# The Dorothy Community

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# Background

## Who are we?

Care City is a community interest company that delivers health and social care transformation of local benefit and national significance.

**Dorothy** is a company that develops technology for people living with dementia, using digital technologies to make everyday life easier for them and those who might care for them.

**TPXimpact** is a digital transformation company supporting organisations to build a better future for people, places, and the planet – through the power of human-centred design.

**TPXimpact** 

Care Citv

Dorothy

## About dementia

Here is a description of dementia outlined by the Longitude Prize on Dementia:

Dementia is caused by different diseases that affect the brain, which mainly affects people over the age of 65. It is a group of symptoms that often get worse over time and include:

- Memory loss
- Confusion
- Problems with words, language and comprehension
- Changing behaviours and a need for assistance in everyday living

Around 50 million people worldwide are living with dementia. The condition devastates lives, causing people a series of losses – of memories, relationships and identity. That number is predicted to increase to 153 million by 2050. There are currently around 900k people in the UK living with dementia.

## **Introducing Dorothy**

The Dorothy App uses Augmented Reality (AR) to create a digital yellow brick road, helping people navigate with a dementia-friendly interface.

It uses Artificial Intelligence (AI) to remind users of daily tasks while keeping them connected to their caregivers. It uses large, high-contrast icons to overcome language and education barriers.

# The Longitude Prize on Dementia

Longitude Prizes started in 1714. Not being able to measure longitude on the sea left ships struggling to stay on course with serious consequences when they didn't. Merchants and captains petitioned the British Parliament to solve the issue of navigating at sea, which culminated in the government issuing The Longitude Act, offering a £20,000 prize (approx £1.5m today) to anyone who could solve it.



In 2022, a Longitude Prize on Dementia was announced. They put out this call: We are calling on innovators around the world to develop digital solutions that support people with dementia to remain independent for as long as possible.

We applied for the Prize, and Care City won the opportunity to develop 'The Dorothy Community'.

Click the video icon or scan the QR code to watch a pitch video explaining the Dorothy Community. Runtime: 3 minutes



## Summary of what we have achieved through the **Discovery Award**

The Longitude Prize on Dementia Discovery Award has allowed us to learn what people living with dementia really want and how important internal wayfinding is to them. We have also established the needs of the businesses and other organisations that would offer the Dorothy app. We have established how much work will be needed to move Dorothy from a prototype to a commercially available service and have identified a path for future innovation to take Dorothy to the next level.

We have co-produced our findings and developed Dorothy with a range of people living with dementia, with a range of different subtypes of dementia, backgrounds, ages and experiences. We have tried Dorothy out in a range of venues and businesses to understand their unique needs and concerns.

All this work means we are excited to apply for funding for the next round of the Longitude Prize on Dementia: the Finalist Awards.



# Our design approach



ETS

# Our design approach

# The challenge

Care City published a landmark report on life in London for those with a diagnosis of dementia. 966 🛛 People living with dementia told us they want to live independently, access their community, socialise with friends, and continue to participate in activities they enjoy. However, many we spoke to do not go out as they or those who care for them are concerned about the struggle to navigate places. Carers and professional care workers found it hard to support people who wished to visit places because of the timely preparation this involved and the lack of capacity to do so.

# The Dorothy Community

Dorothy was originally designed to be used in care homes, supporting residents with mobility issues using a walking frame. Dorothy tested well with these users and it was found to help support independent navigation around care homes.



Click the video icon or scan the QR code to watch a video of Dorothy being used in care homes. Runtime: 1 minute



Our vision was to create 'The Dorothy Community' which existed outside of the care home. People living with dementia could be supported by Dorothy, without the walking frame, to visit public buildings, community spaces, and commercial businesses. Venues would become more dementia-friendly, and, more importantly, people living with dementia would become more autonomous and independent.

Taking Dorothy out of the care home and into other spaces was not a simple translation. There were five barriers to this endeavour:

- 1. We didn't understand where people living with dementia would like to visit
- 2. We didn't understand what a good day out and living independently mean to people living with dementia
- 3. We didn't understand the full scope of needs for everyone involved in the future Dorothy journey: people living with dementia, carers and people who manage spaces
- We didn't understand what the end-to-end service journey, model, and product needed to be, to meet those needs
- We didn't understand the technical development needed to ensure the Dorothy app can be used reliably by our users, as a standalone service



# **Design methodology**

Our design methodology was underpinned by three disciplines:

#### 1. Human-centred design

As design practitioners, this discipline sat at the core of our approach. In practice this meant: focusing on the needs of the people our service would be helping, basing our design concepts on their needs, and learning from testing with real people.

#### 2. Co-design

Co-design and participatory methods heavily influenced our philosophy with this work. In practice this meant: grounding our strategy in where we would test Dorothy in the spaces that people living with dementia truly wanted to access, focusing on what independence meant to individual people, having a steering group of people living with dementia guide our design journey, and responding to the needs of people living with dementia.

#### 3. Inclusivity and equity

As designers of services that support people across society, we understand that the decisions we make can risk excluding people. Especially marginalised communities who experience healthcare inequalities. With that in mind, we worked to ensure we conducted research with a broad demographic of people with different characteristics and considered the impact that different design decisions could have on communities.

At the centre of our design methodology sat a recognition of the duty of care we had for the communities we built relationships with. Services for people living with dementia and carers, as well as volunteerdriven or community groups, play a significant role in the livelihoods of the people attending. These services are a space for people to come together, to share experiences, to seek support, and have respite. We recognised the importance of this and endeavoured to: build long-term, genuine relationships with the communities we worked with, respect their schedule, time, and space, and attend community groups as welcomed participants into the space as opposed to extractive researchers, joining in with activities.

# **Research and testing objectives**

To plan our research and testing, we took the barriers we identified to being able to design the right service for people and set them out as research objectives. We have six in total:



# **Research and testing approach**

When planning our approach for research and testing, we held a commitment to:

- Using a **mixed-methods approach**. We knew that the experience of dementia was a complex space and thought the best way to understand the needs of people who might use our service would be to learn from people's experience through a range of different activities.
- Adapting our research activities to what works best for people. For each research activity we had an idea in mind of what we wanted to achieve. But we wanted to make sure we were flexible to what works best for each individual person or group that we were speaking to. Sharing one's experience of dementia or caring for a person living with dementia is a personal subject – and we wanted to respect that. In practice this meant: working out with groups and individuals how they would like our time together to be, not being beholden to our desired research structure and letting our activities flow naturally, not rushing through things and exploring people's experience in a way that works them, and spending time getting to know people before doing anything.
- **Meeting people in their space.** Throughout the course of the project we met with many people and groups. It was important to us that we went to where these people and groups were located, and that they were in familiar and comfortable surroundings, so they felt at ease in sharing their experiences.

With all that in mind, we ended up doing the following research activities:

- Desk research. We analysed a number of different reports around the experience of dementia and best ways to co-design solutions for people living with dementia.
- Interviews. We had semi-structured interviews with people living with dementia, carers, and people who manage spaces.
- **Generative workshops.** We ran a generative workshop where people living with dementia and carers created a vision of what a good day out looked like to them, overlayed with their current experience and existing barriers.
- Ethnography pilots and testing. We ran ethnographic pilots, which involves conducting research through observation, with people living with dementia and testing sessions of Dorothy in different spaces.
- Working and focus groups. We spent time with different groups to discuss their experiences and get their feedback on Dorothy through testing.



We donated to the groups for using their space and for their time facilitating our session. All attendees, whether or not they engaged in the session, received a high street gift card. When engaging with people living with dementia on the steering group and conducting consultations and tests on Dorothy, we used dementia-friendly interviewing techniques outlined by Ben Williams, the Senior Project Lead, in his blog.



# Who we spoke to

As part of our work, we spoke to many different groups. Below is a snapshot of our sessions:



### South East London Young Onset Dementia Activists (YODA) group, Bromley

The group consists mostly of younger people with fewer health conditions that would impact their mobility. We felt it was the group most likely to use Dorothy.

Most have immediate family members with whom they live and access the community. This group helped identify how people would prefer to interact with Dorothy when they already had their own devices.

### Daffodil Dementia activity group, Nunhead

This group was incredibly warm and welcoming. People with dementia and their extended families attended and saw Dorothy in use. This group often included people who lived alone or in a care facility and travelled alone or with care workers. Many in the group did not have smartphones or tablets, so seeing how they would interact with Dorothy was useful.





