REPORT DEFINING THE NEEDS OF STAKEHOLDERS FOR A WAYFINDING PLATFORM FOR INDIVIDUALS WITH INTELLECTUAL DISABILITIES AND THEIR CARERS

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INTRODUCTION
A significant problem faced by people with intellectual disabilities (ID) is not being able to get to places independently. A study showed that 44.2% of adults with an ID are dependent on others to access community options, which was reported by the participants as the greatest barrier to successfully participate in social activities (McCarron et al., 2011). The life skills needed for community travel and mobility, which include pedestrian skills and transportation, have been identified as critical to improving a person’s competence and quality of life (Leavitt and Terrell, 1984).

Independent travel remains one of the most important unmet needs for individuals with disabilities (Goodkin, 1977). Most rely on care providers for transportation, thus reducing self-determination levels and the desire to learn how to access community options (Sohlberg et al., 2009). This causes lack of independence to the person with ID, an unnecessary burden to their family members and an inefficient use of time from capacitiated professionals that could be allocated towards care, education, and vocational training.

A study that used a series of picture prompts to teach travel to novel destinations showed that individuals who learned to travel more independently were better prepared for the world of work, able to experience more economic benefits related to travel, and relied less on others to get them from place to place (LaGrow et al., 1990). Technology is advancing at great speed and, for most people, it can make life easier by expanding the user’s choices and opportunities. For people with disabilities, technology has the power to enable them to perform daily activities that once seemed impossible.

Assistive technology is a term referred to “any item, piece of equipment or product system whether acquired commercially, modified or customized that is used to increase, maintain or improve functional capabilities of individuals with disabilities” (Bodine and Matthews, 2003). It has the potential to truly empower people with disabilities or cognitive impairments to live the life of their choice. It promotes greater independence by enabling individuals to perform tasks that they were formerly unable to accomplish by enhancing or changing methods of interacting with the technology needed to accomplish such tasks (Cullen et al., 2012).

Currently, the technology solutions for navigation do not address the specific needs from people with ID. In light of advancements in and availability of technology such as smartphones and smartwatches, it appears that it is time for researchers to explore the use of these tools as aids to life skills such as navigation and mobility.
THE WAYTOB SYSTEM

As most people with ID rely on their carers for navigation, which causes lack of independence and quality of life, a navigation tool called waytoB was developed to explore the use of technology as a way to support independent travel. The system consists of a wearable assistive technology with a linked caregiver mobile application to support individuals with ID to specifically navigate outdoor environments and improve their independence, autonomy and social connectedness. The application is divided in two so the carer can add places for the user with ID to go to, who can then access these places on their device and follow user-friendly instructions to get there. The two modules are connected (internet connection necessary) so the user and the carer can easily communicate remotely and live data can be shared between the two.

The smartphone and smartwatch integrated solution works as a substitute to the individual’s escort. It targets individuals with mild to moderate ID to proactively self-navigate their environment to improve their quality of life as well as that of their caregivers.

REQUIREMENTS GATHERING

As a first step in the design of the waytoB system we have conducted a research study to explore the experiences of adults with intellectual disabilities and the people who support them in accessing community options. This report outlines the main findings from this requirements gathering study, which involved 10 participants located in Dublin, Ireland.

Here, we define the key end user groups who took part in this study:

INDIVIDUALS WITH ID:

Must be over the age of 18, diagnosed with mild to moderate ID, capable of providing informed consent, sufficient dexterity to utilise mobile touch screen and wearable smart watch technology.

CAREGIVERS:

Aged 18-90, have been providing formal/informal care/support to the individual with ID for a period of at least six months; ability to communicate clearly, skills to use a smart phone/tablet.
In Ireland, 1.3% of the population suffers from an ID and 3.0% experience difficulty with learning, remembering or concentrating (The Central Office, 2011). 2013 HRB figures show that there are 27,671 (2 per 1000 with mild ID and 3.54 per 1000 for moderate and above) people registered on the National ID Database. A recent Wave 2 report by IDS-TILDA [9] indicated that 64.2% (n=444) of individuals with ID experienced difficulty in getting around their community or do not travel at all. 2012 policy recommendations from the Irish Health Service Executive (HSE) [2] outline a need to develop supports to allow people with disability (including ID) to live independently and be part of their local community.

ID is defined as significant limitations on either intellectual functioning or adaptive behavior that originated before the age of 18. A major personal difficulty for people with ID is ‘way finding’ or navigating their communities. Most ‘way finding’ experiences require an orientation to the environment and time, and an ability to read signs, bus numbers and timetables, among others. All of these are major challenges for people with ID. While technology advances have made independent travelling easier for the general population, the needs of people with ID are not currently addressed. Remembering addresses, filtering out wrong search results and processing instructions while focusing on physical movement can be a challenge. Current mapping smartphone solutions can present challenges for the average user, which are even more complex for individuals with ID. Examples of widely used technological products by the mainstream population are Google Maps\(^1\) and public transport live data mobile applications such as those from Dublin Bus\(^2\), Iarnród Éireann\(^3\) and LUAS\(^4\). These are all text-based and require the user to orientate themselves on a map, read and/or make sense of cluttered timetables. These tasks are many times considered overly complex for someone with an ID or cognitive impairments.

