Electronic Tracking of Users with Cognitive Impairment
Contrasting a Literature Review with Local Experience

Hans Georg Schaathun[1], Sven Inge Molnes[2], Helen Berg[3], and Rigmor Einang Alnes[24]

[1] Aalesund University College, Faculty of Engineering and Natural Sciences, Norway
[2] Aalesund University College, Faculty of Health Sciences, Norway
[3] Municipality of Ålesund, Norway
[4] Centre for Care Research Central Norway

Abstract People with dementia or other kinds of cognitive failure are at risk of getting lost when they are out walking. Depending on weather conditions, this is potentially a life-threatening risk. Electronic tracking is proposed as a tool to allow safe walking, and a help for the caregivers to locate a missing care recipient in the event of getting lost. Many trials of and inquiries into electronic tracking have appeared in recent years. This paper makes a preliminary literature review and reports on a local trial. There are interesting differences in the level of technical difficulties and the drop-out rates of users. A great benefit for many users, many obstacles make it hard to use the technology for others. Too little is known about when the technology is appropriate and how to make it work in practice. We discuss several directions for further research.

1 Introduction

People with dementia or other types of cognitive impairment form a large, and growing group. The group is diverse, with various levels of functioning, physically as well as cognitively, and they require very different levels of care. Many, especially in an earlier phase of dementia, are capable of engaging in normal activities and manage themselves most of the time.

One significant risk faced by this group is that of getting lost and failing to find one's way home. This is often, but not exclusively, related to *wandering*, a condition commonly found in dementia, where the patient embarks on an erratic and seemingly purpose-less walk. It is estimated that 20–25% of community-dwelling patients with dementia have some level of wandering behaviour [1].

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Searches for missing elders with dementia are regularly reported in the press, and occasionally the outcome is fatal, often as a result of exposure and hypothermia. Research shows that among people with the same level of dementia, those who have gone lost in the past are much more likely to be admitted to care homes [2].

The risk of getting lost can be mitigated in different ways. A wide range of methods aim primarily to avoid the person moving out-doors on their own. An extreme solution is a closed ward with locked doors. Softer approaches include music therapy and activities aiming to provide an alternative to lone walking. A direct, positive technique is organised walking groups.

Most of the solutions are based on the assumption, implicit or explicit, that the out-door wandering or walking is the problem to be solved or prevented. However, many people with cognitive impairment, their carers, and next-of-kin, report that walking is a favourite past-time, and many want to walk alone. Such an attitude seems obvious to a large population who enjoy walking and rambling without any clear signs of cognitive impairment. What is sometimes called wandering with a negative stigma when elderly subjects are concerned, is called rambling when younger subjects are concerned and seen as a very healthy, positive activity.

Electronic tracking, commonly using GPS, is a solution aiming to promote safe and independent walking. The user carries an electronic device, allowing a formal or informal carer to track him or her remotely. Thus, the user is able to walk freely and alone. In the event of getting lost, the carer can locate the user and come to assist. Being a clear breech of privacy, electronic tracking is controversial, but some users find it freedom enhancing [3] because the alternative may be confinement in a care home.

Many local councils have tested GPS tracking in recent years, including a local trial led by the municipality of Ålesund in collaboration with surrounding councils. Reading the existing literature, one can easily get the impression of a very mature technology ready for immediate use, at least as soon as the ethical considerations have been properly debated and everybody involved have consented. That is not quite in line with our experience in Ålesund. Out of 16 people joining the trial, only five were still using the technology after six months. When we started on the research for this paper, we wanted to check if our impression of the literature as very positive to the current state of the technology was accurate, or if the technical and practical difficulties that we saw in practice are also reported in the research literature.

In this paper, we make a preliminary literature review covering both engineering and social/health science, to identify known technical, practical, and ethical challenges to electronic tracking of people with cognitive impairment. In this context, we report on the local trial, and we discuss possible approaches to overcome known challenges. The problems transcend the boundaries between the disciplines of engineering and health care, and so must the solutions.

2 Design

The literature review is based on a limited, but systematic search. The search was scaled to be manageable with the available time and manpower and to provide a preliminary overview and collect experience with search strategies. Hopefully, future reviews will cover a wider time span and additional databases. We search two bibliographic databases, IEEExplore for electronic and computer engineering, and Cinahl Complete for health related research. The search is restricted to 2007–2014.

