

**“The pendant has been  
a life-saver”:**

## **An Evaluation of the WanderSearch Programme in Aotearoa New Zealand**

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## Executive Summary

At the request of LandSAR the Donald Beasley Institute conducted an evaluation of the WanderSearch programme in four regions of Te Wai Pounamu (South Island) of Aotearoa New Zealand. Prior to the evaluation a literature search was conducted to explore the use of electronic monitoring systems currently available internationally. The full report includes the findings of the literature review.

A qualitative approach was taken for the evaluation. There were two steps to collecting information about WanderSearch for the evaluation.

The first step involved interviewing the co-ordinators from the four regions to gain an understanding of how the system operated in their region. A broad overview of each of the regional services was gained from the interviews with the co-ordinators. Although there were many similarities, there were also differences in the way that each received referrals; the equipment they had available; and whether or not co-ordinators received a report when a search had been conducted. While two of the co-ordinators were in paid positions, it was also clear that some regions relied on having available volunteers to manage the WanderSearch programme.

The co-ordinators' responses were used to develop questions for the second set of interviews with carers of people using WanderSearch. A total of eight interviews, representing nine users of WanderSearch were conducted, seven being adults with dementia or cognitive impairment and two were children with neuro-disabilities. Two themes captured the content of the interviews.

Leading people into the WanderSearch programme was a sense of "Constant Concern". This theme illustrated the stress they were under worrying about their family member coming to harm or getting lost when they wandered<sup>1</sup>. Carers of older adults tended to accept that the person they cared for had a need to wander and generally allowed a period of time before they would become concerned. In contrast parents of younger children would become concerned immediately they noticed that the child had disappeared. More commonly with the children, a number of strategies, such as fences and locks on doors were being used to prevent them leaving home. Carers of older adults were not consistently using other strategies, although some chose to accompany their spouse on walks, or tried diverting their attention to other activities. Most significantly, this theme highlighted a level of hypervigilance that was affecting the carers health and/or the functioning of the family unit.

<sup>1</sup> Consistent with the wider literature the terms wander/wandering and track/tracking are used in this document. We recognise that these terms do not fully acknowledge the range of reasons why people might walk or go missing, nor the processes involved in locating the person.

Once they began using WanderSearch there was an almost immediate shift to having “Peace of Mind”. This second theme indicated the importance to the carer of knowing that the person they cared for could be found if they became lost. They learnt about WanderSearch in a variety of ways, including direct referrals and internet searches. Supporting their peace of mind was the excellent service they received through the co-ordinators, volunteers, LandSAR and the Police. While some of the people who were wearing the pendants or watches had contributed to the decision about them using WanderSearch, most carers believed that this was a decision that was ultimately up to the carer. That aside, it did also require tacit agreement of the person who wore the pendant, with some taking their pendants off when they chose to do so. Keeping pendants or watches on people was a challenge for some, with people using a range of strategies unique to the person. A major advantage of WanderSearch pendants was the relatively low cost and upkeep. Carers accepted any costs that were involved, such as payment for battery changes in regions where that applied.

Drawing together the findings of a literature review and the interviews the following recommendations should be considered:

1. Written guidelines for consent to use WanderSearch to ensure legal standards are applied.
2. Working with the health and disability sector to ensure that the benefits of and referral process to WanderSearch are visible on their database and known about in relevant services.
3. Consider the addition of a GPS system for those families that it might suit.
4. Continuous product improvement, especially with regard to encouraging people to wear the devices.
5. Ongoing development of assessment processes to fully realise the goals of the Safer Walking Framework.
6. Development of availability of pendants and alternatives at a national level to promote equity.
7. Recruitment strategies that will continue to meet the ongoing need for volunteer involvement in both co-ordination and maintenance of the programmes in regions.

## Introduction

Electronic monitoring for people with neurodevelopmental or neurocognitive impairment, has been introduced in a number of countries. Both publicly-funded organisations and private companies provide a range of electronic equipment to assist in tracking or locating people who become lost through wandering. In Aotearoa New Zealand a radio frequency monitoring system, WanderSearch, is available in regions through a variety of organisations with national co-ordinator through New Zealand Land Search and Rescue (LandSAR).

In 2020, the Donald Beasley Institute was commissioned by New Zealand Land Search and Rescue (LandSAR) to undertake an independent, qualitative evaluation of a selected range of WanderSearch sites in Te Wai Pounamu (The South Island) of Aotearoa New Zealand. The WanderSearch technology is offered as part of the Safer Walking Framework, which has been developed over the past ten years (see: <https://wandersearchnz.org.nz/about/what-is-wandersearch/safer-walking-partnership-framework/> ). This Framework has an emphasis on providing people who might become lost when wandering with a safe mechanism for them to continue to walk.

This report includes a literature review of the use electronic monitoring internationally along with an evaluation of a specific radio frequency WanderSearch programme available in Aotearoa New Zealand. The evaluation centres on the perspectives of family and whanau carers who support one or more individuals who currently use a WanderSearch device. The final recommendations are drawn from points highlighted throughout the report.

# Literature Review

## Introduction

This brief literature review draws on research and professional sources to outline what is known about the development, use, and acceptability of electronic monitoring for people with cognitive impairment. Databases, including Medline (Ovid) and PubMed, were searched using a range of search terms to identify articles that would inform understanding of the relevant issues.

Electronic monitoring is a general use tool able to be adapted and used for any person who has the potential to wander and get lost. The particular focus of this review is on people with neurodevelopmental- or neurocognitive disabilities. Neurodevelopmental disabilities include but are not limited to conditions such as Autism Spectrum Disorder (ASD), Attention Deficit Hyperactivity Disorder (ADHD), Intellectual /Learning Disability. Neurocognitive disabilities include Acquired or Traumatic Brain Injury which could be caused by conditions such as dementia, stroke, or as a result of an accident. Literature related to electronic tracking devices predominantly focus on their role for people with dementia. There is a paucity of research related to their use with people with ASD or learning disability despite their use also being strongly recommended for members of those groups if they have a tendency to wander and become lost. There is a very limited body of literature relating to the use of electronic monitoring with people with a range of other neurodevelopmental or neurocognitive conditions who are at risk of wandering.

While the technology might be the same or similar, there can be major practical and ethical considerations that differ for these various populations. In addition to the differences in populations for whom tracking devices are recommended, another major consideration is the way in which the device works. Devices are more or less invasive in how they track the person, who or where the control of data is managed, the ability of the individual to have control over whether or not they have the device on their person among other details. Perhaps not surprisingly given the more invasive nature of the devices, the majority of the literature focuses on GPS systems rather than the radio frequency system being evaluated for LandSAR. This review is inclusive of both technologies, recognising that there are important considerations that are shared by both.

In order to understand the reason for using electronic monitoring, the review begins by outlining the prevalence and outcomes of wandering for people with cognitive impairment. While data related to prevalence and outcomes in most countries is incomplete, this

information does provide some perspective on what electronic monitoring is aimed at reducing. The above section is followed by a brief outline of the two major forms of electronic monitoring identified in the literature, along with the issues that have been identified as relevant to consider. A major concern for any system is the choice and control that the person might have about being monitored. Therefore, the final sections of this review relate to what is known and what might be relevant to consider about issues such as privacy, autonomy and for whom the technology provides the greatest benefit.

## **Prevalence and outcomes of wandering**

Wandering, or elopement as it is commonly titled in the research literature about ASD, is considered to be a reasonably common event for children with ASD. It is only recently that studies have attempted to measure the actual prevalence, with one study in the United States finding that 26.7% of their survey sample of 3,518 families reporting that their child had attempted to elope within the past 12 months (Kiely et al., 2016). Similar findings from a review of data by Rice et al (2016) also noted that children with intellectual disability without autism had fewer incidents of wandering than those with autism but the difference was not statistically significant, indicating that elopement was not specific to people with ASD. The Kiely study identified further features of the children's behaviour that might make them more likely to elope, which has relevance for assessment of suitability and need for instituting an electronic system of tracking. In addition, they found that families with children who do commonly elope were more likely to have put in place other preventative measures such as physical barriers. That might suggest that the best approach for children is to combine strategies, however it also highlights the difficulty there might be in controlling for variables when assessing the effectiveness of electronic systems.

For people with dementia the prevalence of wandering data differs significantly across studies. In their review of literature Borsje et al. (2015) suggested a range of 18% to 62% across three studies for wandering and agitation. Reliable data about wandering for people with other causes of cognitive impairment was not readily available.

Of itself, wandering or elopement might not be a concern, however the outcome for people who are lost can be fatal. A few studies have retrospectively examined sources for data on the outcomes of people reported missing. In 2012 the National Autism Association in the United States reported on data from the years 2009-2011 where the outcome was a fatality (McIlwain, L. & Fournier, W., 2012). They found that over this time period there were 22 fatalities (15 male), with accidental drowning accounting for 20 of these deaths. Like most of the studies generating this data, they relied on media reporting which is not necessarily going to have captured all cases. Possibly most significant to the current review is that one of these

children wore a tracking device that did not emit a signal once underwater. Interestingly, wandering with these outcomes could be linked to parts of the United States with clear seasonal variation, with most occurring in the summer months. It took between 15 minutes and 20 hours to find the children who had eloped. In addition to the fatal events, McIlwain and Fournier noted outcomes for four children and one adult with autism in the United States. While this group survived, one adult had been struck by a vehicle and experienced a major brain injury, one child was rescued from a neighbour's pool, and the other three were found from 24 hours to six days after they went missing. These children were dehydrated and had minor injuries. Drawing on international media, they demonstrated comparable outcomes had been recorded in Canada, Australia and Singapore.