Furthermore, despite recent progressive policy developments (Department of Health, 2012), Ireland is a prime example of a high-income country which is lagging behind many of its European neighbours in addressing the rights of persons with ID. For instance, it has yet to ratify the UN Convention on Human Rights on Individuals with Disabilities which strives for true social inclusion for people with disabilities, including equal access to information, transport, education, employment and income support (Lee and Raley 2015). There is a need for further research to better understand how to facilitate navigation for people with ID to improve their social inclusion and quality of life.

This study seeks to examine in detail the users needs and requirements of persons with ID to inform the design and development of a smartwatch and smartphone application to support individuals with ID to navigate their local outdoor environments supported by their caregivers. This project is building upon initial work conducted between 2014 and 2015 as part of the ‘4E5 - Innovation in Product Development’ MAI module at the School of Engineering at Trinity College Dublin.

1. https://maps.google.com/  
2. https://www.dublinbus.ie/Your-Journey1/Mobileapps/  
NEEDS AND REQUIREMENTS STUDY
NEEDS AND REQUIREMENTS STUDY

AIMS

This qualitative study was designed to explore the experiences, barriers and motivations people with intellectual disabilities and their carers face while going to new places independently. The findings from this study will be translated into design requirements for the waytoB system, which will be tested within a proof of concept study with 10 dyads end user groups (the dyad consists of an individual with ID and their associated carer).

METHOD

Interviews were carried out with 5 pairs, each composed of one person with intellectual disabilities and one associated carer. Questionnaires were created for each stakeholder group, and an easy-to-read version developed for individuals with ID. The purpose of these questionnaires was to collect basic demographic information about the participants and understand their preferences, barriers and motivations regarding independent navigation.

Each questionnaire was further broken into three sub sections; A, General questions about current experiences with smart technology, B, initial opinions on the concept of the waytoB system and whether it would make independent travel easier, and finally C, thoughts on the current implementation of the system (Appendices I and II).

All interviews were audio recorded and transcribed verbatim for analysis. All transcripts were analysed using thematic analysis.

INTERVIEW STRUCTURE

The interviews were conducted in two different ways, depending on the participant’s preferences: two pairs opted for individual interviews, while three opted for a group interview. In all cases, the answers were anonymised and stored securely on a server. Access to this folder is restricted to the researchers involved in this project.

All interviews were split in three parts, according to three sections of the questionnaire. In the first, the researchers asked open-ended questions to the participants in an informal way to encourage sharing of information. After the questions from section A were answered, the concept of the waytoB system was explained to the participants and the prototype was briefly shown. The participants were able to see it, explore it and ask questions, but not to use it yet. They were asked to look at different features and think about how having these would affect their lives. Then, they were asked to answer a set of questions from section B, in relation to their initial opinions on the system.

Lastly, they were asked to try out the prototype. The carers were asked to register an account, sign in and sign out of their account, add a close location to the favourites list (including uploading a picture and adding a name to the place), refresh the list on the user side, and delete a favourite. Then, the individual with ID was asked to put on the smartwatch, select the waytoB application on the phone, and select the place that was just added. Then, one of the researchers accompanied the individual on the route, while they followed the instructions on the watch. The routes were all very
simple, from the local of the interview to a close location. While they were on the route, another researcher stood with the carer, who tracked the individual’s location on the waytoB system. Then, the pair was asked the questions on section C.

**INCLUSION CRITERIA**

Purposeful sampling was used to select participants and their recruitment was based on the following inclusion criteria:

**INDIVIDUALS WITH ID:**
- Must be diagnosed with mild to moderate (high functioning) level of intellectual disability (ID)
- Aged 18 and over
- Capable of providing informed consent
- Sufficient dexterity to utilise mobile touch screen and wearable smart watch technology. With ability to access and use the emergency button feature.
- The individual with ID must acknowledge that the carer is the main carer/person who provides support
- Must have significant mental capacity to understand what they are consenting to
- Ability to communicate in English

**CAREGIVERS:**
- Aged 18 and over
- Have been providing formal/informal care/support to the individual with ID for a period of at least six months
- Ability to communicate clearly
- Skills to use a smartphone/tablet.
- Ability to communicate clearly in English