2.1 Search strategy

We search for literature in the selected databases. The target for our search can be defined in terms of user group, problem, and class of solutions.

User group: people with cognitive impairment
Problem: user getting lost out-doors, unable to find their own way home
Solution type: technology allowing a carer or next-of-kin to locate the user remotely

Good search words are generally hard to find, and the taxonomies and thesauruses used by the databases we considered offered little help. The term 'cognitive impairment' is little used, especially in the technical literature. Authors tend to use well-known subgroups to exemplify (e.g. Alzheimer patients). To capture as much as possible of the group, we opted for the following search substring:

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elder* OR dementia OR alzheimer
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Restricting the problem and the solution is harder. The solution is probably most correctly described as location tracking, but many authors write just 'tracking', or 'GPS tracking' if GPS is used for the purpose. This risks confusion with activity tracking, physiological monitoring, etc. In the end, we decided to use the following search string and filter out false positives manually:

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track* AND (elder* OR dementia OR alzheimer)
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2.2 Filtering

We conducted a two-stage filtering, with the first two authors acting as independent referees. The first stage was based on title and abstract only. The second stage was based on full-text copies of the articles. The two referees read and classified the papers independently, and discussed the classification to agree on a conclusion. Consensus was obtained in almost all cases in the first stage and every case in the second stage. When no clear-cut agreement was found in the first stage, we erred on the side of inclusion, essentially postponing the decision for the full-text review.

The following inclusion/exclusion criteria were used:

- Include papers which consider outdoor location tracking of users who can be described (loosely) as either patients, elderly, or people with cognitive impairment. We include papers were the given user group is addressed only as a potential user group.
- Exclude papers which focus on one of the following areas, unless they also explicitly and unambiguously address outdoor location tracking:
  1. indoor tracking.
  2. activity or motion tracking.
  3. physiological tracking.
  4. fall detection.
  5. navigation or way-finding.
  6. robotics incl. automatic wheelchairs.

During the second stage of filtering, we also classified the papers on three points:

1. Does the paper use testing or user trials?
2. Are ethical issues considered?
3. Are technical issues considered?

We had originally intended a more detailed classification of ethical and technical considerations, but because almost no paper fitted well with the expected categories, this was postponed to the more detailed review. With respect to the use of testing, there are four main categories:

1. No testing at all
2. Testing, but no usability testing
3. Trials (usability testing) with non-impaired subjects
4. Trials (usability testing) with impaired subjects

A priori we failed to make the distinction between usability testing and other kinds of testing, and only categories 1, 3, and 4 were included. Category 2 was added during the review to handle papers which did not fit elsewhere.

3 Results

Database	Hits	First filtering	Fulltext filtering
IEEExplore	221	20	10
Cinahl Complete	162	22	18

Table 1. Search results.

We conducted the search and filtering as described above. The number of candidate papers after each stage is shown in Table 1. A total of 28 papers were included for further review, and these are listed in Table 2.

We have colour coded the papers. The two grey papers, [4] from IEEExplore and [5] from Cinahl Complete, are news articles. Satisfying the inclusion criterion, they are included, but they discuss no research and make no opinion, and are therefore ignored from here on. Yellow and blue papers are engineering papers from IEEExplore. The yellow ones consider electronic tracking of elderly or people with cognitive impairment in some generality. The blue ones consider one particular subproblem of electronic tracking, rather independent of the target user group. The other papers are from Cinahl Complete. White papers are opinions and analysis, not reporting on scientific studies. The pink papers are research papers clearly relevant to our main questions. The two green papers are research papers with a wider scope, either in terms of proposed solution or in terms of target user group, yet these papers were not clearly excludable by the criteria.

Among the papers excluded based on the full text, there are numerous papers on tracking of elderly or cognitively impaired users for different purposes, such as indoor tracking, analysis of mobility, or wandering detection. There were also papers on tracking of other user groups, including one on pet tracking. Finally, one paper [29] considered the circumstances were drivers with cognitive impairments become lost, and noted the fact that missing incidents are not necessarily linked to wandering behaviour. Cognitively impaired users may very well get lost during planned, routine excursions.

