluded populations. This research found that SMS could be used during the initial stages of addressing the exclusion of PWD and caregivers in an under-resourced context. This type of project would be useful for practitioners and organizations that are interested in laying a foundation for a social support network and development of community participation.

Community-based research is a useful research approach that has not been widely applied to research in rehabilitation or occupational therapy. CBR was

used successfully in this project and could be considered in other rehabilitation project, particularly when working in vulnerable communities. Pertaining specifically to occupational therapy, low cost technology such as mobile phones and SMS may be useful tools for achieving occupational justice, particularly in combination with a CBR approach.

Recommendations for Future Research

Future research could include projects that use SMS or other low cost technology or social media to reduce social exclusion of PWD in higher-income countries in comparison to its use in lower income countries. This could potentially involve rural, isolated communities in higher-income countries. Future comparative research could also be completed in other lower-income countries, comparing the findings and further explore the development of social support, social cohesion and social capital. Future research could also explore the role that stigma plays in social exclusion. It is also recommended that future research have PWD as participants rather than caregivers and consider accessibility of the mobile device as part of the research methodology. It would be interesting for future research to compare whether in-depth training would result in greater project participation.

Conclusion

This community-based research project, based on a partnership between the UofA, UR and the community of El Codito, used SMS as a tool to share information and reduce isolation for 8 caregivers of PWD in the community of El Codito. These caregivers, where seven out of eight were considered socially excluded, participated in a 3-month intervention where they received information and had the opportunity to communicate with each other using SMS. The project was evaluated using primarily qualitative, but also quantitative methods. The evaluation explored: 1) the shared experience of caregivers in the project, 2) their opinions and use of mobile phones in the project and 3) the considerations and constraints associated with the sustainability of the project.

Caregivers experienced the project as a window to possibility; the possibility of a social support network, the possibility of community participation and the possibility of change for this socially excluded population. Caregivers appreciated, enjoyed and found the project to be useful. While they had some challenges using keywords in the project, they were able to learn how to use the system and successfully send messages during the project. Despite having successful outcomes during the project, significant considerations and constraints were identified that limit the ongoing or scaled-up implementation of the project. Although SMS is a low cost technology, a long-term funding source must be found in order to cover the message and coordination costs. Contextual factors of community insecurity and inaccessibility also presented unique challenges for this project. However, the proliferation of mobile phones in Colombia, and many

under resourced communities, provides a feasible method for reducing the exclusion of PWD and caregivers, even in insecure and inaccessible locations.

Bibliography

Andersson, A., Grönlund, Å., & Wicander, G. (2012). Development as freedom - how the Capabilility Approach can be used in ICT4D research and practice. *Information Technology for Development, 18* (1), 1-4.

Bank, W. (1998). World Development Report 1998/99. http://www.worldbank.org/wdr/wdr98/index.htm

Barja, G., & Gigler, B. S. (2007). The concept of information poverty and how to measure it in the Latin American context. *DIGITAL POVERTY*, 11.

Barrantes, R. (2007). Analysis of ICT demand: What is digital poverty and how to measure it? *DIGITAL POVERTY*, 29.

Batchelor, S., Norrish, P., Scott, N., & Webb, M. (2003). Sustainable ICT case histories. *Reading: Gamos Ltd.. Retrieved June, 24*, 2010.

Béland, D. (2007). The social exclusion discourse: ideas and policy change. *Policy & Politics, 35*(1), 123-139.

Bellinger, G., Castro, D., & Mills, A. (2004). Data, information, knowledge, and wisdom. http://courseweb.lis.illinois.edu/~katewill/spring2011-502/502 and other readings/bellinger on ackoff data info know wisdom.pdf

Blanco, A. G. (2012). Discourses of land allocation and natural property rights: Land entrepreneurialism and informal settlements in Bogotá, Colombia. *Planning Theory, 11*(1), 20-43.

Braidotti, R. (2011). *Nomadic Theory: The Portable Rosi Braidotti*: Columbia University Press.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative*

research in psychology, 3(2), 77-101.

Caine, K. J., Salomons, M. J., & Simmons, D. (2007). Partnerships for social change in the Canadian North: Revisiting the insider–outsider dialectic. *Development and Change, 38*(3), 447-471.

Cecchini, S., & Scott, C. (2003). Can Information and Communications Technology Applications Contribute to Poverty Reduction? Lessons from Rural India. http://www.developmentgateway.org/download/181634/cecchini_scott_ICT.pdf

Chapman, R., Slaymaker, T., & Young, J. (2003). *Livelihoods approaches to information and communication in support of rural poverty elimination and food security*: Overseas Development Institute London.

Chigona, W., Beukes, D., Vally, J., & Tanner, M. (2009). Can mobile internet help alleviate social exclusion in developing countries? *The Electronic Journal of Information Systems in Developing Countries, 36*.

Cole-Lewis, H., & Kershaw, T. (2010). Text messaging as a tool for behavior change in disease prevention and management. *Epidemiologic reviews, 32*(1), 56-69.

Cook, A. M. (2009). Using the Web and ICT to Enable Persons with Disabilities. *Biomedical Engineering Systems and Technologies*, 3-18.

Danis, C. M., Ellis, J. B., Kellogg, W. A., van Beijma, H., Hoefman, B., Daniels, S. D., & Loggers, J.-W. (2010). *Mobile phones for health education in the developing world: SMS as a user interface*.

Dearden, A., Light, A., Kanagwa, B., & Rai, I. (2010). *Getting from research to practice in M4D.* Paper presented at the 2nd International Conference on M4D, Kampala, Uganda.

Déglise, C., Suggs, L. S., & Odermatt, P. (2012). Short message service (SMS) applications for disease prevention in developing countries. *Journal of Medical Internet Research, 14*(1), e3.

Dell, N., Vaidyanathan, V., Medhi, I., Cutrell, E., & Thies, W. (2012, May 5-10,). *"Yours is Better!" Participant Response Bias in HCI.* Paper presented at the ACM SIGCHI Conference on Human Factors in Computing Systems, Austin, Texas.

Donner, J. (2010). Framing M4D: The Utility of Continuity and the Dual Heritage of" Mobiles and Development". *The Electronic Journal on Information Systems in Developing Countries, 44*(3), 1-16.

Donner, J., Verclas, K., & Toyama, K. (2008). *Reflections on MobileActive 2008 and the M4D Landscape.* Paper presented at the First International Conference on M4D, Karlstad, Sweden.

Ellahi, A., & Mushtaq, R. (2011). Probing Factors Affecting Knowledge Sharing Behaviour of Pakistani Bloggers. *The Electronic Journal of Information Systems in Developing Countries, 45*(0).

Esposito, N. (2001). From meaning to meaning: the influence of translation techniques on non-English focus group research. *Qualitative Health Research, 11*(4), 568-579.

Family Health International (2009). Mobile Phone Interventions for Reproductive Health (m4RH): Testing the Feasibility of Text Messaging to Improve Family Planning. http://www.fhi360.org/en/Research/Projects/Progress/GTL/mobile_tech.htm

Finlay, L. (2002). "Outing" the researcher: The provenance, process, and practice of reflexivity. *Qualitative Health Research, 12*(4), 531-545.

FrontlineSMS. http://www.frontlinesms.com

Furuholt, B., & Matotay, E. (2011). The Developmental Contribution from Mobile Phones Across the Agricultural Value Chain in Rural Africa. *The Electronic Journal of Information Systems in Developing Countries, 48*.

Galabuzi, G. E., & Teelucksingh, C. (2010). *Social cohesion, social exclusion, social capital*: Region of Peel, Human Services.

Galperin, H., & Mariscal, J. (2007). *Digital Poverty: Latin American and Caribbean Perspectives*: IDRC.

Granholm, E., Ben-Zeev, D., Link, P. C., Bradshaw, K. R., & Holden, J. L. (2012). Mobile Assessment and Treatment for Schizophrenia (MATS): a pilot trial of an interactive text-messaging intervention for medication adherence, socialization, and auditory hallucinations. *Schizophrenia bulletin, 38*(3), 414-425.

Grönlund, Å., Andersson, A., & Hatakka, M. (2008). *Mobile technologies for development–a comparative study on challenges.* Paper presented at the Sig GlobDev Workshop, pre-conference ICIS.

Guo, B., Bricout, J. C., & Huang, J. (2005). A common open space or a digital divide? A social model perspective on the online disability community in China. *Disability & society, 20*(1), 49-66.

Hammersley, M., & Atkinson, P. (2007). Ethnography: Principles in practice: London: Routledge.

Heaney, C. A., & Israel, B. A. (2002). Social networks and social support. *Health behavior and health education: Theory, research, and practice, 3*, 185-209.

Hearn, G. N., & Foth, M. (2005). Action research in the design of new media and ICT systems. *Topical issues in communications and media research*, 79-94.

Heeks, R. (2008). Mobiles for Impoverishment. *ICTs for Development Blog, 22*.

Hills, M., & Mullett, J. (2000). *Community-Based Research: Creating evidence-based practice for health and social change.* Paper presented at the Qualitative Evidence-based Practice Conference, Coventry.

International Telecommunications Union (2010). ICT Facts and Figures 2010. http://www.itu.int/ITU-D/ict/facts/2011/material/ICTFactsFigures2010.pdf

International Telecommunications Union (2011). ICT Facts and Figures 2011. http://www.itu.int/ITU-D/ict/facts/2011/material/ICTFactsFigures2011.pdf

International Telecommunications Union (2012). Core indicators on access to and use of ICT by households and individuals. http://www.itu.int/en/ITU-D/Statistics/Documents/statistics/2013/Core_Indicators.xls

International Telecommunications Union (2013). Fixed (wired)-broadband subscriptions. http://www.itu.int/en/ITU-D/Statistics/Documents/statistics/2013/Fixed_broadband_2000-2012.xls

Israel, B. A., Schulz, A. J., Parker, E. A., & Becker, A. B. (1998). Review of community-based research: assessing partnership approaches to improve public health. *Annual review of public health, 19*(1), 173-202.

Jensen, R. (2007). The digital provide: Information (technology), market performance, and welfare in the South Indian fisheries sector. *The quarterly journal of economics, 122*(3), 879-924.

Kahn, J. G., Yang, J. S., & Kahn, J. S. (2010). 'Mobile' Health Needs And Opportunities In Developing Countries. *Health Affairs, 29*(2), 252-258.

Kelly, J. G., Mock, L. O., & Tandon, D. S. (2001). Collaborative inquiry with African-

American community leaders: Comments on a participatory action research process. *Handbook of Action Research. London, Sage*, 348-355.

Kemmis, S., & McTaggart, R. (2005). Communicative action and the public sphere. *The Sage handbook of Qualitative Research. 3rd Edition. London, Sage*.

Kitzinger, J. (1994). The methodology of focus groups: the importance of interaction between research participants. *Sociology of Health & Illness, 16*(1), 103-121.

Kleine, D., & Unwin, T. (2009). Technological Revolution, Evolution and New Dependencies: what's new about ict4d? *Third World Quarterly, 30*(5), 1045-1067.

Knoblauch, H. (2005). *Focused ethnography*.

Kronenberg, F., Algado, S. S., & Pollard, N. (2005). *Occupational therapy without borders*: Elsevier/Churchill Livingstone.

L'Engle, K., & Vadhat, H. (2009). Mobile phone interventions for reproductive health (m4RH): Testing the feasibility of text messaging to improve family planning. http://www.fhi.org/NR/rdonlyres/e426xemcs6kjxllp2t37p3k2h7sgpol5rjzft4gzqd wztaxjp 7afnh6pck6hedydsyzxzinimbfe3o/FormativeResultsM4RH1.pdf

Lenoir, R. *Les exclus: Un Francais sur dix*. Paris: Editions du Seuil.

Lester, R. T., Ritvo, P., Mills, E. J., Kariri, A., Karanja, S., Chung, M. H., . . . Najafzadeh, M. (2010). Effects of a mobile phone short message service on antiretroviral treatment adherence in Kenya (WelTel Kenya1): a randomised trial. *The Lancet, 376*(9755), 1838-1845.

Litwin, H. (2006). Social Networks and Self-Rated Health A Cross-Cultural Examination Among Older Israelis. *Journal of Aging and Health, 18*(3), 335-358.

Lloyd Laney, M. (2003). Making Information User-Driven.

http://www.dfid.gov.uk/r4d/pdf/outputs/ICCIMUserdriveninfo.pdf

Luper, S. (2004). Epistemic relativism. *Philosophical issues, 14*(1), 271-295.

Mapham, W. (2008). Mobile phones: Changing Health Care One SMS at a time. *Southern African Journal of HIV Medicine, 9*(4), 11.

Maxwell, J., Belser, J. W., & David, D. (2007). *A health handbook for women with disabilities*. Berkeley: Hesperian Foundation.

Mayan, M. J. (2009). *Essentials of qualitative inquiry*. Walnut Creek: Left Coast Press.

McDowell, I. (2006). *Measuring health: a guide to rating scales and questionnaires*. New York: Oxford University Press, USA.

McIntosh, P. (1989). White privilege and male privilege. *Peace & Freedom*, 10-12.

McMahon, R., O'Donnell, S., Smith, R., Walmark, B., Beaton, B., & Simmonds, J. (2011). Digital Divides and the 'First Mile': Framing First Nations Broadband Development in Canada. *The International Indigenous Policy Journal, 2*(2), 2.

Meera, S., Khamtani, A., & Rao, D. U. M. (2004). Information and Communication Technology in Agricultural Development: A comparative analysis of three projects from India. http://www.odi.org.uk/work/projects/agren/papers/agrenpaper_135.pdf

Mendoza, M., & Guevara, J. (2012). *Retos y avances del desarrollo local: Caso El Codito*. Bogota: Universidad del Rosario.

Mikkonen, J., Raphael, D., & York University (Toronto, O. S. o. H. P. a. M. (2010). *Social determinants of health: The Canadian facts*: York University, School of Health Policy and Management.

Minkler, M. (2004). Ethical challenges for the “outside” researcher in community-based

participatory research. *Health Education & Behavior, 31*(6), 684-697.

Minkler, M., & Wallerstein, N. (2008). Introduction to community-based participatory research: new issues and emphases. *Community-Based Participatory Research for Health*, 5-19.

MobileActive. (2007). SMS Suppot Network: Connecting People with HIV/AIDS in Mexico. http://mobileactive.org/sms-support-network-connecting-people-hiv-aids-mexico

Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of counseling psychology, 52*(2), 250.

Morse, J. M. (1991). *Qualitative nursing research: A contemporary dialogue (rev.* Paper presented at the The chapters in this volume are revised versions of papers presented at a two-day symposium in Chicago, Illinois, Nov 16-17, 1987.

Murray, C. J. L., Vos, T., Lozano, R., Naghavi, M., Flaxman, A. D., Michaud, C., . . . Abdalla, S. (2013). Disability-adjusted life years (DALYs) for 291 diseases and injuries in 21 regions, 1990–2010: a systematic analysis for the Global Burden of Disease Study 2010. *The Lancet, 380*(9859), 2197-2223.

Nchise, A., Boateng, R., & Shu…, I. (2012). Mobile Phones in Health Care in Uganda: The AppLab Study. *The Electronic Journal on Information Systems in Developing Countries, 52*(2), 1-15.

Ogden, J., Esim, S., & Grown, C. (2006). Expanding the care continuum for HIV/AIDS: bringing carers into focus. *Health Policy and Planning, 21*(5), 333-342.

Popay, J., Escorel, S., Hernández, M., Johnston, H., Mathieson, J., & Rispel, L. (2009). Understanding and tackling social exclusion: final report to the WHO

Commission on Social Determinants of Health from the Social Exclusion Knowledge Network. Geneva: World Health Organization.

Regmi, K., Naidoo, J., & Pilkington, P. (2010). Understanding the processes of translation and transliteration in qualitative research. *International Journal of Qualitative Methods, 9*(1), 16-26.

Rios, A., Vargas, M., Laserna, R., & Melo, R. (2007). *APOYO A LA POLÍTICA DE APOYO A LAS PERSONAS CON DISCAPACIDAD DEL DISTRITO*. http://www.saludcapital.gov.co/Documentos%20Discapacitados/Forms/AllItems.aspx?RootFolder=http%3a%2f%2fwww%2esaludcapital%2egov%2eco%2fDocumentos%20Discapacitados%2fBancos%20de%20ayudas%20t%c3%a9cnicas&FolderCTID=0x012000A5CE86B3FE2DAA4C9CBB6EF9B919275C

Samuels, D. R. (2007). Connecting with Oppression and Privilege: A Pedagogy for Social Justice. In B. M. Scott & M. Texler Segal (Eds.), *Race, Gender, and Class in Sociology: Toward an Inclusive Curriculum (6th ed.)*. Washington, DC: American Sociological Association.

Sclove, R. E., Scammell, M. L., & Holland, B. (1998). Community-based research in the United States. *Amherst, MA: The Loka Institute*.

Sen, A. (1999). *Development as Freedom*. New York: Anchor Books.

Sen, A. (2000). Social Exclusion: Concept, Application, and Scrutiny. *Social Development Papers*(1).

Shilderman, T. (2002). Strengthening the knowledge and information systems of the urban poor. *April*.

Sife, A. S., Kiondo, E., & Lyimo-Macha, J. G. (2010). Contribution of Mobile Phones to

Rural Livelihoods and Poverty Reduction in Morogoro Region, Tanzania. *The Electronic Journal of Information Systems in Developing Countries, 42*.

Stillman, T. F., Baumeister, R. F., Lambert, N. M., Crescioni, A. W., DeWall, C. N., & Fincham, F. D. (2009). Alone and without purpose: Life loses meaning following social exclusion. *Journal of Experimental Social Psychology, 45*(4), 686-694.

Story, L., Hinton, A., & Wyatt, S. B. (2010). The role of community health advisors in community-based participatory research. *Nursing Ethics, 17*(1), 117-126.

Talyarkhan, S. (2004). *Connecting the first mile: a framework for best practice in ICT projects for knowledge sharing in development*. Rugby: ITDG.

Taylor, A. S., & Harper, R. (2003). The gift of the gab?: A design oriented sociology of young people's use of mobiles. *Computer Supported Cooperative Work (CSCW), 12*(3), 267-296.

The SHM Foundation, Retrieved June 5, 2012 from http://www.shmfoundation.org/health.php

Thew, M., Edwards, M., Baptiste, S., & Molineux, M. (2011). *Role Emerging Occupational Therapy: Maximising Occupation Focused Practice*. UK: Wiley-Blackwell.

Tigo. (2011). http://www.tigo.com.co

Townsend, E., & Polatajko, H. (2007). Enabling occupation II: Advancing an occupational therapy visio for health, well-being and justice through occupation: CAOT Publications ACE.

Townsend, E., & Wilcock, A. A. (2004). Occupational justice and client-centred practice: A dialogue in progress. *Canadian Journal of Occupational Therapy, 71*(2), 75-87.

