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*A Report on the Processes, Procedures, and Findings of*

# THE LOCATING TECHNOLOGY PROJECT

*Submitted to: The Ministry of Community and Social Services*

*Authors:*

*Sue Baptiste  
Elizabeth Steggles  
Nicole Grochowina  
Melissa LeBeau*

accessibly  yours  
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***Graphics:***

*Drea Baptiste / Eyespygraphics*

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# EXECUTIVE SUMMARY

*It [wandering behaviour] has a huge impact because he [John] is not able to experience life. If he goes out with someone, I wouldn't necessarily trust someone to take him out, because I would worry that he would bolt and run away. Less independence, less experiences.*

*~Consumer Trial Participant*

**The Locating Technology Project (LTP)** is an initiative funded by the *Ministry of Community and Social Services* and partnered with *Accessibly Yours* and the *School of Rehabilitation Science at McMaster University*.

*The main objective of the LTP is to identify and then examine existing electronic locating systems that have been designed to assist people with a developmental disability, Alzheimer's disease, other dementias, or autism who have demonstrated wandering behaviour or are at risk of becoming lost.*

The examination of each device focused on (a) determining the feasibility of available locating devices for improving the safety and security of persons facing obstacles in regard to communication and/or cognitive function, (b) underlining the relative merits and limitations of selected technologies and (c) exploring consumer views and ideas related to this dilemma.

A review of the literature has revealed there is disagreement among researchers regarding the definition of 'wandering'. **For the purpose of this study, the following operational definition was used:**

*Wandering is either or both a purposeful or aimless complex behaviour with various presentations including repetitive locomotion, hyperactivity, excessive walking, and agitation, manifested by an individual with cognitive impairment which may lead to safety concerns.*

Divergent information also exists in studies addressing the prevalence of wandering for people with dementia (including people with Alzheimer's disease). These reported differences could be attributed to dissimilar study designs, inconsistencies in the definition of 'wandering', and a broad range of assessment methodologies, study populations, and time period of data collection.

A review of the literature suggested that people who wander are more likely to be male, extroverted, mature adults, using psychotropic medications, experiencing sleep disturbance, and are more cognitively impaired than people with similar diagnoses and stated problems. Current techniques to reduce or prevent wandering behaviour fail to yield strong support, which therefore suggests limited effectiveness in the reduction and management of wandering behaviour. Although there is growing interest in the use of

electronic locating devices, research is lacking in the examination of the impacts of such a device on both individuals who wander, and on their caregivers. This project has sought to improve this disparity in research.

**The Project Team divided this initiative into two phases.** The purpose of **Phase 1** was to conduct a technical evaluation of each device in order to establish a complete description of the attributes, strengths, and limitations of each device. Initial scenario and device testing was performed by students and members of the team. Once the scenario testing was complete, evaluation criteria for the effectiveness, wear-ability, ease of use, and ethical considerations were established. Tested systems that met a pre-determined success rate were selected for trial testing in the second phase of the project.

The purpose of **Phase 2** of the project was to test the effectiveness of the selected technologies with caregivers and people who are at risk of wandering and becoming lost. This implementation served to provide an understanding of the complex realities associated with caring for a person who is at risk of wandering and becoming lost. Following the recruitment stage, potential participants were mailed an information package. Participants were then selected to be either part of the consumer trial or the consumer panel. After a transcribed interview, consumer trial participants were supplied with a device to use for ‘real-life’ testing. They were asked to keep a journal to record the physical and emotional aspects of the experience with the device. After a determined period of time, participants were contacted for a second transcribed interview to share their specific reactions and perceptions of the experience. Consumer panel participants, in group settings in five selected cities, were shown a presentation on wandering behaviour and a demonstration of devices under evaluation and asked to fill out a questionnaire and participate in open format discussions. At the end of each of the five sessions, the questionnaires were collected for data analysis.

Through the analysis of the data collected both from the consumer trial and consumer panel, the project has revealed that among the technologies tested, while there are reported strengths, severe limitations exist in the areas of reliability and practicality. Above all, no one device meets the needs of every individual, family, or caregiver.

Using an electronic locating device to locate people poses ethical concerns and potential moral ramifications. The literature review revealed that limited attention has been paid to these concerns and revealed divergent opinions pertaining to the wear-ability and social acceptance of electronic locating systems for both persons at risk and their caregivers. The wearing of locating devices raised ethical concerns among the project team that included: stigmatization associated with wearing such a device; maintaining the wearer’s dignity; wearer autonomy; caregiver autonomy; criteria for using a locating device or buying a locating device; and the wearer not being cognitively aware of the device. Results from the consumer trial and consumer panel showed participants were also concerned with the associated ethical considerations and while they cited concerns similar to those raised by the project team, they also stated that the device had positive impacts on their lives. Many felt that the device acted as an aid or reinforcement; that it

provided a sense of comfort and brought peace of mind; and that the device gave the promise of future independence and freedom.

The LTP team cannot responsibly recommend that any one device be used exclusively for persons who wander. Certainly, as discussed above and further discussed in the report below, there are certain advantages to some of the devices tested. Equally, however, there are demonstrated weaknesses and limitations. The project team can recommend that anyone searching for an alternative to traditional methods of intervention of wandering behaviour consider researching the use of an electronic locating system. That being said, the LTP team also recognizes that funding needs to assist and support caregivers of people who wander. This need for funding was one of the recommendations raised by the participants of this study. Also recommended by participants, among many other suggestions, was that there be a size reduction in the device, that future designs of devices become more weather tolerable and water resistant, and that the general appearance be changed. The variety of these recommendations show that each individual and their caregiver have different needs and requirements and further confirms that an electronic locating system, while it may be a solution for some, is not the solution for everyone.

Below is the key learning that presented some unexpected conclusions with regard to wandering behaviour and the implications of using an electronic locating system.

### ***Key Learning and Recommendations***

- The literature reviewed is lacking greatly in the definition of ‘wandering’.
- The literature is also lacking any information about ‘bolting’ and ‘elopement’ of people with autism or a developmental disability
- Something as small as an electronic locating device can bring much peace of mind to both the caregiver and the person who wanders.
- Ethical considerations, when contrasted with the safety and security of the person prone to wandering, are not priority for those participating in the study; this may indicate a participant bias.
- The relevance of ethical concerns, such as privacy, when a loved one is at risk of wandering, was thrown into question.

All stakeholders, including: MCSS, School of Rehabilitation Science at McMaster University, people who wander and their caregivers, and manufacturers of locating technologies, involved with the complex issue of wandering have a vested interest in furthering the findings of this project. Key recommendations include: the dissemination of results; a review of the cost implications of assisting people who wander and their caregivers; the development of resource materials; and the further development of electronic locating technologies.

# **1. INTRODUCTION**

# INTRODUCTION

## *1.1 Background and Focus*

On June 30<sup>th</sup>, 2005, the Ministry of Community and Social Services (MCSS) announced the launch of a project to examine the effectiveness of technologies designed to assist people who wander as a result of conditions such as autism, Alzheimer's disease and developmental disabilities. The launch was in direct response to a demonstrated need in the province for the research of existing technologies that could aid persons who wander and are at risk of becoming lost.

Currently, measures to assist people who wander have been created and implemented by families or other caregivers in both community and long term care settings. Until recently, there have been few technologies specifically designed for this purpose although there is a perceived need for reliable and accessible solutions. The RCMP in New Brunswick, through the creation of a Wandering Registry by the Alzheimer's disease Society, reported between 10,000 and 12,000 individuals at risk of wandering in New Brunswick alone. An initiative similar to such a registry exists in Oxford County in Ontario where an objective of the project is to educate families and caregivers about the different approaches and applications available to assist persons who are prone to wandering.

The Locating Technology Project (LTP) is the first of its kind undertaken by MCSS and is focused on determining the feasibility of available locating devices for improving the safety and security of persons facing obstacles in regard to communication and/or cognitive and adaptive functioning as well as underlining the relative merits and limitations of selected technologies. The project additionally seeks to gain an enhanced understanding of the complex realities related to the implementation of locating technology for people at risk of wandering.

A collaboration between the School of Rehabilitation Science at McMaster University and MCSS, the project is approved by the Research Ethics Board of McMaster University (see Appendix A, page 71) and managed by Accessibly Yours (AY), a consultation and service component of the School of Rehabilitation Science at McMaster University in Hamilton, Ontario. AY aims to improve physical, cultural, institutional, and social and emotional environments for the purpose of facilitating individuals in their search for living well and participating in their communities. Addressed are a broad scope of activities, which may include attention to needs related to mobility, motor abilities, sensory skills, size, mental health, communication, and cognition. Given AY's focus on evaluating, advising, and educating families and clients with regard to the application and suitability of Assistive technologies, the AY team is particularly well suited to undertake this project.

## ***1.2 The LTP Team***

**The project team consists of three interconnected groups:**

### **1) The Investigative Team**

The investigative team, as part of Phase 1 of the project, conducted a technical and qualitative evaluation of each technology submitted resulting in a comprehensive description of the functions and potential advantages and disadvantages of the devices.

In Phase 2 of the project the investigative team conducted consumer trials and panels to gain feedback on the technology and its implications.

#### ***Investigative team:***

##### *McMaster University Faculty*

- Sue Baptiste – *Principal Investigator*
- Elizabeth Steggle
- Mary Law
- Paul Stratford

##### *MCSS*

- Elizabeth Garfin

##### *Consumer Representative*

- Gerry Bloomfield

### **2) The Advisory Board**

The advisory board provided information and input to the primary investigator and investigative team of the LTP. Throughout the project, the advisory board guided the investigative team on issues such as evaluation criteria of the technologies, important ethical issues, along with other relevant issues surrounding the research conducted and assisted with participant recruitment.

#### ***Advisory Board Team:***

- James Duncan - *Ontario Agencies Supporting Individuals with Special Needs OASIS*
- Jan Burke-Gaffney – *A consumer representative*
- Angie Szuch – *The Ontario Senior’s Secretariat*
- Elizabeth Yeigh/Laura Bradford - *Ministry of Community and Social Services*
- Cathy Conway – *Alzheimer’s Society of Ontario*
- Nancy Cherry – *Autism Society of Ontario*

- Don Webster – *Search & Rescue, Ontario Provincial Police*
- Other Investigative Team members as appropriate to task
- Operations team members

### **3) Operations Team:**

The operations team was responsible for the day-to-day management of the project.

#### ***Operations Team:***

- Sue Baptiste – *Principal Investigator*
- Elizabeth Steggle – *Investigator*
- Mehdi Tabatabaieinia – *Methodologist*
- Jamie Leslie – *Technical Consultant*
- Nicole Grochowina – *Research Coordinator*

## ***1.3 Project Outline***

### **The project consisted of two phases:**

**Phase 1** was a technical evaluation that field-tested five technologies to develop a complete description of their capabilities, potential, advantages, and disadvantages along with their success rates and reliability percentage. Each technology was also evaluated for its appropriateness in meeting the needs of each individual as well as determining whether these technologies were safe for people to use in Phase 2.

**Phase 2** was the implementation of the technologies in households where there is a demonstrated need for such devices. The technologies tested in this phase were only those that had met the success criteria as defined and identified in Phase 1. This phase consolidated project findings with specific recommendations and conclusions regarding the use of locating technology as a means of improving the safety and security of individuals who may wander and become lost.

## **2. METHODOLOGY**

# INTRODUCTION

## *2.1 Literature Review*

*Well because of his autism, he doesn't understand boundaries, so if we are in a parking lot he will just take off. He just doesn't understand the concept of boundaries, so if the gate is open, he will leave.*

A necessary step in beginning this study was to determine an agreed upon definition of wandering and to ascertain who is affected by wandering, the characteristics of wandering behaviour, the associated impacts of wandering, and intervention for wandering behaviour. (See Appendix B, page 78 for the complete literature review)

### *Definition of Wandering*

There is very limited published research concerning wandering in individuals with developmental disabilities. In fact, a review of the literature shows a lack of general consensus among researchers in terms of defining wandering, revealing that the definition of wandering is poor, unclear, and a source of confusion (Martino-Saltzman, Blasch, Morris, & McNeal, 1991; Price, Hermans, & Grimely Evans, 2005; Rader, 1987). In much of the literature, the term is used to describe a variety of behaviours usually observed in people with Alzheimer's disease or dementia (Silverstein & Salmons, 1996). The term 'wandering' has also been used by some investigators to indicate increased walking, pacing, and aggressiveness in individuals (Cohen-Mansfield & Billig, 1986; Cohen-Mansfield & Werner, 1995; Matteson, Linton, & Bers, 1993) as well as being used to describe people with navigational difficulties, (De Leon, Potegal, & Gurland, 1984), people whose behaviour can be described as aimless movement without specific or appropriate aim (Coltharp, 1977; Snyder, Rupperecht, Pyrek, Brekhus, & Moss, 1978), or as a purposeful behaviour that fulfills a need, for example, to dissipate tension or cope with stress (Coons, 1988; Heim, 1986; Monsour & Robb, 1982; Thomas, 1997). In relation to people with autism, the term elopement is regularly used. Debbaut (2002) describes elopement and wandering as "the repeated behaviour of fleeing or running away from home".

An explanation of such diversity in definition can be attributed to the heterogeneity of the population known to wander (Lai & Arthur, 2003) and the underlying reason for its demonstration (Price et al., 2005). Drawing from these diverse definitions and discussion by the investigative team and advisory board, for the purpose of the current study, the following operational definition of wandering is used:

*Wandering is either or both a purposeful or aimless complex behaviour with various presentations including repetitive locomotion, hyperactivity,*

*excessive walking, and agitation, manifested by an individual with cognitive impairment which may lead to safety concerns.*

## ***Profile and Typologies of People who Wander***

As already mentioned, it is important to emphasize the paucity of any focus in the literature on wandering as seen in individuals with developmental disabilities. Much of the literature reviewed addresses wandering as demonstrated in people with Alzheimer's disease or other dementias. Even with the available evidence, it has been difficult to assess the frequency and prevalence of wandering behaviour in the older population (Coltharp, Richie, & Kass, 1996) and thus to arrive at any conclusive figures (Lai & Arthur, 2003). One must take into account the severity of the disability, because this varies, so do the statistics reporting the frequency of wandering behaviour. For example, Kline et al. (1999) estimated that 17.4% of clients with dementia wander whereas Teri, Larson, and Reifler (1988) reported a prevalence rate of 50% among patients suffering from severe dementia. Additionally, people with Alzheimer's disease are reported to demonstrate a higher frequency of wandering behaviour than people suffering from vascular and other dementias (Cooper & Mungas, 1993; Thomas, 1997). However, these figures also vary. Fifty two percent of the caregivers involved in Silverstein and Salmon's (1996) study indicated that people with Alzheimer's disease or a related disease had wandered and become lost, while Burns, Jacob, and Levy (1990) reported that 90% of people with Alzheimer's disease wander. These differences in prevalence studies may be attributed to: the different study designs; how the researchers defined wandering; assessment methodology; the study population; and time period of data collection (Hope, Keene, & McShane, 2001; Klein et al, 1999; Silverstein, Flaherty, & Tobin, 2002).

Studies have been conducted to develop profiles for people who wander and have demonstrated that wandering behaviour was associated with worsening cognitive impairment (Algase 1992; Algase, Beattie, & Therrien, 2001; Lai & Arthur, 2003; Logsdon, Teri, McCurry, Gibbons, Kukull, & Larson, 1998; Yang, Hwang, Tsai, & Liu, 1999). **Studies have also found that people who wander:**

- are more likely to be: male; using psychotropic medications; experiencing sleep disturbance (Klein et al., 1999);
- are more likely to be extroverted (Dawson & Reid, 1987; Thomas, 1997; Beattie, Dong, & LaGore, 2005);
- are more likely to have speech and spatial deficits (Monsour & Robb, 1982; Dawson & Reid; Algase);
- are more likely to have difficulty with abstract thinking, judgment, spatial skills (Algase, 1992; Rowe, 2003);
- experience a high level of memory loss (Rowe);
- experience a high incidence of psychosocial problems (Snyder et al., 1978)

**Among the diverse profiles of persons who wander, the literature review also revealed the diverse typology of people who wander. Hussian (1987 in Lai & Arthur, 2003) classified four groups of people who wander, including:**

- The exit seekers (trying to open locked exit doors)
- The akathesiacs (moving aimlessly, neuroleptic-induced pacing and restlessness)
- The self-stimulators (seeking stimulation such as turning the door knob rather than to exit)
- The modelers (tagging onto or 'shadowing' others)

**Hope and Fairburn (1990) suggested a descriptive typology of people who wander, divided into the following nine groups:**

- 1) checking
- 2) pottering/aimless fidgeting
- 3) aimless walking
- 4) walking directed towards inappropriate purpose
- 5) excessive activity
- 6) night time walking
- 7) needs to be brought back home
- 8) attempts to leave home

**Based on clinical experience, Stokes (1986) proposed a categorization of wandering to explain the underlying reasons for the behaviour. Reasons included:**

- separation anxiety
- searching
- boredom
- loneliness
- physical discomfort
- coping with stress
- apparent aimless wandering
- disorientation
- night time wandering
- attention seeking

**Debbaudt (2002) suggested the following as reasons people with autism wander:**

- curiosity to return to a place of interest
- obsessive compulsive behaviour such as an attraction to certain locations
- a need for sensory input

## ***Wandering and Associated Impacts***

Wandering behaviour can both positively and negatively impact the individual and his/her caregiver. Positive impacts might include an increase in circulation, decrease in contractures, and promotion of exercise (Heim, 1986; Matteson & Linton, 1996), a need to spend time alone, and relief from boredom (Price et al., 2005). Negative impacts may include falls, fractures, weight loss, fatigue, sleep disturbances, berating, verbal/physical abuse, getting lost, social isolation, and untimely death (Algaier, 2002; Algase, 1992; Algase, Kupferschmid, Beel-Bates, & Beattie, 1997; Devereaux Melillo, & Futrell, 1998; Hughes & Louw, 2002; Rowe, 2003; Tarbox, Wallace, & Williams, 2003). It was also stated that following wandering, death could result from hypothermia, dehydration, or drowning (Rowe 2003).

Such negative consequences contribute to caregiver stress (Miskelly, 2004; Logsdon et al., 1998; Silverstein et al., 2002) and stress experienced by the person who wanders (Price et al., 2005). A study conducted by Rabins, Mace, and Lucas (1982) suggests that over 70% of families caring for people with dementia have reported that wandering caused the family extreme stress. The possibility of a loved one getting lost was cited as a major reason for seeking residential placement (Adilya, Sharma, Allen, & Vassallo, 2003; McShane, Gedling, Kenward, B., Kenward, R., Hope, & Jacoby, 1998; Stewart, 1995; Young, Muir-Nash, Ninos, 1988). Debbaudt (2002) discusses that when people wander and police are notified they sometimes pick up the person and return him or her home but, in other cases, the law enforcement officers become suspicious and call in social service agencies. Safety is a major issue for people who wander and community awareness is often suggested as a method of addressing the problem. However, it is important to consider that this may negatively impact a person's privacy (Debbaudt 2002). As cited in Debbaudt (2002), Moreno (1991) suggests that there are two schools of thought on the impact of raising community awareness: some feel that sharing of information enhances safety while others feel that it leads to prejudgment of an individual.

## ***Intervention for Wandering Behaviour***

There is a growing concern about the application of strategies to manage, reduce, and prevent negative consequences of wandering behaviour (Lai & Arthur, 2003; Siders et al, 2004; Taft, Delaney, Seman, & Stansell, 1993). Traditionally, human and physical restraints, drugs, and locked doors were considered options for the management of wandering behaviour (Price et al., 2005). However, evidence suggests these methods could lead to serious adverse effects such as higher risk of pressure sores, infection, sedation, falls, confusion, anxiety, and violence (Miskelly, 2004; Price et al.; Welsh, Hassiotis, O'Mahoney & Deahl, 2003).

The human rights movement initiated a more appropriate and less restrictive approach to the management of wandering behaviour, which can be divided into patient-oriented and

system-oriented strategies (Brungardt, 1994). Patient-oriented techniques include the use of identification bracelets, photos, and the provision of orientation maps, while system-oriented techniques involve altering the surroundings with subjective barriers such as secure gates, and camouflaged exits, with staff trained in the application of behavioural methods (Brungardt). Debbaudt (2002) discusses the use of technology as a method to manage wandering behaviour. He also suggests similar patient-oriented techniques such as the use of: home security, emergency identification, identification of danger zones (such as water sources), sharing information with neighbours, and additional precautions such as use of fingerprint kits or traffic-warning signs (2002).

Many studies examined various forms of system-oriented techniques using subjective barriers such as tape grids on the floor (Chafetz, 1990; Hewawasam, 1996; Hussian & Brown, 1987; Roberts, 1999) or door (Namazi, Rosner, & Calkins, 1989), cloth panels to conceal doors or door knobs (Dicklinson, McLain-Kark, Marshall-Baker, 1995), mirrors hung in front of exits (Meyer & Darby, 1991; Roberts), and wall murals painted over doorways (Kincaid & Peacock, 2003).

While the results of these studies provide some evidence to suggest such measures can reduce the frequency of exiting behaviour, these techniques have different impacts on clients with different cognitive functioning (Roberts, 1999). An understanding of the environmental, physical, and social factors affecting each individual (Beattie et al., 2005) should therefore be considered in order to select the most effective and least intrusive techniques. For example, placing a mirror in front of an exit door is found to be an effective approach for clients with severe cognitive impairment as measured by the Clinton Assessment Procedure of the Elderly (CAPE) and concealment of doors or doorknobs appears to be less effective with clients with moderate/marked cognitive impairment.

Researchers have also considered the effects of music on wandering behaviour and have found conflicting results. While studies such as that by Cohen-Mansfield and Werner (1995) found that music had no impact on residents of 24 nursing homes, Ragneskog, Kihlgern, Karsson, and Norberg (1996) reported that music played during mealtime resulted in an increase in time spent eating instead of wandering. Additional research, however, is required to confirm the effects of music on wandering.

In the studies mentioned here and in Appendix B (page 78), most were often limited by small sample size, sampling bias, lack of control groups, poorly described participant characteristics including age, sex, and medical diagnosis among other factors (Lai & Arthur, 2003; Price et al., 2005; Siders et al., 2004). Future research is required to investigate the best possible strategies to manage wandering behaviour. Such research will assist caregivers and professionals dealing with the ongoing care of people who wander (Lai & Arthur).

There has recently been growing interest in the use of electronic technologies to locate people who wander (Royal College of Nursing, 2004) and there is some evidence to suggest that people who wander can receive benefits from electronic locating devices

(McShane et al., 1998; Miskelly, 2004). However, more research is required to examine the impacts of electronic locating devices on such clients and their caregivers (Hughes & Louw, 2002). There is the suggestion that these devices can lead to more freedom (McShane; Royal College of Nursing), improvement of overall quality of life (Hughes & Louw), improvement of safety and (McShane, Hope, Wilkinson, 1994; Welsh et al., 2003), and empowerment (Loh, Schietecat, Kwok, Lindboom, and Joore, 2004) of clients who wander. Investigators have considered such devices as better alternatives to traditional strategies such as locked doors and drugs (British Geriatrics Society, 2005; Royal College of Nursing), because they are less restrictive (British Geriatrics Society; Miskelly). McShane et al. (1994) argue that while electronic locating devices do slightly restrict the client, this is a price worth paying for the sake of the client's safety. This issue is one that is considered in great detail in this report.

## *Summary*

The literature review has revealed there exists a limited number of published studies addressing wandering behaviours in populations other than people with dementia. Disagreement among researchers has clearly emerged in attempts to define the term 'wandering' and to reiterate, the following operational definition has been adopted for use in this current study:

*Wandering is either or both a purposeful or aimless complex behaviour with various presentations including repetitive locomotion, hyperactivity, excessive walking, and agitation, manifested by an individual with cognitive impairment which may lead to safety concerns.*

Differences were identified in prevalence studies of people with dementia (including people with Alzheimer's disease) that could be attributed to different study designs; differing definitions of 'wandering'; a range of assessment methodologies; study populations; and time period of data collection.

**Criteria used by researchers to classify wandering behaviour have been identified and include:**

- client's intention
- patterns of independent travel
- pattern of walking
- the underlying reasons for the behaviour

Trends would indicate that people who wander are more likely to be at the lower end of the range of older adulthood, more cognitively impaired, more likely to be men, extroverted, using psychotropic medications, and experiencing sleep disturbance.

Negative outcomes associated with wandering behaviour such as falls, fractures, and getting lost, as well as longer term negative consequences contribute to increased caregiver stress as well as client stress. Although techniques have been suggested for the management of such negative impacts, these studies have failed to yield strong evidence, thus suggesting that their effectiveness is limited in significantly reducing the occurrence of wandering behaviour.

The use of electronic technologies to locate people who wander is gaining interest, as the potential benefits associated with such technologies are considered better than traditional strategies. However, there is a lack of research that examines the impact of such electronic devices on people who wander and on their caregivers.