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### Merton Dementia Hub

This group welcomed us into their space to join in their afternoon activities. People living with dementia and their carers attended. We had an informal discussion as a group to explore where they like to go, how they feel on a good day out, and where they feel they can't go currently. We then joined in some of their planned activities for the day.

### Stevenage Dementia Involvement Group

The University of Hertfordshire set up this group to assist in dementia research and local community projects. The group was a mixture of people living with dementia and carers across a range of ages and backgrounds. For this session, we ran a generative activity where people created a map of what a good day out looked like to them – where they wanted to go, why, and what would prevent them going to specific places. We also tested Dorothy with them in the space, exploring how they expected Dorothy to work and any thoughts they had on how it functioned at the time.

## **Alzheimer's Society UK**

We ran an online focus group with people living with dementia. They were really generous with their time and contributions to help us understand where they enjoy going and why, where they feel they can't go and why, and if there weren't any limits, what a good day out in their local area would look like for them.

The session helped us understand the bigger picture for people living with dementia which helped us make the right decisions about where to test Dorothy.

We wanted to make sure we were testing Dorothy in places and environments that people living with dementia really care about visiting. Other focus groups took place at venues where we tested Dorothy.



# Addressing healthcare inequalities in dementia



As mentioned earlier, we were aware that <u>specific demographics are at higher risk of</u> <u>healthcare inequalities than others</u>. Those at higher risk of developing dementia include women and people from Black, Asian and minority ethnic communities.

To make sure we were identifying the needs of these groups we ensured our research and co-design included a broad base of different demographics living with dementia such as:

- Inner-city, rural, and coastal areas
- People with different subtypes of dementia: Alzheimer's disease, vascular dementia, frontotemporal dementia, mixed dementia, and other types of dementia
- People at various stages of dementia, from those recently diagnosed to those with advanced dementia
- An equal number of men and women living with dementia
- People from ages 50 to 90
- 4% of people from LGBTQ communities
- People from a mix of different ethnicities, including 37% White British

In future phases, we remain vigilant in ensuring our research is inclusive of all demographics and we are identifying any specific needs of these demographics before we meet them in our service.

A breakdown of our engagement can be found in Appendix A: Engagement on page 60.



# Governance



# Governance

# **Care City Community Board**

Projects and prospective bids selected for consideration by Care City are reviewed by our 'Community Board', which reflects the diverse local population of North East London, where they are based. The Community Board helps Care City conceptually determine whether bids match our mission and will help resolve a need that chimes with the everyday challenges they face living in one of the country's most deprived areas.

Care City won the bid for the Discovery award and worked with the Longitude Prize team and Seven Consultancy to support their communications regarding the prize's launch.



Click the video icon or scan the QR code to watch a video launching the prize and discussing our Dorothy project. Runtime: 2 minutes 15 seconds



# 'The Dorothy Community' Project Steering Group

Once the bid was won, a project-level 'Steering Group' was set up. The steering group is made up of different people from our Community Board, people with lived experience of dementia and their carers, and some topic area professionals.



The steering group is expected to meet regularly throughout the project year to oversee the project development process. There was a concern this might put pressure on individuals, who would feel obligated to attend meetings despite not being up to it on a particular day or time or having conflicting medical appointments. It was felt that the best way to mitigate this risk would be to

partner with a local dementia group, the Barking and Dagenham dementia carers group, at the Memory Lane Resource Centre. This lets individual members attend when they wish but ensure as a group there is continuity throughout the project.



The dementia carers group meets once a month. Considering the needs of those with dementia, there may be times when people change their minds while in attendance and do not want to engage. The Centre has resources and staff to support those living with dementia who prefer to engage in other fun activities. Local Admiral nurses and care centre professionals also provided their experience view on the discussions and were viewed as part of the steering group. However, these

professionals were always a minority in the sessions.

The agenda was also kept brief so as not to take up the full amount of time that people came together for the usual peer support. At each meeting, the steering group would get an update on the progress of the project, ask for interpretations of findings from consultations or pilots, and then review upcoming planned work, providing suggestions to make the session run more effectively.





# Findings

Our research helped us to understand the lives and experiences of people living with dementia, which informed our design work in two important ways:

- 1. The bigger picture: Understanding wayfinding and independence when living with dementia. These findings helped us to understand what independence means to people living with dementia, and the barriers to navigating spaces by themselves. This in turn showed us what people living with dementia need from a service that supports independent wayfinding.
- 2. The detail: Understanding the practicalities of using Dorothy when living with dementia. These findings helped us to understand the challenges that people living with dementia face when using a digital app like Dorothy and physical devices like tablets. This showed us what people living with dementia need to be able to use digital and physical products.

Enabling independent wayfinding in public spaces involves three key groups:

- 1. People living with dementia
- 2. Their caregivers
- 3. People managing and working in public spaces

Our findings touch on the experiences and needs of all three of these groups.

# **Understanding wayfinding and independence**

Our research gave us insight into the typical experience of visiting a public space for a person living with dementia. We found that the journey tends to be made up of these steps:



We saw that the experience of visiting a place is made up of more than just the visit itself. There are several decision points which determine whether someone will visit, or return to, a particular venue.



worship could be an important space for people living with dementia.

Here's what we learned about each stage of the journey:

## Knowing where I want to go

We have seen that:

• People living with dementia want support to do everyday things independently. This looks different for everyone, but includes things like going to a café, pub, supermarket or place of worship.

# **44** Yeah, the trips are ok, but **I want to just go to the cafe** and have a decent cooked breakfast. Person living with dementia

- For people living with dementia, independence is less about specific settings, and more about feelings in particular the feeling of being 'normal'.
  - **11** It's more about living that **normal life** that people used to have. Professional

## **L** The most important thing: feeling that **this is wonderful**. Person living with dementia

• People living with dementia have no choice but to visit hospitals and other medical settings. These spaces can be particularly difficult to navigate.

# You need it [Dorothy] at the GP. It's like a warren."Person living with dementia

Throughout this research, people we spoke to shared a number of different spaces they would like to go if possible:

### • Identity-affirming spaces

- LGBTQ social spaces such as bars and community spaces
- LGBTQ museums and exhibitions
- Local and support groups
  - Memory cafes
  - Dementia community
     groups
  - Council meetings
  - Sheltered housing
  - Clubs

- Cultural spaces
- Museums
- Exhibitions
- Theatres
- Concerts
- Dancehalls
- Cinema
- Healthcare spaces

Although we heard this less through our engagement, we do have an existing hypothesis that places of

### Hospitals

- Natural and outdoor spaces
  - Nature walks
  - Parks
  - Country houses
     and gardens
  - Football games
- Everyday spaces
  - Pubs
  - Retail shops
  - Supermarkets

# Deciding where to go

We have seen that:

- People living with dementia are more likely to visit places they already know their way around, or which are small and well signposted.
  - I go to places I've been to before... I tend not to go into new shops. Person living with dementia
- Support with wayfinding could make trips out easier.
  - **G** We could have really used it [Dorothy] on our trip to the Tower of London. It's **so stressful** planning a trip and having people asking all sorts of questions when you arrive, like where the toilets are.

Professional

## Spending time at the place

We have seen that:

- A good day out can have a positive impact on the mood of a person living with dementia.
  - I find navigating the independent cinema fantastic because it's signposted and there's only two screens in it. You walk into it and you feel 'I can cope with this'. That's a good feeling when you walk into somewhere and you feel you can cope with it. Person living with dementia
- People living with dementia experience some staff as impatient, and feel that they view older people as a burden, which makes them feel unwelcome.
  - **1** often think I am part of a group that is often **a problem** for other people: the elderly. Person living with dementia
- Bigger and more complex settings are more overwhelming to people living with dementia. •
  - **for a sign at the new cinema to tell you what's on, where exactly it is. I got lost twice** in that place. I went for a pee and I ended up on the pavement rather than back in my seat. Person living with dementia
- People living with dementia are more likely to have accidents, incontinence or difficulties using the toilet. We have seen that being able to find the toilet quickly and easily is important to them and to their carers.
  - **66** People don't understand when [person with dementia] needs to go to the toilet they need to go, you can't go hunting around for hours. Carer



## Deciding whether or not to return

We have seen that:

- The attitude of staff in spaces is important to people living with dementia, and impacts how they feel in themselves. They are more likely to go back to places where the staff have understood, and responded to, their needs.
  - I can't bear [venue] because they have an attitude problem towards the elderly. Even the security people do. They are **impatient**.
    Person living with dementia
- People living with dementia are less likely to return to places they've found difficult to navigate, or where they've got lost.