Tsai, J., Choe, J. H., Mu Chen Lim, J., Acorda, E., Chan, N. L., Taylor, V., & Tu, S. P. (2008). Developing culturally competent health knowledge: Issues of data analysis of cross-cultural, cross-language qualitative research. *International Journal of Qualitative Methods, 3*(4), 16-27.

United Nations Development Programme (2011). Beyond Trasition: Towards Inclusive Societies. http://europeandcis.undp.org/news/show/BCD10F8F-F203-1EE9-BB28DEE6D70B52E1

UN General Assembly (2007). Convention on the Rights of Persons with Disabilities : resolution / adopted by the General Assemby. http://www.unhrc.org/refworld/docid/45f973632.html

Unwin, T. (2007). No end to poverty. *Journal of Development Studies, 43*(5), 929-953.

Unwin, T. (2009). *ICT4D: information and communication technology for development*: Cambridge University Press.

Wallerstein, N. B., & Duran, B. (2006). Using community-based participatory research to address health disparities. *Health promotion practice, 7*(3), 312-323.

Wenger, E. C., White, N., & Smith, J. D. (2009). *Digital habitats: Stewarding technology for communities*: CPsquare.

Whitehead, T. L. (2005). Basic Classical Ethnographic Research Methods.

Woolcock, M., & Narayan, D. (2000). Social capital: Implications for development theory, research, and policy. *The world bank research observer, 15*(2), 225-249.

Organization, W. H. (2001). International classification of functioning, disability and health : ICF. http://www.who.int/classifications/icf/en/

World Health Organization (2003). Social determinants of health: the solid facts.

http://*www.euro.who.int/__data/assets/pdf_file/0005/98438/e81384.pdf*

World Health Organization (2010). Community-based rehabilitation guidelines. http://www.who.int/disabilities/cbr/guidelines/en/index.html

World Health Organization (2012). Disability and health. *Fact sheet No 352*. http://www.who.int/mediacentre/factsheets/fs352/en/index.html

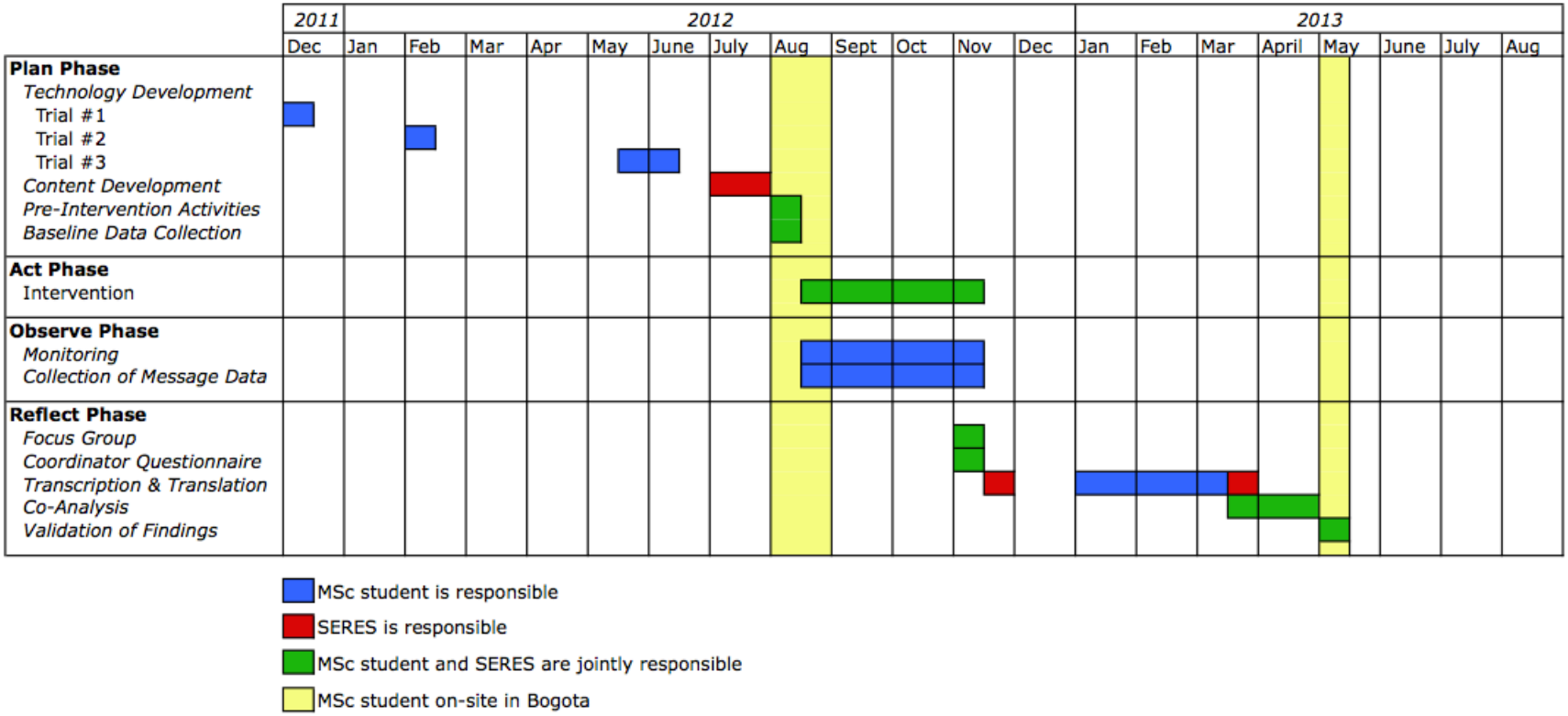
Wright, K. N., Williams, P., Wright, S., Lieber, E., Carrasco, S. R., & Gedjeyan, H. (2011). Ties That Bind: Creating and sustaining community-academic partnerships. *Gateways: International Journal of Community Research and Engagement, 4*, 83-99.

Zakus, J. D. L., & Lysack, C. L. (1998). Revisiting community participation. *Health Policy and Planning, 13*(1), 1-12.

Appendix A

Research Timeline

Research Timeline



Appendix B

FrontlineSMS
General Information

FRONTLINESMS

FrontlineSMS is free software that turns a laptop and a mobile phone or modem into a central communications hub. The program enables users to send and receive text messages with large groups of people through mobile phones. What you communicate is up to you, making FrontlineSMS useful in many different ways.

SMS stands for "short message service." It is also known as text messaging. With the growing popularity of mobile phones, especially in developing countries, SMS has become a familiar and widely used form of communication. It offers advantages over traditional voice services including reduced cost and the ability to send messages to large numbers of people in a short amount of time.

SUCCESS STORIES

"We want people to know that if they are trying to rig the election, there could be someone behind them and that person may send a text message saying what happened" —
Emauwa Nelson, Human Emancipation Lead Project, Nigeria (via the BBC website)

"Based in Africa in a country where broadcast technology is controlled by a dictatorial government, this software has enabled me to communicate with the public at large. I am able to run my project without drawing unnecessary attention to myself - a good thing in this neck of the woods" —
Anonymous FrontlineSMS user, central Africa

WHAT'S THE CHALLENGE?

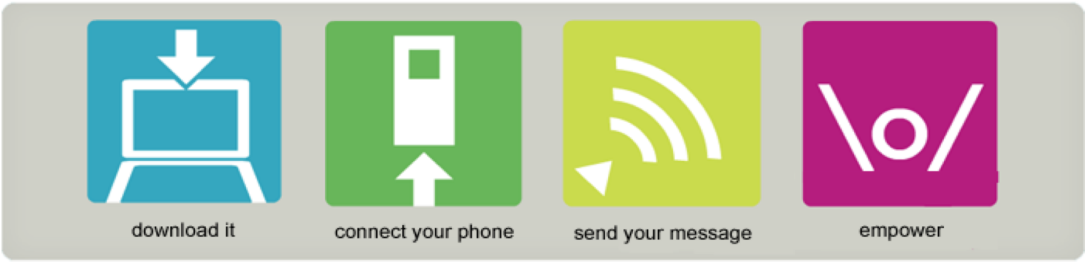
A lack of communication can be a major barrier for many grassroots non-governmental organisations (NGOs) working throughout the developing world. FrontlineSMS is the first text messaging system to be created with this problem in mind. By leveraging basic tools already available to most NGOs - computers and mobile phones - FrontlineSMS enables instantaneous two-way communication on a large scale.

WHAT CAN I DO WITH FRONTLINESMS?

- Human rights and election monitoring
- Disaster relief coordination
- Natural resource management
- Emergency alerts and mobilising task forces
- Field data collection
- Conducting public surveys
- Health care info requests
- Agricultural price updates
- Organizing protests
- Mobile education programs
- Coordinating fundraising efforts
- Providing weather updates

WHERE AND HOW IS IT BEING USED?

FrontlineSMS has been used by NGOs in over forty countries for a wide range of activities including blood donor recruitment, citizen reporting, assisting human rights workers, promoting government accountability, providing security alerts to field workers, election monitoring, the capture and exchange of agricultural market information, distributing weather forecasts, co-ordinating healthcare workers, organising political demonstrations, carrying out of surveys and the reporting and monitoring of disease outbreaks.



WHAT'S DIFFERENT ABOUT FRONTLINESMS?

- Does not require an Internet connection
- Works with your existing plan on all GSM phones, modems and networks
- Laptop-based, so it can be used on the road or during power outages
- Stores all phone numbers and records all incoming and outgoing messages
- All data lives on a local computer, not on servers controlled by someone else
- Scalable: messages can be sent to individuals or large groups
- Enables two-way communication, useful for fieldwork or conducting surveys
- Easy to install and requires little or no training to use
- Is supported by a growing online community of non-profit users around the world

FrontlineSMS allows you to fully manage your contacts, and put them into groups

You can run your own surveys and competitions, which people enter via SMS

You can analyse your survey or competition entries, and export the data to other programs

Messages can be quickly and easily compiled and sent to large numbers of people at once

Track your messages to see which ones have been successfully delivered, and which have not

Receive messages as part of your competitions or surveys, or from staff or community members

Create automatic replies, such as market prices or health information, to help automate your work

Connect, configure and manage multiple phones and devices

FrontlineSMS is available free to all non-profit organisations working for positive social and environmental change. For further details and to request your own copy of FrontlineSMS visit the website at www.frontlinesms.com

About kiwanja.net

kiwanja.net provides mobile communications solutions which address real world issues. Since 2003, we have been helping local, national and international non-profit organisations better utilise information and communication technologies (ICT) in their work. Specialising in the application of mobile technology, we provide a wide range of ICT-related services drawing on over 22-years experience of our Founder, Ken Banks. Non-profits in over forty countries have so far benefited from a range of kiwanja.net initiatives

For more information visit our website at www.kiwanja.net

Installing FrontlineSMS and troubleshooting modems

1. Insert SIM into modem and modem into USB port.
2. Follow the instructions to install the modem's device manager software, which will include the appropriate driver. Normally this will be automated - some modems ask that you install their drivers separately before inserting the device - check the instructions provided with the device.
3. Install and run the device manager software, and then shut down the device manager software and any other programs that use the modem.
4. Download FrontlineSMS from a USB key or from http://www.FrontlineSMS.com/download
5. Install FrontlineSMS.
6. Open FrontlineSMS and go to the 'phones' tab - wait until either a device has appeared in the pane at the top of the window, or all ports have been unsuccessful in finding or connecting to a modem.

Troubleshooting tips

- Ensure the device manager software has started and been fully shut down before starting FrontlineSMS by checking in the Task Manager that no processes relating to it are still running.
- Occasionally the device manager software actually needs to be running for FrontlineSMS to work. If the device is not being recognised by FrontlineSMS, be sure that FrontlineSMS is closed, insert the modem, wait for the device manager software to fully initialise, then start FrontlineSMS.
- Try restarting your computer, remembering to eject and remove the modem before initiating the restart process. Once the computer has restarted, begin again from Step 1. of the sequence described above.

If the device is recognised but not sending or receiving messages

- Check that the device is set to send and receive messages by double-clicking on the device in the Phones tab. A menu window will open with check boxes that describe the approved function.
- Close FrontlineSMS and open the device manager software. Once the driver software is open, use the device manager software to send a test text message to a known phone number in order to ensure that the SIM is activated and has credit.
- Check the device manager software's inbox inbox to see whether messages are being captured by it before reaching FrontlineSMS. If so, you may need to shut down the device manager software or ensure that it is fully initialised before starting FrontlineSMS.
- If the SIM is PIN protected, this protection will need to be removed before FrontlineSMS will connect to the device. Put the SIM into a regular phone to check this, and to remove the PIN if necessary.

Getting FrontlineSMS up and running with a device can be a process of trial and error, as you have to get to know your computer and your modem. Be patient, and willing to try a few things.

Our help files are available online here:

http://help.frontlinesms.com/manuals/1.6.16.3/troubleshooting.htm

You can also ask for help on our forum: http://frontlinesms.ning.com.

USER GUIDE | DATA INTEGRITY

FRONTLINESMS

For Full User Guide (65 pages) see:

http://www.frontlinesms.com/wp-content/uploads/2011/08/frontlinesms_userguide.pdf

Appendix C

Technology Trials Summary

Edmonton and Bogota Group Text Messaging Trials

Summary

By: Tim Barlott BScOT, MSc in Rehabilitation Science Student

April 13, 2012

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Edmonton and Bogota Group Text Messaging Trials – Summary

By: Tim Barlott BScOT, Student MSc in Rehabilitation Science

Introduction

In many under-resourced communities (both within Canada and internationally), people with disabilities (PWD) often have limited information access and are socially isolated - factors associated with poor health outcomes (World Health Organization, 2003; World Bank, 1998). Contributing factors include poverty, geographic isolation, lack of access to computers, and low rates of Internet use. In collaboration with the Universidad del Rosario (UR) in Bogota, Colombia, my MSc research project will develop the use of basic mobile phones to address the needs of an under-resourced community in northern Bogota, named El Codito. Less than 20% of Colombians have computers or Internet access, but over 80% have mobile phones (DANE 2005). Since the people of El Codito have access to mobile phones, our research project proposes to use a mobile-phone, text message based system of providing health information and social interaction for PWD and their families.

The first phase of my MSc research project is the development phase, which includes the technology trials discussed below.

The Technology: The software being used for the trial is FrontlineSMS, an open-sourced text message delivery program developed for international development (FrontlineSMS, 2011). The system requires one computer running FrontlineSMS connected to one mobile phone. This acts as a two-way text-messaging hub. While FrontlineSMS and basic mobile phones have been successfully used for some forms of information distribution, a limited number of projects have utilized mobile phones specifically for the distribution of health information (Cole-Lewis & Kershaw, 2010; Furoholt & Matotay, 2011).

Trial 1 – Edmonton Group Text Messaging Trial

Objectives – Trial 1

1. **Test the technology** – This was the first real-world use of FrontlineSMS for my research project. The goal was to test multiple functions of FrontlineSMS including: *keywords, auto-reply, auto-forward, remote administration, simultaneous message sending, contact groups,* and *data export*.
2. **Test the usability**
3. **Test FrontlineSMS for information distribution**
4. **Test FrontlineSMS for social interaction**

Methods – Trial 1

Dates: December 12-16, 2011

Materials: For this trial, a desktop computer running FrontlineSMS was connected to a USB modem (Sierra Wireless Compass 885) containing a Bell Mobility SIM card. This network-connected computer was located in the Assistive Technology Lab at the University of Alberta.

Participants: This trial consisted of 8 participants: 4 UofA students, 2 SLPs, 1 professor, 1 hospital clinician. All participants were either colleagues of mine or my supervisor, Dr. Adams.

Procedure: The trial began with a basic email to participants with instructions on how to sign up for the trial using their mobile phone. As the trial administrator I sent text messages on a daily basis (using FrontlineSMS) with resources, trial updates and ongoing instructions on how to participate. Participants were asked to respond to questions, sign-up for user-groups, and send social interaction messages according to my instruction. On the last day of the trial, participants were emailed a post-trial questionnaire. This questionnaire was used to evaluate the ease of use and the perceived potential for information distribution and social interaction of the system.

Results – Trial 1

See *Edmonton post-trial questionnaire summary* (Appendix 1a) and *Edmonton group text messaging trial usage data* (Appendix 2a) for details of data and results.

Objective 1: The trial successfully tested the following functions of FrontlineSMS: *keywords, auto-reply, auto-forward, remote administration, simultaneous message sending, contact groups,* and *data export*. The system was reliable with the exception of two technical issues: network issue and message duplication issue.

> ***Network issue***: On one occasion, the network automatically logged off the user during the night, closing down FrontlineSMS, making it impossible to send or receive messages.
>
> ***Message duplication issue:*** On one occasion, the administrator was editing a particular keyword while a participant attempted to use this keyword. FrontlineSMS was unable to send the auto-reply associated with this keyword and began creating duplicate messages. Upon restarting FrontlineSMS, this one participant was sent 10 duplicate messages.

Objective 2: The post-trial questionnaire revealed positive results regarding the overall usability of the system. The ease of use was found to be equivalent to sending a basic text message.

Objective 3: Three instances of information distribution were demonstrated during the trial and in one instance, the option of requesting additional information was offered. The post-trial questionnaire indicated positive results regarding the potential for information distribution.

Objective 4: Three user-groups were established during the trial – the entire group and two sub-groups (blue group vs red group). Participants were given the opportunity to send messages either to the entire group or to their individual user-group. In total, trial participants sent eight social interaction messages.

Discussion – Trial 1

This trial demonstrated a successful real world evaluation of FrontlineSMS. General usability of the system was found to be good and the system was straightforward. Information distribution and social interaction operated as expected and could be scaled up as needed. The system was ready for a similar trial with participants in Bogota, Colombia.

Recommendations from Trial 1

During future implementations of FrontlineSMS, it is recommended that any network-connected computers be disconnected from the network if they are logged off on a scheduled basis. It is also recommended that the administrator take the system "off-line" when doing maintenance in order

to prevent message sending errors. It was also discovered that is important to add variations to each keyword, accounting for punctuation. For example, the keyword associated with sending a social interaction message was "*send to all*," which could be followed by numerous punctuation marks such as: , - : .

Trial 2 – Bogota Group Text Messaging Trial

Objectives – Trial 2

1. **Test the technology** – This trial tested FrontlineSMS using Colombian mobile networks. This trial tested the same FrontlineSMS functions as in Trial 1.
2. **Test the usability**
3. **Introduce the technology to the UR research team** – This was the UR research team's first exposure to FrontlineSMS.
4. **Test FrontlineSMS for information distribution**
5. **Test FrontlineSMS for social interaction**

Methods – Trial 2

Dates: January 31 – February 13, 2012

Materials: For this trial, an HP laptop computer running FrontlineSMS was connected to a USB modem (Sierra Wireless Compass 885) containing a Colombian SIM card. This computer was not network connected, but connected to the Internet using a Wi-Fi connection. This computer was brought to multiple locations throughout the trial including the University of Alberta and my private residence.

Participants: This trial consisted of 6 faculty and staff from the Universidad del Rosario (UR) in Bogota, Colombia. All participants are directly involved with ongoing work in the community of El Codito and will be involved in the implementation phase of my MSc research.