**PARTICIPANT PROFILES**

In this study, we engaged with 5 people (4 males and 1 female) with intellectual disabilities between the ages of 23 and 29 (Mean: 25.2 years) and with their respective carers (2 males and 3 females) between the ages of 33 and 65 (Mean: 54.8 years). Six participants took part in a focus group and all of them (n=10) took part in individual interviews which were conducted in their homes or in a convenient location. An overview of the participants profiles can be seen on Table 1.
Ethical approval was received from the Trinity College Dublin (TCD) Faculty of Health Sciences. The participants were recruited through a variety of sources, including through service providers for people with ID and healthcare professionals. Each participant was assigned a unique identifier to allow anonymisation of personal data collected by the team while still providing the option for the participant to view their data if so requested. Only this coded data was transferred and it was treated as confidential information. Only key personnel within this study have access to the unique identifier and corresponding participant information.

The audio recordings of participants were transferred from the portable recording device to a password-protected folder on a secure TCD server. With regards system data, the study followed EU Directive 95/46/EC on both personal and local data protection laws and ensured that personal data was treated in line with that legal directive. In terms of protection of personal data, this research project enforced the EU Directive 2002/58/EC on Privacy and Electronic Communications (amending Directive 97/66/EC). Special attention was paid to the National Laws and regulations derived from these EU Directives on data storage, protection and privacy.

### Table 1 Overview of participants

<table>
<thead>
<tr>
<th>IDENTIFIER</th>
<th>GROUP</th>
<th>GENDER</th>
<th>AGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.1</td>
<td>Individual with ID</td>
<td>Male</td>
<td>23</td>
</tr>
<tr>
<td>1.2</td>
<td>Caregiver</td>
<td>Male</td>
<td>58</td>
</tr>
<tr>
<td>2.1</td>
<td>Individual with ID</td>
<td>Male</td>
<td>27</td>
</tr>
<tr>
<td>2.2</td>
<td>Caregiver</td>
<td>Male</td>
<td>62</td>
</tr>
<tr>
<td>3.1</td>
<td>Individual with ID</td>
<td>Female</td>
<td>20</td>
</tr>
<tr>
<td>3.2</td>
<td>Caregiver</td>
<td>Female</td>
<td>56</td>
</tr>
<tr>
<td>4.1</td>
<td>Individual with ID</td>
<td>Male</td>
<td>29</td>
</tr>
<tr>
<td>4.2</td>
<td>Caregiver</td>
<td>Female</td>
<td>65</td>
</tr>
<tr>
<td>5.1</td>
<td>Individual with ID</td>
<td>Male</td>
<td>27</td>
</tr>
<tr>
<td>5.2</td>
<td>Caregiver</td>
<td>Female</td>
<td>33</td>
</tr>
</tbody>
</table>
FINDINGS AND RESULTS
In the following sections we have outlined key themes that emerged from the analysis of focus groups and interviews with individuals with ID and their carers. The results for each section A, B and C are presented separately below.

A. CURRENT EXPERIENCES WITH SMART TECHNOLOGY

The results from section A are discussed below. Every caregiver of the initial sample (n=5) possessed and had experience with using a smartphone mobile device - the average period of ownership being 3 years. The same was true of the individuals with ID, all having owned a smartphone for at least 3 years. The Operating System (OS) breakdown was 40% Apple iOS and 60% Google Android, and although the application currently only runs on Android devices, all test participants were informed that the appropriate hardware would be supplied to them for testing. None of the test participants (users or caregivers) owned a smartwatch, nor had any experience in using one even for a short period of time. All the individuals with ID were shown the watch hardware and had a chance to wear it during the interview. All (n=5) users responded that they would be happy using one and that they didn’t experience any discomfort from wearing it.

Regarding the current level of independence, all five (n=5) individuals with ID said they have somewhat limited independence. In summary, individuals who were able to travel alone to destinations, only went to destinations they were extremely familiar with. These journeys always involved the same walking route and public transport combination. Three (n=3) caregivers added that if anything did not go as planned (such as bus delays or road works), this would cause stress and aggravation for the individual with ID. The only way they have to address issues like this is to call the individual with ID and ask them to describe where they are, which is usually not very effective. By using waytoB, the carer can check their location on the phone, contact them instantly and offer guidance. A summary of the responses can be seen on Table 2 and Table 3.