These findings helped us to understand the needs of a person living with dementia when visiting and navigating a space. This allowed us to articulate these key user needs:

As a person living with dementia, I need:

- To feel confident in navigating a space
- Support with wayfinding in lots of different places
- To feel comfortable and welcome when I visit a space
- To be able to find the nearest toilet quickly and easily
- To have my specific needs known when visiting a space

Because the visitor experience is created by the people running and working at venues, it was crucial that we also understood their needs and perspectives.



## Understanding venue managers and staff

In our research with venue managers and staff, we found that:

- Staff running spaces want to know about the needs of the person who is visiting. This includes dementia-specific needs, but also things like allergies.
  - **L** The **biography of the person** would be good. Everyone's at different levels of dementia, aren't they? And if they have a nut allergy... there could be a problem. Venue manager
- It's important to people who run spaces that their staff are properly trained to look after people living with dementia. They need to be able to trust their staff to act responsibly and with empathy.
  - Yeah, just making sure that they [staff] are definitely going to be sympathetic.. like if there's an issue with paying the bill... any scenario where they might be doing something that might throw things off. Make sure we **treat them with sympathy**. Venue manager

From these findings, we identified these user needs:

#### As the person responsible for a venue, I need:

- To understand the dementia-specific, and non-dementia-specific, needs of the person who is visiting my space
- To feel confident that my staff can support the person and keep them safe

#### As a person working in a venue, I need:

- To feel confident that I can support the person and keep them safe
- To know when someone needs support in the moment

## So what?

These findings helped us do two things:

1. Validate the Dorothy Community concept – Our research demonstrated a clear need for support with wayfinding in public places.

Our findings suggest that Dorothy could:

- · Give people living with dementia more independence in public places
- Give people living with dementia more agency in choosing which places they visit, rather than just being able to visit the places they are already used to navigating
- Make the places that people living with dementia have no choice but to visit (like hospitals and medical centres) more accessible
- Shape the design of the end-to-end service journey You can read more about this in the End-to-end service journey section of this document on page 42. These findings will guide us in creating a more inclusive and effective Dorothy.



# Understanding the practicalities of using Dorothy

Understanding what wayfinding and independence mean to people living with dementia helped us to understand what Dorothy needed to do as a service – but this was just one piece of the puzzle. The wayfinding service Dorothy provides is accessed through:

- A digital product: the Dorothy app
- A physical device: a tablet

For Dorothy to work, we needed to understand the experience of using the Dorothy app on a tablet when living with dementia. In order to do this, we tested Dorothy in the types of locations we had learned that people living with dementia wanted to visit.

Here are some of the places where we tested Dorothy:



## Dementia dedicated venues

Sage House offers professional one-to-one support and advice, respite day care for people living with dementia, activities for people with dementia and their carers, support groups, assisted bathing, foot care and massage, dementiafriendly hair specialists, a 'smart zone' (to test innovative technology to help ease daily

tasks) and a café.



## **Sports venues**

People said they would love to watch sports like they used to. <u>The Alzheimer's Society</u> helped facilitate our trial Dorothy at <u>Wembley Stadium</u>, which had recently <u>announced</u> it was dementia-friendly.

Testing took place with a local group from the Brent Dementia peer support group run at Ashford Place.







## Museums



Museums and historic buildings were a popular choice of location. We tested Dorothy, and filmed our concept video, at Eastbury Manor House, run by the local authority and National Trust.



## **Hospitals**



Many people felt that Dorothy would be perfectly suited to help navigate the often labyrinthine maze of hospital corridors.

We tested Dorothy at <u>Homerton Hospital</u> to help people get from the reception to the onsite memory clinic.

Homerton Healthcare



## **Hospitality venues**

During the research for the Care City <u>report</u> on life in London for those with a diagnosis of dementia, many said they wanted to go to the cafe or pub and see their friends again.

We worked with the <u>Askew Road Business</u> <u>Association</u> to identify businesses that would support testing Dorothy, and the <u>Detour Café</u> volunteered to take part.

You can read an in-depth account of one of our testing sessions at Detour Café in the section: **Dorothy pilot: Clodagh's story**.





Through our testing, we found that the experience of using Dorothy is made up of these elements:



Here's what we learned about each element:

## Environment

We have seen that:

- People using Dorothy may need support to get to and from the space, as well as support in the space itself.
  - I don't know exactly what's gone wrong in the past... but sometimes they might get a bit lost, or forget where they are, making sure they get home.
    Venue manager
- Crossing roads is risky whilst using Dorothy.
  - Holding a tablet in front of you could cause a lot of fall problems, not focussing on the world around you. If you focus on the device, you can walk into people or cars.
    Professional
- Mapping roads or routes to venues is risky for the person doing the mapping.
  - **66** Mapping across a road is obviously **dangerous** for the mapper. Project team member, after mapping outdoors

## **Physical device**

We have seen that:

- The tablet can feel bulky and difficult to carry.
  - **It**'s fine for a few minutes of holding... a **hands-free version** would be better. Person living with dementia
- When using Dorothy, people worry about tripping or falling with the tablet.
  - **66** Okay but won't this **trip people up**? They'll be more focused on the device Person living with dementia
- When using Dorothy, people worry about dropping the tablet.

## **11** It looks expensive and **I drop things**. Person living with dementia

- People fear that using Dorothy on a tablet in public would make them seem vulnerable, and make them a target for theft.
  - …a tablet with us, it's going to make everyone around see you need help. Criminals target people with dementia.
    Person living with dementia
- People living with dementia may forget to return the tablet when leaving a space.
  - **You forget son, with dementia you tend to...you know, forget things. So you give us a tablet and it will go in the bag and we will forget we got it.** Go home with it. Then we are accused of stealing!

#### Person living with dementia

• Older people living with dementia can often also have difficulty walking. Dementia may exacerbate the effects of pre-existing disabilities.<sup>1</sup>

## **Digital product**

We have seen that:

• Dorothy recalculates a path when the screen or person moves, causing the pathway to 'shake' on screen. Users found this off-putting.

When a user goes in the wrong direction, the pathway is no longer visible because it is technically behind them. This can cause confusion and disorientation.

#### **66** Can the path be animated as it's unclear if you're facing the wrong way?

• When following the pathway correctly, it is not always fully visible. Sometimes it is off screen, or only a sliver is visible. Again, this can cause confusion and disorientation.

#### **66** Could the path go from the **centre of the screen**?



<sup>&</sup>lt;sup>1</sup> Timlin, G. and Rysenbry, N. (2010) Design for Dementia: Improving Dining and Bedroom Environments in Care Homes. London: Helen Hamlyn Centre, Royal College of Art.

• For some users, the visual design of the pathway made it difficult to follow.

#### **66** Can the path be yellow with black borders so that it's **clear** and **stands out more**?

• When using Dorothy, people wanted more obvious confirmation that they had arrived at their destination.

# **L** It should play a little tune when you're there. I can look down again [at the icon] and see **why I'm here**.

#### Person living with dementia

• Some users found the concept of Dorothy impersonal, preferring human interaction. Many users naturally began talking to Dorothy as though the app was a person.

# **66** *Makes me feel sad – no chat with a human.* So many things no longer involve humans. Person living with dementia

- Some people who are older now do not have crystallised knowledge of technologies like computers and the internet.<sup>2</sup>
- Older people living with dementia are likely to also have a visual impairment. Dementia may exacerbate the effects of pre-existing disabilities (Timlin and Rysenbry 2010).

These findings allowed us to articulate some more specific user needs for people living with dementia:

### As a person living with dementia, I need:

- To feel confident using both the physical device and the app
- To be able to use Dorothy regardless of my cognitive or physical impairments
- To feel confident that I have arrived at my destination
- A way to remind me to give the tablet back
- To not feel guilty if I forget to return the tablet
- An easy way to return the tablet if I have taken it home with me
- To feel safe from theft
- To feel safe from trips and falls
- To feel confident that I won't drop or break the device

<sup>&</sup>lt;sup>2</sup> Buie, E. (2023) Older Adults: are we really designing for our future selves? [PowerPoint presentation]. Camp Digital, 13th April, Manchester.