## ***2.2 Phase 1***

In August 2005, technology providers submitted their Expression of Interest (EOI) to the Ministry. Prior to commencement of Phase 1, the LTP received nine expressions of interest. After the project was approved, three more organizations expressed interest in the study. Following initial set-up, two organizations decided to use technology from another organization and five organizations chose not to participate in the study. Entering Phase 1, the project worked with five participants and their respective devices, named as devices A, B, C, D, and E. Entering Phase 2, the project continued only with devices B, D, and E. The EOIs described their technology and how it might be applied to improve the safety and security of individuals who may wander and become lost. The purpose of Phase 1 was to conduct a technical evaluation of each device to develop a comprehensive description of its attributes and potential advantages and disadvantages. The five technologies that moved forward into Phase 1 of the project were evaluated for their level of appropriateness in meeting the needs of each individual and to identify risk posed to the wearer in an ethical and acceptable manner. For the purposes of this study we will refer to the five technologies as devices A, B, C, D, and E.

### ***Procedure***

With the technologies to be used in Phase 1 determined, 20 students from the School of Rehabilitation Science at McMaster University were recruited for field-testing. These students were divided into four groups of five and provided with one device to test. Four of the five trained students in each group were actively involved in field-testing while one remained on reserve in the event of a student being unable to conduct or complete testing.

Students were instructed to complete four predetermined scenarios and four random scenarios. Each scenario collected information such as time of day; weather conditions; the mode of transportation; starting location; time the scenario began and finished; the

distance from start location to that where the person wandering was found; and the area of wandering. Students were requested to provide feedback once they had completed their field-testing. In addition to the student involvement, three investigative team members and a student were also involved in field-testing due to scheduling difficulties and the need for a quick response to continue to meet the study timeline.

All field-testing teams were provided with a technology device, compass, flashlight, and map of the area; they were all connected to a computer with Internet access if needed, and were given or possessed cell phones. Copies of all information provided for students including information sheet, scenarios, and feedback form are included in Appendix C (page 94).

## ***Reporting Process***

With the field-testing completed and in consultation with the Advisory board, the Investigative team established the following evaluation criteria to provide information on the effectiveness of the system, wear-ability, ease of use, and ethical considerations:

- battery life expectancy
- transmitter size, weight durability, and convenience
- range of the technology
- reliability of the technology and/or system
- time in which the person was found
- time in which a signal could be found
- training required to use the technology
- social acceptance of the transmitter and locating technique
- ethical issues related to the technology
- any additional comments provided by the field testers

Students submitted quantitative and qualitative feedback on their experiences by completing the data sheets provided as shown in Appendix C (page 94). This provided the data required in determining the specific technologies to move forward into the trial (see Tables 1 and 2 for more details on the data collected).

Systems with a success rate of 50% or greater (i.e., found the lost person in 4 or more of the 8 scenarios within 60 minutes) during the trial testing were selected for Phase 2. Accordingly, devices B, D, and E, were selected for Phase 2 of the study. The remaining systems (A and C) had a success rate of 25% and were therefore not selected for study in the Phase 2. Device B was unable to participate in the consumer trial portion of Phase 2 as it is still in the early stages of development.

## ***2.3 Phase 2***

The purpose of Phase 2 of the project is to implement the use of the technologies in households where there lives a person who is prone to wandering. With this implementation, the project team sought to (a) gain a deeper understanding of the complex realities related to caring for a person who wanders and is at risk of becoming lost and (b) to examine the caregivers' perspectives about the application of electronic locating systems. Because a qualitative approach is recommended as an appropriate method for gaining insights into informants' perceptions, thoughts and perspectives, and because such an approach is appropriate for an investigation about which little is known, the qualitative approach is particularly applicable to this study and is used in Phase 2.

### ***Procedure - Recruitment***

Recruitment measures included: a member of the Investigative team presenting for a chapter of the Autism Society the purpose of the study; the circulation of two flyers provided by the research team through Alzheimer's Society, Autism Society, Developmental Service providers, and other groups as identified by the Advisory Board (Appendix D, page 103); the development of a website link from the Accessibly Yours website (<http://www.fhs.mcmaster.ca/rehab/techproject.htm>); and the posting of advertisements a minimum of three times in newspapers of cities where the consumer panels were held (Hamilton, Toronto, Sudbury, Sarnia, and Ottawa) (Appendix E, page 106). These sites were selected as representative of urban/rural and northern/southern locations, as well as reflecting key sites where interest had already been shown in the project. All potential applicants were directed to contact the project research coordinator at McMaster University.

Once identified, primary caregivers of each potential participant were mailed a letter describing the project, an information sheet for caregivers and people who wander, and a consent form. The caregivers were asked to read the material, complete the information sheets and consent form, and return it to the research centre in a stamped self-addressed envelope. After two weeks, if the initial package had not been returned, a follow-up phone call was placed. Once all documents were received, a copy of the signed consent form was returned to the caregiver for his or her files.

### ***Consumer Trial Procedure and Data Collection***

From the 123 responses received in the initial information package, potential applicants were selected using two predetermined criteria: (a) caregivers who provided care for a person who frequently wanders and is at risk of becoming lost, and (b) caregivers who

had the ability to reveal, reflect, and review their own experience as well as that of the person who wanders (see Appendix F, page 108, for more detail). Primary caregivers who met the criteria were selected and randomly assigned to either an interview or to a consumer panel. Of this group, eight primary caregivers were selected for interviewing as a purposive sample of those indicating interest and manageable in terms of location for site visits. The first interview was carried out by one of the investigators at the participants' place of residence. In these interviews, primary caregivers were given an opportunity to invite the person for whom they provide care and who wanders, as well as other caregivers to the session. This was done in the hope of hearing more than one perspective in each interview. However, through participant choice no clients with wandering behaviour were actively engaged in the interview process.

The primary technique applied in the study for collecting data followed a semi-structured interview approach, which included an informal conversation as well as general guided questions. This type of interview helps to explore the research questions. The interviews lasted between 20 and 30 minutes and were audiotaped and then transcribed.

The initial interview served to gain a deeper understanding of what it means to provide care and support for a person who wanders and is at risk of becoming lost, and to learn the daily challenges, fundamental concerns, and difficulties caregivers face.

In this first interview, it was also made clear to participants of Phase 2 that the devices they would be testing were still under development at that time. Shortcomings, limitations, and strengths of the given device were outlined before participants gave their final consent to their involvement in the project.

Following this first interview, applicants were subsequently supplied with an electronic location device. Three of the applicants were assigned the device referred to as D, and five applicants were assigned the device referred to as E. However, upon receiving a description of device E, one applicant declined participation in the study. Participants were cautioned that the devices they would be testing were still under development and should not be completely relied upon in any situation. With the relevant contact information provided, participants were instructed to contact the service providers of their respective device for training and installation.

After 45 days with the electronic locating systems, caregivers were contacted for a second interview. The questions in this interview were developed by the investigators based on the literature review as well as on the information learned in the first set of interviews with the caregivers (see Appendix F, page 108). This second interview served to examine the following:

- how caregivers perceived the electronic locating system
- how caregivers viewed the application of the locating system on a person who wanders and on themselves as caregivers
- what were the limitations, strengths, suggestions, and recommendations in regard to the electronic locating system tested

During the course of the Phase 2 testing of the devices, caregivers were also asked to keep a journal to ensure an accurate telling of any important events (such as loss and rescue efforts), suggestions, or concerns that arose within the 45 day trial. The journal served a dual purpose: caregivers were able to refer to it during the second interview, and following this interview the journal was submitted to the investigative team as further data for analysis.

## ***Consumer Panel Procedure and Data Collection***

Of the initial 123 respondents, those that were not included in the consumer trial were asked to participate in the consumer panel. Across Ontario, 71 people participated in these panels. A breakdown of participants and the respective locations is as follows:

Hamilton – 17 respondents  
Toronto – 25 respondents  
Sarnia – 4 respondents  
Sudbury – 11 respondents  
Ottawa – 14 respondents

Most of the participants at the consumer panels were caregivers of a person who wandered. There were also 6 participants that attended one of the consumer panels as a representative of an agency. Table 1 provides a description of the persons who wander that were represented by their caregivers, for example, information is included such as the number of males over sixty years of age living with Alzheimer's disease in the Ottawa area. Table 1 demonstrates the high participation of caregivers caring for individuals under the age of 20 that have autism.

**Table 1.**  
*Demographic profile of the participating persons who wander*

<b>Location</b>	<b>Hamilton</b>		<b>Ottawa</b>		<b>Toronto</b>		<b>Sarnia</b>		<b>Sudbury</b>	
<b>Population</b>	#	#	#	#	#	#	#	#	#	#
Age Range	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female
<b>Autism</b>										
>20	6	4	3		8	2 <sup>∞</sup>	1		6 <sup>£</sup>	3
21-30	1									
31-40					1					1
<b>Developmental Disability</b>										
>20	1									
21-30	1									
31-40						1				
41-50			1		1					
<b>Down Syndrome</b>										
>20	1					1				
51-60								1*		
<b>Acquired Brain Injury</b>										
51-60					1					
<b>Alzheimer's disease</b>										
51-60			1							
< 60			2	1	1	3				

∞ indicates that one individual has autism and a developmental disability

£ indicates that two individuals have autism and a developmental disability

\* indicates that this individual has Alzheimer's and Down syndrome

The consumer panel participants were shown a power point presentation about wandering behaviour and the purpose of the study was explained, followed by an informative and interactive presentation about electronic locating systems. Participants also had the opportunity to see the locating systems. The results gathered from the data analysis of the first interview with the participants of the consumer trial were formulated into closed-ended questions in survey format and were posed to the consumer panel for comments and feedback (see Appendix G, page 110). Included in the survey were additional questions regarding the realities of caring for a person who wanders as well as impressions and perceptions of electronic locating systems. Participants were also asked to rank the answers in order of importance from most to least if applicable. During the time that participants were answering the questions, they were also encouraged to discuss amongst themselves. Members of the Investigative team who were present at the panel circulated the room at this time and joined in some of the conversations as a means to answer questions objectively and to hear first hand major concerns and opinions regarding the project. Please see Appendix H (page 117) for a methodology overview.

# **3. TECHNOLOGY**

# TECHNOLOGY

## ***3.1 Technology Introduction***

*It would be nice to know what direction he [John] has gone. I am happy to search the forest. I am happy to go down the side road, but they are opposite directions.*

*So it would be nice to have that tool to know what direction he [John] is. And then if he's got a head start, if I'm running, I'm not running in the wrong direction.*

The LTP project recognizes that using such technologies may not be appropriate for everyone. Instead, the project and technologies examined in the study should be considered only as a possible option among other strategies when coping with wandering behaviour. Additionally, all devices tested are still under development and in the early stages of implementation. The technologies reviewed here represent a small sample of many others that are available. Those companies that submitted the devices are commended for their forward thinking regarding potential directions for the uses of their devices and technology.

In the consumer panel questionnaire, participants were asked, “What do you expect from an electronic locating system?”. The majority of answers showed that participants wanted a locating device to do exactly what it promises – to detect the location of the person who has wandered or become lost.

Furthermore, participants of the consumer panel were asked why they were interested in using an electronic locating device. The majority of answers revealed that security and safety were the biggest reasons for caregivers’ interest.

## ***3.2 Electronic Locating Device Technology Overview***

(See Appendix I, page 120)

Varying degrees of locating support are available. Some devices rely on caregivers to find the wearer, while others use a monitoring service such as a call centre to locate the wearer. One of the technologies examined in this project relies on police services to locate the wearer of their device whereas other devices create a geo-fence. The latter is a defined boundary, which, when crossed by the GPS device transmits an alert. Systems that do not use a monitoring service rely on caregivers to perform their own locates of the person wearing the device through a website. In this case, the caregiver would direct another caregiver via cell phone to the location of the person wandering. This requires that the caregiver who is physically searching for the person wearing the device, has the

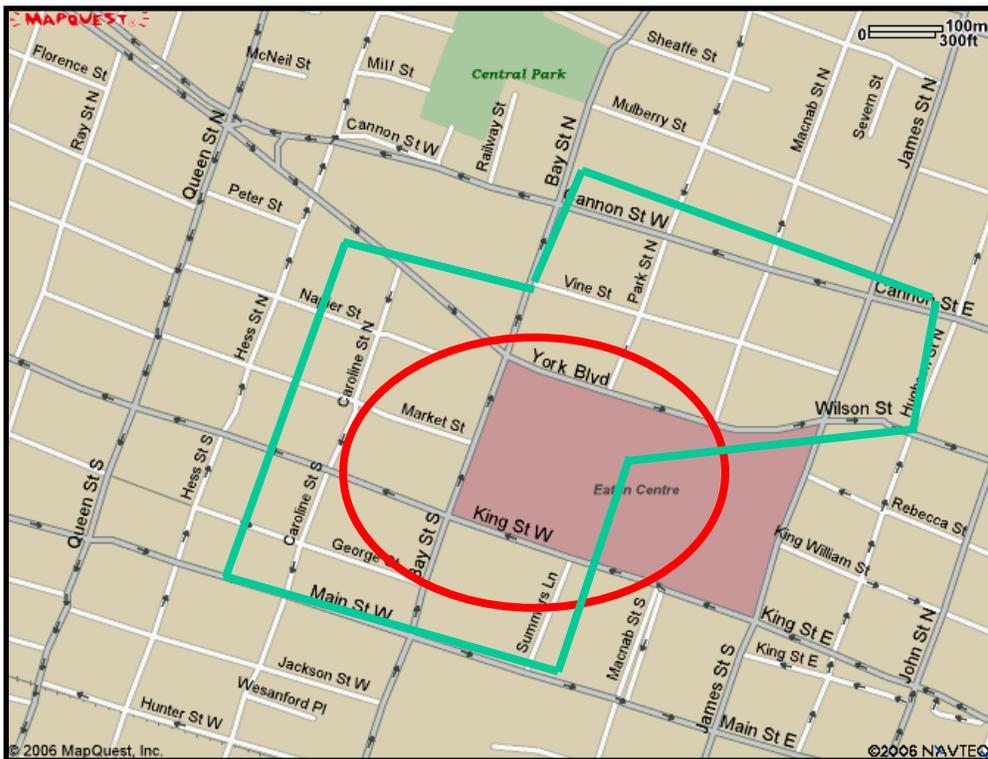
use of a cell phone to communicate with the other caregiver who is providing the directions. It also requires that one or both of the caregivers have knowledge of the area. It should be noted that this might be difficult to undertake while feeling stressed. Systems that use a monitoring service also require that the caregiver have a cell phone so that the service can provide directions on the location of the wearer to the caregiver as they are out searching. This service may be helpful to calm the caregiver.

One system available makes use of police services to locate the person who is wandering, which has the advantage that trained search and rescue personnel are the ones performing the search. They can also more easily gain access to locations that civilians cannot. However the police presence may cause additional stress to both the public and the wearer.

Of the five devices examined in Phase 1 of the project, two distinct types of technology were utilized: Global Positioning System (GPS) and FM (radio). Both technologies have advantages: the GPS based systems provide theoretically exact and historical location information of the person wearing the device whereas FM systems can easily pinpoint the location of a person wearing the device when they are in close proximity.

Devices that operate using a geo-fence do so using a predetermined boundary. This boundary can be circular or polygamous shaped (Figure 1). The GPS device is programmed so that if the device (worn by the person with a tendency to wander) crosses this boundary, an alarm is activated.

**Figure 1. Demonstration of geo-fence shapes**



### ***3.3 Technical Report***

For further information regarding some of the technical terms used in the technical report, please refer to Appendix I (page 120), and for further information regarding the specific features of each device, including those that were not selected for Phase 2 testing, please refer to Appendix J (page 124). Both qualitative and quantitative data are provided in Appendices K (page 126) and L (page 128).

#### ***Device A***

Device A consists of a cell phone wearer device and a website. The cell phone is fully functional and is equipped with A-GPS. The unit tested was a cellular phone. The location information is sent to the organizations website via Short Message Service (SMS) messaging over the Global System for Mobile (GSM) network where the website displays a Mapquest map showing current and historical location of the device. The cell phone itself can also display a map showing its current location. This feature could be useful for a wearer who is more cognitively aware. This particular device is quite socially acceptable for clients, caregivers, and others as it truly is a cell phone. In addition, the phone can be used to contact the wearer directly or for the wearer to contact someone with his/her whereabouts.

Another feature of this device is that the organization's website allows a caregiver to set one or multiple geo-fences, each with a specific radius. When a geo-fence is broken, a message can be sent to either an email address or a SMS cell phone number. In this way, a caregiver could keep track of the wearer's movements. This feature, however, was not found to be very accurate.

Unfortunately, this device was not at all reliable for locating the wearer. During the initial and Phase 1 tests, the unit could seldom establish a satellite link. In addition, the location information was often very inaccurate due to the fact that Mapquest is intended for street navigation and therefore attributes the displayed location to a street address for example, if a person is in a park, the device will show the location of the person on a web-based map will not give the longitudinal and latitudinal coordinates of that person. Other mapping software may provide improved results.

#### ***Device B***

This system includes a wearer device and a monitoring service/call centre. The device is similar in appearance to a large cell phone without a keypad. It uses GPS technology to obtain location information and then sends this information via SMS text message over the GSM network to the organization's call centre. The call centre uses a secure Internet

site to display the current location of the device, although a history of past locations is also available on the website for a selected time period. When the call centre is contacted, they direct the caregiver to the wearer by phone.<sup>1</sup>

Device B has a panic button that is monitored by the call centre and can be disabled by the call centre if required. The power button must be depressed and held for one second in order to turn the unit on or off. There is the potential that the user can remove the battery from the unit, however, the call centre monitors the battery status. The centre can also adjust the internal parameters remotely. The GPS antenna can be hinged open to obtain greater reception. Device B will automatically turn itself on when the charger is unplugged. Geo-fencing is possible with this system however was not available at the time of testing. All of these features should be considered when selecting a locating technology device.

During initial Phase 1 testing, this system performed well outdoors. The call centre was able to direct the caregiver to the wearer, although unable to determine the location of the wearer if they were indoors or underground. The system could, however, show that the wearer was within a structure and indicate if they had exited the structure.

Along with the potential implementation of a call centre, device B also plans to make available a new bracelet style wearer device instead of the large cell phone style in use during testing for this study.

## *Device C*

This system consists of a wearer device similar to a wristwatch and a website. The device itself is a small box approximately the size of two stacked boxes of wooden matches. It uses A-GPS technology to obtain location information and then sends this information via SMS text message over the GSM network to the organization's secure internet site. Current location or history for a selected time period can be displayed from this website.

Unlike other GPS based devices that require the caregiver to program a geo-fence from a website, device C has a 'park' button that creates a geo-fence (100 meter radius) around the current location of the unit. This dynamic geo-fence feature could be useful to groups of caregivers and wearers on outings to, for example, a shopping mall, allowing for more spontaneity for both the caregiver and the wearer.

One disadvantage of this device is the sliding On/Off switch. Users could easily turn the device off, and because no monitoring service is connected with this device, no one would be able to notify the caregiver that the device is turned off. Another disadvantage is that the device is difficult to attach to the user reliably. The organization has provided a

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<sup>1</sup> The call centre is currently under development and hence was not available for testing. A mock-up call centre was used instead.

belt clip holster commonly used for cell phones. This belt clip, however, could easily be removed intentionally or accidentally.

Initial tests of device C were not successful. Typically, poor results were found. During Phase 1 testing, the device did not reliably transmit correct location information to the website.

## *Device D*

This system is paired with police services. It is a special bracelet that corresponds with receiving equipment used by the police of jurisdiction. The wearer device is a FM transmitter that is similar in appearance to a thick-faced wristwatch. The device transmits a signal once per second continuously, on a very specific frequency. A specially trained police operator, using a receiver and antenna designed for this purpose, uses the signal to determine the location of the wearer. The receiver emits an audible beep when the transmitter is detected.

This device relies on police services to provide the search team and maintain a client database. The personal information of the wearer, including a photo, transmitter frequency of each client's device, and unique traits or concerns associated with each wearer, are included in the client database. The organization trains police services detachment's Emergency Response Team (ERT) to use the receivers and the client database. The organization also provides general sensitivity training specific to clients that may use the service. Currently, there is only one police detachment group in Ontario trained and operational with this organization although others are in differing stages of development.

When a client of the organization goes missing, the caregiver contacts the 911 call centre. The 911 dispatch then contacts the police services ERT who then access the database and deploy the search team to the location where the wearer was last seen (as given by the caregiver). One group begins a local door-to-door search (as per standard police search and rescue method without technology) while another group uses the receiving equipment to detect the wearer's radio frequency signal. This second group consists of a search coordinator and at least two teams with the receiving equipment, each with their own vehicle. The coordinator directs the teams throughout the search, with each team using their respective locating equipment.

The teams search first with a magnetically mounted, car top antenna, which is plugged into their receivers. This antenna has omni directional reception and a range of approximately 1 km on flat ground and is used to find any signal. The two cars begin a search grid pattern, blocking off 5 km square areas of no reception.

Once a signal is detected, the search pattern changes. Under the direction of the coordinator, one or both groups may change the antenna to a hand-held, Yagi style with

an increased range of up to 2 km and continue the search on foot. This antenna allows the operator to pinpoint the direction of the transmitted signal. At this point, both groups are coordinated to hone in on the signal. An advantage to this service is that when necessary, the equipment can be used with a helicopter, which increases the range of search.

Phase 1 testing of device D found the wearer in every instance. The only exception to this was when the bracelet was intentionally removed in which case the bracelet was still found. This was the only technology tested that was not greatly impeded indoors.

The organization, combined with a police services search team, is very effective in locating the wearer locally. However, if the wearer was last seen at a location far away from the service base, it would take valuable time to transport the appropriate personnel and equipment to this starting location.

## *Device E*

This system consists of: a bracelet, a base station, a battery pack, a caregiver key, and a website. The bracelet is quite large (36 x 64 x 24 mm), contoured for a wrist. The organization states that the bracelet is water resistant, however, as this feature was not tested, this could not be confirmed. When the bracelet is secured onto the wearer's wrist, it can only be removed by using the caregiver key. The bracelet uses A-GPS to obtain location information and thus has similar technology to that of a cell phone. It communicates the location information to the organization's secure website via SMS messaging over the GSM network. In addition to the location, the device's battery status is also displayed on this website.

Device E also uses a geo-fence that, because it is not radius based, can be configured in any polygon shape. The perimeter of the geo-fence can be directly drawn on a map on the website, and a safe area can be designated, allowing the wearer more freedom. For example, an irregularly-shaped geo-fence, originating from the wearer's home, can include a school, a friend's home, and the grocery store. The organization has a call centre that will contact the caregiver should this predetermined geo-fence be broken. Presently, the geo-fence is drawn by the organization (although it is determined by the individual and his/her caregiver), however, in the future, caregivers will have the ability to set this feature and alter it periodically to address changing needs. However, during testing, the geo-fence was radius based.

Another feature of this device includes automatic conservation of battery power while the bracelet is in close proximity to the base station. This is possible through a radio frequency (RF) link. When the bracelet is moved a certain distance away from the base station, it leaves the low-power 'sleep' mode and begins to relay its position to the website. The organization was unable to provide the exact range of this link at the time of testing. The purpose of this feature, according to the organization, is to increase battery life so that recharging is only required once every two weeks for the average user.

Unfortunately, given the short time constraints of initial Phase 1 testing, this feature remained untested.

This particular system has a unique method for recharging the bracelet unit. The base station acts as a charging station for a battery pack. When a battery pack is fully charged, a light goes out on the base station. It can be attached to the bracelet unit to recharge its internal batteries, and can subsequently be removed only with the caregiver key. A light on the top of the battery pack remains on until the bracelet is fully charged. This method allows the bracelet to remain on the wearer at all times.<sup>2</sup>

The bracelet of device E also has a panic button, which initiates a 2-way audio link, over the GSM cellular network to any predetermined phone number. Alternatively, it is possible for the caregiver to contact the wearer. This 2-way audio feature could allow a caregiver to communicate with the wearer directly (or other persons nearby), offering another means for assisting the wearer. This feature was tested during Phase 1 and although it did work, the test wearer took some time to determine from where the voice originated.

This device has several unique features that could prove useful for people who wander and their caregivers. However, it is currently being used on a regular basis in Europe and has only been used for consumer trials in Canada.

### ***3.4 Consumer Trial Feedback on Devices Tested***

In the second interview (Appendix F, page 108) after the device testing was complete, the consumer trial participants were asked about their experience with the electronic locating systems. For purposes of simplicity, the person using the device is referred to as “John”.

The first question asked: Please tell us about your experience of using the electronic locating system.

Four caregivers tested device E and they appeared to be quite divided in their experiences. One caregiver explained,

*John did not tolerate the wristband monitor at all. He wore it for a maximum of 5 minutes. At about 2-3 minutes he started rubbing and pulling and almost biting the wristband. He got quite upset with it. Despite 5 or 6 attempts, he never got used to it, and really never wore it for more*

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<sup>2</sup> A series of four successful tests were performed where the unit was initially discharged. Device E was tested while being charged by the battery pack (and out of range from the base station). After only 3.5 hours of testing, a fifth test was attempted. The device’s bracelet was at 25% battery power and unable to broadcast its location properly. The caregivers in the fifth test were not successful in locating the wearer.

*than 5 minutes. Good idea, but the technology and the size of the wristband really didn't work for him.*

Caregivers of one group home also reported difficulties with the bracelet not staying on, either because it had fallen off or because John had removed it. Additionally, the same caregivers were unable to use the device (E) when John left to go to work as the geo-fence feature could not support the distance from the group home to his place of work. Another participant of the consumer trial had issues with the battery charge of device E as well as difficulty receiving a signal.

