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Extended safety and support systems for people with dementia living at home

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Abstract

Purpose – The purpose of this paper is to highlight the complexity surrounding the implementation of advanced electronic tracking, communication and emergency response technologies, namely, an extended safety and support (ESS) system for people with dementia (pwd) living at home. Results are presented from a Swedish demonstration study (2011-2012) conducted in 24 municipalities.

Design/methodology/approach – It is a descriptive intervention study with a pre-post test design. Questionnaires were administered to pwd, carers and professionals at the outset and eight months later. ESS logging data were analyzed.

Findings – ESS usage rates varied widely. A total of 650 alerts were triggered, mainly when the pwd was outdoors. Activities were reduced amongst pwd, most likely due to a progression of their disease. Carers noted that pwd were more independent than previously on those occasions when they engaged in outdoor activities. Staff considered that nearly half of pwd could remain living at home due to the ESS, compared with a third amongst carers. In total, 50 per cent of carers felt it was justified to equip their relative with an ESS without their explicit consent, compared to one in eight staff.

Research limitations/implications – A limitation is the amount of missing data and high drop-out rates. Researchers should recruit pwd earlier in their illness trajectory. A mixed-methods approach to data collection is advisable.

Practical implications – Carers played a crucial role in the adoption of ESS. Staff training/supervision about assistive devices and services is recommended.

Social implications – Overall, use of ESS for pwd living at home was not an ethical problem.

Originality/value – The study included key stakeholder groups and a detailed ethical analysis was conducted.

Keywords Informal carers, Advanced electronic tracking, Communication and emergency response technologies, Demonstration study, Home care, People with dementia

Paper type Research paper

Background

In Sweden the vast majority of older people live in their own homes with help from family members and/or friends, neighbours and relatives. Despite a history of a generous welfare state, there has been a clear trend since the 1980s of a reduction in the number of nursing home beds and an emphasis on community care policies, in particular ways to enable older people to age “in place” (Johansson *et al.*, 2011). In this regard, dementia care is no exception such that people with mild to moderate dementia illness often remain living in their own homes with help from their spousal carer or from their adult children (National Board of Health and Welfare Sweden (NBHWS), 2010). Mild dementia indicates an early stage of the illness during which the person is able to manage their daily life without much help from others. Moderate dementia indicates a stage when the illness has progressed so that the person requires regular help and support from others to manage their daily life (Ragneskog, 2013). Home help and home care services in the municipalities are primarily targeted towards those older people living alone at

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home whose relatives do not live close by (Johansson *et al.*, 2011). Long-term care in designated nursing homes for people with dementia (pwd) is allocated by Needs Assessors primarily for people with more advanced dementia whose relatives do not live close by or, alternatively, as a result of spousal carer burden/ill health (NBHWS, 2010). Advanced dementia indicates the final stages of illness when the person requires help with all or nearly all personal activities of daily living (such as eating, drinking, toileting and hygiene needs) (Ragneskog, 2013). Currently, in Sweden there are approximately 150,000 people with a diagnosis of dementia and approximately 24,000 people are diagnosed yearly with dementia, the most common of which is Alzheimer's disease (Sköldunger *et al.*, 2012).

As in many other EU member states, municipalities are constantly seeking ways to control care costs whilst striving to maintain the quality of care. In Sweden, care costs for pwd account for more than 40 per cent of the total care costs for older people (NBHWS, 2010). The majority of these costs include services such as respite care at home, institutional respite care and nursing home. Likewise, similar to policy makers in other countries, the Swedish government are interested in the role that technology can play in the sustainability of long-term care.

To this end, the government commissioned the Swedish Institute of Assistive Technology (SIAT) to co-ordinate a major programme called, "Technology for Older People (2007-2012)" with a total budget of over 14.5 million euros. The overall aim was to stimulate and support the development of products, housing and services that can help to make everyday life easier for older citizens and their relatives. "Better support for carers" was a prioritised area within the second phase of projects alongside, "Development of care for older people with help from welfare technologies". Several funded projects were carried out which focused on the use of "smart home" technologies to enable pwd to live more independent lives in their own home (Swedish Institute of Assistive Technology, 2013). Three major test-bed sites for assistive technologies were funded in three municipalities across Sweden (Västerås, Norrköping and Göteborg) to assist in the implementation of new products and services on a larger scale. These included e-home help services and functional living environments (Dahlberg, 2013b). New products and services were also designed with the aim of making everyday life easier for pwd and their carers, such as a user friendly mobile "phone and a pre-programmed medical dispenser that sends a signal to remind the person to take their medication and, where appropriate, a programmed alarm system to inform a carer if the person does not take their medication even when reminded (Swedish Institute of Assistive Technology (SIAT), 2012). An integrated information and communication technology (ICT)-based support service (the ACTION service, see, Magnusson *et al.*, 2005) was implemented and evaluated by older people with advanced chronic illnesses and their carers living in 13 rural municipalities in the north of Sweden (Bergström *et al.*, 2010; SIAT, 2012). A "check list" was researched and developed together with an educational intervention to help health and social care professionals in their discussions with pwd and their carers regarding the availability and choice of assistive products and services (Rosenberg and Nygård, 2010). It is within the second stream of funding from the SIAT that the project described in this paper received its major funding together with additional support from the Alzheimer's Association.

Cellular communicator with emergency response, Global Positioning System (GPS) tracking and geofencing – extended safety and support (ESS) system

A study was conducted to explore the effects of the use of an ESS system on the everyday lives of older pwd living at home and their family carers. The study was carried out by researchers at the University of Borås, together with the company, "Posifon AB, Göteborg, Sweden" who developed the internet application of an Israelian technology (GeoSkeeper™, Aerotel Medical Systems Ltd, Holon, Israel, www.aerotel.com/images/products/prod_pdf/LifeCare/lifecare_geoskeepe.pdf).

