DWSI Final Report 30th June 2017

Dementia Wristband Report

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Project summary

This research project explored the use of new wearable and mobile technologies to support independent living and social interactions in the community for people living with dementia and their carers, more safely and for longer.

The three key aims of the project were to:

- Assess the potential acceptability, and usability of a mobile phone App and wearable wristband solution
- Test the use of the technological in the everyday life contexts
- Evaluate the usability and utility of a mobile phone App and digital wristband to reduce social isolation and improve health outcomes

The research project had two stages:

Stage 1 - Acceptability, utility and usability of the devices
This stage of the project focused on developing initial understandings of the ways in which the proposed technological solutions work and potentially meet the needs of people living with dementia and their carers.
This was achieved through:
- Technology testing by the project team members. This gave the team a better understanding of the device used in the project.
- Interviews with people with dementia and their carers, and with health and social care professionals. The interviews explored whether participants were receptive to, and what they thought about, the proposed solutions. Any concerns they had about the tracking technology in general or about the technology used in the project were also examined.

Stage 2: Real world testing of the wristbands and smartphone App
Research participant's trialled the technology, as part of their everyday lives, for up to three months. During this period the research team worked closely with them to provide training and technological support and used a multi-method data collection focused on semi-structured interviews and observation to capture their experiences of using the technology.

The participants living with dementia and their carers were given the opportunity to choose the technology that best suits them, either a wristbands or a smartphone application.

Key findings

In summary, through the interviews and focus groups and real world technology testing the research team and SME partners found there are issues around:

- the use of technology for people living with dementia and their carers – for some people it was seen as a real benefit, others did not want to engage with the technology or have others know where they were.
- education, information and support for people living with dementia and their carers to use new technologies; even when delivered via familiar technologies this can be challenging and needs support and time
- support for family/other carers who are key to the support of mobile and wearable technologies.
- support for people who do not have a local or remote family carer who can support the use of new technologies needs to be considered.
- current GPS technologies not being accurate as a stand alone way of finding someone who may be lost or needing support.
- safeguarding – which needs to take an holistic approach and include more traditional and 'paper based' safeguarding systems such as the Herbert protocol,
- emerging and new technologies, which are developing constantly but a national approach is still missing;
- the challenges for unpaid carers and people living with dementia to around exploring options around new technologies and deciding what are the best/cost effective options for their situations.
- wearable and mobile technologies which can support people to be more independent in the community, but the technologies need to be: introduced early; affordable and be more easily supported by family and professional care givers as appropriate.

Final project report

Contents

Background and context

This is the final report of a research project on wearable technology for people living with dementia and their family carers. The project was a collaboration between Manchester Metropolitan University (MMU) and a Small-Medium Enterprise company (SME), KMS Solutions Ltd, who developed, designed and procured a range of mobile and wearable technologies that had the potential to support people living with dementia and their family carers.

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The participants living with dementia were given the opportunity to choose the technology that best suits them, either a wristbands or a smartphone application. These are explained in more detail in Section 3 – *Technology tested in the project,*

but it is worth to note here that all of the research participants chose to use the wristband. None of them used a smartphone so this option was best suited for them.

Background literature

There are over 500,000 people with dementia living in the community, most supported closely by unpaid carers (Alzheimer's Society 2014a). People living with dementia and their carers often experience social isolation and loneliness because of the memory, physical and communication challenges that can develop with dementia. Up to 40% of people living with dementia in UK reported feeling lonely (Alzheimer's Society 2014b), and 8 out of 10 carers reported feeling lonely or socially isolated because of their caring role (Carers UK 2014). This has then promoted an interest in, and need for, technologies that can support people living with dementia and their carers to live safely at home for as long and socially connected as possible.

Going out for a walk is an activity most people take for granted. However, with the changes in cognitive ability created by dementia, often linked to loss in confidence, many people living with dementia have fewer opportunities to go out: only about half of people living with dementia in UK go out daily (Alzheimer's Society 2014b). Purposeful walking (or wander-walking) is common with many people who have dementia. This term describes persistent and repetitive walking behaviour, which many people with dementia experience. This can be caused by various reasons: restlessness, boredom, loneliness, anxiety or as a side effect of medication, a form of communication or as a form of exercise (Hughes 2013). Despite the negative connotations associate with wander-walking, this activity has social and health benefits for people living with dementia including cognition, functional ability, mood, and sleep quality (Bantry White and Montgomery, 2015). Nonetheless, carers and professionals have the dilemma of balancing the independency and autonomy of the people living with dementia against the risks and anxiety of an individual getting lost. Memory problems and confusion can lead a person with dementia getting lost or confused even in familiar surroundings. Survey data showed that 43% of people living with dementia had been lost at some time. Although most had been found quickly, 14% had been lost for six hours or over on at least one occasion and 28% had been lost on more than five occasions (Pot et al., 2012 citing McShane 1998). This significantly increases the chances of the person living with dementia being involved in a precarious situation (Pot et al., 2012; Meredeth and Vikki, 2003). Moreover, these experiences can be distressing to the person with dementia and their carers. The risks and experiences of getting confused, lost or regular purposeful walking can result in reduced activity and increased social isolation. Moreover, the challenges of managing purposeful walking can increase carer stress. People living with dementia who get lost have a greater chance of being admitted to formal care settings (Pot et al 2012; Rasquin, Willems, de Vlieger, Geers, & Soede, 2007) with significant cost impacts. Time and cost impacts are not limited to health and social

care services. In cases where the person with dementia is not found quickly, emergency services are called to help. The estimated police costs of missing person enquiries attributable to dementia range between £22.1 and £40.3 million per year (Alzheimer's Society 2014a).

Technology is widely used in hospitals, care homes and increasingly in people's homes to support wander-walking, safe movement, autonomy, continuity of care and dignity (Mental Welfare Commission for Scotland, 2007). Devices that assist care (Assistive Technology) include:

• Sensor pads (beds, chair, floor)

• Nurse/carer call systems

• Panic buttons, pendants, and cords

• Fall and movement sensors

• Electronic tagging and tracking systems

• CCTV/video surveillance

• Intruder alerts (MWCS, 2007: 2).

In the context of wander-walking, new technologies can provide additional support. However, many current forms of technology that aim to support people living with dementia are commonly introduced late and are used as a form of surveillance that inhibit, rather than promote, engagement with the community. Previous uses of assistive technology with people with dementia have included equipment such as movement or door exit sensors. These focus on keeping the person with dementia safe by confining them to their home, or alerting someone if they leave (Mental Welfare Commission, 2005). In contrast, the assistive technology investigated in this project aims to support the independence and autonomy of the person living with dementia by enabling them to continue with everyday life activities, including going outside of the home environment.

Gerotechnology is a rapidly growing field and many devices are becoming available to monitor people's health, safety, and location. People living with dementia and their carers can access assistive technology through three routes: *formal, off-the-shelf, and do-it-yourself. Formal* devices are accessed from health and care services typically following a 'needs' assessment by a professional. *Off-the-shelf* are devices purchased independently from the private sector and *do-it-yourself* devices are everyday items that are adapted by the carer (Gibson et al 2015: 3).

Solutions that can support independent mobility in the community are important as they can enhance independence, reduce social isolation, keep people safe and delay admission into long-term care. Research indicates that carers receive the most

benefit from technology through reduced anxiety over the person with dementia's safety (Gibson et al 2015).

It must be noted, however, that the use of technology to monitor people has ethical implications concerning the rights of the individual. Hughes (2015) noted the issues concerned physical and virtual restraint, right to privacy and freedom, avoidance of harm, and the legislative framework covered by the Mental Capacity Act 2005 (England and Wales) and the Adults with Incapacity Act 2000 (Scotland). Wearing visible technology may also put the person with dementia at risk through identifying them as potentially vulnerable (Robinson et al, 2007).

By providing a more mobile, innovative solution the proposed project aimed to demonstrate benefits for:

1) the person living with dementia,

2) their carers

3) improved health outcomes and cost effective use of health, social care and emergency services.

The role of emergency services in the context of wander-walking and dementia is important as the UK Missing Persons Bureau 2015/16 Report (2016: 6) recorded 135,382 missing individuals of which 1.49% and 1.89% were recorded with Alzheimer's and/or Dementia, respectively (UKMPB 2016: 45[1]). In such scenarios the person with dementia is often reported to the Police as 'missing' with the compulsion to 'wander-walk'. This affects 15 – 60% of people living with dementia (Robinson et al, 2007). The Police not only respond to people with dementia that have gone missing but also when carers, care home, and hospital staff cannot cope (Brown, 2013). The financial cost of missing persons is hard to judge but a medium risk, medium term missing person investigation costs between £1,325.44 - £2,415.80 (Shalev-Greene and Pakes, 2012). The financial cost of medium risk cases (147,550), based on 76% of all missing incidents in England and Wales is in the range £195m to £356m per annum (UKMPB, 2016).

Recognising the issues highlighted in the background literature, the study undertaken therefore aimed to take account of multiple stakeholders perspectives throughout the study.

Research team and partners

The proposed research was funded by the Greater Manchester Academic Health Science Network's (GM AHSN) Technology Innovation Challenge's funding call for

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[1] *This is an assessment made by the officer completing the form and more than one category can be selected*

research to examine the role of assistive technology in reducing social isolation to support recover, health and wellbeing.

