

Supporting safe walking for people with dementia: User participation in the development of new technology

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L. McCabe, A. Innes. Supporting safe walking for people with dementia: User participation in the development of new technology. Gerontechnology 2013;12(1):4-15 doi:10.4017/gt.2013.12.1.006.00. **Background** Assistive technology is increasingly used to support people with dementia. One area attracting debate is the use of GPS systems. This paper presents the views of 12 people with dementia, 3 caregivers and 5 older people about GPS devices to promote safe walking. **Methods** Two focus groups were held, one in Scotland and one in England. Two researchers facilitated each group. Audio recordings were fully transcribed. Data were analysed using a qualitative, thematic approach. **Results** Walking and 'getting out and about' were common activities for participants and they reported that a GPS device would support them to go out independently with more confidence, or as their dementia progressed. Participants offered opinions on the design of the device and how it might be used in practice. GPS devices for people with dementia are considered useful by older people, people with dementia and family caregivers to support independence and increase self-confidence. Potential users of the device appear less concerned with the ethical issues relating to 'tagging' than those writing in academic journals and the media although they are interested in how the device might be used to promote independence rather than just as a safety precaution offering caregivers peace of mind. They also recommended that GPS devices be discreet rather than exacerbate any potential stigma. **Conclusions** Potential users of safe walking devices can see real potential to use the devices to increase independence while family carers see the benefits of reducing risk and addressing safety concerns. The inclusion of a user-engagement element to the device design process provided valuable information about how GPS devices might be used in the real world and specific ideas about different aspects of the device.

Keywords: GPS, dementia, assistive technology, family carers, older people, independence

There are currently over 35 million people with dementia worldwide and this is projected to increase to 115 million by 2050¹. As the number of people with dementia increases there are growing concerns about how to meet the cost of care provision². Assistive technology offers a way to support people with dementia to live independently and there are initial findings that suggest that assistive technology may delay the move to residential or institutional care³. As such finding ways to promote independent living through safe walking devices can potentially support the policy drive outlined in the UK Prime Ministers Challenge on Dementia⁴ where the creation of dementia-friendly communities is promoted enabling people to live well within their communities for longer. Limited effort has been made to ensure user involvement in the design and delivery of assistive technology, particularly by older people^{5,6}. Presenting and including the views of people with dementia is an established practice in social and health science research^{7,8} although this is less developed for assistive technology research.

Assistive technology has been used in many different ways to support people with dementia, for example, door alarms, bed sensors, home monitoring systems⁹⁻¹¹. Topo's⁹ review of studies of technology to meet the needs of people with dementia highlights that technology is most commonly provided in residential care settings and operated by staff. This type of technology might be termed surveillance technology as it often monitors the location and behaviour of people with dementia and as such raises ethical debate about its use¹². Fewer studies discuss technology operated by people with dementia themselves^{13,14}.

The technology described in this paper is to support safe walking for people with dementia. Many people with dementia express a need to walk and be active¹⁵. Although often a normal part of life, walking may be interpreted (pathologised) as 'wandering' when it comes to those with dementia as it is perceived as a high-risk activity. There is some evidence that people who are said to 'wander' are more likely to be admitted to residential

User participation

care¹⁶ and 'wandering' is found to be stressful for carers¹⁷. However, there are many different reasons for behaviour described as 'wandering' and the term does not lead to sufficiently careful attention to these reasons¹⁸. Few studies have investigated what approaches can be used to support people who 'wander'. A systematic review by Robinson et al.¹⁹ found little evidence for the use or efficacy of non-pharmacological interventions to reduce this behaviour. They report that walking, exercise and music may have some positive effect but research evidence is scarce. Wigg²⁰ finds that enabling people, who have been labelled as 'wanderers', to walk can decrease anxiety and increase well-being. Wigg²⁰ suggests that the use of surveillance technology, rather than physical restraints such as locked doors, can be an option for improved quality of life. As noted, wandering can be seen as a risky behaviour and for carers (paid and unpaid) of people with dementia a common concern is about getting lost²¹. For professionals the focus is often on reducing risk and they report litigation concerns should a problem arise²². For carers there is a balancing act between reducing risk and promoting independence and also considering risks to themselves²³. Assessment of risk is a subjective process and depends on the individual's viewpoint. Gilmour et al.²¹ interviewed professionals, family carers and people with dementia and noted differences in the risks identified within different groups, the people with dementia themselves did not report any risks in their lives. This research engages with people with dementia and their carers to gain understanding about risk taking in relation to walking and getting out and about.