See Figure 1 and Table I. The ESS system consists of the following components:

1. Built-in cellular speakerphone: via an embedded quad-band GSM (global system for mobile communication)/GPRS (general packet radio service) module and built-in cellular speakerphone, GeoSkeeper™ enables voice calls to be made to numbers stored in speed

Figure 1 The built-in cellular speakerphone and mobile alarm device



Table I Technical specifications of the ESS

Dimensions	65 × 46 × 17 mm 2.6" × 1.8" × 0.7"
Weight (battery included)	75 g 2.6 oz
Operating temperature	-10° ÷ 55°C 14° ÷ 130°F
Battery	3.7 VDC/660 mAh Po-Li (rechargeable)
Standby time (typical)	Up to 90 hours
Talk time (typical)	1.5 hours
Tracking time (typical)	> 24 hours (@10 min interval)
Safety call button	1
Speed dialing buttons	3 (user programmable)
Speaker and microphone	Internal
Automatic call answering	Included (programmable)
Wireless module	Telit GE863-GPS
Network	Dual-band GSM/GPRS (900/1,800) (850/1,900 coming soon)
GPS chipset	SiRF III
GPS antenna	Active built-in
GSM antenna	Integrated

dialling buttons (e.g. a relative, practitioner, alarm centre) or to be received from any caller or from the remote monitoring centre.

2. GPS location and tracking: via its geofencing feature, GeoSkeeper™ enables accurate location of users in need. In the event that the wearer wanders outside a specified zone (e.g. local neighbourhood or community), the system can alert the monitoring centre and/or a relative/family carer or care practitioner.
3. Fully Programmable GeoSkeeper™: is fully programmable over the air. Users, relatives/family carer or care practitioners can programme various features, such as speed dialling numbers, automatic answering, various alerts (e.g. when battery is low), geofencing area via a user-friendly web-based interface.
4. The alarm handling and other functions relating to its use are managed by the family carer or practitioner depending on which is most appropriate in a given situation. Training as well as continuing user support are provided by Posifon AB.
5. The search function is activated in three ways:
 - The user presses the button on their mobile alarm.
 - The user passes the agreed security zone.

- The carer initiates the search function via accessing the internet programme on their personal computer or laptop. This starts the search function which in turn activates the user's GPS so that the carer can find her/him on the electronic map.

Previous studies of GPSs within dementia care

The last five years has seen a growing interest within the empirical literature of GPS or electronic tracking devices for pwd. The vast majority of these studies consist of pilot studies involving small samples of participants and are often qualitative designs (see e.g. White and Montgomery, 2014; Olsson *et al.*, 2012, 2013; Pot *et al.*, 2012; Robinson *et al.*, 2009). Results thus far highlight the potential for GPSs to have a positive impact with regards to enabling an enhanced sense of independence and a greater sense of freedom for pwd and their relatives. A number of study participants were able to go out more often on their own which gave them more freedom and in turn led to less conflicts with their relatives about going out alone (Pot *et al.*, 2012; Olsson *et al.*, 2012, 2013; White *et al.*, 2010). A common finding across these recent studies is that the system led to a greater sense of security for both the pwd and their relatives. Further, participant family carers of pwd had a tendency to be less anxious and worried following a three-month period of using a GPS (Pot *et al.*, 2012). The same study did not highlight an impact on reducing carers' feelings of role overload. However, a larger scale study involving 76 dyads (pwd and their carers) revealed that greater mobility and time spent outdoors by care recipients using a tracking device led to lower caregiver burden amongst their relatives (Werner *et al.*, 2012).

Recent empirical studies, including a "head to head" discussion in the BMJ, highlighted the ethical dilemma of balancing the needs of the pwd and respecting her/his autonomy, integrity and dignity contra the needs of their family carer to protect and ensure the safety and security of their relative with dementia (White and Montgomery, 2014; Landau *et al.*, 2009; Landau and Werner, 2012; McShane, 2013; Olsson *et al.*, 2012; O'Neill, 2013). Critics argued that the use of electronic tracking systems are used primarily to ensure the well-being of family carers and/or care staff to the detriment of the personhood of pwd (O'Neill, 2013). Several studies further highlighted the importance of involving pwd at an early stage of their dementia illness in the information and decision-making process regarding electronic tracking systems together with their relatives and care professionals (Landau *et al.*, 2011; Landau and Werner, 2012; Olsson *et al.*, 2012). Further, participatory research studies emphasised the feasibility of active involvement of people with early stage dementia, with support from their family carers, within the design process to create devices and services which are more acceptable and responsive to their needs and situation (Hanson *et al.*, 2007; Robinson *et al.*, 2009).

Aim

The demonstration study (2011-2012) presented in this paper focused on the views and experiences of all three major stakeholder groups, namely pwd living at home, their family carers (co-dwelling spouse/partner or adult child/ren living close by or at a distance) and staff (frontline care practitioners and decision makers) involved in the use and implementation of the ESS in 24 municipalities in Sweden. The paper gives a summated account of the views and experiences of all three groups followed by a discussion of methodological considerations regarding research involving pwd. An ethical analysis arising from these key results is presented with reference to concepts of freedom, autonomy and personal integrity amongst pwd, and also their carers, and reference is made to the notion of just distribution of resources at the municipality level. The aim being to highlight the complexity of issues arising from the implementation of advanced electronic tracking, communication and emergency response technologies, such as the ESS system for pwd living at home.

Methods and procedure

The study is a descriptive intervention study with a pre-post test design. A series of questionnaires were designed for each of the main target groups (pwd, family carers and professionals) which were administered immediately prior to the commencement of the study and immediately following the eight-month test period. A first draft of the questionnaires was formulated based on

prior experiences from initial testing of the ESS. The items for each questionnaire were discussed with several pwd, a group of carers and with an officer at the SIAT who had extensive expertise in the area of older people, carers and use of assistive technologies. As pwd and carers commented that the respective questionnaires were too lengthy and complex, the initial versions were shortened and the wording of the items was made easier to understand (see Tables II and III for an overview of the main topics included in the questionnaires for each participant group).

A shortened version of the Geriatric Depression Scale was also administered pre-post test to consenting pwd and their primary family carer (Leshner and Berryhill, 1994). Ethical approval was gained from the regional ethical review board in Gothenburg.

The project commenced with a nine-month recruitment period which initially consisted of informing care managers and practitioners working within care for older people in the participant municipalities about the study. Practitioners (dementia nurse, occupational therapist, family carer advocate, dementia care development worker and Needs Assessor) then acted as contact persons who recruited potential participants to the study. Thus, pwd were selected based on their need for municipal support and assistance. Contact was also made with civil society organisations such as the Alzheimer's Association for assistance with recruitment of potential participants. Potential participants were given verbal and written information about the study and given the opportunity to ask questions and discuss issues relating to their possible involvement. Those pwds and their carers whom formally agreed to take part subsequently signed a written informed consent form. Following completion of the baseline questionnaire outlined above, participants were then given "hands on" training by Posifon staff about how to use the ESS. Posifon's customer contact person was also available for additional supervision and support throughout the study period for all three stakeholder groups as appropriate. The questionnaire data was entered into an Access database for further analysis. During the study period, data were collected continuously via the internet-based alarm portal. Each alarm was individually logged within this portal and the third author examined the data and calculated what type of alarms were triggered and the number of triggers per participant.