Our review identified one previous review paper, [24]. Published in 2007, it only reports on literature prior to the start of our search. Robinson *et al.* [25] also made a systematic review, but of non-pharmacological interventions to reduce wandering. They consider location tracking as one such solution, but none of the reported trials used such technology.

4 Review

We have reviewed the 28 relevant papers with respect to three topics: ethics, technical challenges, and the authors' attitude to the technology. The opinion papers are naturally only relevant to the last topic, so we leave them out for the first two.

4.1 Ethical Challenges

Privacy is the main ethical concern, addressed virtually by every relevant paper from Cinahl Complete. Users may feel controlled by the tracking device [2], and it brings Orwellian associations [17]. Hughes [18], citing [30,31], notes that electronic tracking is widely recognised as a form of restraint.

Electronic tracking has a dual and ambiguous effect in terms of independence and autonomy. For some users, the alternative to electronic tracking is to be confined indoors, and in the most extensive trial that we found [2], 45% of respondents with dementia perceived increased freedom from their caregiver with tracking. Others experience less freedom, and [2] quotes:

Paper	Relevance/Testing	Ethics	Technology	Comment
[6]	No usability testing	—	Bandwidth	Prototype
[7]	No usability testing	—	No opinion	Power conservation
[8]	No testing	Considers privacy	No opinion	Cryptography
[4]	News brief	—	—	New product
[9]	No usability testing	—	Challenges noted	Power conservation
[10]	Preliminary testing, no systematic evaluation	—	Challenges identified	
[11]	Non-elder subjects, no usability testing	—	Possible opinion	Power-efficiency
[12]	No testing yet	Mentioned	Improvements proposed	Social network
[13]	No testing yet	Mentioned	Improvements proposed	Social network [12]
[14]	No testing	Considers privacy	No opinion	Privacy protection
[15]	Opinion	Negative	No opinion	
[5]	News report	—	—	Mentions many products
[16]	Opinion	Positive	No opinion	
[17]	Opinion	Positive	No opinion	
[18]	Analysis	Skeptical	No opinion	
[19]	No testing	Discussion	—	
[20]	No testing	Discussion	No opinion	
[21]	No testing	Recommendations	Marginal mention	
[1]	No testing	Discussion	Importance noted	Check conclusion
[22]	No testing	Discussion	Importance noted	design criteria
[23]	Pilot observation	No opinion	Positive, but identifies challenges	
[2]	Trial	Discussed	Positive	Low drop-out rate
[24]	No testing	Balancing	No opinion	
[25]	No relevant test	Limitations	Addressed	Tracking is not a main focus
[26]	Opinion	Positive	No opinion	
[27]	Trial	Positive	Problems	inter-disciplinarity
[28]	No testing	No opinion	Comparison	Considers various user groups

Table 2. Classification of relevant papers identified in the review.

> *Before using GPS, my husband allowed me to go downtown by myself. Now I can only go there of (sic) taking my GPS.*

Hughes [18] also asks the question:

> *What is the greater breach of rights, electronic surveillance or restriction and restraint in care homes?*

The authors reporting on studies not using trials of the technology appear to tend towards the view of tracking technology as a restraint. The three trials reported in our sample, in contrast, report that independence and freedom is increased, at least for a significant number of users. In an older trial [32], according to [24], none of the family carers who had experience with the technology felt that it increased the independence of the care recipient. There is no compelling evidence, and if a conclusion is to be made, it has to be that the technology works very differently for different users.

Besides the privacy and civil liberties issue, a couple of other ethical concerns are raised:

1. Technology may replace human contact [24,19].
2. There may be stigma associated with wearing a tracking device [24]. In particular electronic tracking is associated with tagging of criminal offenders [19].
3. The tracker may increase risk, e.g. by making the wearer a target for theft [24].

Dr. Landau's groups in Israël is behind five of the trial-less research papers, addressing a range of questions relating to ethics using both quantitative and qualitative studies with subjects including both professional carers, family caregivers, and cognitively intact elders. All this work leads into a set of recommendations [21] in 2012. Notably, they recommend that the decision to use tracking technology should be made within the family, but with professional advice. Furthermore, they recommend that elders be asked about their opinion and priorities while still cognitively able. The authors share Hughes' view of electronic tracking primarily as a restraint, and in their studies the strongest motivation in favour of the technology is the caregivers' peace of mind.