<table>
<thead>
<tr>
<th>QUESTION/IDENTIFIER</th>
<th>1.1</th>
<th>2.1</th>
<th>3.1</th>
<th>4.1</th>
<th>5.1</th>
</tr>
</thead>
<tbody>
<tr>
<td>Owns smartphone</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Years using smartphone</td>
<td>3</td>
<td>5</td>
<td>3</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Owns smartwatch</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Comfortable wearing a smartwatch</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Experience with other navigation applications</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Internet access on phone</td>
<td>x</td>
<td></td>
<td>x</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Android OS</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Apple iOS</td>
<td></td>
<td></td>
<td></td>
<td>x</td>
<td>x</td>
</tr>
</tbody>
</table>

Table 2 Summary of responses from individuals with ID in section A
Section B was utilised to gather the opinions from both stakeholders about the most important aspects that need to be in place to allow both parties to feel comfortable with independent travel. We also wanted to gauge an opinion on whether the currently implemented system could go anyway toward improving this experience. The main theme from caregivers that came out was concern about whether the individual with ID using the system may get lost. Three respondents (n=3) said they would be confident that they would call for help, whereas the other two (n=2) said they might panic or ask a stranger for help. All interviewed caregivers (n=5) also mentioned that a vulnerability to theft would be a concern of theirs.

The main concerns brought up by the individuals with ID and their carers regarding independent travel are shown on Table 4.

When asked whether they thought the proposed system would help alleviate these concerns, all respondents stated that their concerns for travelling would be reduced due to the tracking GPS function. They were also asked whether any aspects could be added or removed from the application to help further, including new feedback features, details to the user interface or any functionality improvements. Four caregivers said no and one suggested the measurement of perspiration, which is not in the remit of the project as sensors from the watch cannot accurately collect this. All five carers said that current feedback features available (heart rate and GPS) were enough to offer sufficient peace of mind for them.

### Table 3 Summary of responses from carers in section A

<table>
<thead>
<tr>
<th>QUESTION/IDENTIFIER</th>
<th>1.2</th>
<th>2.2</th>
<th>3.2</th>
<th>4.2</th>
<th>5.2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Owns smartphone</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Years using smartphone</td>
<td>3</td>
<td>2</td>
<td>3</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Internet access on phone</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Android OS</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Apple iOS</td>
<td></td>
<td></td>
<td>x</td>
<td></td>
<td>x</td>
</tr>
<tr>
<td>Caree takes part in</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>independent travel</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Table 4 Main concerns brought up by individuals with ID and their carers regarding independent travel

<table>
<thead>
<tr>
<th>CONCERNS/IDENTIFIER</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting lost</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Getting robbed</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Getting in an accident</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Losing belongings</td>
<td>x</td>
<td>x</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Panic Attack</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
<td>x</td>
</tr>
<tr>
<td>Seizure</td>
<td></td>
<td></td>
<td>x</td>
<td>x</td>
<td></td>
</tr>
</tbody>
</table>
C. INITIAL THOUGHTS AFTER USING WAYTOB

Section C was the first chance for the interviewees to have a hands on experience with the waytoB prototype. This was a chance to conduct usability testing and take notes and feedback. The user testing was conducted on both the applications for individuals with ID and for their caregivers, so both had the chance to give their input.

INDIVIDUALS WITH ID:

As part of Section C, the individuals with ID were asked to use the waytoB system and give their opinion on it. Firstly, they were asked to go to the place added to the favourite list by their carer. All the routes were extremely simple and started at the location of the interview. All of the participants completed the route, but they still needed support from their carers. The main issues faced were the display of the wrong direction on the watch due to lack of calibration of the device and delayed prompts due to the route suggested by the application, which was based on the Google Maps Directions API. During the journey, the participant was also asked to contact their carer through the waytoB app on the phone. After completing all the tasks, test participants rated a series of 5-point likert scale questions that ranged from: 5- Strongly agree; 4- Agree; 3- Indifferent; 2- Disagree; and 1- Strongly Disagree (See Appendix I). A summary of the responses from the individuals with ID in this section can be seen in Table 5.

The short test performed by the individual with ID, with support from their carer and the researchers, is part of the co-design approach, in which the researchers are able to gather feedback at the same time the user experiences the solution. This helps in the collection of feedback, which can be done through observation and discussion. The outcomes from these observations and discussions are presented below:

1. All the participants seemed to agree waytoB would make independent

<table>
<thead>
<tr>
<th>STATEMENT/ID</th>
<th>1.1</th>
<th>2.1</th>
<th>3.1</th>
<th>4.1</th>
<th>5.1</th>
<th>AVG.</th>
</tr>
</thead>
<tbody>
<tr>
<td>waytoB would make navigation easier</td>
<td>5</td>
<td>4</td>
<td>4</td>
<td>5</td>
<td>4</td>
<td>4.4</td>
</tr>
<tr>
<td>Watch was more convenient than the phone</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>3</td>
<td>2</td>
<td>2.8</td>
</tr>
<tr>
<td>Vibration of the watch was enough</td>
<td>5</td>
<td>4</td>
<td>3</td>
<td>4</td>
<td>4</td>
<td>4.0</td>
</tr>
<tr>
<td>Comfortable knowing their carer could see their location</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>2</td>
<td>3</td>
<td>2.8</td>
</tr>
<tr>
<td>Following arrows was easy</td>
<td>4</td>
<td>4</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>4.0</td>
</tr>
<tr>
<td>Easy to contact the carer</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>4</td>
<td>1</td>
<td>2.2</td>
</tr>
</tbody>
</table>
The carers were asked to register an account, sign in and sign out of their account, add a place to the favourites list (including uploading a picture and adding a name to the place), refresh the list on the user side, and delete a favourite.