People with dementia report that walking is an enjoyable activity that helps keep them fit, relieves tension and increases independence¹⁹. There is also increasing evidence for the benefits of physical activity for people with dementia²⁴⁻²⁶. One barrier to physical activity for people with dementia is features of the outdoor environment and some research has been undertaken looking at ways to improve access to outdoor environments for older people, with good outcomes^{27,28}. Another way to support walking and physical exercise for people with dementia is the use of assistive technology. The most commonly used devices to support safe walking are those that utilise GPS technology to help locate people.

This paper presents findings from the user consultation element of a study with commercial partners around developing a GPS device that aims to give people with dementia more confidence to go out independently and to help carers locate the person with dementia if needed; it is described as a safe walking device.

GPS-based devices have been used to support people with dementia since the mid-1990s. The use of tracking devices has raised ethical questions that often overshadow evidence on the usefulness of the device²⁹. There are concerns that use of these devices is a form of surveillance which may further stigmatize people with dementia^{30,31}; and questions abound around the ability of people with dementia to consent to using a GPS device. McShane, Hope and Wilkinson³² argue that the ethics of using of GPS-tracking systems are no different to those concerning locked or alarmed doors but, they argue, these are rarely scrutinized and debated in the same manner. Research finds that family carers place more importance on quality of life in balance with concerns about surveillance^{22,23,33}. Most agree that GPS technology has its place but must be provided using a comprehensive person-centred assessment^{22,30,34-36}. There are a limited number of published studies piloting GPS devices and often these have been undertaken with just a few participants^{17,37}. The outcomes for people with dementia and their carers have been mixed and how the device is used varies between different individuals and depends on current strategies for care and support. Few people with dementia have been included in these studies due to participant recruitment challenges^{17,37}.

There have been calls for research that engages directly with people with dementia and gathers their views of technology for safe walking^{19,22,37-40}. There are also concerns that companies developing assistive-technology devices should work closely with potential users and their carers to ensure devices meet the actual needs of service users and their carers^{40,41}. This paper presents the views of people with dementia and their carers about safe walking through the use of a GPS device and as such contributes to the growing literature about assistive technology for those with dementia, from the perspective of those concerned with and affected by dementia.

METHODS

The aim of this research was to explore the ideas and opinions of potential users about a GPS device. The research reported here uses an evaluation approach from the formative stage of this process⁴². This research fed into the early stages of the product development process undertaken by the technology partners. The research is also influenced by the user-involvement agenda promoted in policy and research about older people and people with dementia in the UK. The project involved collaboration between researchers and technical companies involved in the development and production of GPS devices; the findings from this research were fed back to technological partners.

User participation

Focus groups

Focus groups were the selected method as they are known to be effective fora for discussion on specific topics and provide good environments for sharing views and opinions⁴³. Focus groups have been used with older people to elicit their views on assistive technology (for example Seale et al.⁶ and Robinson et al.³⁹). This is also a well established research method for involving people with dementia⁴⁴⁻⁴⁶. The project received ethical approval from the authors' University Ethics Committee.

A key aim of the study was to hear the opinions of different groups of potential users of a GPS device. To meet this aim a range of organisations working with people with dementia and those supporting older people from black and minority ethnic communities were approached and asked about their willingness to host a focus group. A support group for younger people with dementia in Scotland and a day centre providing care for older people and people with dementia from African-Caribbean communities in England agreed to host meetings. Therefore, two focus groups with people with dementia, their carers and other older people were held. All of these groups were included as they were considered potential users of a GPS device or supporters of someone using the device and so offered relevant viewpoints for the technical companies.