However, one of the participants in the consumer trial was so pleased with device E that she did not want to return it after the testing period and stated that she would make arrangements with the service provider to continue using the device:

*Well I want to keep it. I spoke to [the service provider] about continuing with it, and he said it's not going to be available until 2007. I'll have to work around it somehow, because I really feel like, I mean, I've been wanting this for such a long time, and tried to buy one out of the US but it didn't do anything. There was no satellite for Canada. And the company has since gone out of business.*

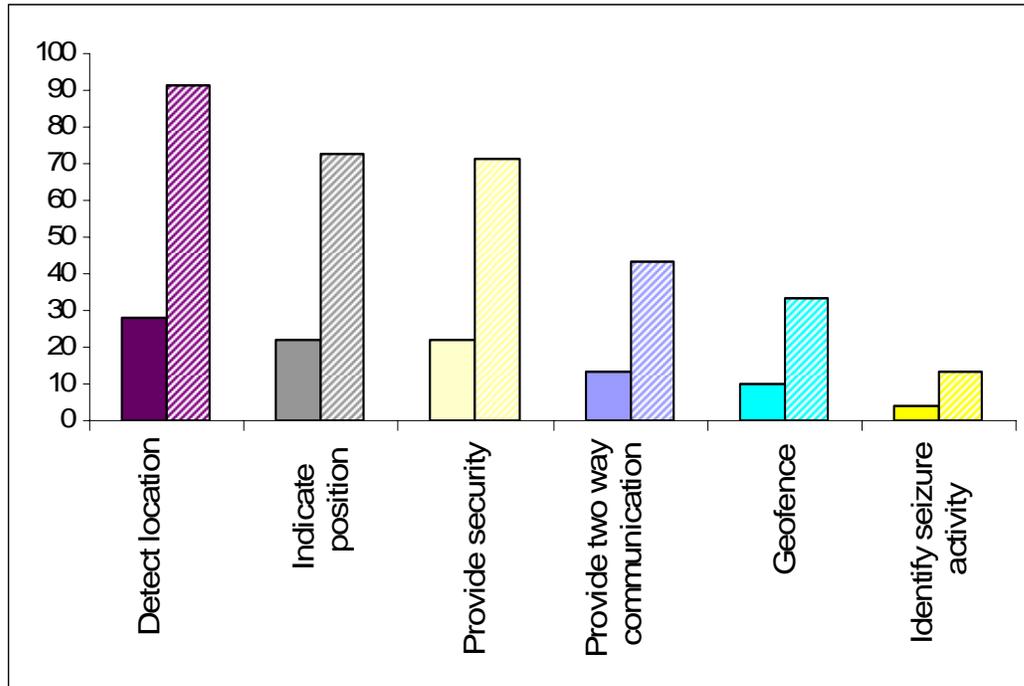
In contrast to the somewhat mixed responses to device E, the three caregivers that tested device D were all generally pleased with the device and did not experience any difficulties with the device during the testing period.

Another point worth noting, as responded in the fourth question of the second interview (Have you used the electronic locating system in any search and rescue efforts?), is that none of the caregivers actually had an instance where they had to use the device and the service provider for any search and rescue efforts. The electronic locating system, therefore, was not used to locate anyone during the consumer trial.

### ***3.5 Consumer Panel Feedback***

As mentioned in the introduction of the technology section, consumer panel participants were asked about their expectations for an electronic Locating System. Participants listed specific expectations, which are outlined in Figure 2. For all bar graphs used, the solid bar represents the percentage of participants that answered the question and the lined bar represents the percentage of answers that fell into the specified category

**Figure 2. “What do you expect from an electronic locating system?”**



Answers (n = 224) participants (n = 69) gave to the question "what do you expect from an electronic locating system". Solid, coloured bars represent the percentage of participants that answered the question and the patterned bar represents the percentage of answers that fell into the specified category. Participants were likely to give more than one answer to the question.

Above all, participants expected that such a system be able to detect the location of the person wandering. Less cited but perhaps more interesting, is that some participants expected an electronic locating system to identify the onset of medical conditions, such as seizure activity. This showed not only a variance in expectations, but a diversity in the functions of the device itself.

Also mentioned in the introduction to this section, participants were asked why they were interested in using an electronic locating device. Figure 3 shows a divergence in responses to this question, which further confirms the diversity among the needs and requirements of each participant.

**Figure 3. “Why would you use an electronic locating system?”**

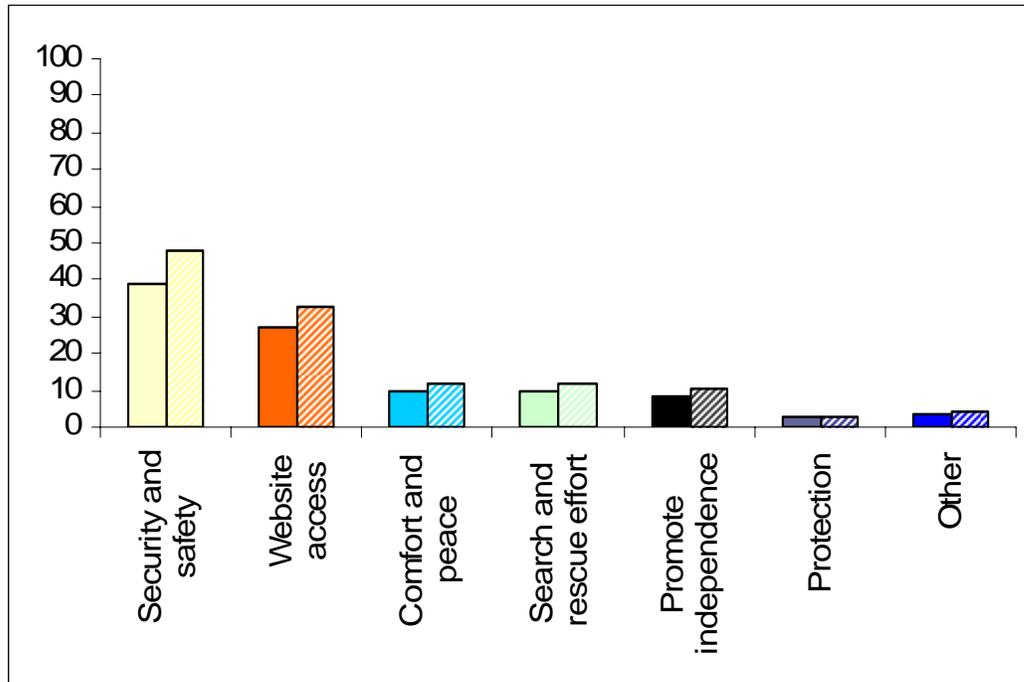


Figure 3: Answers (n = 82) participants (n = 67) gave to the question "why would you use an electronic locating system". Solid, coloured bars represent the percentage of participants that answered the question and the patterned bar represents the percentage of answers that fell into the specified category. Participants were likely to give more than one answer to the question.

### ***3.6 Limitations and Strengths of the Technology***

Following Phase 1 testing, devices were ranked in the following order:

1. Device D
2. Device B
3. Device E
4. Device C
5. Device A

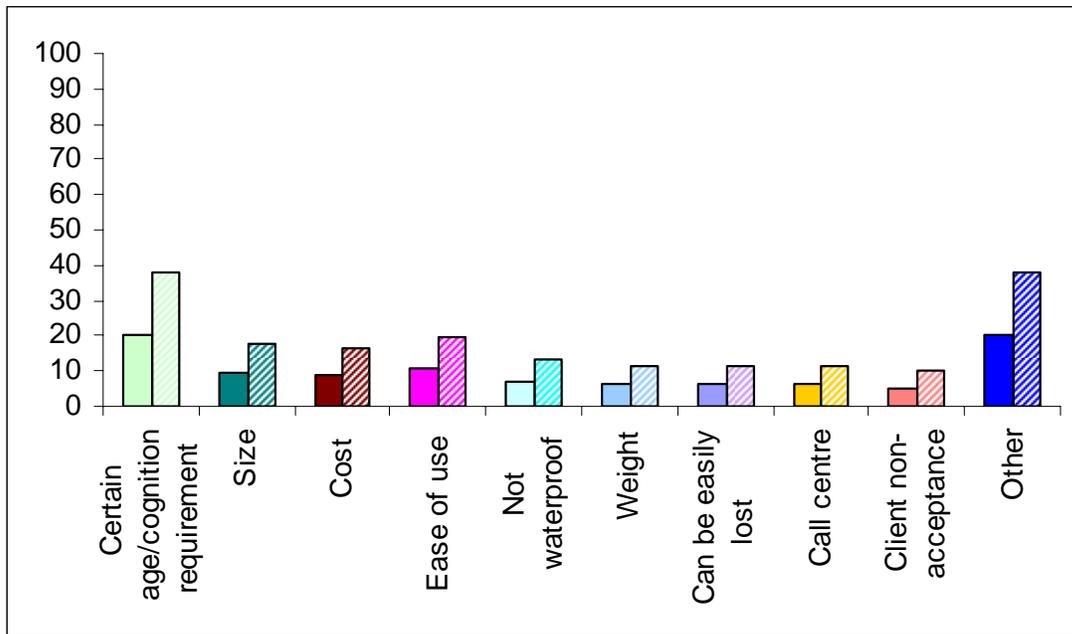
It is the opinion of the members of the project team that no submitted technology or service is ideally suited for the intended purpose. Each device has qualities that could be incorporated into a more robust design. However, taking into account the demonstrated and tested features, devices D, B, and E appear to be the most effective and have shown the greatest potential for future use in the situations tested in Phase 1.

Some limitations of the technology tested are as follows:

- No device tested included a feature to alert either the caregiver or a call centre if the device was removed from the wearer.
- With the exception of device B, none of the technologies tested had an alarm feature to signal if the wearer had fallen to the ground.
- All devices included a cost, with initial wearer device fees ranging from \$420.00 to \$610.00, and ongoing monthly fees (such as monitoring costs) ranging from \$14.00 month to \$40.00/month.
- In some technologies, such as device B, the battery pack is removable, which can pose an obvious risk to the wearer.

Additionally, the consumer panel noted specific limitations in those devices seen (i.e., B, D and E). The most commonly cited limitation of device B was that the manufacturer had in place a certain age or cognition requirement of the person to be wearing the device.

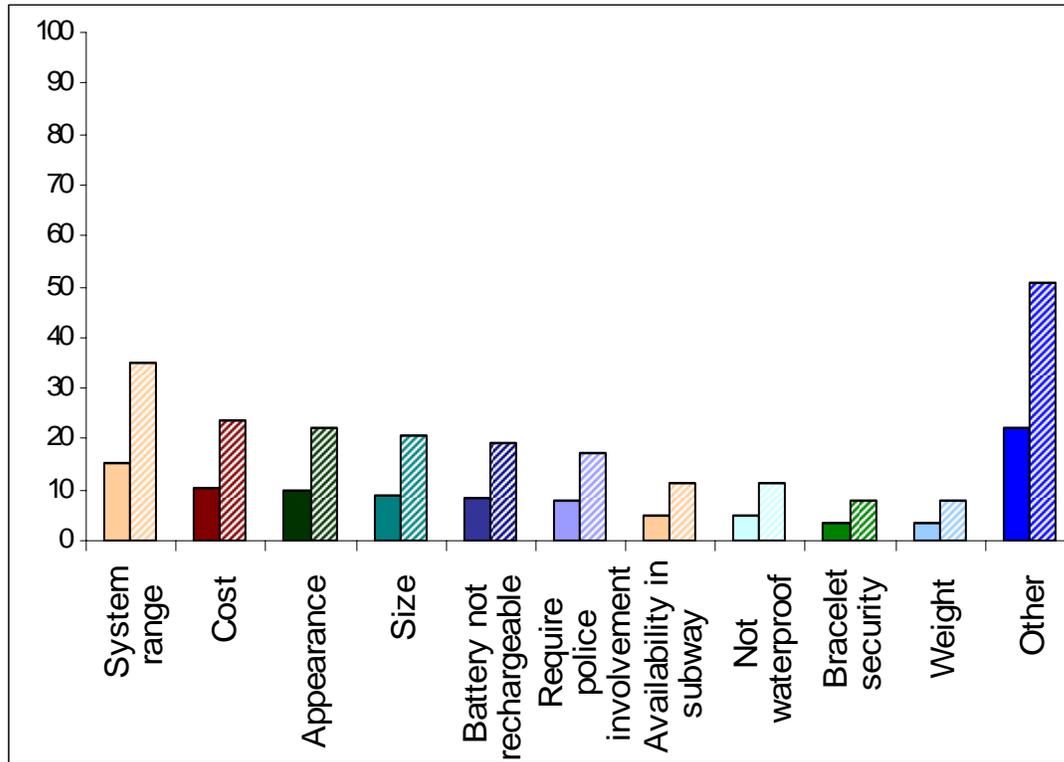
**Figure 4. Strengths of System B**



Specific strengths (n=114) of system B according to the consumer panel participants (n = 61). Solid, coloured bars represent the percentage of participants that answered the question and the patterned bar represents the percentage of answers that fell into the specified category. Participants were likely to give more than one answer to the question.

In device D, the most often cited limitations were the range of the system and the cost of using such a device.

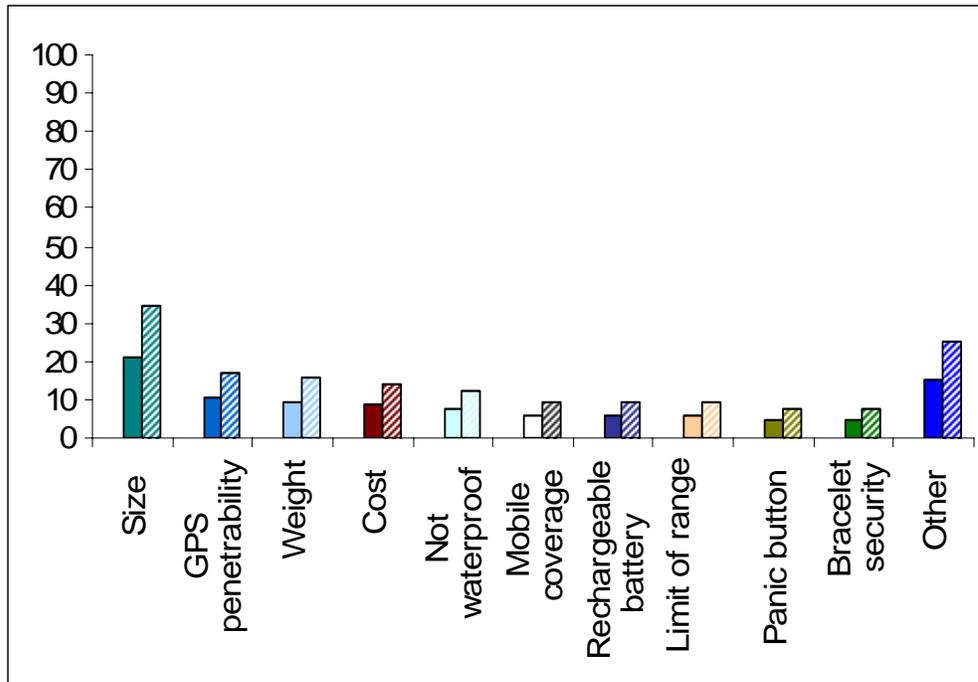
**Figure 5. Limitations of System D**



Specific limitations (n=143) (system D) according to the consumer panel participants (n = 63). Solid, coloured bars represent the percentage of participants that answered the question and the patterned bar represents the percentage of answers that fell into the specified category. Participants were likely to give more than one answer to the question.

With device E, participants of the consumer panel most often cited the size of the wearer device and the system's inability to penetrate structure as limitations.

**Figure 6. Limitations of System E**



Specific limitations (n=104) of system E according to the consumer panel participants (n = 64). Solid, coloured bars represent the percentage of participants that answered the question and the patterned bar represents the percentage of answers that fell into the specified category. Participants were likely to give more than one answer to the question.

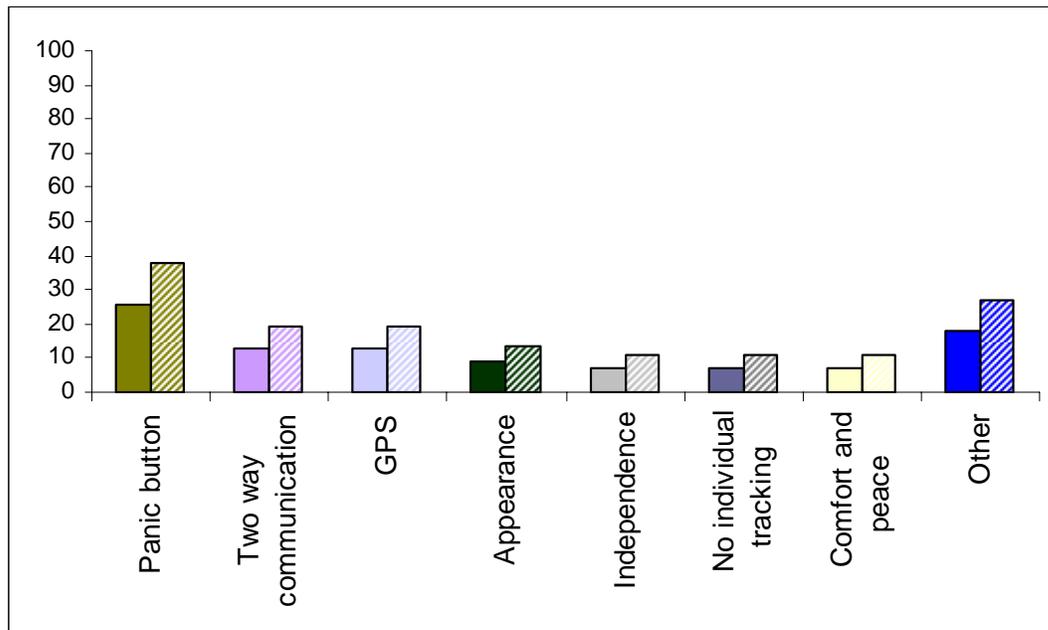
Some strengths or advantages noted by the project team concerning the tested technology are as follows:

- Potential uses for people who should be under surveillance; (c) people at risk of elopement.
- Devices that include the geo-fence feature allow for increased independence for the wearer.
- In technologies where there is a call centre or monitoring service, caregivers are offered further support that may help them during times when the wearer is lost. Generally, the consumer trial participants were pleased with both service providers, with one participant stating:

*It's been very good so far. No problems. They have checked in on us. They have been very accommodating. They are willing to meet with us in the evenings or at our convenience, which is very good.*

Consumer panel participants were also asked about the strengths of devices B, D and E. The most cited strength of device B was the panic button feature.

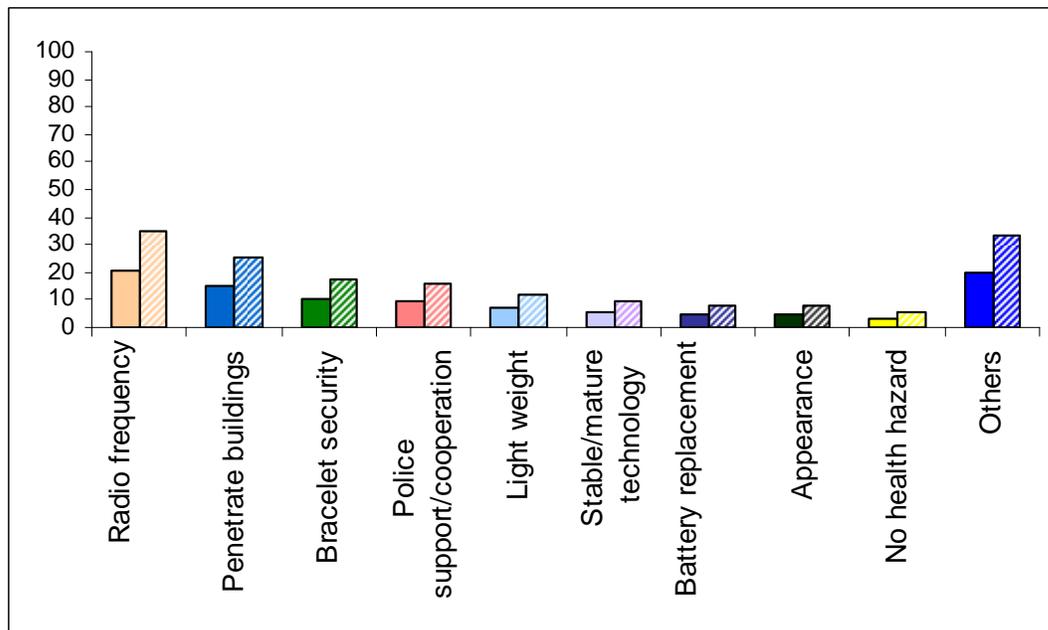
**Figure 7. Strengths of System B**



Specific strengths (n=55) of system B according to the consumer panel participants (n = 37). Solid, coloured bars represent the percentage of participants that answered the question and the patterned bar represents the percentage of answers that fell into the specified category. Participants were likely to give more than one answer to the question.

With regard to device D, participants cited the radio frequency and the device’s ability to penetrate buildings as the two highest strengths.

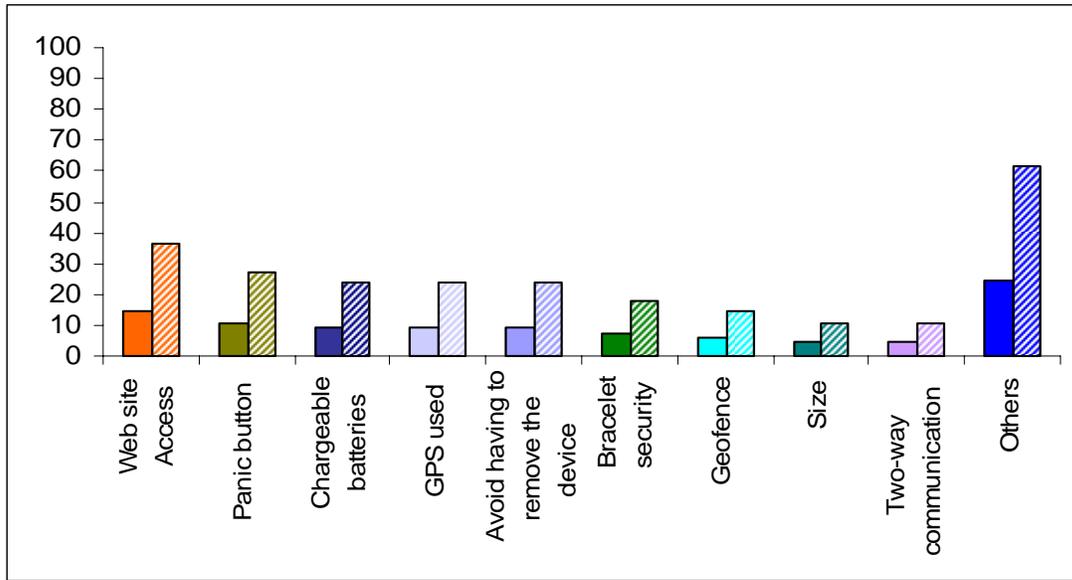
**Figure 8. Strengths of System D**



Specific strengths (n=87) of system D according to the consumer panel participants (n = 51). Solid, coloured bars represent the percentage of participants that answered the question and the patterned bar represents the percentage of answers that fell into the specified category. Participants were likely to give more than one answer to the question.

The two highest strengths of device E were cited as the website access and the panic button feature.

**Figure 9. Strengths of System E**



Specific strengths (n=104) of system E according to the consumer panel participants (n = 64). Solid, coloured bars represent the percentage of participants that answered the question and the patterned bar represents the percentage of answers that fell into the specified category. Participants were likely to give more than one answer to the question.

### 3.7 Summary

The analysis of responses from the consumer trial and the consumer panel, indicates security and safety for the person prone to wander as the number one reason cited for showing interest in electronic locating systems. Participants, above all, expected the devices to be fully able to locate the person wearing the device should they go missing or become lost. What became increasingly evident, however, both through the phase 1 and the consumer trial in phase 2, is that, not only is some of the technology coming available not reliably capable of locating a person, but that the devices and systems are not always comfortable or practical for the wearer or the caregivers. Above all, it is clear that no one device meets the demands of every individual and their family or caregiver.

**4. ETHICAL  
CONSIDERATIONS  
AND MORAL  
RAMIFICATIONS**

# ETHICAL CONSIDERATIONS AND MORAL RAMIFICATIONS

## *4.1 Literature Review*

The ethical and moral ramifications of electronic locating devices have been articulated in literature such as that of Welsh et al. (2003) and Royal College of Nursing (2004). Among other literature, it has been argued that electronic locating devices may impose restrictions on a client's basic rights such as liberty, freedom, privacy, and dignity (Bach, Keyserlingk, & Somerville, 1989; Huges & Louw, 2002; Loh et al., 2004; Royal College of Nursing).

Furthermore, such devices have been used for locating criminals and wild animals, which could lead to stigmatization and negative connotation when attempting to apply the same technology to individuals exhibiting wandering behaviours (Loh et al., 2004; Royal College of Nursing, 2004).

When using electronic locating devices, therefore, care should be taken to consider the moral issues and above all, to consider the best interests of each individual client (Hughes & Louw, 2002; McShane et., 1998). Additionally, when developing a comprehensive plan of care (Welsh et al., 2003), one must consider all alternative available strategies and apply a multidisciplinary study of the behaviour (McShane et al.; Eltis, 2005).