Procedure: The trial began with an email message to participants, with a one-page instruction sheet on how to sign up for the trial using their mobile phone. While the one-page instruction sheet was primarily in English, the entire trial was completed in Spanish. The majority of the Spanish language translations were confirmed with a Spanish-speaking colleague in Edmonton who is also a professor at the UR in Colombia. I have very basic Spanish language skills and when this colleague was not available, I relied on Google Translate to confirm my translation. As the trial administrator, I sent text messages on a daily basis (using FrontlineSMS) with resources, trial updates and ongoing instructions on how to participate. Participants were asked to respond to questions, sign-up for user-groups, and send social interaction messages according to my instruction. On the last day of the trial, participants were emailed a post-trial questionnaire. This questionnaire was used to evaluate the ease of use and the perceived potential for information distribution and social interaction of the system

Results – Trial 2

See *Bogota post-trial questionnaire summary* (Appendix 1b) and *Bogota group text messaging trial usage data* (Appendix 2b) for details of data and results.

Objective 1: The trial reliably tested all necessary functions of FrontlineSMS without any technical issues. No issues occurred regarding the use of a Colombian SIM card, roaming on Canadian networks, to send international text messages to Colombia.

Objective 2: The post-trial questionnaire revealed positive results regarding the overall usability of the system. The trial maintained the simplicity of sending a basic text message.

Objective 3: The UR research team expressed positive overall impressions of FrontlineSMS. The UR research team expressed a desire for a more advanced demonstration of the system.

Objective 4: Four instances of information distribution were demonstrated during the trial and in one instance, the option of requesting additional information was offered. The post-trial questionnaire indicated neutral responses regarding the potential for information distribution. The UR research team believe that their impressions of this potential may improve with a more advanced demonstration.

Objective 5: Three user-groups were established during the trial – the entire group and two sub-groups (Cartagena group vs Santa Marta group). Participants were given the opportunity to send messages either to the entire group or to their individual user-group. In total, trial participants sent seventeen social interaction messages. The post-trial questionnaire indicated positive responses regarding the potential for social interaction.

Discussion – Trial 2

Contextual Considerations

Trial Content: During both trials, I sent fictional content. At times, this content was intended to be humorous and did not explicitly demonstrate the intended purpose of the system. For example, rather than providing a true *health tip*, I supplied a fictitious fact about how to alleviate tears while cutting onions. Prior to sending this "silly" content during the Bogota trial, I was advised by a Colombian colleague that it would be more helpful to send relevant content. It was their opinion that those messages would not be viewed as humorous within the Colombian context. I attempted to create contextually relevant user-groups (people who prefer Cartagena for a vacation vs. people who prefer Santa Marta), but there was limited participation with this topic. The post-trial comments lead me to believe that the trial would have had greater participation if the system explicitly demonstrated its potential to help people in El Codito. For example, I could send a set of 3 messages outlining how a community member could acquire a wheelchair or establishing user-groups based on type of disability (i.e. hearing impaired user-group). While the trial incorporated this on a very basic level, it seems it was not in enough detail for the Bogota participants.

Language challenges: This trial was conducted entirely in Spanish even though I have very basic Spanish language skills. I confirmed the majority of my messages with Spanish speaking colleagues, but there were multiple instances where questions were asked in Spanish and I incorrectly responded to these messages. The participants were aware of the circumstances and were not offended, but I believe it may have negatively impacted the trial at times. This experience reinforces the need for local involvement during the implementation phase. It is not only important that administrators/coordinators speak Spanish, but also speak the common language of the people of El Codito (i.e. understand local phrases and sayings, avoid technical jargon, etc).

It will also be important to have direct consultation from the UR on the identification of Spanish keywords. For example, the keyword "*enviar a equipo del rosario*" was established to trigger FrontlineSMS to send a message to the Rosario Team, but participants often alternately sent the keyword as "*enviar al equipo rosario*". It will be important, firstly to simplify keywords as much as possible and secondly to set-up FrontlineSMS with all common alternative keywords.

This trial demonstrated an error free implementation of FrontlineSMS using Colombian mobile networks. General usability of the system was found to be good and the system was straightforward. Information distribution and social interaction operated as expected and can be scaled up as needed.

Recommendations from Trial 2

The UR research team has requested to continue the trial with more complex integration of health information distribution and user-groups, using real-world information rather than fictional content. I will work with the UR research team to develop a more in-depth demonstration. While the UR research team was impressed with the potential of this technology for impacting the lives of people in El Codito, they wish to continue with this trial prior to working with community members in our collaborative research project.

Conclusion

These trials will inform the implementation of my MSc research, which will provide PWD in El Codito with an affordable and sustainable method for accessing health information and social interaction. The proposed research also has the potential to impact the lives of PWD or other vulnerable populations who have similar challenges within Canada and Alberta.

Edmonton Group Text Messaging Trial - Post-trial questionnaire

Questions 1=worst, 5=best	Participant 1	Participant 2	Participant 3	Mean Response
1. How easy was the text messaging trial to use?	5	5	5	5
2. How clear were the initial instructions?	5	5	5	5
3. How clear were the instructions throughout the trial sent by text message?	4	5	5	4.667

Questionnaire Comments

Usability

"the text messaging trial was very easy and straight forward"

"It was easy. I do have experience with text messaging and it was no different than expected"

Clarity of instructions:

"Your instruction for some text were not directive. EX. "Send to all", If you would like to send a message VS Please send a message."

*"I was unsure though how **much** you expected us to participate, i.e. I wondered if we should be commenting more, but I have a feeling that was kept intentionally open to give us flexibility based on how much we wanted to contribute."*

Positive impressions about the trial:

"I liked the whole concept, it's a great way to keep people connected if there is little other media to do so."

"I enjoyed seeing the results when I sent a text with a specific command (EX. "more information")"

"I did feel connected with a group..."

Problems encountered in the trial

"I was one of participants that received lots of texts initially, but afterwards everything went very well."

Bogota Group Text Messaging Trial - Post-trial questionnaire

Questions 1=strongly disagree 3=neutral 5=strongly agree	Participant 1	Participant 2	Mean Response
1. The trial was easy to use.	5	5	5
2. The initial instructions were clear and easy to understand.	4	5	4.5
3. The instructions sent by text message during the trial were clear and easy to understand.	5	3	4
4. Language (poorly composed Spanish messages) negatively impacted the trial.	2	3	2.5
5. The trial demonstrated the potential for distribution of health information.	3	3	3
6. The trial demonstrated the potential for social interaction.	4	5	4.5

Questionnaire Comments

Positive impressions about the trial:

"I liked the use of the technology"

"It is cheap and easy to use"

Recommendations and comments about the trial:

"The system appeared to not be very flexible regarding asking a question, perhaps language of the sender was a factor"

"We would like to continue the trial with more complex messages to better demonstrate the use of the system"

"The system could be improved with more detailed content and if message senders were identified in the message"

"It is necessary that we speak the same language, meaning that we understand the use of Spanish and English, but also in technical language, academic, and usual"

Edmonton Group Text Messaging Trial Usage Data - December 12 - 16, 2011

	Sender	*Message sent by FrontlineSMS*	*Message received by FrontlineSMS*
General Usage			
Initial Subscription	**Admin**		
	Auto-reply: Initial subscription (2 msgs per participant)	16	
	Participant		
	Sent: Initial Subscription		8
	Sent: Confirmation message from participant		8
Help	**Admin**		
	Sent: Instructions on how to receive "help"	8	
	Auto-reply: Response to request for "help"	0	
	Participant		
	Sent: Requests for "help"		0
Remote Administration	**Admin**		
	Sent: Message command sent by Admin via mobile phone		2
System Monitoring	**Admin**		
	Test and monitoring messages (Sent to admin only)	55	
Trial Completion	**Admin**		
	Sent: Instructions/request for participants to "unsubscribe"	8	
	Auto-reply: Response "unsubscribe"	5	
	Participant		
	Sent: "Unsubscribe"		5
Error Messages	Total duplicate messages sent in error	12	
Information Distribution			
	Admin		
	Sent: Information Distribution messages (i.e. onions)	8	
	Auto-reply: Request for more information (i.e. more onions)	4	
	Sent: Pre-conclusion message to participants	8	
	Sent: Trial conclusion message to participants	8	
	Participant		
	Sent: Request for more information (i.e. more onions)		4
Social Interaction			
	Admin		
	Sent: Request to join user-groups (blue vs red)	8	
	Auto-reply: Response to joining user-group	8	
	Sent: Instructions - sending messages within a user-group	8	
	Sent: Instructions - sending messages to all participants	8	
	Sent: Example - sending messages to user-groups	8	
	Sent: Example - sending messages to all participants	8	
	Auto-forward: Forwarded social interaction messages from participants, either to user-groups or to all participants	36	
	Participant		
	Sent: Subscription to user-groups (red vs blue)		8
	Sent: Social interaction messages, sent within user-group or to all participants		8
TOTAL messages sent by FrontlineSMS		216	
TOTAL messages received FrontlineSMS			43
TOTAL messages sent and received during Edmonton Trial			259

Bogota Group Text Messaging Trial Usage Data - January 31 - February 13, 2012

	Sender	*Message sent by FrontlineSMS*	*Message received by FrontlineSMS*
General Usage			
Initial Subscription	**Admin**		
	Auto-reply: Initial subscription (2 msgs per participant)	14	
	Participant		
	Sent: Initial Subscription		7
	Sent: Confirmation message from participant		7
Help	**Admin**		
	Sent: Instructions on how to receive "help"	7	
	Auto-reply: Response to request for "help"	0	
	Participant		
	Sent: Requests for "help"		0
Remote Administration	**Admin**		
	Sent: Message command sent by Admin via mobile phone		2
System Monitoring	**Admin**		
	Test and monitoring messages (Sent to/from admin only)	21	18
General Instructions/Corrections	**Admin**		
	Sent: Messages to remind participants of correct keyword usage	12	
Error Messages	Total messages sent in error	0	
Information Distribution			
	Admin		
	Sent: Information Distribution messages	25	
	Auto-reply: Request for more information	1	
	Participant		
	Sent: Request for more information (i.e. more onions)		1
Social Interaction			
	Admin		
	Sent: Request to join user-groups (Cartagena vs Santa Marta)	8	
	Auto-reply: Response to joining user-group	4	
	Sent: Instructions - sending messages within a user-group	4	
	Sent: Instructions - sending messages to all participants	7	
	Sent: Example - sending messages to user-groups	4	
	Sent: Example - sending messages to all participants	6	
	Auto-forward: Forwarded social interaction messages from participants to entire group	81	
	Auto-forward: Forwarded social interaction messages from participants within user-groups (Cartagena group or Santa Marta group)	4	
	Participant		
	Sent: Subscription to user-groups (Cartagena vs Santa Marta)		4
	Sent: Social interaction messages sent to entire group		8
	Sent: Social interaction messages sent within user-group		16
TOTAL messages sent by FrontlineSMS		198	
TOTAL messages received FrontlineSMS			63
TOTAL messages sent and received during Edmonton Trial			261

Cole-Lewis, H., Kershaw, T. (2010). Text messaging as a tool for behavior change in disease prevention. *Epidemiologic Reviews, 32*, 56-69.

DANE (2005, 05 22). *Departamento Nacional de Estadistica*. Retrieved 03 06, 2011, from DANE: http://www.dane.gov.co/daneweb_V09/index.php?option=com_content&view=article&id=307&Itemid=124

FrontlineSMS (n.d.). Retrieved 10 03 2011, from http://www.Frontlinesms.com

Furoholt, B., & Matotay, E. (2011). The developmental contribution from mobile phones across the agricultural value chain in rural Africa. *The Electronic Journal on Information Systems in Developing Countries, 48*(7), 1-16.

World Bank (1998). *World Development Report 1998/99: Knowledge for Development*. Retrieved 10 03 2011, from http://www.worldbank.org/wdr/wdr98/index.htm

World Health Organization. (2003). *WHO.* Retrieved 10 03 2011, from *http://www.euro.who.int/__data/assets/pdf_file/0005/98438/e81384.pdf*

Appendix D

Workplan & Suggested Activities

El Enlace Pre-Intervention Workplan *(suggested)*

__ Confirm 3-week schedule

__ Review: technology trials, content development, population description phase

__ Discuss participant recruitment and participants

- __ Consent forms completed
- __ Demographic information forms completed (including self-perceived health
- __ Multidimensional social exclusion index
- __ Measurement of digital poverty

__ Determine El Enlace Administration Team roles (Figure 3.1)

__ Discuss how project changes will be made during the intervention (governance)

- __ What is the process if conflicting opinions arise, who makes decision.

__ Determine risk-response protocol for managing emergent situations

__ Plan rough timeline for 3-month intervention schedule and regular Skype meetings

__ Set-up Colombian SIM and computer (test remote desktop)

__ Review message content and structure

__ Technology introduction and training

- __ LD Team Administrator(s)
- __ Information Distribution Leader
- __ Social Interaction Pilot Leader
- __ Health Resource Person

__ Review Instruction sheet, makes adjustments as needed (keywords, phone numbers)

__ Plan for pre-intervention home visits

__ Pre-intervention home visits (10) – participants meet researchers and subscribe

__ Meet with Comcel and Tigo, mobile providers as arranged by LD Team

__ Test all FrontlineSMS functions

__ START THE INTERVENTION

__ Discuss the development of a sustainability strategy

- __ Economic sustainability
- __ Social sustainability
- __ Institutional sustainability

__ Discuss and plan for post-intervention data collection (e.g. interview questions, interviewers, transcription, translation, collaborative thematic analysis)

__ Discuss post-intervention plans (e.g. sustainability, scaling up, Text to Change)

__ Discuss how to increase community-engagement

__ Discuss communication plans during intervention (every two weeks? month?)

__ Discussion of other programs that El Enlace could support

Appendix E

FrontlineSMS Setup Instructions & Troubleshooting

FrontlineSMS – *Setup, Instructions and Troubleshooting*

For additional assistance, contact Tim Barlott at tbarlott@ualberta.ca

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Included supplies

1 – Laptop computer – HP Pavilion g6

1 – Power cord

2 – GSM modems – Sierra Compass 885

1 – SIM card

1 – Carrying case

Initial setup:

These initial setup instructions are important when the project computer is being setup for the first time or if is being moved to a new location

Below are detailed setup instructions:

1. Computer setup –
    a. Remove the laptop from its carrying case, plug the power cord into the laptop (on the right side) and plug the other end into a power outlet.
    b. Open the laptop and turn on the laptop by pressing the power button.
2. GSM modem setup –
    a. Make sure the SIM card is inserted in the GSM modem as indicated in the picture and on the back of the device. If the SIM card feels stuck or is not easy to insert, DO NOT force it into the modem. If this happens, remove the SIM card, ensure it is oriented properly and reinsert.

b. The SIM card should click in place and not be sticking out at all. See picture

3. Connecting the GSM modem to the laptop
    a. With the laptop powered on and logged on using the password, you are ready to insert the GSM modem into the laptop.
    b. Make sure that the program FrontlineSMS is NOT open.
    c. Insert the GSM modem into any of the 3 USB ports.
    d. Wait for the power icon (see picture) to light up blue. Once the power icon is blue, wait for a minimum of 30 seconds for the modem to initiate.
        i. If the data connection icon starts to slowly blink blue, do not worry, this is not a bad thing.
        ii. If the power icon is red, continue to wait. If it remains red for more than 5 minutes, remove the GSM modem from the USB port and restart the computer. Once the computer has restarted, go back to step number 3 again.
4. Starting FrontlineSMS
    a. Once the GSM modem has been inserted and the power icon is blue, you may open the program called FrontlineSMS. The icon is located on the desktop (double-click this icon) and on the bottom taskbar (single-click this icon). See picture
    b. FrontlineSMS will now spend the next 2-3 minutes detecting the attached GSM modem. You will notice that the bottom left side of the FrontlineSMS screen says “Iniciando el Administrador Telefonico”.
    c. There will be two events that indicate FrontlineSMS has connected to your GSM modem:
        i. The data icon on the GSM modem is now slowly blinking blue
        ii. In FrontlineSMS, under “Ultimos eventos” it will say “ Telefono Conectado: C885”

        **** If these two events do not occur (e.g. icons on the modem are red), you must close FrontlineSMS, disconnect the GSM modem and start again from step 3.*

    d. Your GSM modem is successfully connected to FrontlineSMS! You are now ready to start sending messages!
5. Sending a test text message
    a. To demonstrate that FrontlineSMS is successfully setup, try sending yourself a test text message!
    b. Ensure you are still on the “Inicio” tab, if not, select this tab on the top of the FrontlineSMS screen
    c. Under “Enviar SMS” on the left side of the screen enter a phone number in the space beside “Para”
    d. Next, enter your message by typing in the box below. As you type, you will notice a number beside “Caracteres restantes”, this

indicates the maximum number of characters remaining for this particular message. The maximum characters allowed for a text message is 160.

i. FrontlineSMS will allow you to input more than 160 characters, splitting your message into 2 text messages, but this is NOT recommended. This may result in sending incomplete messages.

*** IMPORTANT *** ***The project cannot send messages if any of these things occur***

- DO NOT TURN OFF THE PROJECT COMPUTER

- DO NOT CLOSE THE LID OF THE PROJECT COMPUTER

- DO NOT CLOSE FRONTLINESMS

- DO NOT DISCONNECT THE GSM MODEM

The setup order IS important. The order (simplified) must ALWAYS be:

Turn on computer

Connect GSM modem

Open FrontlineSMS

Daily Morning Routine

- *An ID Team Administrator will complete these steps each day*

1. Ensure that the project computer is still turned on
2. Ensure that the FrontlineSMS application is still open
3. Ensure that the GSM modem is connected to FrontlineSMS
    a. The power icon on the modem is blue
    b. The data icon is slowly blinking blue
4. *(Optional step)* Send a test message to yourself from FrontlineSMS
    a. *(Optional step)* See step 5 from Initial Setup for instructions on sending a test message

5. IF there is a problem with any of these steps, see the Troubleshooting section below

* Tim will also access the project computer remotely every morning to ensure things are working properly. Tim will send a text message to the administration team stating the system is functional.

Daily Morning Routine if no one from SERES is available to check on the computer

* Tim will access the project computer remotely every morning to ensure things are working properly. Tim will send a text message to the administration team stating the system is functional.

(Optional steps)

1. The person who is acting as the ID Team Administrator may send the following text message to the project phone number to ensure the system is working properly:

    Hola el enlace

2. If the system is functioning properly, the ID Team Administrator will receive an automatic reply from the project phone number within 10 minutes.

3. If there is no reply and no one will be available to troubleshoot at SERES for over 1 hour, contact Tim by email (tbarlott@ualberta.ca) stating that there is a technical issue. Tim will attempt to fix the issue remotely

Troubleshooting

The majority of all technical problems can be solved by following the instructions in this section.

If you follow these instructions and are unable to resolve the issue *or* if no one is available to follow these steps, email Tim (tbarlott@ualberta.ca). He will attempt to fix the issue remotely. After consulting with Tim, if the issue is unresolveable it is likely a mobile network issue and someone will need to call the mobile provider at: _____.