Prior to the focus groups taking place, gatekeepers at each location were provided with information sheets and asked to distribute these to their members. The information sheets provided a short introduction to the project and set out what would be expected of participants. Both focus groups were held at times when the participants would normally be present at the given locations to avoid any inconvenience for those attending. Consent was obtained from all service users and their family caregivers. Following a verbal discussion about the focus group with each participant, consent forms were then signed by all participants. In Scotland, participants were white British or Scottish from a local area characterised by small towns and villages. In England, participants were of African-Caribbean descent and lived in

city locations (*Table 1*). In group one all people attending the drop-in centre that morning agreed to take part while in group two, 9 out of 23 people attending the day centre on that day agreed to take part in the focus group.

Both focus groups were facilitated by two researchers, one taking a lead in guiding the discussion, with the second taking notes and providing additional support for individuals with hearing or speech impairments when required. All researchers were experienced social researchers with proficiency in working with people with dementia. The discussions in the focus groups were recorded using a digital recorder and fully transcribed and each lasted approximately 90 minutes. The focus groups explored current strategies for safe walking by people with dementia and also focused on ways a GPS device might provide additional support and promote independence. Factors impacting on the usability of a GPS device were also discussed. A topic guide was used to structure the discussion within the focus group (*Table 2*).

All participants in both focus groups were able to contribute to the ongoing discussion although some required more encouragement and support from the researchers. In the second group that involved both people with dementia and other older people the researchers did not note differences between these groups in terms of the amount of participation but some of the people with dementia did require a little more time and encouragement to speak. The researchers addressed questions using individuals' names and clear eye contact to encourage people to speak if they had not given their opinion on a particular topic, before moving on to the next topic. In both focus groups the participants knew all or most of the others taking part and were observed to encourage each other to speak and ask each other's opinions during the discussions. Participants, particularly those in the first focus group, expressed their enjoyment of taking part. Participants were encouraged to contact the researchers or service provider who hosted the meeting if they wanted to provide any additional comments following the focus groups.

Table 1. Focus groups characteristics; All participants were over 60 years of age

Participant characteristic	Focus group	
	1	2
Origin	Central Scotland: rural, villages, small towns	Central England: urban, cities
Descent	White Scottish, British	African-Caribbean
Gender	4 women, 7 men	6 women, 3 men
Number attending	11 (including 3 women carers)	9 (including 4 with probable dementia)
Mental ability	People with dementia, family carers	People with dementia, other older service-users
Physical ability	Unaided walking	Mixed: unaided walking, use of walking stick or walker, wheel chair (1 person)
ID	S1-11	E12-20

User participation

Table 2. Focus group topic guide to be used by discussion leaders

Introduce the research project and the device being developed
What experience do you have with technology (explore different examples of technology)?
Would you suggest any improvements to the technology you have used?
What types of technology would be useful for you to support your independence outwith your home (explore further when/how these would be used)?
What impact could this type of technology have on your day to day life (explore issues of independence, risk and safety)?
What makes technology easy to use (explore specific design features)?
Additional question for people with dementia:
What features would you recommend for a device used to help you stay safe when out walking and away from your home (prompts: size, colour, location to be worn etc.)?
Additional questions for family carers:
What functions would a device need to help you feel comfortable and relaxed about your relative being away from your home independently? (prompts: call centre link, link to your own phone etc.)

Data analysis

A thematic analysis was undertaken to provide in-depth detail on the views of people with dementia and their carers^{43,47}. Themes were developed both before analysis, based on the project aims, and during analysis to pick up new and emerging themes within the data. An initial list of thematic categories was generated from the project aims and the field notes taken by researchers and this guided initial coding of the data. Transcripts were

read and reread by two members of the project team to ensure familiarity with the data and the list of thematic categories adapted to ensure all themes were identified. Open coding was also used to ensure that all issues of importance to focus group participants were identified.

Thematic analysis of the data identified broad coding categories relating to: habits and patterns of walking among people with dementia; current strategies for staying safe; and more specific themes about the design and use of GPS devices. Sub-themes such as risk, independence, safety and quality of life and how these relate to the idea of safe walking were also identified. A second round of analysis, based on the project aims, investigated data relating to use of technology, and GPS devices specifically, which clarified the following themes: pros and cons of GPS devices, uses of GPS devices, ethical use of GPS devices and important features of GPS devices particularly size, style, battery life and usability. The analysis also compared data from the two field sites within each theme to identify similarities and differences between these sites. The coding was undertaken and checked by two members of the project team according to a coding scheme (Table 3). Quotes from the focus groups are presented in the findings to illustrate key themes from the data analysis.