The papers from IEEExplore hardly ever discuss ethical issues. They might mention that ethical problems exist [12,13]. When ethics is addressed, it is in terms of an engineering problem derived from ethical concerns. For instance, privacy enhancement is a well-known and general problem in cryptology and information security. When we are concerned about the breach of privacy in location tracking, it is natural to develop and adapt such privacy enhancing techniques to the tracking system. This is a straight forward engineering research problem, which can be undertaken without any further debate as to whether the privacy breach is acceptable or not. Two papers in our review [8,14] propose privacy enhancing solutions.

4.2 Technical Challenges

A large number of technical challenges and limitations are mentioned in the literature:

1. cost of the device [24]
2. difficult to use, need for training [24]
3. technical problems [24]
4. size of the device, charging of the device [24,18]
5. increased demand on family carers [24,18]
6. location readings are sometimes inaccurate, especially indoors or close to buildings [18]

The most widely addressed issue is the poor battery life, sometimes needing recharging several times a day. Apart from the obvious thought that the future will bring us better batteries which last longer, this problem can also be tackled by a more energy thrifty tracking system. The cause of the poor battery life is that transmitting location queries to the GPS satellite requires a lot of power. A key question is then, how often do we need to obtain an accurate position? Three of the engineering papers consider solutions with solutions to reduce the number of queries, while still providing accurate position data when required.

Only four of the papers report on any kind of usability testing or observation. Only preliminary trials with informal observations are reported in [10]. McShane [23] does also not report any details such as number of participants or number of drop-outs. Only [2] and [27] report on any numbers. The first had five drop-outs out of eleven participants, whereas [27] had 33 subjects and five drop-outs. Thus, all of the trials are fairly small, and [10] conclude that further study is needed to 'understand the target elderly user group of this dedicated AGPS terminal and to enhance its features and design'.

None of the papers make any clear statements about the maturity of the technology. Since none of the above mentioned challenges are presented as potential show-stoppers, one can easily get the impression that the technology is mature and easy to use.

4.3 Attitude to the Technology

Finally, we wanted to gauge authors' attitude in favour of or against the use of technology. This proved difficult, as no strong and obvious indications could be found in the research papers. With a large sample, searching more databases, one might be able to find indicators through a structured application of text analysis. Only the four opinion and the single analysis paper (white entries in Table 2) voiced clear opinions, three in favour and two against.

5 Local trial

In stark contrast to the relatively positive and encouraging impression from the literature, experience from the local trial are negative by comparison. Deployment of the tracking technology and integration into the daily routine of the

#	Reasons	Category
1	User felt monitored. Too many lights.	UI +
2	Inconvenient with extra device in addition to mobile phone. Charging is a hassle. No great need for tracking.	Battery, Extra device, +
3	Poor speak/listen function. Uncertain whether an alarm has been sent. Extra device to bring.	UI, Extra device
4	Next-of-kin did not have time to follow up. Hassle to take care of battery and charging, and make the user bring the device.	Procedures, Battery
5	Worked badly with the informal carer who would use the system. Was stressed when the alarm did not respond immediately and there was a lag in the tracking.	Procedures, Technical
6	User pushed the alarm button all the time, a lot of noise for the receiver.	UI?
7	The user became too ill to go out alone.	Health
8	Next-of-kin did not have time to assist. A lot of hassle with charging and to remember bringing the device.	Procedure, Battery
9	The user got electric shock. The mains plug was broken. Next-of-kin and the user found that the device was insufficiently developed for the target group. Too many buttons on the device, unreliable alarm functionality	UI, Technical
10	The home care service found charging too much of a hassle. Difficult to find good procedures to let the user remember to bring the device.	Procedures
11	Insufficient mobile phone coverage to track via SMS, and to validate the operation of the alarm function. Impossible to phone to the device. (Was able to track the device when it was out-doors.)	Technical, UI

Table 3. Background of the eleven drop-out cases out of 16 subjects in the Ålesund trial.

users and their carers proves very difficult. Out of the sixteen GPS trackers deployed at the start of the project, only five were still in use after six months. The eleven drop-out cases are listed in Table 3.