Results

Study participants

At the outset, 24 municipalities participated and at the end of the field study questionnaires were completed by a total of 30 staff members within 16 participant municipalities. In all, 56 per cent of these staff were decision makers and the remaining staff were practitioners (occupational therapists, dementia care nurses and assistant nurses). Initially, 76 pwd and their carers agreed to participate. In total, 63 pwd and 62 carers completed the initial questionnaire and 20 pwd and 36 carers completed the final questionnaire. The main reasons for non-completion of the questionnaires amongst pwd and carers were as follows: lack of use of the ESS as no one was available to help manage the alarm, progression of the dementia illness and increased needs for help with ADLs resulting in entry to nursing home and technical failures.

A description of the study sample at the pre-test and post phase is summarised in Table IV.

At the outset of the study, a quarter of participants already had a safety alarm in their home and 79 per cent required some form of support from the municipality. Post study, over half of the participant carers expressed that they needed more support.

Usage of the ESS

The study sample comprised of 36 pwd whose carer had completed both the pre- and post questionnaires and whom used the system for a median length of time of 165 days per user. The maximum usage period was eight months. However, the extent of usage amongst users varied considerably from daily use through to non-use of the system. In total, 80 per cent of users had used the system at least once and half of the users triggered alerts at least eight times.

A total of 650 alerts were triggered. These included alerts triggered by users themselves, those triggered when users moved out of the pre-agreed electronic security zone and searches triggered by carers as illustrated in Figure 2. The system also enabled calls to take place from the

Table II Person with dementia and family carer questionnaires

<i>Person with dementia</i>		<i>Family carer</i>	
<i>Pre-study questionnaire</i>	<i>Post-study questionnaire</i>	<i>Pre-study questionnaire</i>	<i>Post-study questionnaire</i>
Demographic data	Levels of activity	Demographic data and habitation in relation to the pwd	Perceptions of the pwd's levels of activity
Current services received (self, others in same household)	Frequency of outdoor activities and security when outdoors alone or with someone else	Year the carer noted the first symptoms of dementia and when the diagnosis was confirmed	Perceptions of the pwd's outdoor activities alone and together with the FC
Frequency of doing outdoor activities	How ESS has affected them (if at all) with regards to activity levels, independence, feelings of anxiety, security	Extent to which his/her life situation has been affected by the user having a dementia illness	Level of security and anxiety (if any) about the pwd being out alone, going missing
Perceptions of own safety and security when outdoors alone or with someone else	Specify in a list of options in which situations it felt good to have the ESS	Current services received (self, others in same household)	Views about accompanying the pwd on outdoor activities and level of effect (if any) on their own activities
Views, preferences and expectations regarding the ESS	Level of importance of each of the main functions of the ESS	Perceptions of the pwd's levels of activity together with the carer	The extent to which the ESS is used, at what times it is used and the importance of the different functions
Well-being	Level of satisfaction with the way the ESS works and the look and feel of it	Level of security and anxiety (if any) about the pwd being out alone, going missing	Carer's assessment of change in user's care needs during the last year and the effect of the ESS with regards to the need for long-term care
GDS-20 Geriatric Depression Scale	If they will continue to use the ESS	Carer's views about accompanying the user on outdoor activities and level of effect (if any) on their own activities	How the use of ESS has affected the pwd's activity levels, independence, feelings of anxiety
Level of help (if any) with completing the questionnaire	GDS-20 Geriatric Depression Scale	Who will help the user to manage the ESS and who will manage the different functions	How the pwd's use of the ESS when doing outdoor activities has influenced their own feelings of security and life situation
	Level of help (if any) with completing the questionnaire	Expectations about the extent to which the ESS will be used and the importance of the different functions	Give their views as to whether the ESS infringes on the user's integrity and if it is appropriate to equip the user with the ESS without his/her permission and to ascertain the whereabouts of the user's positions without his/her knowledge
		Projected change in user's care needs in the forthcoming year	The carer is asked to state to what extent (if any) they consider that different some from the home help and some from the ESS infringe on the integrity of the pwd
		Extent to which the user having the ESS will affect their own feelings of security and life situation	Satisfied with the way the ESS works and the "look and feel" of it if they will continue to use the ESS
		Well-being	Well-being
		GDS-20 Geriatric Depression Scale	GDS-20 Geriatric Depression Scale

Table III Staff questionnaires

<i>Pre-study questionnaire</i>	<i>Post-study questionnaire</i>
Respondent's position in the municipality and responsibilities in the study	Respondent's position in the municipality and responsibilities in the study
Expected benefits of using the ESS: for users, carers and the municipality	Experienced benefits of using the ESS for users, carers and the municipality
Perceived risks with using the ESS	Experienced risks with using the ESS
Perceived cost savings for the municipality associated with using the ESS	Perceived cost savings for the municipality associated with using the ESS
Municipality's use of other "traditional" alarm systems and experiences of using GPS alarms	Problems experienced in relation to the use of the ESS
Municipality's responsibility for acting on incoming alerts from a security alarm system in the home and organisation of the alarm function	Their views as to whether the ESS infringes on the user's integrity and if it is appropriate to equip the user with the ESS without his/her permission and to ascertain the whereabouts of the user's positions without his/her knowledge
	When does s/he think that the municipality will act to disseminate mobile security alarms within care for older people?
	To what extent s/he thinks that the municipality will finance/give allowances for ESS
	What unclear points does s/he consider exist in the supply of ESSs within care for older people regarding technical/functional status, organisational aspects, economic considerations, in relation to needs assessment and other unclear aspects