Common problems (see next section for solutions):

1. *There is no problem, but I want to test the system to see if it's working*
2. *Computer is off when I arrived this morning*
3. *Computer will not turn on*
4. *Computer is on, but FrontlineSMS is not open*
5. *GSM modem is blinking red lights or has no lights on at all OR GSM modem data icon is not blinking a blue light*
6. *GSM modem has been disconnected*
7. *GSM modem is damaged. If was disconnected, fell on the floor and someone stepped on it…crushing it*
8. *Everything looks fine, but FrontlineSMS is not sending or receiving messages*
9. *I have followed all these instructions, but it is still not working*
10. *All other questions*

Problem solutions

1. *There is no problem, but I want to test the system to see if it's working*
    a. The administration team can test the system at any time by sending the following text message to the project phone number:

        Hola el enlace

    b. If the system is functioning properly, the team member will receive an automatic reply from the project phone number within 10 minutes.

2. *Computer is off when I arrived this morning*
    a. Ensure the power cord is plugged into the side of the laptop
    b. Ensure the power cord is plugged into the power outlet
    c. Disconnect the GSM modem from the USB port
    d. Turn on the computer (press the power button)
    e. When prompted for a password, enter: ***elcodito***
        i. For detailed instructions on this setup, see the Initial Setup instructions starting with step 3
    f. Once logged into Windows, plug in the GSM modem to any of the 3 USB ports.
    g. Wait for the power icon to turn blue
    h. Once the power icon is blue, wait 30 seconds and open FrontlineSMS
    e. FrontlineSMS spend the next 2-3 minutes detecting the attached GSM modem.
    f. There will be two events that indicate FrontlineSMS has connected to your GSM modem:
        i. The data icon on the GSM modem is now slowly blinking blue
        ii. In FrontlineSMS “Inicio” tab, under “Ultimos eventos” it will say “ Telefono Conectado: C885”

3. *Computer will not turn on*
    a. Ensure the power cord is plugged into the side of the laptop
    b. Ensure the power cord is plugged into the power outlet
    c. The computer is still unresponsive
        i. Disconnect the GSM modem
        ii. Close the laptop lid
        iii. Flip the computer upside down, slide the battery release button and remove the battery.
        iv. Wait at least 30 seconds with the battery out
        v. Put the battery back in, make sure it clicks in place and the release button has slid back into place.
        vi. Make sure the power cord is in place, open laptop and attempt to turn it on.
    d. When prompted for a password, enter: ***elcodito***
        i. For detailed instructions on this setup, see the Initial Setup instructions starting with step 3
    e. Once logged into Windows, plug in the GSM modem to any of the 3 USB ports.
    f. Wait for the power icon to turn blue
    g. Once the power icon is blue, wait 30 seconds and open FrontlineSMS

g. FrontlineSMS spend the next 2-3 minutes detecting the attached GSM modem.
h. There will be two events that indicate FrontlineSMS has connected to your GSM modem:
    i. The data icon on the GSM modem is now slowly blinking blue
    ii. In FrontlineSMS "Inicio" tab, under "Ultimos eventos" it will say " Telefono Conectado: C885"

4. *Computer is on, but FrontlineSMS is not open*
    a. Check to see if power icon on the GSM modem is blue
        i. If it is not blue, disconnect it, wait for 30 seconds and then reconnect it to the USB port.
    b. Once the power icon is blue, wait 30 seconds and open FrontlineSMS
    c. FrontlineSMS spend the next 2-5 minutes detecting the attached GSM modem.
    d. There will be two events that indicate FrontlineSMS has connected to your GSM modem:
        i. The data icon on the GSM modem is now slowly blinking blue
        ii. In FrontlineSMS "Inicio" tab, under "Ultimos eventos" it will say " Telefono Conectado: C885"

5. *GSM modem is blinking red lights or has no lights on at all OR GSM modem data icon is not blinking a blue light (but the power icon is blue)*
    a. Disconnect the GSM modem from the USB port
    b. Close the FrontlineSMS program
    c. Reconnect the GSM modem to any of the 3 USB ports.
    d. Wait for the power icon to turn blue
    e. Once the power icon is blue, wait 30 seconds and open FrontlineSMS
    f. FrontlineSMS spend the next 2-3 minutes detecting the attached GSM modem.
    g. There will be two events that indicate FrontlineSMS has connected to your GSM modem:
        i. The data icon on the GSM modem is now slowly blinking blue
        ii. In FrontlineSMS "Inicio" tab, under "Ultimos eventos" it will say " Telefono Conectado: C885"

6. *GSM modem has been disconnected*
    a. Examine the end of the GSM modem to see if it has been damaged
        i. If the GSM modem looks damaged, see Troubleshooting section 6

b. If the GSM modem is not damaged, close the FrontlineSMS program
c. Reconnect the GSM modem to any of the 3 USB ports.
d. Wait for the power icon to turn blue
e. Once the power icon is blue, wait 30 seconds and open FrontlineSMS
f. FrontlineSMS spend the next 2-3 minutes detecting the attached GSM modem.
g. There will be two events that indicate FrontlineSMS has connected to your GSM modem:
    i. The data icon on the GSM modem is now slowly blinking blue
    ii. In FrontlineSMS "Inicio" tab, under "Ultimos eventos" it will say " Telefono Conectado: C885"

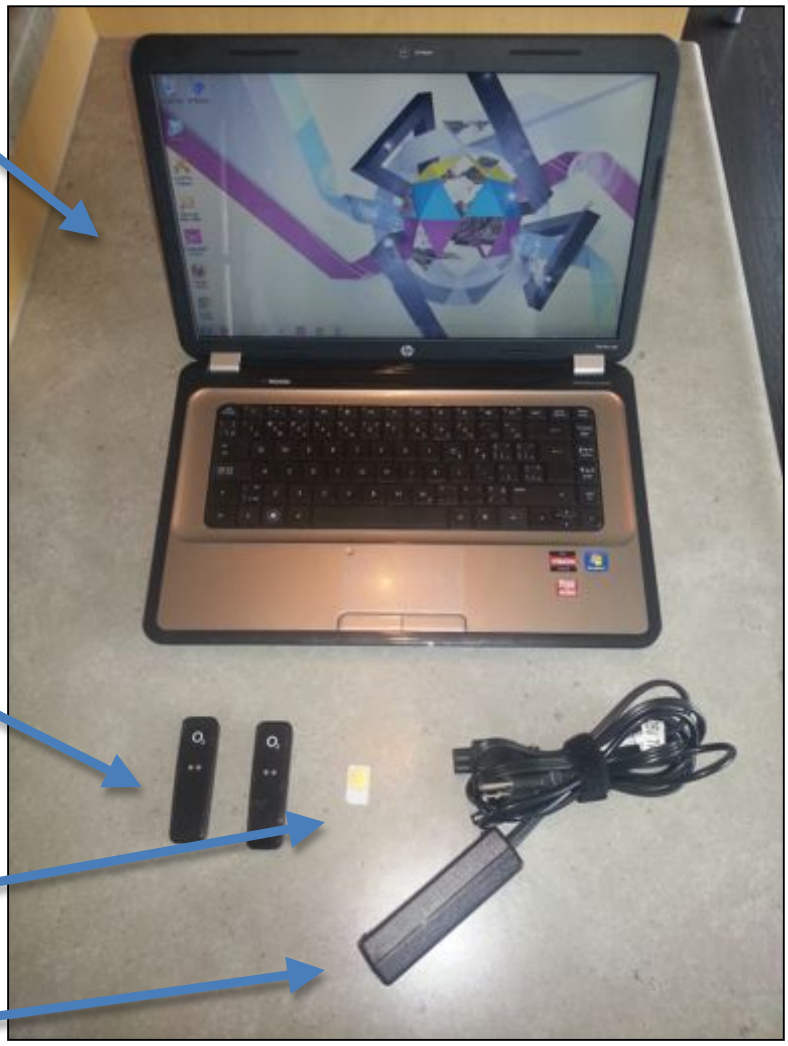
6. *GSM modem is damaged*
    a. If possible, take a couple pictures and email these pictures to Tim (tbarlott@ualberta.ca)
    b. Remove the SIM card from the GSM modem
        i. The SIM card is held in place in a spring-loaded slot.
        ii. Press the SIM card into the modem, this should trigger the spring to release the SIM card.
    c. Find the second GSM modem from the carrying case
    d. Insert the SIM card into the GSM modem as indicated in the picture in the Initial Setup section. There is also a diagram on the back of the GSM modem that shows how to insert the SIM card. If the SIM card feels stuck or is not easy to insert, DO NOT force it into the modem. If this happens, remove the SIM card, ensure it is oriented properly and reinsert.
    e. The SIM card should click in place and not be sticking out at all. See picture
    h. Reconnect the GSM modem to any of the 3 USB ports.
    i. Wait for the power icon to turn blue
    j. Once the power icon is blue, wait 30 seconds and open FrontlineSMS
    f. FrontlineSMS spend the next 2-3 minutes detecting the attached GSM modem.
    g. There will be two events that indicate FrontlineSMS has connected to your GSM modem:
        i. The data icon on the GSM modem is now slowly blinking blue
        ii. In FrontlineSMS "Inicio" tab, under "Ultimos eventos" it will say " Telefono Conectado: C885"

7. *Everything looks fine, but FrontlineSMS is not sending or receiving messages*
    a. This can happen from time to time
    b. Disconnect the GSM modem from the USB port
    c. Close the FrontlineSMS program
    d. Reconnect the GSM modem to any of the 3 USB ports.
    e. Wait for the power icon to turn blue
    f. Once the power icon is blue, wait 30 seconds and open FrontlineSMS
    g. FrontlineSMS spend the next 2-5 minutes detecting the attached GSM modem.
    h. There will be two events that indicate FrontlineSMS has connected to your GSM modem:
        i. The data icon on the GSM modem is now slowly blinking blue
        ii. In FrontlineSMS "Inicio" tab, under "Ultimos eventos" it will say " Telefono Conectado: C885"

8. *I have followed all these instructions, but it is still not working*
    a. Disconnect the GSM modem
    b. Close the FrontlineSMS program
    c. TURN OFF THE COMPUTER
        i. Leave the computer off for a minimum of 30 seconds
    d. Turn back on the computer and follow steps from Troubleshooting section 1
    e. If, after following the instructions again you are unable to send a test message, email Tim (tbarlott@ualberta.ca). Tim will attempt to fix the issue remotely or arrange a Skype call to troubleshoot with you.
    f. After all options have been explored, the issue may be related to the mobile network. In this case, someone will need to contact the mobile provider at: _____ to enquire about the issue.

9. *All other questions*
    a. If you have any other question, please feel free to email Tim anytime at tbarlott@ualberta.ca
    b. Tim is glad to answer ANY of your questions, receive any of your comments, or just converse via email

Images of supplies and setup



The GSM modem:

Front

Back

Inserting the SIM card into the GSM modem

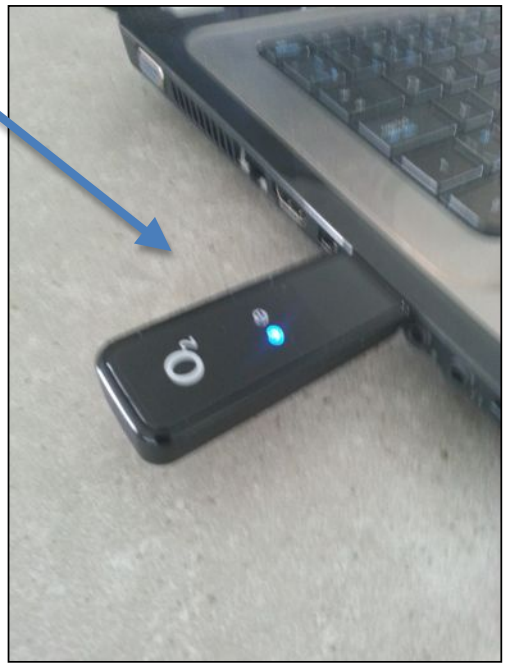
1.

2.

3.

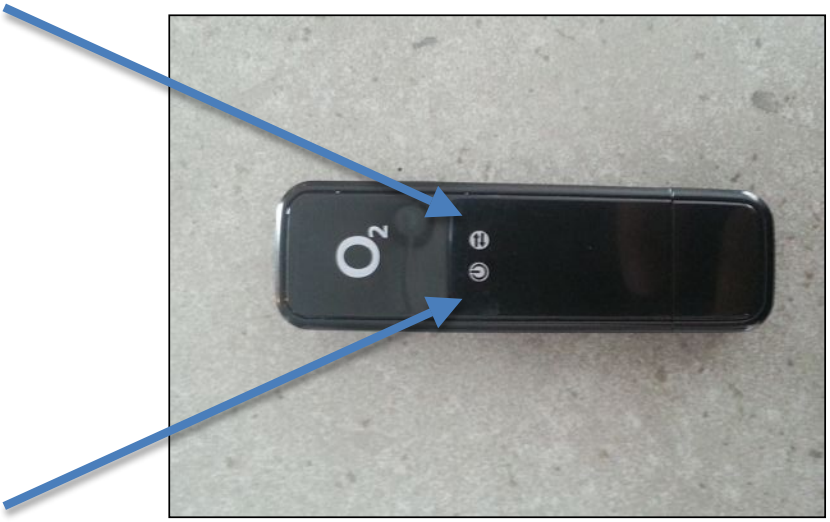
4.

The GSM modem inserted into the USB port



Data Connection Icon

- light is supposed to slowly blink blue in normal use

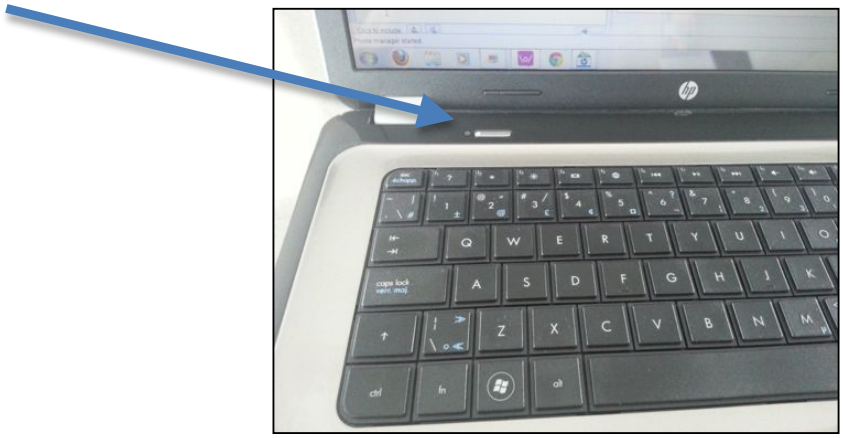


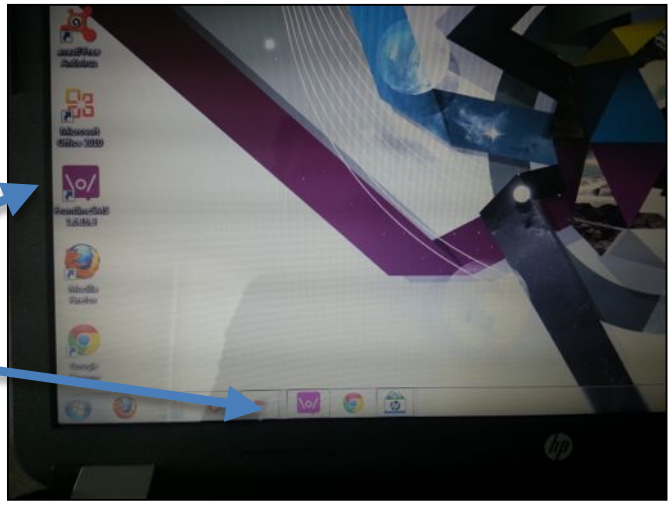
Power Icon

- light is supposed to be solid blue when in use

3

Laptop Power Button





FrontlineSMS Program Icons

FrontlineSMS - Configuración, instrucciones y solución de problemas

Para asistencia adicional, por favor contacte a Tim Barlott en el correo electrónico: tbarlott@ualberta.ca

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Elementos incluidos

1- Computador portátil – HP Pavilion g6

1- Cable de corriente

2- Modems GSM – Sierra Compass 885

1- SIM card

1- Estuche portátil

***IMPORTANTE* El Enlace no puede enviar mensajes si una de estos eventos acontece:**

-Si el computador está apagado (recuerde siempre debe estar prendido)

-Si baja la pantalla del computador

-Si se cierra el programa Frontline SMS

-Si se desconecta el modem GSM

Configuración inicial:

Estas instrucciones iniciales son importantes y necesarias cuando el computador sea configurado por primera vez o cuando sea cambiado su lugar.

A continuación se encuentran las instrucciones para la configuración:

1. Configuración del computador

    a. Retire el computador del estuche portátil, conecte el cable de corriente al computador y al tomacorriente (revise que las conexiones concuerden una con la otra).

    b. Prenda el computador oprimiendo el botón de inicio.

2. Configuración del modem GSM

    a. Revise que la SIM card esté insertada en el GSM modem como lo indica la imagen y en la parte posterior del dispositivo. Si la SIM card no entra fácilmente o si está atascada, no la fuerce para que entre al modem. Si esto llegara a pasar, retire la SIM card y asegúrese que la SIM card está siendo insertada en la dirección adecuada.

b. La SIM card debe hacer click en el momento en el que queda insertada en el modem.

3. Conexión del modem al computador portátil

a. Para programar el modem, el computador portátil tiene que estar prendido y se debe asegurar que el programa Frontline SMS no esté abierto.

b. Inserte el GSM modem en uno de los tres puertos USB del computador.

c. Espere a que el ícono de energía se encienda (Ver la imagen). Una vez que el bombillo azul esté encendido, espere por un minuto para iniciar el modem.

I. Si el ícono de conexión empieza a alumbrar de forma intermitente, no se preocupe, no es algo malo.

II. Si el ícono de energía empieza a alumbrar mediante una luz roja, siga esperando. Si permanece rojo por mas de cinco minutos, remueva el modem del puerto USB y reinicie el computador. Una vez el computador haya sido reiniciado, vuelva al numeral 3 y comienzo el procedimiento desde allí.

4. Iniciando Frontline SMS

a. Una vez haya sido insertado el modem y el ícono de energía esté azul, usted puede iniciar el programa Frontline SMS. El ícono está situado en el escritorio y en la barra inferior (vea la imagen).

b. Luego de abrir Frontline SMS, el programa demorará entre 2 a 3 minutos en detectar el modem GSM. Usted encontrará que el botón al lado izquierdo de Frontline SMS dice: “Iniciando el administrador telefónico”.

c. Usted puede saber si Frontline SMS está conectado al modem GSM, si alguno de los siguientes dos eventos suceden:

I. Si el ícono de conexión del modem GSM está parpadeando lentamente en color azul

II. Si en el programa Frontline SMS, en la sección de “Últimos eventos”, dice: “Teléfono conectado C885”

*** Si ninguno de estos eventos sucede, usted debe cerrar FrontlineSMS, desconectar el modem GSM y comenzar nuevamente desde el numeral tres.

d. Cuando el modem GSM esté conectado a Frontline SMS, usted puede iniciar el envío de mensajes.