## *4.2 Identified Ethical Concerns*

As work progressed with the LTP, the need to discuss the ethical concerns apparent with regard to people who are at risk of wandering potentially using a locating technology device. Upon review of various documents including: the Canadian Charter of Rights and Freedoms, the Ontario Human Rights Code, and the Rights Based Technology Development, the following ethical concerns and questions were revealed and considered:

### **Stigma:**

- The use of such a device could broadcast to the general public that the wearer has a disability. This may lead to social isolation and exclusion.

### **Consent Issues:**

- Currently, there are no protocols in place to determine who makes the decision regarding the wearing and use of the device.

- Similar to the above point, what if the person who wanders does not want to wear such a device but is forced to by a caregiver? Furthermore, what kind of authority should group homes hold over persons who are prone to wandering when in regards to wearing such a device? Does the home have the right to impose a locating device if the family is not involved?
- The protection of people with reduced autonomy should include protecting the scope and ability such persons have for personal autonomous decision-making. The guardians must make every effort to facilitate, enhance, and expand this scope. What is the protocol should the wearer wish to withdraw from using the device?
- Another aspect that has yet to be determined, is deciding who is eligible to use this technology and if there should be specific criteria to determine eligibility (i.e., is a medical record required).
- What kind of ethical concerns should be considered if the person who is wearing the device is not cognitively aware of this fact?

**Privacy:**

- The device potentially imposes on the freedom and privacy of the wearer. By wearing a device that the person's location is known at all times which restricts privacy and freedom.
- Sharing of personal client information such as name, address, phone number, health or personal data with the organization's operations therefore threatening client confidentiality.

**Dignity:**

- The stigmatization associated with wearing such a device may cause harm to the wearer's sense of dignity and self worth.
- The team placed high importance on maintaining the dignity of the person who wanders; this may be a problem if the person is wearing an identifiable device such as a bracelet.

**Confinement:**

- In settings where sensor alarm systems are employed, the person may feel 'captive' within a specified area. In addition, in residential settings with such alarm systems, individuals that do not wander may feel restricted in their freedom

**Loss of Personal Contact:**

- Misuse of systems to save care costs may lead to a decrease of personal contact or supervision

The advisory board discussed ethical concerns and agreed to a list of principles that have been adapted from the Canadian Charter of Rights and Freedoms and the Human Rights Commission. These principles should be followed whenever making decisions about the use of locating technology, especially when a variety of unfamiliar people such as doctors or administrators may make decisions that may compromise autonomy, identity, privacy, control, and feelings of self worth from vulnerable people. **The principles are:**

1. People must have the right to have their needs met and the right to participate in all decisions affecting their well-being.
2. People have the right to have someone of their choice to act on their behalf if and when necessary or preferred
3. People have the right to privacy and confidentiality.
4. People have the right to be informed and have access to information pertaining to him/herself.
5. Ensure that children and adults with a developmental disability and elders have access to both internal and external individuals, organizations, and every opportunity for assistance in taking advantage of their right to complain i.e. Child Advocate Office of Ontario.
6. Promote, portray and act toward children and adults as fully human and valued people.
7. Promote the full inclusion of children and adults in the life of the community, and more particularly in relationship with people who are members of the community.
8. Support people to have nurturing relationships with their families.
9. The family is recognized and appreciated as the legal guardian of the child or adult where necessary. This means the family is in control of decisions. It means that there are expectations on parents/guardians to make decisions in the best interests of the person.
10. Children and adults with a developmental disability who are without family have access to an outside advocate who will commit to being involved in decisions about the life and quality of life of the child.
11. Children and adults are seen and responded to as people who can be both loved and members of families, and as people with whom others would want to enter into relationship.

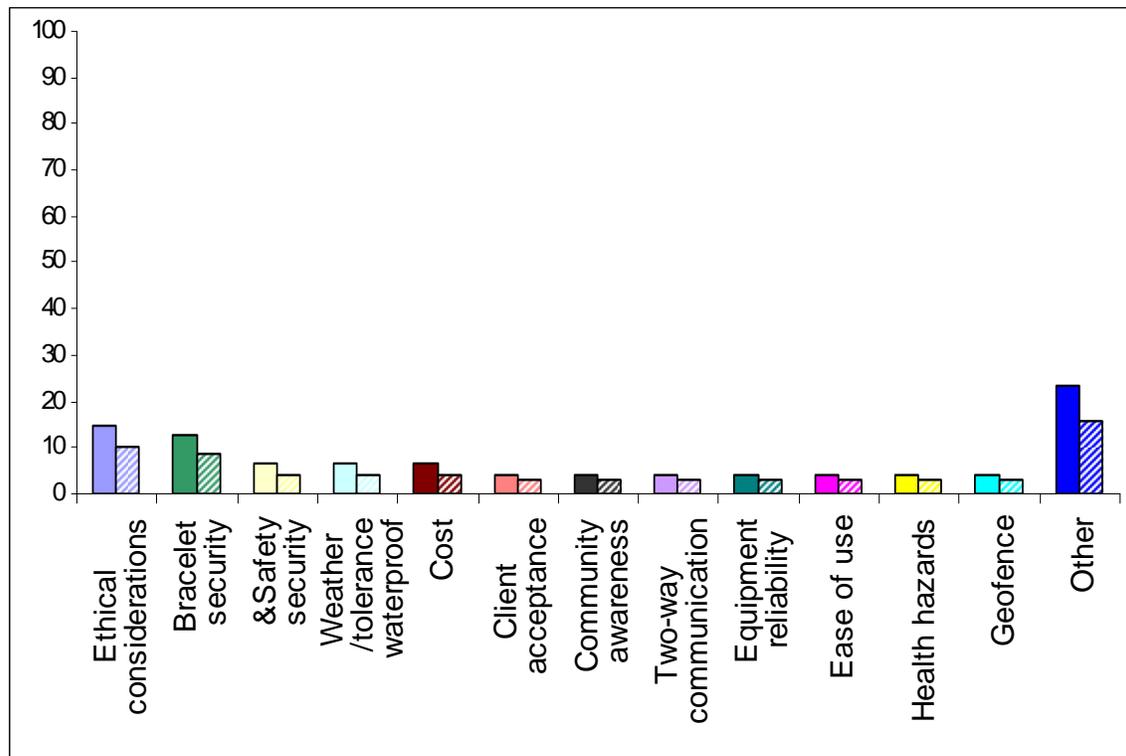
There are many decisions that must be made when deciding to use or not to use electronic locating technology. There is potential for increased autonomy, responsibility, and

growth and development of the individual with proper use of the technology. Bach et al. (1989) suggest the need to establish a framework for decision-making completed on a case-by-case basis that consumers can use. This decision-making framework should both protect individuals from the potential abuse of fundamental rights and interest which the application of the technologies to particular individuals present and ensure fair and just allocations where the service facilitated by the technologies can be demonstrated to be in the individual's best interests (1989).

### 4.3 Consumer Trial and Consumer Panel Feedback on Ethical Concerns/Implications

In the consumer panel questionnaire, when participants were asked if there was anything further that came to mind when considering electronic locating systems, ethical considerations figured most highly among answers, which further shows the need to fully investigate the ethical and moral concerns associated with the use of electronic locating systems.

**Figure 10. "Is there anything else that crossed your mind when you think about using electronic locating systems?"**



Answers (n = 47) participants (n = 47) gave to the question " is there anything else that crossed your mind when you think about using electronic locating systems ". Solid, coloured bars represent the percentage of

participants that answered the question and the patterned bar represents the percentage of answers that fell into the specified category. Participants were likely to give more than one answer to the question.

Further to the discussions and concerns raised by the LTP team, when consumer trial participants were asked, “What are the limitations and strengths of the electronic locating system?”, they answered:

*People notice it right away, so it looks kind of institutional-like, so for a young child, if I could suggest anything to the manufacturers, if it's geared towards children, maybe, in the future, also that it was made to look more childlike, with bright colours or something, just so that it's not noticeable as much.*

*If they could make it look more childlike so people don't notice it quite as much.*

In response to the question “Did the technology have any effects on John’s life and yours? In what way?”, none of the participants believed that the electronic locating system provided any practical impacts on John’s life. However, and interestingly enough, participants stated that instead, the electronic locating system had the following impacts on their own lives:

- The devices acted as an aid or reinforcement. One participant said,

*It's like having a guardian angel for her, you know, someone who has an extra helper out there... You are still going to be very vigilant in taking care of her, but the fear of if you lose her she will be gone forever [is not as prevalent].*

- The devices provided a sense of comfort and peace. The following response was heard during the interview:

*...it really gives me peace of mind, so I am sure that it will give other people peace of mind too, if they have a wanderer in their life. I can say to you that the piece of mind that that little device gives me is amazing.*

- There were similar comments in the journals caregivers kept:

*The peace of mind that this device [electronic locating system] will bring is truly unbelievable! Thank you! (May 8, 2006)*

*We are very excited about the prospects of using this GPS watch, getting peace of mind from it. (May 8, 2006)*

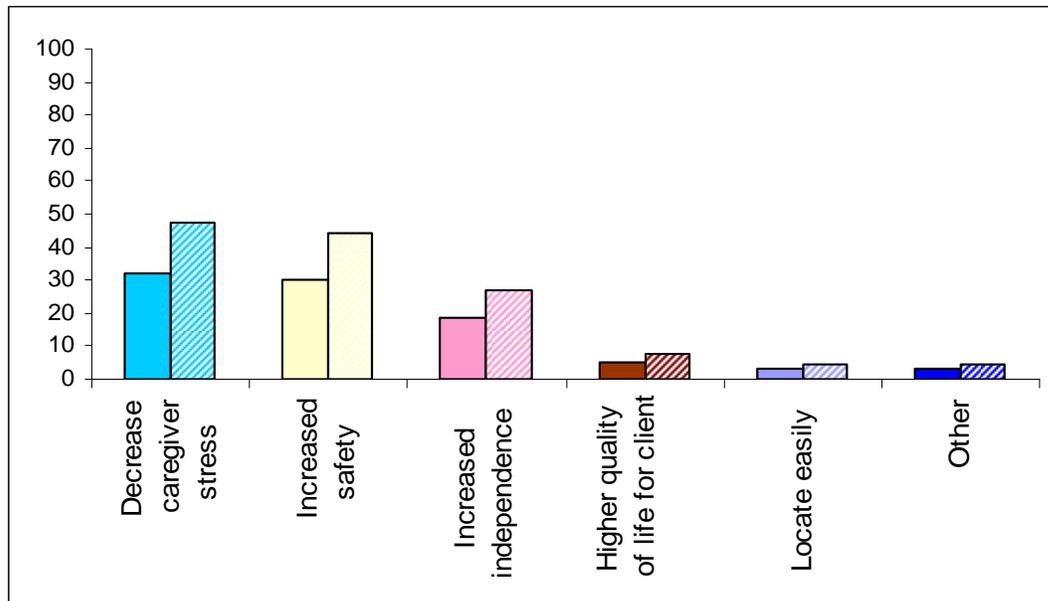
- The devices gave promise of the possibility of future independence. The following comments were made:

*It [electronic locating system] didn't make him more independent during this test, however, we believe that this device and the system that comes with it would give him independence and freedom in the future. So we feel confident about the device, but the test itself was not perfect for this purpose.*

*For my children [with wandering behaviour], it will be more in the future, because I would like to give them a little more independence when they get older. Right now I have to watch them constantly anyways, because they are only 4, but if I would like to give them more independence when they get older, like maybe let them go to the park themselves or something, I would probably be more able to do that if I know that they've got their bracelet on.*

Similar responses were received in the consumer panel questionnaire.

**Figure 11. “Do you think the electronic locating systems would affect John’s life and others, in what way?”**



Answers (n = 93) participants (n = 63) gave to the question "do you think the electronic locating systems would affect John's life and others, in what way". Solid, coloured bars represent the percentage of participants that answered the question and the patterned bar represents the percentage of answers that fell into the specified category. Participants were likely to give more than one answer to the question.

Participants of the consumer trial were also asked, “Was John fully informed about the electronic locating system?” This question specifically addressed the concern raised by the LTP team in terms of the person wandering not being cognitively aware of wearing the device and if this infringes at all on basic human rights. Participants who responded to the question confirmed this concern saying that either John was not aware at all, or that it was too difficult to explain the device and its function to him.

In summary, the original concerns raised by the LTP team were not necessarily shared concerns of the consumer panel and consumer trial. Contrary to the concerns raised by the LTP team, participants stated more positive ethical impacts of the use of electronic locating systems such as peace of mind and promise of future independence.

# **5. EMERGING INSIGHTS**

# EMERGING INSIGHTS

## *Advances in Tested Technology*

As the process of the project has unfolded, all the technologies included in final testing have undergone varying forms of development. These have included: adaptations to design, broader planning for inclusion of service in new regions, and additional features to devices.

### *5.2 Emerging Insights*

A number of insights emerged that related both to the technology itself and to potential users:

Locating technology is utilizing three main types of technology; these are GPS, AGPS and FM. Although the technology is developing rapidly, it appears that none yet provides a foolproof solution for all applications. It is also apparent that locating systems are utilizing technology that was developed primarily for asset location. Developers do not appear to have a good understanding of the concepts and the distinct needs of people who wander but they are anxious to gain a better understanding of the human dilemma and develop more appropriate equipment. One result of this enthusiasm is the potential to develop links between the research team and developers in order to meet consumer needs more quickly and appropriately.

The literature review revealed that most research on wandering relates to people with Alzheimer's disease or other dementias. However, despite significant efforts to recruit participants who were representative of a wide range of diagnoses, there was significantly more interest from people with autism and their caregivers. Board members from groups that were not well represented in the trials and panels provided the following possible insights: caregivers of people with Alzheimer's disease may consider a device as 'just another thing' that may cause stress; that the family has yet to acknowledge that there is a problem; or possibly when a loved one is at risk of wandering, the family does not want to 'experiment' with safety. Other reasons suggested were individuals with developmental disabilities may have philosophical concerns around tracking people, since many people with developmental disabilities are adults, they may have chosen not to be tracked; individuals may be in small group homes where there is close supervision and therefore there may be less concern for the wandering behaviour; or possibly because this group has a wide range in functional abilities the propensity to wander may be lower in the group as a whole in comparison to other groups/populations.

Another human factor that emerged from the study is that locating technology is needed for two significantly different purposes. The first is to locate people who are missing and at risk of harm. The second is to provide to people who wander who do have a greater cognitive capacity a sense of security and increased independence.

# **6. RESEARCH IMPLICATIONS**

# RESEARCH IMPLICATIONS

## *6.1 Future Research*

As with other aspects of the study, this topic may apply to the technology itself and/or to the consumer. With regards to the technology, there is an obvious need to develop more reliable, accurate, and acceptable solutions. The technology must be able to locate people accurately and in all locations, for example, underground, under water, over a geographically wide area. The wearer device must be small and unobtrusive and should not “label” people; it must be acceptable to the wearer, should not be easily removed and should provide an alarm if it is removed. In addition, most participants said that they would like to have the ability to use their own search resources rather than rely on police.

As previously stated there is very little research on the needs of people who wander, particularly for people who have autism. This is an area of priority for future research to determine: current options and resources available and used (technical and non-technical), what do these cost and how are people paying for them. There is also a need to better understand the lived experience of people who wander and their caregivers. This study revealed a very urgent need for assistance and it would be invaluable to develop a self assessment tool that would assist people in determining their specific needs and what type of solutions might best meet those needs.

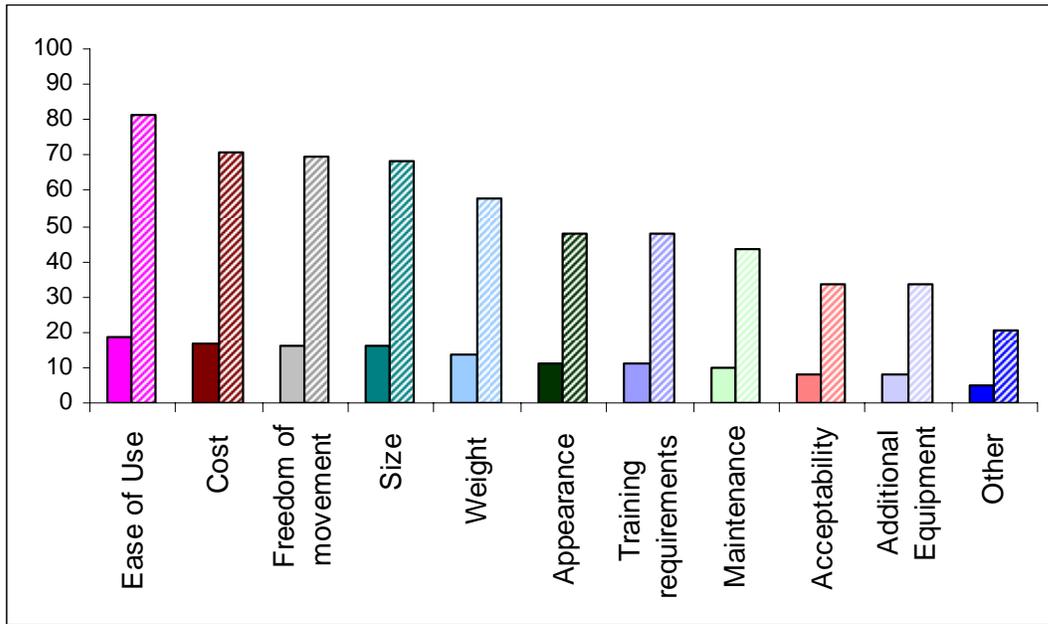
Another area of potential inquiry would be the further exploration into the impact of wandering as a community responsibility. In addition, from the literature review there were some cues regarding the need for ongoing research. These include: the effects of music on wandering behaviours; developing and piloting management strategies for caregivers; and, the impact of electronic devices on users and their caregivers.

## *6.2 Recommendations and Conclusions*

Above all and as already mentioned, the LTP team would like to make clear that the use of locating technology devices is not a blanket solution, nor is it a coping strategy that is ideal for everyone. The technologies included in this project are, however, suggested strategies for people searching for an alternative to traditional methods of intervention for wandering behaviour.

Above all, participants of the consumer panel placed priority on ease of use for any electronic locating system. The below results should serve as a recommendation to any manufacturers of similar systems.

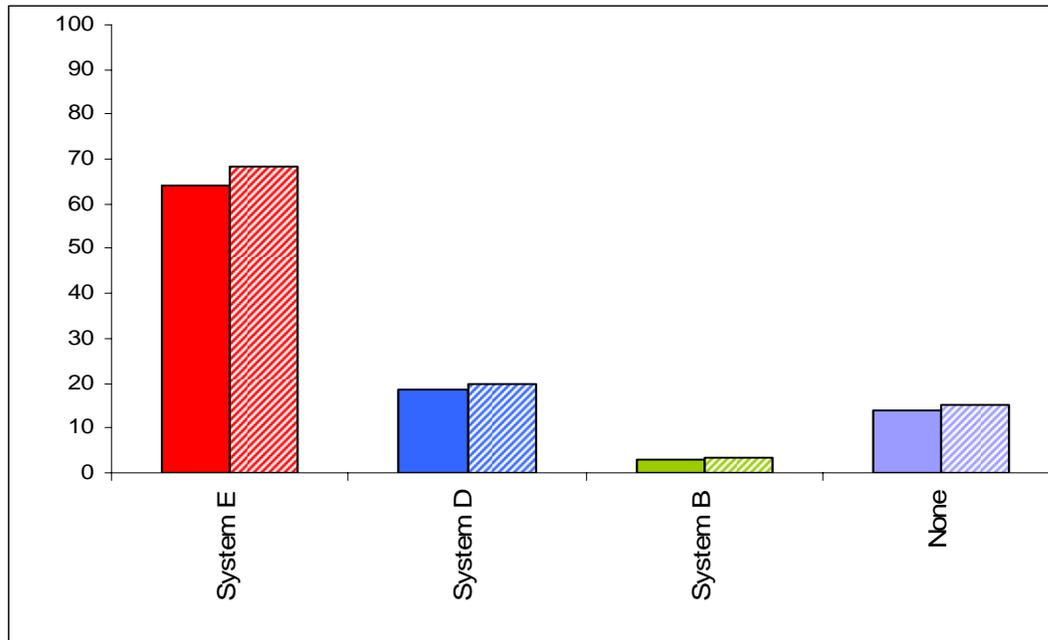
**Figure 12. “What is the most important thing for you when selecting an electronic locating system?”**



Answers (n = 396) participants (n = 69) gave to the question " what is the most important thing for you when selecting an electronic locating system". Solid, coloured bars represent the percentage of participants that answered the question and the patterned bar represents the percentage of answers that fell into the specified category. Participants were likely to give more than one answer to the question.

The consumer panel were asked which of the electronic locating systems they would choose in Part Two of the questionnaire and approximately 64% of the participants selected device E.

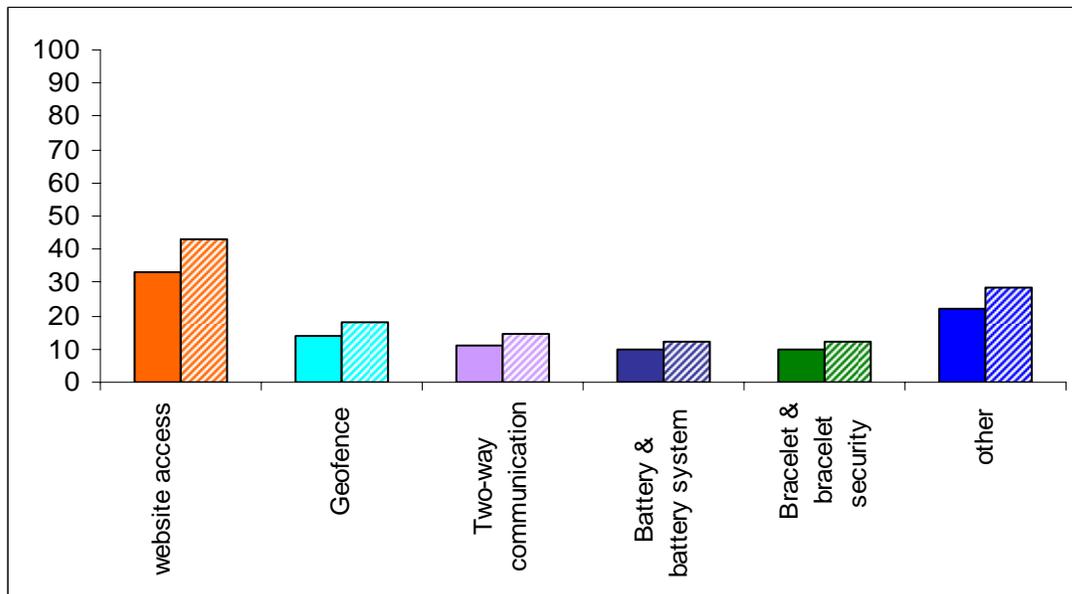
**Figure 13. “Which locating system would you choose?”**



Answers (n = 64) participants (n = 60) gave to the question "which locating system would you choose". Solid, coloured bars represent the percentage of participants that answered the question and the patterned bar represents the percentage of answers that fell into the specified category. Participants were likely to give more than one answer to the question.

As a second part to this question respondents were asked to explain their decisions and of the participants that selected Device E, many responses showed the website access associated with this particular system prevailed as the reason for making this choice.

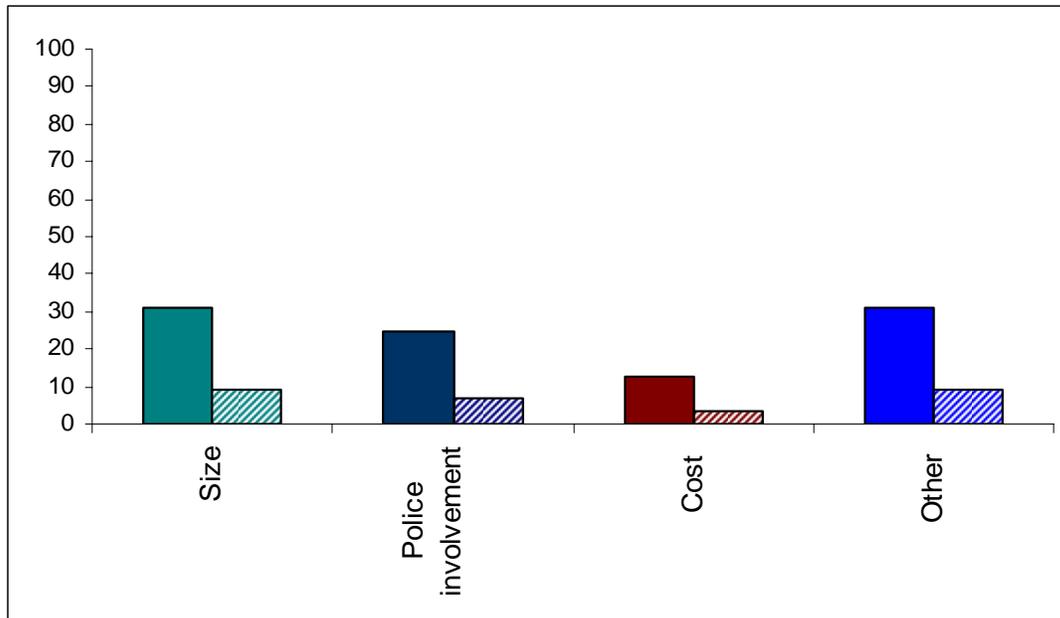
**Figure 14. Reasons for Choosing System E**



Reasons (n = 72) participants (n = 56) gave for choosing system E. Solid, coloured bars represent the percentage of participants that answered the question and the patterned bar represents the percentage of answers that fell into the specified category. Participants were likely to give more than one answer to the question.