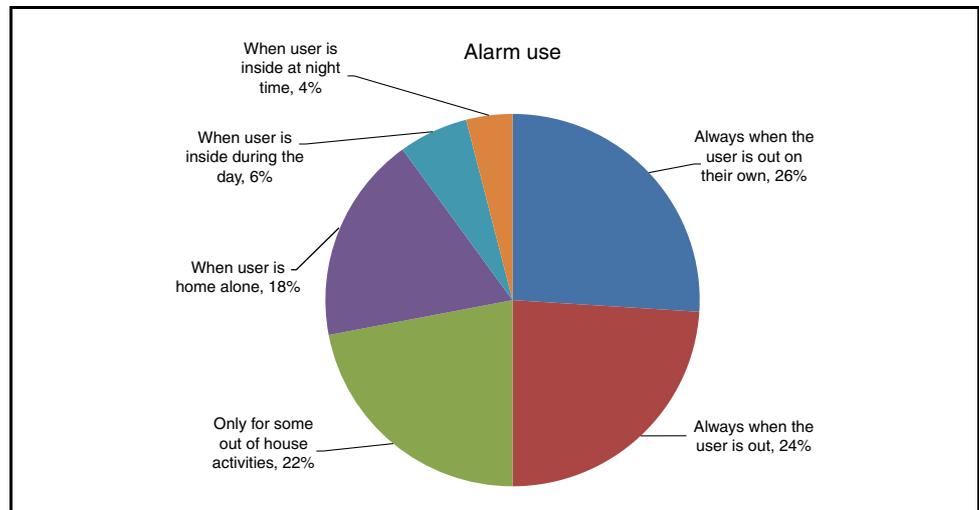
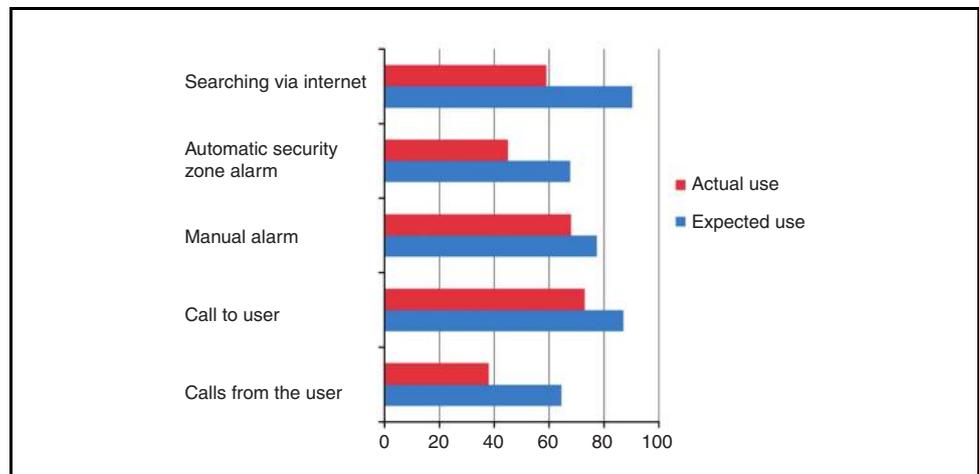
Table IV Characteristics of the sample, pre- and post-test

<i>Pre-test</i>	<i>Persons with dementia</i>		<i>Family carers</i>	
	<i>Pre-test</i>	<i>Post-test</i>	<i>Pre-test</i>	<i>Post-test</i>
<i>Gender</i>			<i>Gender</i>	
Female: 27	Female: 9		Female: 39	Female: 25
Male: 36	Male: 11		Male: 23	Male: 11
<i>Age</i>			<i>Age</i>	
Mean: 74.7 years	Mean: 75.7 years		Mean: 62.2 years	Mean: 64 years
Range: 49-99 years	Range: 60-99 years		Range: 32-80 years	Range: 32-80 years
<i>Living arrangements</i>			<i>Relationship to pwd</i>	
38% lived alone	29% lived alone		64% spousal carers	70% spousal carers
3% sheltered accommodation			27% adult children	22% adult children
<i>Level of education</i>			3% daughter/son in-law	4% daughter/son in-law
35% had a minimum of sixth form education	41% had a minimum of sixth form education		2% other relatives	4% other relatives
<i>Sign of depression^b</i>			4% other	
Female: 15%	Female: 8%		<i>Level of education</i>	
Male: 46%	Male: 33%		60% had a minimum of sixth form education	59% had a minimum of sixth form education
<i>Time from when first sign of dementia was observed^a</i>			<i>Retirement</i>	
Average: 5.3 years	Average: 5.3 years		50% were retired	56% were retired
Range: 1-17 years	Range: 1-17 years		<i>Pwd's dementia had a significant impact on their lives</i>	
<i>Dementia diagnosis</i>			70% of carers	70% of carers
Average: 3.2 years	Average: 3.7 years			
Range: 15-0.5 years	Range: 15-0.5 years			

Notes: ^aAccording to their respective carers; ^baccording to the General Depression Scale-20 items

user to the carer and vice versa. The majority of users (89 per cent) had used at least one of the functions during the study period.

The alert function in the ESS was used in three-quarters of the alert cases (72 per cent) in connection with the pwd being outdoors. However, the alarm was used in a quarter of cases (28 per cent) in connection with activities within the home. In nearly a fifth of cases (18 per cent) it was in connection with the pwd being alone at home. Figure 3 highlights expected and actual usage of the different functions of the alarm system by users. Expected usage figures are taken

Figure 2 Range of activities for which the ESS was used**Figure 3** Expected and actual use of the different functions of the ESS during the study period

from the pre-test questionnaire data that included an item regarding participants' expectations of the ESS (see Table II).

There were not any specific reliability problems highlighted with the ESS. Nevertheless, the ESS in keeping with other GPS systems, sent false alarms if it was placed too close to the user's home and the search function did not work indoors. As a result, the provider of the ESS recommended to have a security zone of not less than 200 metres from the user's home.

Outdoor activities, integrity and sense of security amongst pwd

The initial questionnaire data completed by pwd ($n=63$), revealed that a third of users (32 per cent) cycled and more than a half (60 per cent) went on unrestricted walks. The majority of users replied that they did not use any assistive devices at all (see Table V).

Nearly all users (83 per cent) stated they got out of the house at least once a day or more often. A third replied that they were accompanied by someone else when they were outdoors.

Table V Proportions (%) of persons with dementia with ability to move around

	<i>Person with dementia</i>		<i>Family carer</i>	
	<i>Pre-test</i>	<i>Post-test</i>	<i>Pre-test</i>	<i>Post-test</i>
<i>Biking</i>	32	13	25	16
<i>Jogging</i>	8	3	5	5
<i>Walking</i>				
Unlimited length	60	30	61	38
Up to one kilometre	25	37	23	41
Less than 50 metres	6	3	3	11
<i>Walk with help of assistive devices</i>				
Unlimited length		10	8	5
Up to one kilometre	13	10	10	22
Less than 50 metres	6		2	–
<i>Walk with support from another person</i>				
Unlimit length	8	7	5	3
Up to one kilometre	11	17	10	21
Less than 50 metres	2	3		3
Number of subjects	63	20	62	36

Three-quarters (70 per cent) of pwd stated at the study outset that they would not feel that they were being watched over if their relative could see their whereabouts. Less than one in ten (8 per cent) admitted that they would feel so to some extent and approximately a fifth (18 per cent) replied that they did not know. With the help of an ESS, 14 per cent felt that they could be more independent, one-fifth that they could be less anxious (18 per cent) whilst over a third (35 per cent) felt they could feel more secure (see Table VI).