The funding from GM AHSN was aimed to bring together academics, local industry and health care partners. This research project had three partners working on the bid and initial research: research team from Manchester Metropolitan University (MMU), SME company KMS Solutions Ltd, and Stockport Memory Clinic from Pennine Care.

The initial plan for the research was that the team from Meadows would work to recruit and assess research participants from their current or recent memory clinic clients, KMS Solutions would provide the technology, and the team from MMU would conduct the research. There were, however, changes and challenges for each partner's participation during the project.

Manchester Metropolitan University

The research team was mainly based in Faculty of Health, Psychology and Social Care. The team was led by Dr Josie Tetley, Professor of Nursing (Ageing and Long-term conditions), and advised by Dr Jenny Fisher (Senior Lecturer in Health and Social Care) and Dr Matthew Sullivan (Senior Lecturer in School of Science and the Environment).

The fieldwork initially conducted by Dr Emma-Reetta Koivunen (Faculty of Health, Psychology and Social Care). However, during the project she was appointed into a new role, at the early stages of the fieldwork. At this time the project was slightly delayed due to issues with NHS ethics approval and because of this issues with recruitment, and delays in accessing technology (for details of both see below section 1.4). Dr Koivunen was keen and able to continue her involvement in this research project but with less time than planned. Three staff members were recruited to support the project part-time, Dr Robin Hadley, Donna Davenport and Ambily Satish (all in Nursing).

KMS Solutions Ltd

KMS Solutions Ltd are an SME technology company based in Manchester. KMS have expertise in developing innovative healthcare solutions that can enhance the independence and peace of mind for service users and carers. To date they have procured the Keep In Touch (KIT) wristband and worked in partnership with a telecoms provider (O2/Telefonica) and a City Council to develop an android MyTrav App that provides a digital travel training solution for people at risk of getting lost.

From KMS their director and founder Chris Etchells worked most closely with the research project. His role in the delivering the project was to liaise with the research team and train them in using the equipment, provide the technology and help with any technical problems research participants had during the project. Chris and his colleague John Hearns also were involved in developing the research project and took part in the communication with people living with dementia training.

Stockport Memory Clinic (The Meadows)
At the start of this project the NHS partner were Stockport Memory Clinic (the Meadows), who are part of Pennine NHS Foundation Trust. The Memory clinic is a specialised unit caring for people with dementia in a patient and community setting. This is a multidisciplinary team including Nurses, Occupational Therapists and Speech and Language Therapists who have links to wider services including the Community Mental Health Team (CMHT) in Greater Manchester and Stockport NHS Foundation Trust.

Working with Pennine NHS Foundation Trust four key clinicians were involved in setting up and planning the research project. Rachel Price, Clinical Lead in Old Age Liaison, Carol Rushton, Clinical Lead (Nursing), Elaine Ratcliffe, Occupational Therapist and Dr Jackie Kindell, Speech and Language Therapist.

The Memory Clinic assesses patients with a range of dementias and the initial plan was for them to be involved closely with advising the project and helping to recruit participants in the study by promoting the project. The team from the Meadows supported the team in an advisory and training capacity, particularly around communicating with people living with dementia.

The technology evaluated in the project
In this project the research participants were given the option of two technological devices. This approach was selected to allow participants to select the solution they feel best suits them at their current stage of dementia and their circumstances.

The devices offered to the research in this project were:

1. An android smartphone application **MyTrav**, and
2. A wearable and portable GSM/GPS based **tracking watch**.

During the initial interview the different technologies were discussed with the participants and their circumstances were explored to help decide which equipment would suit them best.

How the technologies work

The MyTrav App enables people to create signposted and prompted journeys for the user which are stored on the App. Journeys consist of a start and end point with a series of landmarks in between. As the user starts the journey they are presented with a prompt, generally in the form of a photo of the landmark accompanied with either a recorded voice or text instruction as to what to do next. The application also includes a simple telephone directory, where photographs can be included in addition to the name of the person. This can be used to call for help when required.

The KIT wristband watch enables the person living with dementia to contact a nominated carer with a simple one click button. If they need assistance, with one click of a button on the wristband it dials programmed numbers until it is answered. KMS use a roaming SIM card with the wristbands, this means that they have a better network coverage than those limited to one network only.

The mobile phone watch was linked to a smartphone application, which the carer had on their own smartphone. This enables a carer to locate the user of the technology in a case of an emergency but the system can also be set to 24 hour tracking mode. A carer can then see the whereabouts of the user at any time, regardless of whether they are on a journey or not.

The carer can also call the person wearing the wristband directly via the wristband.

Low battery power automatically triggers a call to the carer. If the battery should run flat then the last known position is stored on the platform which can be accessed using the application.

During the study the mobile phone watch was produced by a Chinese manufacturer and used smartphone application called TAKIT. By the end of the study KMS Solutions had worked with the manufacturer to market their own branded KIT version of the mobile phone watch.

Aims, methodology and research participants

The aims of the project were to explore:

- The acceptability, utility and usability of the devices by people living with dementia and their family carers
- How the proposed technological solutions work in everyday life use by people with dementia?
- How the proposed technological solutions meet the needs of people living with dementia and their unpaid carers?

The research project was divided into two work packages:

1. Interviews about wearable technology for people living with dementia
a) with health and social care professionals and police
b) with people living with dementia and their carers

2. Testing the technology in the daily life of people living with dementia

The research was conducted within Greater Manchester. A total of 29 people took part in the different aspects of the study, as detailed in Table 1 below. The following sections detail the data collection in each aspect of the data collection.

Who	Number of participants
People living with dementia	8
Unpaid carers	10
Professionals	11
Total	**29**

Table 1: Overview of research participants.

Analysis

The data collected during the study included field notes of interview visits; interview transcripts from interviews and email correspondence with research participants. These were analysed thematically using qualitative data analysis software NVivo.

Key themes and issues were drawn together to explore:

- All participants:
  - Previous knowledge, experiences and views about tracking technology;
  - Views about the specific technology tested and any ideas for improvement;

- People living with dementia and their carers were also asked about:
    - Their experiences of daily life with dementia, particularly any experiences of the person living with dementia getting lost outside, or them or the carer having less confidence about the person living with dementia going out alone.
- In the technology testing stage of the study we also analysed:
    - The benefits research participants gained from the technology;
    - The challenges research participants encountered in using the technology;
    - The potential impact of the technology to people with dementia, their family members and carers.

Work package 1 - Interviews with professionals

The objective of this phase of the project was to gather the opinions and experiences of health and social care professionals and the police, concerning the use of tracking technology as part of the care environment for people living with dementia and their carers. The aim was to hold one focus group but challenges in scheduling a convenient time led the research team to hold one focus group and three one-to-one interviews.

In addition to interviewing health and social care professionals, organisations working with technology for people living with dementia were involved in the study. These were Stockport Metropolitan Borough Council's Adult Social Services, and Stockport Homes Carecall, who manage the telecare services (total 4 members of staff), and the charity Good Deeds Trust, who offer Dementia Buddy badges (2 people).

The research team used the same topic guide for all professional groups, but also discussed the technologies and approaches that the organisations working with technology have found useful. In addition the interview, Stockport Metropolitan Borough Council's Adult Social Services team provided us access to their own in-house report about testing different wearable tracking devices. See Table 2 for an overview of participants.

Who	Number of participants
Health care professional	2
Social care professional	6
Police officer	1
Charity staff	2
Total	**11**

Table 2: Professional research participants

The focus group with staff was also attended by Chris Etchells from KMS to present their technology and answer questions about it. All meetings followed the Focus Group for Professionals format (Appendix 1). The majority of interviews were held at a Manchester Metropolitan University building. The interview with the police officer was held at a police station and the interview with the local authority was held in their premises.

Professional Participant recruitment

The participants for this element of the project were recruited through the Manchester Metropolitan University (MMU) staff email list, MMU's Service user and carer group, Greater Manchester Police Force and word of mouth. Following initial contact, potential research participants received an information sheet about the study and were given the opportunity to discuss, and ask questions about the project and the technology. Refreshments and lunch were offered but no payment was offered or made.

Inclusion / exclusion criteria

The inclusion criteria for the professional focus groups / interviews was:

- Currently practising in health and/or social care.
- A serving police officer.
- Have experience of working with, and/or caring for people living with dementia.
- Have experience of technology in relation to working or caring for people living with dementia.

Data collection

The data collection for the focus group and interviews utilised a semi-structured interview approach. This methodology was deemed the best suited for the collection of data about the professionals' views and experiences regarding the use of technology in the care of people living with dementia.

The research participants were interviewed once. Written informed consent was obtained at the start of the interview and verbally confirmed at the end of the interview.

The focus group and interviews explored people's views and experiences about

- the use of technology to support people living with dementia;
- tracking technology for people living with dementia;
- the proposed technology that was to be used in the research project (the wristband, smartphone app and the carer application).

Professionals views about wearable technology for people living with dementia

This section presents the research findings from Stage 1 interviews with health and social care professionals, with the police and with people living with dementia and their unpaid carers.