Table 3. Thematic categories in the coding scheme

Current strategies for safe walking
Safe, home zones
Taxi
Phone
Just stop
Find someone you know
Purpose of device
Safe walking
Alert response – panic button or other setting
Independence, quality of life
Safety, avoidance of risk
Something to use on holiday
Reduce carer stress
Reduce user stress
Differences between focus groups
Safety, avoidance of risk
Independence, quality of life
Ethics
Links and similarities with tagging for criminals
Public and media perception
Not such a big deal for potential users
Access to and storage of data
Realistic expectations and best interests
Wearability and design
Colour
Size
Watch, pendant, put in bag
Battery life
Fixed vs. removable
Passive vs. active device
Something that can be concealed
Avoiding stigma
Responding to device
How to trace person – small screen vs. computer vs. text alert
Who responds: Family, carer, police, call centre

RESULTS

All participants reported a clear wish and need for a device that would promote safe walking for people with dementia, reiterating previously reported findings (Table 4)¹⁵.

“it would be a brilliant thing, because you can’t keep us wrapped up in cotton wool, no way we can do that, because we have a life and a life to lead. We would like to lead it” (Person with dementia [S1]).

“I would like something like that, anything that is going to help me go a further distance with confidence within myself” (Person with dementia [S5]).

User participation

Table 4. Key findings of both focus groups on how a GPS device might be used

Theme	Focus group	
	1	2
Usefulness	GPS is useful and desirable	GPS is useful and desirable
Safe without new technology	Staying on familiar ground Relying on local acquaintances	Staying away from areas perceived as unsafe
Quality of Life and independence	Going out and maintaining independence is key to quality of life when people habitually walk long distances alone	Safety and health takes priority over quality of life and independence
Safety and security	Staying safe is important, currently no high risk If dementia symptoms worsen, the need for a device will increase	A call or panic button is helpful in case of falls or getting lost
Ethics and stigma	Usefulness of the device to support independence outweigh ethical concerns (people with dementia and carers)	Discreet device to avoid increased stigma and risk of stealing Ethical debate on 'tagging' not felt as important

Getting out but staying safe

Most participants remained active in their local communities although there was more reluctance to do this from those living in the city location. People with dementia and their carers had strategies in place to ensure safety while away from their homes. These varied, from a 'dementia dog' which guided their owner home, to reliance on living in a small town where most people would recognise you. The most common approach was to stay within an area that was familiar to the person with dementia and perceived to be safe, a 'safe' or 'home' zone.

"Well when I go out I always try to keep to the same area, so if I have a problem, I know where to go, I can go to maybe somebody along the road, a neighbour or that or I can go down to my daughter-in-law's house, but it's kind of a certain area" (Person with dementia [S7]).

"If I'm out of my area I do find it difficult even from here back home" (Person with dementia [S5]).

In the group where participants lived in village and small town locations (focus group one) safety was about staying within places that were familiar, in the city living group (focus group two) participants' safety was more about the types of places they would avoid. Some participants expressed a wish to go out of these safe zones and thought the proposed device might give them that option.

A few people talked about phoning for help if they got lost, either to call a taxi or someone else to come and pick them up. There were a number of problems with this. First, the need to access a phone as mobile phones could be forgotten or difficult to use and public phones are much less common. Second, there were concerns about how long the taxi would take to arrive if it was a busy place or time of day.

For participants living in smaller towns and villages their main option was to simply stop when they realised they were lost and wait for someone they knew to come along. This seemed to work quite well for some, especially for one man whose wife was well known in their community. Similar findings were reported by Gilmour et al.²¹ for people with dementia living in small towns where risks of getting lost were reduced by living in a familiar place.

The range of strategies suggests that GPS devices might be used in different ways to enhance current lifestyles of people with dementia.