Table VI Frequencies (%) of outdoor activities, sense of security, expectations and experiences of using the ESS according to the study sample (pwd)

	<i>Pre-study</i>	<i>Post-study</i>
<i>How often does s/he get out</i>		
Several times a day	43	20
Once or twice per day	40	30
Several times per week	14	10
Once or twice a week	3	7
Less than once a week		7
Never		27
<i>How often does someone accompany him/her outdoors?</i>		
Several times a day	13	10
Once or twice per day	18	20
Several times per week	21	23
Once or twice a week	8	10
Less than once a week	28	7
Never	8	3
<i>Pwd's degree to which they feel they are being monitored by their relative</i>		
Not at all	70	
To some extent	8	
To a great deal	18	
Do not know	33	47
<i>Pwd's expectations and experiences of using the ESS</i>		
<i>Pwd's level of security when they are out on their own</i>		
None	18	33
More active	2	3
More independent	14	3
Less anxious	18	17
More secure	35	20
Number of subjects	62	20

Two-thirds (66 per cent) of users noted that they were out in the forest or nature several times a month. Of these pwd a third (36 per cent) expressed that they never or seldom had company when they were outdoors. A third of users (33 per cent) replied that they would have liked to go out more often. However, two-thirds (67 per cent) stated that they did not feel secure when they were out on their own. Nearly three-quarters (70 per cent) expressed they wanted company when they were out. Half (50 per cent) of users agreed to some extent that they had got lost and over a third (38 per cent) that they had fallen when they were out alone (see Tables VI and VII).

From the questionnaire data, it was evident that carers were more worried than pwd for what might happen whilst their relatives were outdoors. At the study outset, a fifth (20 per cent) of users expressed some anxiety about falling whilst out and this figure was much higher amongst carers (73 per cent) ($n = 62$). Similarly, whilst more than half (54 per cent) of users stated they were worried that they would get lost and a fifth (19 per cent) that they could be ill whilst they were out, the corresponding figures were considerably higher amongst carers. Namely, all carers worried for the pwd getting lost and two out of three carers (63 per cent) worried that the pwd could become ill (see Table VII).

During the study period, activities were reduced amongst participant pwd. Carers initially stated that a quarter (25 per cent) of their relatives cycled and this figure reduced to approximately a seventh (16 per cent) post study. Similarly those pwd that according to the carers could go as long a walk as they liked reduced from nearly two out of three (61 per cent) at the outset to approximately a third (38 per cent) post study (see Table V). Nevertheless, carers stated that those outdoor activities that were carried out by pwd were carried out more independently than previously. Initially, three out of four (74 per cent) of carers expressed that they accompanied their relative on outdoor activities. Post study, this figure had reduced to approximately every other carer (57 per cent).

Table VII Outdoor activities (%) according to the study sample

	<i>Person with dementia</i>						<i>Family carer</i>					
	<i>Pre-study^a</i>			<i>Post-study^b</i>			<i>Pre-study^c</i>			<i>Post-study^d</i>		
	<i>Disagree</i>	<i>Partly agree</i>	<i>Fully agree</i>	<i>Disagree</i>	<i>Partly agree</i>	<i>Fully agree</i>	<i>Disagree</i>	<i>Partly agree</i>	<i>Fully agree</i>	<i>Disagree</i>	<i>Partly agree</i>	<i>Fully agree</i>
Pwd can go out whenever he/she wants to	3	13	76		10	53	5	16	74		24	65
Pwd would like to go out more often	40	18	15	30	13	10	37	21	29	30	46	8
Pwd prefers not to go out	81	8		53	13	3	69	10	10	62	14	5
Pwd would like to have company when s/he goes out	21	57	13	7	27	37	21	47	26	14	41	38
Pwd would prefer to go out on their own	48	21	10	27	23	7	39	29	26	43	35	
Pwd feels that it is difficult to not be able to go out when s/he wants to	37	10	18	20	10	13	36	18	31	46	24	14
Pwd always needs to be accompanied	62	19	8	40	13	10	58	19	15	30	27	32
Pwd finds it difficult to always ask for company when s/he wants to go out	51	18	6	27	17	7	45	18	21	32	38	5
Pwd would go out more if s/he could	35	14	11	17	17	13	37	23	23	43	24	14
Pwd has fallen when s/he has gone out on their own	49	19	19	40	7	10	50	26	19	62	5	22
Pwd has got lost when s/he was out on their own	38	19	31	30	20	17	24	34	37	22	35	32
Worried that the pwd will fall when they are out on their own	71	17	3	43	7	13	24	28	45	30	27	32
Worried that the pwd will become ill when s/he is out on their own	70	17	2	50	7	7	34	19	44	41	22	22
Worried that the pwd might get lost when out on their own	38	41	13	30	27	10		26	73	8	32	51
Worried that the pwd might become assaulted when out alone	78	10	5	40	13	7	57	21	16	51	16	14

Notes: ^a $n = 63$; ^b $n = 20$; ^c $n = 62$; ^d $n = 36$

Carers' sense of security and their life situation

A third of carers who completed the post test questionnaire ($n = 36$) considered that the ESS helped their relative to remain living at home. The ESS affected carers' perceived life situation and their sense of security. Post study approximately half (49 per cent) of the carers stated that the ESS had increased their sense of security and over half (54 per cent) stated that it had had a positive impact on their everyday life because their relative had the device with them when they were out on their own. Likewise, two-thirds of carers (65 per cent) stated that the system had helped to reduce their anxiety completely or at least partially and more than half (54 per cent) stated that their stress had been reduced fully or at least partially. A third of carers (32 per cent) stated that they had fully or partially got more time for their own activities. Table VIII reveals how use of the ESS affected carers' perceived activities, stress and anxiety.