The digital product, and therefore the user experience, is underpinned by technology. Therefore we also needed to understand the technical and technological opportunities and limitations impacting the Dorothy app.

	User experience The experience of using Dorothy		
Environment Where the product is used	Physical device <sup>iPad</sup>	Digital product The Dorothy App	
		Interactions How the user interacts with the product	Visual design How the product looks
		Technology The technology driving the product	

Here's what we learned about the technology driving Dorothy:

## Technology

Through research and testing, we can see that there are limitations to the current technology that powers Dorothy. We made these observations:

- Mapping spaces is slow and sometimes unreliable. The larger the space, the more difficult the mapping.
  - Sometimes, Dorothy can take a while to locate where it is in a venue. Some tests show that iPhones or iPads with 'Light Detection and Ranging' (LiDAR<sup>3</sup>) sensors work better.
  - Dorothy does not always give straight pathways. Sometimes, a person follows the path, and Dorothy creates mini-circles as they walk along it.
  - Sometimes, a pathway would appear to have moved. This was especially a problem with longer corridors, such as at hospitals. Users felt Dorothy was trying to get them to move into the walls.
- Sometimes, Dorothy does not recognise small obstacles like narrow pillars or prominent skirting boards. Dorothy would direct people to go through these objects.
- If any element of the technology fails (e.g. connectivity, hardware, app), users will need additional support both with the technology and with wayfinding.



<sup>&</sup>lt;sup>3</sup> Introduced in 2020, the LiDAR scanner is available on the Pro and Pro Max models of the iPhone 12, 13, 14, and 15, as well as the third-generation 11-inch and fifth-generation 12.9-inch iPad Pro models from 2020 and later. The Lidar scanner can detect objects up to 5 metres.

### So what?

Our findings showed that the experience of using Dorothy when living with dementia is driven by the environment, physical device, digital product and underlying technology. Our findings informed our design work in each of these areas:

#### Environment

Our findings about personal safety changed our model of where and how we see Dorothy being used. Whereas our initial goal was for Dorothy to be used everywhere, we now see Dorothy as a tool for inside places:



#### Physical device

We explored various options for supporting users to hold and carry a tablet, as well as alternative devices. You can read more about this in **Appendix D** on page 66.

#### Digital product

We made several iterations to the features, functionality and visual design of Dorothy as a result of our findings. You can read more about this in **Appendix D** on page 66.

#### Underlying technology

See the What's next? (Technology) section of this document on page 51 to read our plans for developing the technology that underpins Dorothy.

Taken together, our findings informed the design decisions we made when developing and iterating the Dorothy Community as both a service and product.



# **Dorothy pilot: Clodagh's story**

In September 2023 we were introduced to Clodagh by Caroline Needham, a friend of the project who works for London Borough of Hammersmith and Fulham. Clodagh lives in London and has a dementia diagnosis. We spoke to Clodagh and asked if she would be interested in spending time together to get to know about each other and run an ethnographical pilot for the day, with her testing the Dorothy experience at her local cafe. She was excited to be involved and in December 2023 we spent the day together.

The pilot was hugely insightful. We learnt about Clodagh's life living with dementia, her desires on where to go, and her needs in having a fantastic, independent day out. The insights were fundamental in helping us understand how the future Dorothy service would need to work for the people that might use it.



I need to know [shops] don't see me (as someone living with dementia) as something negative. I don't go out to feel rejected, but you get this feeling. I used to go to a lot of galleries. [After using Dorothy] I feel optimistic. [People living with dementia] need help to do things we could do before. You're on the right track. It's so easy. The design is spot on. I just loved how [Dorothy] picked up where you ate. I could feel myself relaxing and trusting it.

We would like to extend a huge thank you to Clodagh for her participation.





# Design outcomes



Section of

# **Design outcomes**

# **Contacting people via Dorothy**



Feedback showed us that when a person living with dementia goes to a venue using Dorothy, they would like to be able to contact a member of staff for assistance. Pressing a person icon would connect them to a staff member, or if the person has a Dorothy profile, it could connect them to their designated emergency contact.

Additionally, rather than using Dorothy to direct them to a fixed location (such as the dining area) then, people living with dementia said they would like it to direct them to their family member or carer accompanying them on the trip to the venue. Dorothy would track the carer app on their mobile phone and provide a pathway to the carer.

Click the video icon or scan the QR code to watch a video demonstrating using this at a museum in our Dorothy Community concept. Runtime: 5 minutes 13 seconds



Reviewing this concept, the Dorothy Product Manager felt that it might be more practical to enable the family member or carer to use Dorothy to meet up at a designated location. This is because a new system would need to be created for Dorothy to track the carer's phone and then put that location onto its own map. This does not mean that it can not be done. However, allowing both parties to be directed to one location is a simple workaround, meaning that precious development resources can be focused on other developments.

# Changes to the user interface based on feedback

## Iconography

Dorothy was set up to work at care homes, it has available:

Person

Seating

Food

Food

Bed/Rest

New icons will need to be developed for different venue locations:

1.	Ward/Clinic	4.	Activity/Games room	7.	Cloakroom	<b>10.</b> Female toilet
2.	Hairdressing	5.	Therapy room	8.	Gift shop	
3.	Computer room	6.	Physio/Exercise room	9.	Male toilet	

Based on what we heard from people, we identified a list of changes to be made to the user interface and experience of using Dorothy:

Area	Potential user interface changes
Path refresh rate	People suggested that once the path was determined, it could be fixed, with only necessary changes made if a person was going the wrong way.
Turnaround indication	People suggested that having the pathway start in the middle of the screen would help them know where to go.
Pathway guidance	People suggested that having an arrow to point to the pathway, if the view had moved away from the pathway and it was off-screen, would help if a person stopped following it.
Arrival notification	People suggested that having a larger message or notification in the middle of the screen and an audio notification would help them realise they had arrived.
	People also sometimes forget why they are following the pathway, so a message to say 'You have arrived at the [Toilet]' might be helpful.
Clearer interface designs	People suggested having a black border on the yellow pathway would make it stand out more clearly.
	People felt that the pathway may be easier to follow if it could be animated, with the arrows moving in the direction the person had to walk.
	People felt that having text under the icons would help users determine what the icons meant if they felt confused.
	People felt that audio alerts and descriptors could add to the experience and support those who process information better through audio.
Reminder notifications	People suggested that Dorothy could remind them to return the tablet if they had walked too close to the exit, using both an audio and visual reminder.
	People suggested that Dorothy could remind those using it to take medication, using both an audio and visual reminder.
Audio interface	People suggested that being able to use Dorothy via verbal requests would be easier for them to use. This would involve a process to determine what is meant when specific requests are made – for example, a person using it might say 'I want a cup of coffee' and Dorothy directs them to a drink serving area.

# **Technical and technological implications**

Throughout our research - specifically, the venue visits and pilots we delivered - we exposed a number of technological implications for us to consider.



### Alternative mapping processes

Mapping can take time, presently about 110m<sup>2</sup> an hour. It requires the mapper to record the floor from several angles before moving to the next part that needs to be mapped. If this is not done, then Dorothy tends to misalign the map. At this rate, it would take us approximately a month to map the whole of Wembley Stadium. It is hoped that LiDAR can help map spaces with more speed. We are also looking for potential partners who may be able to increase the speed of mapping.

### Working in low-light environments

Some spaces, such as theatres and sports venues, hold events at night. Dorothy has an alert to say when there is not enough light for it to work. It is hoped that introducing LiDAR would help it work in more low-light environments.



# **Overcoming barriers to the adoption of Dorothy**

Dorothy was designed to work on a tablet fitted onto a person's mobility aid, such as a Zimmer frame. However, only a small proportion of people use such an aid, so the question remained: how will most people interact with Dorothy?

#### Using the existing tablet interface

**On a person's own device** – This is the easiest and most preferable option for the general populace. However, this requires design work to develop a process for letting people download new maps for the places they want to visit. This will be one of the avenues that people can use to access Dorothy. Our steering group and others we consulted with were concerned about the digital divide of an older population.

#### Alternative Dorothy interfaces for users

Dorothy requires some minimum specifications to work: a camera and motion sensor to locate the person in a mapped space, a way to inform the person where to go and a processor to run the Dorothy programme.