Quality of life and independence, or safety and security

For potential users and their carers, ideas about the purpose of GPS devices were split between the potential to increase independence and therefore improve quality of life and the ability to increase safety and security for users thereby reducing stress for both carers and those they care for. Similar themes were found by Robinson et al.¹⁹ in a review of related literature where the main benefits were increased confidence and reduction in stress and release of time for carers.

Participants suggested different purposes for a GPS device and a range of different potential outcomes. They thought a device could be used for safe walking, that is to give the person with dementia the confidence to go out with the knowledge that they could call for help or someone would be able to find them should they get lost. Second, it could be used to alert the need for a response, for example, when the user presses a panic button; when they leave their safe zone; or when they have been gone for longer than expected. The first use addresses issues of independence and confidence for the user while the second is more about how the carer could

User participation

use the device to reduce stress and anxiety both for themselves and the person with dementia. Participants thought both uses were appropriate although there were some differences in opinion between the two focus groups.

In focus group one there was interest in a device that would allow participants to go out independently with the knowledge that they could call for help or someone could come and find them if they got lost. Two individuals in this group went for long walks and although currently had no problems finding their way home they could see a time when a safe walking device would be useful. This group also highlighted the potential for the device when on holiday or in unfamiliar places. One couple reported going on a cruise for their last holiday so they would be reassured about not getting lost, however, they did not really enjoy being on the cruise ship and would have preferred a different kind of holiday. Reassurance for potential users and their carers was important and it was felt a GPS device would help with this.

In the second focus group, individuals generally did not go out as much and did not go far from their home. Their concerns were more about safety and security, risk of falls, illness due to diabetes or any other injury or negative event. This group was held close to the centre of a large city where people may not wish to walk around on streets they do not perceive to be safe.

There were also some differences in the physical abilities of focus group participants with the first group consisting mainly of men who were able to walk independently, some of whom appeared very fit. In the second group there were more individuals who were frail and who relied on walking aids and wheel chairs to get around. The differing needs of the groups and individuals suggest the need for a device that can be used flexibly to meet a range of needs.

“Would you like to be able to go a bit further? Is that something you’d like to be able to do?” (Researcher).

“Not really, because I don’t really walk very well. I’ve got a bad back, and I can’t see from this side properly so that’s why I don’t really...but if I had something and if I’m somewhere and I can’t find my medication, suppose I pass out or anything, that would be a good idea to have a button that you press it, you know” (Older service user [E12]).

One question that was raised by participants was who would respond to the device if an alert was raised. Most felt that a family member or other carer would be the best person to respond but

the police would be a good alternative as they are easily recognised.

“Well for my sake it would need to be my wife, my daughter and my next door neighbour...Obviously you need to have a selection because your wife can’t be there twenty-four seven, sitting waiting on you” (Person with dementia [S5]).

“I would go further than that, I think if your wife wasn’t available you would want a second one [person to respond]. I think the second one should be the police” (Person with dementia [S7]).

The issues and ideas raised by participants suggest different ways a GPS device might be used to support people with dementia. GPS devices need to adapt to fit the habits of individuals and the support networks available to them. However, Hughes and Campbell³¹ caution that devices must be used appropriately to offer greater autonomy for people with dementia while avoiding the risk of inappropriate invasion of an individual’s privacy. Staff working with people with dementia may need clear protocols for the use of GPS devices³⁵.

Ethics and stigma

Some individuals thought they would be embarrassed for people to know if they were using a device while others were quite happy to be open about its use. Participants did discuss the similarity of GPS devices to those used to tag criminals but, perhaps surprisingly, they didn’t feel that this was problematic as long as the device was improving quality of life or increasing safety.

“Well it’s like somebody in prison and they have to strap ...and if they go somewhere that they shouldn’t or whatever they can track them down. It’s more like the same idea. Not directly, but indirectly it’s more or less the same idea.” (Older service user [E14])

“Is that a problem do you think?” (Researcher).

“Not really if somebody’s life’s in danger, it can’t be a problem if you do care for the person. Because to care for someone that’s why you make the effort to go to that extreme” (Older service user [E14]).