Users' and carers' views about the usability of the ESS

Over a third of users (37 per cent) ($n = 20$) who completed the post questionnaire stated that they were satisfied with the mobile alarm system. This figure was higher for carers as two-thirds of carers (65 per cent) responded that they were satisfied with how the system functioned and a quarter (24 per cent) were partially satisfied. Carers' expressed a preference for improved battery capacity, less hassle with finding their relative's position and enhanced sound volume. Only a third (38 per cent) of carers were satisfied with the "look and feel" of the system, whilst a third (38 per cent) were partially satisfied and a fifth (22 per cent) were dissatisfied. Both users and carers commented that the mobile alarm was too large. Users emphasised that it was too heavy to wear on their arm and a user noted that it was clumsy on his wrist. Users and carers also explained that the weight of the device together with the fact that the armband was made of rubber made it warm to wear on the arm. A user suggested that it should be made of different material to avoid it being so sweaty on the arm when worn. Carers also reported that their relative perceived the GPS to be too valuable to be used outdoors and feared losing it. Approximately half (51 per cent) of the carers were satisfied and a quarter (24 per cent) were partially satisfied with the internet-based service function. There were several suggestions for it to be made easier to use which focused on being able to access this function via the carer's mobile phone as opposed to their PC or lap-top computer.

Carers' views about the integrity of the pwd

Three-quarters of carers (73 per cent) considered that the ESS did not infringe on the pwd's integrity. Half of the carers (49 per cent) perceived that it was ok to equip the pwd with an ESS without their explicit consent. Likewise, two-thirds of carers (65 per cent) considered it was ok to obtain the whereabouts of the user's position without their knowledge (see Table IX).

User and carer acceptance of the ESS

It was not possible to clearly differentiate from the questionnaire data between users and their carers who used the system daily, regularly as opposed to occasionally or not at all. Reasons for use or non-use appeared to be rather complex and although a key factor was the progression of the user's dementia illness, there were also other relevant aspects. For instance, the personal habits or interests of the user. Users who stated that they enjoyed being outdoors appeared to

Table VIII Perceived effects (%) of the ESS upon carers' activities, stress and anxiety levels

	<i>To what extent has the ESS affected participant carers</i>		
	<i>Yes (%)</i>	<i>To some extent (%)</i>	<i>No (%)</i>
Less stressed	35	19	27
More time for own activities	5	27	49
Less anxious	51	14	19

Note: $n = 36$

Table IX Carers' and practitioners' views (%) of using the ESS in relation to ethical issues

	Agree		Partly agree		Disagree		Do not know	
	Carer	Practitioner	Carer	Practitioner	Carer	Practitioner	Carer	Practitioner
The EES does not infringe on the integrity of the pwd	73	44	19	31	3	6	5	19
It is appropriate to equip the pwd with the EES without their expressed consent	49	13	32	38	11	25	5	25
It is ok to locate the whereabouts of the pwd without their knowledge	65	13	19	50	8	13	5	25

Notes: *n*: carers = 36; practitioners = 30

be more willing to use the ESS. A carer wrote in the "additional comments" section of the questionnaire that her husband who enjoyed walking never wanted to be without his mobile alarm and he always had an extra one in his pocket in the event that the battery wore down on the one he was wearing. Whereas, other participants expressed a lack of interest and/or willingness to try the ESS and stated to the carer or staff member helping them to complete the questionnaire that they could manage their situation by themselves. Further, the pwd's use or non-use of the ESS was also related to the carer's attitudes about the ESS and perceived levels of security. For example, if carers were more sceptical of the benefits of the ESS and if they worried that the pwd should get lost then they did not tend to allow the pwd to go outdoors alone.

Staff's views and experiences

Staff within 14 participant municipalities who replied to the municipality post questionnaire were nearly all in agreement (with the exception of one municipality) that the ESS gave increased security and freedom for pwd and their carers. Staff respondents in the municipality that did not reply favourably had a total of three users and they were all in the more advanced stages of their dementia illness. In two cases, the primary carer lived more than an hour's driving distance away and home help staff were responsible for the alarm. All three users withdrew from the study immediately after the initial start test period. Primary responsibility for the ESS rested with home help staff in only eight cases across the entire participant municipalities. Of these, in only two cases were pwd able to complete the study. This finding is confirmed by staff's initial perceptions that carers were responsible for communication and management of the alarm system in 60-80 per cent of cases depending on the type of alarm. Further, staff considered that home help staff could contribute in approximately 25-30 per cent of situations. In total, 40 per cent of participant municipalities had their own remote monitoring centre for managing security alarms and home help/on-call group managed normal security alarms.

An initial assessment from the 24 participant municipalities concerning projected savings associated with the use of the alarm indicated that staff were of the opinion that 85 per cent of pwd could live at least one more year in their own homes. Post study, staff from 12 municipalities replied that nearly half (42 per cent) of pwd could remain in their own home due to the ESS and for more than half of the users (58 per cent) it meant cost savings for the municipality in terms of avoiding searches for people who had gone missing. Staff recognised that the ESS demanded input from carers yet they considered that increased engagement from home help staff could increase the possibility for pwd to remain living at home. A couple of staff commented that it was important not to under estimate the importance of the pwd's ability to co-operate. A total of seven municipalities replied that they were lobbying to ensure that users and carers could continue to use the ESS after the end of the project. Five municipalities had made a formal political decision to include the ESS as part of its support to pwd and their carers and two municipalities had begun the purchasing process.

Municipal staff (*n* = 30) answered items regarding perceived acceptance of the ESS by pwd and their carers. Staff perceived that only 13 per cent users had a negative attitude towards the system and corresponding figures for carers were nil. Staff considered it was no longer

appropriate to continue with the ESS in a total of seven cases. In only one case was this due to the user's negative attitudes. In the remaining cases the reason was a result of the advanced progression of the users' dementia such that they were no longer able to benefit from using the system. Staff acknowledged that the ESS was usually accepted up to the point where care needs were such that they could no longer be managed solely by the family. Staff reported that there were additional formal services provided to participants during the study period due to the progression of their dementia illness. Namely, respite care services, home help services or entry to nursing home.

In all, nine of the 12 municipality staff admitted that the greatest perceived risk associated with the use of the ESS was that people relied too much on the technology. Only two respondents highlighted fears regarding the users' ability to use the ESS and that users felt they were being watched over. Nearly half of the staff (44 per cent) agreed that the ESS did not infringe on the integrity of the pwd. One in eight staff considered that it was appropriate to equip the pwd with a ESS without their expressed consent and the same number felt it was appropriate to be able to locate the whereabouts of the pwd without their knowledge (see Table IX).

