Co-designing for dementia: The Alzheimer 100 project

Lauren Tan¹, Deborah Szebeko²

¹ PhD candidate, Northumbria University, Newcastle upon Tyne and Design Council, London ² Founder and Director, thinkpublic. Project Lead, Alzheimer 100 project. PhD candidate, Middlesex University, UK.

REVIEW

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Corresponding Author: Lauren Tan Northumbria University Newcastle United Kingdom fiorucci@hotmail.com

Abstract

This paper will profile the Alzheimer 100 project and illustrate design practice utilised in a health context. More specifically the paper will discuss:

- Co-design: The approach used by design consultancy thinkpublic to involve a dementia community throughout the project;
- Key design-led methods used: Including the establishment of a dedicated project website, film-making and a Co-design Day;
- The project's results: Including a film, signposting service concept and range of product and service prototypes;
- The project's legacy: Spanning multiple levels including a legacy at a policy level; and
- The project's key learnings: Which provide important insights into how design can work effectively in a health context.

Designers and design-led methods can bring innovative solutions to healthcare, but just as importantly, its approach places key healthcare stakeholders at the heart of developing these solutions. Projects such as Alzheimer 100 provide us with practical case studies to deepen our understanding of how designers, design-led methods and approaches can be applied to meet challenges facing healthcare today.

List of abbreviations

UK: United Kingdom NHS: National Health Service NE: North-East Dott 07: Designs of the Time SMART: Skills, Memory and Recreational Therapy BBC: British Broadcasting Corporation Alzheimer's disease is the most common cause of dementia and affects around 700,000 people in the UK, costing the economy £17 billion a year [1]. By 2025, it is projected that over a million people in the UK will be affected by dementia [1]. If Alzheimer's care is not significantly improved, health and social care will struggle to meet demand and escalating costs. In 2007, a project called Alzheimer 100 was established. A London-based design consultancy thinkpublic, worked with a dementia community to demonstrate how healthcare can benefit from a more people-centred approach to developing health-related products and services. It used co-design as the process to do this and resulted in many successes, learnings and a strong legacy.

"The common perception about design is that it is expensive, flashy and something that has little to do with healthcare management and service improvement." [2] Quoted from an article written by Deborah Szebeko in 2008 for the Health Service Journal

Design has long been seen in society as the job of "someone else" who might create a flashy chair, expensive item of clothing or colourful poster. To consider that design has something to offer in a health context is perplexing and not necessarily complementary to its widespread perceptions. But this paper seeks to illuminate the recent attention design has been receiving from many different disciplines. This attention has not been for the flashy, expensive or colourful products of design, but for the people-centred thinking and co-design approaches which are increasingly becoming relevant to a number of different contexts, such as healthcare. It is these practices of design, that have begun to demonstrate alternative ways of approaching challenges by placing people at the centre of product and service development.

This paper is about an application of design practice in a health context. It is about how a team of designers worked with healthcare professionals and healthcare users, to develop people-centred services for dementia using an approach called co-design [3].

The challenge and dementia care in the UK

Alzheimer's disease is the most common cause of dementia. Dementia is a term used to describe the progressive symptoms in individuals where loss of memory, mood changes and communication problems [4] reflect the advancement of the fatal disease. As symptoms develop, those with dementia increasingly become dependant on others to help fulfil daily tasks and activities. The dementia community involves not just those with the disease, but three to four times as many



people who provide informal and unpaid care [1]. Presently, 700, 000 people have dementia in the UK costing the economy £17 billion per year [1]. By 2025, it is projected that over a million people will have dementia in the UK [1] and if Alzheimer's care is not significantly improved, health and social care will struggle to meet this demand and the its escalating costs.

In 2007, a project called Alzheimer 100 (its namesake paying tribute to the 100+ years since Alzheimer's was first discovered) aimed to look at innovative ways to meet these challenges of dementia in the UK. The project ran in the North-East (NE) of England as part of a larger initiative called Dott 07 (Designs of the Time). Dott 07 was operated by the Design Council and the North-East (NE) regional development agency, One NorthEast. It explored through seven main projects how design could drive public sector innovation [5]. Alzheimer 100 was one of the design projects undertaken and at the same time coincided with the UK Government's plans to develop the nation's first National Dementia Strategy. Plans for the strategy were announced in 2007 and stated a focus on three key areas:

- Improving awareness of dementia;
- Early diagnosis and intervention; and
- Improving quality of care. [6]

For many years prior to 2007, the NE dementia community had been involved in several small projects to improve dementia care. While many good ideas emerged from these projects, they were not sustainable due to their small scale and the absence of a high-level determination to change. The Alzheimer 100 project was a timely opportunity to engage the wider dementia community and explore different approaches to involve people with dementia and their carers in developing dementia care for the 21st century.