By comparison, reasons for choosing device D were quite different, with the size of the device being cited as the main reason for choosing this device.

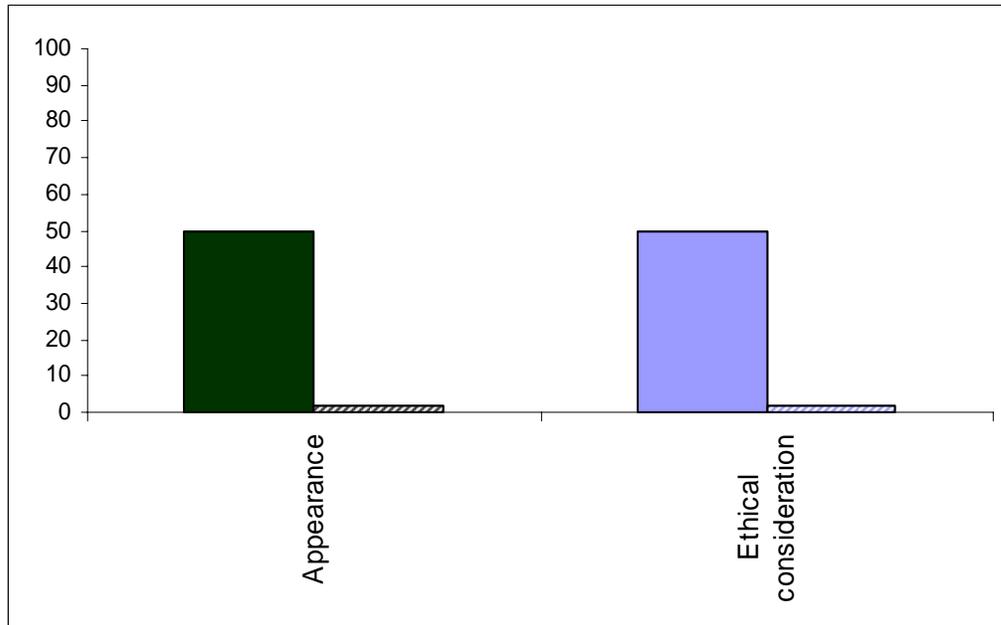
**Figure 15. Reasons for Choosing System D**



Reasons (n = 2) participants (n = 56) gave for choosing system B. Solid, coloured bars represent the percentage of participants that answered the question and the patterned bar represents the percentage of answers that fell into the specified category. Participants were likely to give more than one answer to the question.

Device B, which scored lowest in this question and subsequently had very minimal responses to explain why the participants had chosen the device, had the same number of responses for the two explanations cited. Interestingly, device B was the only system where participants cited ethical considerations as a reason for choosing this particular device. Ethical considerations did not factor in the choice of any other electronic locating system.

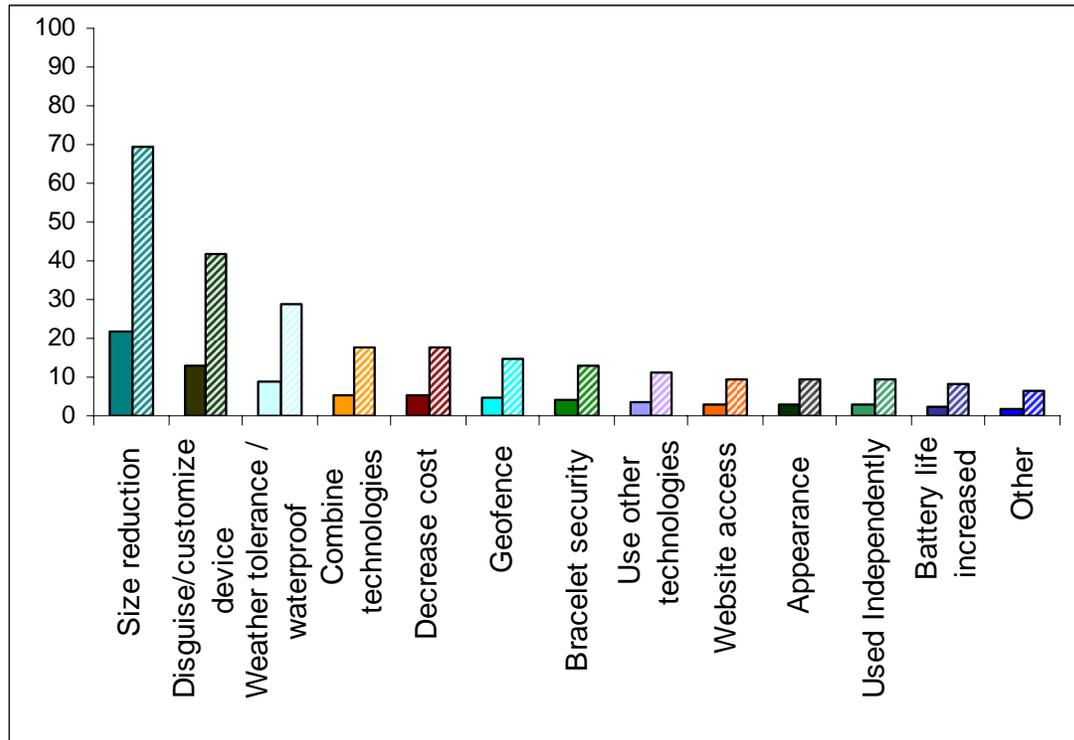
**Figure 16. Reasons for Choosing System B**



Reasons (n = 2) participants (n = 56) gave for choosing system B. Solid, coloured bars represent the percentage of participants that answered the question and the patterned bar represents the percentage of answers that fell into the specified category. Participants were likely to give more than one answer to the question.

Participants of the consumer panel were also asked if they had any suggestions to improve upon the electronic locating systems presented. Ultimately, these suggestions show where real improvements can be made.

**Figure 17. Recommendations participants gave to improve the electronic locating system**



Recommendations (n = 198) participants (n = 62) gave to improve the electronic locating system. Solid, coloured bars represent the percentage of participants that answered the question and the patterned bar represents the percentage of answers that fell into the specified category. Participants were likely to give more than one answer to the question.

With size reduction and disguising or customizing the device being the most highly cited recommendations for improvement, this further supports the idea that ethical considerations, such as social stigmatization, play an important factor for many of participants when and if they choose to use such a device or system.

In addition to the recommendations cited in Figure 16, one consumer trial participant stated that funding could occur through public awareness.

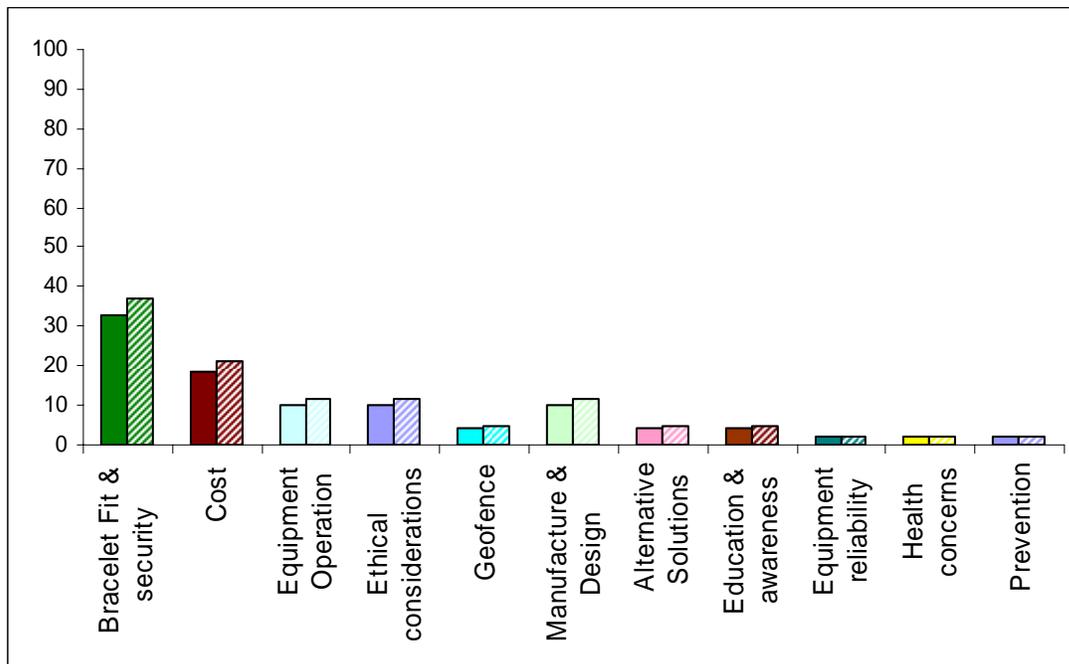
*Well, I understand everything has to do with funding. I just think working on getting more knowledge out to the public and to the government, so maybe there will be more funding and it will be more accessible to everyone that needs it. As far as the way they are doing stuff, I can't see any complaints. I know they are working at getting the equipment out to all the different police service branches, you know, if that stays going in that direction, I think it's good. But I think it's up to the government to help with the funding and what not. Not everyone else.*

*I definitely think it should be mandatory, that the government should be helping us a lot more than they do. If John were to go missing, it could be*

*hours before we could find him, and he would probably be dead. So the police are going to be searching for him for hours, whereas with this device or with any device, they would be able to find him.*

Panel participants were also invited to share any additional information they thought important to raise with regard to locating technology. Several participants, similar to comments raised by those in the consumer trial, commented on the cost involved with using many of the systems and suggested that the government pay for the use of the system or that it should be tax deductible. Individuals should be able test the systems without cost. In addition, manufacturers should be encouraged to further develop and improve their products. Results of projects such as LTP should be widely shared with potential funding agencies such as the Ontario Assistive Devices Program (ADP) and other social assistance agencies. Other responses reaffirmed that devices will work differently for each individual and the family/caregiver; electronic locating systems are not the answer for everyone.

**Figure 18. “Is there any additional information you would like to share with us?”**



Answers (n = 49) participants (n = 43) gave to the question "is there any additional information you would like to share with us". Solid, coloured bars represent the percentage of participants that answered the question and the patterned bar represents the percentage of answers that fell into the specified category. Participants were likely to give more than one answer to the question.

Above all and as already mentioned, the LTP team would like to make clear that the use of locating technology devices is not a blanket solution, nor is it a coping strategy that is ideal for everyone. The technologies included in this project are, however, suggested strategies for people searching for an alternative to traditional methods of intervention for wandering behaviour.

Above all, participants of the consumer panel placed priority on ease of use for any electronic locating system. The below results should serve as a recommendation to any manufacturers of similar systems.

All stakeholders involved with the complex issue of wandering have a vested interest in furthering the findings of this project. **Key recommendations include:**

**MCSS:**

- Distribute results of study
- Identify the scope of consumer needs, including funding, to assist people who experience the stress of caring for people who wander
- Promote research and development within the electronic locating device industry in partnership with consumers
- Work together with consumers to promote community building networks to assist caregivers and other consumers cope with wandering behaviours

**School of Rehabilitation Science, McMaster**

- Develop guidelines for caregivers and consumers to enhance coping strategies
- Develop guidelines to assist consumers select potential technology
- Develop equipment/systems in conjunction with manufacturers and/or academic engineering department
- Identify what funding is needed and by whom
- Promote the development of an agenda for future research
- Establish academic links between rehabilitation and engineering
- Delve further into the ethical considerations surrounding electronic locating devices

**People who wander and their Caregivers**

- Work with McMaster on guideline development
- Disseminate information regarding the results of the project
- Work together with MCSS to promote research and development of electronic locating devices
- Work together with MCSS to promote community building networks to assist caregivers and other consumers cope with wandering behaviours

**Manufacturers**

- Continue development of equipment and the evaluation of emerging technology; this could be accomplished in collaboration with the School of Rehabilitation Science, McMaster University
- Design and build electronic locating devices according to the needs of the different populations as presented here

# **7. KNOWLEDGE TRANSFER**

# KNOWLEDGE TRANSFER

It is proposed that the knowledge gained in this study be disseminated by three communication methods: written, verbal and by means of the Worldwide Web.

## **Written**

The final report will be disseminated to consumer organizations, manufacturers, service providers, and law enforcement officials. The information provided to these groups will depend upon their needs. A variety of formats will be available such as entire report hard copies and a summarizing fact sheet about the study findings. Papers will also be submitted to a number of academic journals e.g. Assistive Technology, Canadian or American Journal of Occupational Therapy, the International Journal of Therapy and Rehabilitation and other journals suggested by the Board.

A brochure will be developed that may be handed to participants and conference participants and will be available for downloading from the website.

## **Verbal**

The results of the study will be presented at the SARSCENE conference in October 2006. A press release of the study findings will be used to disseminate information.

## **Worldwide Web**

The results of the study will be posted on the web site of the School of Rehabilitation Science at McMaster University with links to the participating organizations including MCSS.

## **8. REFERENCES**

# REFERENCES

- Adilya, B.S., Sharma, Allen, S.C., & Vassallo, M. (2003). Predictors of a nursing home placement from a non-acute geriatric hospital. *Clinical Rehabilitation*, 17, 108-113.
- Algaier, D.L. (2002). How communications technology reduces risk? *Nursing Homes*, 51(9), 37.
- Algase, D.L., Beattie, E.R.A., & Therrien, B. (2001). Impact of Cognitive Impairment on Wandering Behaviour. *Western Journal of Nursing Research*, 23(3), 283-295.
- Algase, D.L., Kupferschmid, G., Beel-Bates, C.A., & Beattie, E.R.A. (1997). Estimates of stability of daily wandering behaviour among cognitively impaired long-term care residents. *Nursing Research*, 46(3), 172-178.
- Bach M., Keyserlingk, E., & Somerville, M. (1989). *Rights-Based Technology Development*. Toronto: The Roeher Institute.
- Beattie, E., Dong, J., & LaGore, S. (2005). "A Comparison of Wandering Behaviour in Nursing Homes and Assisted Living Facilities". *Research and Theory for Nursing Practice: International Journal*, 19(2), 181-196.
- British Geriatrics Society. (2005). Electronic tracking of patients with dementia and wandering using mobile phone technology. *Age and Aging*, 34, 497-518.
- Brungardt, G.S. (1994) Patient restraints: New guidelines for a less restrictive approach. *Geriatrics*, 49(6), 43-50.
- Burns, A., Jacob, R., & Levy, R. (1990) Psychiatric phenomena in Alzheimer's disease. (IV). Disorder of behaviour. *British Journal of Psychiatry*, 178, 86-94.
- Chafetz, P. (1990) Two-dimensional grid is ineffective against demented patients existing through glass doors. *Psychology and aging*, 5(1), 146-147.
- Cohen-Mansfield, J., & Billig, N. (1986). Agitated behaviours in the elderly II. Preliminary results in the cognitively deteriorated. *Journal of American Geriatrics Society*, 34, 722-727.
- Cohen-Mansfield, J., & Werner, P. (1995). Environmental influences on agitation. An integrative summary of an observational study. *American Journal of Alzheimer's disease Care and Related Disorders and Research*, 10(1), 32-39.
- Coltharp, W., Richie, M.F., & Kass, M.J. (1996) Wandering. *Journal of Gerontological Nursing*, 22, 5-10.

- Coltharp, W. (1977). Effects of a protected hospital ward area on wandering and non wandering geriatric patients. *Journal of Gerontology*, 32, 573-577.
- Coons, D.H. (1988). Wandering. *American Journal of Alzheimer's disease Care and Related Disorder Research*, 3, 31-36.
- Cooper, J.K., & Mungas, D. (1993). Risk factor and behavioural differences between vascular and Alzheimer's disease dementias: The pathway to end-stage disease. *Journal of Geriatric Psychiatry and Neurology*, 6, 29-33.
- Debbaudt, D. (2002). Autism, advocates, and law enforcement professionals: recognizing and reducing risk situations for people with autism spectrum disorders. London: Jessica Kingsley Publishers.
- De Leon, M.J., Potegal, M., & Gurland, B. (1984). Wandering and parietal signs in senile dementia of Alzheimer's disease type. *Neuropsychobiology*, 11, 155-157.
- Department of Justice Canada Canadian (n.d.) "Charter of Rights and Freedoms" Retrieved August 24, 2006 from [http://laws.justice.gc.ca/en/const/annex\\_e.html#I](http://laws.justice.gc.ca/en/const/annex_e.html#I)
- Devereaux Melillo, K., & Futrell, M. (1998). Wandering and Technology Devices. Helping caregivers ensure the safety of confused older adults. *Journal of Gerontological Nursing*, 24(8), 32-38.
- Dicklinson, J.I., McLain-Kark, J., Marshall-Baker, A. (1995). The effects of visual barriers on existing behaviour in a dementia care unit. *Gerontologist*, 35(1), 127-130.
- Eltis, K. (2005). "Society's most vulnerable Under Surveillance: the ethics of tagging and tracking dementia Patients with GPS technology: A comparative View". *Oxford University Comparative L. Forum* 3. [oucif.iuscomp.org](http://oucif.iuscomp.org).
- Heim, K.M.(1986). Wandering Behaviour. *Journal of Gerontological Nursing*, 12(11), 4-7.
- Hewawasam, L.C. (1996). The use of two-dimensional grid patterns to limit hazardous ambulation in elderly patients with Alzheimer's disease. *NTresearch*, 1, 217-227.
- Hope R.A., & Fairburn, C.G. (1990). The nature of wandering: A community-based study. *International Journal of Geriatric Psychiatry*, 5, 239-245.
- Hope,T.,Keene, J.,& McShane, R.H. (2001) Wandering in dementia: A longitudinal study. *International Psychogeriatrics*, 13 (2), 137-147.
- Hughes, J.C., & Louw, S.J., (2002). Electronic tagging of people with dementia who wander. *British Medical Journal*, 325, 847-848.

- Hussian, R.A., & Brown, D.C. (1987). Use of two-dimensional grid patterns to limit hazardous ambulation in demented patients. *Journal of Gerontology*, 42, 558-560.
- Kincaid, C. & Peacock, J.R. (2003). The effect of wall mural on decreasing four types of door-testing behaviours. *Journal of Applied Gerontology*, 22(1), 76-88.
- Kline, D.A., Steinberg, M., Galik, E., Steele, C., Sheppard, J.M., Warren, A., et al. (1999). "Wandering behaviour in people with dementia. *Journal of Advanced Nursing*, 44(2), 173-182.
- Lai & Arthur. (2003). Integrative Literature Reviews and Meta-Analyses wandering behaviour in people with dementia. *Journal of Advanced Nursing*, 44(2), 173-182.
- Law, M, Cooper, B, Strong, S, Stewart, D, Rigby, P, & Letts, L. (1996). The Person-Environment-Occupation Model: A transactive approach to occupational performance. *Canadian Journal of Occupational Therapy*, 63(1), 9-23.
- Logsdon, R.G., Teri, L., McCurry, S.M., L.E., Kukull, W.A., & Larson, E.B. (1998). Wandering: A significant problem among community residing individuals with Alzheimer's disease. *Journal of Gerontology*, 53B(5), 294-299.
- Loh, J., Schietecat, T., Kwok, T.F., Lindboom, L., & Joore, P. (2004) Technology applied to address difficulties of Alzheimer's disease patients and their partners. Vol. 65. *ACM International Conference Proceeding Series* (pp. 18). Amsterdam: ACM Press
- Martino-Saltzman, D., Blasch, B., Morris, R.D., & McNeal, L.W. (1991). Travel Behaviour of nursing home residents perceived as wanderers and non-wanderers. *Gerontologist*, 31(5), 666-672.
- Matteson, M.A., & Linton, A. (1996). "Wandering Behaviours in Institutionalized Persons with Dementia". *Journal of Gerontological Nursing*, 22(9), 39-46.
- Matteson, M.A., Linton, A., & Bers, V. (1993). Vision and hearing screening in cognitively impaired older adults. *Geriatric Nursing*, 14, 294-297.
- McShane, R., Gedling, K., Kenward, B., Kenward, R., Hope, T., & Jacoby, R. (1998). The Feasibility of Electronic Tracking Devices in Dementia: A Telephone Survey and Case Series. *International Journal of Geriatric Psychiatry*, 13, 556-563.
- McShane, R., Hope, T., & Wilkinson, J. (1994). Tracking patients who wander: Ethics and the new technology. *Lancet*, 343, 1274.
- Meyer, R., & Darby, S.J. (1991). Does a mirror deter wandering in demented older people? *International Journal of Geriatric Psychiatry*, 6, 607-609.

- Miskelly, R. (2004). A novel system of electronic tagging in patents with dementia and wandering. *Age and Aging, 33*(3), 304-306.
- Monsour, N., & Robb, S.S. (1982). Wandering behaviour in old age: A psychological study. *Social Work, 27*, 411-416.
- Moreno, S. J. (1991). High functioning individuals with autism: advice and information for parents and others who care. Indiana: MaaP Services, Inc.
- Namazi, K.H., Rosner, T.T., & Calkins, M.P. (1989). Visual barriers to prevent ambulators Alzheimer's disease patients from exiting through an emergency door. *Gerontologist, 29*, 699-702.
- Ontario Human Rights Commission (n.d.) "The Ontario Human Rights Code". Retrieved on August 24, 2006 from <http://www.ohrc.on.ca/english/code/index.shtml>.
- Price, J.D., Hermans, D.G., & Grimely Evans, J. (2005). "Subjective barriers to prevent wandering of cognitively impaired people". *The Cochrane Database of Systematic Review, 4*.
- Rabins, P.V., Mace, N.L., & Lucas, M. (1982). The impact of dementia on the family. *Journal of the American Medical Association, 248*, 333-335.
- Rader, J. (1987). A comprehensive staff approach to problem wandering. *Gerontologist Society of America, 27*(6), 756-759.
- Ragneskog, H., Kihlgern, M., Karsson, I., & Norberg, A. (1996). Dinner music for demented patients. *Clinical Nursing Research, 5*(3), 262-282.
- Roberts, C. (1999). The management of wandering in older people with dementia. *Journal of Clinical Nursing, 8*(3), 322-323.
- Royal College of Nursing. (2004). *Restraint revisited: Rights, risk, and responsibility*. London: Royal College of Nursing.
- Silverstein, N.N., & Salmons, T. (1996). *He comes back home eventually: Wandering behaviour in community-residing persons with Alzheimer's disease registered in Safe Return*. University of Massachusetts.
- Silverstein, N.M., Flaherty, G., & Tobin, T.S. (2002). *Dementia and wandering behaviour*. New York: Springer Publishing Company.
- Snyder, L.H., Rupprecht, P., Pyrek, J., Brekhus, S., & Moss, T. (1978). Wandering. *Gerontologist, 18*, 272-280.

- Stewart, J.T. (1995). Management of behavioural problems in the demented patient. *American Family Physician*, 52(8), 2311-2320.
- Stokes, G. (1986). *Common Problems with the elderly confused; Wandering*. London: Winslow press.
- Taft, L.B., Delaney, K., Seman, D., & Stansell, J. (1993). Dementia care: creating a therapeutic milieu. *Journal of Gerontological Nursing*, 19, 30-39.
- Tarbox, R.S.F., Wallace, M.D., & Williams, L. (2003). Assessment and treatment of elopement: A replication and extension. *Journal of Applied Behaviour Analysis*, 36, 239-244.
- Teri, L., Larson, F.,B., & Reifler B.V. (1988). Behavioural disturbance in dementia of the Alzheimer type. *Journal of American Geriatrics Society*, 36, 1-6.
- Thomas, D. (1997). Understanding the wandering patient. A continuity of Personality Perspective. *Journal of Gerontological Nursing*, 23(1), 16-24.
- Welsh, S., Hassiotis, A., O'Mahoney, G., & Deahl, M. (2003). Big Brother is watching you – the ethical implications of electronic surveillance measures in the elderly with dementia and in adults with learning difficulties. *Aging and Mental Health*, 7(5), 372-375.
- Yang, C.H., Hwang, J.P., Tsai, S.J., & Liu, C.M. (1999). Wandering and associated factors in psychiatric in-patients with dementia of Alzheimer's disease type in Taiwan: clinical implications for management. *Journal of Nervous and Mental Disease*, 187, 695-967.
- Young, S.H., Muir-Nash, J., & Ninos, M. (1988). Managing nocturnal wandering behaviour. *Journal of Gerontological Nursing*, 14(5), 6-12.

# **APPENDIX A**

*Research Ethics Board Consent Form*

## RESEARCH ETHICS BOARD

December 16, 2005

PROJECT NUMBER: 05-442  
PROJECT TITLE: Locating Technology Project  
PRINCIPAL INVESTIGATOR: Professor S. Baptiste

This will acknowledge receipt of your above-named study submitted to the Research Ethics Board. As requested we have provided an expedited approval for your study. This study has been reviewed and approved by members of the REB and has been given an expedited *final* approval. The submission, including the Information Sheet and Consent Forms, Phase 1 and Phase 2 were found to be acceptable on both ethical and scientific grounds. This study will be presented for information to the full Research Ethics Board at their meeting to be held on December 20, 2005. **Please note** we have attached a copy of the consent form with the REB approval stamp affixed—all consent forms and recruitment materials used in this study must be copies of the attached materials.