Discussion

Following on from the study results, the discussion initially highlights the central role played by dementia carers regarding the adoption of the ESS system in the study. An ethical analysis arising from the study subsequently forms the main focus of the discussion. The ESS system is analyzed from the perspectives of freedom, autonomy and personal integrity amongst pwd, their carers and a just allocation of resources at the municipality level. Finally, an outline of the major methodological considerations arising from the study is provided with an emphasis on conducting research with pwd.

It can be seen from the results that municipality staff played a much more peripheral role in the management of the ESS compared to the dementia family carers as the main responsibility for the system lay with home help staff in only a minority of cases. Likewise, staff considered that the primary responsibility lay with carers in the majority of cases (60-80 per cent) with staff playing a complementary role in only some cases (25-30 per cent). This highlights the central role played by family carers within this study in the adoption of the ESS amongst pwd living at home and confirms previous findings by the authors of the crucial support role of carers in the use of new technologies to enable frail older relatives to remain living at home (Hanson *et al.*, 2007; Hanson and Magnusson, 2010; Magnusson *et al.*, 2002; Magnusson and Hanson, 2012). However, it also points to the need for appropriate training and education for frontline practitioners and decision makers in the use and implementation of new technologies and products for older and disabled people and their carers (Magnusson and Hanson, 2012; Andersson *et al.*, 2012). The study reveals in keeping with the authors' previous findings that for optimal benefit to be gained from the use of new technologies it is important that they are introduced much earlier within the illness trajectory whilst pwd have sufficient cognitive capacity to make informed choices about the use of various assistive devices and services, including electronic tracking devices such as the ESS, within the context of their everyday lives (Hanson *et al.*, 2007; Hanson and Magnusson, 2010). More widely, at a societal and policy level, the results are indicative of the increasingly central role family carers play in the care and support of older people in Sweden today (Szebehely and Trydegård, 2012).

Thus, it can be argued that the results of this study tend to highlight the carer as the main beneficiary of the use of ESS by their relative with dementia. In turn this begs the question of whether use of ESS can really promote independence amongst pwd? In our ethical analysis of the study's results we have focused on three relevant aspects: impact on the freedom and autonomy of the pwd and carer, impact on the privacy of the pwd and finally impact on a fair distribution of resources within the municipality. An important basis for the analysis has been the notion that ethical aspects need to be weighed against each other, implying that an ethical cost can be accepted if the corresponding ethical benefit is large enough. At the same time, there might be stricter ethical boundaries which we need to keep within and which are less open for negotiation (Bolmsjö *et al.*, 2006; Sandman and Munthe, 2009).

When it comes to freedom and autonomy there are two relevant questions. First, whether the use of the ESS affects participants' ability to make valuable choices, i.e. be more self-determined and self-sufficient (Sandman and Munthe, 2009). Second, to what extent does the use of the ESS take place under informed consent. To be able to make valuable choices, does not only include actually making choices and acting on them – but also having an alternative that is valuable in more aspects than what would have been the case without the ESS. During the study we found that pwd spent less time outside their homes (most likely due to the progression of their dementia). On the other hand, it is emphasised that the alternative of spending time outside on their own is more favourable with the ESS, i.e. it can be done with increased security and with a greater degree of independence. Our interpretation is that the freedom of pwd has thus been increased compared to a situation where ESS is not used. This seems to counter the critique by O'Neill (2013) who argued that tracking devices are mainly used for the good of carers and not to benefit pwd. However, O'Neill discussed wandering behaviour and not more freely chosen outdoor activity by the pwd and it is not clear whether his critique would also affect the use of ESS for pwd in the above situation. This relates to the fact that the study is performed with the informed consent of the pwd. It needs to be observed that this amounts to a general consent, as we lack more specific data on whether there have been instances when the pwd has chosen not to use the ESS. If not used by the pwd, is this due to an autonomous choice not to use it since it is considered to interfere with the privacy of the pwd or can we find other reasons for this? We find carers referring to the ESS being experienced as awkward and warm to wear. We also find carers reporting the pwd finding the ESS too valuable to be used outdoors for fear of losing it. It is important to note that we find strong support for using the ESS against the consent of the pwd amongst carers. However, it is difficult to interpret whether this amounts to actually disrespecting the pwd's autonomy or if it implies an implicit consent. It has been argued that carers tend to prioritise safety of the pwd before autonomy (O'Neill, 2013; McShane, 2013). However, since the ESS appears to enable the pwd to be more free to move about than without the ESS, the carer acting on such an evaluation might end up being even more restrictive of the autonomy of the pwd (by simply not allowing him/her to go out or always accompanying him/her).

When it comes to privacy, at the outset of the study we found that the majority of pwd did not find the ESS to be an intrusion of their privacy. Obviously, participants might consist of a biased selection finding privacy to be of lesser importance to them. However, it is worth observing that 10 per cent of participants decided to take part despite the fact that they found the ESS to intrude to some extent on their privacy. This could be interpreted as if they were willing to some extent to sacrifice their privacy to get the benefits of freedom and security. Family carers reveal an even stronger support for the idea that the ESS is not an intrusion into privacy (cf. O'Neill, 2013; McShane, 2013). Here we need to remind ourselves that the alternative to an ESS is accompanying the pwd, which generally is a greater intrusion into privacy given the amount of information that the carer assimilates compared to the ESS. At the same time, since carers are willing to collect information about the whereabouts of the pwd without their consent, they seem to value the security and safety of the pwd higher than their privacy as has been suggested by other authors (O'Neill, 2013; McShane, 2013).

In the data we find an interesting discrepancy between attitudes towards privacy amongst carers compared to professionals. This could lead to a more restrictive use of the ESS when decided by professionals than what is warranted given pwd's attitudes and those of their carers within the context of this study. However, we need to remind ourselves that professionals according to health and social care regulations are under obligation to respect the privacy of pwd and other user groups (Swedish Code of Statutes, 1982:763, 2001:453). Such a restrictive attitude amongst professionals is warranted to a large extent given the possible dissemination of information via information systems and professional groups within care for older people. Yet, at the same time this needs to be balanced against the possible benefits for pwd and their carers.