Methodology

This paper draws upon case study work undertaken on the Alzheimer 100 project in order to illustrate how design can be applied in health. This work is situated within a broader doctoral investigation into all seven Dott 07 design projects. The research is currently titled: Understanding design methodology in the public and social sector: Seven roles of designers in Dott 07 and their relevance to sustainable development contexts. As little literature currently exists on the application of design in the context of public sector innovation, a Grounded Theory approach was employed whereby theory is generated from the data collected [7]. Grounded Theory was found to lie in congruence with the embryonic state of the subject of inquiry.

"Research areas for which existing theory seems inadequate" requires a utilization of novel approaches to such investigations [8]. Eisenhardt proposes a roadmap for generating theory from case study research [8]. Eisenhardt's [8] roadmap brings together Glaser and Strauss's [7] Grounded Theory principles, Yin's [9] Case Study Method and Miles and Huberman's [10] approaches for anaylsing data, all of which have been employed within this current doctoral investigation.

The case study work undertaken for Alzheimer 100 triangulates data from various sources to develop an indepth understanding of the use of design in a health context. The hybrid research methodology triangulates data from literature reviews, desk research, documentation of Dott 07 events held in 2007 and an extensive qualitative research phase conducted from 2007-8. The qualitative research phase undertook indepth one-on-one interviews with the designers and project stakeholders of the Dott 07 projects. In the projects, the research aimed to understand how design was used in a health context. Two lead designers were interviewed to understand design methodology utilised in the project, and three project stakeholders directly involved in the project, were interviewed to gain perspective on experiences of using design in health where it had not previously been employed. Analysis of the data included various techniques such as coding of interview transcripts [7]; case study development of the projects [9]; data reduction and display techniques [10]; and peer review sessions to discuss research findings [11].

In addition to this, the paper has been co-authored with the lead designer on the Alzheimer 100 project and has been reviewed by a key project stakeholder, to ensure a well-rounded view of project experiences. A limitation to the research methodology has been that not more designers and project stakeholders were engaged in the qualitative research phase. Due to the quantity of projects that came under the Dott 07 initiative, the qualitative research phase was limited to interviewing a maximum of four to five project participants (designers and project stakeholders) per project. Another limitation to the research has been the little opportunity for participantobservation during the project. This was due to timing in commencement of the doctoral investigation, but the interview data acknowledges project participant's views, as reflections on experiences of utilising design in a health context.

Applying design in a health context

The Alzheimer 100 project was carefully considered in its set up. It took six months to recruit an appropriate design consultancy. This included numerous meetings with different design consultancies and many stakeholders from around the region, such as the Alzheimer's Society, National Health Service (NHS) staff, and academics. By the time the right design consultancy was recruited, Alzheimer 100 had a tight time frame to deliver the project and little opportunity for extra fund-raising beyond the Dott 07 sponsorship [12] for additional resources during the project.

It was social innovation and design consultancy, thinkpublic, who were appointed to work on Alzheimer 100. The project would demonstrate how healthcare could benefit from a more people-centred approach to developing services. Thinkpublic would lead an approach that incorporated practical and creative design-led methods [13] to involve stakeholders of dementia to



generate ideas and make decisions based on their experiences, rather than focusing on only improving technology and drugs [14]. Thinkpublic would use co-design [3] as the approach to do this.

What is co-designing for health?

London-based policy think tank DEMOS provide a broad definition of co-design, drawing on international perspectives of using co-design in the public sector. DEMOS state that the approach of co-design is about:

- The participation of people;
- A development process;
- The creation of ownership; and
- Being outcomes-based [15].

For more than five years, thinkpublic have been pioneering co-design practices in health, having worked with the National Health Service (NHS) Institute for Innovation and Improvement, the UK Government's Department of Health, and Luton and Dunstable Hospital, among many others. Thinkpublic state that the general principle of co-design sees patients as equal and valued partners in their care, rather than being only receivers of care. To enable this, thinkpublic use co-design as a process whereby key stakeholders (e.g. patients, carers, professionals and even healthcare cleaners) share experiences and challenges around specific issues and devise ideas and actions to address these issues, tapping into the available skills and resources to do so. This process is facilitated and supported by designers and design-led methods, both of which create the appropriate environment for the participation of people in identifying key issues, and developing ideas in response to them. As a result, co-design creates ownership of the outcomes for key stakeholders who can now be part of the solution [3].

To explain co-design in practice, the following section profiles some key design-led methods used in Alzheimer 100. These were:

- 1. The use of communication platforms;
- 2. Storytelling and;
- 3. A Co-design event.