We are pleased to issue final approval for the above-named study for a period of 12 months from the date of this letter. Continuation beyond that date will require further review and renewal of REB approval. Any changes or amendments to the protocol or consent form must be approved by the Research Ethics Board.

We wish to advise the Research Ethics Board operates in compliance with ICH Good Clinical Practice Guidelines and the Tri-Council Policy Statement.

Investigators in the Project should be aware that they are responsible for ensuring that a complete consent form is inserted in the patient's health record. In the case of invasive or otherwise risky research, the investigator might consider the advisability of keeping personal copies.

A condition of approval is that the physician most responsible for the care of the patient is informed that the patient has agreed to enter the study. Any failure to meet this condition means that Research Ethics Board approval for the project has been withdrawn.

PLEASE QUOTE THE ABOVE-REFERENCED PROJECT NUMBER ON ALL  
FUTURE CORRESPONDENCE.

Sincerely,



F. Jack Holland, MD, FRCP, FRCP(C)  
Chair, Research Ethics Board

/dm

All correspondence should be addressed to the REB Chair and forwarded to:  
REB Secretary, Henderson Campus, 90 Wing, Room #1  
711 Concession Street, Hamilton ON L8V 1C3  
Telephone: 905-527-4322, ext. 42013  
Fax: 905-574-5645



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## Participant Information and Consent Form

### **Title of Study: Locating Technology Project- Phase 1**

#### **Locally Responsible Investigator and Principal Investigator, Department/Hospital/Institution:**

Susan Baptiste, MHSc Professor, School of Rehabilitation Science, McMaster University, 1280 Main Street W. Hamilton, ON, L8S 4L9

#### **Co-Investigator(s), Department/Hospital/Institution:**

Elizabeth Steggles, OT Reg. (Ont.) Manager, Independence Technologies, Hamilton Health Sciences

Mary Law, PhD Professor and Associate Dean (Health Sciences) Rehabilitation Science

Paul Stratford, M.Sc. Professor School of Rehabilitation Science

Elizabeth Garfin, MA Policy Analyst, Development Services Branch, Ministry of Community and Social Services

**Sponsor:** Ministry of Community and Social Services

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I understand that I am being invited to participate in the field-testing of locating technologies for people at risk of wandering and getting lost. Researchers at McMaster University are organizing this project in partnership with the Government of Ontario, Ministry of Community and Social Services. I will be asked to answer questions and report back on your experience of using the technology, particularly about the capabilities, potential advantages and disadvantages of the technologies that you are testing.

It has been explained to me that I am being asked to take part in the field-testing of locating technologies for people at risk of wandering and getting lost. The purpose of the field-testing is to look at the capabilities and potential advantages and disadvantages of the technologies. I will be asked to explain my experiences with the technology, highlighting what I feel are the capabilities and potential advantages and disadvantages of the technologies. When they store the data, the researchers will take out the names of the people in the notes so that nobody will be recognizable. They will keep the record of what was described on computer. Only those with a password will be able to read what was said. Paper copies will be kept in a locked cabinet. All electronic and paper copies will be destroyed after 10 years. Members of the research team are the only ones who will read the record.

I understand that the information will be kept confidential. No one will be identified. If the results are published, I will not be known in any way. Any information that is written or presented in reports or papers will include only summary data and will not identify participants.

I also understand that I may decline to answer any of the questions and that I may pull out from the testing at any time and that this will not affect my status at the university in any way.

I know that the investigators will answer any of my questions about the study and my part in it. I will receive a signed copy of this form.

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Printed Name

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature of Witness

\_\_\_\_\_  
Printed Name

\_\_\_\_\_  
Date

I have explained the nature of the study to this person and believe he/she understood it.

\_\_\_\_\_  
Signature of Investigator

\_\_\_\_\_  
Printed Name

\_\_\_\_\_  
Date

If you have any questions regarding your rights as a research participant, you may contact Susan Baptiste, 905-525-9140, extension 27804.





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## Participant Information and Consent Form

### **Title of Study: Locating Technology Project- Phase 2**

#### **Locally Responsible Investigator and Principal Investigator, Department/Hospital/Institution:**

Susan Baptiste, MHSc., Professor, School of Rehabilitation Science, McMaster University, 1280 Main Street W. Hamilton, ON, L8S 4L9

#### **Co-Investigator(s), Department/Hospital/Institution:**

Elizabeth Steggles, OT Reg. (Ont.) Manager, Independence Technologies, Hamilton Health Sciences

Mary Law, PhD Professor and Associate Dean (Health Sciences) Rehabilitation Science

Paul Stratford, M.Sc. Professor School of Rehabilitation Science

Elizabeth Garfin, MA Policy Analyst, Development Services Branch, Ministry of Community and Social Services

#### **Sponsor: Ministry of Community and Social Services**

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Your family is being invited to participate in a research project on locating technology conducted by Susan Baptiste because of your connection to a community agency that supports families with developmentally delayed or dementia affected people.

In order to decide whether or not you want to be a part of this research study, you should understand what is involved and the possible risks and benefits. This form gives detailed information about the research study, which will be discussed with you. Once you understand the study, you will be asked to sign this form if you wish to participate. Please take your time to make your decision.

#### **Why is this research being done?**

People at risk of wandering and getting lost require constant care and supervision; there can be much stress, worry and lost time when they need to be located. Locating technology has the potential to lessen the need for constant supervision as well as assist in quicker locating of a person when lost. Currently, there is not much evaluation of this technology that has been done.

#### **What is the purpose of the study?**

The purpose of this study is to assess and test various technologies for finding persons who are at risk of wandering and getting lost.

#### **What will my responsibilities be if I choose to take part in the study?**

If you volunteer to participate in the following study we will ask you to do the following things:

You will be asked to wear or work with certain locating technology. You and your family will be asked to respond to questionnaires and interviews regarding the experience with each technology tested.

You are being asked to take part in research regarding the application of locating technologies for people at risk of wandering and getting lost. The point of the research is to look at the capabilities and potential advantages and disadvantages of the technologies in an actual living situation.

**What are the possible risks and discomforts?**

The project team recognizes the potential ethical difficulties related to the exploration of locating technologies and the need to ensure the privacy of individuals who participate in the project.

**How many people will be in this study?**

At the present time, the exact number of participants is not known, as that will be determined in the first part of the study. However, there will be about ten or twelve people involved with each kind of technology being tested. The total is likely to be around 30 people.

**What are the possible benefits to me and/ or society?**

The possible benefits to participants, the scientific community and society at large is that it has the potential to decrease the incidence of persons lost due to wandering, decrease the time a person is “lost” after wandering, as well as decrease the stress families will experience regarding those in their care that have the potential to wander. U.S. statistics report 46% of persons who wander are a survival risk if they are not located within 24 hours. This is a troublesome problem that requires considerable person power to deal with currently and could be assisted greatly with this type of technology deployed in the field.

**If I do not want to take part in the study are there other choices?**

You may choose not to join this study. You can withdraw from this study at any time, even after signing this consent form. Choosing not to participate in this study will in no way affect your families’ care or treatment.

**What information will be kept private?**

Your data will not be shared with anyone except with your consent or as required by law. All personal information such as your name, address, phone number, will be removed from the data and will be replaced with a number. A list linking the number with your name will be kept in a secure place, separate from your file. The data, with identifying information removed will be securely stored in a locked office in the research office.

For the purposes of ensuring the proper monitoring of the research study, it is possible that a member of the McMaster University Research Ethics Board may consult your research data. However, no records that identify families by name or initials will be allowed to leave the university or hospital. By signing this consent form, you or your legally acceptable representative authorize such access.



If the results of the study are published, names will not be used and no information that discloses identity will be released or published without specific consent to the disclosure. However, it is important to note that this original signed consent form and the data that follows, may be included in your health record.

**Can participation in the study end early?**

If you volunteer to be in this study, you may withdraw at any time and this will in no way affect the quality of care your families receives at this institution or the agency you were recruited from. You have the option of removing your family's data from the study. You may also refuse to answer any questions you don't want to answer and you will still remain in the study.

**If I have any questions or problems whom do I call?**

If you have any questions about the research now or later, please contact Susan Baptiste at 905-525-9140, ext 27804.

**Consent Statement**

**SIGNATURE OF RESEARCH PARTICIPANT/LEGALLY-AUTHORIZED REPRESENTATIVE**

**We have read the preceding information thoroughly. We have had the opportunity to ask questions, and all of our questions have been answered to our satisfaction. We agree for our family to participate in this study. We understand that we will receive a signed copy of this form.**

\_\_\_\_\_  
Signature of Participant                      Printed Name                      Date

\_\_\_\_\_  
Signature of Participant                      Printed Name                      Date

\_\_\_\_\_  
Signature of Witness                      Printed Name                      Date

I have explained the nature of the study to this person and believe he/she understood it.

\_\_\_\_\_  
Signature of Investigator                      Printed Name                      Date



# **APPENDIX B**

*Literature Review*

# INTRODUCTION

This paper will present an overview of the literature addressing wandering behaviour in elderly people with dementia. While acknowledgement is made that wandering behaviour is also common in others with dementia, developmental disabilities and autism, a review of the literature has revealed that there is a heightened incidence of wandering behaviour in people with dementia. There is very limited published research concerning elopement in individuals with developmental disabilities, with the main focus being upon assessment and management of behaviours resulting in elopement or elopement attempts.

An approach to the definition of wandering will be presented, followed by an exploration of the prevalence of wandering among people with dementia. Classification criteria will be examined through typologies of wandering, followed by demonstration of profiles of people who wander. Wandering may have positive and negative impacts for individuals and their caregivers, therefore such impacts will be presented after which various strategies applied to the management of wandering behaviour will be discussed. A brief review of the ethical and moral implications of the use of electronic locating devices will be presented.

## *Defining Wandering*

A review of the literature has revealed the non-existence of a general consensus among researchers for defining the term “wandering”. It has been claimed that wandering behaviour has been poorly (Rader, 1987), diversely (Martino-Saltzman, Blash, Morris, & Wynn McNeal, 1991) and unclearly (Price, Hermans & Grimely, 2005) defined in the literature causing great confusion (Martino-Saltzman, Blash, Morris, & Wynn McNeal, 1991). The term “wandering” has been used to describe a variety of behaviours usually observed in people with Alzheimer’s disease or dementia (Silverstein, et al, 2002). “Wandering” has been used by some investigators as a term to demonstrate increased walking, pacing, and aggressiveness (Cohen-Mansfield & Billig, 1986; Cohen-Mansfield & Werner, 1995; Matteson et al. 1993). Others have stated that clients who “wander” have navigational difficulties (De Leon et al., 1984), that is, such individuals who have difficulty finding their way.

While some researchers consider “wandering” behaviour as aimless movement without a specific or appropriate aim or goal (Coltharp, 1977; Snyder, Rupprecht, Pyrek, Brekhus, & Moss, 1978), others have considered “wandering” as purposeful behaviour that fulfills needs such as a means of dissipating tension and coping with stress (Coons, 1988; Heim 1986; Monsour & Robb 1982; Thomas 1997). Some attempts were also made to relate wandering behaviour to some social and safety concerns; for example, the Alzheimer’s Society defines wandering behaviour as “aimless or purposeful motor activity that causes a social problem such as getting lost, leaving a safe environment, [or] intruding places” (<http://www/alz.org/care/caregivingchallenges/wandering.asp>).

Such diversity in the definition of “wandering” behaviour may be due to the heterogeneity of the population known to wander (Lai & Arthur, 2003), and the underlying reason for its demonstration (Price et al., 2005).

**For the purpose of the current study, the following operational definition is used:**

*“ wandering is either or both a purposeful or aimless complex behaviour with various presentations including repetitive locomotion, hyperactivity, excessive walking, and agitation, manifested by an individual with cognitive impairment which may lead to safety concerns.”*

## ***Prevalence of Wandering Among People with Dementia***

Wandering behaviour has received moderate attention in the literature (Thomas, 1995). Although some researchers (e.g. Hope et al., 1994; Klein et al., 1999; Teri et al., 1988) have reported the prevalence of wandering, it has been considered difficult to assess the frequency of wandering behaviour in the older population (Coltharp, Richie, & Kass, 1996) and thus to arrive at any conclusive figures (Lai and Arthur 2003). Klein et al. (1999) estimated that 17.4% of clients with dementia wander, whereas Hope et al. (1994) found a 63% incidence wandering in clients with dementia, living in a specifically defined community. Cohen-Mansfield and Billig (1986) estimated 38% of clients with dementia wander while Teri et al. (1988) reported a higher prevalence rate of 50%; however, in contrast to Cohen–Mansfield and Billing’s clients, these patients suffered from severe dementia. Thus it appears that the prevalence of wandering among patients with dementia increases with the increasing severity of the disorder.

Prevalence rates of wandering in people with Alzheimer’s vary in the literature although studies suggest that clients with Alzheimer’s disease are reported to demonstrate a higher frequency of wandering behaviour than people suffering from vascular and other dementias (Cooper & Mungas, 1993; Thomas, 1997). Over half (52%) of the caregivers involved in Silverstein and Salmons’ (1996) study indicated that people with Alzheimer’s disease or a related disease had wandered and become lost. Logsdon et al. (1998) suggest that 65% of people with Alzheimer’s disease wander at some point in the disease process whereas Teri et al. (1988) report 26% wander, while Burns et al. (1990) suggest 90% of Alzheimer patients wander.

The estimate of wandering prevalence in nursing homes or assisted residential settings also varies immensely from 24% (Hoffman et al., 1987) to 100% (Algase et al., 1997). Such differences in prevalence studies may be attributed to: the different study designs; how the researchers defined wandering; assessment methodology; the study population; and time period of data collection (Hope, Keene, & McShane, 2001; Klein et al., 1999; Silverstein et al., 2002).

## *Typologies of Wandering*

Given the diverse nature of wandering behaviour, various criteria were considered to classify people who wander (Thomas, 1995). Client's intention was considered by Hussain (1987 in Lai and Arthur, 2003) in classifying four groups of people who wander, including:

- the exit seekers (trying to open locked exit doors);
- the akathesiacs (moving aimlessly, neuroleptic-induced pacing and restlessness);
- the self-stimulators (seeking stimulation such as turning the door knob rather than to exit); and
- the modelers (tagging onto or 'shadowing' others).

Martino-Saltman et al. (1991) used patterns of independent travel as a method of characterization: direct (involves traveling from one location to another without diverting); random (involves traveling to many locations within a defined area without repetition); pacing (refers to back-and-forth movement within a limited area); or lapping (characterized by circling large areas).

A quantitative variable of "time-in-motion" was used by Thomas (1995) to classify people who wander into two groups of those who wander continuously and sporadically. While "continuous wanderers" have a constant interest in moving, "sporadic wanderers" are occasionally on the move more likely due to disorientation. A descriptive typology of wandering in people with dementia was also suggested by Hope and Fairburn (1990).

They divided people who wander into nine groups including:

- 1) checking;
- 2) pottering;
- 3) aimless walking;
- 4) walking directed towards inappropriate purpose;
- 5) walking directed towards an appropriate purpose;
- 6) excessive activity;
- 7) night time walking;
- 8) needs to be brought back home; and
- 9) attempts to leave home.

Based on clinical experience, Stokes (1986) proposed a taxonomy of wandering to explain the underlying reasons for the behaviour. Reasons included: separation anxiety; searching; boredom; loneliness; physical discomfort; coping with stress; apparent aimless wandering; disorientation; night time wandering; and attention seeking.

## *Profiles of People who Wander*

Some studies have been conducted to develop profiles for people who wander, and have demonstrated that:

- Wandering behaviour was associated with worsening cognitive impairment (Algase 1992; Algase et al. 2001; Lai & Arthur, 2003; Logsdon et al. 1998; Yang et al. 1999,);
- They are more likely to be: male; using psychotropic medications; experiencing sleep disturbance (Klein et al. 1999);
- They are more likely to be extroverted (Dawson 1987, Thomas 1997, Beattie et al., 2005);
- They are more likely to have speech and spatial deficits (Monsour & Robb 1982, Dawson & Reid 1987, Algase 1992);
- They are more likely to have difficulty with abstract thinking, judgment, spatial skills (Algase, 1992; Rowe 2003);
- They experience a high level of memory loss (Rowe 2003);
- They experience a high incidence of psychosocial problems (Snyder et al., 1978); and
- Wandering has also been associated with a greater amount of time spend alone (Snyder, et al., 1978).

## *Wandering and Associated Impacts*

Wandering behaviour can impact the individual and his/her caregivers both positively and negatively. Positive impacts might include an increase in circulation and oxygenation, decrease in contractures, and promotion of exercise (Heim 1986, Matteson & Linton 1996), a need to spend time alone, and relief from boredom (Price et al. 2005). Furthermore, Cohen-Mansfield et al. (1991) found that pacing was a good indicator of good physical health in six nursing home residents with severe cognitive impairment as indicated by a good appetite, less pain felt, fewer physical diagnoses, and less of a need for medications.

While there may be some benefits to wandering, there are also some negative effects caused by this behaviour. Negative impacts of wandering behaviour may include falls, fractures, weight loss, fatigue, sleep disturbances, berating, verbal/physical abuse, getting lost, social isolation, and untimely death (Algaier, 2002; Algase et al. 1997; Algase 1992; Devereaux Melillo & Futrell 1998; Hughes & Louw 2002; Rowe, 2003; Tarbox, Wallace, & Williams, 2003). It was stated that death could result from hypothermia, dehydration, or drowning following wandering (Rowe, 2003).

Such negative consequences have contributed to a marked increase in caregiver stress (Miskelly, 2004; Logsdon et al., 1998; Silverstein et al., 2002) as well as stress experienced by the person who wanders (Price et al., 2005). A study conducted by Rabins

et al. (1982) suggests that over 70% of families caring for people with dementia have reported that wandering caused the family extreme stress. The possibility of a loved one getting lost was also regarded as a major reason for seeking residential placement (Adilya, Sharma, Allen, & Vassallo, 2003; McShane et al., 1998; Stewart, 1995; Young, Muir-Nash, Ninos, 1988).

## *Intervention for Wandering Behaviour*

Traditionally, human and physical restraints, drugs, and locked doors were considered options for the management of wandering behaviour (Price et al., 2005). Evidence suggests these methods could lead to serious adverse effects including higher risk of pressure sores, infection, sedation, falls, confusion, anxiety and violence (Miskelly, 2004; Price et al., 2005; Welsh, Hassiotis, & Deahl, 2003), hence the growing concern in the field and in the literature about the application of other strategies to manage, reduce, and prevent negative consequences of wandering behaviour (Lai & Arthur, 2003; Siders et al., 2004, Tafet et al., 1993).

The influence of the human rights movement causes a greater emphasis to be placed on adopting a more appropriate and less restrictive approach to the management of wandering behaviour. Such management strategies can be divided into patient-oriented and system oriented (Brungardt, 1994). Patient-oriented techniques include the use of identification bracelets, photos, and the provision of orientation maps, while system-oriented techniques involve altering the surroundings with subjective barriers such as secure gates, camouflaged exits, with staff trained in the application of behavioural methods (Brungardt, 1994).

Some researchers classify behavioural management strategies into pharmacological and non-pharmacological techniques (Siders et al., 2004). Pharmacological techniques refer to the use of psychotropic medications to reduce the rate of wandering. Non-pharmacological techniques refer to using subjective barriers, walking/exercise, specialized environments, behavioural techniques, Some investigators (Szwabo et al., 1991; Kamei et al., 1996) have examined the impacts of pharmacological interventions on wandering behaviour. However, no statistically significant or long-term differences in wandering behaviour were reported, therefore the emphasis of this review will be on non-pharmacological approaches.

Many studies examined various forms of subjective barriers such as using tape grids on the floor (Chafetz, 1990; Hewawasam, 1996; Hussian & Brown, 1987; Roberts, 1999) or door (Namazi et al., 1989), cloth panels to conceal doors or door knobs (Dicklinson et al., 1995) mirrors hung in front of exits (Meyer & Darby, 1991; Roberts, 1999), and wall murals painted over doorways (Kincaid & Peacock, 2003). The results of these studies appear to provide some evidence to suggest that the application of tape grids, mirrors and camouflage can reduce the frequency of exiting behaviour.

Methodological flaws exist in these studies and results of these studies should therefore be interpreted cautiously. Roberts (1999) also demonstrates that these techniques have different impacts on clients with different cognitive functioning. For instance, the application of a mirror placed in front of an exit door is found to be the most effective approach for clients with severe cognitive impairment as measured by the Clinton Assessment Procedure of the Elderly (CAPE) and concealment of doors or door knobs appears to be less effective with clients with moderate/marked cognitive impairment. Consideration should be given by those enforcing such techniques to understand the environmental, physical, and social factors affecting each individual (Beattie et al., 2005) in order to select the most effective and least intrusive techniques.

Some empirical studies examine the benefits of structured and unstructured activities and exercises for people who “wander” (Arno & Frank, 1994; Cohen-Mansfield & Werner, 1995; Holmberg, 1997; Roberts, 1999; Rosswurm et al., 1986). These studies generally support the notion that structured or unstructured activities reduce the occurrence of wandering behaviour. Care should however be taken not to generalize the results of these studies due to methodological shortcomings (Lai & Arthur, 2003).

Cohen-Mansfield and Werner (1999) assessed the effects of an enhanced environment on the behaviour of 27 nursing home residents who wander and found that participants of their study spent significantly more time in enhanced areas and also demonstrate less exit seeking behaviours.

Researchers have also considered the effects of music on wandering behaviour and have found conflicting results. Cohen-Mansfield and Werner (1995) observed pacing in 24 nursing home residents while music was played compared to no music played. They found that exposure to music had no effect on pacing. By contrast, Ragneskog et al. (1996) reported that music played during meal time resulted in an increase in time spent eating and less time wandering during meal time. Additional research is required to confirm the effects of music on wandering.

A number of studies have also been conducted to assess the impacts of effectiveness of behavioural techniques (Heard & Watson, 1999; Hussian, 1982; McEvoy & Patterson, 1986). These studies yield some evidence to suggest that the use of behavioural techniques can reduce wandering behaviour. For instance, Heard and Watson (1999) completed a functional analysis of wandering behaviour followed by differential reinforcement other behaviour such as access to tangible items. Findings indicated that wandering behaviour was reduced 60% to 80% in all study participants. However, as discussed below, these studies have methodological flaws and were undertaken only in long-term care facilities. Future longitudinal studies should be completed to determine the effects of these techniques on clients who live in the community (Siders et al., 2004).

To date, studies have examined the impacts of non-pharmacological techniques on wandering behaviour failing to yield strong evidence of their effectiveness in significantly reducing the occurrence of wandering behaviour (Lai & Arthur, 2003; Price et al., 2005; Siders, et al., 2004). Furthermore, most studies discussed above were not

rigorous and often limited by: small sample size, sampling bias, lack of control groups, poorly described participant characteristics including age, sex, and medical diagnosis, use of heterogeneous interventions, lack of randomized controlled trials, lack of a definition for wandering, and lack of longitudinal studies (Lai & Arthur, 2003; Price et al., 2005; Siders, et al., 2004). Future research is required to investigate the best possible strategies to manage wandering behaviour. Such research will assist caregivers and professionals dealing with the ongoing care of people who wander (Lai & Arthur, 2003).

Although alarm systems are widely used in most long-term care facilities, there is a dearth of research in the literature about the effectiveness of utilizing such systems (Siders et al., 2004). One study conducted by Negley et al., (1990) examined the effect of a security system on wandering behaviour of five residents of a nursing home. The security system provided audio and sound alarm when clients entered a monitored area. Negley et al., (1990) reported that installation of a security device can reduce wandering behaviour, however, this study was limited by a small sample size and no data from a control group.

There have recently been growing interest in the use of electronic technologies to locate people who wander (Royal College of Nursing, 2004). There is some evidence to suggest that people who wander can receive benefits from electronic locating devices (McShane, et al., 1998; Miskelly, 2004). However, more research is required to examine the impacts of electronic locating devices on such clients and their care givers (Hughes & Louw, 2002).

Some researchers argue that electronic locating devices can lead to more freedom (McShane et al., 1998; Royal College of Nursing, 2004), improvement of overall quality of life (Hughes & Louw, 2002), improvement of safety and security (McShane et al. 1994; Welsh et al., 2003), and empowerment (Loh et al., 2004) of clients who wander. Other investigators have also considered such devices as better alternatives to traditional strategies such as locked doors and drugs (British Geriatrics Society, 2005; Royal College of Nursing, 2004), because they are less restrictive (British Geriatrics Society, 2005; Miskelly, 2004). Others feel that while electronic locating devices do slightly restrict the client, this is a price worth paying for the sake of the client's safety (McShane et al., 1994).

While there has been growing interests about the application of electronic technologies to locate people who "wander", some concerns were also expressed about ethical considerations of such devices.