5. Enviar un mensaje de prueba

a. Para demostrar que Frontline SMS está exitosamente configurado, usted puede intentar el envío de un mensaje de texto.

b. Para enviar un mensaje, asegúrese de estar en la sección “inicio”. Si no, selecciónelo en la parte superior de la pantalla de Frontline SMS.

c. Debajo de “Enviar SMS” sobre el lado izquierdo de la pantalla, ingrese el número telefónico en el espacio al lado de “Para”.

d. A continuación, escriba el mensaje en el espacio de abajo. A medida que usted va escribiendo el mensaje usted notará un número al lado de "Caracteres restantes"; esto indica el número máximo de caracteres que usted tiene permitidos para escribir el mensaje. El máximo de caracteres permitido para cada mensaje de texto es de: 160.

***Frontline SMS le permite ingresar mensajes de más de 160 caracteres, dividiendo la comunicación en dos mensajes. No obstante, esto no se recomienda ya que puede resultar en mensajes enviados de forma incompleta.

** El orden de la configuración es importante, por eso esta siempre debe ser:*

1. *Prenda el computador*
2. *Conecte GSM modem*
3. *Abra el programa Frontline SMS*

Rutina diaria

- Un miembro del Equipo Interdisciplinario deberá completar estos pasos cada día

1. Asegurarse que el computador del proyecto está todavía prendido
2. Asegurarse que el programa Frontline SMS está todavía abierto
3. Asegurarse que modem GSM está conectado a Frontline SMS
    a. El ícono de energía debe alumbrar azul
    b. El ícono de conexión debe parpadear lentamente de color azul
4. (Paso opcional) Enviar un mensaje de prueba desde Frontline SMS
    a. (Paso opcional) Ver paso 5 de configuración inicial para las instrucciones de envío de mensajes
5. Si existe algún inconveniente con alguno de estos pasos, ver la sección de solución de problemas que a continuación se presenta.

** Tim accederá al computador del proyecto todas las mañanas desde un control remoto para asegurar que El Enlace trabaja adecuadamente.*

Rutina diaria si nadie en SERES está disponible para revisar el computador

** Tim accederá al computador del proyecto todas las mañanas desde un control remoto para asegurar que El Enlace trabaja adecuadamente.*

(Pasos opcionales)

1. La persona que actúe como miembro del equipo administrador puede enviar el siguiente mensaje de texto al número telefónico del proyecto, para asegurarse que el sistema trabaja adecuadamente:

    Hola el enlace

2. Si el sistema funciona adecuadamente, el equipo administrador recibirá una respuesta automática del número telefónico del proyecto. El mensaje no se debe demorar más de 10 minutos en ser enviado.

3. Si no se produce ninguna respuesta y no hay ninguna persona disponible para solucionar el problema, por favor contactar a Tim en el correo electrónico: tbarlott@ualberta.ca. Tim intentará arreglar el problema remotamente.

Solución de problemas

La mayoría de los problemas técnicos se pueden resolver siguiendo las instrucciones de esta sección.

Si usted sigue estas instrucciones y no es posible solucionar el problema o si no hay alguien disponible que siga estos pasos, por favor enviar un correo electrónico a Tim (tbarlott@ualberta.ca). El intentará resolver el problema.

Si después de consultar a Tim el problema continúa, es probable que se trate de una dificultad con la red de telefonía celular y alguien deba llamar al proveedor: *Claro*

Problemas comunes (ver la siguiente sección para su solución):

1. No hay problema, pero quiero hacer una prueba del sistema para ver si funciona

2. El computador lo encontré apagado cuando llegué esta mañana

3. El computador no prende

4. El computador está prendido, pero Frontline SMS no está abierto

5. El modem GSM está alumbrando en color rojo, o no está alumbrando, o la luz del modem GSM no está parpadeando

6. El modem GSM está desconectado

7. El modem GSM está dañado

8. Aparentemente todo está bien, pero Frontline SMS no está enviando o recibiendo mensajes

9. He seguido todas las instrucciones, pero todavía no funciona

10. Otros problemas

Solución de problemas

1. No hay problema, pero quiero hacer una prueba del sistema para ver si funciona

a. El equipo administrador puede enviar el siguiente mensaje de texto al número telefónico del proyecto, para asegurarse que el sistema trabaja adecuadamente:

Hola el enlace

b. Si el sistema funciona adecuadamente, el equipo administrador recibirá una respuesta automática del número telefónico del proyecto. El mensaje no se debe demorar más de 10 minutos en ser enviado.

2. El computador lo encontré apagado cuando llegué esta mañana

a. Asegúrese que el cable de corriente está conectado (al computador portátil y al tomacorriente)

b. Desconecte el modem del puerto USB

c. Prenda el computador

e. Una vez haya entrado a Windows, conecte el modem a alguno de los puertos USB

f. Espere hasta que el ícono de corriente se prenda (color azul)

g. Una vez el ícono de corriente esté azul, espere 30 segundos y abra el programa Frontline SMS

h. Frontline SMS demora entre 2-3 minutos para detectar el modem GSM

i. Usted puede saber si Frontline SMS está conectado al modem GSM, si alguno de los siguientes dos eventos suceden:

I. Si el ícono de conexión del modem GSM está parpadeando lentamente en color azul

II. Si en el programa Frontline SMS, en la sección de "Últimos eventos", dice: "Teléfono conectado C885"

3. El computador no prende

a. Asegúrese que el cable de corriente está conectado (al computador portátil y al tomacorriente)

b. El computador todavía no responde

I. Desconecte el modem GSM

II. Cierre la pantalla del computador

III. Voltee el computador, libere la batería del computador y remuévala

IV. Espere por lo menos 30 segundos con la batería sin conectar

V. Luego coloque la batería de vuelta en el computador, asegúrese que esté bien puesta y asegúrela

VI. Revise que el cable de corriente esta en lugar debido, abra la pantalla del computador y préndalo

d. Una vez haya entrado a Windows, conecte el modem a alguno de los puertos USB

e. Espere hasta que el ícono de corriente se prenda (color azul)

f. Una vez el ícono de corriente esté azul, espere 30 segundos y abra el programa Frontline SMS

g. Frontline SMS demora entre 2-3 minutos para detectar el modem GSM

h. Usted puede saber si Frontline SMS está conectado al modem GSM, si alguno de los siguientes dos eventos suceden:

I. Si el ícono de conexión del modem GSM está parpadeando lentamente en color azul

II. Si en el programa Frontline SMS, en la sección de "Últimos eventos", dice: "Teléfono conectado C885"

4. El computador está prendido, pero Frontline SMS no está abierto

a. Revise que el ícono de corriente del modem GSM es azul

I. Si está de color azul, desconecte y espere 30 segundos y luego reconecte el modem al puerto USB del computador

b. Una vez el ícono de corriente esté azul, espere 30 segundos y abra el programa Frontline SMS

c. Frontline SMS demora entre 2-5 minutos para detectar el modem GSM

d. Usted puede saber si Frontline SMS está conectado al modem GSM, si alguno de los siguientes dos eventos suceden:

I. Si el ícono de conexión del modem GSM está parpadeando lentamente en color azul

II. Si en el programa Frontline SMS, en la sección de "Últimos eventos", dice: "Teléfono conectado C885"

5. El modem GSM está alumbrando en color rojo, o no está alumbrando, o la luz del modem GSM no está parpadeando

a. Desconecte el modem GSM

b. Cierre el programa Frontline SMS

c. Reconecte el modem GSM al computador

d. Espere hasta que el ícono de corriente se prenda (color azul)

e. Una vez el ícono de corriente esté azul, espere 30 segundos y abra el programa Frontline SMS

f. Frontline SMS demora entre 2-3 minutos para detectar el modem GSM

g. Usted puede saber si Frontline SMS está conectado al modem GSM, si alguno de los siguientes dos eventos suceden:

i. Si el ícono de conexión del modem GSM está parpadeando lentamente en color azul

ii. Si en el programa Frontline SMS, en la sección de "Últimos eventos", dice: "Teléfono conectado C885"

6. El modem GSM está desconectado

a. Examine el modem GSM para ver si está dañado

i. si el modem parece dañado, vea la sección 6 de solución a problemas

b. Si el modem GSM no está dañado, cierre el programa Frontline SMS

c. Reconecte el modem GSM a alguno de los puertos USB del computador

d. Espere hasta que el ícono de corriente se prenda (color azul)

e. Una vez el ícono de corriente esté azul, espere 30 segundos y abra el programa Frontline SMS

f. Frontline SMS demora entre 2-3 minutos para detectar el modem GSM

g. Usted puede saber si Frontline SMS está conectado al modem GSM, si alguno de los siguientes dos eventos suceden:

i. Si el ícono de conexión del modem GSM está parpadeando lentamente en color azul

ii. Si en el programa Frontline SMS, en la sección de "Últimos eventos", dice: "Teléfono conectado C885"

7. El modem GSM está dañado

a. Si es posible, tome un par de fotos y envíeselas a Tim (tbarlott@ualberta.ca)

b. Retire la SIM card del modem GSM

i. La SIM card está situada en la ranura del puerto USB

ii. Presione la SIM card hacia el modem, así se logra soltar y retirar la SIM card

c. Busque el segundo modem GSM en el estuche portátil

d. Inserte la SIM card en el nuevo modem como lo indica la imagen en la sección inicial de la configuración. También puede observar un diagrama en la parte posterior del modem que muestra como insertar la SIM card. Si la SIM card parece estar atascada o no es fácil de insertar, no la fuerce. Si esto pasa, remueva la SIM card, asegúrese que la SIM card está orientada en la posición correcta y reinsértela de nuevo

e. La SIM card debería hacer click en la posición correcta y debe encajar a la perfección

f. Reconecte el modem GSM a alguno de los puertos USB del computador

g. Espere hasta que el ícono de corriente se prenda (color azul)

h. Una vez el ícono de corriente esté azul, espere 30 segundos y abra el programa Frontline SMS

i. Frontline SMS demora entre 2-3 minutos para detectar el modem GSM

j. Usted puede saber si Frontline SMS está conectado al modem GSM, si alguno de los siguientes dos eventos suceden:

i. Si el ícono de conexión del modem GSM está parpadeando lentamente en color azul

ii. Si en el programa Frontline SMS, en la sección de "Últimos eventos", dice: "Teléfono conectado C885"

8. Aparentemente todo está bien, pero Frontline SMS no está enviando ni recibiendo mensajes

a. Esto puede suceder de vez en cuando

b. Desconecte el modem GSM

c. Cierre el programa Frontline SMS

d. Reconecte el modem GSM al computador

e. Espere hasta que el ícono de corriente se prenda (color azul)

f. Una vez el ícono de corriente esté azul, espere 30 segundos y abra el programa Frontline SMS

g. Frontline SMS demora entre 2-3 minutos para detectar el modem GSM

h. Usted puede saber si Frontline SMS está conectado al modem GSM, si alguno de los siguientes dos eventos suceden:

i. Si el ícono de conexión del modem GSM está parpadeando lentamente en color azul

ii. Si en el programa Frontline SMS, en la sección de "Últimos eventos", dice: "Teléfono conectado C885"

9. He seguido todas las instrucciones, pero todavía no funciona

a. Desconecte el modem GSM

b. Cierre el programa Frontline SMS

c. Apague el computador

i. Deje el computador apagado por 30 segundos

d. Prenda el computador y siga los pasos de la sección 1 de solución a problemas

e. Si después de haber seguido las instrucciones, usted todavía no puede enviar mensajes de textos, escríbale a Tim (tbarlott@ualbert.ca). Tim intentará arreglarlo remotamente o propondrá una reunión vía Skype para solucionar el problema.

f. Si después de consultar a Tim el problema continúa, es probable que se trate de una dificultad con la red de telefonía celular y alguien deba

llamar al proveedor al teléfono número:_____.

10. Otros problemas

a. Si usted tiene otra pregunta o duda, no duda en escribirle a Tim. El estará dispuesto para resolver cualquier duda, recibir cualquier comentario o para conversar vía correo electrónico.

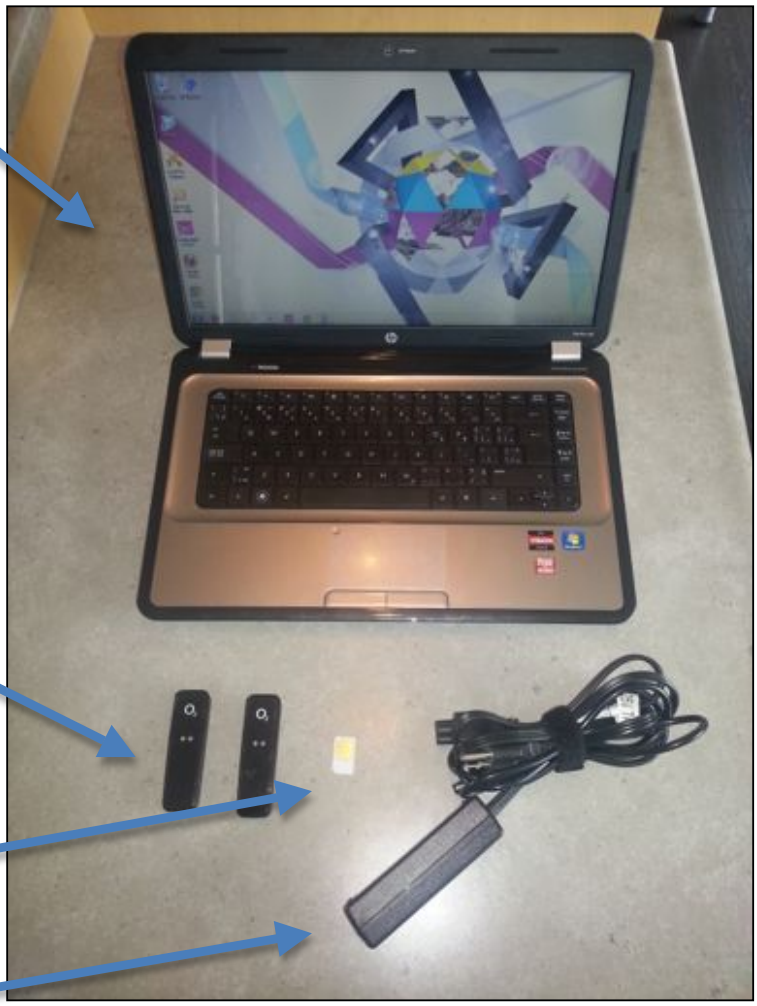
Imágenes de las partes y la instalación

Computador Portátil

Modem GSM (2)

SIM card

Cable de corriente



1

El modem GSM:

Frente Revés

Insertar la SIM card en el modem GSM

1.

2.

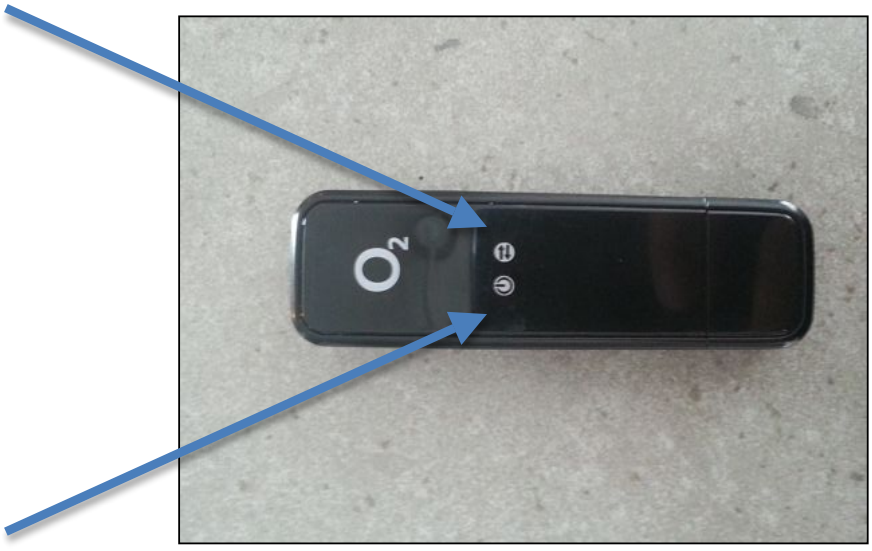
3.

4.