The best hope for adoption requires the person to use the device with as little impact to how they would normally act or increase their cognitive load. Consultations took place to review alternative interfaces for Dorothy. Here are the results:


#### Face



#### Glasses

There are several versions of smart glasses on the market, and few of them currently (as of May 2024) allow an Augmented Reality overlay to display the pathway. Consultations informed us that people living with dementia didn't like the concept of having something on their face when they were not used to it. There were also safety concerns about having something that obscures a person's sight. Overall it was felt this would not be a route that would lead to the greatest adoption.



#### **Hearing aid**

Many asked if there could be a hearing aid version of Dorothy, telling the person when to turn. There were several issues with this approach, firstly, it would be language-based, and you would need to understand the terms being used. This could have issues for people who do not speak the language Dorothy is provided in (we are hoping for international adoption). Some people living with dementia may know a language that Dorothy is provided with, but as their dementia progresses, they may lose their ability to speak that language. Secondly, it would rely on the person hearing the instructions responding promptly, something that not all could do. Thirdly, some were concerned about how people living with dementia would respond to disembodied voices. Overall it was felt this would not be a route that would lead to the greatest adoption.

#### **Shoulders**



#### Haptic feedback for shoulders

One concept brought to us was a haptic feedback device that would be mounted on the shoulders, which was developed by TPXimpact lead designer Anisha Kanabar. The device was in a prototype stage and was not yet configured to adapt to Dorothy. It would need a camera to locate itself, and it would give feedback to the user with a vibration on a person's shoulder indicating which way to go. Consultations felt that people living with dementia might be confused as to what the vibration would mean. There were also concerns about how a device used to help a person navigate to the toilet might not be best suited when it vibrates. It was felt that this was worth follow-up testing in year two.



#### Shoulders



#### Tablet on a gooseneck stand

This turned out to be the most popular way to use Dorothy on a tablet. This was surprising, as our steering group had dismissed this idea, but user testing showed that people did not object to the smaller screen, felt the pressure on their neck was not noticeable and preferred something that left their hands free. It was popular with people with walking sticks. It was also noticed that when people wore this device, the public around about would give the person space, it seemed to communicate non-verbally that the user was using a mobility aid. This aid will be one of our offers for support when using Dorothy.

Chest



#### **Chest Harness for tablet**

We reviewed several harnesses designed to hold a tablet for a person. People found that these worked well, but most found them to be uncomfortable and awkward to put on and restricted movement. It took the longest time to put on and take off, and venue organisations said that this would not be preferable when visitors arrived. Overall it was felt this would not be a route that would lead to the greatest adoption.



Humane Al pin – This new device is advertised as an Al companion chest-mounted pin, worn using magnets. It has a laser projector that projects onto a person's palm instead of a screen. Although it can not project information on the floor, it was the closest commercially available technology we could see to the **Dorothy Device** that we wanted to build. Currently, the organisation is only taking orders in the US, and we were unsuccessful in our efforts to reach out to Humane. We would like to continue reaching out in the second year and welcome any support to make a connection. We are concerned that this device, as is, requires a high cognitive load to operate and so would not be suitable for our target audience.

#### Hands



#### Tablet in cover/case

Testing showed that people living with dementia were very concerned about dropping a tablet without some protection. Some even refused to hold the tablet without a case. After focus group discussions, we found that people wanted a case or cover with handles to help them grip the tablet more easily and possibly with a shoulder strap. The three-handled tablet was found to be the most popular.

The colour of the device was also a big concern for people living with dementia. Many of the tablet cases with handles were clearly designed for children, and people using Dorothy did not want what they considered a 'juvenile' colour. Black was eventually selected for our testing as it was considered neutral. Another approved colour was blue, the shade of the forget-me-not flower, which is long associated with dementia. Other colours prompted debate as to perceived femininity or masculinity. We want to do further research into colours in year two. This aid will be one of our offers for support when using Dorothy.

Feet



#### Laser projectors on shoes

Path Finder is a shoe that projects laser lines to support walking and prevent 'freezing of gait', a common symptom of Parkinson's disease. The laser cues are activated by pressure when the wearer touches down on the ground. We have reached out to the developers of this product. It would have to be adapted significantly to work with Dorothy. Venue organisations were concerned about how long it would take to put these devices on and off when arriving at venues. People were also concerned about how to interact with such a device and if an extra device would be needed nearer the mouth to input voice commands. We would like to review the options for this in year two.

#### Separate from the person



#### **Tablet on stand**

Conceptually, this aid was the most popular design. It could be held onto and become a walking aid for those who need it. If a person had a fall, then they could let go of the stand, and they were not concerned about the damage to the tablet. People were also concerned about the injury that could be caused by a tablet hitting the person in the face or chest if they fall, especially as the screens are glass. However, when we tested the stand, we found users kept bumping their feet into the stand's wheels and brakes. A potential workaround using the stand with an armature designed to hold the device away from the stand was also found to be unsuccessful, as it made the body of the stand too far away to hold. Overall it was felt this would not be a route that would lead to the greatest adoption.

### Summary of aids to use in conjunction with Dorothy

Name of aid/intervention	Will Dorothy continue to invest in this aid?	How will Dorothy invest in year two?
A person's own device	✓	Develop the app
Glasses	×	N/A
Hearing aid	×	N/A
Tablet on a gooseneck stand	1	Primary popular tablet aid
Haptic feedback for shoulders	$\checkmark$	Research viability
Chest harness for tablet	×	N/A
Humane AI pin	$\checkmark$	Research viability
Tablet in cover/case	1	Second most popular tablet aid
Path Finder	1	Research viability
Tablet on stand	×	N/A
Dorothy Device	1	Create prototype





# **Dorothy Device**



In an effort to meet the user requirements established by our user engagement, we designed our own stand-alone wearable device. People had told us that they wanted to use Dorothy hands-free and preferred not to have a screen. The principal came after discussing the most successful ways to help people living with dementia navigate around hospitals. Professionals from St George's Hospital in Tooting stated that having a painted line on the floor was the most successful, but "you can't have a painted line everywhere."

British Standards Institute (BSI) 's recent standard, 'Design for the Mind Neurodiversity & the Built Environment – PAS 6463', provides guidance on designing the built environment for a neurodiverse society. It highlighted examples such as Liverpool Street Station, where lines have been painted on the floor to help people navigate the complex space. It is true that lines couldn't be painted for each individual for every journey they wanted to take, but maybe there would be a way to digitally project a line on the floor for people to follow.

There are examples of laser projectors being built into devices to project something in front of them, such as the **Blaze Laserlights** attached to Transport for London's Santander Cycles, which can project a beam up to 6 metres in front of the bike. We were unsuccessful in our efforts to reach out to the manufacturers of these devices.

CAD designer <u>Gary Cox</u> designed and 3-D printed prototypes of the Dorothy device based on the smallest commercially available laser projector we could find. Iterations of the device were made based on feedback from consultations:



One consultation suggested that it should be worn with a lanyard. This would be something that people are familiar with and used to wearing. It would be hand-free and not rely on the type of clothing people would wear. Organisations were also happy with this design as it matched the concept of audio guides often provided by visitor attractions.

The device could be paired with a person's Dorothy account to download their preferences via a QR code on the back or used as a stand-alone device.





Discussions have taken place with **EG Technology**, a product design, engineering and development specialist based in Cambridge, UK. They create medical devices and consumer products and reached out to us after the announcement of being a discovery winner for the Longitude Prize on Dementia. We would look to partner with them at the next stage of the Prize to develop a working Dorothy Device by the end of year two.

# **End-to-end service journey**

### The future Dorothy community service

After reflecting on the design decisions we needed to articulate what the end-to-end service journey would look like for Dorothy. It was important to show the parts of the journey that Dorothy would enable. Doing this helped us to design both the digital and physical experiences that need to be in place for this service to work for all users.



### Settling on two core user experiences to ensure equity

Reflecting on the stories we explored of people living with dementia, we recognised that **our service, as currently designed, was at risk of excluding those with later progression and higher support needs**. This was because there was no way for Dorothy to capture these support needs and for the needs to be made known to people who manage spaces.

To help us address this, we created a simplified scale to show the specific conditions for these two types of people living with dementia. We know that the landscape and experience of dementia is far more complex than this – but this mental model was helpful in thinking about how we could address this potential exclusion.