Key design-led methods for co-designing in Alzheimer 100

1. Communication platforms: Inviting and involving the dementia community

Thinkpublic developed many channels and opportunities for the dementia community to get involved in the project. An accessible 'brand' was created for the project that explained what it was about, and provided a visual link to tie all promotional communications together throughout the project. This communication included pamphlets (Figure 1) which were mailed out to spread awareness and invite participation, and a project-specific website (see Figure 2 or visit http://www.alzheimer100.co.uk) built by thinkpublic to document the project process and provide an additional channel for feedback. The brand also provided a way for those involved to share and explain the project with others. To further galvanise the community, an initial stakeholder meeting was hosted by thinkpublic. Over 100 people attended this meeting to discuss the project direction, including academics, healthcare professionals, service providers, and people with dementia, carers and designers.

From the initial stages of the project and throughout, thinkpublic aimed to "provide the best and most open platform for something to happen" [16]. Communication platforms can gather the right people together for a codesign project, and they also create awareness among the wider community and at many different levels. For example, the website was particularly effective in raising awareness among management level in a local health care centre. A psychiatric nurse who participated in the Alzheimer 100 project explained:

"There was always information on the website so you could access it and just see what people were doing with things. It gave you a regular update. [The website] cascaded up to my manager who took it to a managerial forum." [17]

Designers at thinkpublic used a variety of communication channels to invite and involve people in the project. Communication platforms also communicate and celebrate the project throughout its process and the website, still live today, acts as an accessible repository of experiences and events from the project.

2. Storytelling and Skills Sharing: Capturing experiences of daily life with dementia

As part of the project's co-design process, film would be used to document daily life and challenges of people with dementia and their carers. The storytelling in the film would act as a "conversation tool" [18] to inspire new ideas for dementia care at the Co-design event.

To develop content for the film, thinkpublic needed to acquire capacity and high levels of trust from the dementia community. Due the wide geographical spread of the community, capacity from the Alzheimer's Society was needed to film and interview on a daily basis. High levels of trust among the community would also be needed for everyone to feel comfortable in front of, and behind, the camera. To overcome these project challenges, thinkpublic recruited the SMART team (Skills, Memory and Recreational Therapy) a community of under-65's with dementia and their carers, to film and capture stories of daily life with dementia. As the SMART team had never used film technology before, thinkpublic hosted a Skills Share Day to up-skill the team (Figure 3). Thinkpublic and a camera trainer from the BBC (British Broadcasting Corporation) provided a day of training for filming and interviewing [16] [18]. From here, the SMART team spent the next few weeks filming, to capture footage which thinkpublic edited and used to produce a film. The resulting film was used at the Co-design Day event to profile daily experiences with dementia to inspire new ideas for future dementia care [16] [18].



3. Co-design Day: Co-creating actionable ideas

Thinkpublic hosted a Co-design Day (Figure 4) an event that provided a space and time for people to come together, share stories, identify challenges and generate ideas in response to them. Around 100 people attended the Co-design Day at the Copthorne Hotel in Newcastle upon Tyne [19]. The day was set up like a "market place of challenges" [18] with market stalls each representing a challenge. The first activity of the day was to vote on the most important challenges as a community. Each individual voted with colourful balloons, an entertaining way to get people participating and engaged with the challenges of living with dementia [18].

The votes identified five key challenges Alzheimer 100 would move forward with. These were:

- The difficulty in navigating numerous dementia support services available;
- The long hours worked by carers with little or no support;
- The lack of public awareness and the stigma attached to dementia;
- The social isolation of people with dementia and their carers;
- The tendency for carers to be over-protective of people with dementia. [14]

For the rest of the morning, thinkpublic facilitated relationship building and networking through various activities such as viewing artwork by the community, testing out demonstrations of new technology in dementia care and visiting café areas to have conversations around issues. Thinkpublic's aim was "...to use the space in the morning so people talk to each other and network" [18] and in doing so, help establish vital relationships to get people to work together more effectively in co-designing.

In the second-half of the Co-design Day, people moved into small co-design teams to focus and address the five challenges voted on in the morning [18]. Each team was set the task of giving themselves a name, logo and slogan (Figure 5). The team names and slogans were:

- AT Enablers: "No Task too Hard";
- The Chain Gang: "Together we go further";
- Marauders Encouraging Mental Stimulation: "No Task too Hard";
- NGE Not Good Enough: "Moving Forward and Beyond"
- BEST Team (Better Early Stage support and mentoring): "Start as you mean to go on." [20]

Each team spent the rest of the afternoon focusing on one challenge and forming an agenda to address that challenge. At the end of the Co-design Day, five co-design teams left with a brief and plan of how they would move their challenge forward [18].

In the following weeks, the teams worked together on their proposals and had the opportunity to visit thinkpublic Design Clinics. The Design Clinics provided design support sessions to help move ideas forward, for example thinkpublic designers helped teams develop and communicate ideas in more tangible ways.