### ***Ethical and Moral Implications***

The ethical and moral ramifications of electronic locating devices have been articulated in the literature (Royal College of Nursing, 2004; Welsh et al., 2003). It has been argued that electronic locating devices may impose restrictions on a client's rights including liberty, freedom, privacy, and dignity (Bach, Keyserlingk, & Somerville, 1989; Hughes & Louw, 2002; Loh, et al., 2004; Royal College of Nursing, 2004).

Furthermore, such devices have been used for locating criminals and containing wild animals, which could lead to stigmatization and negative images in attempting to apply the same logic to other individuals exhibiting wandering behaviours (Loh, et al., 2004; Royal College of Nursing, 2004). Care should therefore be taken when using electronic locating devices to consider the moral issues, and to consider as a priority the best interests of each individual client (Hughes & Louw, 2002, McShane et al., 1998), when developing a comprehensive plan of care (Welsh et al., 2003), to apply a multidisciplinary study of the behaviour, and to consider all alternative available strategies. (McShane et al., 1998; Eltis, 2005).

## *Summary*

This literature review has revealed that there is a limited number of published studies addressing wandering behaviours in populations other than dementia. Disagreement among researchers has clearly emerged in attempts to define the term “wandering”. **The following operational definition has been adopted for use in this current study:**

“wandering is either or both a purposeful or aimless complex behaviour with various presentations including repetitive locomotion, hyperactivity, excessive walking, and agitation, manifested by an individual with cognitive impairment which may lead to safety concerns.”

Differences were identified in prevalence studies of people with dementia (including people with Alzheimer’s disease) that could be attributed to different study designs; differing definitions of “wandering”; a range of assessment methodologies; study populations; and time period of data collection.

**Criteria used by researchers to classify wandering behaviour have been identified and include:**

- client’s intention,
- patterns of independent travel,
- pattern of walking, and
- the underlying reasons for the behaviour.

Trends would indicate that people who wander are more likely to be at the lower end of the range of older adulthood, more cognitively impaired, more likely to be men, extroverted, using psychotropic medications; and experiencing sleep disturbance.

While it is acknowledged that wandering behaviour has both positive outcomes (an increase in circulation and oxygenation) and negative outcomes including (falls, fractures, getting lost), longer term negative consequences contribute to increased caregiver stress as well as client stress. Various techniques have been suggested for the

management of such negative impacts; however, these studies have failed to yield strong evidence, thus suggesting that their effectiveness is limited in significantly reducing the occurrence of wandering behaviour.

Although there have recently been growing interest in the use of electronic technologies to locate people who wander, there is a lack of research that examines the impact of such electronic devices on clients who wander and their caregivers. Furthermore, it would appear that the importance of the ethical and moral ramifications of the use of electronic locating devices have not been well articulated and explored.

## *References:*

- Adilya, B.S., Sharma, Allen, S.C., & Vassallo, M. (2003). Predictors of a nursing home placement from a non-acute geriatric hospital. *Clinical Rehabilitation*, **17**, 108-113.
- Algase, D. L. (1992). "A Century of Progress: Today's Strategies for Responding to Wandering Behaviour". *Journal of Gerontological Nursing*, **18**(11): 28-34.
- Algase, D.L., Beattie, E.R.A., & Therrien, B. (2001). Impact of Cognitive Impairment on Wandering Behaviour. *Western Journal of Nursing Research*, **23**(3): 283-295.
- Algase, D.L., Kupferschmid, B., Beel-Bates, C.A., & Beattie, E.R.A. (1997). Estimates of stability of daily wandering behaviour among cognitively impaired long-term care residents. *Nursing Research*, **46**(3). 172-178.
- Algaier, T. (2002). How communications technology reduces risk? *Nursing Homes*, **51**(9). 37.
- Arno, S., & Frank, D.I. (1994). A group for "wandering" institutionalized clients with primary degenerative Dementia. *Perspectives in Psychiatric Care*, **30**(3), 13-16.
- Bach, M., Keyserlingk E., & Somerville, M. (1989). *Rights-Based Technology Development*. Toronto: the Roeher Institute.
- Ballard, C.G., O'Brien, J., James, I., & Swann, A. (2001). *Dementia: Management of behavioural and psychological symptoms*. New York: Oxford University press.
- Beattie, E., Dong, J. & LaGore, S. (2005). "A Comparison of Wandering Behaviour in Nursing Homes and Assisted Living Facilities." *Research and Theory for Nursing Practice: International Journal*, **19**(2): 181-196.
- British Geriatrics Society. (2005). Electronic tracking of patients with dementia and wandering using mobile phone technology. *Age and Aging*, **34**, 497-518.
- Brungardt, G.S. (1994). Patient restraints: New guidelines for a less restrictive approach. *Geriatrics*, **49**(6): 43-50.
- Burns, A., Jacob, r., & Levy, R. (1990). Psychiatric phenomena in Alzheimer's disease. (IV). Disorder of behaviour. *British Journal of Psychiatry*, **175**, 86-94.
- Chafetz, P. (1990). Two-dimensional grid is ineffective against demented patients existing through glass doors, *Psychology and aging*, **5**(1), 146-147.

Cohen-Mansfield, J., & Billig, N. (1986). Agitated behaviours in the elderly II. Preliminary results in the cognitively deteriorated. *Journal of American Geriatrics Society*, **34**, 722-727.

Cohen-Mansfield, J., & Werner, P. (1995). Environmental influences on agitation. An integrative summary of an observational study. *American Journal of Alzheimer's Care and Related Disorders and Research*, **10**(1), 32-39.

Cohen-Mansfield, J., & Werner, P. (1999). Outdoor wandering parks for persons with dementia: A survey of characteristics and use. *Alzheimer's Disease and Associated Disorders*, **15**(2), 109-117.

Cohen-Mansfield, J., & Werner, P., Marx, M.S., & Freedman, L. (1991). Two studies of pacing in the nursing home. *Journal of Gerontology*, **46**, M77-M87.

Coltharp, W, Richie, M.F., & Kaas, M.J .(1996). Wandering. *Journal of Gerontological Nursing*, **22**, 5-10.

Coons, D.H. (1988). Wandering. *American Journal of Alzheimer's Care and Related Disorder Research*, **3**, -31-36.

Cooper, J.K., & Mungas, D. (1993). Risk factor and behavioural differences between vascular and Alzheimer's dementias: The pathway to end-stage disease. *Journal of Geriatric Psychiatry and Neurology*, **6**, 29-33.

Cornbleth, T. (1977). Effects of a protected hospital ward area on wandering and non-wandering geriatric patients. *Journal of Gerontology*, **32**, 573-577.

Dawson, P., & Reid, D.W. (1987). Behavioural dimension of patients at risk for wandering. *Gerontologist*, **27**(1), 104-107.

De Leon, M.J., Potegal, M., & Gurland, B. (1984). Wandering and parietal signs in senile dementia of Alzheimer's type. *Neuropsychobiology*, **11**, 155-157.

Devereaux Melillo, K., & Futrell, M. (1998). Wandering and Technology Devices. Helping caregivers ensure the safety of confused older adults. *Journal of Gerontological Nursing*, **24**(8): 32-38.

Dicklinson, J.I., McLain-Kark, J., Marshall-Baker, A. (1995). The effects of visual barriers on existing behaviour in a dementia care unit. *Gerontologist*, **35**(1), 127-130.

Eltis, K. (2005). "Society's most vulnerable Under Surveillance: the ethics of tagging and tracking dementia Patients with GPS technology: A comparative View" Oxford University Comparative L. Forum 3. [ouclfiuscomp.org](http://ouclfiuscomp.org).

Heard, K., & Watson, T.S. (1999). Reducing wandering by persons with dementia using differential reinforcement. *Journal of Applied Behaviour Analysis*, **32**, 381-384.

Heim, K.M. (1986). Wandering Behaviour. *Journal of Gerontological Nursing*, **12**(11): 4-7

Hewawasam, L.C. (1996). The use of two-dimensional grid patterns to limit hazardous ambulation in elderly patients with Alzheimer's disease. *NTresearch*, **1**, 217-227.

Hoffman, S.B. Platt, C.A., Barry, K.E. (1987). Managing the difficult dementia patient: The impact on untrained nursing home staff: *American Journal of Alzheimer's Care and Related Disorder Research*, **2**(4), 26-31.

Holmberg, S.K. (1997) A walking program for wanders: Volunteer training and development of an evening walker's group. *Geriatric Nursing*, **18**(4), 160-165.

Hope, R.A. and Fairburn, C.G. (1990). The nature of wandering: A community-based study. *International Journal of Geriatric Psychiatry*, **5**, 239-245.

Hope, T. et al. (2001). "Wandering in Dementia: A Longitudinal Study". *International Psychogeriatrics*, **13**(2) 137-147.

Hope, T., Tilling, K.M., Gedling, K., Keene, J.M., Cooper, S.D., & Fairburn, C.G. (1994). The structure of wandering in dementia. *International Journal of Geriatric Psychiatry*, **9**, 149-155.

Hughes, J. C., & Louw, S.J. (2002). Electronic tagging of people with dementia who wander. **325**, 847-848.

Hussian, R.A. (1982). Stimulus control in the modification of problematic behaviour in elderly institutionalized patients. *International Journal of Behavioural Geriatrics*, **1**(1), 33-42.

Hussian, R.A., & Brown, D.C. (1987). Use of two-dimensional grid patterns to limit hazardous ambulation in demented patients. *Journal of Gerontology*, **42**, 558-560.

Kamei, S., Oishi, M., & Takasu T. (1996). Evaluation of fasudil hydrochloride treatment for wandering symptoms in cerebrovascular dementia with p-magnetic resonance spectroscopy and xe-computed tomography, *Clinical Neuropharmacology*, **19**, 428-438.

Kincaid, C., & Peacock, J.R. (2003). The effect of wall mural on decreasing four types of door-testing behaviours. *Journal of Applied Gerontology*, **22**(1)76-88.

Klein, D.A., Steinberg, M., Galik, E., Steele, C., Sheppard, J.M., et al. (1999). "Wandering behaviour in community-residing persons with dementia". *International Journal of Geriatric Psychiatry*, **14**, 272-279.

Lai and Arthur. (2003). Integrative Literature Reviews and Meta-Analyses wandering behaviour in people with dementia. *Journal of Advanced Nursing*, **44**(2): 173-182.

Logsdon, R.G, Teri, L., McCurry, S.M., Gibbons, L.E., Kukull, W.A., & Larson, E.B. (1998). Wandering: A significant problem among community residing individuals with Alzheimer's disease. *Journal of Gerontology*, **53B**(5), 294-299.

Loh, J, Schietecat, T., Kwok, T.F., Lindboom, L., and Joore, P. (2004). Technology applied to address difficulties of Alzheimer's patients and their partners.

Martino-Saltzman, D, Blasch, B, Morris, R.D., McNeal, L.W. (1991). Travel Behaviour of nursing home residents perceived as wanders and non-wanderers. *Gerontologist*, **31**(5), 666-672.

Matteson, M.A. and Linton, A. (1996). "Wandering Behaviours in Institutionalized Persons with Dementia". *Journal of Gerontological Nursing*, **22**(9): 39-46.

Matteson, M.A. and Linton, A., Bers, V. (1993). Vision and hearing screening in cognitively impaired older adults. *Geriatric Nursing*, **14**, 294-297.

McEvoy, C.L., & Patterson, R.L. (1986). Behavioural treatment of deficit skills in dementia patients. *Gerontologist*, **26**, 475-478.

McShane, R., Hope, T., & Wilkinson, J. (1994). Tracking patients who wander: Ethics and the new technology. *Lancet*, **343**, 1274.

McShane, R., Gedling, K., Kenward, B., Kenward, R., Hope, T., & Jacoby, R. (1998). The Feasibility of Electronic Tracking Devices in Dementia: A Telephone Survey and Case Series. *International Journal of Geriatric Psychiatry*, **13**, 556-563.

Meyer, R., & Darby, S.J. (1991). Does a mirror deter wandering in demented older people? *International Journal of Geriatric Psychiatry*, **6**, 607-609.

Miskelly, F. (2004). A novel system of electronic tagging in patents with dementia and wandering. *Age and Aging*, **33**(3), 304-306.

Monsour, N., & Robb, S.S. (1982). Wandering behaviour in old age: A psychological study. *Social Work*, **27**, 411-416.

Namazi, K.H., Rosner, T.T., & Calkins, M.P. (1989). Visual barriers to prevent ambulators Alzheimer's patients from exiting through an emergency door. *Gerontologist*, **29**, 29-699-702.

Negley, E.N., Molla, P.M., & Obenchain, J. (1990). The effects of an electronic system on confused patients. *Journal of Gerontological Nursing*, **16**(8), 21-24.

- Price, J.D., Hermans, D.G., & Grimley Evans, J. (2005). "Subjective barriers to prevent wandering of cognitively impaired people". *The Cochrane Database of Systematic Review*, **4**.
- Rabins, P.V., Mace, N.L., & Lucas, M. (1982). The impact of dementia on the family. *Journal of the American Medical Association*, **248**, 333-335.
- Rader, J. (1987). A comprehensive staff approach to problem wandering. *Gerontologist Society of America*. **27**(6)-756-759.
- Ragneskog, H., Kihlgern, M., & Karsson, I., Norberg, A. (1996). Dinner music for demented patients. *Clinical Nursing Research*, **5**(3), 262-282.
- Roberts, C. (1999). The management of wandering in older people with dementia. *Journal of Clinical Nursing*. **8**(3) 322-323
- Royal College of Nursing. (2004). *Restraint revisited: Rights, risk, and responsibility*. London: Royal College of Nursing
- Rosswurm, M.A, Zimmerman, S.L., Schartz-Fulton, J., & Norman, O.A. (1986). Can we manage wandering behaviour? *Journal of Long-Term Care Administration*, **14**(3), 5-8.
- Rowe, M.A. (2003) People with Dementia who Become Lost. *American Journal of Nursing*, **103**(7): 32-39.
- Siders, C., Nelson, A., Brown, L.M., Joseph, et al., (2004). Evidence for implementing non-pharmacological interventions for wandering. *Rehabilitation Nursing*, **29**(6), 195-207.
- Silverstein, N.M., Flaherty, G., & Tobin, T.S. (2002). *Dementia and wandering behaviour*. New York: Springer Publishing Company.
- Silverstein, N.M., & Salmons, T. (1996). *He comes back home eventually: Wandering behaviour in community-residing persons with Alzheimer's disease registered in Safe Return*. University of Massachusetts.
- Stewart, J.T. (1995). Management of behavioural problems in the demented patient. *American Family Physician*, **52**(8), 2311-2320.
- Stokes, G. (1986). *Common Problems with the elderly confused: Wandering*. London: Winslow press.
- Snyder, L.H., Rupperecht, P., Pyrek, J., Brekhus, S.& Moss, T. (1978). *Wandering*. *Gerontologist*, **18**, 272-280.

Szwabo, P., Woodward, V., Grossberg, G.T., & Shen, W.W. (1991). The use of Alprazolam for decreasing problem wandering in geriatric patients. *American Journal of Alzheimer's Care and Related Disorder Research*, **19**, 30-39.

Taft, L.B., Delaney, K., Seman, D., & Stansell, J. (1993). Dementia care: creating a therapeutic milieu. *Journal of Gerontological Nursing*, **19**, 30-39.

Tarbox, R.S.F., Wallace, M.D., & Williams, L. (2003). Assessment and treatment of elopement: A replication and extension. *Journal of Applied Behaviour Analysis*, **36**, 239-244.

Teri, L., Larson, F.B., & Reifler, B.V. (1988) Behavioural disturbance in dementia of the Alzheimer type. *Journal of American Geriatrics Society*, **36**, 1-6.

Thomas, D. (1995). "Wandering: A Proposed Definition". *Journal of Gerontological Nursing*, **21**(9): 35-41.

Thomas, D. (1997). Understanding the wandering patient. A continuity of Personality Perspective. *Journal of Gerontological Nursing*, **23**(1) 16-24.

Welsh, S., Hassiotis, A., O'Mahoney, G., & Deahl, M. (2003). Big Brother is watching you – the ethical implications of electronic surveillance measures in the elderly with dementia and in adults with learning difficulties. *Aging and Mental Health*, **7**(5): 372-375.

Yang, C.H., Hwang J.P., Tsai, S.J. and Liu, C.M. (1999). Wandering and associated factors in psychiatric inpatients with dementia of Alzheimer's type in Taiwan: clinical implications for management. *Journal of Nervous and Mental Disease*, **187**, 695-697.

Young, S.H., Muir-Nash, J., & Ninos, M. (1988). Managing nocturnal wandering behaviour. *Journal of Gerontological Nursing*, **14**(5), 6-12.

# **APPENDIX C**

*Phase 1 Qualitative and Quantitative Data  
Collection Forms*

# ROLES, RESPONSIBILITIES, AND OTHER DETAILS

## *Terms:*

### **Caregiver:**

The person using the technology to locate the person who wanders. This person is responsible for recording the direction of their travel and the number of persons surrounding them if the shadower is not present with them.

### **Shadower:**

Follows the caregiver and records the direction of travel of the caregiver and the number of persons surrounding them OR uses the internet to assist the caregiver

### **Person who wanders:**

The person who will wander according to the set scenario or one made up by him/herself. This person is responsible for completing the “Scenario Set Up” sheet.

### **Recorder:**

Follows the person who wanders. Records the direction of travel of the person who wander and # persons around them each minute on the data sheet.

## *Expenses & Stipend:*

All persons involved in Phase 1 will receive a \$150 stipend for their participation. All involved will need to submit a void cheque along with their date of birth, social insurance number, and their mailing address and telephone number for direct deposit. All will receive a T4A for income tax purposes. Since three cellular telephones are required for each of the technologies being tested, each person participating that uses a personal cellular telephone will be reimbursed \$25 (to a maximum of \$75/group) to cover any expenses incurred while they are involved with the project. Should those participating not have access to a cellular telephone; the study will provide them with one. Other expenses such as car mileage and bus passes will be covered with valid receipts.

## *Scenarios:*

Each group will complete a total of 8 scenarios over the course of Phase 1 testing. Four scenarios have already been provided. The remaining four are to be determined by the person who wanders. At no time shall the person who wanders share the location of their travel with any other person involved in the group or other groups prior to completing the

scenario. This will ensure an objective testing phase. The four non-predetermined scenarios are available so that each group will attempt to tracked and located in the seven listed locations on the “Scenario Set-Up” sheet.

Each person will be in each role twice (i.e. be a caregiver for two scenarios, a shadower for two scenarios, a person who wanders for two scenarios, and a recorder for two scenarios). Upon completion of all scenarios, each group member will complete the ‘Overall Criteria Sheet’.

# SCENARIOS

## *Scenario 1:*

### *Individual going to and from a Doctor's appointment, then has lunch*

#### CAREGIVER & SHADOW:

Start in the lobby of IAHS. Synchronize watch with the person that will wander. Start timer. Wait 10 minutes. Begin to locate the person that wanders and the recorder.

#### PERSON WHO WANDERS & RECORDER:

1. Start in the lobby of IAHS. Synchronize watches with caregivers. Start timer.
2. Walk out of the IAHS front door (beside cafeteria).
3. Turn RIGHT and follow COLLEGE AVENUE past psychology building
4. Turn RIGHT, follow road (walking towards 'Main street') around to the front of MUMC (hospital).
5. Enter MUMC at the front main entrance and walk towards waiting area immediate in front of you.
6. Sit in the waiting area for 2 minutes.
7. Leave waiting area and turn RIGHT towards the red elevators.
8. Take the elevator to the parking level.
9. Leave the elevator area by the doors on the right.
10. Walk out the doors, turn LEFT and walk towards the yellow elevators.
11. Take the yellow elevator to the first floor.
12. Exit elevator and walk STRAIGHT towards the "Market place" where you will sit and wait until you are found or 1 hour has gone by.

## *Scenario 2:*

### *Parent allowing child to go for lunch at Burger King with friend*

#### CAREGIVER & SHADOW:

Start in the lobby of IAHS. Synchronize watch with the person that will wander. Start timer. Wait 10 minutes. Begin to locate the person that wanders.

#### PERSON WHO WANDERS & RECORDER:

1. Start in the lobby of IAHS. Synchronize watches with caregivers. Start timer.
2. Exit lobby by the door opposite the cafeteria (facing Main street).
3. Walk out past the smoking area towards Main street.
4. Cross MAIN STREET at the lights at the front of McMaster campus.
5. Once across the street, head west towards LELAND STREET.
6. At Leland, turn LEFT.
7. Walk to GLENMONT STREET, turn RIGHT.

8. Follow to HOLLYWOOD, turn RIGHT.
9. Walk until MAIN STREET and turn LEFT.
10. Follow MAIN STREET until you reach BURGER KING.
11. Wait at burger king until you are found or 1 hour has passed.

***Scenario 3:***  
***Person feels like going for a walk***

CAREGIVER & SHADOW:

Start in the lobby of IAHS. Synchronize watch with the person that will wander. Start timer. Wait 10 minutes. Begin to locate the person that wanders.

PERSON WHO WANDERS & RECORDER:

1. Start in the lobby of IAHS. Synchronize watches with caregivers. Start timer.
2. Walk out of the IAHS front door (beside cafeteria).
3. Walk towards the engineering building.
4. Walk through the green space towards the STERLING STREET (near the Student Centre).
5. Walk through the underpass between UNIVERSITY HALL and GILMOUR HALL.
6. Continue walking straight past EDWARD HALL.
7. Once you have passed WOODSTOCK HALL, Turn RIGHT immediately (before you reach Heddon Hall) and walk behind it.
8. You will see a trail ahead and to the right of you. This is “Chegwin Point Trail”.
9. Walk on the trail for 3 minutes then turn around and wait at the trail entrance until found or 1 hour has passed.

***Scenario 4:***  
***Parent and adolescent with autism go shopping at Limeridge Mall***

CAREGIVER & SHADOW:

Start at a THE BAY entrance (from outside, WENTWORTH STREET. Beside PREMIER SALON). Synchronize watch with the person that will wander. Start timer. Wait 10 minutes. Begin to locate the person that wanders.

PERSON WHO WANDERS & RECORDER:

1. Start at a THE BAY entrance (from outside, WENTWORTH STREET. Beside PREMIER SALON) Synchronize watches with caregivers. Start timer.
2. Follow the path RIGHT and walk towards the escalator, go UP.
3. At top of escalator, turn RIGHT and walk towards mall entrance.
4. Once in the mall, take the escalator DOWN. Once down, walk to the RIGHT and enter "UP CLOSE". Walk to the back of the store turn around and leave.
5. Turn RIGHT out of the store and walk towards SECOND CUP, turn RIGHT and walk towards the FOOD COURT.
6. Take escalator UP. At top, enter THE BAY HOME STORE.
7. Follow the path towards the ELECTRONICS department/area and look around for 1 minute.
8. Follow the path towards the LARGE APPLIANCES and follow the path out of the store.
9. Walk down the mall hallway towards GARAGE CLOTHING, outside of it there is a set of STAIRS, take them DOWN.
10. At bottom of stairs, turn LEFT and walk down the hallway until you reach an escalator. Take the escalator UP. At the top, enter SEARS, follow the path to the LEFT towards the ELECTRONICS department/area. Wait there until found or one hour has passed.

# SCENARIO INFORMATION SHEET

SCENARIO # \_\_\_\_\_ TEAM \_\_\_\_\_

CAREGIVER'S NAME: \_\_\_\_\_

SHADOWER'S NAME: \_\_\_\_\_

PERSON WHO WANDERS' NAME: \_\_\_\_\_

RECORDER'S NAME: \_\_\_\_\_

*Please indicate the following:*

TIME OF DAY:  morning (6:00-12:00)  afternoon (12:00 – 18:00)  
 evening (18:00 – 24:00)  night (0:00 - 6:00)

WEATHER: (check off all that apply)

cold (< -2 °C, > -15°C)  warm (room temp. ~ 20°C)  
 freezing (< -15 °C)  snow  
 foggy  cloudy  
 sunny  raining

MODE OF TRANSPORT OF PERSON WANDERING:

car  bus  
 bike  walking  
 running

START LOCATION:

inside  outside

DESCRIPTION OF START LOCATION:

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LOCATION:

basement (underground)  beside a tall building  
 lower level - parking lot  upper level (inside) - parking lot  
 rural area  forest  
 shopping mall (indoor)  inside a tall building  
 outside  water  
 near something that would cause static (i.e. Hydro line, transformer)

START TIME: \_\_\_\_\_  am  pm

FOUND / TERMINATION LOCATION:

inside  outside

DISTANCE FROM START LOCATION: \_\_\_\_\_ km

DESCRIPTION OF FOUND / TERMINATION LOCATION: \_\_\_\_\_

---

FOUND / TERMINATION TIME: \_\_\_\_\_  am  pm

**DATA SHEET**  
SCENARIO # \_\_\_\_\_

**TEAM**

\_\_\_\_\_

\_\_\_\_\_

Mode of  
Transportation

Time from Start (min)

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
Direction of Travel (N,S,E,W)															
# persons around															

	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30
Direction of Travel (N,S,E,W)															
# persons around															

	31	32	33	34	35	36	37	38	39	40	41	42	43	44	45
Direction of Travel (N,S,E,W)															
# persons around															

	46	47	48	49	50	51	52	53	54	55	56	57	58	59	60
Direction of Travel (N,S,E,W)															
# persons around															

# OVERALL CRITERIA SHEET

Team: \_\_\_\_\_

Name: \_\_\_\_\_

<i>Criteria</i>	<i>Specifics</i>
Battery	Life Expectancy _____ How often did it need to be charged? _____ _____
Transmitter	Size _____ Weight _____ Volume _____ Durability _____ Does it generate heat? _____ Convenience _____ Life expectancy _____
Range	How far can the person wander & still be located? _____ _____
Reliability	Did the system work in all areas? _____ _____
Timing	How fast was a phone call answered by the call centre? If Applicable _____ _____ Average Time to identify where the person _____ Average Time to locate the person _____ Was the time to locate the person practical? _____ Why or Why not? _____ _____
Training	Was the training provided enough to use the technology? _____ Why or Why not? _____ Is a refresher course required? _____
Social acceptance	Of the transmitter _____ Of the Locating Device _____ _____ _____
Ethical Issues	_____
Limitation:	_____
Strength:	_____

## ADDITIONAL COMMENTS:

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

# **APPENDIX D**

*Recruitment Flyers*



Are you concerned about a loved one getting lost?