A more recent study in Australia has used a similar method to explore the outcomes for people with dementia who go missing due to wandering (MacAndrew et al., 2018). They reviewed a five-year period from 2011 to 2015. Identifying information was available for 130 people, with more males (74%). There was no additional data for 38 people, therefore the outcomes relate to 92 (74%) of those initially reported as missing. Of this group, 73 were found alive and 19 deceased. Of those deceased just one was found in a body of water, with the majority found in bushland. Length of time missing for the 92 with outcomes reported ranged from less than six hours to over one week. Notably, in addition to the deaths, 18 were found injured or unwell. To compare the outcomes for people with dementia who go missing in Japan, Kikuchi et al. (2019) utilised data held by the National Police Agency and local Police Departments. Initially surveys were sent to 776 family members of people with dementia who had gone missing. There were equal numbers of those who had survived with those who had not. Surveys were returned by 160 family members, representing 88 people with dementia who had survived and 72 who died. Key findings from their analysis included that living alone, being found in the local area and the length of time taken to locate the person were significantly related to the person having died. Hypothermia and drowning were the leading causes of death.

In summary, these studies demonstrate that the risk expressed about people with cognitive impairment wandering is well-founded. However, where a comparison has been offered, they also demonstrate that many more people who wander are found or return of their own volition. In a later section in this review this balance between risk and allowing people freedom to wander is discussed in more detail. Before outlining these debates, the following section provides an overview of electronic monitoring devices and their acceptability in more practical terms.

## The electronic monitoring devices

Essential to understanding the literature related to electronic monitoring is the means of electronic messaging used by the particular device discussed. Commonly, they either use a Global Positioning System (GPS) or radio frequency (RF). One study that evaluated the two technologies found the GPS system to be more useful in terms of more quickly finding the person and having a wider range, however they also noted that the RF system would work indoors, in contrast to GPS systems (Bulat et al., 2016). A useful summary of these two main technologies is offered by Yang and Kels (2017). They identify GPS as receiving a satellite signal that is able to calculate the position of the person with the device. That information is sent to the monitoring person. Accuracy is very good and it can cover a large area. However, it does require a clear path and signals. A feature that appears to be popular in the literature relating to GPS-based technology is that a virtual boundary can be set to alert if the person moves beyond it, and that it has the capacity to increase speed and accuracy through additional features. In comparison, radio frequency technology emits radio waves and it is these that are received by a locating antenna. The signal is able to be detected from the ground or air but the radio frequency of the receiver must be tuned appropriately. There is a limited signal range but there is the capacity to either manually activate or create a virtual boundary. Through the creation of a “tag” (radiofrequency identification) it can track when a person moves through an area. As Lin et al. (2014) found, there are numerous options of tracking devices available for people to choose from and a quick search on the internet identifies that both systems are available in Aotearoa New Zealand.

Recent literature has recognised the importance of people adopting the system that best suits their needs. A project in Germany drew on collaboration between researchers with a sociological focus and technical experts to design a responsive monitoring system (Wan et al., 2016). Interviews with family members and care staff illustrated the range of perspectives that people had in relation to the appropriateness of tracking devices for people with dementia who are prone to wander. The balance between an individual’s autonomy and a carer’s desire to reduce risk provided some concern. In addition they noted that family structures are inclusive of power relationships and these, rather than individual choice, could determine how decisions about using tracking devices were made. Practical issues with the device that they chose to test included the size of the tracker being deemed to be too large. There were various opinions as to what elements of the device presented challenges to a person’s autonomy, including whether or not to use the digital fence capability and how frequently it should be monitored. Overall, the findings from this type of research illustrates the complexity of matching an individual’s needs to a device that is commercially available. The GPS device and associated IT requirements required people using them to be trained,

having sufficient IT capacity within their home or organisation and having support to manage the system readily available. Ultimately, while there were distinct advantages for those who trialled the devices, these comparatively complex systems are costly in terms of personal autonomy and finances. Furthermore, they must fit with the model of care best suited to supporting the person who tends to wander and become lost.

In a similar project based in the UK, Procter, Wherton and Greenhalgh (2018) identified a number of considerations for successful adoption of GPS trackers with people who are living in the community with dementia. Good case management is critical and unfortunately, they found that there were multiple organisational factors affecting the usability of the trackers for families. These factors were predominantly due to the way in which the various services were constrained financially or by policy. Matching a device to the person's needs required more than the formal system they were using, whereby a short-term "contract" for the organisations providing trackers limited them to the assessment of the person and matching them to a device. This was shown to be inadequate for users who required continuity of service as they adapted and learnt to use the technology. It illustrates the challenge when the model of care relies on separate contracts for specific services. GPS trackers rely on there being a person available who can follow up and find the person when they become lost. The trackers used in this study provided information to the person who was identified (usually a family member) as well as warnings to the monitoring centre. For both groups there are a number of issues that can arise. The most problematic appeared to be the false alerts related to the geo-fence boundary. For family members, who might live some distance to their relative, this meant unnecessary concern as well as being costly in terms of their time. For monitoring centre staff there was an obligation to raise the alarm, whether or not they believed it to be a false alarm. This study highlights the complexity of successful introduction of GPS tracking devices, particularly that they do not provide an easy or cheap answer to enabling people with dementia who wander to remain in their home.

In their recent review of the literature, Siriam, Jenkinson & Peters (2019) reinforced the need for codesign of assistive technology in order to make it useful to people with dementia and their families. While this review covered a wide range of assistive technology, their findings related to informal carers' experiences noted that there was more literature on the use of tracking devices than most other types of technology. Not too surprisingly, in their review they found similar issues common in the above literature (neither of those studies were included in their review). Including; the weighting of safety over autonomy, the sense that a tracking system might increase freedom, and challenges related to the acceptability of the device to the person with dementia as well as the person monitoring the device. Such issues appear to

be consistent over time and have previously been highlighted by studies not included in this review such as Bantry White, Montgomery and McShane (2010) and Landau, et al. (2009). In addition, establishing the benefit of such devices has remained a problem in most studies, with Siriam et al. suggesting that might be because the outcome measures used are not sensitive enough to measure change.

Usability and acceptability were a focus for Holthe et al's (2018) systematic review. While they reviewed articles with a similar broad range of devices as Simian et al. (2019) their focus for inclusion of articles meant a different selection from the literature. Acceptability of tracking technology depended upon reliability and performance of the technology as experienced by the users. Users also needed to feel that the device matched their identity, for example, a watch-style might be more acceptable than a device that attaches to a person's belt. Interestingly, they commented that usability of technology often improved as users became more familiar with it, further supporting other studies that identify the need for education and follow-up. While the participants in the studies were identified as users, it is important to note that less than half of the studies included people with cognitive impairment or dementia, the perceptions of family carers and/or staff were reported. This lack of input from the people being monitored raises important ethical issues.

### **Balancing safety with autonomy and freedom**

While the population as a whole has come under increasing electronic surveillance with the development of technology, raising multiple ethical issues, the specific issues that arise for people who are being monitored by tracking technology predominantly revolve around the balance of risk with the right to autonomy. Autonomy includes being able to make choices about movement within the home and community, having privacy, as well as choosing if you want to have a tracking device to assist if you become lost. For a small proportion of those who do wear or carry a tracking device the latter option might require supported decision making.

Risk versus autonomy is not a simple equation when considering harm for people who wander and get lost. As noted in their 2003 article, Welsh, et al. reminded us that there has been a history of constraining people with locks and medication to ensure that they don't wander. The introduction of a tracking technology that provides the opportunity for people to wander, while keeping them safe, might be seen as much less damaging to autonomy than practices which confine the person indoors using physical or pharmacological restraints. Driving some of the move to improving and increasing technological means for keeping people safe in their own homes is the preference for older people to remain out of care facilities for as long as possible. The majority of the articles that address technology for people with dementia relate the move to both the aging population, with a predicted

associated increase in the number of people who will require some level of supervision, and the philosophical move to community care (see for example, Landau et al., 2010; Holthe et al., 2018).

Timing can be important however, as the use of locating technology when a person would not otherwise be confined challenges a rationale that considers tracking to be the less invasive option. For people with dementia, the progressive nature of their condition will change the need for tracking, potentially increasing the need as their confusion becomes more significant and before they require more intensive care as their mobility declines. For children with learning disability and/or autism, the need can become less as they mature and, if usage is prolonged, can interfere with their developing autonomy (Brisebois, 2019). To justify the use of tracking technology for anyone with impaired cognitive functioning, regardless of the underlying reason, regular and appropriate assessment of the technology is essential to fairly balance the risk with the person's autonomy.