From the perspective of a fair use of common resources it could be argued that if the use of ESS for pwd is not associated with severe ethical problems, as this study seems to indicate, and at the same time saves resources that can be used for other care purposes – this could be interpreted as a cost efficient and fair use of resources. A cost analysis was conducted within the

context of this study for the SIAT which revealed cost savings for the municipality in terms of delayed entry to nursing home and reduced call out costs for pwd who had gone missing (Dahlberg, 2013a). At least in a Swedish context, having an ethical platform for health-care priority setting where cost-efficiency plays an important role, a more cost-efficient use of resources without losing important care aspects would be recommended (Proposition, 1996/1997:60). It can be argued that increasingly within many national priority setting guidelines, cost efficiency is considered a central if not exclusive feature from a fairness perspective.

Finally, it is important to remind ourselves that the conclusions in this ethical analysis are related to pwd being able to decide on the use of an ESS system and being able to move about independently outdoors and not to pwd with wandering behaviour (O'Neill, 2013). Likewise, it does not show *per se* that the use of ESS is generally ethically acceptable for pwd with mild or moderate dementia. Rather, what it highlights is that it is not generally an ethical problem and it is important to emphasise that we need to make an ethical evaluation for each individual pwd when deciding whether the use of ESS is warranted. In keeping with the literature in the field of early stage dementia and decision making (see Tyrrell *et al.*, 2006; Whitlatch *et al.*, 2006), we would advocate for a discussion to take place between the pwd, their next of kin together with the dementia care nurse or occupational therapist at an early stage of the confirmed dementia illness whilst the pwd has sufficient cognitive capacity to make informed decisions about the sorts of assistive devices and services that would be acceptable to him and his/her significant others in the context of their everyday lives. This would include the use of systems such as the ESS with the aim of enabling the pwd to stay in their own home for longer. We suggest that such a discussion could be made easier with the use of a structured instrument. To this end, one of the authors (LS) was recently commissioned by the SIAT (2013-2014) to engage in collaborative work on such an instrument. This initiative forms part of a larger government-based initiative focusing on evidence-based practice development work within health and social care for adults with reduced cognitive capacity and support for their carers.

Having given an ethical analysis of the main results arising from the study, the major methodological considerations arising from the study are now raised. A strength of the study is that it endeavoured to include the views and experiences of the main groups of people using the ESS, namely pwd, their family carers and staff (decision makers and practitioners) working in the municipality. This is important when considering the successful implementation of new assistive devices and services within the public care sector, particularly as negative staff attitudes can often impede mainstream take up (Magnusson and Hanson, 2012). The data interestingly highlighted differing views amongst the different stakeholders. First, between the perspectives of pwd and those of their carers from the initial questionnaire data and primarily concerning the perceived risks inherent with the pwd being outdoors unaccompanied. In this case, carers had a much more restrictive view which is confirmed in other dementia studies (Barnford and Bruce, 2000; Livingston *et al.*, 2010) and also more widely in caregiver research concerning frail older people (Izal *et al.*, 2005; Thompson *et al.*, 2010). Likewise, there were differences amongst carers and staff participants regarding the extent to which the ESS enabled pwd to remain living in their own home for longer. Staff stated that nearly half of pwd could remain living at home longer, compared to a third amongst carers. However, differences were more marked concerning integrity issues regarding the use of ESS. In this instance, carers were much less restrictive than staff such that half of the carers felt it was justified to equip their relative with an ESS without their explicit consent compared with one in eight of staff. These diverging views were previously outlined above in the ethical analysis discussion.

A limitation of the study is the amount of missing data and high drop-out rates amongst pwd (over 30 per cent) from the pre-post test study period. This was mainly due to the progression of dementia illness amongst participants which either made it unfeasible for them to continue in the study. Alternatively they were unable to complete the post questionnaire themselves. Most often, it was the co-resident carer who assisted the pwd with the questionnaires, alternatively carers completed the post-carer questionnaire which asked for the carer's perceptions of their relative's views and experiences of the ESS. Even if it was with some assistance, the views of a number of users ($n = 20$) were heard as they provided concrete advice about the usability of the ESS. Their views were also confirmed by their carers which led to subsequent changes in

the design of the ESS following the completion of the project. Nevertheless, as highlighted earlier in the results, the use of questionnaire data with limited numbers of pwd made it unfeasible to clearly differentiate between users and their carers who used the system regularly compared to those who only used it occasionally or not at all. Further studies adopting a longitudinal approach with larger numbers of users and more resources for data collection are required in order to provide an indication of an optimal match between the pwd and the technology in the process of supplying the ESS.

Previous research attempting to involve pwd highlighted the challenges of seeking to hear the voices of pwd themselves (Hubbard *et al.*, 2003). Within qualitative research, it is acknowledged that the use of a structured interview format in the form of a casual conversation by a skilled interviewer is mutually beneficial in terms of the pwd's well-being and for the quality of data obtained by the interviewer (see Clark and Keady, 2002; Hellström *et al.*, 2007; Hubbard *et al.*, 2003). This approach was not feasible in this particular study due to lack of project resources for a trained research assistant to carry out interviews in different municipalities across Sweden. Nevertheless, it is an important consideration in future research studies in this area - especially in light of the authors' (LM, EH) previous successes with the design and initial testing of an ICT-based support system for pwd and their carers. This user-centred service was co-constructed via interviews and user group sessions with people with early stage dementia and their significant others (Hanson *et al.*, 2007) and subsequently pilot tested with the use of separate focus groups for pwd and their carers (Hanson and Magnusson, 2010). A common message within the literature is the need for innovative approaches which enable the views and experiences of pwd to be heard within everyday contexts. For instance, by the use of videofilm (Cooke, 2003), focus groups (Savitch *et al.*, 2006), ethnographic approaches and use of theatre (Alm and Newell, 2008; Newell *et al.*, 2011).

To conclude, our study about the ESS for pwd, their carers and practitioners was conducted within a major programme, "Technology for Older People" (SIAT, 2013). This initiative included several projects concerning "smart home" technologies to enable pwd to live more independent lives in their own homes. This study adds to our current understanding of the critical role played by informal carers in the testing and adoption of new technologies (in this case the ESS system) to enable older pwd to stay in their own home for as long as possible. Further, we would argue that assistive technologies need to undergo a balanced ethical analysis in general, but also in relation to each specific individual user. In relation to the tracking devices that formed the focus of this study, the ethical analysis revealed that there are no general ethical problems in relation to the core ethical concepts of autonomy, privacy or with regards to the use of common resources. Finally, we recognise that our study of the ESS and more broadly the role of assistive technologies, need to be understood within the context of everyday problems and issues that pwd and their families face in their daily lives (Yeandle, 2014).

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