Carers, in other studies, also prioritised issues of safety over those of privacy^{23,38}. Some participants, particularly in focus group two, expressed concerns about the stigma associated with dementia and felt that a safe walking device might add to this. A visible device could make an individual more vulnerable to stigma and prejudice. This is discussed further below in the section on the design of the device. It is clearly a consideration for service providers to ensure users’ concerns about stigma are addressed and that devices are designed in a way that minimises this.

User participation

Designing a GPS device

The research participants had much to say about what the design features of a GPS device should be. An important issue was that a device should be inconspicuous; a device that was quite obvious might increase vulnerability and stigma.

“Yes. It’s not that, it’s just that you can be labelled, oh, you know, so-n-so’s really suffering from dementia... And people only recognise you as somebody who’s suffering from dementia, not as Mr Jones or Mr Smith or...” (Older Service user [E16]).

Safety was a concern. A visible device might be something that other people might attempt to pull off and steal. Around half of the participants in focus group two were looking for something that could be worn under a shirt or hidden by a long sleeve. Robinson et al.³⁹ also reported that people with dementia request devices that are small and unobtrusive.

Participants also gave their views about charging the battery for a GPS device. One of the key points raised was that clear and correct information should be provided about battery life. The discussion on the length of battery life had two sides. First, a long battery life is desirable. It was not considered practical to charge a device every day. Taking the device off to charge it each evening would mean it could not be used at night time when, for some, it would be very important. Daily charging would also increase the likelihood of a device being forgotten. However, if the battery life was too long then people may forget to charge it regularly.

There seemed to be a general agreement and acceptance that a watch style design would be the best for such a device rather than a pendant or box design.

“I like the idea of a watch aye. Aye. I’m saying a watch but a thing about that size [demonstrates small size with fingers] so you don’t want a box” (Person with dementia [S1]).

However, there were several people in focus group two who already used a pendant call button within their home and felt that something similar would be best for them. Indeed the best solution for them would be to have a pendant that worked inside and out.

“Yes, I would like something, as long as it’s nice as a necklace. What would it be like?” (Person with dementia [E17]).

There were few strong views on what the colour or design of a device might be. One man did

express the view that it should not be pink. One suggested that it could be luminous so as to be easily seen. Most potential users requested that it be small, about the size of a large digital watch. In other studies devices have been found to be too large and uncomfortable to wear or carry^{38,40}.

“Anything bar pink...We don’t want to go about like Lily the Pink” (Person with dementia [S3]).

One person with dementia had the idea to use a design like a compass for a device. It would not need to have a working compass in it but the compass design would remind the user as to the purpose of the device.

For many of the potential users and carers there was real interest in having a panic button as part of a GPS device. Many individuals were used to using a call button or cord within their homes. They felt it would be useful to have something that would then continue to work when they left their home. People with dementia, carers and other services users were clear that a panic button would be useful.

“If you were able to press something or in some way to alert people, you would like that too, so you could actually push something” (Researcher).
“Oh aye, I mean anything that’s going to help me, I’ll have a go at it, it’s as simple as that, if it’s a watch or a thing round your neck, a peace of mind for my wife and my family I’ll have a go at it” (Person with dementia [S9]).

Participants were asked if they would want to wear a device that was fixed or difficult to remove but there was no clear answer to this. Some participants with dementia felt that a device that was difficult to take off would be useful as they often forget things like their watches. If their carer had to help take it off then it would help remind them to put it back on again.

“Say you went to the swimming pool you couldn’t take it off and forget it, because it would be stuck to your wrist” (Researcher).

“I think that’s good, a better rule, a pretty good one, that’s why they make it that way because it suits everybody” (Person with dementia [S5]).

However, having a fixed device might raise further concerns about the ethics of using GPS devices and this topic is returned to in the discussion section below.

There were comments made by potential users about how alerts should be received. This also links to the discussion above on who responds to an alert. Participants felt that something that a

User participation

carer or responder could take about with them would be the most useful way to receive an alert. Carers wanted to be contacted wherever they might be. The use of the internet was ruled out as individuals did not have the relevant skills to use computers in this way, however, alerts to mobile phones might be a feasible option. One person with dementia suggested a small screen like that used for satellite navigation devices in cars that would allow carers to trace the whereabouts of their relative directly. Another suggested something that would enable the carer to communicate with the person using the device, a two-way method of communication.