After completing all the tasks, test participants rated a series of 5-point likert scale questions that ranged from: 5- Very easy; 4- Easy; 3- Indifferent; 2-Difficult; and 1-Extremely difficult (See Appendices I and II). A summary of the responses from the carers in this section can be seen in Table 6.

All five carers found the pairing between their module of the application and the user’s module very easy (5.0). The syncing between the two modules (5.0) was also rated very easy by all (n=5) participants. Adding a new place to the favourites list (3.2) proved to be the most difficult task, as two carers found it easy, two were indifferent and one found it hard to complete the task. The main issue encountered here was the size of the map on the phone, which was not big enough. Adding names and pictures to the place added (4.8) and viewing and deleting places from the destination list (4.6) was rated very easy or easy by all five carers. However, two respondents stated that they found the pictures would only confuse their caree, as they are able to read. One carer also suggested that audio was added to the system, to also include people with visual impairments.

Registering an account (4.2) was rated very easy by two carers, easy by caregivers:

1. Navigation easier for them;
2. Most of the participants liked using the watch and considered it more convenient, but did not perceive its advantages as much as their carers, who felt the use of the watch would decrease their vulnerability to theft and the likelihood of them getting into accidents;
3. The vibration on the watch was noticeable enough that all the participants noticed all the vibrations along the journey. It was suggested by one of the participants that different vibration patterns could be used for different instructions;
4. Although two participants were not very comfortable with their carers knowing their location during the journey, they stated that this is still better than not being able to go to new places by themselves. One of the participants found it reassuring that their mother could watch over them and make sure they were safe;
5. The use of the arrows was simple and intuitive for all users. Some of them were nervous before the journey as they could not tell left from right, but once they saw how simple the interface on the watch was, they became calmer and were able to follow the instructions easily; and
6. Contacting the carer was not an easy task for four out of five participants. All of them hoped there was an easy-to-access button on the watch, instead of having to go on the phone to do this.

Their responses (Table 5) confirm the outcomes stated above. All participants agreed or strongly agreed that the application would make navigation easier (4.4). Four out of five participants felt indifferent in relation to the use of the watch over the phone (2.8), and one disagreed with the statement that it was more convenient than the phone. Four out of five of the participants agreed or strongly agreed that the vibration of the watch was enough to notice a new prompt being displayed (4.0), and the other was indifferent to the statement. Two participants disagreed they would feel comfortable knowing their carer could see their location during the journey (2.8), while one felt indifferent and the other agreed with the statement. Regarding the use of arrows displayed on the watch as direction prompts (4.0), one respondent found it very easy, three found it easy and one found it indifferent. It is noticeable that the main issue was with contacting the carer (2.2), as only one participant agreed it was easy to do this.

The average score across all the questions was 3.4/5. The participants considered the prototype useful to aid them navigate independently. However, they encountered a few problems and made suggestions that will be taken into consideration for the next versions of the prototype.

CAREGIVERS:

The carers were asked to register an account, sign in and sign out of their account, add a place to the favourites list (including uploading a picture and adding a name to the place), refresh the list on the user side, and delete a favourite.

After completing all the tasks, test participants rated a series of 5-point likert scale questions that ranged from: 5- Very easy; 4- Easy; 3- Indifferent; 2-Difficult; and 1-Extremely difficult (See Appendices I and II). A summary of the responses from the carers in this section can be seen in Table 6.

All five carers found the pairing between their module of the application and the user’s module very easy (5.0). The syncing between the two modules (5.0) was also rated very easy by all (n=5) participants. Adding a new place to the favourites list (3.2) proved to be the most difficult task, as two carers found it easy, two were indifferent and one found it hard to complete the task. The main issue encountered here was the size of the map on the phone, which was not big enough. Adding names and pictures to the place added (4.8) and viewing and deleting places from the destination list (4.6) was rated very easy or easy by all five carers. However, two respondents stated that they found the pictures would only confuse their caree, as they are able to read. One carer also suggested that audio was added to the system, to also include people with visual impairments.
other two carers and indifferent by the fifth one. Logging in and out of the application (4.2) was very intuitive for three of the carers, who rated this task as very easy, while one felt indifferent towards it and the other found it hard and needed help from the researchers.