Given the range of levels of technology in everyday life it was important to find the participants' levels of awareness concerning technology in general and tracking technology in particular. The awareness and views of professionals concerning trackers and technology for persons with dementia were gathered through one focus group and two individual interviews. The focus group consisted of two professionals from different backgrounds: community social work and nursing, respectively. The former [A-FG2] drew on her familial and professional experience of people living with dementia and the latter [B-FG2] drew on her nursing experience in hospital and community settings. Further individual interviews were held professionals the social work [D-MS] and nursing [E-MF] fields, respectively. Participant D-MS drew on her on-going experience of her mother's dementia. Participant E-MF, drew on her experience of community nursing and her present teaching role in community nursing. A member of the research team, a qualified community nurse and nursing academic [F-DD] also added in their experiences of using technology in the focus group.

Technology

The social and nursing professionals' awareness of technology was influenced by their professional experience. All the professional participants used computers, printers and mobile phones but did not refer to those items when asked about their knowledge of technology. This highlights how embedded some forms of technology in people's day-to-day activity. Those from a nursing background were familiar with the use of technology in the monitoring of clients health.

- *The type of technology that I am familiar with things like tele-health, so remote health monitoring etc., I mean district nurses are already using technology with, for remote consultations etc. tele-health time stuff… I mean the stuff like tele-care stuff all the monitors and that that they use massive scope, they really do make people's lives a lot easier and reassuring for both the client and for the relatives (E-MF).*

- *From a personal experience, I was a technophobe 20 years ago. You know? Did a degree handwritten with pen and paper and then got someone to type it … I was terrified of switching on a computer. Obviously that's, you know, in terms of both personally and professionally I've had to develop and gain those skills (B-FG2).*

- *The Satnav has changed my life because before that, in a car if I was going somewhere I didn't know, I got lost everywhere I went. (F-DD).*

In terms of thinking about the technologies, although GPS is widespread there are still areas that are 'dead zones' and this has implications for how affective tracking technology can be.

- *So yes, I mean Salford for example, they're almost paperless, over in Glossop they can't get signals so again it depends on the areas… Some of the technology at work is fine and some areas you can't get signals, so it's actually obsolete and I also know cases where stuff has been put in at great expense and then it's like "Good grief it doesn't work because signals are not strong enough" (E-MF).*

The range of equipment available in each field and the degree of interaction with the technology was also assessed in the context of participants' professional experience and practice.

- *You have your very basic technology like your care call pendants, your sensor alarms, you know, bed sensors – things like that – that we make referrals to all the time. - Its very limited [range of technology] (A-FG2).*

- *In terms of the actual equipment yes it's hard to keep up with it but that's the same with any type of technology, probably about two thousand and one blood sugar monitors. I've, on more than one occasion gone in and some type of equipment has changed and I've said can you tell me how to use it, hold my hands up, or have you got an instruction book or can you hang on and I'll go and get a colleague. If there is a new piece of equipment that keeps turning up then, well I know from experience that nurses would actually ask for some type of training package or they'd go and actually find out, get a rep round or something. (E-MF).*

Conversely, the focus group discussion revealed the differences between health and social care regarding technology in practice and training.

- *But even me as a practitioner, I can do it as an individual but maybe as an organisational role there is no adoption of tech- there's no consistent adoption of technology – maybe down to the individual – practitioner themselves saying, "Oh, that's a good thing." … How we bring technology into social work practice instead of just being an assessor? What I mean is - I know that technology is not in - it's not in academic social work practice.*

Overall, the professional's knowledge of technology reflected their personal and professional experience. The use of technology in the different fields was apparent and was significant in how these participants interacted and related to technology.

Tracking technology

The use of technology for location tracking is continuing to expand and covers many areas: individuals tracking their fitness, employers tracking vehicles and personnel, parents tracking their children, owners their pets, and health and care services tracking their clients. There is an increasing range of devices that service the market including: badges, belts, fobs, pendants, and wrist worn devices.

- *Tracking technology? Well I know there's all sorts of things, there's like the GPS type stuff as well. I know that there are alarms that you can use for animals and for humans as well and I think one of my friends used to have a wristband on her child at one point. So I know they're not new - they've been around, I'm sure they've developed a lot. (E-MF).*

- *My only experience of tracking technology comes from, going back to my criminal justice, is people being tagged so that's about it. (D-MS).*

The professionals, both through personal and work experience, noted the need to assess the capacity of the wristband device and how this might be experienced by people living with dementia.

- *Patients with dementia are obviously going to have additional problems in terms of dexterity, perhaps, or cognitive behaviour around having- they use the technology. So I suppose for me it's about how we overcome some of those problems. (A-FG2)*

- *So, there are really nuance little things about positioning and peoples speed of processing information and peoples capacity to retain information, retain new skills which are all affected technology. (D-MS).*

- *She couldn't learn a new skill and she couldn't retain the information, she wouldn't know what it is now in the same way she doesn't know what the pendant alarm is. I think this is probably for people, if its reliant on the person with dementia having some insight into it, having some skills around it. It's probably not for people who are very late on unless it can be controlled by somebody other than the person with dementia, like I say unless it's some sort of system which activates for me to take control of. (D-MS).*

- *So whatever technology there is needs to take account of really small nuanced things about the way people live their lives, so if it was something*

like her getting lost she'd need to know what the thing was, know where it was and know what to use it for and how to use it which is not undoable in perhaps the early stages of dementia, it's impossible now there's no way she could do that now. (D-MS).

- *So yes, technology's great but it has its drawbacks. It's not the panacea for everything. So it works for some people, it will work for some people and if it solves or supports and makes life easier in some way for people with dementia and their families that's fine. But as I said, it's got to be, it's got to be focused on the patient, on the client and not used for surveillance purposes or to replace the health professional or a friend in society. (E-MF).*

A major area of concern for the professional participants was the ethical considerations of tracking technology.

- *It's interesting when you look at the literature – both academic literature and the kind of popular media: there's a lot of concern around the ethics of tracking and kind of the rights of the individual and all that. (A-FG2)*

- *Who's benefit is it for, is it for the benefit of the person, is it for the benefit of their carer or their relative, is it for the benefit for the healthcare or social care style, who's benefit is it for? (E-MF).*

- *I think it's who's got access to the tracking. You know? If it's in that person-the client's best interests and they, you know, some may have agreed to it, and the family are happy with that and they're the only people who've got access to the tracking. (B-FG2)*

Personal experience challenged the professional ethical debate.

- *Speaking as somebody who's got a vulnerable adult to care for who might get lost I'd say to the human rights activists, "Bugger off" because I'd rather know my mum's safe. (D-MS).*

The vulnerability of PWD was acknowledged. However, technology was viewed not only as an aid against vulnerability but possibly leading to another form of susceptibility: 'virtual vulnerability'.

- *So somebody who's- you know, people with dementia – they are vulnerable. You know? Some can be vulnerable – very vulnerable (B-FG2).*

- *The other thing that bothers me with my background is criminality in the community and what you don't want is somebody wearing something that a criminal will automatically think hang on I know what that is, that person's vulnerable. (D-MS)*

Furthermore, concern was expressed with regard to issues around the impact of technology on the carer.

- *You've got to be really careful with technology - that it's a false sense of security. (D-MS)*

- *I think there's a danger of relying on machines they're like a safety net, if people have I don't know, a wander mat or something it's like mum and dad will be okay because it's the wander mat, it's like okay well that's not going to stop them climbing out of a window. (E-MF).*

- *I wonder if it could become almost like addictive though in a less than positive way for relatives. You know that they are, your mum has dementia, you're concerned about her, you know she's gone out with her thing on and you're checking, you're checking again and you're continually checking. It becomes an addictive behaviour which actually could be quite restricting for the relatives, the relatives health. (E-MF).*

Vulnerability to the changing market of health and social through policy change was spotlighted.

- *I know that there have been tele-care systems, tele-health systems that have been put in and people, it was free at first when they had the government pump priming money and now people have to pay or they can only get it for so long and then they have to pay and I think that is why because then you're given something and then taking it away because they cannot afford to pay. So you know I would like to see an equality in terms of provision. So, it's not just people who can afford to pay that are able to get these things, quite often those that have the money have more ability to use other sources of support and that whereas people that are most vulnerable are often the ones that don't have the money. (E-MF).*

Furthermore, there was an awareness that carers and families were adapting everyday mobile phone technology to monitor the people living with dementia.

- *Around the kind of tracking technologies and what they found when we spoke to the team in the Dementia Support Unit they said some families are using 'Find my iPhone'. So, if they have two iPhones that are connected, the family member can track the person wherever they are using the iPhone, so-people are kind of using this kind of technology even if they're not kind of officially accessing it.*

The professionals view of technology in general and tracking technology in particular, demonstrated a wide range of experiences and opinions. How the

different professions trained, worked with and accessed technology raised questions concerning the training of social care professionals. The juxtaposition between individual personal and professional experience highlighted the practical and ethical questions that assistive and tracking technology raises.

Greater Manchester organisations working with technology for people living with dementia

As the initial work developed the research team came across statutory and charitable organisations who use technology to support older people and carers in the community. The services provided and quotes from member of both organisations are now given and as part of the professionals response to using technology in community care contexts and supporting people living with dementia.