DISCUSSION

Participants were interested and enthusiastic about the idea of a safe walking device although only one of them had any experience of such a device. They felt it would be beneficial and something they would be interested in using. People with dementia who were coping well at the time of the research could see a potential future need for a GPS device to enable them to continue living as they do now and going out and about on a regular basis. Participants thought there might be different uses for such a device, that it could be used for increasing independence or reducing anxiety and stress for carers and people with dementia. This reflects the different perspectives on risk, as discussed by Gilmour et al.²¹, while the person with dementia sees the need to continue to be independent and perceives the GPS device as a tool to support that, carers perceive risks in walking and getting out that the GPS device can help to address through the ability to find people when lost. Both uses were felt to be appropriate by the research participants.

The literature to date would suggest that safe walking devices are most often used to reduce carer stress and perhaps not utilised fully to give people with dementia more independence^{37,38}. There are a limited number of published studies piloting GPS devices and often these have been undertaken with just a few participants^{17,37}. The outcomes for people with dementia and their carers have been mixed and how the device is used varies between different individuals and depends on current strategies for care and support. In most studies the GPS device was found to offer carers more peace of mind and reduced their stress^{15,37,38}. However, use of the device did not always mean that the person with dementia was given any more freedom; the carer might just use the device as a back-up to other strategies such as locked doors^{15,38}. A study examining surveillance technology had similar findings; technology was used to supplement other measures such as locked doors¹². There is also no evi-

dence that people with dementia are found any quicker than those without a device³⁹ but there is evidence that devices do help in finding the person if lost^{17,37}. This would suggest that currently devices are used to minimise risk rather than promote risk-taking and independence. For many in these focus groups the desire to maintain or increase independence is clear but it would seem that more support is required for carers as well as practitioners to facilitate the use of GPS devices in this more creative and flexible way.

Using GPS devices with people with dementia in a manner that supports safe walking rather than just reducing carer stress starts to address some of the ethical concerns raised in the literature, particularly that the device be used for the benefit of the individual⁴⁸.

Robinson et al.¹⁹ highlight that significant ethical concerns remain in the research literature about the use of electronic tracking for people with dementia. The use of tracking devices has raised ethical questions that often overshadow evidence on the usefulness of the device²⁹. The attraction of the popular media had raised the profile of this debate and is illustrated in the headline from the *Scottish Daily Mail* (15th June 2010): 'Alarm over 'tagging' of pensioners'⁴⁹. There are concerns that use of these devices is a form of surveillance which may further stigmatize people with dementia^{30,31}; and questions about the ability of people with dementia to consent to using a GPS device. McShane et al.³² argue that the ethics of using of GPS tracking systems are no different to those concerning locked or alarmed doors but, they argue, these are rarely scrutinized and debated in the same manner. The Nuffield Institute of Bioethics⁴⁸ suggest a number of factors which should be considered when using assistive technology for people with dementia: (i) The person's own views and concerns, past and present, for example about privacy; (ii) The actual benefit which is likely to be achieved through using the device; (iii) The extent to which the carers' interests may be affected, and (iv) The dangers of loss of human contact.

The assessment of risk for an individual and the way in which that can be addressed through the use of technology is complex and in-depth knowledge of individuals is needed to facilitate decision making in the best interest of the person with dementia²¹. Most agree that GPS technology has its place but must be provided using a comprehensive person centred assessment^{22,30,34-36}.

It was interesting to note that participants in this study were more interested in the potential ben-

User participation

efits of the device over and above any concerns they might have about ethical issues, and this mirrors others findings in the literature^{23,33}. Participants were in favour of a device that could not be easily removed as this would help them to remember to wear it. This seems to contradict concerns in the literature about 'tagging'¹⁹.