El modem GSM insertado en el puerto USB

Icono de Conexión a Datos

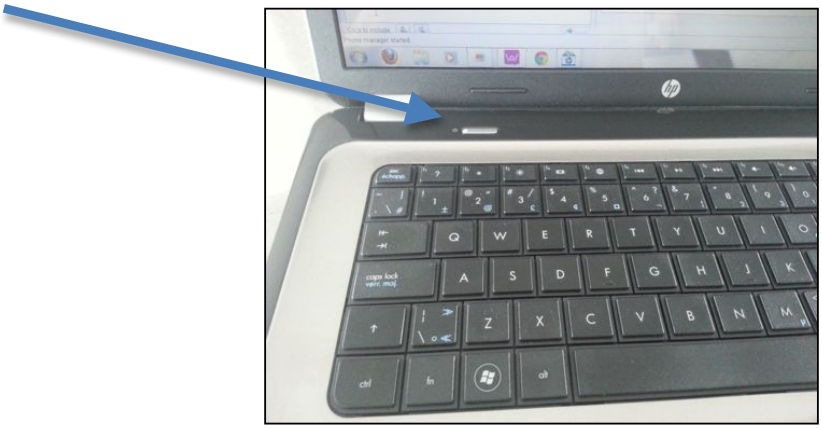
- La luz azul debe parpadear lentamente durante uso normal

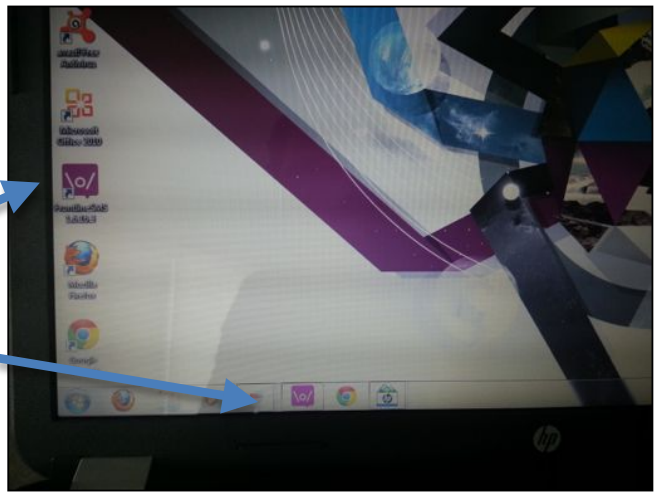


Icono de Encendido

- La luz azul de este icono debe permanecer encendida durante uso normal

Ícono de encendido del computador portátil





Iconos del programa FrontlineSMS

4

Appendix F

Intervention Keywords

Coordination Team - Information

Keywords – *remember that ALL keywords must be sent to the project phone number **3208107249** and must have a space after the keyword.*

Info – to send information to participants. This will also be received by the administration team

Received by participants as: "El Enlace informacion - _____"

Administrador – to send a message to the administration team

Received by administration team as: "De *'nombre'* - _____"

Hola el enlace – to test if the system is working

The system will auto-reply: "Hola *'nombre"*"

For administration team to send a message to specific participants, start the message with their name followed by a space:

Ana
Carmenza
Claudia
Diana
Esperanza
Liliana
Maria
Nelson
Stella
Yolanda

Received by participants as: "De *'nombre'* - _____"

To send a message to specific members of the administration team, start the message with their name followed by a space:

Tim
Monica
Indira
Francene
Patricia
Paola

Received by team member as: “De *‘nombre’* - _____”

Participant keywords:

Cuidadores – to send a message to other participants (social interaction). Will also be received by the administration team

Received by participants as: "De *'nombre'* - _____"

Pregunta – to ask a question of the administration team (health or general). Will be received by only the administration team

Received by administration team as: "Pregunta de *'nombre'*- _____"

Auto-reply to the participant: "Gracias por su mensaje espere su respuesta"

Cancelar – to cancel subscription to the El Enlace project

Auto-reply to the participant: "Gracias pr su participacion"

Received by administration team as: "Cancelar de *'nombre'*

If keyword is incorrect, recipients will automatically received this message:

"Sorry, the keyword was incorrect. Please use a keyword as listed in your instructions. For example, cuidadores o pregunta. Gracias"

Equipo de administración - Información

Palabras clave – Recuerde que todas las palabras clave deben ser enviadas al número telefónico del proyecto ***3208107249*** *y deben darle un espacio después de la palabra clave.*

Info – para enviar información a los participantes. Este mensaje también será enviado al equipo de administración

El mensaje es recibido de esta forma por los participantes:
"Info- _____"

Administrador – para enviar un mensaje al equipo de administración

El equipo de administración recibe el mensaje de la siguiente forma:
"De *'nombre'*- _____"

Hola el enlace – para probar si el sistema funciona

El sistema responderá automáticamente: "Hola *'nombre"*"

Para responder a una pregunta. Este mensaje también será enviado al equipo de administración Para que el equipo de administración envíe mensajes a participantes específicos, el mensaje debe iniciar con los nombres de los participantes, seguido por un espacio. A continuación se expone un ejemplo:

Enviar ana
Enviar carmen
Enviar claudia
Enviar diana
Enviar esperanza
Enviar maria
Enviar nelson
Enviar stella

Los participantes recibirán el mensaje de la siguiente forma:
"Respuesta- _____"

Para enviar un mensaje a miembros específicos del equipo de administración, empiece el mensaje con los nombres de las personas, seguidas por un espacio:

Monica
Indira
Francene
Patricia

Juliana

Paola
Sebastian
Anai

Los miembros del equipo recibirán el mensaje de la siguiente forma:
"De *'nombre'* - _____"

Palabras clave para los participantes:

Cuidadores – para enviar un mensaje a otros participantes (interacción social). Estos mensajes también serán recibidos por el equipo de administración

Los mensajes son recibidos por los participantes como:
"De *'nombre'* - _____"

Pregunta – para formular una pregunta al equipo de administración (salud or tema general). Estos mensajes serán recibidos unicamente por el equipo de administración

Los mensajes son recibidos por los participantes como:
"Pregunta de *'nombre'*- _____"

Respuesta automática a los participantes: "Gracias por su mensaje espere su respuesta"

Cancelar – para cancelar la suscripción a El Enlace

Respuesta automática al participante: "Gracias por su participacion"

Los mensajes son recibidos por el equipo de administración: "Cancelar de *'nombre'*

**Si la palabra clave es incorrecta, las personas que reciben el mensaje recibirán la siguiente respuesta automática:*

"Lo lamento, la palabra clave is incorrecta. Por favor utilice las palabras claves que aparecen en las instrucciones. Por ejemplo, cuidadores o pregunta. Gracias"

Appendix G

Participant Fact Sheet and Instructions

Fact Sheet

The El Enlace project is for people with disabilities in El Codito. Participants will receive health information text messages. Participants will be able to interact with other participants using text messages. All text messages will come from the project phone number: *3106090271*. This phone number can ONLY send and receive text messages and *does not receive phone calls.*

The El Enlace project is a collaboration between the University of Rosario, the University of Alberta (in Canada) and the community of El Codito. With your participation we can expand the project to other people with disabilities in El Codito.

Cost

It is FREE to receive messages from El Enlace.

Your mobile provider will charge you if you send a text message as a part of the project.

Participant Requirement

- *Disability* - Either you or a family member living in your home has a disability
- *Mobile Phone* – Someone in your household must have a mobile phone subscription. This mobile phone must have the ability to receive text messages
- *Willingness* to receive a minimum of 3 text messages every week

Confidentiality

Your name will not be shared with other participants. You will be asked to create a username for the project.

Questions about the study?

If you have any questions you can call Edgar Luna (ph 3414006) or Nadia Rodriguez (ph 3414006). Edgar and Nadia are both professors at the University of Rosario. You may also contact local community leader Patricia Puentes (ph 123456789).

When?

El Enlace will begin on August 27, 2012

El Enlace - Instructions

- Send all messages to the project phone number: ***3106090271***
- ***All*** messages ***must*** begin with the keywords identified below
- The El Enlace administrator will receive all messages even if sent incorrectly. The El Enlace administrator will send a message to clarify your intent.

Subscription

The El Enlace research team will register your phone number when they visit your home.

Health Information Questions

If you have a question about the health information you receive, send your question to the project phone number. If you have a general health question, send your question to the project phone number. An El Enlace leader will respond to your question within 24 hours.

Social Interaction

Follow these instructions if you would like to send a text message to all El Enlace participants:

Begin a text message with: ***SEND TO ALL***

Then continue with your message

Example of a message I could send to other participants:

"send to all, good morning everyone, I hope you have a great day"

How this message would be received by other participants:

"From Tim - good morning everyone, I hope you all have a great day"

Technical Assistance

Are you are having difficulty participating in the project and need help? Send the following message to the project phone number and someone will contact you within 24 hours:

HELP

Unsubscribe

Do you want to stop participating in the project? Send the following message to the project phone number:

STOP

Thank you for your willingness to participate in this project! We look forward to working with you over the next 4 months.

We hope you enjoy participating in the El Enlace project.

El proyecto El Enlace es para cuidadores de personas en condición de discapacidad que viven en el sector El Codito, los cuales recibirán información sobre salud y otras tematicas de interes a través de mensajes de texto. Asi mismo los participantes podrán interactuar entre ellos usando mensajes de texto y haciendo preguntas al equipo del proyecto.

El proyecto El Enlace es una colaboración entre la Universidad del Rosario, la Universidad de Alberta (en Canadá), y la comunidad de El Codito. Con su participación podremos expandir el proyecto a otras personas con discapacidad de El Codito.

Costo

Es GRATIS recibir mensajes de El Enlace.

Se hara entrega de tarjetas prepago a los participantes para uso del proyecto, es decir para el envio de los mensajes correspondientes.

Requisitos para participar

- *Discapacidad*- Usted o un miembro de su familia que vive con usted esta en condición de discapacidad.
- *Celular*- Alguien en su casa debe tener un celular activado. Este celular debe poder recibir mensajes de texto.
- *Disposición* para recibir un mínimo de 3 mensajes de texto cada semana.

Cuando?

El Enlace iniciara el 22 de Agosto del 2012.

El Enlace – Instrucciones

- Envíe todos los mensajes al numero celular del proyecto: ***3208107249***
- ***Todos*** los mensajes ***deben*** empezar con la palabras claves mencionadas a continuación.
- El administrador de El Enlace recibirá todos los mensajes incluso si son enviados de forma incorrecta. Si esto sucede, el administrador le enviara un mensaje para clarificar su intención.

Suscripción

El equipo de investigación de El Enlace registrara su numero de celular cuando visiten su casa.

Preguntas sobre Información de interes

Si usted tiene alguna pregunta sobre la información que reciba, envíe su pregunta al numero celular del proyecto. Un líder de El Enlace responderá a su pregunta en las siguientes 24 horas o el lunes en caso de que su pregunta sea realizada el fin de semana.

Interacción social

Siga las siguientes instrucciones si desea enviar un mensaje a todos los participantes de El Enlace. Es importante que Ud conozca que lo primero que debe hacer para enviar un mensaje es escribir un comando (palabra), el cual se le dira a continuación. Por favor no coloque ningun signo de puntuación después del comando, unicamente deje un espacio.

Comunicacion entre participantes

Si ud quiere relacionarse con otras personas que se encuentran en el proyecto, escribales un mensaje.

Empiece el mensaje con: **cuidadores**

Ejemplo de un mensaje enviado a todos los participantes:

"cuidadores buenos días para todos, espero que tengan un buen día"

Los otros participantes recibirían este mensaje, de la siguiente manera:

"De (nombre de la persona que envia el mensaje)- buenos días para todos, espero que tengan un buen día"

Comunicación con el equipo gestor del Enlace

Si Ud quiere hacer una pregunta al equipo del Enlace sobre informacion que desee conocer, siga lo que se indica a continuacion. Despues de enviada la pregunta Ud recibira un mensaje de confirmacion de recibido y quedara en espera de la respuesta. En caso de tener alguna dificultad tecnica, por favor indiquelo al equipo con el mismo commando.

Empiece el mensaje con: **pregunta**

Ejemplo de un mensaje enviado al equipo del enlace:

"pregunta donde puedo ir para que me asesoren sobre colocar un derecho de peticion"

"pregunta no estoy recibiendo los mensajes, que hago"

Cancelar suscripción

Desea dejar de participar en el proyecto?

Empiece el mensaje con: **cancelar**

Gracias por su disposición para participar en este proyecto! Estamos muy felices de trabajar con usted durante los próximos 3 meses.

Esperamos que disfrute participar en el proyecto El Enlace.

Appendix H

Consent Forms

PARTICIPANT CONSENT FORM

Title of Study: *The impact of using a mobile phone, text messaging system for health information access and social interaction for people with disabilities in an under-resourced Colombian community*

Principal Investigator: Tim Barlott

Supervisor: Dr. Kim Adams

Project title: *El Enlace.*

Why am I being asked to participate in this research study?

You are being asked to participate in this project because you have a disability and live in El Codito. You are also a member of a disability program in El Codito.

We think that people with disabilities in El Codito have difficulty accessing health information. People with disabilities in El Codito also have difficulty leaving their own homes. This makes it difficult to access clinics and to interact with people in the community.

Many people in El Codito have mobile phones. This project will use mobile phones to help people with disabilities. The El Enlace project will last for 3 months. As part of the project you will receive regular health information text messages. This project will give you the opportunity to interact with other participants using text messages.

At the completion of the project you will be asked to receive an interview. This interview will help us understand your experience participating in the project.

Before you make a decision one of the researchers will go over this form with you. You are free to ask questions if you need to clarify anything. You will be given a copy of this form for your records.

What is the reason for doing the study?

We will study the use of mobile phones for sending information and social interaction. We will study this use of mobile phones for people with disabilities in El Codito. We want to understand your experience participating in the El Enlace project.

What will I be asked to do?

You will be asked to register your mobile phone number with the project. Once registered you will receive health information text messages as part of the project. You will receive a minimum of 3 text messages every week. At times you will have the option of receiving additional information. If you choose you can follow the instructions to request this additional information. You have the option of sending social interaction messages if you choose. You are free to send as many or as little messages as you choose.

After 3 months you will be asked to participate in a 2 hr focus group. In this focus group you can describe and discuss your experience participating in the project with other participants and researchers. There are no right or wrong answers to the focus group questions. We want to hear many different viewpoints and would like to hear from everyone. We hope you can be honest even when your responses may not be in agreement with the rest of the group.

This focus group will be tape-recorded so that researchers can review the focus group discussion. The team will look for themes, similarities and general observations in the focus group recording.

Who will read my text messages?

You may choose to send text messages as part of the project. Only the other participants and the project administrators will receive these text messages. At the end of the 3-month project the research team will analyze all the messages that were sent by participants. These messages will be organized into themes. Some messages may be quoted when sharing the research findings but will not include any personally identifiable information.

What are the risks and discomforts?

We do not believe there will be any risks or discomforts from participating in this research.

Researchers have made plans to minimize any risks to study participants. If any inappropriate messages are sent during the project by a participant (example: discriminatory, illegal, etc) project administrators will intervene. After the first occurrence of an inappropriate message an administrator will warn the participant. If a second instance occurs the participant will be blocked from sending additional messages.

What are the benefits to me?

You will have the opportunity to receive new health information and ask health questions. You will also have the opportunity to interact with others who have a similar disability. Your involvement will help improve the El Enlace project for future use in El Codito. This research will help improve healthcare for people with disabilities.

Do I have to take part in the study?

Being in this study is your choice. You can change your mind and leave the study at any time. Leaving the study will not affect the care you receive from the University of Rosario. Leaving the study will also not affect the care you receive from health professionals. You can also choose to leave the focus group at any time.

What will it cost me to participate?

There are no costs associated with basic participation in the study.

Your mobile provider will charge you if you send a text message as a part of the project.

Will my information be kept private?

We will do everything we can to keep your information private. Your name or other identifiable information will be removed from our records at the end of the study. The data we share from this study will not include any of your personal information. In some situations the law requires us to release your information. As a result we cannot guarantee absolute privacy. We will make every legal effort to make sure that your information is kept private.

All information will be kept in a locked office at the University of Rosario and the University of Alberta.

After the study is done we will continue to securely store the data from the study. The University of Alberta and the University of Rosario will keep data for 5 years after the end of the study.

If you choose to leave the study early we will stop collecting information from you. But we will need to keep the data that we have already collected.

Focus Group Confidentiality

We cannot guarantee confidentiality in a focus group setting. All information that is collected by researchers will be kept confidential. In respect for each other, we ask that the responses made by all participants be kept confidential.

What if I have questions?

If you have any questions about the research, please contact:

Edgar Luna – University of Rosario

Phone: 3414006 ext 222

or

Nadia Rodriguez – University of Rosario

Phone: 3414006.

If you have any questions regarding your rights as a research participant, you may contact the Research Ethics Board in Canada at 780-492-2614. This office has no affiliation with the study investigators.

CONSENT

Title of Study: *The impact of using a mobile phone, text messaging system for health information access and social interaction for people with disabilities in an under-resourced Colombian community*

Principal Investigator: Tim Barlott **Phone Number:** 780-237-2595

Study Supervisor: Dr. Kim Adams **Phone Number:** 780-492-0309

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to leave the study at any time, without having to give a reason and without affecting your future medical care?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to your records, including personally identifiable health information?	☐	☐

Who explained this study to you?

_____

I agree to take part in this study:

Signature of Research Participant

_____

(Printed Name)

_____

Date:_____

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee_____ Date _____

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT

CONSENTIMIENTO INFORMADO

El impacto del uso de un sistema de mensajes de texto de teléfonos móviles, en el acceso a información en salud e interacción social de personas en condición discapacidad en una comunidad vulnerable Colombiana.

Investigador Principal: Tim Barlott

Supervisor: Dra. Kim Adams

Título del Proyecto: *El Enlace.*

Lo hemos invitado a participar en este estudio porque usted es una cuidadora de una persona en condición de discapacidady vive en El Codito**.** Dicho proyecto tendrá una duración de tres meses.

Creemos que las personas en condición de discapacidad tienen dificultades para acceder a diferentes tipos de información por ejemplo: salud, así como para salir de su casa, resultándoles difícil desplazarse a los servicios de salud y/ o interactuar con otras personas en la comunidad.

Este proyecto hará uso de teléfonos celulares para ayudar a las personas en condición de discapacidad y sus cuidadores.

Como parte del proyecto usted:

- Recibirá mensajes de texto con información de su interés.
- Podrá relacionarse con otros participantes vía mensajes de texto. Podrá enviar sus dudas sobre el tema de discapacidad a los gestores del proyecto.
- Participará en una entrevista, al finalizar el proyecto, lo cual nos permitirá valorar su experiencia como participante del proyecto.

Antes de tomar una decisión, uno de los investigadores revisará este formato con usted. Siéntase en libertad de hacer preguntas si necesita clarificar algo. Le daremos una copia de este formato.

¿Cuál es la razón para hacer este estudio?

Estudiaremos el uso de teléfonos celulares para enviar información y para la interacción social. Estudiaremos el uso de teléfonos celulares con este propósito en cuidadores de personas en condición de discapacidad en El Codito. Queremos entender su experiencia participando en el Proyecto El Enlace.

¿Qué se me pedirá que haga?

Le pediremos que registre su número celular en el proyecto; una vez registrado el número celular, usted recibirá mensajes de texto sobre diversos temas, entre ellos salud. Recibirá un mínimo de 3 mensajes de texto por semana, en algunos momentos usted tendrá la opción de recibir información adicional. También podrá seguir las instrucciones para pedir más información y así mismo podrá enviar mensajes para relacionarse con otros si así lo desea. Usted es libre de enviar la cantidad de mensajes que desee.

Después de 3 meses, nuevamente nos contactaremos con usted y le pediremos que participe en un grupo focal de dos horas de duración. En este grupo focal usted describirá y discutirá su experiencia de participación en el proyecto con los otros participantes y los investigadores.

No hay respuestas correctas ni erradas. Solo queremos escuchar sus opiniones y puntos de vista. Queremos escucharlos a tod@s. Esperamos que ustedes sean honestos incluso cuando sus respuestas no esten de acuerdo con la de los demas.

Este grupo focal sera grabado asi los investigadores pueden revisar las discusiones generadas en el grupo focal. El equipo de investigadores observara temas, puntos de encuentro y generalidades en estas grabaciones.

¿Quién va a leer mis mensajes de texto?

Solamente los otros participantes y los gestores del proyecto. Solo ellos recibirán estos mensajes de texto. Al final de los tres meses del proyecto, el equipo gestor analizará todos los mensajes enviados por los participantes. Estos mensajes serán organizados por temas. Algunos mensajes serán citados cuando se estén compartiendo los resultados de la investigación pero no incluirán ninguna información personal o de identificación.

¿Cuáles son los riesgos o incomodidades?

No creemos que haya ningún riesgo o incomodidad como resultado de participar en este estudio.

No obstante, los gestores del proyecto tienen un plan de emergencia con el fin de minimizar los riesgos a los participantes en caso de aparecer.

Si algún participante envía un mensaje inapropiado durante el proyecto (por ejemplo: discriminatorio, irrespetuoso, ilegal, etc.) los gestores del proyecto intervendrán, de modo que al ocurrir esta situación por primera vez, se dará un aviso al participante. Si el participante vuelve a enviar un mensaje inapropiado, el participante este será bloqueado y no podrá enviar más mensajes.

¿Cuáles son mis beneficios?