Stockport council's Adult Social Services provide a pro-active telecare service and look actively for different solutions and the circumstances of the person living with dementia to decide which solutions work best for them, these could be technological or other. They have done in-house testing of wearable trackers of different types (including watches, pebbles, smartsoles). In the review they examined ease of use of device, accuracy of GPS signal, battery life, web portal functionality and cost. They found with some devices that they are not very accurate. At the moment they provide one model, but will look at different ones if the functionality of that does not meet the needs of a client.

> *"It's needs based so when we're having the conversations either with the social worker if it's clear that this isn't going to meet the need we then will look at other options. " (Stockport council staff member)*

When these devices are provided to clients, in addition to an unpaid carer being able to track them, Stockport Homes Carecall provide service to be an additional contact if needed.,

They also found the devices are best suited for people in early stages of their dementia, and particularly the call function in the trackers can be confusing for someone with more advanced dementia:

> *"I'm still not convinced that even though this one does it, about voice on these. I think for   your very, very early stages when people are starting to get themselves a bit confused and   they're able to understand what they've got that's fine, that's no problem, I think for the   level of issues of the people we're getting they're quite far down the journey I think it would   be quite scary." (Stockport Home staff member)*

a charity 'Good Deeds Trust'. The charity provide a wristband, badge and keychain for people with dementia, that has their name and contact details for a carer. The personal details are not outwardly visible, but the details are readable using a smartphone. These devices not for tracking people, but can help people who are lost be identified and help them to return to their home/carer. In the Greater Manchester context, the charity started working in Wigan and works closely with Wigan Police, Transport for Greater Manchester and the Fire Service. It is well known locally as well as further out in other areas. They suggest a small donation for the technology but do also provide them for free. Compared to tracking devices these are very low cost and simple technology, that do not require technical knowledge from people living with dementia or their family members.

The Police and People Living with Dementia

Locally, Greater Manchester Police (GMP) have been proactive in raising dementia awareness throughout the organisation. GMP was one of the first forces to sign up to Dementia Action Alliance (DAA). The alliance was formed in 2010 and consists of 'over 150 national organisations across England' (Dementia Action Alliance 2017). Members of the DAA commit to improve the lives of people living with dementia and their carers by enabling organisations to connect, share best practise, take practical action, influence policy, and improve attitudes and understanding of dementia (DAA, 2017). Consequentially, GMP has committed to:

'…pledge to support those with dementia and their families, to live safe lives and to feel supported within their communities. This will improve the quality of life for sufferers, their families and the communities in which they live and work'.

On the practical level GMP officers and staff attend 'Dementia Friends' training. Moreover, GMP support and promote the use of technology by people with dementia and their carers.

'GMP will continue to raise awareness of devices that can assist those with dementia and their loved ones, such as the Guardian Angel Dementia Buddy devices and the Dementia Emergency App'.

A male PC presented the view of the police concerning PWD who are reported missing.

> *'I mean missing people for this force are huge. I think we're second outside of London for the number of reported missing people. We're the first port of contact for when people go missing … we categorise our missing's high, medium, and low [through a 12 question risk assessment]. Someone, who went missing with dementia would be reported as a missing person straight away and usually in our system we look at grading [the risk]. So has the*

person got any capacity? Well if they've got dementia they haven't got any capacity. They'd be what's deemed a high risk missing.'

The categorisation of a missing person as high risk consequently involves extensive use of resources.

o *'In terms of people with dementia, they would probably be categorised as high risk every time they went missing. It's very, very resource intensive. It would usually mean that every single person, no matter what they were doing, would drop what they were doing and start looking for that person. If they've got a mobile telephone we might go to the service provider and try and ping their phone for triangulation but obviously triangulation tells you, yes, they're in an area but never gives you a definitive. A lot of the time you're just boots on the ground, looking for people.*

One major issue for the police is recognising the person with dementia who has gone missing. A recent photograph and a description of clothes greatly aids both CCTV operators and searching police officers.

o *A lot of people, you know, if you're elderly, never been in contact with the police, getting a picture of someone is very, very difficult and the biggest difficulty is in care settings. What you find in care settings is that, staff that work there, they don't know the people they're looking after. We get other ones where they live at home, carers come in and then they'll go wandering and you know, by the time the carer's been round … to get them up, feed them at lunch then come to put them to bed. You know, you've got a long time to get away there. We still do get a proportion of people who go missing from home addresses where the price of care as well... People like families round to look after relatives now rather than, you know, in a care setting.'*

• *I mean I think the software would have to be developed so it said, right, there's a system that the police log in to. There's a criteria for logging in, you can [Unclear] you know, do it for missing because obviously we've got to comply with relevant legislation because technically if someone didn't know they were being tracked then that would constitute intrusive surveillance.*

• *I think it's a great idea. I think the design - I think there's going to be a massive stigma around people wearing them. I think from a police point of*

view being able to track somebody who has gone missing, you know, that's a potential life saver but only if we can have access to – if you're allowing your third party I think it would, like, tracking an IPhone when it goes missing.'

o *'Trying to find someone that's missing is very, very difficult. It really is. It's probably one of the most challenging and complex things that we do'*

In addition to the interview a female serving police officer provided practical information via an email and noted:

I've attached details of the E Card which are given out for free by GMP to all with an additional need who wish to carry one, so not just dementia.

GMP are unable to say how many missing people reported had Dementia unfortunately as there isn't a specific code for dementia we can pull data out with. But if I examine all incidents reported to GMP which refer to Dementia we had close to 20,000 last year.

Our statistical data for Missing Persons from 01 Apr 16 to 31 Mar 17:

The 16/17 figures show an increase, across the Force, of **1523 individuals** (1046 Adults / 477 under 18's) from 12004 individuals to 13,527 individuals.
The figures also show an increase, across the Force, of **8677 missing incidents** (which means a single episode) (3225 for adults and 5452 for under 18's) from 24,677 incidents to 33,354 incidents.

Similar data for the past 3 years has shown an increase in incidents of approx. 20% per year, but this year's increase is clearly more than 20%.

Financial costs :
Using the University of Portsmouth's estimated cost of a missing person investigation (circa 2012) of £1325.44 per medium risk incident, the cost to GMP of missing person investigations has in a 12 month period increased from £32M to £44,208,725.76.

GMP continue to advertise and distribute Emergency Cards (E cards) to members of the public with dementia/ disabilities who request them to aid in communication if they ever need assistance' (DAA, 2016).

The information provided by the police was of particular importance as by noting that there were no specific codes for people missing who had dementia illustrates why the costs to emergency services, associated with wander-walking, are difficult to estimate. Further work on this issue is then needed. However, through the interviews

with health, social and emergency care providers, it is became clear that there are multiple stakeholders who have an interest in providing and evaluating how technology can support for people living with dementia and their carers.

Interviews with people living with dementia and their carers

The second stage interviews examined whether participants: were receptive to, and what they thought about, the role of technology for people living with dementia and their carers, and the proposed solutions, including any concerns they have. The plan was to conduct one focus group with older people and their carers, but this evolved into individual interviews. This was partly due to scheduling issues but also because many participants preferred to do an interview in their homes rather than in the university as initially planned. One interview was conducted in the university with a person with dementia who lived alone, A further three interviews were conducted with people with dementia and their unpaid carers. A total of 7 people were involved in this part of the study, participants are coded as IV (Interview) 1-7.

Who	Number of participants
Person living with dementia	4
Unpaid carers	3
Total	**7**

Table 3: Interviews with people living with dementia and their unpaid carers

Recruitment of Participants Living with Dementia and Carers

The research team promoted the research via the Age Friendly Manchester newsletter, MMU's Service user and carer group. Additional contacts were made with local support groups across Greater Manchester.

Inclusion / exclusion criteria For potential research participants living with dementia Inclusion criteria for the focus groups was:

- being in the early stages of dementia;
- having capacity to understand the study. Further details of assessment of capacity are given below.
- preferably have a carer (either a co-resident carer or another carer closely involved) who can support them to take part in the focus group.

Data collection

The data collection for these interviews utilised a semi-structured interview approach. This methodology was deemed the best suited for the collection of data of the views and experiences of people living with dementia and their unpaid carers about the use of technology in the care of people living with dementia.

The research participants were interviewed once. Written informed consent was obtained at the start of the interview and verbally confirmed at the end of the interview.

The interviews covered people's views and experiences about

- the use of technology to support people living with dementia;
- tracking technology for people living with dementia;
- the proposed technology that was to be used in the research project (the wristband, smartphone app and the carer application).

Themes arising from the interviews identified that there were three distinct areas related to the use of technologies and how these might support people living with dementia and/or their carers:

Impact of dementia on everyday living:
Wanting to remain independent
Previous experience with technology:

Impact of dementia on everyday living: When asked about the impact of the condition on everyday living it was clear that whilst memory and loss of short term memory were difficult they were not the overriding challenges. When asked if they had got lost all the participants had had some experiences of this for a range of periods of time resulting in a great deal of stress for both the person with dementia and their relatives and carers. Familiarity with the area was a key factor so if people had lived in the area for a long time they felt more confident to go out independently. However, when areas were being developed or there were road works or diversions people became disorientated and less confident in going out alone.

Memory was highlighted as a particular challenge as well as concentration levels. The first interview was used as a pilot. On reflection the researchers felt it was quite long as the participant became anxious part way through and asked if was going to be much longer. As a result interviews undertaken after this were modified for those taking part in the study either just to be interviewed or interviewed and going on to trial the devices.

