Jurojin: Designing a GPS Device for People Living with Dementia

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Abstract. Memory loss is the most common symptom of dementia. The impact is such that people living with dementia (PLWD) lose the ability to find their way to previously familiar locations, such as local amenities, and without the aid of others, find themselves confined to home. PLWD report they would like to be able to live unsupported for as long as possible [3] and in this regard the ability to walk to amenities also provides exercise which has been shown to be particularly beneficial for PLWD. This paper presents the Jurojin project which arose out of the Dress/Sense competition to design wearable technology that would positively impact on an individual's health. It details the challenges of the design process, examines PPI (Patient and Public Involvement) feedback and considers whether there might be lessons to be learnt beyond simply designing for PLWD.

Keywords: Dementia · GPS · Exercise · Design

1 Introduction

1.1 Living with Dementia

The number of people living with dementia [PLWD] worldwide is estimated to be 35.6 million [1]. Memory loss is the most common symptom of dementia [2]; however, it is the loss of independence due to increased reliance on others that PLWD find most difficult to cope with [3]. The impact of memory loss is such that PLWD lose the ability to find their way to what used to be familiar locations, such as local amenities; and without the aid of others, they find themselves confined to home. PLWD report that they would like to be able to live unsupported for as long as possible [3], and in this regard the ability to walk to local shops and amenities would have added benefits to an individual's well-being. Exercise is part of a healthy lifestyle across the lifespan [4], and is important for PLWD [5]. Exercise programmes designed for PLWD have had positive results [6, 7]. Exercise can aid cognition, reduce apathy, aid sleep, muscle strength and balance, which in turn can prevent falls [5, 8, 9]. Based on existing evidence, feedback from PLWD, and those supporting PLWD, there appears to be a need for developing wearable, user-friendly GPS technology designed for PLWD.

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1.2 Developing a Wearable GPS Technology for PLWD

The EPSRC funded Interdisciplinary Research Collaboration Sphere (http://www.irc-sphere.ac.uk/) is focused upon addressing a range of healthcare needs by utilizing 'non-medical networked sensors in a home environment.' As a part of their activities they held the Dress/Sense competition in 2014 looking for teams 'to design a wearable item that will have an impact on an individual's health'. Through a series of three workshops participants drawn from disciplines as broad as science, medicine, engineering, art and design worked together to identify potential projects and then form teams to create a prototype to address a particular issue. Workshops were provided introducing participants to technological and health issues and teams were provided with a basic kit that included the Arduino Lilypad development board, a range of basic sensors and conductive thread.

The authors' of this paper were members of one of the teams formed as a part of this process who alighted upon the need for a wearable GPS system for PLWD as described above. Whereas many pieces of new technology foreground their novelty and innovation, what became one of the most interesting aspects of the challenge was that the memory loss affecting PLWD make it difficult for them to learn new skills; this can also result in them being wary of trying anything new. This presents an interesting set of circumstances for anyone designing for PLWD because the novelty and choice so often prioritized by new technologies now becomes a barrier to its use. Given that there is currently no known cure for dementia, if there is to be 'design for all' there is a clear need to address systems that can be used by the 35.6 million PLWD. But this is a need not just affecting those immediately living with the condition given that the proposed freedoms afforded by the device should not be at the cost of already pressed carers having to deal with complexities hidden from the user.

The Jurojin prototype was the result of the team's examination of these issues. In itself this demanded the consideration of alternative strategies in for the systems inputs and outputs. This led to a development process which moved away from screen based interfaces, and the consideration of alternatives that prioritized simplicity that could be incorporated into a wearable. This had to deal with the means by which destinations were input into the device as well as the way routes would be conveyed. Beyond this consideration was also given to strategies that might make the system itself more familiar. This paper will discuss the approaches taken by the team and the initial responses of feedback from people currently supporting, and who have previously supported PLWD as well as the initial responses of PLWD. It will then go on to consider what guidance might be provided for those seeking to design systems for PLWD.

2 Method

2.1 Design Process and Challenges

The initial design for Jurojin arose from discussion between team members (whose skills included clinical experience of PLWD). As a part of this process there was also input from advisors who were a part of the Dress-Sense workshops and who possessed

medical or technical expertise. These discussions highlighted what were initially quite different approaches to the use of technology. Although many technologists are increasingly involved with user centered design, the discipline often begins with technology, with the result that it can often become a 'solution' that is looking for a problem.