Usted tendrá la oportunidad de:

- Recibir nueva información general con respecto a temas de discapacidad y salud,
- También tendrá la oportunidad de hacer preguntas y resolver sus inquietudes.
- De igual modo, podrá interactuar con otros cuidadores de personas en condición de discapacidad.

Su participación ayudara a mejorar El Enlace para su uso futuro en El Codito y en consecuencia ayudará a reducir las barreras a la información de los cuidadores y las personas en condición de discapacidad.

¿Tengo la obligación de participar?

No. Estar en este estudio es su decisión. Usted puede cambiar de opción en cualquier momento y decidir abandonar el estudio. Dejar de participar no va a afectar de ninguna manera su participación en actividades con la Universidad del Rosario. Dejar de participar tampoco va a afectar de ninguna manera la atención que recibe de profesionales de la salud.

Usted también puede decir abandonar el grupo focal a cualquier momento de este.

¿Cuánto me cuesta participar?

No hay ningún costo asociado con participar en este estudio.

Nosotros nos encargaremos de pagar los mensajes de texto de acuerdo a su plan de telefonía celular.

¿Mi información será confidencial?

Si. Toda información será archivada en un archivador bajo llave en la Universidad del Rosario y la Universidad de Alberta. Los datos que sean compartidos de este estudio no incluirán ninguna información personal ni datos de identificación.

Haremos todo lo posible para que su información permanezca confidencial. Su nombre y toda información identificable será removida de nuestros archivos al finalizar el estudio. En algunos casos la ley puede requerir acceso a la información. En este caso, no podemos garantizar total privacidad. Haremos todos los esfuerzos legales por asegurar que su información sea mantenida en confidencialidad.

Después del estudio, la Universidad del Rosario y la Universidad de Alberta guardaran los datos por 5 años más de manera segura de acuerdo a políticas de las Universidades.

Si usted elige retirarse del estudio, pararemos cualquier proceso de recolección de información con usted. Sin embargo, la información que ya haya sido recolectada no podrá retirarse.

Confidencialidad del Grupo Focal

Nosotros no podemos garantizar confidencialidad en un grupo focal. Lo que si aseguramos es que la información recopilada por los investigadores permanecerá confidencial. Buscando un ambiente de respeto y comprensión, pedimos que todos los participantes mantengan la confidencialidad de las respuestas de los otros participantes.

¿Qué pasa si tengo preguntas?

Si usted tiene alguna pregunta sobre esta investigación, por favor contacte:

Mónica Mendoza – Universidad del Rosario

Teléfono: 2970200 ext. 7737

Si usted tiene alguna pregunta acerca de sus derechos como participante en este estudio, usted puede contactar al Comité de ética en Investigación en Salud en Canadá en el 780-492-2614. Esta oficina no tiene ninguna afiliación con los investigadores del estudio.

CONSENTIMIENTO INFORMADO

Título del estudio: El impacto del uso de un sistema de mensajes de texto de teléfonos móviles, en el acceso a información en salud e interacción social de personas en condición discapacidad en una comunidad vulnerable Colombiana

Investigador Principal: Tim Barlott **Teléfono:** 780-237-2595

Supervisor: Dra. Kim Adams **Teléfono:** 780-492-0309

	Si	No
¿Entiende usted que ha sido invitado a participar voluntariamente en una investigación?	☐	☐
¿Ha leído y recibido una copia de la hoja de información?	☐	☐
¿Entiende los beneficios y posibles riesgos de participar en esta investigación?	☐	☐
¿Ha tenido una oportunidad para hacer preguntas y discutir sus dudas?	☐	☐
¿Entiende que es libre de retirarse en cualquier momento, sin necesidad de dar una razón y sin que afecte sus servicios de salud?	☐	☐
¿Se le ha explicado el tema de confidencialidad?	☐	☐
¿Entiende usted quién tendrá acceso a los datos y a su información de contacto?	☐	☐

¿Quién le explicó este estudio?
_____

Acepto participar en el estudio:

Firma del participante
_____

(Nombre)
_____

Fecha: _____

Considero que la persona que firma este formato entiende lo que implica participar en este estudio y acepta participar de forma voluntaria.

Firma del investigador o designado _____ Fecha _____

LA HOJA DE INFORMACION DEBE SER ADJUNTADA A ESTE CONSENTIMIENTO INFORMADO Y UNA COPIA DEBE SER ENTREGADA AL PARTICIPANTE

Appendix I

Demographic Information Form

Demographic Information Form

Date Demographic Information Form was competed: (____/____/____)
(*DAY/MON/YEAR*)

Name of Participant: _____

Participant Pseudonym: _____

Type of participant *(circle)*: *Person with disability* OR *Caregiver*

Name of Parent/Caregiver: _____

Name of person completing form: _____

Date Informed Consent Signed: (____/____/____)
(*DAY/MON/YEAR*)

Demographics

Date of Birth: (____/____/____)
(*DAY/MON/YEAR*)

Address: _____

Phone Number: _____

Gender (check one): ___ Male ___ Female

Medical Conditions

1. _____
2. _____
3. _____
4. _____
5. _____
6. _____

Do you or a family member have a mobile phone: ___Yes ___No

How often do you text message? *(circle below)*

Never / Less than once a month / Once a month / Once a week / More than once a week / Daily

How confident do you feel sending text messages? *(circle below)*

Not very confident / Somewhat confident / Confident / Very confident

What kind of phone subscription do you have? ___Pre-paid ___Monthly contract

How much assistance do you need to leave your home? *(circle below)*

None, I'm independent / Assistance from one / Assistance from more than one / Unable to leave home

Assessments

How do you feel about your health? *(circle below)*

7	*6*	*5*	*4*	*3*	*2*	*1*
Delighted	*Pleased*	*Mostly Satisfied*	*Mixed (equally satisfied & dissatisfied)*	*Mostly Dissatisfied*	*Unhappy*	*Terrible*

Registration of People with Disabilities (*comments*): _____

Date assessment was competed: (____/____/____)
(*DAY/MON/YEAR*)

Measurement of Digital Poverty (*comments*): _____

Date assessment was competed: (____/____/____)
(*DAY/MON/YEAR*)

Multidimensional Social Exclusion Index (*comments*): _____

Date assessment was competed: (____/____/____)
(*DAY/MON/YEAR*)

Additional comments:

_____

_____

_____

_____

_____

_____

_____

Formato de Información Demográfica

el enlace

Fecha en la que el formato de Información demográfica fue completado: (____/____/____)
(*DÍA/MES/AÑO*)

Nombre del Participante: _____

Nombre de la persona que completo el formato: _____

Fecha de la firma del consentimiento informado: (____/____/____)
(*DÍA/MES/AÑO*)

Información demográfica:

Fecha de nacimiento: (____/____/____)
(*DÍA/MES/AÑO*)

Dirección: _____

Número de teléfono: _____

Genero (seleccione uno): ___ Masculino ___ Femenino

Condiciones Médicas Cuidador

1. _____
2. _____
3. _____

Condiciones Medicas Persona con discapacidad

1. _____
2. _____
3. _____

Usted o alguien de su familia tiene un teléfono celular: ___Yes ___No

Que tan frecuentemente usted usa mensajes de texto? *(señale a continuación)*

Nunca/Menos de una vez al mes/Una vez al mes/Una vez a la semana/Mas de una vez a la semana/ A diario

Que tan cómodo se siente enviando mensajes de texto? *(señale a continuación)*

No muy cómodo / Algo cómodo / Cómodo / Muy cómodo

Que clase de plan celular tiene usted? ___Pre-pago ___Post pago

Nombre de la compañía de su proveedor: _____

Evaluaciones

Como se siente con relación a su salud? *(señale a continuación)*

7	*6*	*5*	*4*	*3*	*2*	*1*
Muy complacido	*Contento*	*Satisfecho en general*	*Ni lo unto ni lo otro (igualmente satisfecho e insatisfecho)*	*Insatisfecho en general*	*Descontento*	*Terrible*

Medida de pobreza digital (*comentarios*): _____

Fecha de la evaluación: (____/____/____)
(*DÍA/MES/AÑO*)

Índice de exclusión social multidimensional (*comentarios*): _____

Fecha de la evaluación: (____/____/____)
(*DÍA/MES/AÑO*)

Comentarios adicionales:

_____

_____

_____

_____

_____

_____

Appendix J

Measurement of Digital Poverty

Measurement of Digital Poverty

			Telephone Use						Computer & Internet Use		
			Owns fixed-wire	*Owns mobile*	*Uses for voice calls*	*Uses for text-messaging*	*Uses for email*	*Uses for mobile Internet*		*Owns a computer*	*Computer has Internet access*
	Owns Radio	Owns Television	Owns Telephone						Uses Internet in Telecentres	Computer & Internet at Home	
Household Response **select all that apply*											<- *Supplementary fields*
Extremely Digitally Poor	✓	✓	x						x	x	
Digitally Poor	✓	✓	✓						x	x	
Connected Household	✓	✓	✓						✓	x	
Connected Household 1	✓	✓	x						✓	x	
Connected Household 2	✓	✓	✓						✓	x	
Digitally Wealthy	✓	✓	✓						✓	✓	

(Barrantes, 2007) *Items in italics were added to the standard measurement*

Measurement of Digital Poverty

Questions

1. Household owns a radio - y/n
2. Household owns a television – y/n
3. Household owns a telephone – y/n
    a. Owns a fixed-wire phone – y/n
    b. Owns a mobile phone – y/n
        i. Uses mobile phone for voice calls – y/n
        ii. Uses mobile phone for text messaging – y/n
        iii. Uses mobile phone for email – y/n
        iv. Uses mobile phone for internet – y/n
        v. Uses mobile phone for other – y/n

        Other: _____
4. Members of household use Internet in Telecentres (e.g. Internet café) – y/n
5. Household owns a computer and uses Internet at home – y/n
    a. Owns a computer – y/n
    b. Home computer has an Internet connection – y/n

Medición de pobreza Digital

Nombre: _____ Fecha: _____

Preguntas

6. La casa cuenta con radio - s/n
7. La casa cuenta con televisión – s/n
8. La casa cuenta con teléfono – s/n
    a. Cuenta con teléfono fijo
    b. Cuenta con celular – s/n
        i. Usa celular para llamadas – s/n
        ii. Usa celular para mensajes de texto – s/n
        iii. Usa celular para consultar el correo electrónico – s/n
        iv. Usa celular para navegar en internet – s/n
        v. Usa celular para otros – s/n

            Otros: _____
9. Miembros de la familia usan internet fuera del hogar (ej: café Internet, colegio) – s/n
10. Miembros de la familia tienen un computador y usan internet en la casa – s/n
    a. Tienen un computador – s/n
    b. El computador en casa tiene conexión a internet – s/n

Appendix K

Multidimensional Social Exclusion Index

Multidimensional Social Exclusion Index (United Nations Development Programme, 2011)

Dimensions	***Indicator***	***Yes / No***
Economic Exclusion	1. *Inequality*: At-risk-of-poverty rate (below the national poverty line)	
	2. *Subjective basic needs*: In the past 12 months the household has not been able to afford three meals a day, or pay bills regularly, or keep the home adequately warm, or buy new clothes and shoes	
	3. *Employment*: Being unemployed or discouraged worker	
	4. *Financial services*: Lack of access to a bank account in one's own name	
	5. *Material deprivation_housing*: The household cannot afford a bed for everyone in the house	
	6. *Material deprivation_amenities*: Household needs a washing machine, freezer or microwave but cannot afford one	
	7. *Material deprivation_ICT*: Household needs a computer or internet but cannot afford one	
	8. *Overcrowding*: Household with approximately less than $6m^2$ per person	
Exclusion from Social Services	9. *Public utilities*: Household with no running water or sewerage system	
	10. *Public utilities*: Household heats with wood or with no heating device	
	11. *Education*: Low educational achievements (basic schooling) and early school leavers	
	12. *Education*: Household could not afford to buy school materials for every child in the past 12 months	
	13. *Education*: Household with young children not in school or pre-school	
	14. *Heath care*: Household could not afford medication or dental checks for every child in the past 12 months	
	15. *Health care*: Medical needs not being met by the healthcare system	
	16. *Social infrastructure*: Lack of opportunities to attend events due to distance or lack of transportation	
Exclusion from Civic and Social Life	17. *Social capital*: Rare or infrequent social contact with family or relatives	
	18. *Social capital*: Rare social contact with friends	
	19. *Social capital*: Lack of support networks that could help in the event of emergency	
	20. *Social participation*: In the past 12 months the household has not been able to afford inviting friends or family for a meal or drink at least once a month	
	21. *Social participation*: The household has not been able to afford to buy books, cinema or theatre tickets in the past 12 months	
	22. *Civic participation*: Inability to vote due to lack of eligibility or distance or inability to get to polling station	
	23. *Civic participation*: No participation/membership in associations, teams or clubs	
	24. *Civic participation*: No participation in political/civic activities	

** See referenced report for details and scoring*

Índice de exclusión social multidimensional (Programa de las Naciones Unidas para el desarrollo, 2011)

Nombre: _____ Fecha: _____

Dimensiones	***Indicador***	
Exclusión Económica	1. *Inequidad*: En riesgo de pobreza o vive por debajo de la línea nacional de pobreza . X (NA)	
	2. *Necesidades básicas subjetivas*: En los últimos 12 meses, las personas que habitan esta vivienda no han podido tener tres comidas al día, o pagar sus cuentas de forma regular, o comprar nuevas prendas de ropa o zapatos.	
	3. *Empleo*: Desempleo o trabajo en condiciones que no son optimas	
	4. *Servicios Financieros*: La persona no tiene acceso a una cuenta bancaria a su nombre	
	5. *Vivienda en inadecuadas condiciones*: En la casa no hay una cama para cada persona que habita la vivienda	
	6. *Deprivaciones materiales*: Las personas en la vivienda necesitan una lavadora, nevera o microondas pero no pueden pagarlo.	
	7. *Deprivaciones material- TICs*: Las personas en la vivienda necesitan un computador o internet peo no pueden pagarlo.	
	8. *Hasinamiento*: Cuantas personas viven en esta casa**?** _____ Cuantos metros cuadrados tiene esta casa? _____ Vivienda con aproximadamente menos de $6m^2$ por persona	
Exclusión de servicios sociales	9. *Servicios Públicos*: La casa no tiene sistema de alcantarillado o acueducto.	
	10. *Servicios Públicos*: La casa se mantiene caliente con madera o no hay sistema de calefacción. (NA) La casa tiene servicio de luz electrica.	
	11. *Educación*: Bajos niveles de acceso a la educación (educación básica) o ha dejado el colegio antes de terminar.	
	12. *Educación*: La familia no ha podido pagar útiles escolares para cada niño en los últimos 12 meses.	
	13. *Educación*: Familia con niños pequeños que no asisten al colegio o jardín.	
	14. *Salud*: La familia no ha podido pagar medicamentos o chequeos dentales para cada niño en los últimos 12 meses.	
	15. *Salud*: Las necesidades de salud no son cubiertas por el sistema de salud	
	16. *Infraestructura social*: Falta de oportunidades para asistir a eventos debido a la distancia o a la falta de transporte.	
Exclusión de la vida social y cívica	17. *Capital social:* Contacto social con familiares no es frecuente	
	18. *Capital social*: Contacto social con amigos no es frecuente	
	19. *Capital social*: Falta de una red de apoyo que pueda brindar ayuda en caso de emergencia.	
	20. *Participación social*: En los últimos 13 meses, la familia no ha podido invitar a familiares o amigos a comer, tomar onces o compartir una bebida por lo menos una vez al mes, debido a los costos que esto implica.	
	21. *Participación social*: La familia no ha podido comprar libros, ir a cine o pagar algún tipo de actividad de entrenamiento en los últimos 12 meses.	
	22. *Participación cívica*: Inhabilidad para votar debido a la distancia del puesto de votación, inaccesibilidad o dificultad para desplazarse.	
	23. *Participación cívica*: no participa o es miembro de grupos, asociaciones u organizaciones o clubes.	
	24. *Participación cívica*: no hay participación en actividades políticas o cívicas.	

Resultado - Al menos 9(de 24) deprivaciones, en al menos 2 de las 3 dimensiones **TOTAL**

Appendix L

Daily Update Email Sample

Tim Barlott <tbarlott@ualberta.ca> 30 October, 2012 9:09 PM

To: Monica Alexandra Mendoza Molina <monica.mendoza@urosario.edu.co>, Indira Velasquez Hernandez <indira.velasquez@urosario.edu.co>, Francene <francene8310@gmail.com>, Sebastian <alvarado.juan@ur.edu.co>, Anai <anai.mejias@hotmail.com>
El Enlace messages - October 30

Hola,

Please see the messages below, they require attention. Palabra clave incorrecta, stella y luz.

30 de octubre

PALABRA CLAVE INCORRECTA, STELLA Y LUZ: Cuidador de stella me gustaria Saber donde es el almuerzo y hasta que hora
respuesta automática: Lo lamento, la palabra clave es incorrecta. Por favor utilice las palabras claves que aparecen en las instrucciones. Por ejemplo, cuidadores o pregunta. Gracias
respuesta automática: Recuerde que debe poner un espacio despues de la palabra clave (cuidadores o pregunta) para que el mensaje se envie de forma correcta.

PREGUNTA de Stella y Luz: de stella me gustaria saber donde es el almuerzo y hasta que hora gracias

CUIDADORES de Patricia: el almuerzo es en la zona campestre de la universidad del rosario hasta la una o dos pm

PREGUNTA de Carmen: muchas gracias x la invitacion rober y yo asistiremos porfa mas datos del transporte

CUIDADORES de Patricia: el punto de encuentro para transporte es en la bahia que queda en tres esquinas del corito

PALABRA CLAVE INCORRECTA, STELLA Y LUZ: Cuidador de stella cuenten con nuestra asistencia
respuesta automática: Lo lamento, la palabra clave es incorrecta. Por favor utilice las palabras claves que aparecen en las instrucciones. Por ejemplo, cuidadores o pregunta. Gracias
respuesta automática: Recuerde que debe poner un espacio despues de la palabra clave (cuidadores o pregunta) para que el mensaje se envie de forma correcta.

Unanswered questions

Carmen's question from October 29:
PREGUNTA de Carmen: cuando hay un encuentro con todos los cuidadores y el grupo de investigacion espero verlos pronto muchas grcias por todo

Carmen's question from October 8:
PREGUNTA de Carmen: la discapacidad intelectual q es lo q mas afecta en la persona q la tiene y quisiera saber algunas causas q la producen muchas gracias y muchas bendiciones

Saludos,
Tim

On 2012-10-29, at 9:44 PM, Tim Barlott <tbarlott@ualberta.ca> wrote:

> Hola,
>
> Es un mensaje de actualización para 29 de octubre
>
> **29 de octubre**
>
> *CUIDADORES de Patricia:* el enlace los invita a un almuerzo el dia 15 de noviembre a partir de 8 30 am hay transporte favor confirmar asistencia solo se puede llevar un acompañante
>
> **Unanswered questions**
>
> *PREGUNTA de Carmen:* cuando hay un encuentro con todos los cuidadores y el grupo de investigacion espero verlos pronto muchas grcias por todo
>
> Carmen's question from October 8:
> *PREGUNTA de Carmen: la discapacidad intelectual q es lo q mas afecta en la persona q la tiene y quisiera saber algunas causas q la producen muchas gracias y muchas bendiciones*

Appendix M

Focus Group Guide

Focus Group Guide – Project El Enlace

Prior to the focus group

If possible provide participants with name cards or pieces of paper to fold in front of them with their name.