Using this scale as a guide, we thought of two core user experiences that we could design for Dorothy:



Welcome screen for Dorothy showing the two user experiences

#### Pick up and explore

This would be for someone early on in this dementia journey. They will have lower support needs and perhaps are not visiting places with a carer. In this scenario, the person living with dementia can simply **pick up a tablet that has Dorothy loaded at a place** and use it to navigate around.

#### • Login and explore

This would be for someone later on in their dementia journey. They will have higher support needs and are most likely visiting places with their carer. In this scenario, the person living with dementia can **create an account which stores all their support needs**. When they arrive at a place, the tablet with Dorothy loaded can **scan a QR code which "loads" their profile so the person managing a space is aware of all their support needs**.

Having these **support needs known and met will be crucial to ensuring people living with dementia** are able to access spaces that in their current state, they might not feel comfortable going to. Examples of the support needs we are capturing are:

- What type of toilet they would like to use (accessible, male, female, gender-neutral)
- Preferred name of the user
- Carer's name and emergency contact details
- Any known allergies
- Any needs they would like to share
- What helps if they seem confused
- How often they would like to take breaks

For both user experiences, the vast majority of their journey would be the same. The key difference is that for one case there is an added flow of creating an account.

F	Pick up and	l explore						
Journey	Knowing where I want to go	Deciding where to go	Travelling to the place	Spending time at the place	Travelling home	Deciding whether or not to return		
Steps	Arrive at the place	Pick up iPad and load Dorothy	Explore the space using Dorothy	Return Dorothy on the way out	Travel back home			
L	.og in and	explore						
Journey	Knowing where I want to go	Deciding where to go	Travelling to the place	Spending time at the place	Travelling home	Deciding whether or not to return		
Steps	Setting up a Dorothy account	Recording details and support needs	Arrive at the place	Pick up iPad and load Dorothy	Scan QR code and load profile	Explore the space using Dorothy	Return Dorothy on the way out	Travel back home

Our journeys for the two user experiences



### Planning the starting scenarios we must design for

After having identified what the structure of an end-to-end service journey looks like for a person living with dementia, we created a set of **starting scenarios** with **user needs** aligned to them to help us create the right digital experience and make sure we are meeting the needs of people.

For these journeys, we focused on three users:

#### 1. A museum manager

This is someone who manages a physical space and is responsible for hosting the Dorothy service in their space.

#### 2. A person living with dementia and their carer

This is someone who is looking to have a good day out, enabled by the Dorothy service.

#### 3. A museum employee

This is someone who works in the physical space and is responsible for customers.

User	Starting scenario
Museum manager	A museum manager needs to map the museum. The museum is often busy, and they have a lot to do.
Museum manager	A museum manager needs to update the map of the museum because they've changed the layout. The museum is often busy, and they have a lot to do.
Person living with dementia and their carer	A person living with dementia and their carer are setting up an account on Dorothy.
Museum manager	A museum manager wants to know about the person living with dementia before they arrive. Ultimately, they are responsible for health and safety and for the customer experience.
Person living with dementia and their carer	A person living with dementia arrives at the museum. They're not familiar with the layout of this museum – it's not one they've been to often.
Person living with dementia and their carer	A person living with dementia needs to use the toilet. They don't know where the toilet is.
Person living with dementia and their carer	A person living with dementia gets a notification about taking a break and their medication.
Person living with dementia and their carer	A person living with dementia wants to find a person to help them.
Museum employee	A museum employee is there to help the person living with dementia. Helping customers to find their way around the space is one of their responsibilities.
Person living with dementia and their carer	A person living with dementia has finished using Dorothy and needs to give it back to the space.

# Creating the digital aspects of the future service

Once we had settled on the starting scenarios and user needs we needed to address, we started to prototype how this would work. We created steps for each scenario and low-fidelity prototypes for digital screens that would enable each step.

Gradually, after interrogating each step, prototype, and our mental model of "how" this all might work, we moved to higher-fidelity digital wireframes that could be **fully tested with users** and **be ready for build**.



Initial prototype concepts



Our scenarios and steps prototype





*Our digital wireframes for the future journey* 

*Our wireframe for adding points to a map* 





You can find digital wireframes for the end-to-end service journeys here.

# Creating the service model to support Dorothy

After creating our end-to-end service journey for Dorothy, we needed to think about the model that would underpin it. The aim here was to summarise the commercial and operational aspects of the model – not to explain how the journey would work for users, but to explain how that journey would be enabled.



We have provided further detail on what the operational responsibilities of the different user groups are:

- People living with dementia and carers This group of users **don't have any operational responsibilities**. They are focused on using the service. They are the **primary users** of our service.
- People who manage spaces This group of users have some operational responsibilities, in order for the service to work. They are the direct customers of our service.
  - Setting up their Dorothy account
  - Mapping their physical space
  - Maintaining and updating the map of their physical space
  - Providing Dorothy-loaded tablets to customers
  - Supporting customers using Dorothy •
  - · Ensuring iPads are returned



#### • The Dorothy team

This is the team that are designing, launching, and maintaining the Dorothy service. They are the **providers** of the service. This group has many operational responsibilities.

- Designing the Dorothy journey
- Creating all technical and non-technical aspects of the journey
- Marketing Dorothy and building awareness across user groups
- Onboarding customers onto the Dorothy service
- Maintaining all user accounts for Dorothy
- Providing technical support to people who manage spaces
- · Learning from real-world user experiences
- Iterating the Dorothy journey from learnings

Creating this service model has also been helpful for planning what the future of Dorothy looks like. Now that we have these responsibilities set, we can create a roadmap for the next phase of work to move Dorothy from a well-evidenced concept to a live service.

# Our theory of change for The Dorothy Community

After reflecting on what the end-to-end service journey looks like and designing it to meet the needs of people living with dementia, we have created a first draft of what our theory of change is for The Dorothy Community:



This theory of change is the foundation of how we will make sure we are reaching our intended impacts. It will change over time as we learn more.

One of our discoveries in research challenged our thinking about how The Dorothy Community will truly drive the change we want to see in society, to improve the lives of people living with dementia:

#### **6** For people living with dementia, independence is less about specific settings and more about feelings – in particular the feeling of being 'normal'.

Independence means different things to different people. The associated *impacts* of living independently are also different. Some may be looking to visit a space independently to feel a greater sense of integration with society whereas others may be looking to directly connect with cultural artefacts. This is a complex, interconnected space that is unique for every person.

The takeaway for our team is that whilst The Dorothy Community intervention, we believe, will have the impact of greater independence – we will need to spend more time in future pilots understanding what longer-term benefits this independence will bring for each individual and whether Dorothy had helped deliver that. This will most likely come from co-designing our monitoring and evaluation work at a very individual level with people living with dementia and carers. This might look like:

- Spending time building long-term relationships with people living with dementia and carers •
- Understanding how they want to feel after having used Dorothy to support a number of visits in their local community – do they want to feel greater social cohesion? Do they want to feel closer to friends? Do they want to have more new experience? Or something else?
- Working with them whilst they may use Dorothy across multiple visits to spaces and seeing how they get on
- Reflecting together, after time has passed, on whether Dorothy helped them to feel the ways they wanted to after a visit

A second new understanding for us is that Dorothy doesn't need to enable end-to-end independence but can rather have a greater impact by enabling **moments of independence**.

At the start of our project, our mental model was that Dorothy would help people living with dementia by using it across a whole visit to a space. However, there are many people living with dementia that only visit spaces with their carer and are closely supported throughout their visit. It might be that in this scenario, the person living with dementia may only use Dorothy once in their whole visit - to go to the toilet or to find their own way to a resting area.

Despite being a smaller "moment" of independence than we first envisioned, we believe if Dorothy is used to enable them we can have a greater collective impact on independence and quality of life.



# What's next?



# What's next?

There's a lot of work to be done to move Dorothy from our future service concept here to a live service being used in a place. There are three areas our team needs to make progress on in the next phase of work:

#### 1. Organisational

Related to anything regarding Dorothy as an organisation – the commercial model, team structures, and more.

#### 2. Design

Related to anything regarding the design of Dorothy digital and physical experiences for users.

#### 3. Technology

Related to any technology development regarding Dorothy.

There will inevitably be a need for these disciplines to work together on individual priorities. Below, we have listed out what these priorities are for the next phase. Please note there will be further planning and work to do. These are immediate priorities.

# Organisational

The focus here will be to establish Dorothy as an organisation with clear roles and business infrastructure to maintain Dorothy as a live service.