Fundamental to assessment, it is argued that there should be caution about the focus on management and prevention of wandering for people diagnosed with ASD (Brisebois, 2019; Solomon & Lawlor, 2018) as well as other cognitive impairments (Wherton et al., 2018). To understand why the person is wandering, it is important to explore the meaning for the person. To simply pathologise the behaviour for all people with ASD who wander, firstly denies their right to freedom of movement and secondly absolves others from responsibility to find out what is happening in the person's life (Brisebois, 2019). The voice that is silenced in the strategies for autistic children who wander, tends to be the child themselves, raising ethical concerns about their autonomy. Balancing the risk factors and the natural anxiety of parents or carers with the child's right to self-determination requires careful assessment before initiating an electronic system. In addition, it would be important to regularly review the need as the child develops. For people with ASD, the literature that is available would suggest that the electronic systems most commonly in use do allow tracking of the person at all times, with the devices using Global Positioning System (GPS) and often sewn into garments.

In Bantry White and Montgomery's (2014) qualitative study with carers, safety clearly took priority over other factors when making decisions about using tracking technology for their family member with dementia. Even though some participants acknowledged that it might diminish the person's privacy, the desire to keep them from physical harm was a strong motivator for using the technology. Providing greater opportunity for freedom and independence was seen as a benefit, in that they felt the electronic monitoring meant the person was able to get out and about in their community. Recognition of the relational aspect

of caring in these contexts, participants also noted the freedom from worry they felt due to their family member having the tracking system. However, in common with the critical autism literature (Solomon & Lawlor, 2018), Bantry White and Montgomery have concerns about how risk and safety are portrayed for people with dementia. In order to justify the balance of risk over autonomy, there needs to be a realistic determination of actual risk to the person who wanders. There is no certainty that the concern families have about risk for their family member is realistic, also noted in consideration of ethical issues by Yang and Kels (2017).

Risk assessments generally aim to be objective, yet are frequently based on implicit assumptions about wandering behaviour that suggest it is purposeless and a sign of confusion and agitation (Wherton, et al. 2019). Through their exploration of the wandering behaviour of seven participants, Wherton, et al. demonstrated the sociocultural nature of wandering, pointing out that a balanced approach to risk assessment would include understanding the multiple social and economic factors that might be relevant. Necessary considerations therefore include a full assessment of the person within their context and careful decision-making in terms of the technology and how it is adopted to best meet their needs. Not only does such an approach more realistically assess risk for that person, it also ensures that their autonomy is not restricted beyond their level of risk.

## **Decision-making and consent**

An important component of autonomy is the right to make decisions about one's own care and treatment. While family members might be very concerned about the person's safety, any form of electronic monitoring has the potential to invade a person's privacy. People can vary in terms of how they value personal privacy (Yang & Kels, 2015). For some people having another person decide as to whether or not they use electronic monitoring might be seen as a major challenge to their autonomy. The research demonstrates mixed opinions as Bantry White and Montgomery (2014) demonstrated when they asked their participants about their attitudes towards, and the consent process that was undertaken when deciding to use a tracking system with their family member. The responses ranged from those that believed it was justifiable to use subterfuge and hide the device on the person, to those who respected full and informed consent. While each participants' personal values will no doubt have influenced them, it was evident that the relationship that they had with the person was also important. Hence, in some cases the decision was focused on the benefit to the person with dementia, in other cases the relative used their need for reassurance as the motivator. Memory also affected consent, in terms that people could forget that they had consented within quite short periods of time. Thus, even when consent had been given, it could not be assumed that the person was going to be willing to carry a tracking device.

To overcome some of the challenges with obtaining the individual's consent, Bantry White and Montgomery asked family members for their suggestions as to how the decision might be made when the person did not provide their own consent. Those interviewed preferred a process that included involvement of all the family and others involved in the person's care and support and guidance for family members making decisions. Their emphasis on family having a pivotal role in decision-making reflected an earlier survey where the spouse of the person and the family member most involved with the person were seen as the best decision-makers (Landau et al., 2011). That study drew on the perceptions of 296 participants including family members of people with dementia and professionals. Interestingly, the person with dementia was rated as the third potential decision-maker, highlighting that their autonomy was less valued than the overall good the location device might offer for all the family.

A major issue for autonomy, where memory is a component of the cognitive impairment, is whether or not the person is capable of deciding and then remembering their decision about whether or not they would accept being electronically monitored. Where memory loss is gradual, advanced decision-making might provide a solution and, at the very least, indicate what the person thought they would want at the time (Bantry White & Montgomery, 2014). However there appears to be little literature that has explored opinions as to whether or not people would accept being electronically monitored should they begin to wander and get lost. Landau et al. (2010) touched on the idea by asking participants (family carers and professionals) in their focus groups if they would be willing to sign living wills agreeing to electronic tracking if in the future they were assessed to require it. Views were varied, perhaps indicating that this approach might be of limited use.

For children or adults with cognitive impairment there is not necessarily an opportunity to gain consent in advance. Of those children with ASD or learning disability, wandering generally presents early in their life, while others who might benefit from this technology are likely to have had a sudden, acute injury to their brain. The default is often to appeal to best interest, which, as above, tends to have a family rather than individual focus. An alternative that should be considered is a supported decision-making approach. Supported decision-making has the potential for developing self-determination, which is seen as a way to promote the younger person's evolution to adulthood (Shogren et al., 2019). In a similar way, supported decision-making might aid those with an acute brain injury to maintain or regain their sense of self-determination. As a model that addresses over-reliance on others to make decisions for people, supported decision-making clearly puts the person at the centre of decisions about their life (Shogren, et al.). It reflects the comments above about the need

to understand the socio-ecological meaning of wandering to the person (Brisebois, 2019; Solomon & Lawler, 2018; Wherton et al, 2019). Furthermore, supported-decision making assumes competence, aligning it with the United Nations Convention of the Rights of Persons with Disability (2006). Effective supported decision-making requires assessment of and provision for the supports the person might need as well as continuous re-evaluation of the need for supports as the person's competency and their life changes (Shogren et al., 2019).

## **Conclusion**

As was evident from the literature search conducted for this review, electronic monitoring for people with dementia has received much more attention than the use for other population groups. While there will be multiple reasons behind this balance of evidence, it is likely that the pressure to find a safe way for people to remain in the community as they age has contributed. There is, potentially, also greater concern about monitoring people who have previously had their competence and autonomy unquestioned compared with younger people for whom it is often assumed that care-givers will make decisions in their interest. However, the above literature that highlights socio-ecological factors in wandering behaviour, clearly challenge all assumptions. Based on these findings, any future research exploring the use and acceptability of tracking devices must incorporate questions that develop our understanding of why people are wandering, what else people have tried as a way to keep the person safe, what the person being tracked understands as the purpose of tracking devices, and how the decision to use a tracking device was made.

## Method for evaluation of WanderSearch

### **Aim:**

To evaluate the WanderSearch programme from the perspective of those using the service in four regions of Te Waipounamu

### **Method:**

A descriptive qualitative approach was taken to this evaluation (Bradshaw, Atkinson & Doody, 2017; Patton, 2002). This method was suited to this study as it assisted with understanding the perspective of those people interviewed in relation to their use of WanderSearch.

The evaluation occurred in four regions of Te Waipounamu. The regions were selected for the variety of services that provided the WanderSearch equipment, the range in numbers of people who were using WanderSearch pendants and their geographical area. Recruitment of participants within the regions was initially through the co-ordinators, who were asked to identify and request participation from people who currently or previously had a member of their family or rest home wearing a pendant. In identifying potential participants, they were asked to consider variety in order to maximise the opportunity to gain a range of perspectives on WanderSearch. In research terms, this is known as convenience, purposive sampling and it aligns with the chosen method of qualitative description (Bradshaw et al., 2017).

Interviews with four regional co-ordinators and eight people who had family members or were care providers were completed. Regional co-ordinators were interviewed (see Appendix A) to provide detail about how the WanderSearch system operated within their locality with the intent that this information would assist the interviewer with questions for the families and other carers. From that information a semi-structured interview guide was developed, with the questions for family or other carers focused on their experience with WanderSearch (see Appendix B). Responses to questions at early interviews provided additional guidance for later interviews.

While the main purpose of the interviews with the co-ordinators was to understand the way that the service functioned in their region, their background information indicated key themes that might be useful for the national organisation to consider. These themes will be outlined in the subsequent result section of this report.

Seven interviews with carers were via telephone or an online audio-visual link and one in person. Data collection occurred via notes written at the time of interview which were typed immediately after completion. Interviews ranged from approximately 20 to 60 minutes in

length, with the timeframe dependent on the information that the person wished to share. All participants were provided with written information and signed a consent form prior to their interviews (see Appendix C). In the following results section, care has been taken to limit the diagnostic or other identifying information of people involved in the evaluation.