Pre-focus group script

Welcome everyone; we are so glad you could all make it today and so grateful for your participation in El Enlace!

As you know, my name is Monica and I will act as the moderator in our focus group today. This is Francene she will be the co-moderator. During this focus group I will ask questions, and then invite you to discuss the question amongst yourselves. The goal is not to answer to the moderators, but rather to have a group discussion with other participants.

The moderator's role is to ask specific questions and then sit back and listen. I will not offer opinions or responses to your discussion. I may redirect the conversation if things become too off topic. The co-moderator will assist the process and take notes about the discussion during the focus group.

We want to hear many different viewpoints and would like to hear from everyone during this focus group. We hope you can be honest even if your responses are not in agreement with the rest of the group.

The focus group will be audio recorded through two digital recorders placed on each side of the table. All of your recorded comments and responses to questions will be kept confidential. Your name and any other identifiable information will not be reported. Any of the materials that come out of our discussion will be evaluated only by researchers working on this study and will be kept secure and protected. We ask that you also respect the privacy of other participants and ask that the responses made by all participants be kept confidential.

Our discussion will last about 90 minutes, with a break in the middle.

You are welcome to leave the room at any time, for example, if you wish to visit the bathrooms or for another reason. Also please help yourself to refreshments.

- Describe the location of the bathrooms.

- Describe the location of the nearest emergency exit.

Ground rules (before turning on the digital recorders):

- Please speak one at a time so that the recording is clear.
- Please speak up, loudly enough for the digital recorder to capture your voice.
- Please turn off cell phones (if possible).
- Please try to state your name before speaking.
- Please avoid tapping the table or rustling papers, as this will the audio recording and make listening (and transcription) difficult.

Tim wishes that he could be a part of this event and discussion. Here is something he asked us to share with you at this meeting.

Focus Group Questions

Start audio recording.

Introductory statement:

The goal of this focus group is to understand your experience and opinions on participating in the project.

Before we start, let's go around the table to introduce ourselves.

** after asking the first questions, remind participants to state their name before answering.*

*** the prompts after each question are only intended to stimulate additional discussion if needed or to focus the discussion if necessary.*

1. To start, what are your general thoughts about the project? What was it like participating in the project?

2. What was it like interacting with other caregivers in this project?

> *(Prompt: If you did not send any social interaction messages, explain whether you felt part of the interaction without sending any messages?)*

3. What was it like to be able to interact with a healthcare professional in this project?

4. What was it like to interact with caregivers and healthcare professionals in *this particular (text messaging)* way?

> *(Prompt: If you could choose between interacting with caregivers or healthcare professions in this way and how you did before the project, which would you choose? Why?)*

5. What was it like to have access to information that was sent during the last 3 months?

> *(Prompt: How useful was the information? What kind of messages was most helpful? How was it useful?)*

6. What was it like to receive information in *this particular (text messaging)* way?

(Prompt: If you could choose between receiving information in this way and how you did before the project, which would you choose?)

7. Looking back on the whole project (interaction and information), were there any messages in particular that stand out in your memory?

(Prompt: At one point, Maria (one of the participants) asked a health question to all participants. Claudia responded to this question with information and a home remedy. What was it like to receive information from another participant rather than a healthcare professional?)

8. Explain whether the messages were ever difficult to understand?

9. Describe the difficulty (how easy or how difficulty) of sending and receiving text messages in the project?

(Prompt: Describe whether the keywords were difficult to use or not?)

10. Did participating in this project impact your experience of caregiver stress or burden? Explain whether or not you think this type of project has the potential to impact caregiver stress for parents who have child with a disability?

11. If this project were able to continue on a long-term basis, describe whether you would be interested in continued participation? Would cost be an important factor in your continued participation?

12. How could the project be improved? Do you have any concerns about the project?

Any other comments that have not been covered?

General comments for the moderator:

I know that your team has experience conducting focus groups. These recommendations will likely only reinforce things that you already know and do…

Focus group notes

After the focus group, take 5-10 minutes to take brief notes. These notes will be used in the analysis to give richness to the data as appropriate.

Take note of the physical environment. Where was everyone sitting? What were the participants doing during the focus group? Fidgeting with their pencil? Chewing their fingernails?

Do the participants look nervous? How? Relaxed? How?

General Recommendations

Try to conduct the focus group in a quiet space with a limited amount of distractions.

When asking questions, try not to lead their response.
Examples of a leading questions: "How helpful was this project for you?"

Prompts:
During the focus group, if you find yourself wanting to know more about something, ask about it! Use these sample prompts to dig further.

If participants are discussing a question, and there is something intriguing that you would like them to talk more about:
"Could you discuss more about that?"
"A number of you are saying _____, what do you mean by that?"

Clarifying questions:
If you are not exactly sure what a participant means with a response, don't be afraid to clarify.
'Do you mean that …….'
'Is it fair to say that…'

Silence – do not be concerned with silence. Give participants the opportunity to think about their response and have time to respond. Sometimes silence can also indicate to the participant that you would like more information about a topic.

Participation – Try to encourage all participants to participate in the conversation. Be mindful of participants who are not participating, but also respect their wishes to remain quiet if they choose.
'There are a couple of you that have not shared much, do you have anything to add to this discussion?"

Guia de Grupo Focal – Projecto El Enlace

Antes del grupo focal

En lo posible, de a los participantes tarjetas con sus nombres o stickers para que puedan identificarse durante la sesión.

Guía para introducir el grupo focal

Bienvenidos todos; estamos muy contentos de que hayan podido venir hoy y muy agradecidos por su participación en El Enlace!

Como ya saben, mi nombres _____ y seré la moderadora de nuestra sesión de hoy (Mónica o Francene?). Ella es _____ y será la co- moderadora. Durante esa sesión grupal voy a hacerles algunas preguntas, y lo que quisiera es que pudieran discutir entre ustedes y con nosotras. El objetivo no es contestar las preguntas del moderador como tal sino discutir entre todos.

El rol del moderador es hacer las preguntas y luego escuchar la discusión sin intervenir. No les daré mis opiniones o respuestas durante la discusión. En ocasiones, puede que re dirija la conversación si nos estamos saliendo mucho del tema. La co- moderadora ayudara en este proceso y tomara notas sobre la discusión durante la sesión.

Queremos oír diferentes puntos de vista y que todos puedan participar de esta discusión. Esperamos que se sientan con la confianza de ser honestos en sus respuestas incluso si estas no están de acuerdo a lo que el resto del grupo piensa.

La sesión será grabada con el uso de dos grabadoras de voz puestas a cada lado de la mesa. Todos sus comentarios y respuestas a las preguntas serán totalmente confidenciales. Su nombre y otra información sobre su identidad no será reportada. Los materiales que salgan de esta inclusión serán únicamente revisados por el quipo de investigadores y serán mantenidos confidenciales y seguros. Les pedimos también que seamos todos respetuosos de los comentarios de otros participantes y de su privacidad, manteniendo todo en confidencialidad.

Nuestra discusión tardara aproximadamente 2 horas con un descanso en la mitad de _____.

En cualquier momento pueden salir del salón si así lo quieren, por ejemplo, para ir al baño o por cualquier otra razón. También por favor esperamos que disfruten los refrigerios.

- Describir la ubicación de los baños.
- Describa la ubicación de las salidas de emergencia.

Indicaciones (antes de prender las grabadoras):

- Por favor hablen por turnos para que la grabación sea clara.
- Por favor hablen lo suficientemente duro para que la grabadora registre los comentarios.
- Por favor apaguen en lo posibles sus celulares o pónganlos en silencio.
- Por favor traten de decir siempre su nombre antes de empezar a hablar.
- Por favor eviten doblar papeles o golpear la mesa porque la grabadora registra estos sonidos y hace difícil después entender.

Tim desearía poder hacer parte de este evento y discusión. Esto es algo que escribió y nos pidió que compartiéramos con ustedes: (Podría escribir algo y mandárselos para que ustedes lo lean acá o hacer un corto video y que ustedes lo pongan. Pensaba por ejemplo en saludar por skype pero eso les agrega a ustedes trabajo en términos de conexión a internet en el sitio y eso*)*.

Preguntas Grupo Focal

Iniciar grabación .

Enunciado de introducción:
El objetivo de este grupo focal es entender su experiencia y opiniones acerca de su participación en el proyecto (El Enlace).
Antes de empezar, por favor presentémonos, cada uno diga su nombre.

** después de hacer las primeras preguntas, recordar a los participantes que digan su nombre siempre antes de hablar para la grabación*
*** las preguntas para profundizar son solo para estimular mayor discusión o comentarios adicionales, o para enfocar la discusión si es necesario.*

1. Para comenzar, cuales son sus pensamientos generales sobre el proyecto? Como fue participar en El Enlace?

> **No se queden en esta pregunta mucho tiempo. Es una pregunta para empezar y ayudar a que se empiece la discusión pero la información saldrá en las otras también.*

2. Como fue interactuar con otros cuidadores durante este proyecto?

> *(Pregunta de profundización: si usted no envió menajes de interacción social explique si se sintió parte de la interacción sin haber mandado mensajes?)*

3. Como fue el poder interactuar con un profesional de la salud en este proyecto?

4. Como fue el interactuar con cuidadores y un profesional de la salud de esta forma en particular (mensajes de texto)?

> *(Pregunta de profundización: Si usted pudiera escoger entre interactuar con cuidadores y profesionales de la salud de esta forma y como lo hacia antes del proyecto, cual escogería y por que?*

5. Cómo fue tener acceso a información que fue enviada durante los últimos tres meses a través de El Enlace?

> *(Pregunta para profundizar: Fue útil esta información? Qué clase de mensajes fueron los más útiles?)*

6. Como fue el recibir información de esta forma en particular (mensajes de texto)?

(Pregunta para profundizar: Si usted pudiera elegir entre recibir información de esta forma y como lo hacia antes del proyecto cual escogería? Por que?*)*

7. Revisando los objetivos del proyecto (interacción e información), Hubo algún mensaje en particular que se haya quedado grabado en su memoria?

(Pregunta para profundizar: En un punto, María (una de las participantes) le hizo una pregunta de salud a todos los participantes. Claudia respondió a esta pregunta con información y un remedio casero. Como fue el recibir información de otro participante en vez de recibirla de un profesional de la salud?)

8. Explique si los mensajes fueron difícles de entender?

9. Describa la dificultad (muy difícil o muy fácil) de recibir o enviar mensajes de texto en este proyecto

(Pregunta para profundizar: Describa si el teclado fue difícil de usar o no)

10. Participar en este proyecto impactó sus experiencias de estrés o carga como cuidador? Explique si para usted este tipo de proyectos tienen potencial para impactar el estrés de los padres y madres como cuidadores de niñ@s con discapacidad

11. Si este proyecto pudiera continuarse a largo plazo, estaría usted interesado/a en continuar participando? Si el costo del proyecto estuviera cubierto, estaría usted dispuesto a participar? Por que o por que no?

12. Como podría mejorarse este proyecto?

Tiene algún comentario o preocupación sobre el proyecto?

Tiene usted algún comentario que quiera hacer que no se haya cubierto?

Comenatrios generales para l@s moderador@s:

Sé que su equipo tiene gran experiencia conduciendo grupos focales. Estas recomendaciones probablemente solo van a reforzar cosas que ya saben y hacen…

Notas del grupo focal

Después del grupo focal, por favor tome diez minutos para tomar notas breves sobre lo observado en el grupo. Estas notas serán usadas en el análisis para capturar la riqueza de los datos como sea apropiado.

Tome nota del ambiente físico. Donde están sentados? Quá está haciendo el participante durante la entrevista? Jugando con un lápiz? Mordiendo sus uñas?

Como se ve el participante? Nervioso? Relajado?

Recomendaciones generales

Trate de conducir el grupo focal en un espacio silencioso con una cantidad limitada de distracciones.

Cuando haga las preguntas, trate de no conducir la respuesta del participante.

Ejemplos de preguntas conducentes: “Que tanto le ha ayudado este proyecto?”

Preguntas para obtener más información:

Durante el grupo focal, si sienten que quieren saber mas sobre algo o tener mas información, pregunte! Utilice las preguntas de apoyo para obtener más información.

Si el participante responde una pregunta, pero hay algo que lo intriga y que quisiera que el participante le hablara mas sobre eso, haga preguntas como:

“Podría hablarme un poco mas sobre eso?”

“Que quiere decir con eso . . .?”

Preguntas para clarificar:

Si no esta seguro de lo que el participante quiere decir exactamente con su respuesta, no tema buscar mayor clarificación.

‘Quiere decir que …….’

‘Seria apropiado decir entonces que usted…’

Silencio– no se preocupe por los silencios. Dele al participante la oportunidad para pensar sus respuestas y para responder. Algunas veces el silencio sirve para indicarle al participante que usted desea mas información sobre el tema.

Participación – Intente promover la participación de todos los participantes en la conversación. Tenga presente los participantes que no están participando, pero también sea respetuoso de sus deseos de permanecer en silencio.

“Hay algunas personas personas que no han compartido mucho con nostros. Tienen algo que añadir a esta conversación?”

Appendix N

Coordinator Questionnaire

El Enlace Administration Team Questions

1. What was it like communicating with caregivers in this project?

2. What are your opinions regarding (alt: was it like) communicating and sharing information with caregivers in this particular (text messaging) way? What did you like? What did you dislike?

3. If you could choose between interacting with caregivers in this way and how you did before the project, which would you choose? Why?

4. What was it like to receive interaction and information messages as an administrator of the project?

5. Looking back on the whole project, describe any messages that particularly stand out in your memory?

6. Describe the difficulty (how easy or how difficulty) of sending and receiving text messages as an administrator in the project?

7. Describe whether or not you believe this project was helpful for participants?

8. How could the project be improved? Do you have any concerns about the project?

9. What was it like collaborating with an international partner for the development and implementation of this project?

    a. What do you think was successful about the international collaboration?

    b. What do you think could have improved the international collaboration?

10. Describe the considerations with respect to the university that impact the long-term continuation of a project like this. (Consider also your role within the university related to the continuation of this project)

11. Describe the considerations within the community that impact the long-term continuation of a project like this.

12. What do you think would be a good way to share the findings (and validate after analysis) with participants?

13. What method of knowledge dissemination do you think participants would like? For example: A brief column about the project in a local newspaper, a local flyer, etc. Describe whether you think this is something that participants should be contacted about to see if this is important to them?

Preguntas al Equipo Administrador de El Enlace

1. Como fue comunicarse con los cuidadores en este proyecto?

2. Cuales son sus opiniones acerca de la comunicacion y compartir informacion con los cuidadores bajo la forma de mensajes de texto? Que le gusto? Que le disgusto?

3. Si usted pudiera escoger entre interactuar con los cuidadores usando mensajes de texto y como lo hacia antes de este proyecto, cual escogeria? Por que?

4. Como fue interactuar y recibir mensajes de texto como administrador de este proyecto?

5. Mirando el desarrollo del proyecto, podria describir algun mensaje que en particular haya quedado en su memoria? Por favor decriba las razones por las cuales ese mensaje l@ impacto.

6. Defina la dificultad (que tan facil o que tan dificil) fue enviar y recibir mensajes de texto como administrador/a en este proyecto. Explique las razones de su respuesta.

7. Describa si usted cree o no cree que este proyecto fue benefico para los participantes

8. Como podria el proyecto ser mejorado? Tiene alguna preocupacion o inquietud sobre el proyecto?

9. Como fue colaborar con un actor internacional en el desarrollo e implementacion de este proyecto?

    a. Que considera usted que fue exitoso en esta colaboracion internacional?
    b. Que considera usted que podria ser mejorado en esta colaboracion internacional?

10. Describa las consideraciones con respecto a la Universidad que impactan la continuacion a largo plazo de un proyecto como estos. (Considere su rol o relacion con la Universidad).

11. Describa las consideraciones al interior de la comunidad que impactan a largo plazo la continuacion de un proyecto como estos.

12. Cual podria ser una buena estrategia para compartir los hallazgos/resultados (y validar los analisis del proyecto) con los participantes?

13. Cual considera usted que puede ser un buen metodo de diseminacion del conocimiento que los participantes puedan encontrar benefico? Por ejemplo: Una columna breve sobre el proyecto en un periodico local, un volante de informacion, etc. Cree usted que los participantes deberian ser contactados para discutir esto con ell@s?

Appendix O

Braun & Clarke's Thematic Analysis

Table 1: Phases of Thematic Analysis

Phase	Description of the process
1. Familiarising yourself with your data:	Transcribing data (if necessary), reading and re-reading the data, noting down initial ideas.
2. Generating initial codes:	Coding interesting features of the data in a systematic fashion across the entire data set, collating data relevant to each code.
3. Searching for themes:	Collating codes into potential themes, gathering all data relevant to each potential theme.
4. Reviewing themes:	Checking in the themes work in relation to the coded extracts (Level 1) and the entire data set (Level 2), generating a thematic 'map' of the analysis.
5. Defining and naming themes:	Ongoing analysis to refine the specifics of each theme, and the overall story the analysis tells; generating clear definitions and names for each theme.
6. Producing the report:	The final opportunity for analysis. Selection of vivid, compelling extract examples, final analysis of selected extracts, relating back of the analysis to the research question and literature, producing a scholarly report of the analysis.

Braun & Clarke, 2006

Table 2: A 15-Point Checklist of Criteria for Good Thematic Analysis

Process	No.	Criteria
Transcription	1	The data have been transcribed to an appropriate level of detail, and the transcripts have been checked against the tapes for 'accuracy'.
Coding	2	Each data item has been given equal attention in the coding process.
	3	Themes have not been generated from a few vivid examples (an anecdotal approach), but instead the coding process has been thorough, inclusive and comprehensive.
	4	All relevant extracts for all each theme have been collated.
	5	Themes have been checked against each other and back to the original data set.
	6	Themes are internally coherent, consistent, and distinctive.
Analysis	7	Data have been analysed - interpreted, made sense of - rather than just paraphrased or described.
	8	Analysis and data match each other - the extracts illustrate the analytic claims.
	9	Analysis tells a convincing and well-organised story about the data and topic.
	10	A good balance between analytic narrative and illustrative extracts is provided.
Overall	11	Enough time has been allocated to complete all phases of the analysis adequately, without rushing a phase or giving it a once-over-lightly.
Written report	12	The assumptions about, and specific approach to, thematic analysis are clearly explicated.
	13	There is a good fit between what you claim you do, and what you show you have done - i.e., described method and reported analysis are consistent.
	14	The language and concepts used in the report are consistent with the epistemological position of the analysis.
	15	The researcher is positioned as *active* in the research process; themes do not just 'emerge'.

Braun & Clarke, 2006