Table 6 Summary of responses from carers in section C

<table>
<thead>
<tr>
<th>TASK/ID</th>
<th>1.2</th>
<th>2.2</th>
<th>3.2</th>
<th>4.2</th>
<th>5.2</th>
<th>AVG.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Register account</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>4</td>
<td>5</td>
<td>4.2</td>
</tr>
<tr>
<td>Pair the user’s phone</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5.0</td>
</tr>
<tr>
<td>Log in and log out</td>
<td>3</td>
<td>2</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>4.0</td>
</tr>
<tr>
<td>Add a new place</td>
<td>3</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>4</td>
<td>3.2</td>
</tr>
<tr>
<td>Add a name and picture to the place</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>4</td>
<td>4.8</td>
</tr>
<tr>
<td>Viewing and deleting places</td>
<td>4</td>
<td>5</td>
<td>4</td>
<td>5</td>
<td>5</td>
<td>4.6</td>
</tr>
<tr>
<td>Syncing between the two modules</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>5.0</td>
</tr>
</tbody>
</table>

The average score across all the questions was 4.4/5. In overall terms, users rated the prototype system as easy to set up and use. However, it is noted that a number of design considerations were suggested for implementation to improve the functionality and usability of the system.

After the user’s first journey, their carers were asked another set of questions regarding the navigation aspect of the system. Test participants rated a series of 5-point Likert scale questions that ranged from: 5- Strongly agree; 4- Agree; 3- Indifferent; 2- Disagree; and 1- Strongly Disagree. They also rated the live feedback feature (GPS) from: 5- Very useful; 4- Useful; 3- Indifferent; 2- Not useful; and 1- Pointless and rated how easy it was to contact the user from: 5- Very easy; 4- Easy; 3- Indifferent; 2- Difficult; and 1- Extremely difficult. A summary of the responses from the carers regarding their thoughts and feelings during the user’s journey can be seen in Table 7.

Two of the carers stated that they strongly agreed that the system offered them peace of mind while the user was on the journey (4.4), while the other three agreed. The live feedback (4.4) was also rated highly, as two rated it very useful and three rated it useful. However, three of them did not find the navigation instructions easy enough for their caree to follow by themselves (2.4), as they still needed their help to get to the desired place. More testing needs to be conducted and data regarding location accuracy and orientations needs to be collected to understand how to improve the user’s experience regarding navigation. Initiating contact with the user was also rated poorly (1.6), as four out of five carers found it hard to identify the call button, which was placed inside a sub-menu on the application header.

The average score across all the questions was 3.2/5. Overall, the carers considered the prototype useful for both the individual with ID and themselves, and were particularly impressed with the feedback feature. On the other hand, they did not think the navigation feature was robust enough and would not trust the individual with ID to get to their destination independently by using the system as it was.
Table 7 Summary of responses from the carers regarding the user’s journey

<table>
<thead>
<tr>
<th>STATEMENT/IDENTIFIER</th>
<th>1.2</th>
<th>2.2</th>
<th>3.2</th>
<th>4.2</th>
<th>5.2</th>
<th>AVG.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Offered peace of mind</td>
<td>4</td>
<td>4</td>
<td>5</td>
<td>4</td>
<td>5</td>
<td>4.4</td>
</tr>
<tr>
<td>Easy to navigate</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>2</td>
<td>4</td>
<td>2.4</td>
</tr>
<tr>
<td>Live feedback was very useful</td>
<td>4</td>
<td>4</td>
<td>5</td>
<td>4</td>
<td>5</td>
<td>4.4</td>
</tr>
<tr>
<td>Initiating contact with the user was very easy</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>1.6</td>
</tr>
</tbody>
</table>
STRENGTHS AND LIMITATIONS
This study employs an adaptive action research trial design. Action research is a period of investigation that ‘describes, interprets and explains social situations while executing change intervention aimed at user improvement and involvement’ (Waterman et al, 2001). The strength of this approach is the capability to generate solutions to practical problems, while garnering research methods (e.g. situation analysis, participant observation, in-depth interviews) to understand the context of use and needs and experiences of the users. With waytoB this will allow for system modifications based on quantitative and qualitative methodologies (e.g. data collected from system and user interviews/focus groups).

The study also follows the co-design methodology, which actively involves all stakeholders in the design process to help ensure the result meets their needs and is usable. By asking the participants to test the solution, the researchers were able to observe them and collect feedback they might have missed otherwise.

This qualitative study was designed to explore the experiences, barriers and motivations the involved stakeholders face while a person with ID is navigating. This was accomplished by 5 sets of in-depth interviews with 5 pairs, each composed of one individual with ID with their respective carer. The low sample size can be explained by the financial constraints of the study, as it envolved providing each pair of participants with a set of two smartphones and one smartwatch.