A content driven descriptive analysis was used for the interviews with the family and other carers. For the purpose of evaluation, this method of analysis provides sufficient information from which to review current practice, while it is enriched by the use of examples to aid understanding (Bradshaw et al. 2017; Patton, 2002).

Familiarisation with the data is commonly the first step in qualitative analysis (Bradshaw et al., 2017). For this evaluation the same person conducted the interviews and collated the responses, with relevant data being extracted and grouped according to content. This resulted in the identification of content-driven themes. From this initial grouping of the data into themes and subthemes, further analysis focused on similarities and differences in the experience of the participants.

# Results

This section begins with the results from the interviews with the co-ordinators. The results from the interviews with the people using WanderSearch devices follows.

## The co-ordinators

A broad overview of each of the regional services was gained from the interviews with the co-ordinators. In addition to their knowledge of the WanderSearch system within their region, other regions and the national organisation, it was evident that the pathway to becoming involved had been different for each person. This section is divided into two main sections. The first much larger section is further divided into subsections and contains the information that was shared regarding the co-ordinators knowledge of the WanderSearch system. The second, albeit brief section, has been separated to illustrate the personal pathway for the co-ordinators becoming involved. This is done to highlight the unique skills each person brings to their role.

## The WanderSearch System

### How the local programme developed

There were different pathways for each region in adopting WanderSearch. The impetus in both Nelson and Christchurch came from individuals who had wandered, where a need was identified for a better system for finding people by those involved in the searches. In this regard the early development of WanderSearch in New Zealand can be seen as a series of local initiatives. At the time, it was an individual involved with LandSAR in Nelson who developed the equipment. In contrast, both Westport and Dunedin began using WanderSearch after the value of the technology had been shown in these other regions. It was a request from a person moving into the Westport area that initiated their involvement. While it turned out that this person did not need a device, Westport LandSAR Inc. recognised the potential of the equipment and sought funding from local organisations to set up the service. Local organisations continue to support and fund pendants in Westport. For Dunedin, it would appear that the challenge of securing funding led to a slow introduction of WanderSearch equipment. Initially the local Alzheimer's support group took on the responsibility, however the Dunedin District LandSAR Committee now co-ordinates now co-ordinates the service.

It is possible that the different routes to the development of WanderSearch has led to how the equipment is used in each region. For both Nelson and Westport, it is people with dementia or associated conditions that are currently using the technology. In Canterbury and

Dunedin the equipment is used by children and adults who have a tendency to wander or become lost. Their underlying conditions include dementia, autism, and learning (intellectual) disability.

Canterbury is the only one of the four districts that has an independent charitable trust set up to manage the co-ordination of WanderSearch. The Canterbury region is large, encompassing the whole province and, recently, including South Canterbury. As a consequence of the large area that this Trust covers, and the diverse population using the equipment, the role of the coordinator grew into a part-time paid position.

### **Local variation in system processes**

Although there were many similarities, there were also differences in how WanderSearch was organised in each region. These are outlined here under three subsections; referrals, equipment, and reporting of searches to the co-ordinators.

#### ***Referrals***

As will be documented in the results of the interviews with people using WanderSearch, referrals were their main introduction to the service in their region. In addition to finding out about the service, the co-ordinators were also asked how they assessed the need for people who had been referred.

Referrals were more commonly made by the Police (after conducting searches for people), or organisations that supported people with dementia, including Dementia Canterbury and the local Alzheimers field work teams. In Nelson, the co-ordinator also had a relationship with the local DHB and received referrals from their social work team. Co-ordinators did mention that a few people found out about WanderSearch through internet searches for something that would help when their family member went missing. Less commonly people had heard about WanderSearch from another member of the public who had used the service. The comparatively small community of Westport combined with a coordinator who had strong connections within the community meant that she could suggest the service to people who she recognised might find it useful. The co-ordinators' responses suggest that there is scope to build a more robust referral process, along with ensuring a wide-reaching education campaign inclusive of both family and whanau carers and organisations supporting people who tend to wander.

Once a referral was received co-ordinators contacted the person or nominated family member. There were a few referrals that came through rest homes and these were followed up initially with the manager, with co-ordinators then making a time to meet with the relevant people to discuss suitability of the equipment for their needs.

All co-ordinators agreed that the person who would be wearing the pendant would be included in the assessment conversation, if at all possible. In addition to consent issues, this was essential to having them accept wearing the pendant at all times. Co-ordinators identified that a positive approach with information delivered at a level that the person understood was usually helpful in getting them to accept their pendant or alternative. However, co-ordinators also suggested that most people were not competent to provide informed consent, either due to their advanced dementia or cognitive development if it was a child. Consent documentation varied along with recognition of Enduring Power of Attorney and the (il)legitimacy of people “consenting” for others where they had no legal power. There was general recognition of the need for standardised consent forms. The current practice in some areas is to accept the signature of the person identified as primary carer as meeting consent requirements. A future action identified through this evaluation is gaining a legal opinion on two important issues, (1) the consent of the person to wear the pendant and agree to be tracked if necessary, and (2) the care and management of the pendant, given that the equipment is on loan.

Ongoing assessment was deemed to be important, with the battery change time being a chance to check on acceptability and need for ongoing use. For example, children can outgrow the need for a pendant, while people with dementia frequently become less active and therefore less likely to wander over time.

### **Equipment**

The co-ordinators identified the equipment available in their region, how they introduced the equipment to new users and any costs to the users. They were also asked what they knew about how the system works in their region. In this case, those with search and rescue experience had the advantage of having a comprehensive understanding of how searches would be conducted and the equipment that would be used. However, all knew the basics, such as that it was a radio frequency system and that maintenance of the equipment was critical to ensure it was effective if a search became necessary. All co-ordinators also had knowledge of alternative tracking systems using GPS technology and could identify where these might be more suitable. Both Dunedin and Canterbury had people using both systems, commonly because the GPS allowed for geofencing. One co-ordinator emphasised informing the Police if the person was using both technologies as a way to assist searches. It was noted that radio frequency tracking was more reliable for a range of reasons, most notably the lack of satellite cover in the more remote regions of the South Island.

Access to equipment varies between the regions, both in terms of the pendants available for loan and the number of receivers available for a search. The receivers are generally held by

the local Police, with LandSAR holding the three in Westport. It was noted that the Police Call Centre needed to be aware of this in order to direct call outs after hours (there had been an occasion when the call went to Nelson Police, who then did not contact Westport LandSAR). The Dunedin co-ordinator noted that they currently had two receivers but due to the terrain around the city it would be useful to have a third. They are looking to get a third to better triangulate their searches and thus increase the ability to more accurately pinpoint a person's location. Given New Zealand's terrain, it could be considered a basic requirement for regional service providers to have access to three receivers.

The organisations co-ordinating WanderSearch own the pendants that they loan out. This creates inequities of access as supply can be determined by the number of pendants the organisation can afford as well as which groups of the population they see as eligible for a pendant. Alternatives to pendants were not available in all four regions. For effective implementation of the Safer Walking Framework, provision of and access to pendants might benefit from a national approach to ensure they are readily available for those people who would benefit.

Pendants and the alternative options of wrist bracelet or key ring were generally provided free of charge after the person has been assessed. All co-ordinators believed it was important to assess whether or not a pendant (or other device) was suitable for the person and their care situation. There were a number of factors that they considered, including acceptability for the person who would be wearing the pendant but also the rationale that the family or other carers provided for wanting the person to have a pendant. The Safer Walking Framework had influenced the advice given as well as suitability for pendants. While the Framework implies that wandering occurs via foot, co-ordinators recognised that people with dementia have increasing access to equipment such as electric bikes and mobility scooters, meaning that they can cover greater distances in less time.

If a pendant is lost the wearer may be required to pay for a replacement. This does depend on the region and the circumstances. Rest Homes seem to be a site where device loss is more common, with the suggestion that this might be due to the multiple people who are caring for a person and the challenge of ensuring that they are all familiar with how the equipment works. For example, understanding that the device should stay on the person all the time and does not need to be removed for showers etc. Receivers have been used to locate missing pendants but that is dependent on the Police or LandSAR teams volunteering their time, and while helpful in terms of ensuring the person is not without a pendant for long, it is possibly not cost effective when compared to the cost of production of the pendants.

In the regions with fewer people using WanderSearch batteries are generally replaced by the co-ordinator. Canterbury has introduced a charge of \$55.00 for battery replacements, but there is discretion to waive this fee where there is financial hardship. In that region the co-ordinator is assisted by volunteers to make battery changes. It was noted that battery changes provided an opportunity to reassess the need for a pendant and to check that it was being used appropriately.

### ***Reporting of searches to co-ordinators***

The organisation responsible for WanderSearch in the region provided a key difference in terms of what the particular co-ordinator knew about searches. For the two regions where LandSAR were responsible, the co-ordinators generally had direct involvement and knew that a search had been conducted, along with the outcome of that search. The only exception was if the Police carried out the search and did not involve LandSAR.

Communication between the Police and LandSAR was deemed very important and there was some concern that not all events of wandering might be accounted for if LandSAR were not involved. For both Nelson and Canterbury reporting was less direct or immediate. The Nelson co-ordinator did not necessarily know at all if a search had been conducted. Canterbury had the most advanced system in terms of recording searches with a weekly report coming from the Police. This information was entered into a spreadsheet.