The research to date has also looked at the design of GPS devices as done in this study with comparable findings to those in this research. Research demonstrates significant challenges with the devices currently available from the viewpoints of people with dementia, their carers and practitioners. For example, the size of current devices is reported to be too large; devices are too cumbersome, heavy and difficult to wear^{22,38-40,50} and the battery life is too short^{17,22,37,50}. The device may be too complicated for the person with dementia to operate^{17,50}. There are wider concerns that people with dementia may be unable to operate assistive technology devices⁵¹. Nygard and Starkhammar's^{51p153} findings indicate that habitual actions and familiar motor movements were important in the successful use of technology. Problems with using the GPS device are also reported by carers who find that it adds to their workload and they face problems ensuring the person with dementia wears the device^{17,22,37,50}. There are suggestions that devices would be better if they were designed to look like everyday objects such as a watch or brooch to avoid stigmatisation to users^{39,1}. The participants in this study wanted a small, discreet device that was designed like a watch and was light and wearable.

On the basis of the data collected the authors were able to make a series of recommendations to influence the future design and development of GPS devices that genuinely presented the views of potential users of the device and their family carers (Table 5). These recommendations are summarised below:

(i) Good quality assessments are the key to success in using safe walking devices, therefore,

awareness and understanding of the device needs to be increased among staff who undertake needs assessments of older people and people with dementia. Good quality assessment processes should also ensure that the device is used in an ethical manner.

(ii) Innovative approaches are required to ensure the device is used consistently. Ideas for this include attaching the device to something with a vital function such as a set of keys, or sewn into a favourite jacket. Support is usually required from carers to help with wearing and charging the device.

(iii) Products, and the systems supporting them, need to be flexible and responsive to meet the varied needs of people with dementia and their carers.

These recommendations present clear implications for the future design and development of GPS devices suggesting that technology companies need to work more closely with potential end users of devices as well as developing devices that can be used in more flexible ways to adapt to different needs and lifestyles. There is huge potential to develop and use devices that can promote living well with dementia and promote inclusion in communities that work towards the dementia-friendly agenda set out in UK policy.

Study limitations

This study is a small scale user-engagement project to provide information and advice to technical companies developing a new safe walking device for people with dementia. The participants were recruited using a purposive sampling approach and are not representative of the general population of people with dementia. The sample was selected to include people from different geographical settings (rural and urban) and including people from black and minority ethnic communities. As such the findings are not generalizable to the wider population. Future research could build on these findings by conducting focus groups with a more representative sample

Table 5. Recommended characteristics of a GPS device to support going out

Theme	Requirement
Style	Watch preferred; some favoured a necklace/pendant design
Size	Small; the size of a large watch
Colour & design	Having a choice out of a selection of subdued colours Waterproof Looking like a compass to alert the user (one participant)
Weight	Lightweight to increase comfort and wearability
Battery	2-3 days battery life to ensure regular charging while avoiding a daily task
Alerts	To be received as SMS on a mobile phone
Call or panic button	Should be present
Device removal	Divided opinion: a fixed device would not be forgotten, but more ethical concerns, and could be difficult to remove (requiring a key)

User participation

and by allowing participants to engage directly with safe walking devices and to try out the different functions of the devices.

CONCLUSIONS

The findings presented from our consultation with service users and carers above demonstrate the usefulness of including the potential users of technological devices in the development stage of device design. Although a small-scale study, the ideas and opinions offered by the focus group participants provide clear messages about the design and usability of GPS devices. However, participants would have preferred an actual and active device to comment on rather than talking hypothetically about GPS devices and this approach was adopted in a later part of the research. Future research should demonstrate devices to participants and include a range of user groups. The high profile of ethical concerns relating to safe walking or so called 'tagging' devices is not reflected in our data. Participants were clear that any device should be

discrete and not add to any stigma they might face but overall they were not concerned about being 'tagged' if there was a benefit to their independence and quality of life.

Assistive technology and GPS tracking devices specifically are of interest to potential users and they are enthusiastic about the potential benefits in their lives. The range of views presented in this paper and the differences found between people living in different areas emphasise the importance of developing technologies that are flexible and can be adapted for individual users. For devices to be successful, consideration must be given to the use of devices in the real world and take on board the concerns and opinions of those who might use them. It is not simply about the design and functionality of the device but about how people with dementia and their carers are assessed and supported to use the device in a manner that meets the needs and wishes of the people with dementia while addressing concerns of the carer.

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User participation

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