The trial was conducted during 2013 in the region of Sunnmøre. The users would be using the tracker for a six-month period. Data were collected using two interviews with the next-of-kin or informal carers, and where possible, also the cognitively impaired user person. One interview was done prior to the trial, without the users having to commit to taking part in the trial beforehand. This interview also served to provide information about the service and the trial. The second interview aimed to evaluate the trial and was arranged after the trial was complete. A total of 22 users took part in the original interviews, 16 of whom went on to take part in the trial. For the six users who did not go on to the trial, the family and the project manager agreed that the tracking service did not suit the user's needs. Five users kept using the tracker for the full six-month period. Of the eleven users who dropped out, five failed to take part in the evaluation interview, but partial data about their experience and reasons for dropping out was collected informally via phone or when the equipment was returned.

Both interviews where transcribed and subjected to a qualitative, inductive content analysis. Further information about the trial can be found in [33], and hopefully in future papers.

As we can see, the reasons given for not using the GPS tracker are composite in most cases. Yet, there are a few classes of problems which seems to explain most of the drop-outs. We have tried to categorise the reasons in the third column of the table.

UI (user interface) several users had problems which could seemingly easily be resolved with simple modifications to the user interface.

Technical several users noted functional problems, incl. problems with tracking, reception, or the alarm. This is a more diverse group than UI problems and have less obvious solutions.

Extra Device several users disliked the extra device to be carried, an issue which we also found reported in the literature.

Procedures reliable use depends not only on the technical system but also on good habits and interplay between the user and the formal and informal carers. This category may cover both difficulties in incorporating the technology in the daily routines, and insufficient time on the carers' part.

Battery the need for frequent charging was impractical for many users.

Health inevitably, some patients will give up using the technology because the health deteriorates. When they are no longer able to go outside, there is no need for the tracker.

Generally, the problems match problems reported in the literature, or they are fairly obvious and natural to expect. What is surprising is that the problems are so severe that they make two thirds of the respondents give up.

The users include both users in care homes, users living with a spouse, and users living alone with a family member being responsible for the tracker service. The five users who completed the trial include two living with a spouse and three

in care homes. For some of the users in care homes, their liberty depends on the staff on duty. Some members of staff are reluctant to use the tracker service. The resident is only allowed to leave the care home if there is staff on duty comfortable with the technology.

Some of the problems have obvious solutions and others do not. Clearly, the health related reasons are inevitable, but they only accounted for one out of our eleven cases. In contrast, two obvious alternatives exist for a user who dislikes the extra device. Tracking functionality could easily be integrated in an app running on a smart phone, for users of such phones. Alternatively, a worn device could be used, for instance with the electronics sown into a coat. Each proposal will require its own ethical assessment. Several initiatives exist to develop mobile phone apps to track people with cognitive impairments [34,3]. Even if currently available apps do not match the requirements, it is only a question of time before suitable apps are widespread.

Problems relating to procedures are much more fundamental than the technical problems, and the solutions are not obvious. Part of the problem is that user manuals describe only the technical features. They do not explain how to make the product useful in real life. Often it is possible to work around technical limitations, such as the short battery life, as an added organisational challenge. In contrast, no technical innovation can dissolve the need for good, practical routines to make the system work in daily life. The solutions are likely to grow out of trial and error over some time.

Problems concerning charging are well-known in the literature, and potentially diverse. Good procedures are needed to get the batteries charged regularly. Improvements to the charger design might make the task easier and more manageable.

The user interface is a particularly interesting category. A boon for one user can be a show-stopper for others. Take the alarm button for instance. It is obviously useful for a user with sufficient cognitive ability to use it well. However, for one user in the trial, abuse prevented further use of the system.

The participants in Ålesund (and also in [3]) generally report that the tracker gives increased freedom and independence and allows the users to live longer in their own home. This is in some contrast to the literature, where the focus often was on increased safety while the freedom to walk autonomously was constant. In our trial, the choice is often between living at home using the GPS tracker, or moving into a care home with supervision around the clock.

6 Discussion

Given the limited extent of our studies, with relatively few relevant articles discovered and few users in the trial, our discussion seeks questions for further research, rather than answers and final solutions.

Tracking technology has proved very useful for a considerable group of users. However, it does not work for everyone, and while the literature can offer com-

prehensive advice on how to handle ethical issues, there is very little to be found on the technical and practical issues.