While the Police and LandSAR can record searches and thus provide information relevant to the overall provision of WanderSearch, consistent feedback to the co-ordinators would provide the opportunity for them to offer a reassessment of the person's needs.

### ***Knowledge of other regions and the national organisation***

The co-ordinators from Dunedin, Westport and Canterbury had all attended the most recent workshop in Wellington, which was organised by the national co-ordinator. The Nelson co-ordinator was not able to attend that workshop, however she had been to previous similar events. All agreed that these forums were useful and provided the opportunity to share information and learn about how WanderSearch was organised in other regions. In relation to the most recent conference, the co-ordinators identified that they had a better understanding of the Safer Walking Framework. This knowledge had a positive effect for one co-ordinator in terms of her choosing to remain in her position. It was also reported that this knowledge was transferred to how they subsequently carried out assessments of people referred to them for the WanderSearch technology.

There was strong support for the national co-ordinator employed through LandSAR. Those interviewed identified a number of skills she had brought to the role. They appreciated the work that she was doing to standardise the services across the regions. In addition to the national meeting, there is now a Facebook site for co-ordinators to share information and both the national coordinator and the administration person are very accessible to the regional co-ordinators. Contact with the national co-ordinator is reported to be more frequent than in the past and has included more site visits, which local co-ordinators value.

### **Becoming involved in WanderSearch**

While the main focus for the interviews with the co-ordinators was to gain an understanding of how the system worked in their region in order to frame the subsequent interviews with users of WanderSearch, each shared some information about how they became involved in the work. This brief section highlights aspects of their journey which might inform subsequent considerations for the role of co-ordinators.

The co-ordinators in Dunedin, Nelson and Westport had been involved through their organisations from the inception of WanderSearch in their area. For the Westport and Dunedin co-ordinators their long history with Search and Rescue (either land or sea) provided an interest in finding people who are lost. The Nelson co-ordinator had her interest aroused at a debriefing session following a difficult search (as noted above, this was the search that initiated the development of the tracking equipment). In contrast the Canterbury co-ordinator learnt about WanderSearch when she was looking for part-time work on an employment site, it was her background in seeking funding, administration and people-focused work that she saw as a match for what the Canterbury Trust sought.

The Dunedin and Westport volunteers appeared to have pivotal roles in the way that LandSAR had become involved in their region. Both indicated that their positions grew from their determined effort to have an effective search method for vulnerable people in their region. Although they took over from early initiatives, the development of the service into its current form has mostly been led by them, albeit with support from various individuals and groups.

To support WanderSearch in their region both volunteer co-ordinators have identified further roles for themselves. In Westport the co-ordinator assists with training of search and rescue volunteers. She ensures that a variety of settings are used to familiarise people with how the tracking system would work in a range of conditions. As well as the actual tracking procedure, she also advises that a female is included in the search team, her rationale being that their softer voices assist with calming a person. When communicating with the person, once found, her advice is to agree and work with their thinking.

The Dunedin coordinator uses her search and rescue experience to be with the family or carer who is waiting for an outcome from the search. She has negotiated with the police to be with the carer, reassuring and explaining the search process. This is a role normally undertaken by a police officer. As there have been no recent searches in the region, this role is yet to be evaluated.

Common across all co-ordinators is a background in employment that has a people-focus and it is these skills they draw on when engaging individuals and families in decisions about using the WanderSearch technology. In addition, they have worked in situations that required administration skills. Both sets of skills appear to be relevant to the co-ordination role and can be identified in job descriptions for paid positions. A potential challenge for the future might be replacing the volunteer co-ordinators with appropriately skilled people as the previous experience and systems knowledge of the current two volunteers should not be underestimated. In addition, the idiosyncratic way in which each person learnt about WanderSearch might also suggest the need to develop a public awareness strategy and ensure that the programme in each region is identified in the voluntary sector for future recruitment.

### **The carers of people who use WanderSearch**

Following an approach from their local co-ordinator, eight carers agreed to be interviewed about their use of WanderSearch. Three regions were represented in these interviews. All those interviewed identified their role as a carer of a person or people who had pendants or watch devices, with three of these carers reflecting on past use and five current use. The main reason for no longer having the pendant was because the person that they cared for had moved into a secure residential care facility.

Six carers were representing people with dementia or cognitive impairment, their relationship to the person was wife (3), daughter (1), husband (1) or as a manager of a rest home that supported two adults (1). The additional two carers were parents of children, one being a father and one a mother. Their children had neurodevelopmental disabilities that included but was not limited to ASD. One “child” was now of adult age, while the other was of school-age. Most people were using the pendants, watches were used by few and no one used a key ring. In some regions, pendants were the only available option.

Analysis of the interview records resulted in the identification of two themes. The first “constant concern” highlights the worry experienced by those caring for people who might wander. The second “peace of mind” recognises a common comment from those interviewed when asked what the WanderSearch programme meant for them.

## “Constant concern”

A frequent response from people when asked about why they had started using WanderSearch was a desperate need to address the concern they had regarding their family member or person they supported becoming lost. Although a few had experiences of their family member becoming lost to the point where a formal search had been undertaken, it was also clear that some were addressing their concern about what would happen if they did become lost. As an outcome of this concern, people talked about “watching him like a hawk” or being in a state of constant vigilance. One woman reported biking or driving around the neighbourhood to find her husband as a frequent response when he didn’t come home. This constant state of alertness, often accompanied by the physical exertion of searching, was particularly evident for those older adults who were caring for their spouse with dementia, and meant they were often exhausted by the time they sought help. Underlying the concern of all those interviewed was the risk of the person being harmed when they were wandering. Both parents of young children and some of the carers of people with dementia or cognitive impairment noted that the person they cared for was not aware of basic road safety.

People with dementia displayed various patterns to their wandering. For some it seemed to be associated with their early life, for example, they would return to the locality of their family home. Other reasons included simple enjoyment, at times related to people who had always been trampers, or who had jobs that had required them to be active; seeking out previous activities or hobbies. For example, one man who had enjoyed sailing would say he was going to look at boats, while another woman would frequently go to her local shopping area. However, it was also common for there to be no obvious reason for the person to wander with comments such as “If he wanted to go, he went” illustrating the drive that some felt was underlying the person that they cared for leaving home. Wandering at night time was much more concerning for carers. Three of the carers of people with dementia noted that the person they cared for was increasingly likely to want to wander at night and would often become agitated if they attempted to stop them. For example, one woman noted that her husband would claim that he was going to work, despite never having been a night worker. A husband mentioned being woken in the night by someone knocking on the door and finding his wife, who he thought was asleep, being returned home by a member of the public or police. While husband and wives cared for their spouse at home for as long as they felt able, their move into a care facility was associated with the person with dementia wandering at night and/or becoming increasingly agitated, angry or violent.

The children who had pendants or watches had been wandering from an early age. Parents were more likely to use language such as “run” or “take off”, indicating the speed with which they went. The children also tended to be agile and able to climb or work their way out of

areas that were fenced. Schools in particular presented an increased opportunity for the child to wander if they were not fenced. It was mentioned by the parents that these children did not have fulltime teacher aid hours, potentially leading to less close supervision. It was not clear to the parent of the younger child why he wandered, but it was thought that it might not be something that he could control and that he was simply responding to a “felt need to just run”. The parent of the young adult had noted that their son was more likely to “take off” when he had heightened anxiety. There were various triggers that could raise his level of anxiety, including unexpected events or if he was feeling remorse regarding something he had done. The length of time the person was away from their home did not always relate to the level of concern the carer had while they were away. Their concern depended upon the person and their pattern of wandering, including if they returned home by themselves. Spouses generally accepted their husband or wife being away for prolonged walks in the daytime, even when it was not a previous habit. This time away could be eight or more hours. In contrast, parents of young children were more likely to be immediately concerned if their child was not able to be located at any time of the day.

While constant supervision was the primary response to the concern that people would wander, some other strategies were also adopted. The children lived in homes that were fully fenced, with locks on gates and/or doors. One parent noted that they had assessed all schools in the city prior to enrolling their children so that they could choose the one that they felt would be the most secure. While locked gates were available for some people with dementia, their spouses were more likely to be concerned that they would hurt themselves if they tried to climb over the gate so would not consistently lock the gate. A variety of other strategies were mentioned, including ensuring the person was wearing a high visibility vest if they were daytime wandering and still reliably coming home; distraction and redirection to keep them busy at home; and, arranging a support person, or accompanying themselves when the person went out, which often involved having to move fast to keep up with the person. Having someone accompany the person had the added advantage of ensuring they were aware of risks to their safety, such as when crossing roads. This strategy was used for a woman with a cognitive impairment who was otherwise still enjoying being out and about independently.