As noted above the team had identified the need to move away from screen based interfaces and wished to prioritize simplicity. Arguably, this is a challenge faced by all satellite navigation systems because of the dangers that can be caused through split attention. From a technological perspective this broader problem informed ideas that sought to make use of haptic feedback/vibration in each arm to inform users of the need for changes in direction (in as much that it would address any potential issues of confusion between left and right). This approach was also encouraged by one of the technology advisors because it was felt that such an approach had the potential to address the question of split attention for all users. However, input from those with experience of PLWD quickly highlighted the problematic nature of such an approach. This was because if a garment suddenly started to vibrate, its 'novelty' would most likely upset the user who would then be inclined to discard the wearable. In this way it rapidly became apparent that the novelty we have so often considered to be a defining virtue in new technology would most likely be detrimental to the creation of a device for PLWD. To this extent it could be argued that in some circumstances the design of a 'natural user interface' should avoid the inclusion of novel features.

As a result of these discussions it became apparent that despite a desire to innovate audio was the most appropriate form of feedback. In order to appropriately address the safety of users a single ear piece would be used and preferably a bone conductive device so that spatial nature of environmental events reaches the ears unhindered. Whilst everyday users might consider GPS for a range of activities its use for PLWD would be limited to a small range of 'regular' destinations such as local cafes, supermarket, post office/post box and of course home. Given that what us becoming an increasingly unfamiliar world the familiar can be a comforting point of reference for PLWD, the use of tailored audio also provided an opportunity for carers to be able to add messages/prompts along a route thereby providing a familiar touchstone for users. This is important and as the Alzheimer's Society points out in its *Dementia-friendly technology charter* 'it is very important to personalize technology for each individual and not present it as part of a 'set menu' or 'dementia package'.' [10].

2.2 GPS Accuracy

Before deciding what kind of instructions would be provided it was important to ascertain the limitations of GPS tracking. Consumer devices based around single receivers are reported to have around 5-10 m precision (ordinance survey [11]) and high accuracy devices 3.5 m. The exactitude of this data can be further affected by environmental conditions that impact on the propagation of GPS signals. These factors can include the weather and signal reflection off of buildings, particularly within urban and city environments. Given that development was based around the use of Arduino and an AdaFruit GPS 'break out' board, the accuracy of the device was tested against

known location data and to check the accuracy of an additional function written to provide point to point measures of distance (however this did assume the earth was a perfect sphere). The purpose of this function was to measure the user's distance from waypoints and to use this to trigger the delivery of instructions. A fine tuning of this distance was built into the prototype through the use of potentiometer to adjust this parameter. Despite the manufacture's claim that the board possessed the accuracy similar to or greater than other devices (3 m) testing within Bristol confirmed a precision of around 5-10 m with a relatively stable output within this range, however this was achieved with the board's passive antenna. The use of an active antenna would increase the number of satellites detected and boost the accuracy of position finding. However in many ways working to a lower accuracy meant that instructions would need to take this into consideration by providing an appropriate set of environmental references for users such as buildings or features that provide local reference points and this might provide a more user friendly means of delivering instructions.

Having examined the data provided by GPS systems it was found that the device can be used to detect the direction that somebody is moving (using the same method as most commercial GPS devices) and through this infer the orientation of the user. Whilst this might work quite well in devices such as vehicle satellite navigation systems this would become problematic if somebody on foot became confused and was turning on the spot. Although the prototype utilized the assumed orientation provided by the GPS sensor it was decided that the incorporation of a compass into the system would be important at a later date.

Given that the project was developed over a relatively short timeframe the prototype used simple routes hardcoded into the device; however that this was a prototype built on the Arduino platform future development would examine increasing onboard storage or the utilization of an SD card, something that was present on the prototype due to the use of a wav shield to deal with delivery of instructions to users.

2.3 Context

Designing a wearable GPS system for PLWD meant that many of the features that would be expected of other systems would not be a requirement for the system. Although all GPS systems are used to help people move around unfamiliar locations, the unfamiliarity experienced by PLWD is of a different kind to those of us who might be traveling to an unfamiliar city. Commercial devices have to content with a multitude of potential destinations and routes. Instead of this we were looking to support PLWD to make the local journeys that those of us who do not live with dementia take for granted; as we have noted this would be limited to a small range of 'regular' destinations such as local cafes, supermarket, post office/post box and home. Although the device would be tailored for a set of destinations the inclusion of mobile GSM technology could be utilized to draw down data from facilities such as Google Maps if users were to stray off of route. The potential disadvantage might be that a switch from a familiar voice to the automated systems associated with GPS device might be disconcerting for the user. Alongside this the addition of GSM into the device would allow notifications of position to be utilized. Devices capable of tracking PLWD are

available and although welcomed by carers, their reception by PLWD hasn't been as positive and has been compared with the electronic tagging of offenders. Tracking is perceived as a loss of independence [12] so its inclusion would most likely be perceived as a feature contrary to the very thing that the device is intended to promote. As it stands the use of tracking systems has an ethical dimension that should include the informed consent of 'users'. Although it wasn't included in the initial prototype if this feature was included it would ideally be something that is enabled by the user when they wish to obtain assistance.