Priorities for the future are:

- Set the roadmap for the next phase which would includes developing the end-to-end journey for • Dorothy and running a number of private pilots
- Set up the team structure by discipline with clear scope and responsibilities •
- Further build connections with organisations listed for potential pilots in the next phase •
- Establish all infrastructure required to function as a commercial organisation •



# Design

The focus here will be to **further test smaller aspects of the end-to-end service journey and design the journey of how organisations will come on board to using the Dorothy service**.

Priorities for the future are:

- Test the journey for people who are managing spaces with different people to make sure it meets their needs
- Work with the technical team to create the iterated version of Dorothy
- Create an onboarding journey for places that will use Dorothy
- Plan how monitoring and evaluation would work for each private pilot

# Technology

The focus here will be to **develop the end-to-end service journey** for Dorothy and **have set up the infrastructure for private pilots**.

Priorities for the future are:

- Develop the front-end digital aspects of the end-to-end service journey
- Develop the back-end tech infrastructure to enable the end-to-end service journey
- Deliver a number of quality of life improvements for Dorothy identified from this report
- Plan how live service management and support will run for private pilots

We have listed in further detail later in this document which technological improvements we would like to focus on to improve the quality of the Dorothy experience.





# Who might we work with in the next phase?

# Who might we work with in the next phase?

From our piloting in the last year we have built a number of relationships with organisations that are enthusiastic about making their spaces inclusive and more dementia-friendly:

#### North East London Integrated Care Board (NEL ICB) NHS sites

NEL ICB's Director of System Improvement & Infrastructure has asked Care City to help pilot integrating Dorothy into their signage teams at two locations: Homerton Hospital in Hackney, where we did testing in our discovery phase, and Porters Avenue Health Centre in Beacontree. The pilot would involve the impact on staff who manage the buildings, how much work is involved, how regularly the maps need to be updated and extensive user testing with members of the public.

#### Sage House

We are hoping to test Dorothy's long-term usage at Sage House. It would be a location where new features can be implemented, and it regularly has an audience of people living with dementia who could benefit.

#### **Eastbury Manor House**

When the technical issues regarding Dorothy working on various floors are overcome, we plan to return to Eastbury Manor House to pilot its use over a longer period.

We are in negotiations to test in the second year at:

- Tesco store(s) To consider the commercial offer in more detail •
- Kew Gardens An outdoor location to test weather and lighting conditions •
- Victoria and Albert Museum A venue with a high level of visitors

### **Relationships**

We aim to continue developing our relationships throughout the second year with:

- **Askew Road Business Group** •
- Cafe Detour, Askew Road •
- Wembley Stadium •



We want to make connections with organisations that could help us develop Dorothy from a technological aspect:

- <u>Akara.ai</u> NEL ICB is also working on a project with Akara.ai, which has developed 'Advanced Disinfection Robots' for the hospital. Part of the disinfection robots' functioning involves mapping the hospital several times a day, and it was hoped that we could work together to help Dorothy with their mapping.
- Humane To get support with developing the Dorothy Device
- Briteyellow Indoor navigation developers for railway stations
- HyperAR AR Indoor navigation
- Merlin Entertainments Venues for testing Dorothy
- Disney Diversity and Inclusion to discuss young onset dementia and venue testing
- Any other organisation that wants to trial Dorothy

# Technological implications and improvements for Dorothy

Here is a summary of the technological issues highlighted in our discovery award findings and the level of resources expected to be required for the next stage to address these issues. Many of these issues impact each other, and some can be resolved concurrently.

Issue	9	Year two resource implication (in person-weeks)
1.	Ability to create user profiles	2pw
2.	Ability to contact staff/carer from app	2pw
3.	Resolve path refresh rate	8pw
<b>4</b> .	Ability to indicate the person should turn around	2pw
5.	Resolve the pathway going off the screen	8pw
6.	Improve arrival notification	4pw
7.	Implement changes to the appearance of the pathway	8pw
8.	Make the pathway animated	4pw
9.	Change/expand icons	2pw
10.	Audio alerts	2pw
11.	Notification to return the device to the venue	2pw
12.	Notification to alert the user based on something in their profile (ie. medication)	2pw
13.	Voice interaction	8pw
14.	Test devices with LiDAR to improve device location	Budgetary impact

15.	Resolve how to make paths straight	8pw
16.	Improve map/pathway stability and maps moving issue	8pw
17.	Ability to add obstacles to maps	8pw
18.	The ability for users to download a map onto their device from a QR code	2pw
19.	Support the prototype development of Dorothy Device	12pw
20.	Increase the Dorothy iconography	2pw
21.	Test alternative mapping processes	2pw
22.	Test working in low-light environments	4pw
<b>23</b> .	Resolve 'Extend Map' function is not working	1pw
24.	Allow adding icons from the map view	1pw
25.	Enable working on different floors	4pw
26.	Resolve the keyboard issue	1pw
27.	Resolve the login issue	1pw
28.	Create mapping instructions	1pw
29.	Resolve moving icons	2pw
30.	Enable wheelchair-friendly routes	8pw
31.	Recreate app based on Wireframe	2pw
Total		129pw

We are proposing to use software engineers to complete the work on Dorothy outlined above. One engineer will be expected to complete 38pw of work per year, including 2 weeks for onboarding onto the project. We will need 3 engineers to complete the work within one year.

# **Preparation for the Finalist Awards**

Year Two will focus on using all our learning from the Discovery Prize to improve the Dorothy experience:

- The Dorothy team will oversee the technology development plan
- Care City and TPXimpact will continue with project management and user testing
- EG Technology will prototype the standalone Dorothy Device



# Appendices



# **Appendix A**

# Engagement

# Location

Most focus group consultations took place in London, England. However, consultations took place across the country in various settings, including inner city, rural, and coastal areas.



# Breakdown of engagement





Demographics of those living with dementia who participated in user testing of Dorothy:



# Sexuality





## First language





# Appendix B

# Dorothy in the media

20/06/23	Rory Cellan-Jones	22/06/23	Thiis Magazine
20/06/23	UK Fundraising	23/06/23	Infotec news
20/06/23	Yahoo Finance	23/06/23	Pharmiweb.com
20/06/23	PR News Wire	26/06/23	Digital Health
21/06/23	Caring Times	23/06/23	The Rooftop News
21/06/23	NELFT	27/06/23	Charity Today



28/06/23	Healthcare DM		22/08/23	Daily Mail on Sunday
30/06/23	<u>B Daily</u>		12/09/23	BBC Worldwide Arabic Edition
02/07/23	HT World		28/09/23	Longevity Technology
30/06/23	Care City		09/10/23	Charity Today
05/07/23	Longevity Technology		04/10/23	Daily Express
11/07/23	In your area		22/11/23	The Rooftop News
11/07/23	Laboratory News			
	30/06/23 02/07/23 30/06/23 05/07/23 11/07/23	02/07/23 HT World 30/06/23 Care City 05/07/23 Longevity Technology	30/06/23B Daily02/07/23HT World30/06/23Care City05/07/23Longevity Technology11/07/23In your area	30/06/23 B Daily Image: Comparison of the





18/08/23 Skills for Care

# Appendix C

# Dorothy is a personal journey

Ilya Rybin started developing Dorothy in his free time in 2018, having been inspired by his grandpa, who passed away in 2008 after living with dementia in his latter years. His grandfather would get lost in new environments and later even in his own house. He continuously required assistance and directions, something that was quite distressing for him.

Ben Williams, Senior Project Lead at Care City, previously worked evaluating care at care homes. Once, he was called in to review the care of an older resident who was labelled as non-verbal. After sitting with the man for a while, the man opened up and said that he used to be a keen mountain climber, but now his health had deteriorated to such an extent that he couldn't use his legs to walk around his room. He was able to speak, but he had stopped talking because he felt so depressed.

In speaking to the care staff, they were shocked but acknowledged that taking residents outside, even to a local cafe, was extremely difficult for them. They would have to visit the place before the trip to assess the location and find out where things like the toilets would be, and they had no resources to be able to spend that time. So Ben started looking for ways to help places become more accessible and get more people out of care homes and into the community.