Either before they adopted WanderSearch or after, some people also used a GPS system to track their family member. For the younger child the additional functions, such as being able to set boundaries, was a benefit. However, if the child was likely to damage a GPS capable product it was not as useful due to the cost of repair and replacement. This rationale also applied if the child was repeatably damaging a pendant and the risk of them coming

to harm seen as less in a cost/benefit analysis. One person used GPS with her husband because it meant that she could track his wandering and could independently find him when she became concerned. In this case, the GPS system was added after they obtained the pendant. Their initial choice of WanderSearch was based on it being highly recommended by Dementia Canterbury. However, she ultimately found the GPS system better suited to how she cared for her husband, allowing him space to wander while also supervising at a distance. Notably, she was confident in using the GPS technology, including an understanding of the data requirements and maintenance. The rest home manager had tried a GPS system before finding WanderSearch, however the GPS was limited because it did not work inside the rest home and sent false messages suggesting the person had moved outside the geo fence when they were actually still in the rest home.

While it made minimal difference to their level of concern, a number of the participants told stories that reflected the responsiveness of the public. For the man who wandered for hours in the country, neighbours would phone his wife to let her know they had seen him, the direction he was headed and that he seemed alright. Three people told of their spouse being returned home by members of the public who came across them. Sometimes these were people they knew and sometimes they were strangers but all had taken the time to find out who they were and locate where they should be. These stories often provided some lighter moments as they recounted how their husband or wife drew on their well-rehearsed manners to thank the person for the ride home.

### **“Peace of mind”**

Referrals to the WanderSearch programme had come from various sources. Some people had searched websites for a suitable product, others were referred directly by Police or organisations such as Dementia Canterbury. District Health Board sites, such as Older Person’s Health were not noted as sources of information about WanderSearch. Regardless of the way that they found out about WanderSearch, the relief that each person felt was similarly expressed. As well as “Peace of mind” another common response was “A load taken off my shoulders”. Behind these words, was also the relief from the physical exhaustion that they felt. For some it was the first time they had slept through the night. For the rest home manager, there was the reassurance that they would be able to locate the person if they needed to do so, for example if they didn’t return from a daytime outing. At night time it meant that there was a system in place to locate the person which did not require a major interruption to the care they provided to other residents. Typically, they would have fewer staff on duty in the evening and drawing on them to conduct searches created a potential risk both for other residents and staff.

The co-ordinators of WanderSearch were reported as usually being quick to respond to requests for information, to conduct assessments and supply equipment. People were generally happy with the ongoing support they received. Some offered “plaudits all round” when referring to the overall service, inclusive of Police and LandSAR, others noted that the service was “wonderful” and “excellent”. One family mentioned that their initial introduction to WanderSearch was less successful as the organisation at that time had not notified the number for the radio frequency to the Police. While the child was found without the aid of WanderSearch in this instance, it has been more reassuring for the parents that this region now provides WanderSearch pendants through LandSAR.

The people interviewed were in general agreement that the decision to use WanderSearch was ultimately up to them or the family of the person who was wandering. Involving the person with dementia was part of the process but the emphasis on their involvement reflected the need to have their cooperation to wear the pendant or watch. In some cases, the person making the decision had Enduring Power of Attorney which had been activated but a number did not. Justification for making the decision was captured in the belief that the overall good of being able to locate the person if they went missing overrode individual autonomy, with one person summing this up by asking “who is the pendant for?”.

For both parents interviewed, the initial decision to use WanderSearch came from them and their partner. However, they involved their children who had reached a stage of understanding the purpose of the pendant. One child wore his pendant around his neck and secured to prevent him from removing it. He was aware of the purpose of the pendant but his parents felt that he did not yet fully understand the risks associated with him “running”. This was illustrated by his response to his mother’s explanation that he might get hit by a car, to which he replied that he would be alright because he would “go underneath the car”. The young adult who continued to use WanderSearch carried his watch along with his cell phone when he left the house. For his parents, WanderSearch provided the reassurance they needed to encourage his greater independence within the community, they also liked that it was comparatively discreet. Given that he had the choice not to take it with him, his consent to use WanderSearch could be inferred.

For the person wearing the pendant or watch, compliance could be an issue. Carers found various ways to encourage the person to accept the pendant. For one man, it was likened to a greenstone pendant that his grandson had recently received. However, there was no clear pattern to how to encourage continual wear of the pendant or watch. For some people it did not seem to be an issue, while others noted the pendants were uncomfortable or for reasons not evident to them, their husband or wife would take it off. For those older adults less likely

to wear their pendant all the time, a compromise was for them to take it when they went out. This did rely on them understanding and accepting the purpose of the pendant and carers did note that they were not always consistent in taking it with them. One woman kept her pendant with her house keys as a way to remember. In the rest home a system to prompt regular checking had been put in place and along with putting the pendants on bright orange lanyards, this made it easy for staff to notice if they were not on the person.

Keeping pendants or watches on children was a greater challenge. One family interviewed had previously had a pendant for two children. They had stopped using it for one child who persistently damaged the pendant because they paid for replacements (which they felt justifiable but was becoming a financial burden). This family decided that he was becoming sufficiently predictable when he ran therefore they had less concern about not being able to locate him. The other child had the pendant firmly attached around his neck and was unable to remove it. For the young adult, the decision was made while he was a child that his skin sensitivity meant that he was not able to wear either the pendant or watch. While his family found a system for him to keep the watch with him when he goes out now, the reliance on him wearing the watch or pendant has been an ongoing concern for them. They recognise that this is an issue that is not easily resolved.

The main ongoing maintenance of pendants or watches for carers is the battery change. For some this was an opportunity to ask further questions and it was valued that co-ordinators made time to meet with them when changing batteries. While this personal approach was clearly important for some, there were people who were happy to have other arrangements for replacement batteries. One man noted that he left the old battery in his mailbox so that the volunteer could replace it with a new battery for him to fit that day. A problem he initially had with this arrangement was that he didn't check the battery number to confirm the battery swap had occurred before replacing with the "new" battery. He quickly learnt to check the number and, from his experience, suggested that be clearly included in instructions if people are going to take responsibility for their own battery changes. Covid-19 had also had an impact on battery changes, with a rural person explaining that she no longer had to travel to a larger centre for the battery swap. She now received the new battery by mail and returned the old the same way, which was working well for her. She was able to put her payment for the battery directly into the Trust's account. The Trust in Canterbury had introduced a charge for battery changes. Participants from that region were asked about the acceptability of the charge and all agreed that it was reasonable. The rest home passes the charge onto the family and it was reportedly accepted by them.

A primary purpose for people having WanderSearch pendants or watches is to enable them to be located if they go missing, however the reality for some of the people interviewed was that their family member or person they supported had never needed a search initiated. Their use provided a contrast to the people who had multiple searches. The younger child using a pendant had a GPS tracker as well and this had been used to find him. For that family the pendant was considered to be a back-up, which they saw as more reliable because of the battery life and ability to be used if outside of an area with GPS capability. The other young person with a watch had been the subject of more than one search. The parent recounted one event when they contacted the Police and LandSAR one evening when it was noted that their son was not at home and he was located and returned home within an hour. Another occasion he had caught the wrong bus and got off at a shopping centre. WanderSearch was not used and it was primarily due to him being known by the taxi company that he was returned home safely in a taxi. While the length of time people were missing appeared to increase when they were not wearing a tracking device, there were numerous stories of people being returned home by members of the public or the police who had noted that they appeared lost and after finding sufficient information were able to locate their home.

While six people were interviewed about using WanderSearch with older adults, they represented seven users as the rest home had two people using pendants. Four of these had not had a search initiated since getting their pendant. This number included the two people in the rest home and two rural-living participants. Despite no searches being necessary, the rural people might be seen as at high risk of becoming lost, in one case because of the distance walked and the other because it was an unfamiliar environment having moved there following a neurological event that resulted in cognitive impairment. For the three remaining adults, two had been the focus of numerous searches and the other person had experienced two searches since getting a pendant. Notably, these people had also been the subject of searches prior to getting pendants. After getting their pendants, two of the carers were initially hesitant to make the 111 call when their spouse went missing the first time. The third person did not indicate any hesitancy and had made the call a number of times. Response from the Police was an important consideration for future calls. Two of the three were satisfied with the Police and LandSAR response. For one person this included LandSAR staff staying with her and then accompanying her to the hospital while her husband was treated for hypothermia. The other person was overwhelmed by the Police presence the first time she called 111. She had not expected four Police to arrive at her door late at night, thinking they had the information they needed to begin the search. Initially she thought she was “not going to do that again”, however she subsequently called them about five to six times. As with the husband that has made numerous calls to 111 to initiate a search for his wife, she

was not sure how often the Police actually used WanderSearch to locate her husband. While the husband realised that he did not know for certain, he felt there was hesitance from the Police to call out LandSAR teams during the daylight hours but thought this was not an issue at night. Generally, his wife did not need medical attention after becoming lost, the exception being one time when she fell. Throughout the searches for her he did feel well supported, he was able to call 111 if she returned home and the call generally went to the person who took his initial call.