Explanations need to be simple, clear and concise. Visual aids really helped with understanding the applications.

Showing all three devices/ applications in one session appeared overwhelming with Participant **IV-1** saying "*How complicated is all this?*" when asked if we could show her the fob.

Participant **IV-1** also became more anxious towards the end of the focus group interview asking "*Have you got a lot more to go through?*"

From the initial interview it became clear that when interviewing people for studies such as this consideration should to be given to: the length of interviews; the type of questions asked and the amount and type of information given regarding the study. In particular, it may be necessary to incorporate short breaks or break the interview into separate session. As a result, the researcher team adapted the interview schedule to address this for other participants as the study progressed.

The participant said:
"My bigger problem is short term memory because you can't remember what you just said and things like that. It's other things as well like ...can't count money, can't read a normal watch, get lost, get stuck for words. It's not just all the memory it's other things as well which, ...which compiled everything and it's other things like getting washing and dressed in the morning which is a problem as well. So it's other things as well as just memory, so yes..." **IV5**

Wanting to remain independent for as long as possible was given high priority by all the respondents and their carers. Asking for help and not feeling stupid were seen as both positive and negative aspects of living with the condition. Remaining independent relied on the support of family, friends, local community and networks as well as familiarity of the area they lived in.
"No I will be as independent as long as I can, you know what I mean, yes?" I have got a very, very good friend, yes, ...she's my rock, yes **IV5**

Relinquishing a driving licence was extremely distressing and seen to have a huge impact upon the person's independence. This is evident from an interview with a participant and their carer:
> *"I stopped driving. I can't drive. Lots of things I can't do now... The car's gone and I hate that. I loved that car".* The carer responded "*Yes. That was the thing that really upset you, wasn't it? Yes.. stopped driving,*
>
> The carer went on to explain *"He was going around the roundabout the wrong way, so-...."* **IV7 (carer)**

Previous experience with technology:
In exploring the use of technology in everyday contexts, all participants had some experience of technology. Examples of previous technology identified in the interviews included a: Dictaphone/PC/Mobile/Care call/talking watch/ audio books / CD player. However, interestingly not all participants necessarily recognised these as examples of technology.

Participants had some previous experience of companies being set up to help people who had dementia and were at risk of getting lost e.g. Contact For Me. However, some of these companies had gone out of business and then participants were not aware of any others providing similar service/ reputable. They felt that there was limited information from healthcare professionals and social services and often had to seek out information themselves which meant some people gave up or found devices which were not suitable.

Barriers: Participants were asked about potential barriers to using assistive technology particularly in relation to privacy and deprivation of liberty. Views on liberty/ tracking from other people as portrayed in the media- are often seen as taking liberty away but participants felt this was not the case suggesting that not everyone has the confidence to ask if they get lost so any device addressing this issue would help with this.

One participant said:
"I know people say it takes your liberty away. It doesn't, I am sorry I would be very happy walking around with a thing on my wrist if I get lost that's not my liberty, that's security for me. I would be very happy with that, yes, yes very happy with that. Some people aren't, but I would be very happy with that, yes..." **IV5**

Supporting factors
In terms of what factors might support people living with dementia and their use of technology, through the interviews it was identified that the following factors should be taken account of:
- Familiarity – was the device similar to something that they had used in the past
- The look of the device- not too bulky needs to look like normal watch with an option to choose a 12 and 24 hour clockface.
- Different types of fastening/ dexterity were significant in that different participants preferred different fastenings depending on their ability to manipulate objects. One participant suggested an elastic expandable type of strap that could be slipped on and off and required no manipulation to fasten it. This is a consideration for future developments when designing fastenings.
- Simplicity
- Got to be accessible easy to use

- Generally participants liked the look of the device as it resembles a normal watch. One participant
  a. said *"It looks excellent. Simple enough, even for a non-techy like me".***IV6**

Another said *"Okay. I mean, I think the thing that attracted us to the thought of it is the fact*

it's a watch, because the problem with this is it's reliant on- you don't always take your keys

or you can't always find your keys, can you? Even when they're in your bag, sometimes you

*struggle to find your keys now. Whereas this, if it's on your wrist, it's not difficult to find".***IV7**

Participants and their carers felt this type of device was more user friendly and would be more acceptable rather than for example a device that was worn around the neck or carried as there would be a tendency to forget it unlike this device which was more like wearing a watch.

This was supported by another participant who had tried a device from social services but it had not been helpful as their carer said – *"...which I haven't actually used yet because, for one reason or another, I was going to put it in his pocket every time he went out and he used to dash off out before I knew he'd gone....*

Following the interviews with professional stakeholders, people living with dementia and carers the research team took the recommendations forward into the technology testing phase of the study.

Technology testing

The aim of this stage of the research project was for people living with dementia to trial the technology in their daily life. The aim was to recruit up to 10 people living with dementia, but due to challenges with the technology the research team had to limit the number to four. This enabled the team to support these participants more closely to ensure the equipment was useful for them. Research participants in this stage of the project included:

Who	Number of participants
People living with dementia	4
Primary carers	4
Other carers / family members	3
Total number of participants	**11**

Table 4: Research participants in technology trial

The biographical details of the research participants in this stage of the project are detailed in Table 5 below.

Who	Age	Gender	Living situation	Main carer	Other carers in study
Case 1-EG	80s	Female	Lives alone in supported housing	Daughter	Son-in-law
Case 2-JH	90s	Female	Lives alone	Daughter	None
Case 3-LC	60s	Female	Lives alone	Daughter	None
Case 4-KB	60s	Male	Lives with partner	Partner	Sister and brother-in-law

Table 5: Biographical details of research participants in technology trial

Participant recruitment

The research participants for this stage were recruited through the same approach as detailed in the focus group recruitment. Following initial contact, the potential research participants received an information sheet about the study and were given an opportunity to discuss and ask questions about the project and the technology.

Inclusion / exclusion criteria For potential research participants living with dementia the inclusion criteria for the technology testing was:

- Being in the early stages of dementia;
- Having capacity to understand the study. Further details of assessment of capacity are given below.
- Being able to go out in the community alone

- Have an unpaid carer, or several, who are also willing to take part in the study and can support their use of the technology. This was an essential criteria as each participant needed a carer who had the tracking application on their smartphone. The application only worked in certain smartphones, which meant that not everyone who expressed an interest was able to take part in the technology testing.

Data collection The data collection for the technology testing used a multi-method approach, with a combination of unstructured interviews and participant observation. This methodology was deemed the best suited for data collection with people living with dementia and their carers to collect best possible data in a way that is least disruptive to the research participants.

The research participants were met a minimum of three times:
1. an initial meeting,
2. for installation of the equipment
3. a final interview.

In two out of the four cases the research team had to meet the participants an additional time to resolve technical problems with the wristband which in some instances resulted in the need to provide replacement wristbands.

Visit 1: Interview and participant observation
This visit was conducted with a carer and the research participant living with dementia in their own home, or other suitable location.

The visit had two purposes,
1- To understand the daily life and challenges of the person living with dementia and their carer by exploring
    o the everyday life routines of the person living with dementia, particularly going out in the community, walks, shopping and so on;
    o their key unpaid carers and other support;
    o previous experiences and current views of technology, both of the person living with dementia and their main unpaid carers

2- To discuss the technology with the research participants, both for them to understand what the equipment does, explore if it is suitable for them, and to gain their views about the equipment

Visit 2: Installation

In most cases a separate follow up visit was organised to install the equipment. This was done by one of the researchers who was trained by KMS Solutions to carry out the installations. In one case the installation was done during the initial visit, but they also were visited for a second time due to technological problems with the equipment. This visit also included a brief semi-structured interview to follow up issues arising from the first visit.

Visit 3: Interview and participant observation at the end of the user trial.

The purpose of the visit was to explore the experiences with the equipment of the person living with dementia and their carer, including: both positive experiences and challenges or barriers to using it. The visit also investigated if there had been any changes in the research participants situation, including any changes in health, support needs or other arrangements.

In one case the final feedback was provided by email. This was in a case where the research participant living with dementia developed health issues during the study. Their daughter was the main carer and participated in the study with her mother. She also had another family member ill during the study which meant she did not have time to do another interview in person. The researcher discussed this with her, and suggested either taking part by email, or withdrawing from the study. They decided the best approach was that she would provide final feedback by email. An important aspect of doing research with people in vulnerable situations, and their carers is to be aware of the complexities and pressures in their lives, and to plan and adjust the research approach accordingly.

Email updates and diary

The research participants were asked to keep brief diaries to log their experiences. In practice this was done through email contact by a research team member with the participants who replied with their experiences.

Exit procedure

The wristbands require a mobile telephone SIM card to function which requires a contract with a mobile telephone company. During the project the research participants were able to use the technology for free for a maximum of three months. At the end of the trial, participants were given the offer to keep the wristband and with a telephone contract for a year. After this, they would have to purchase a SIM card and set up a mobile phone contract at their own cost. Three out of the four research participants chose to keep the tracking watches after the study.

Ethics and safeguarding

The research team applied for ethical approval from Faculty of Health, Psychology and Social Care's Ethics Committee at Manchester Metropolitan University for each stage of the study.