2.4 Route Selection

On one level the limited set of routes provided by the system simplified the requirements of the user interface but once again the tendency towards technological innovation drove initial suggestions within the team. Initially, the need to incorporate this into a wearable appeared to complicate this; however, the incorporation of a natural interface into a wearable began to reframe the teams thinking around this issue. Having discussed the requirements of an interface for PLWD the use of symbols presented itself as an appropriate way forward. When this was considered against the range of conductive materials available for wearable technology a simple solution became apparent. Given that the decision had been made to make use simple icons for the destinations the use of conductive ribbon and press studs presented the opportunity to use the visual metaphor of the road provide to provide a simple switch to each destination (Fig. 1). These could be embroidered or transferred into garments. Given that conductive ribbon provides a number of conductive tracks the design of a press stud capable of distinguishing between these tracks might provide additional opportunities to tailor functionality.

2.5 Evaluation Strategy

This exploratory study used purposive sampling to gather feedback on the Jurojin concept and subsequent prototype.

2.6 Participants and Procedure

Phase one was to gather feedback about the design concept of Jurojin. Emails outlining the concept with accompanying pictures were emailed by the co-author to six individuals who have previously supported PLWD in either a paid or non-paid role. The email content was analyzed to explore common themes regarding the concept. In addition feedback was received as a part of the Dress/Sense competition.

Phase two was to gather feedback about the Jurojin prototype. A DVD was produced by the lead author showcasing the prototype. This DVD was sent to PLWD and their carers for feedback.

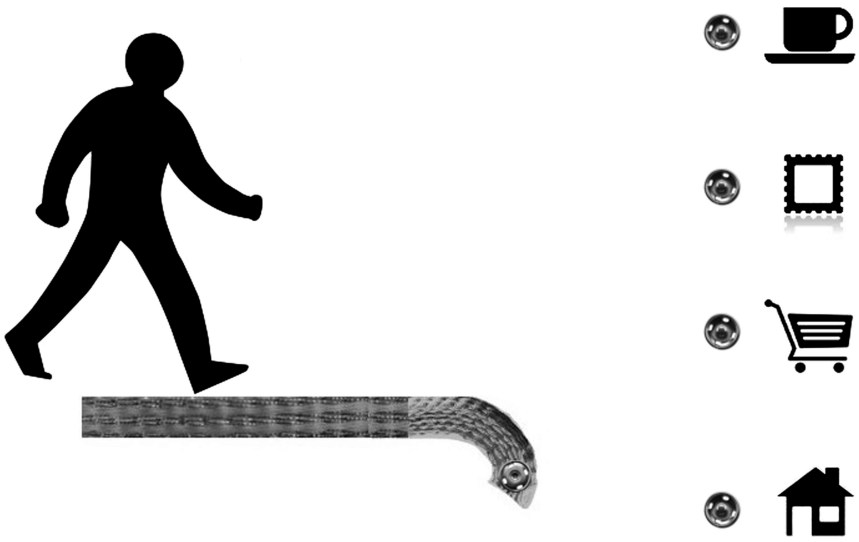

Fig. 1. User interface design

3 Results

Phase one results of email feedback had all those who were contacted stated that wearable GPS technology could be useful for PLWD to allow greater independence outside the home. Feedback indicated the importance of having personalized clothing with this technology embedded, for example, one carer suggested that if the technology were embedded in a body warmer this might be the type of garment that is put on daily on top of any other clothing. This would minimize the risk of the PLWD forgetting to put on a different piece of clothing that housed the device. Similarly one of the professionals suggested building the device into a shirt, as males in particular often wear shirts daily and therefore could have a series of shirts with the device. Another professional indicated that it would be important to identify which piece or pieces of clothing the PLWD wear most often and adapt these with the device.

In terms of user interface, the importance of the 'home' function was felt very significant. Two individuals felt that a device which only had a 'home' button could be a basic device available for PLWD. One professional noted that as part of a local project raising awareness of dementia in local shops, a PLWD had been able to go out alone more as shopkeepers were directing the PLWD home as they were leaving their premises. A wearable GPS would allow the PLWD to safely reach their destination as well as return home again without reliance on others.

One professional felt that a device which was ultimately linked to, for example, a spouses smartphone, so that the spouse to track where the PLWD was if they hadn't returned home for some time would be useful. As has been noted the team had discussed building in this feature, but felt in the given timescales it was better to work on a simple device. However, this feedback suggested the importance of this monitoring in future developments of the device.