One of the first ways he tried was to bring 360-degree video experiences to people with extremely limited mobility within care homes. Working with students learning 360-degree video production from the UCL, they created tours of the British Museum and trips to the beach, local parks, and other places for people to watch while wearing virtual reality headsets. Residents of the care homes were extremely receptive to this. He was encouraged to see recreovr.co.uk be part of the Alzheimer's Society Accelerator Programme. But Ben felt more could be

done and has been looking for

ways to break the barriers of people being stuck at home, and so has been looking for projects that could help accomplish this.



# Appendix D

# **Design decisions: service and product**

We heard rich stories from many people throughout our research and learned about the experience of living with dementia and using Dorothy at different levels – social system, service, and product.

We reflected upon this and made a number of design decisions on how Dorothy would need to work in the future to best meet the needs of the people using it.

We made design decisions about the Dorothy service and product. Let's explain what we mean by this:

#### Service

These are decisions regarding the end-to-end journey that Dorothy will support. They won't necessarily be linked to specific aspects of the digital product such as the user interface. We make decisions on: what places should Dorothy be used in? What parts of a journey should Dorothy enable?

#### Product

These are decisions regarding the Dorothy digital application. They may be specifically linked to how the digital product will need to work. We make decisions on: what icons should we use? What are the digital steps that users go on?

Level	Design Decision
Service	Dorothy will only enable the 'Spending time at the place' and 'Travelling home' steps of our identified journey
Service	People living with dementia can use Dorothy on a device borrowed from a place without creating an account
Service	People living with dementia and their carers can access more functionality and receive an enhanced service if the person living with dementia creates an account
Service	People living with dementia can register to use Dorothy without needing their own device
Service	Places must create an account in order to use Dorothy
Service	Place accounts exist at the place level, not at an individual level
Service	Places are responsible for mapping their own space(s)
Service	Users living with dementia can use Dorothy on a device borrowed from a setting without needing to share any personal data
Service	Users living with dementia can share more personal data in order to access increased functionality and an enhanced service experience
Service	Setting users need a suitable device to be able to use Dorothy (mapping the space and accessing information about users living with dementia)



Service	Users living with dementia can use Dorothy on their own device by downloading the app
Service	People living with dementia will have a range of physical assistance technology to use Dorothy – such as a goose neck or wheely stand – managed and provided for by the person managing a space
Product	People who manage spaces can create multiple maps for a single setting
Product	Setting users can create, edit and delete maps
Product	Setting users can create, edit and delete icons to locate key points of interest
Product	Setting users will be prompted to include specific details about key points of interest
Product	Key points of interest in a space are: toilets, somewhere to rest, somewhere to eat and drink and somewhere to get help from another person
Product	Setting users can preview maps before publishing them
Product	Setting users can access personal data about a user living with dementia, with their consent
Product	Carers can access personal data about a user living with dementia, with their consent
Product	The design of the user interface for users living with dementia will incorporate large buttons, minimal visuals and audio/visual notifications
Product	Dorothy will remind users living with dementia of where they are (i.e. what setting they are in)
Product	Dorothy will remind users of when they need to take medication, if this information has been shared via a user account
Product	Dorothy will help navigate a person living with dementia to a space for them to take medication if the required information has been shared via a user account
Product	When a user living with dementia uses Dorothy on a borrowed tablet, Dorothy will remind them to return it before leaving the setting
Product	People living with dementia will be able to provide care-specific information when creating an account such as: carers name and contact details, needs they would like to share, any allergies, what people can do if they feel stressed or anxious, what can help if they seem confused, how often they would like to take breaks, and what type of toilet they would like to use
Product	People living with dementia who have created an account will have a QR code which will allowed for their account details to be loaded onto a Dorothy-enabled tablet owned by a space

We will go into greater detail about how these design decisions informed our future design of the end-to-end service journey later in our story.

# Appendix E

# Meet the Dorothy Community team

### Dorothy



#### Ilya Rybin, Co-Founder, Product Manager

Ilya is a software engineer turned product manager. He previously worked for Mapbox on mapping and autonomous driving technology for customers, including Toyota and BMW. He has moved to Bolt, a ride-hailing company where he manages its mapping and location technology team. Ilya started developing Dorothy in his free time in 2018, having been inspired by his grandpa, who passed away in 2008 after living with dementia in his latter years. Ilya originates from Belarus but relocated to Germany when the Russian-Ukrainian war began.



#### Dr Samir Shah, Co-Founder, Consultant Psychiatrist

Dr Shah is a London-based neuropsychiatrist with a passion for digital health. Clinically, he runs an inner-city, socially diverse diagnostic dementia clinic. He co-founded Dorothy with Ilya to create a thoughtful solution that not only empowers and enables those with dementia but also supports their carers.

Dr Shah is also an experienced healthcare leader and the Chief Clinical Information Officer for NELFT. He clinically heads large-scale digital transformation across an organisation that provides care to over 4 million people.



**D** The Dorothy Community

### **Care City**



#### Matt Skinner, CEO

Matt is an experienced leader in complex design, change, and technology projects. He is a strategist, entrepreneur, speaker and facilitator. Before joining Care City, Matt was a senior leader in digital agencies TPXimpact and FutureGov, delivering complex technology and change projects in government and health. Before that, he worked in local government social care. At FutureGov, Matt led the design and implementation of the Casserole Club initiative, an innovative technology and social change project to help address social isolation and food poverty, successfully scaling it in the UK and Australia. At TPXimpact, he grew the consulting team from 80 to 200, building a portfolio of complex digital programmes in health, local and central government.

Matt joined Care City in 2022. He sponsors several projects, including our work with UCLP and the Mayor's Office on dementia innovations. He advocates for human-centred design approaches, open-source technology and agile and iterative delivery.



#### **Ben Williams, Senior Project Lead**

Ben joined Care City in 2019 and has worked on managing health innovation integration for social care, the NHS, Local Authorities, and Integrated Care Boards. He was part of the committee that wrote the national NICE dementia guidance NG97 and remains an Expert Advisor for NICE. He has many years of experience as a social care practice excellence advisor, safeguarding lead, and policy officer for a large housing and care provider. During this time, he set up the 'Dementia Friendly London Housing Group', which is now run by the Mayor of London's office. Before that, he was an independent mental capacity advocate, supporting people who were unable to make a decision. He developed expertise in mental capacity, safeguarding, and end-of-life support. He also worked for a carers charity and a sign language translation team.



#### **Rachel Fuller, Communications Director**

Rachel leads Care City's marketing and communication activities, working alongside the team to showcase our work and achievements and collaborating with our partners to encourage brand advocacy. She is also passionate about ensuring people's voices are heard and accurately represented. She has over 25 years of experience in B2B and B2C strategic and partnership marketing from various industries, including finance, insurance, engineering, education, and support.



### **TPXimpact**



#### Sarah Fox, Senior Service Designer

Sarah is a Senior Service Designer at TPXimpact. As a Senior Service Designer, she works with clients and collaborators across disciplines to better understand and solve complex social problems. Sarah specialises in bringing a human-centred focus, helping teams to deliver better outcomes for the people they serve, and centring design decisions around their lives, stories and needs. Before joining TPXimpact, Sarah was employed by a mental health charity as the Co-production Coordinator for a local NHS IAPT service. Alongside local citizens, she designed and mobilised a service-wide co-production model that embedded co-design into governance, culture and practice.

Before that, Sarah has multiple years of experience delivering transformation, innovation and improvement across the public sector, including local government and the NHS.



#### **Dave Robson, Lead Service Designer**

Combining speciality experience in service design, innovation and strategy, Dave leads multidisciplinary teams in understanding needs and designing interventions that create better outcomes for people. Previously, Dave was a Strategy Advisor for NHS England, where he helped address service strategy problems. His work involved supporting the design of a new community diagnostic service model. Before that, Dave worked as an innovation lead at Accenture, where he designed and launched an innovation healthcare fund for various charities and NGOs. Dave also lectures and coaches about healthcare design at DigitalHealth.London, Imperial College London, TOPOL Digital Fellowship, and Experience Haus.



#### Iain O'Neil, Managing Partner

Ian is an experienced digital and technology leader. Iain has a proven track record of building multidisciplinary teams across government, in the NHS and the private sector.

He deeply believes in technology's power to transform services to improve people's lives.



#### Anisha Kanabar, Lead Designer

Anisha's background is in Design Research, Industrial Design, and engineering. She's always been attached to the health sector, building products and services, from physical products to digital ones. She also has lived experience caring for someone with dementia, so this project is really exciting for her to support.