Particular issues with this study were safeguarding aspects related to giving people living with dementia new technology and their cognitive ability to understand the limitations of the equipment and give consent to the trial.

When introducing the technology, the research team made it clear to the participants and their carers that the device is an aid that was on trial. They should not change their usual practices, such as using telephone or contacting emergency services if they were concerned of the whereabouts of the person living with dementia.

Each family were also provided with Herbert Protocol form (see Appendix 1). This is a scheme used by some police forces and other agencies. The aim of the form is for carers to have useful information ready "which could be used in the event of a vulnerable person going missing. Carers, family members and friends can complete in advance, a form recording all vital details, such as medication required, mobile numbers, places previously located, a photograph etc. In the event of your family member or friend going missing, the form can be easily sent or handed to the police to reduce the time taken in gathering this information." (West Yorkshire Police, 2017).

While the project team aimed to give research participants the opportunity to test one of two technological options (mobile phone watch or a smartphone application), all research participants chose to trial the same option (the mobile phone watch).

The research team had agreed to only offer the MyTrav smartphone app only those who were current smartphone users, as learning to use a smartphone by someone living with dementia, as part of this research project, was not feasible. None of the research participants with dementia used a smartphone so the tracking watch was the only option for them. This was expected as recent surveys of mobile phone use suggest that only 28% of all adults aged 65-74 and only 8% of adults aged over 75 years were using a smartphone in the UK in 2015, compared to 70% of all other age groups (Ofcom 2016:41).

Trialling the technology in everyday life of people living with dementia

There were four research participants living with dementia who trialled the equipment. How successful this was different in each case and varied due to many different reasons, such as the impact dementia has on the cognitive ability of the person living with the condition; the relationship between carer and person with dementia; the technological awareness and competence of both the person living with dementia and the carer; as well as the timing of starting the use the device.

For this technology a dyad of a person with dementia and a carer was required as the watch had to be 'tracked' by someone on their smartphone application. The carers in this study were all family members. Their role was also to facilitate the use of the wristband by the person living with dementia and be the first point of support.

Three out of them found the equipment useful, despite each encountering technical and other challenges with them. However, this type of technology is not suitable for everyone, for different reasons. In this study, for one research participant the technology was not helpful. This family's experiences are described later in this report, see case study 2.

The tables below give a brief introduction to the three research participants who used the tracking watch successfully, detailing their circumstances and the key issues they had with the technology.

Case 1-EG	
Person living with dementia	EG, female in her late 80s.
Carers involved in study	Her daughter is her main carer. Her son-in-law very competent user of technology and able to support EG with it Both involved in the study
Living situation	EG lives in support housing
Going out	EG mainly goes out alone to walk to her daughter's house.
Key issues	The family had some problems with the technology but were fairly competent and happy to work around those, and were happy to keep using it. EG's son lives in Scotland and family reported he also found it relief to be able to see mum's activities. The family is discussing with the housing scheme to see if the warden from there could also be a contact on the watch

Case 3-LC	
Person living with dementia	Female, in mid-60s, recently bereaved. Lives alone, supported by daughter who lives close by
Carers involved in study	Her daughter is her main carer. She is competent with technology and was able to resolve some problems herself.
Living situation	LC lives alone, she is recently bereaved.
Going out	LC goes out mainly when accompanied with someone, she has had a few problems and has lost her confidence about going out.
Key issues	LC had a simple mobile phone but had problems using it – by the end of the study she was competent with the watch and used it for social calls also. They had some technical problems with the watch but mother & daughter were fairly happy and able to work around it. Despite the problems very positive on the technology and keen to keep using it.

Case 4-KB	
Person living with dementia	Male, early onset Alzheimer's, in his 60s.
Carers involved in study	His partner involved throughout the study His sister and her husband involved in the first visit and also had the smartphone app during the study.
Living situation	Lives with partner, she works full time. KB works part-time in a dementia day centre
Going out	KB is often home alone and goes for walks with dog or to the pub. He does not bring his mobile, and his partner worries about him and can't contact him.
Key issues	They found the watch very useful, and only had minor technical issues that resolved themselves. Very positive and straight forward experience, they are keen to keep using the device.

Need for the technology / motivation to be involved in the study

The family carers had experiences where they were unable to locate the person with dementia. These can be very concerning to the family members, as research participants describe:

> "I lost her [EG] in Stockport one day and it really, really worried me because I didn't know, and she wouldn't, she wasn't answering her phone. I don't know whether she couldn't hear it or whether it wasn't working or what but she

wasn't answering her phone and I couldn't get in touch with her…" [Case 1 - EG's daughter]

In one case the main carer was employed, and her partner KB (Case 4) was often home alone. Part of his daily routine would be to go for a walk with their dog, or go to the local pub:

"So the reason we were interested in this is that, we can, at the moment KB walks the dog a lot and if ever he got lost or, you know. So it's, sort of we know, we can contact him and if he got into difficulty or anything. It's peace of mind for me really, when I'm at work and not here… Because KB doesn't really communicate with me the way he should. I think it's, he just goes off and doesn't leave me notes… and then I come in from work and I don't know where he is, you know. I usually find him in the same place but, you know there could be a time when he's not there. I've said to him, you know it will backfire on him one day. I just don't, you know I might just assume he's at [the pub] and then he's not. You know, he is in trouble. So that's why we were interested. [Case 4-KB, partner]

These experiences can also be concerning to the person living with dementia. Case 3-LC explains when she was attending an appointment and the taxi driver was going to drop her off somewhere near-by but unfamiliar to her:

"So I said I'm not getting out. I don't know where I am. He said you're getting out here and I went I ain't getting out here because I don't know where [I am]" [Case 3-LC]

She explains she had her phone and was able to sort out to get to where was going to, but that she was very upset by the experience:

"By this time I was in floods of tears because I was absolutely mortified that I was going to be lost in Manchester with no way of getting anybody… by the time I got to the place I was an absolute complete and utter wreck… every time I thought about it I burst into tears" [Case 3-LC]

This experience has made her lose her confidence about going out on her own, particularly to unfamiliar places:

"I am very reluctant even to go in a taxi if it's somewhere I'm not really sure where I'm going. So I am very reluctant to go… I don't know whether I would venture to places that I was a bit uncertain of now but I don't know." [Case 3-LC]

There are different solutions to help coping with everyday life challenges caused by dementia, such as getting lost. The ones used by the research participants included a card with contact details. Case 1-EG's daughter explained that her mother has one of these cards in her bag, and once when EG got lost, a stranger was able to call her daughter because of this card.

Also research participant 3-LC, explained that she would be happy to ask for help and would try to look for someone she could trust to ask for help:

> *"Yes I would need to but probably would ask, probably would have to be somebody like a traffic warden or a policeman or an ambulance man. Somebody who I could actually trust… I would probably go for somebody or a shop, go in a shop and ask the shop person rather than somebody on the street. I think so but sometimes when you panic your brain does not work the same as it would have."* [Case 3-LC]

Part of the problem in these cases was caused by the challenges the person living with dementia had using their phone, or would not carry a mobile phone with them. While there are many simple-to-use devices, these are not suitable for everyone. One of the research participants [C3-LC] had bought a simple-to-use mobile phone, but did not find this easy to use. When 3-LC carried it in her pocket, it had accidentally called her daughter. This made 3-LC uncomfortable and she would often not turn it on. They also had problems with the volume, which would be so quiet that her family could not hear what she was saying.

These issues made the research participants interested in tracking devices. All the carers were aware of these devices in advance and were very keen to try them in the study.

Challenges understanding and learning to use the technology

The tracking watch used as part of the project and worn by the research participants has four buttons. One of these is silver coloured and clearly tactile, similar as a button in regular watches. This is the only button that a person wearing the watch will need to use. The watch also has three buttons, which are more blended into the watch (e.g. they are the same colour as the watch). Each of these has a purpose (on/off button and phone directory) but these do not need to be used by the wearer of the watch and were not shown to the research participants. The director from the

technology company explained that "they're deliberately black [in a black watch] because we didn't want confusion" (Chris E from KMS – focus group 1).

For the person living with dementia, all they would have to do is press the silver button to initiate a call with their main carer. The SME company explained how they saw this working: "*So that's all they have to do. Press and hold the silver button. Away they go… it's as simple as that for the person wearing it.*"

In the use trial it did not turn out to be that simple for all the research participants. If the silver button is pressed once, it initiates a call with the main contact via the system. However, if the button is pressed again, this cancels the call. The research participants required some practice to learn how to press the button, but the three participants discussed in this section were comfortable using it in the end.

When research participant 3-LC first saw the watch, she was bit concerned about the buttons: *"I won't have to faff about what all these buttons will I? I'm not good otherwise having to faff about with the buttons." (3-LC)*

However, she learned to use the buttons, particularly the contact list. She felt more comfortable using the watch to make phone calls and was able to use the watch to call different family members. The other two participants were told to only focus on the silver button, but did not use it to initiate calls.

5.3 Technical challenges and dealing with those

There were several technical issues with the tracking watch during the trial. Two key ones, location accuracy and charging issues are discussed below.