Some feedback questioned the use of a single ear piece and how this would fit with PLWD with hearing aids. This had been considered in the design stage, it was felt for the purposes of developing a prototype the single ear piece would be used as this was cheap to purchase. However, alternative audio bone headphones could be used which sit behind the ear if this suited the needs of the PLWD.

It was also noted that one of the difficulties experienced with dementia is the lack of insight into changes in oneself. Consequently timing of promoting use of wearable technology would be key to the PLWD accepting the need for the device, and subsequently integrating it into activities of daily living.

Feedback was also received from the Dress/Sense competition focused on the positive aspects of the device; however a more critical evaluation was sought by the authors. This raised two issues concerning technical aspects of the device; one being that of battery life and the other being the device's use in buildings.

Phase two results at the time of writing are yet to be received. These are of importance to the project given that we are seeking the input of PLWD themselves and will be featured when the paper is presented.

4 Discussion

Initial feedback has lent support to the notion of a wearable GPS device for PLWD. The choice as to which garment the device is embedded within remains although this is an issue that has been dealt with in a different way by the products that have made it to the market. These have tended to be wearable in the sense of jewelry. Almost all of these products have been a smart watch or a variation on it such as the jawbone activity tracker and the Nike FuelBand, each of which takes the form of a bangle. Other wearables have experienced faltering development, as has been seen with the Google Glass and other smart glasses being withdrawn from the market. Indeed the viability of such devices has been questioned by Apple's chief executive Tim Cook who stated that 'We always thought that glasses were not a smart move, from a point of view that people would not really want to wear them'.

Although wearables that are embedded into garments reduce the visibility of the device in question the danger is that this would restrict it to one garment. To this extent it would make sense for a modular system to be developed whereby some elements become a part of the garment, such as the root selection, and others could be switched between garments as the seasons or taste required. Given the importance of appropriately integrating its use into the lives of PLWD one would suspect that the device should be as unobtrusive as possible so as not to label the user. Being able to fit this technology into familiar clothing would also be a positive feature.

Whilst tracking was seen as benefit by some there are still ethical issues concerning this matter. This is often seen as a positive feature for carers, who have the reassurance of being able to locate the PLWD if something were to happen. It has been noted that the device could have a 'panic button' so that users could request assistance; but such feedback also prompts the question as to whether the device might make use of a timer, such that tracking could become active after an agreed period of time.

The issue of battery life has been examined and the fact that the interface does not make use of a LCD display dramatically increases this. In fact the reported battery life of tracking devices that are commercially available for PLWD can be up to a week of use. The use of active antenna with the GPS can increase power consumption because they have a built-in low-noise amplifier. To this extent it would need to be questioned whether increasing the degree of accuracy provided through the addition of an active antenna is worth sacrificing battery life. The issue of the devices use indoors does present issues. The devise is intended to be used by PLWD to make local journeys and increase their independence and to a large extent the assumption had been made that the device would be used to get to local amenities. At this stage the PLWD would not be driving or using public transport independently. As a result the larger 'mall' style shopping environments are not likely to be a destination however this does raise the issue of how destinations that possess multiple exits might be dealt with.

5 Conclusion

Although it is still an ongoing process, the initial stage of PPI (Patient and Public Involvement) evaluation has demonstrated a perceived value in the development of a wearable GPS system for PLWD. The development of such a system brings with it a range of issues that will benefit from user input and as always users should be at the center of the design process, although the extent to which this is possible is different when dealing with conditions such as dementia where the demands that are placed on participants needs particular consideration.

The issue of consent is also important given the ethical issues concerning the data generated by such devices. Such considerations also need go beyond the immediate issues such as the active tracking of PLWD. This is because GPS devices (including the one used) have data logging facilities hardcoded into the device that store location data every 15 s for approximately 16 h. However it is also clear that solutions can be created that ethically address the concerns of diverse interests, particularly if these concerns are tackled as a part of the design process rather than being a 'bolt on' consideration that is dealt with at a later date.

In many cases it's the case that 'innovation' foregrounds technology, in this instance a different approach was required. The move towards natural interfaces has often featured new technologies and arguably, it is often the case of technologies in search of a solution. The creation of natural interfaces should push technology to the background, so that as far as possible, the interface is not perceived. PLWD face particular challenges concerning processes that involve concentrating, planning or organization that mean any interface should ideally provide simple and direct options for the user. Although it might be argued that designing a wearable GPS system for PLWD is a special case, the use of any technology should advantage the user and place them and the things they are engaged with first, rather than making technology the center of attention. To this extent the lessons learnt when designing systems for PLWD might be of value to us all in our engagement with technology.

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