## **THE LOCATING TECHNOLOGY STUDY**

Do you care for someone who wanders? Are you concerned that they may get lost? Would you like to help find solutions to this problem? If so, you are invited to participate in a study that is being conducted by McMaster University in partnership with the Ontario Ministry of Community and Social Services.

accessibly  yours  
enhancing environments for wellness & occupation

## **Q. Why should I take part in the study?**

**A.** Wandering behaviour often results in decreased safety and independence for the individual and is a constant worry for caregivers. There are emerging technologies that may help to resolve these issues but we need to evaluate them. By taking part in the study you may be helping not only yourself but also other people who are coping with this difficult problem.

## **Q. Who is eligible to participate?**

**A.** People of any age who are at risk of wandering and their caregivers. People may have conditions such as Alzheimer's disease, acquired brain injury, a developmental disability or autism.

## **Q. What is the technology like?**

**A.** There are different types. Generally they use wireless tracking technology or global positioning systems (GPS) and the user carries a device that resembles a cell phone or wears a bracelet.

## **Q. What will I be expected to do?**

**A.** Initially you will be expected to attend a training workshop. After this you will be asked to use the locating technology for up to two months between April and June 2006. You will then provide feedback on your experience.

## **Q. Will it cost me anything to participate?**

**A.** All reasonable expenses will be covered. e.g. mileage, telephone calls

If you are interested in learning more or becoming involved please contact:

Nicole Grochowina  
ph: 905-525-9140 ext 26896  
e: grochn@mcmaster.ca  
or

Mehdi Tabatabaeinia  
ph: 905-525-9140 ext 22047  
e: tabatab@mcmaster.ca



McMaster  
University



## THE LOCATING TECHNOLOGY PROJECT

Do you care for someone who wanders? Are you concerned that they may get lost?

Would you like to help inform the ongoing development of technologies that can assist with addressing this problem? If so, you are invited to participate in a demonstration of locating technology on which you will be asked to provide your opinion. The session is part of a study that is being conducted by the School of Rehabilitation Science at McMaster University in partnership with the Ontario Ministry of Community and Social Services.

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**Q. Why should I take part in the session?**

**A.** Wandering behaviour often results in decreased safety and independence for the individual and is a constant worry for caregivers. There are emerging technologies that may help to address these issues but we need to know more about what kinds of technologies are most user friendly for individuals and their caregivers and/or families. We also need to evaluate the technologies that currently exist. By taking part in the session you will be providing us with valuable feedback that may help not only yourself but also other people who are coping with this difficult problem.

**Q. Who should take part?**

**A.** People of any age who are at risk of wandering and their caregivers. People may have conditions such as Alzheimer's disease, acquired brain injury, a developmental disability or autism.

**Q. What is the technology like?**

**A.** There are different types. Generally they use wireless tracking technology or global positioning systems (GPS) and the user carries a device that resembles a cell phone or wears a bracelet.

**Q. What will I be expected to do?**

**A.** A demonstration of the various devices will be provided then you will be asked to complete a brief questionnaire and provide your perspective on the use of this kind of technology. You may also help us by taking part in a discussion group after the demonstration. We want to hear what you think of the technology and what features would help you the most.

**Q. Will it cost me anything to participate?**

**A.** All reasonable expenses will be covered. e.g. mileage, telephone calls

**Q. How long will the session take?**

**A.** The session will take approximately 2 hours.

If you are interested in participating and would like more information or to register, please contact:

Nicole Grochowina  
phone: 905-525-9140 ext 26896  
email: grochn@mcmaster.ca



**APPENDIX E**  
*Newspaper Recruitment Advertisement*



accessibly  yours  
enhancing environments for wellness & occupation

**Do you care for someone  
who wanders?**

**Are you concerned that they may get lost?**

You are invited to participate in a study conducted  
by **McMaster University** in partnership with the  
Ontario Ministry of Community and Social Services.

McMaster  
University 

**Please contact Nicole:**

phone: 1-866-922-0246

email: [grochn@mcmaster.ca](mailto:grochn@mcmaster.ca)

# **APPENDIX F**

*Phase 2 Consumer Trial Interview Questions*

## **FIRST INTERVIEW QUESTIONS**

1. Please tell us about John and his wandering behaviour?
2. How does John's wandering behaviour affect his life, siblings, and yours?
3. Would you tell us about John's daily routine?
4. Are staff members working in school/day care fully aware of John's wandering behaviour?
5. What strategies do you have in place to deal with wandering behaviour?
6. Have you searched for available resources for better management of wandering behaviour? If so, what did you find/
7. Have you received any training about wandering behaviour and its management? If yes, please describe it.
8. What other resources would you require to deal more effectively with wandering behaviour?
9. What are your suggestions and recommendations for better management of wandering behaviour?
10. Is there any additional information that you would like to share with us?

## **SECOND INTERVIEW QUESTIONS**

1. Please tell us about your experience of using the electronic locating system?
2. Did the technology have any effects on John's life and yours? In what way?
3. Have you considered the electronic locating system as an aid or replacement?
4. Have you used the electronic locating system in any search and rescue efforts?
5. Please tell us about your experience of the service provider?
6. What are the limitations and strengths of the electronic locating system?
7. What are your recommendations to improve the electronic locating system?
8. Is there anything else that you would like to add?

# **APPENDIX G**

*Phase 2 Consumer Panel Questionnaires*

# PART ONE:

## *Wandering Behaviour*

Please check the answer that most applies to you, or rank in order of importance if one or more apply. (1=most important)

**A. What bothers you most about John's wandering behaviour?**

Lack of communication skills

Lack of general understanding of wandering behaviour

Safety and security

Memory loss and disorientation

Seizure/medical problems

Other \_\_\_\_\_

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**B. Are you worried more about the future or the present?**

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**a. What do you do now to deal with the wandering behaviour?**

Extra security locks

Physical barriers

Constant supervision

Distraction and diversion

Increased support personnel

Alarm system

Other \_\_\_\_\_

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**b. Who do you think is mostly affected by John's wandering behaviour?**

Himself

Residents/ roommates/classmates

Parents

General community

Siblings

Other \_\_\_\_\_

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**E. What do you think is the most significant impact of the wandering behaviour on John himself?**

Social contacts

Safety and security

Family contacts

Outings and leisure activities

Working

Losing/finding a group home or residence

Independence

Physical/psychological health

Other \_\_\_\_\_

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**F. What do you think is the most significant impact of the wandering behaviour on John's parents?**

- |   |   |
|---|---|
| <input type="checkbox"/> Time                           | <input type="checkbox"/> Unnecessary environmental barriers |
| <input type="checkbox"/> Finance                        | <input type="checkbox"/> Family functioning                 |
| <input type="checkbox"/> Outings and leisure activities | <input type="checkbox"/> Physical/psychological health      |
| <input type="checkbox"/> Level of responsibility        |   |
| <input type="checkbox"/> Other _____                    |   |

**G. What do you think is the most significant impact of the wandering behaviour on John's sibling/roommates?**

- |  |   |
|--|---|
| <input type="checkbox"/> Time                            | <input type="checkbox"/> Physical/psychological health      |
| <input type="checkbox"/> Level of Responsibility         | <input type="checkbox"/> Unnecessary environmental barriers |
| <input type="checkbox"/> Level of family/staff attention |   |
| <input type="checkbox"/> Other _____                     |   |

**H. What resources would you need to deal more effectively with the wandering behaviour?**

- |  |  |
|--|--|
| <input type="checkbox"/> Support services      | <input type="checkbox"/> Tracking devices  |
| <input type="checkbox"/> Funding               | <input type="checkbox"/> Respite services  |
| <input type="checkbox"/> Training for yourself | <input type="checkbox"/> Training for John |
| <input type="checkbox"/> Other _____           |  |

**I. Have you received any training about wandering behaviour and its management? If yes, please describe it.**

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**J. Have you searched for available resources for better management of wandering behaviour? If so, what did you find?**

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**K. What do you expect from an Electronic Locating System?**

- |  |  |
|--|--|
| <input type="checkbox"/> Detect location   | <input type="checkbox"/> Identify seizure activity     |
| <input type="checkbox"/> Indicate position | <input type="checkbox"/> Set alarms                    |
| <input type="checkbox"/> Provide security  | <input type="checkbox"/> Provide Two way communication |
| <input type="checkbox"/> Other _____       |  |

**L. Do you see an Electronic Locating System as an aid or replacement for the things you do already to deal with wandering behaviour?**

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**M. Why would you use an Electronic Locating System?**

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**N. What is the most important thing for you when selecting an Electronic Locating System?**

- |  |  |
|--|--|
| <input type="checkbox"/> Size                | <input type="checkbox"/> Ease of use                       |
| <input type="checkbox"/> Weight              | <input type="checkbox"/> Maintenance                       |
| <input type="checkbox"/> Appearance          | <input type="checkbox"/> Cost                              |
| <input type="checkbox"/> Acceptability       | <input type="checkbox"/> Training requirements             |
| <input type="checkbox"/> Freedom of movement | <input type="checkbox"/> Additional equipment requirements |
| <input type="checkbox"/> Other _____         |  |

**O. Is there anything else that crosses your mind when you think about using Electronic Locating Systems?**

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**P. Is there any additional information that you would like to share with us?**

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**Q. How did you hear about the Locating Technology Project?**

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# PART TWO:

## *Electronic Locating System*

**A. What are the limitations and strengths of each Electronic Locating System?**

Device	Strengths	Limitations
D		
E		
B		

**B. Which Electronic Locating System would you choose? Please provide explanations.**

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**D. What are your recommendations to improve the Electronic Locating Systems?**

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**E. Do you think the Electronic Locating Systems would affect John's life and others? In what way?**

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**F. Is there any additional information that you would like to share with us?**

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# **APPENDIX H**

*Methodology Overview*

# METHODOLOGY OVERVIEW

All data gathered from caregivers participating in interviews and consumer panels was stored in a secure environment and analysed at the McMaster coordinating site. All data was entered in coded form and the “hard copies” stored in secured file cabinets. The codes that link the name of the participant and the project participants was kept confidential by the principal investigator and secured in a locked cabinet. All data was checked regularly to look for missing and/or incorrect information to enable retrieval of correct information in a timely fashion. Length of data storage was determined through discussion and decisions made at the Advisory Group and will conform to expectations of the University and the provincial government. Issues related to intellectual property was determined through discussion and decisions made at the Advisory Group.

Additionally, the investigative team was responsible for monitoring the safety and efficacy of this trial. The project biostatistician will be responsible for overseeing the reliability, interim and final data analyses.

## **Quality Control Procedures:**

1. Project assessors were trained to complete data collection.
2. Participants were located by investigators using a project database to ensure that assessments are completed in a timely fashion and schedules were completed within a two-week window of the re-assessment date.

Regular meetings were held with the project team to monitor recruitment, respond quickly to any issues raised by any of the families, therapists or assessors and to ensure the methodological rigor of the project.

The aims of qualitative research methods were to uncover and make sense of the meaning that individuals bring to phenomena rather than to verify relationships between variables. Qualitative researchers demonstrated that their findings were not based on subjective opinion and that their results were credible. In addition to ensuring trustworthiness, qualitative investigators must be also conscious of methodological issues to ensure that their research demonstrated due rigor.

The following strategies were used in this study to ensure that the present research was rigorous: (1) member checking; (2) Feedback; and (3) presentation of raw data.

### <sup>1-</sup> **Member checking:**

All the interviews were transcribed in full and categorized into major themes which reflected caregivers’ ideas, concerns, and suggestions. The results of the data analysis were presented as a checklist. All caregivers received a copy of the checklist for further suggestion, clarification, and/or verification of the accuracy of the interpretation. This

helped to confirm the themes and meanings of the interviews and correct any miscommunication, miscomprehension, and inaccurate perception of the key issues.

- 2- **Feedback:** All participants of the consumer panel were asked to rank the answers in order of importance from most to least if applicable. This provided an additional source of information about the realities related to caring for a person who wanders and their perspectives about electronic locating systems.
- 3- **Presentation of raw data:** Representative statements from caregivers were presented as traceable raw data for inspection. This provided an additional way of demonstrating the credibility of the study.

All data was stored in a secure environment and analysed at the McMaster coordinating site. All the interviews were transcribed verbatim into typewritten format to collect all data together in the same format. All transcripts were read carefully and repeatedly to ensure familiarity with the material, and to identify descriptions for categories and subcategories. Attempts were made to distinguish the important themes which may not have necessarily been the most frequent issues.

The next step was to assign codes to the units of data according to the themes. A system of 'open coding' was selected for this study in which the analysis sought to 'open up' the transcripts in order to name and categorize the data. Once all transcripts were coded, the research team reviewed the coding structure and made refinements as well as further classification of codes. This served to clarify any confusion or duplication which may exist in the initial coding. Then, all data which had the same codes were collected together representing a report for each code. As stated earlier, in order to maintain the confidentiality of the participants of the study, pseudo-initials were used in their representative statements when they name their relatives or significant others.

In order to undertake a deeper and more sensitive analysis, the research team used the 'constant comparative method' in this study. That is, "the research team simultaneously codes and analyzes data in order to develop concepts". By continually comparing specific incidents in the data, the research team refined those concepts, identified their properties, explored their relationships to one another, and integrated them into a coherent theory". Accordingly, in a process called 'axial coding' data were rebuilt and new connections were made among categories and subcategories. This leads to a further clarification of the key terms. The results of such a process of data analysis were theories that were interpretations of data grounded in reality.

Data gathered from the consumer panels was also analyzed using SPSS Program.

# **A P P E N D I X I**

*Table 2: Technology Overview*

Article I. <u>Device</u>	C1	C2	D	B	A	E
Locating technologies used (FM, GPS, etc)	A-GPS with REFLEX (pager technology)	A-GPS with GSM transmitter (for SMS messaging)	FM transmitter and receiver	GPS (location) & GSM-SMS (link to monitoring)	A-GPS with GSM transmitter (for SMS messaging)	A-GPS (bracelet) and RF to base station
<b><u>Wearer device</u></b>						
Description	a black box	a small black box	a bracelet with FM transmitter	a large cell phone without dialling buttons	a cell phone	a bracelet with large transmitter
Signal range	most of Canada, US and Mexico	most of Canada, US and Mexico	5 km (maximum)	within GSM cell phone range limits	where GSM network available	within GSM cell phone range limits
Frequency of signal transmissions	adjustable 2 to 120 minutes	adjustable 2 to 120 minutes	1 per second - continuous	adjustable 1 sec and up	every 2 minutes	adjustable - 1 minute and up (only active when out of RF range from base station)
Potential obstructions	underwater, underground, near tall buildings, inside buildings, locations with high electronic interference and dense foliage	underwater, underground, near tall buildings, inside buildings, locations with high electronic interference and dense foliage	underground, tall buildings, locations with high electronic interference	underwater, underground, near tall buildings, inside buildings, locations with high electronic interference and dense foliage	underwater, underground, near tall buildings, inside buildings, locations with high electronic interference and dense foliage	underwater, underground, near tall buildings, inside buildings, locations with high electronic interference and dense foliage
Battery type	Lithium-ion, 3.6 V, 1000mAh	Li-ion, 3.7V, 1000mAh - charges in about 3 hours	3.6 V, 370mAh Lithium coin cell (Tadiran TL-5186)	Lithium-ion rechargeable	Li-ion, 3.6 V	rechargeable
Battery life	not tested	manufacturer claims - From full charge, 20 hrs. min. in continuous mode	30 - 45 days	10 hours and up	less than 8 hours when software is running	manufacturer claims approx. 2 weeks - normal use
What happens when removed from wearer?	nothing	nothing	nothing	nothing	nothing	nothing
Indoor use (1=very poor to 5=excellent)	not tested	1	5	1	1	1
Outdoor use (1=very poor to 5=excellent)	not tested	2	5	3	2	3
Waterproof (1=very poor to 5=excellent)	1	1	5	1	1	3
Reliability (1=very poor to 5=excellent)	not tested	2	5	4	1	3
Size - (W) x (L) x (H) in mm.	56 x 85 x 25	45 x 66 x 25	20mm at each end, 34mm in the middle (widest part) x 40 x 13	47 x 130 (155 with ant.) x 25	55 x 115 with ant. x 25	36 x 64 x 24
Weight - in grams	120 grams	87 grams	22 grams	165 grams	135 grams	54 grams

**Table Continued**

<b><u>Monitoring/locating:</u></b>	<b>C1</b>	<b>C2</b>	<b>D</b>	<b>B</b>	<b>A</b>	<b>E</b>
Equipment required (hardware, software, etc)	computer with high speed internet, cell phone, map of city	computer with high speed internet, cell phone, map of city	tuneable FM receiver with yagi antenna	monitoring service, cell phone	computer with high speed internet, cell phone, map of city	computer with high speed internet, cell phone, map of city
External service required?	no	no	yes, Police of Jurisdiction	yes, call centre	no	yes, call centre
Training required (user, caregiver, monitoring)	minimal to navigate web site	minimal to navigate web site	OPP, 2 days	yes for battery charging	minimal to navigate web site	minimal to navigate web site
Location tracking (map, address, direction)	Google Earth or DM Solutions map on web site	Google Earth or DM Solutions map on web site	auditory beeps	map with lat. & long. coordinates, direction of travel	Mapquest map image on web site	map image on web site
Panic alarm	no	yes	no	yes	no	yes
Fall alarm?	no	no	no	yes	no	no
Boundaries for free movement	not tested	geofence	N.A.	geofence is possible but not included in service now	geofence	within range of base station and geo-fencing
Reliability (1=very poor to 5=excellent)	1	2	5	3	1	2
Protocol for finding person	2 caregivers required, 1 at computer, 1 finding person, both communicating by phone	2 caregivers required, 1 at computer, 1 finding person, both communicating by phone	caregivers call 911, police of jurisdiction sends out info. to Emergency Response Team	contact service by cell phone - "client missing", caregiver finds person with directions from service	2 caregivers required, 1 at computer, 1 finding person, both communicating by phone	2 caregivers required, 1 at computer, 1 finding person, both communicating by phone

**Table Continued**

Device	C1	C2	D	B	A	E
<b>Fees:</b>						
Wearer device	\$610.00	\$650.00 for unit + \$35.00 for SIM card	\$422.50 + Police of Jurisdiction services	approx. \$500.00	Cellular fees - approx.\$25.00/month and up (depending on model# and service provided)	\$420.00
Initial	0	0	0	0	0	0
Ongoing	Approx. \$14.00/month monitoring	\$14.35/month monitoring	\$35.00/month maintenance fee	approx. \$30 to \$40 per month	\$15.00 to 25.00/ month \$20.00/annum mapping fee	\$30 to \$35/month
Locate	Approx. \$112.00 for 1000 pings (locates)	Approx. \$112.00 for 1000 pings (locates)	included	no	0	included
Additional	0	0	receivers cost \$3380 each, 2 required plus 2 days training at \$2500 (max. 12 people)	no	0	a fee may be levied for high locate clients
<b>Potential uses:</b>						
Wandering	yes	yes	yes	yes	yes	yes
Surveillance	yes	yes	yes	yes	yes	yes
Elopement	yes	yes	yes	yes	yes	yes
Independence	no	no	no	no	no	yes - geofence can be any polygon
<b>Portable:</b>	yes	yes	no	yes	yes	yes
<b>Support:</b>						
Availability	no	no	yes from volunteers & system staff	yes from monitoring service	no	yes from monitoring service
Required?	no	no	volunteers to change batteries	yes from monitoring service	no	yes from monitoring service
<b>Weaknesses:</b>	units did not work	It does not work very often	Only police use receivers	Battery pack is removable	It does not work very often	not yet fully operational in Canada
	battery life	battery life	battery life	battery life	battery life	0
<b>Strengths:</b>	0	park button creates geo-fence	proven technology	monitoring service could help calm caregiver	0	battery life
	0	0	0	0	0	monitoring service could help calm caregiver

# **APPENDIX J**

*Glossary of Terms*

# GLOSSARY TERMS

**A-GPS** – Assisted Global Positioning System is a technology that uses an assistance server (cell tower) to cut down the time needed to find the location. Less processing power needs to be employed in the mobile GPS receiver (phone) because the cell tower will already “know” its position (through GPS). The phone only has to relay any GPS signal it receives to the tower to narrow down its location.

**Caregiver** – A person who is responsible for the well being of the wearer.

**FM** – Frequency Modulation, the process of varying the frequency of a Radio Frequency carrier wave in accordance with the amplitude and frequency of transmitted signal.

**Geo-fence** – A boundary of GPS coordinates. When the device crosses in or out of this boundary a signal is generated, typically as an alert.

**GPS** - Global Positioning System, also know as Autonomous GPS (the US military refers to it as NAVSTAR GPS - **N**avigation **S**ignal **T**iming **A**nd **R**anging **G**lobal **P**ositioning **S**ystem). GPS is a satellite-based navigation system that uses a network of 24 satellites placed into orbit by the U.S. Department of Defence. In the 1980s it was made available for civilian use without fees of any kind. A device with GPS uses triangulation from the Ultra High Frequency (radio) signal received from the satellites to determine the user’s location. More accurate the positional information is obtained, as more satellites are “visible” to the device. Generally, the device must “see” at least 3 or 4 satellites to get an accurate position. GPS is intended for outdoor use only. Buildings, terrain, electrical interference or even very dense foliage can effect signal reception. It typically will not work underground, underwater or inside buildings.

**GSM** - Global System for **M**obile communications is a digital cellular communications system. GSM 900 (MHz) is used in Europe and Asia; GSM 1900 (MHz) is used in the North America.

**SMS** – Short Message Service is a service, available on digital GSM networks, that allows text messages (of up to 160 characters) to be sent and received via the network operator's message centre to a mobile phone or from the Internet, using a so-called "SMS gateway" website.

**Wearer** – A person who is wearing the locating technology.

**Yagi Antenna** – A type of directional antenna, named after one of the Japanese inventors.

# **APPENDIX K**

*Qualitative Feedback on Tested Systems*

TABLE 3

# QUALITATIVE FEEDBACK ON TESTED SYSTEMS

System	<i>The testers agreed upon the following points:</i>
Device A	<ul style="list-style-type: none"> <li>• The GPS signal was lost within buildings and in the woods</li> <li>• The map provided on the web was not detailed enough for an absolute location</li> <li>• It requires an internet connection which is not available everywhere</li> <li>• The technology is not reliable</li> </ul>
Device B	<ul style="list-style-type: none"> <li>• The size of the device is socially acceptable as it can be hidden although remembering to take the device could pose many problems. Locating a person using maps and compasses drew attention to the caregivers.</li> <li>• The requirement of charging and turning on the device on is impractical</li> <li>• The device did not work within buildings and took too long to refresh the signal thus it is deemed as unreliable</li> <li>• The call centre should have a way to determine the battery life</li> </ul>
Device C	<ul style="list-style-type: none"> <li>• The web page was under construction and needs repair</li> <li>• The device was often not locatable by the computer system</li> <li>• If the person could be located, finding them was not difficult, but it was unreliable</li> </ul>
Device D	<ul style="list-style-type: none"> <li>• There are social acceptance issues surrounding the locating format using the police. It causes a great deal of disturbance to others around and could be scary for the person being located.</li> <li>• The band with which +the device is attached could easily be detached by cutting.</li> <li>• The technology works well from a search and rescue point of view but does not promote independence.             <ul style="list-style-type: none"> <li>• The technology works well when trained police officers are close by, the times would be much longer should the person being located be far from the detachment site.</li> </ul> </li> </ul>
Device E	<ul style="list-style-type: none"> <li>• The device is obvious and presents a potential for stigmatizing</li> <li>• However, independence was promoted through a two-way voice communication and a polygon shaped geofence</li> </ul>

# **APPENDIX L**

*Qualitative Feedback on Tested System*

TABLE 4

# QUALITATIVE FEEDBACK ON TESTED SYSTEMS

System	Successful Attempts	Average Time (min.) to Find Wearer*
Device A	2/8	54
Device B	7/8	26
Device C	2/8	38
Device D	8/8	24
Device E	4/8	27

\* for successful tests only

*A Report on the Processes, Procedures, and Findings of*

# THE LOCATING TECHNOLOGY PROJECT

*Submitted to: The Ministry of Community and Social Services*

***It [wandering behaviour] has a huge impact because he [John] is not able to experience life. If he goes out with someone, I wouldn't necessarily trust someone to take him out, because I would worry that he would bolt and run away. Less independence, less experience.***

*- Consumer Trial Participant*



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