The next phase of the study, the proposed PoC trial, aims to test the system both in terms of usability and functionality, assessing impact on user quality of life. Ten (n=10) participants with ID and their associated primary caregiver (n=10) will take part. While sample size is often cited as a key factor in determining the potential success of a study, this is more relevant for Randomised Controlled Trial (RCT) studies that seek to answer specific questions regarding the full efficacy of interventions (Does it work?) and is less relevant for PoC studies which relate also to care and service improvement (How does it work?) (Lee, 2014). Thus, a pragmatic approach was taken to determine sample size and two important factors were reviewed:

(i) that it is large enough to provide a reliable analysis of the system and
(ii) small enough to be financially feasible.

Analysis of literature suggests overall sample size in a PoC technology trial is low. A recent review of 1030 studies on health based ICT-AT interventions between 2005 and 2013 suggests methodologically robust samples sizes from n=17 to n=21 (Wood, 2015). The PoC trial will incorporate n=20 individuals into the trial.
CONCLUSIONS

IMPLICATIONS FOR DESIGN

The requirements gathering process has elicited a number of user requirements based on stakeholder needs. The data collected was thoroughly analysed to help define the design requirements of the waytoB system. This initial requirements phase has helped in identifying:

- Important concerns regarding independent travel that both the individuals with ID and their carers face and should be addressed by the system;
- Usability of the current system: how intuitive and easy-to-use it is to the individual with ID and their carer; and
- Usefulness of the system to support the user to navigate independently.

USER REQUIREMENTS

After reviewing the feedback from the interviews and focus groups and conducting a stakeholder analysis, the outputs were translated into user requirements (UR), as follows:

- UR1: There must be location and heart rate feedback from the individual with ID to the carer. This was shown to alleviate concerns with the individual getting lost, having a panic attack or a seizure.
- UR2: The system must have the wearable aspect to it. This was shown to alleviate concerns regarding getting robbed and getting into accidents while navigating;
- UR3: Notifications regarding lack of movement should be implemented to allow the caregivers to get alerted if the individual with ID gets lost, falls, or loses their phone;
- UR4: A panic button should be easily accessible to the individual with ID both on the phone and on the watch so they can effortlessly contact their carer;
- UR5: The navigation aid should have arrows displayed on the smartwatch interface, prompted by vibration;
- UR6: The system must show the list of routes in both text and pictorial formats. However, the addition of pictures needs to be optional, as it may confuse some users;
- UR7: Audio options should be added to both the routes list and the navigation instructions for people with visual impairments.
- UR8: The map on the carer’s side needs to be as big as possible to ensure ability to view routes;
- UR9: Calibration checks must be implemented to ensure the correct functionality of the system.

NEXT STEPS

PRE-TRIAL (‘FRIENDLY PILOT’)

The prototype system will be trialled with five members of the research team to ensure the system is robust.

ITERATIVE DESIGN AND TESTING

10 end users will be engaged in a co-design workshop and in usability testing of the system.

MAIN POC TRIAL

The main trial will have 20 participants (10 individuals with ID and 10 caregivers) and it will last three months (from November 2017 to January 2018). A report detailing the outcomes from the PoC tria will be made available in 2018.


APPENDIX 1

QUESTIONNAIRE - INDIVIDUAL WITH ID

Section A
In this section, we would like to ask you some general questions about your current circumstances and experience with smartphone and smartwatch technology. Your answers will only be used anonymously – your name will not be associated with any comments that you make.

1. Name: _____________________________

2. Age: __________

3. Gender: Male ☐ Female ☐

4. Where do you live? (Place name e.g. Dublin) ________________________

5. Do you own a smartphone? Yes ☐ No ☐

6. If so, how many years have you been using a smartphone? _________

5. Do you own a smartwatch? Yes ☐ No ☐

6. If not would you be comfortable wearing a smartwatch on a regular basis? Yes ☐ No ☐

7. Have you had any experience in using an application such as Google maps? If so, please provide some details.
_______________________________________________________________________
_______________________________________________________________________

8. Do you have Internet access throughout the day on your smartphone?
   Yes ☐ No ☐

9. Operating system of smartphone
   Google Android ☐
   Apple iOS ☐
   Windows Phone ☐
   Other ☐

Section B
As you are aware, this application is about designing a solution that will try and allow everyone to feel comfortable getting places on his or her own. We would like to ask you a few questions about some of your experiences.