Location accuracy

The satellite system used by device in the trial was not always fully accurate. It would give the location of the watch in the local area but it might be some streets away. This was particularly the case in more rural areas. Families were made aware of this at the start of the trial and with the awareness they were able to work around that:

> "But it only gives like the general area where he is, but that's fine." [4-KB, partner]

Case 1-EG's son-in-law explains that when EG is in her home,

"Depending on which satellite or which mast it picks up, it can give a different address… So it can actually, you know [her] home could be one of four addresses, I think..the satellite will pick it up at the back of the house, but not the front. So if she's sitting in the lounge in the front, it might pick up a different location." (1-EG, son-in-law)

Because the family understand the limitations of the technology they can make it work:

"But we've worked that out, haven't we, though.. we know that means she's at home. "(1-EG, son-in-law)

Charging

The charging of the device is done with a USB charger that attaches to the watch magnetically. Most research participants found it problematic as the charger cable could detach from the watch easily:

"Because it's not the easiest way of charging it, you know… it can easily fall off, so… We worked out a place where she obviously could leave it with it on top, you know. Because It's only got a short...a short lead. So it, you know, couldn't put it where we were going to put it. So it ended up in the kitchen, but it's fine." (Case 1-EG, son-in-law)

Despite the different problems and challenges with the equipment, in these three cases the person living with dementia and their family members were happy to keep using the device. Cases 1-EG and 3-LC had several problems and each needed a replacement watch due to the technical issues during the pilot. However, in both cases a family member (1-EG's son-in-law and 3-LC's daughter) had previous experiences of using technology and were comfortable to try out different things and in some cases were able to resolve problems themselves. In these cases the importance the support network was significant – but also they felt the usefulness of the device was worth the effort they had to put into it.

Making the technology part of daily routines

Part of the research set up was to introduce the tracking watch to the person living with dementia early enough in their dementia journey. The aim of this was that that they would both be able to learn to use the new device, and to make it part of their daily routines.

In Case 1 the device was managed mainly by EG's son-in-law DO, and also by his wife, EG's daughter. The son-in-law, DO, was competent with technology and was happy to install the device not only to his own but also to his wife's phone after minimal instructions. He aimed to keep the process as simple as possible for EG. For example, of some of the practical details of how the wristband operated, he felt EG did not need to know that:

> *"I won't even tell her it's there, you see, so...The least she has to worry about the better." (Case 1, EG – son-in-law)*

During the installation visit he also explained EG was good with routines, and that they would aim to make her wearing the wristband a part of those. During the final interview it was clear that they had succeeded in this and EG was wearing the wristband daily.

When asked about her views about the watch at the end of the study EG stated: *"Well I've got used to it."* Her daughter explains:

> *"So she put it on, and she's been wearing it every day since, so got used to it. In fact you didn't have it on one day because it was charging up or something, and you felt a bit without it, didn't you? Yes a bit lost without it really." (1-EG, daughter)*

Technology isn't a solution for everyone

Through the case study work the research team were able to identify some issues that impacted on the none use of the technologies trialled through the project. The person living with dementia and their carer had some technical problems. While the watch was swapped during the study the person living with dementia did not feel it was suitable for her and was not sure about how she felt about her daughter knowing where she was. The issues that affected the none use of the watch are illustrated through case study 2

Case 2-JH	
Person living with dementia	Female, early 90s
Family members involved in study	Daughter
Living situation	Lives in her own flat but next to supported housing. Staff from supported housing have expressed concerns about her to her daughter

Going out	She is very active, goes out daily either on bike or walking.
Key issues	Daughter was keen on technology as mother doesn't use mobile and struggled with home phone too.
	Her daughter works in a different town and has had to call around to local cafes and pubs at times to try find where her mother is when she is not answering home telephone.
	JH expressed concerns about the technology in the initial interview.
	Daughter told in later interview that they struggled with the technology and were not able to use it.

Need for the technology

JH is a retired GP, she used to live abroad but since retiring and starting to have memory problems she moved back to England. The area she lives in now is close to where she used to live previously. Her main carer is her daughter, who lives in the same area. However, she works at a different area and can not get to her mother fast in case there are problems. JH also has care worker coming in twice a week.

JH is very independent and active, both aspects that are important for her quality of life. She goes out on her bike and walking, as well as on the bus. Often when her daughter is looking for her there are various places, in different directions, where she could have gone. JH going out on the bike has also been a concern as she has a few accidents with it.

JH's daughter tells she's had to call her mother's local café and pub looking for her when she's due for an appointment, or when she can't get hold of her:

> *And they [in the pub] know you as well, so, I go in and go, is she here, and they go no, no she's not, but she was here earlier. (Case 2-JH, daughter)*

JH's daughter was very interested in the technology and it's different functionality. She thought it would be helpful:

> *That's great. Yes, sounds perfect that. It's got more on it than I thought. I thought maybe it was just a one way thing, where I'd be able to, you know if she got in a mess, but actually that's brilliant. It's actually got a phone, so the speaker and, you know. That's even better really. (Case 2-JH, daughter)*

Challenges understanding and learning to use the technology and technical issues

In the initial interview JH was not quite sure about how the technology worked. She also was not comfortable with the idea that her daughter could see where she was, and who with.

> *JH's daughter: Oh I could spend my evenings looking at where you've been.*
>
> *JH: Don't know whether I want you to know.*

She later continued:

> *Well it's like, it's like always going with somebody, sort of keeping their eye on me. Which sometimes, when I just pop across the road or something like that, I don't think I need somebody to look at me and say what are you doing? (Case 2-JH)*

JH's daughter tried to explain to her that she wouldn't do that. For her, she felt that by being able to check remotely where her mother was, she would have less need to question her. She also suggested that if JH was further away from home late in evening, she could go and pick her mother up. However, despite JH and the two researchers present trying to explain the benefits of the watch and how it works, JH was uncertain with it:

> *Yes. I understand that. It's just that I don't, I mean.. [I don't want] nobody ringing me up and saying where are you going now and where are you, you know, or that sort of thing. (Case 2-JH)*

JH's daughter also realised that her mother would struggle to charge the watch. However, after some consideration she realised they could ask the care worker to charge it, if she herself would not be available. She thought the functionality of being able to see the level of charge on her smartphone app useful.

In the end JH accepted that they would trial the watch for a while and see if it was helpful. It wasn't. JH struggled to understand what the watch was for, she didn't like the feel of the bulky watch on her wrist, and she couldn't understand the buttons it had:

> *I thought that the concept of the dementia wristband was very good but we did have   some practical problems using it.*

> *It was rather bulky and as a consequence my mother had a tendency to remove it.*

My mother was unable to understand the function of the wristband and was not able to operate the buttons on the watch in order to use it to communicate. (Case 2-JH, daughter).

Further, JH lives in a fairly rural area. The tracking watch did not work well in the area as it was not accurate with location tracking:

The sat nav function of the watch was inaccurate and unreliable in the area where my mother lives. (Case 2-JH, daughter)

Conclusion: considering which technology is suitable

When I asked JH's daughter why did she think her mother didn't get on with the tracking watch, she reflected that both her mother's independent personality as well her dementia were factors:

I think that it reflected her independent personality (Case 2-JH, daughter)

..in my mother's case it was the stage of dementia that she has reached that prevented her from understanding how it operated. (Case 2-JH, daughter)

However, being part in the study and seeing the potential of tracking devices inspired JH's daughter to purchase a simpler tracker, which is attached to her mother's handbag. JH had problems fully understanding this also:

It also has a function whereby she could press a button on the pebble which would contact me if she needed help. She does not understand this and sometimes activates it by mistake but the tracker device is working well. (Case 2-JH, daughter)

They were in early stages of using this and have not had to use in emergency yet – but have used to find JH's handbag:

…it does depend on her having her handbag with her (which she generally does) but it was useful last week when she lost her handbag! (Case 2-JH, daughter)

Challenges encountered in the research project

The research plan was adjusted and modified as the project progressed to adapt to various challenges. This is not unusual in a research project working with multiple aspects including new technology, working with people living with dementia and university, industry and NHS collaboration.

The challenges that caused delays and changes in the project were around four key issues: working with new technology; working with multiple partners; recruitment of research participants and staff changes.

Limitations of the research

This was a small scale study, with 29 people taking part but only 4 people trialling the technology. The study shows the interest and need for tracking technology for people living with dementia.

Working with new technology in the context of dementia

- The technology company experienced delays with having the devices ready for trialling. This delayed the start of the technology testing stage of the project.
- When the research team trialled the tracking watch, they encountered some technical problems, particularly with the accuracy of the GPS tracking (similarly the challenges research participants encountered
- Most participants had problems with installation of the software and connecting the watch or with other technical issues with the watches.
- People who were put forward an expression of interest, with their carers, to trial the new technologies were not able to manage or use the tracking watch either because of their circumstances or level of dementia, or because of the technical requirements of the devices.

These issues meant the research team had to limit number of participants to four cases (the aim initially had been 10).

Working with multiple partners – and ethical issues

A collaborative research project with academic, industry and NHS partners required careful planning to balance the priorities of each party.

The plan was for the project to apply for NHS ethics approval. However, once the project was started, the research team realised that various challenges would make it difficult to gain approval in a reasonable timeframe. Challenges included working with vulnerable adults, with technology that was new, and with an industry partner and with ten planned research participants for the technology testing. The team

decided to change the recruitment strategy and apply for MMU ethics instead. Unfortunately this decision also meant the NHS partners were not able to be actively involved in the project but could remain in an advisory capacity. As a result alternative methods had to be used to recruit people living with dementia and their unpaid carers which resulted in additional delays.