## **Conclusion**

The eight people interviewed provided information about a range of situations where WanderSearch equipment was being used to enable people to be tracked should they go missing. For some carers this was a response to events where the person they cared for had gone missing, while for others it was an anticipatory response linked to a concern that the person might go missing. Regardless of how they were introduced to WanderSearch there were few concerns with the service that was provided. Everyone that was interviewed spoke highly of their co-ordinators, and the Police and LandSAR support.

## Discussion and Recommendations

Drawing together the literature review findings and the results from the evaluation interviews, this section notes some specific aspects for further consideration. As with any qualitative evaluation, there are obvious limitations to generalising the findings, including that only four regions of Aotearoa New Zealand were included in the evaluation and recruitment was limited to convenience sampling. However, these limitations aside, the people who participated in this evaluation have provided important information for LandSAR to consider as they develop their contribution to the Safer Walking Framework.

### What is the purpose of WanderSearch tracking and who is it for?

An important question to consider in evaluating a tracking device is the purpose of the device. The results from this evaluation demonstrate that while the primary purpose was understood to be about finding the person should they go missing, the more immediate felt value was the reassurance it provided to the caregiver. As Siriam et al. (2019) noted, it is difficult to measure such emotional/psychological responses, however such reassurance has the potential to positively impact the life of both the person cared for and their carer in numerous ways. From that perspective it would be naïve to discount the value of WanderSearch for those people who did not wander after receiving a pendant or watch.

Like all tracking equipment, initiating and maintaining WanderSearch does have implications for the autonomy of the person wearing a pendant or watch. As highlighted in the literature review, it is not simple to measure the significant risk of someone going missing against their choice to wander (Bantry White & Montgomery, 2014; Brisebois, 2019; Solomon & Lawlor, 2018; Wherton et al., 2019). Similarly to Bantry White & Montgomery's findings, the carers in the current evaluation also believed that the decision to use WanderSearch was primarily their decision and justified on the basis of the reassurance it provided to them that if their family member did go missing they could be found. Balancing the benefit of such reassurance with the actual risk of the person going missing and the person's willingness to wear a pendant, brings the provision of tracking equipment into an ethical and legal space. Going forward there would be a case for clarifying the legal position for decision-making around the use of WanderSearch. Under the New Zealand Health and Disability Code, Right Seven identifies the right to make an informed choice and give informed consent to treatment and care (<https://www.hdc.org.nz/your-rights/the-code-and-your-rights/>). While there is an understanding that parents of young children will make decisions in the child's best interest and that carers of adults might hold an Enduring Power of Attorney that has been activated to legally provide for them making decisions they understand to be what the person would

want, it was evident that decisions to use WanderSearch were not consistently based on application of Right Seven. In consideration of the arguments regarding autonomy and risk assessment in the international literature about tracking devices, it would be timely to address the legal position for organisations that are providing the WanderSearch equipment.

### **How did people find out about WanderSearch?**

As previously mentioned, people were very happy with the service once they had made contact. There were gaps in how people came to know about WanderSearch that might be improved. Essentially, the gaps could be traced to organisations that could be expected to know about WanderSearch and therefore to refer people, but that did not. District Health Board (DHB) services differed, even within a single DHB. For those people who searched for a device that could assist them, their success depended on the search words they used. Organisations that appeared to be most reliable for referring people were the Police and Dementia Canterbury.

### **Were people using other means to keep people safe?**

The national meetings for co-ordinators of WanderSearch provided them with a better understanding of the Safer Walking Framework. This Framework is inclusive of assessment and implementation of other strategies that people might use to keep their family member from becoming lost when they are out walking. In the interviews with family carers, there was a clear difference between the number of alternative strategies being used with children to those being used with older adults. When a young child with a neurodevelopmental disability left the care of their family or school, it was seen as needing an immediate response. In contrast the approach of many of the carers who had a spouse that wandered was, at least in the early stages, more relaxed with a request for assistance to find them often predetermined by what the person knew about their behaviour. These differences were evident in the choice and implementation of strategies that might confine the person to a specified area. If not already available, the development of an assessment pathway suited to each group might further guide co-ordinators when assessing people with ways to enable safe walking. Support for such a socio-material approach was highlighted in the literature review (Wherton et al., 2019).

In terms of the Safer Walking Framework, it is notable that no tracking device would prevent the person coming to harm on roads or in water, both of which are identified as contributing to deaths in the international literature (Kikuchi et al., 2019; MacAndrew et al., 2018; McIlwain & Fournier, 2012). The ability (or lack of) to safely negotiate roads was mentioned by a number of carers, while some were also concerned about nearby waterways. At best

tracking equipment provides a prevention strategy for these incidents if the person is able to be located before they come to harm. This does highlight an issue for assessment of people with dementia when the carer is hesitant to initiate a search. It is likely that cognitive decline will affect judgement and the tolerance for how long the person is wandering might change over time. To assist the co-ordinators in their role of supporting people using WanderSearch, it would be helpful to have more consistency in reporting to them when searches have been conducted. While the Canterbury co-ordinator received a weekly report, Nelson, as the other region where the co-ordinator did not have a direct link to LandSAR, did not have a reporting system. Being notified of a search would provide the co-ordinator with the opportunity to check if additional strategies might assist the person to keep safe.

GPS technology had a vital role in preventing the need to initiate a formal search for two people, which suggests this might be a suitable technology to recommend in some situations. However, there were a number of situations where it was clearly not appropriate and overall the radio frequency pendants or watches were preferred. International literature does suggest that GPS systems have more challenges for those using the technology (Procter et al., 2018; Wan et al., 2016), however, as the two users in the evaluation demonstrated, confidence with the technology made it a valuable alternative for them.

## Recommendations

Drawing on the preceding section and findings reported in the results the following recommendations are offered for consideration.

8. Written guidelines for consent to use WanderSearch to ensure legal standards are applied, consistent with current legislation and the United Nations Convention on the Rights of Persons with Disabilities, and the Health and Disability Code of Rights.
9. Working with the health and disability sector to ensure that the benefits of and referral process to WanderSearch are visible on their website and known about in relevant services.
10. The addition of a GPS system being available as an alternative or in combination with a pendant for those people who would benefit from the additional features that GPS can offer.
11. Continuous product improvement, especially with regard to encouraging people to wear the devices.
12. Ongoing development of assessment processes to fully realise the goals of the Safer Walking Framework.

13. Development of availability of pendants and alternatives at a national level to promote equity.
14. Recruitment strategies that will continue to meet the ongoing need for volunteer involvement in both co-ordination and maintenance of the programmes in regions.

## References

- Bantry White, E., Montgomery, P. & McShane, R. (2010). Electronic tracking for people with dementia who get lost outside the home: a study of the experience of familial carers. *British Journal of Occupational Therapy*, 73 (4), 152-159.
- Borsje, P., Wetzels, R., Lucassen, P., Pot, A., & Koopmans, R. (2015). The course of neuropsychiatric symptoms in community-dwelling patients with dementia: A systematic review. *International Psychogeriatrics*, 27(3), 385-405. doi:10.1017/S1041610214002282
- Bradshaw, C., Atkinson, S., & Doody, O. (2017). Employing a qualitative description approach in health care research. *Global Qualitative Nursing Research*. <http://dx.doi.org.ezproxy.otago.ac.nz/10.1177/2333393617742282>
- Brisebois, J. (2019). Discrimination legitimized by tragedy: the use of GPS tracking devices for individuals with autism – a protective safety measure or unlawful invasion of privacy? *Journal of High Technology and Law*, 19(2), 509-533.
- Holthe, T., Halvorsrud, L., Karterud, D., Hoel, K-A., & Lund, A. (2018). Usability and acceptability of technology for community-dwelling older adults with mild cognitive impairment and dementia: a systematic literature review. *Clinical Interventions in Aging*, 13, 863-866.
- Kiely B, Migdal TR, Vettam S, Adesman A (2016). Prevalence and Correlates of Elopement in a Nationally Representative Sample of Children with Developmental Disabilities in the United States. *PLoS ONE* 11(2): e0148337. doi:10.1371/journal.pone.0148337
- Landau, R., Auslander, G., Werner, S., Shoval, N., & Heink, J. (2010). Families' and professional caregivers' views of using advanced technology to track people with dementia. *Qualitative Health Research*, 20(3), 409-419. doi: 10.1177/1049732309359171
- Landau, R., Auslander, G., Werner, S., Shoval, N., & Heink, J. (2011). Who should make the decision on the use of GPS for people with dementia? *Aging and Mental Health*, 15 (1), 78-84. doi: 10.1080/13607861003713166
- Landau, R., Werner, s., Auslander, G., Shoval, N., & Heinek, J. (2009). Attitudes of family and professional care-givers towards the use of GPS for tracking patients with dementia: an exploratory study. *British Journal of Social Work*, 39 (4). 670-692. doi: 10.1093/bjsw/bcp037
- Lin, Q., Zhyang, D., Chen, L., Ni, H., & Zhou, X. (2014). Managing elders' wandering behaviour using sensors-based solutions: A survey. *International Journal of Gerontology*, 8, 49-55. <http://dx.doi.org/10.1016/j.ijge.2013.08.007>
- MacAndrew, M., Schintker, L., Shepherd, N., & Beattie, E. (2018). People with dementia getting lost in Australia: Dementia-related missing person reports in the media. *Australasian Journal of Aging*, 37(3), E97-E103. doi: 10.1111/ajag.125
- McIlwain, L., & Fournier, W. (2012). Lethal outcomes in *Autism Spectrum Disorders (ASD) wandering/elopement*. USA:National Autism Association.