1. What are your main concerns about travelling somewhere on your own?
_______________________________________________________________________
_______________________________________________________________________

2. Do you think the application we’ve developed would make it easier for you?
_______________________________________________________________________
_______________________________________________________________________
3. If not, what aspects of the system do you think would need to be added/removed to make it easier?
________________________________________________________________________
________________________________________________________________________

4. What do you think causes for concern for your carer when you travel alone?
________________________________________________________________________
________________________________________________________________________

5. What do you think might help them help to support you in their carer role?
________________________________________________________________________
________________________________________________________________________

Section C
The purpose of this questionnaire is for us to gain feedback based on your initial thoughts after completing a test with the app as part of the interview. Please be as honest as possible as this a critical component of the system

1. Using the app would make it easier to find your way to your destination.
   Strongly agree ☐ Agree ☐ Indifferent ☐ Disagree ☐ Strongly disagree ☐

2. Having the app show directions on the smartwatch was more convenient than having to look at your phone.
   Strongly agree ☐ Agree ☐ Indifferent ☐ Disagree ☐ Strongly disagree ☐

3. The watch vibration when a new turn coming up was noticeable enough.
   Strongly agree ☐ Agree ☐ Indifferent ☐ Disagree ☐ Strongly disagree ☐

4. Would you say you were comfortable knowing your caregiver was able to see your location on their phone?
   Strongly agree ☐ Agree ☐ Indifferent ☐ Disagree ☐ Strongly disagree ☐

5. How easy did you find following the arrows to help you go the right way?
   Very Easy ☐ Easy ☐ Indifferent ☐ Difficult ☐ Extremely difficult ☐

6. How easy would you say it was to initiate contact with your caregiver?
   Very Easy ☐ Easy ☐ Indifferent ☐ Difficult ☐ Extremely difficult ☐

7. Any further thoughts on your experience with the application?
________________________________________________________________________
APPENDIX 2

QUESTIONNAIRE - CAREGIVER

Section A
In this section, we would like to ask you some general questions about your current circumstances and experience with smartphone technology. Your answers will only be used anonymously – your name will not be associated with any comments that you make.

1. Name: ________________________________
2. Age: __________
3. Gender: Male □ Female □
4. Where do you live (Place name eg. Dublin): ______________________
5. Do you own a smartphone? Yes □ No □
6. If so, how many years have you been using a smartphone? ________
7. Do you have Internet access throughout the day on your smartphone? Yes □ No □
8. Operating system of smartphone:
   - Google Android □
   - Apple iOS □
   - Windows Phone □
   - Other □
9. Does the person you care for ever take part in independent travel? Yes □ No □
10. If so, please describe some details

Section B
As you are aware, this application is about designing a solution that will try support both carers and individuals with ID feel comfortable with independent travelling. We would like to ask you a few questions about some of your experiences as a carer to try and understand what you think are the most important aspects on a system trying to achieve this goal.

1. What are your main concerns about letting the individual partake in independent travel?

_______________________________________________________________________
_______________________________________________________________________
2. Do you think the proposed system would help alleviate some or all of these concerns?
_______________________________________________________________________
_______________________________________________________________________

3. If not, what aspects of the system do you think would need to be added/removed or altered to help alleviate these concerns?
_______________________________________________________________________
_______________________________________________________________________

4. What are your main concerns you have in relation to yourself as a caregiver about when an individual is undertaking a journey independently?
_______________________________________________________________________
_______________________________________________________________________

5. Do you think the feedback features provided are enough to offer sufficient peace of mind?
_______________________________________________________________________
_______________________________________________________________________

Section C
The purpose of this section is for us to gain feedback based on your initial thoughts after using the application for the first time.

1. How difficult did you find it to open the application and register an account?
Very Easy □  Easy □  Indifferent □  Difficult □  Extremely difficult □

2. How difficult did you find it to pair the users phone with your account?
Very Easy □  Easy □  Indifferent □  Difficult □  Extremely difficult □

3. How difficult did you find it to log in and out of the accounts?
Very Easy □  Easy □  Indifferent □  Difficult □  Extremely difficult □

4. How difficult did you find it adding a new place to the routes list?
Very Easy □  Easy □  Indifferent □  Difficult □  Extremely difficult □

5. How difficult did you find it adding a corresponding name and picture to a place?
Very Easy □  Easy □  Indifferent □  Difficult □  Extremely difficult □

6. How difficult did you find it viewing and deleting a place from the list of favourites?
Very Easy □  Easy □  Indifferent □  Difficult □  Extremely difficult □

7. How satisfied were you with the syncing between the places you added and the ones displayed on the users device?
Very Satisfied □  Satisfied □  Indifferent □  Unsatisfied □  Extremely unsatisfied □

8. Did the application offer you full peace of mind while the individual was completing their journey?
Strongly agree □  Agree □  Indifferent □  Disagree □  Strongly disagree □

9. The app was easy to navigate around and access all relevant information.
Strongly agree □  Agree □  Indifferent □  Disagree □  Strongly disagree □

10. How would you describe the live feedback (GPS) to the caregiver’s device?
Very useful □  Useful □  Indifferent □  Not useful □  Pointless □
11. Are there any other types of feedback you feel would help offering peace of mind? If so please note them below.

_______________________________________________________________________
_______________________________________________________________________

12. How easy would you say it was to initiate contact with the user?
Very Easy □  Easy □  Indifferent □  Difficult □  Extremely difficult □