Conclusions and recommendations

The initial plan for delivery of the study was to offer people choice over the devices they used. The research team was aware that: the person's dementia; their personality and the support networks are all factors in successful integration of new devices into the daily lives of people living with dementia. Three research participants succeeded in using the device, however, as identified in Case Study 2, one participant who did not use the tracking watch, while she had support from her daughter to use the watch, her independent personality and the stage of her dementia made it hard for her to understand the watch and make it meaningful for her.

In summary, through the focus groups and real world technology testing the research team and SME partners found there are issues around:

- the use of technology for people living with dementia and their carers – for some people it was seen as a real benefit, others did not want to engage with the technology or have others know where they were.
- education, information and support for people living with dementia and their carers to use new technologies; even when delivered via familiar technologies this can be challenging and needs support and time
- support for family/other carers who are key to the support of mobile and wearable technologies.
- support for people who do not have a local or remote family carer who can support the use of new technologies needs to be considered.
- current GPS technologies not being accurate as a stand alone way of finding someone who may be lost or needing support.
- safeguarding – which needs to take an holistic approach and include more traditional and 'paper based' safeguarding systems such as the Herbert protocol,
- emerging and new technologies, which are developing constantly but a national approach is still missing;
- the challenges for unpaid carers and people living with dementia to around exploring options around new technologies and deciding what are the best/cost effective options for their situations.
- wearable and mobile technologies which can support people to be more independent in the community, but the technologies need to be: introduced early; affordable and be more easily supported by family and professional care givers as appropriate.

Appendix 1 The Herbert Protocol

West Yorkshire Police (2017) *The Herbert Protocol Missing Person Incident Form.* Available at https://www.westyorkshire.police.uk/dementia/herbert-protocol. Accessed 24th May 2017.

Appendix 2 SME learning from the research

The two technologies description Keep In Touch (KIT) wristband and My Trav - App

Kit Wristband

How works

KIT is a personal safety communications and location device designed for vulnerable people and their carers.

KIT is a wrist worn mobile phone with built in location services using GPS/Wi-Fi and LBS technologies. With KIT your loved one can maintain their independence and you can have peace of mind knowing that you can contact each other with a simple press of a button and you can see where you loved one is using our TAKIT App

SOS call and message alert. If the SOS call button has been activated or a voice message has been sent the TAKIT App will send you an alert to inform you of this.

Real time tracking. Up to 15 people can be authorised by the administrator to see the location of the wearer by simply tapping the Lock feature on the TAKIT App you can see the current location of KIT.

Super low power consumption. Charging kit is simple with its magnetic inductive charger. Just connect the magnetic head of the cable to the metallic contacts on the back of the watch (rotate the connector until the magnets pull it in position) and connect the other end of the cable to a USB power source.

KIT is designed to work anywhere in the world where GSM service is available. We have selected a specially designed SIM card service for KIT that is not dependent on any one mobile network. Our roaming SIM will automatically find a mobile network service if there is one available in your location. As you change location if the mobile service drops on that network then, our SIM service will find the next best available network in your area.

Track route. If you want to see where your KIT wristband has been over any time period, simply Tap Track function on the TAKIT App to see a sequence of previous locations of KIT. Choose a period of time to display and then tap OK to view.

MyTrav

Developed with Newcastle City Council, KMS has developed an Android App "MyTrav" which is currently in Beta Testing. MyTrav is designed to enable children with Special Education Needs (SEN) to undertake independent travel.

MyTrav enables a travel trainer to create any journey to be undertaken by the user and store this journey on the app. Journeys consist of a start and end point with a series of landmarks in between. As the user starts the journey they are presented with a prompt, which is generally in the form of a photo of the landmark accompanied with either a recorded voice or text instruction as to what to do next.

As the user approaches the next landmark and they reach a pre-defined and configurable radius form the landmark the next prompt will appear.

If the user goes off journey they will receive an alert and will be asked if they require help and are offered a range of options from triggering an emergency alert to phoning one of a number of contacts or sending a text message.

The anticipated time to travel between landmarks is also a configurable value in MyTrav and if a user is beyond this time MyTrav will trigger an alert.

The user can see their progress through the journey and can look at is as a linear series of landmarks or on a map view. When a journey is completed the user receives a message congratulating them on completing the journey.

Carers for the user can access the secure b.con platform, which enables them to monitor the progress of the user. When a user, goes off route, fails to arrive or is beyond the allotted time to travel between two landmarks the carer will receive either a text or email alert.

Interviews

It was an excellent process for KMS to be involved with. It added to our previous early research knowledge of what people's perception of technology was, what it might be able to do for them and the fears and concerns people who had Alzheimer's of using technology and the families and carers concerns for the person they were concerned about.

Our learning was that people who had Alzheimer's who took part in the interviews had a good understanding of their condition and what the future issues /risks might be for them. This included the concerns of the families who supported them. They also understood that technology could be a safeguard for them and were receptive to the possibilities technology could offer.

For family members is was a familiar story that we had heard repeatedly of concern for the person who had Alzheimer's and the issues they faced and faced in the future.

This was the first time we had a chance to hear from the professionals. It was an interesting learning process for us especially with the difference in perception of depravation of liberty. Was it enabling or was it monitoring??? Who decides?? Also, that technology was not covered in their academic or on-going learning.

The conclusion from the interviews were.

Pros'

It looked like a watch.

Simple to use.

My family can see me.

Con's

Would it be worn?

It's not for me?

Would it work?

Deprivation of liberties concerns.

Most of the people we interviewed were not technology savvy. They had old mobile devices. Still used phones for basic functions.

It also became clear that MyTrav was not going to be a suitable product to test in this sample. It needs far more support to set up. We have travel trainers to do this.

Family members weren't at a level of technical capabilities to set journeys up. Nor were the researchers. People who had Alzheimer's did not have the historical smart phone use to adopt the use of the app.

Live Environment.

We at KMS wanted to hand over the technology to the researchers for them to carry out the install so we could see where the difficulties would arise if the product landed on someone's door step and the family member was expected to open the box and set the device up. Register on the app. Pair the watch with the app. Utilise the app functionality.

We then wanted to see how the device would function in a live environment and how people used the device or not. What problems did they encounter?

Learning.

The device was difficult to set up and pair if you had no technology or little technology involvement. We have learnt from that experience and have imputed a commercial strategy where the device is delivered to the individual with the sim card in and tested that it is functioning properly. For face to face set up, we also support the downloading of the Takit app and the registering with the app and pairing of the device.

KIT has three location antennas.

The GPS antenna was accurate in an outside setting and functioned well when a GPS signal could be gained. For GPS, a device needs a reasonable line of site to the satellite. Physical infustructre impedes GPS significantly.

The Wi-Fi antenna was accurate and worked well in enclosed spaces so a person could still be seen within a building or built up area. We are reliant on accurate Wi-Fi mapping. We did notice if it hit a large generic Wi-Fi service on a very few occasions it could throw you off to a different location.

The LBS antenna was the worst location performer. People notice that they could be a significant distance from where they were. This is the triangulation of your location through phone masts. The further the phone masts the more inaccurate. What we have noticed through feedback and not necessarily through this piece of research is

that at least we have a starting point. We are also able to use the track function which shows clearly the signal being bounced around between the different location services. This then allowed a more accurate source of where the person was and had been. The movement between the antennas was not clear the person with the app or they did not understand the differences.

The Sim card. We started out using was an O2 sim card. We know from our own scientific tests that the actual GSM antenna in our device out performed better than some mobile phones. But using a network specific sim meant we were tied to an O2 service being available. Some people found that they did not have good coverage. So, during the research we sourced a Telenor roaming sim. This started on the Vodafone network but if there was no coverage it would then search for an O2 or EE network. This is the best available option of total network coverage. We now install this sim in the KIT wristband.

The charging of the device. Some people found that the magnetic charge could drop of the device. We have looked to improve the magnetic strength and have added into the instruction manual to charge the device watch face down (this is more stable) We are also going to build a charging cradle.

The App

We have learnt that the device can't be installed and paired quickly. It's a bit like setting up your new smart phone. It does take about a15-20 minutes process to download the TAKIT app register yourself an account and then pair the watch. We are adding this information to the user manual and it has influenced how we sell the devices directly to customers.

We have designed an instruction manual around all the experiences that have come out of this research process. We are going to add online instruction videos

We are also building a complete new platform and application that will improve the app experience for the person supporting the individual who is wearing the watch.

Conclusion

We are thrilled that most the participants are going to carry on using the devices. We see this as a great endorsement of the solution capability we wanted to offer.

It has been an amazing learning process for us. To develop a product that can support to keep vulnerable people safe. It is imperative we have these research and learning opportunities. It allows SME's like us to have a better chance of bringing a successful solution into the commercial environment that benefits people who did not have a solution before.

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Recruitment

Alzheimer's Society's Dementia Café in Macclesfield

East Cheshire Council

Humphrey Booth Resource Centre

Salford Community and Voluntary Services

Together Dementia Support CIC

Trafford Housing Trust