- New Zealand LandSAR (2013). *Partnership framework – safer walking (wander) SAR*. <https://LandSAR.govt.nz/sar-system-support/wandersafer-walking/>
- Patton, M. (2002). *Qualitative Research & Evaluation Methods* (3rd ed.), Thousand Oaks, Sage.
- Procter, R., Wherton, J., & Greenhalgh, T. (2018). Hidden work and the challenges of scalability and sustainability in ambulatory assisted living. *ACM Transactions on Computer-Human Interaction*, 25 (2). <https://doi.org/10.1145/3185591>
- Rice, C., Zablotsky, B., Avila, R., Colpe, L., Schieve, L., Pringle, B., & Blumberg, S. (2016). Reported wandering behaviour among children with autism spectrum disorder and/or intellectual disability. *The Journal of Pediatrics*, 174, 232-239. <http://dx.doi.org/10.1016/j.jpeds.2016.03.047>
- Shogren, K., Wehmeyer, M., Martinis, J., & Blanck, P. (2019). *Supported Decision-Making: Theory, research and practice to enhance self-determination and quality of life*. Cambridge, UK, Cambridge University Press.
- Siriam, V., Jenkinson, C., & Peters, M. (2019). Informal carers' experience of assistive technology use in dementia care at home: a systematic review. *BMC Geriatrics*, 19 (160). <https://doi.org/10.1186/s12877-019-1169-0>
- Solomon, O & Lawlor, M. (2018) Beyond V40.31: Narrative Phenomenology of Wandering in Autism and Dementia. *Culture Medicine and Psychiatry* (2018). 42, 206–243 <https://doi.org/10.1007/s11013-017-9562-7>
- United Nations (2006). *United Nations Convention on the Rights of Persons with Disabilities*. United Nations. <http://www.un.org/disabilities/convention/conventionfull.shtml>
- Wan, L., Müller, C., Randell, D., & Wulf, V. (2016). Design of a GPS monitoring system for dementia care and its challenges in academia-industry project. *ACM Transactions on Computer-Human Interaction*, 23 (5). <http://dx.doi.org/10.1145/2963095>
- Wherton, J., Greenhalgh, Procter, R., Shaw, S., & Shaw, J. (2019). Wandering as a sociomaterial practice: extending the theorization of GPS tracking in cognitive impairment. *Qualitative Health Research*, 29(3), 328-344. Doi: 10.1177/1049732318798358
- Yang, Y.T., Kels, C. (2017). Ethical considerations in electronic monitoring of cognitively impaired. *Journal of the American Board of Family Medicine*, 30(2), 258-263. Doi: 10.3122/jabfm.2017.02.160219

# Appendices

## Appendix A

### WanderSearch

#### Interview Questions – Co-ordinators

Thank you for agreeing to talk with me about WanderSearch and the Safer Walking Initiative.

1. Can you please tell me about your current position and how you are involved with the Safer Walking initiative and WanderSearch?
2. Tell me about the training and preparation you have had for working in this position.

We will now focus on the WanderSearch programme and your understanding of how it works in your area and nationally.

3. This programme has been adopted in various regions, tell me what you know about the nationwide programme, including your contact with other regions, LandSAR and the police etc.
4. Tell me about how it fits within your region, for example, who funds it, which organisations are involved, how you work with these organisations.

WanderSearch relies on people being available to assist with the search.

5. What do you know about the search process and the people involved, for example, their backgrounds, training they receive in searching for this vulnerable group of people?
6. How do you communicate with them?
7. Are you able to share any data on the effectiveness of the device for people in your area? For example, the number of people who have been searched for, outcomes, time from notification to finding the person.

I would like to focus now on the people that are using the tracking device.

8. How many people are using the device in your area?
9. What are the range of conditions that people have who use the device?
10. What do you know about how they found out about and were attracted to using this device?
11. How do you assess the person and their family for suitability to use the device? What do you discuss with them?

Finally, some question on your perceptions about the device and the Safer Walking Framework.

12. What do you see as the opportunities and barriers to these initiatives?

13. Do you have any concerns about the use of such devices? (such as ethical, professional)

14. Any similar programs or tracking devices that you are aware of?

15. Is there anything else that you would like to add? Talk about?

## Appendix B

### WanderSearch

#### Interview Questions – Families

Thank you for agreeing to talk with me about the WanderSearch device that your family member wears.

Please tell me about your relationship to the person who wears the WanderSearch device.

1. What led to your family member wearing the device? (make sure they include nature of cognitive impairment as well as any incidents)
2. What do you see as the purpose of your family member wandering? (prompts might be, is it aimless, escaping a situation, visiting meaningful places etc.)
3. Have other strategies been used to keep them from getting lost or coming to harm? (prompts might be, locks, alarms, behaviour modification)
4. What do you see as the benefits and harms of using a WanderSearch device for the person, their family or carers? (prompts could include ethical issues of consent, privacy, complacency on the part of carers, reassurance)
5. What type of device do you use and how has your family member responded to wearing the device? Do they know they are wearing a WanderSearch device? Do they understand why they are wearing it? (check for tolerance of the device)
6. Has your family member gone missing since wearing the device? Tell me about that/ those events. How and where were they found? Who found them (as in organisation/ personnel)? How long after it was first noticed that they were missing did it take to find them?
7. If the interviewee chose this device, why did you choose it and what other devices did you consider? Tell me what you know about how the device works.
8. If the interviewee did not make the decision about the person wearing the device: What do you think about a WanderSearch device being worn by your family member? Who made the decision? Who do you think should be involved in decision-making about WanderSearch devices?
9. Is there anything else that you would like to share about the WanderSearch device and its suitability for your family member?

## Appendix C

### WanderSearch Evaluation Information Sheet

The Donald Beasley Institute (DBI) has been contracted to evaluate the WanderSearch (WanderTrack) system. The DBI is a national, independent, non-profit research organisation based in Dunedin. We are committed to ethical, inclusive and transformative research and projects that promote the rights of disabled people. For further information about the work of the DBI see: [www.donaldbeasley.org.nz](http://www.donaldbeasley.org.nz)

Investigators:



Dr Brigit Mirfin-Veitch



Dr Jenny Conder

#### Introduction

You are invited to take part in an evaluation of WanderSearch. It is your choice whether or not you take part. If you don't want to take part you, you don't have to give a reason and it won't affect you in any way. If you do want to take part now and change your mind later, you can pull out at any time.

This information sheet is to help you to decide whether or not to take part. There are 3 pages including the consent form.

#### Purpose of the evaluation

The evaluation of WanderSearch is to find out how people are using it, whether it meets their needs or the needs of the services supporting it, ideas that might improve the technology or the service provided.

#### What will your participation involve?

One of the investigators will interview you. The interview should take approximately 40 minutes. You will be able to choose how and where the interview takes place. We can interview you in person, on the telephone or through zoom. The questions we ask you will relate to your use of WanderSearch and what lead you to using this system.

### **What are the benefits or risks to taking part in the evaluation?**

It is likely that benefits of this evaluation will include improvement of the service overall. You might not directly benefit. There is no obvious risk to you taking part in this evaluation.

### **What are your rights?**

The information that you provide will be included in a final report. You will not be identified in the report and your information will be combined with all information collected. That means that others will not know you participated or what you told us.

The Donald Beasley Institute has processes that ensure confidentiality of personal information. We will store your information on password protected computers and delete the information as soon as the evaluation is complete.

### **Who do you contact if you want further information or have concerns?**

If you have any questions, concerns or complaints about the evaluation at any stage you can contact:

Dr Brigit Mirfin-Veitch (Director)

Telephone number: 03 479 2162

Email: [bmirfin-veitch@donaldbeasley.org.nz](mailto:bmirfin-veitch@donaldbeasley.org.nz)

## WanderSearch Evaluation Consent Form

*Please tick to indicate you consent to the following*

	YES	NO
I have read, or have had read to me in my first language, and I understand the Participant Information Sheet.		
I have been given sufficient time to consider whether or not to participate in this evaluation.		
I have had the opportunity to use whanau/ family support or a friend to help me ask questions and understand the evaluation		
I am satisfied with the answers I have been given regarding the evaluation and I have a copy of this consent form and information sheet.		
I understand that taking part in this evaluation is voluntary (my choice) and that I may withdraw from the study at any time.		
I consent to the investigators collecting and processing my information.		
If I decide to withdraw from the evaluation, I agree that the information collected up to the point when I withdraw may continue to be processed.		
I understand that my participation in this evaluation is confidential and that no material, which could identify me personally, will be used in any reports on this study.		
I know who to contact if I have any questions about the evaluation in general.		
I wish to receive a summary of the results from the evaluation.		

Print name: .....

Signature: .....

Date: .....