6.1 Interpreting discrepancies

Why does our trial have a much higher drop-out rate than trials reported in the literature? We have no certain answer to this question. The authors [27] reporting the largest trial, with only five drop-outs out of 33, noted that their sample predominantly had medium to high education, which may make them more familiar with technology in general and thus more likely to use it. In the local trial, the subjects span all social classes, levels of education, and stages of dementia.

None of the trials give any details about the cognitive impairment of the participants. It is well known that later stages of dementia makes it very hard, in general, to accept new solutions or new habits, and this (unsurprisingly) appears to be the case also for GPS tracking in particular. There is evidence [3] that there is a rather narrow window where tracking can be introduced. Without any objective assessment of the cognitive ability, the results from different trials cannot be expected to be comparable.

We also found a discrepancy in the ethical viewpoints. In the literature, the dominant view is of tracking as a form of restraint. In our trial, the dominant view of users and informal carers was that tracking gives greater freedom. This is not necessarily a difference in the attitude. It could very well be a difference in the *a priori* situation. The users who report increasing independence appear be those who have reached a point where independent wandering is no longer an option. Thus the alternatives has become either tracking or confinement, with tracking as the lesser restraint. Users who are well enough to walk on their own, albeit with some risk, can only be expected to experience greater safety and/or less privacy.

It is tempting to hypothesise that drop-out cases in our trials have had more advanced dementia than what the typical subject in the other trials. Such a hypothesis could explain both the difference views on tracking as freedom enhancing or restraining, and the higher drop-out rates. However, there is no support for this hypothesis in the our data. The only feature characterising successful use of the tracker, is a carer with outstanding motivation and will to succeed.

6.2 Confinement versus Surveillance

As noted electronic tracking is commonly a viewed as a restraint. As a means of surveillance it is an intrusion on privacy, and justly controversial. However, there is the the opposing view that tracking gives added freedom, voiced by users themselves, because the alternative is a care home which is perceived as more restraining.

This conflict is evident in a couple of cases with users in care homes. Locking doors to keep residents inside is a well established practice, and rarely up for debate. Many members of staff are reluctant to take up the new technology,

which could allow the freedom for residents to move outside with acceptable risk. We have not inquired into the reasons for this reluctance, it could be either ethical concerns or general technophobia.

We should be very concerned that the wide-spread practice of locking vulnerable people in is hardly ever up for debate, while, at the same time, surveillance is controversial to such an extent that one may have to search for legal loop-holes to deploy it. Is surveillance really a greater intrusion than indoor confinement?

In general, one should not expect ethical considerations to generalise across cultures. However, there is a certain ethical awareness, which may generalise. Compromises are necessary; different forms of restraints are used for safety reasons. Restraint is bad, but safety is good, hence the compromise. It is important to be aware of all of these compromises, and they should be reassess continuously as innovation opens up new opportunities. New solutions must not be resisted simply because they are intrusive in an absolute sense. Instead, they should be compared to existing intrusions, and the best overall compromise should be chosen from the user's viewpoint.

6.3 Call for a holistic approach

Engineering and health science literature take different attitudes to problems and technical flaws, and there is a gap to fill between the disciplines. In the health sciences such problems are frequently used as arguments against the use of technology. In engineering such problems are merely research problems. They require solutions, and we can find them.

None of the papers we have found put the ethical and technical short-comings into their full context. Engineering researchers do not involve users when they gather requirements or define the problems, and involvement of users in health science is restricted to evaluating technology as is, rather than expressing visions and desires for tomorrow.

These problems have been pointed in the more general context of eHealth technologies [35]. Like van Gemert-Pijnen *et al.* we believe that the solution is in a holistic approach, i.e. an emphasis on the whole as something more a sum constituent parts. It is not sufficient to make inter-disciplinary projects where the constituent disciplines define their own work-packages and are content with project meetings once every blue moon. A holistic approach requires exchange of ideas as part of day-to-day work. As the understanding of the research problem matures during a project, this understanding must be shared continuously so that the stake holders remain consorted throughout.

The present paper is the result of the newly founded Arena for Learning about Welfare Technology (ALV), which is a collaboration between the Municipality of Ålesund, Ålesund University College, NAV Assistive Technology, and the Centre of Care Research Central Norway. It spans three faculties within the college and both health administration, IT services, and the Public Property and Housing Services within the local council. Having already established weekly meetings and with a demonstration and laboratory flat currently under construction, we hope to be able to establish a holistic research and development process. One

may call it an experimental lab, think tank, demonstration flat, or innovation room. Even though these words may bring up different associations, they all spring out of the same philosophy, that innovation is the result of people with different ideas getting together, thinking together, and working hands-on with real problems and real gadgets.

The lack of holism is also evident in every-day administrative processes. Technology for use in care homes often require built-in facilities, such as cabling. Too often, the civil engineers are on their own in the planning and construction of a building, lacking the users' understanding of how the rooms are going to be used and lacking, for instance, IT services' understanding of how to enable technological solution. The holistic thinking is missing from most educational services, in research, and in the government organisations.

6.4 User-Centric Development

A necessary condition for the holistic approach is effective involvement of the user. Although user involvement is a widely recognised virtue, with terms such as user-centred design in engineering and user-centred development in software engineering [36], it may be hard to realise in practice.

For nurses and nursing researchers, user-centricity is of course central to their professionalism. Systematic processes for user-centric design of technology and services are, in contrast, are not found in a nursing curriculum. In fact, technology is sometimes seen as a threat to human- and user-centric care.

Even in engineering, it is easier to grasp user-centricity as an ideal or a general attitude, more than as a structured methodology to give concrete help in the development of new systems. An amalgamation of development lifecycles from engineering, user understanding from nursing, and innovation processes from innovation and entrepreneurship is a very promising way forward.

6.5 Variations over the solution

Tracking technology can be used in many different ways, and existing trials and surveys of health care applications have failed to address this. Common solutions to ensure safety in face of wandering is a straight-forward surveillance system. The care recipient carries a tracker which reports the location to a server (via the mobile phone network) at regular intervals. The care giver can contact the server to see the reported locations at any time, typically via a web page, but other means are possible. No surprise that these systems make us think of big brother.

Such a surveillance system is a significant intrusion on privacy. It is always on, and the carer can snoop at any time, independently of the users situation and need. The engineering literature discuss less intrusive solutions based on the same tracking technology.

Geo-fencing is mentioned by several engineering authors as well as [23]. A geo-fence is a boundary enclosing the area considered *safe* for the user. A geo-fencing solution would let the user wander freely without surveillance within the

geo-fence. If the users leaves beyond the geo-fence, an alarm is raised and full tracking functionality can be enabled.

Many of the technical papers consider wandering detection, i.e. artificial intelligence aiming to identify wandering behaviour, such as an erratic walking route or deviation from habit or plan. Wandering detection has several applications, but one application is similar to the use of geo-fence suggested above. When a wandering state is detected, an alarm can be raised and full tracking surveillance enabled.

Either geo-fencing or wandering detection can be used to limit the surveillance and prevent abuse (or at list reduce the risk of abuse). It would also be possible to allow tracking only after the care recipient has been out of the house for a certain period of time. I.e. if the user is out walking for a reasonable duration, no surveillance is possible. If he does not return on time, on the other hand, tracking is enabled. All of these solutions would preserve privacy in many every-day situations while still allowing tracking in the event of an incident. Admittedly, there is still a risk that the user may *feel* controlled and monitored, even if actual surveillance is blocked.

The users in our trial did not have homogeneous needs. Some of the drop-out users had specific needs for which the service was ill-suited. In particular, one couple wanted to use the GPS tracker for travels abroad. Firstly, there is the challenge of finding one's way through the airport, which is an indoor environment for which GPS is ill-suited. Secondly, there is the use case where the couple are walking together, and the cognitively impaired user gets lost in a crowd. The carer can track via his/her mobile phone, but this is based on SMS which can be slow and has no guarantees. In practice, the lag could be several minutes, which was not acceptable to the users. This is seems to be use cases tacitly ignored both by the developers and procurers.

7 Conclusion

Having reviewed literature on electronic tracking for users with cognitive impairment and observed the results of a local trial, we note that many important questions go unanswered or insufficiently answered. Technology uptake is slow, and it does not always have the expected impact or benefit in practice. The literature answers neither why, nor how one could do better.

Many of the problems fall in a gap between engineering research and health sciences. A holistic approach is needed to develop technology and services which work together for real users. More research is required to establish structured methodologies for user-centric development.

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