The Alzheimer 100 Co-design Day helped people come together on the community's most important and prevalent challenges. Its design-led methods formed creative activities to help bring issues to life and inspire action. The subsequent Design Clinics provided continuity and support for the co-design teams throughout the project process.

The outcomes from the Alzheimer 100 project resulted in a suite of innovative ideas. These ideas were proposed visually and tangibly with the help of thinkpublic designers and were showcased at the Dott 07 Festival in Newcastle upon Tyne in October 2007. At the end of the project, Alzheimer 100 resulted in:

- **A set of personas:** An amalgamation of real-life stories captured in four key characters describing life with dementia (Figure 6);
- A light box visualization of current dementia support services: Showing the 80+ disparate, and unconnected services available to the community (Figure 7);
- A Signposting Service prototype and products: A proposal to help the community navigate the disparate dementia services, mostly through a 'signposter', a person who would guide and direct people to relevant and appropriate dementia services (Figure 8);
- A model of a Safe Wondering Garden for a care home: A garden concept which would give a dementia care home community more freedom, shelter, colour, mobility, interaction and opportunities for outdoor activity (Figure 9);
- A volunteer mentoring service for carers: This would help carers, who often have little or no support to share daily duties. The model was inspired by existing organisation, Time Bank, who encourage and support a network of people and businesses in volunteering activities [21];
- Proposals for dementia cafés at high street locations: There are already more than sixty dementia cafes around the UK, "that provide support and information for people affected by dementia [which] create a welcoming, relaxed setting where people could share their fears and concerns about dementia and receive help and support." [22]. The Alzheimer 100 project looked to both celebrate this idea and propose locating dementia cafés in more visible locations;
- A 15-minute film profiling dementia and capturing daily life of people with dementia and their carers: The film captures real-life footage taken by the SMART team on the Alzheimer 100 project. With an easy-to-understand introduction to dementia and chronicling of several personal stories, the film has been one of the most successful outcomes of the Alzheimer 100



project due to its collaborative approach and helping raise the profile of dementia. While initially for use as a conversation tool in the project process, the film today is currently being disseminated at conferences, presentations and in training sessions [17] to capture the hearts and minds of a wider audience by relaying real-life experiences of living with dementia (Figure 10).

The breadth and scope of the Alzheimer 100 project outcomes reflect the innovative ideas that can result from a co-design approach to develop dementia care. These ideas illustrate that daily life with dementia can be improved by understanding and improving the experiences of people who deal with dementia daily and that such improvements need not always involve technology and drugs.

The Alzheimer 100 project was an ambitious endeavour to develop innovative dementia care. Time and budget limitations of the project meant that no idea got implemented in the run-time of the project. But the success of Alzheimer 100 lies not in the implementation of these ideas (though two-years on, thinkpublic are delivering the Signposting Service) but in the demonstration and impact of co-design in health. The doctoral investigation into Alzheimer 100 has tracked and begun to uncover an ongoing legacy of the project. In these final sections, this legacy will be profiled as well as some learnings to consider for future applications of design in health.

The ongoing legacy of the Alzheimer 100 project

The Alzheimer 100 developed a strong legacy on an individual, community, organizational, regional and policy level. Six months post-project, interviews undertaken with key stakeholders identified that skills gained from the project had been transferred into daily professional practice. On an individual level, the project stakeholders spoke about the skills and confidence they gained from the Alzheimer 100 project's co-design approach:

"We learnt about communication skills— It made me think about what we were talking about, what we wanted back from people, how to relax people and how to engage them [...] the project certainly gave us a lot more confidence. I would have never spoken on camera, or given an interview to anybody. And it developed skills with technology— Computer skills, doing presentations etc... [The project] gave me insight into skills I probably knew I had, but never had to use." [23]

On a professional community level, a NE branch of the Alzheimer's Society has since adopted co-design approach in their own service development. The branch says that Alzheimer 100, "helped us look at ways that, instead of thinking about the service, let's design the service." [23]. A few months after the Alzheimer 100 project ended, the design of a new couple's service was undertaken at the branch. This service would give support to couples in a relationship dealing with dementia. Methods from the Alzheimer 100 project were adopted and used in the development of the service. For example the interviewing techniques from the Skills Share Day were used to understand what would be needed for an

effective couple's service. The branch explained:

"... we used a lot of the prompts that we had used in the [Alzheimer 100 project] in interviewing people in a different way. Instead of going to do an assessment, we did it as an interview." [23]

On an organizational level, the project demonstrated to the Alzheimer's Society that co-design was a viable approach to developing health care services. Twelve months after the project finished the Alzheimer's Society re-commissioned thinkpublic to develop and deliver the Signposting Service idea. This service, now known as Dementia Advisors, has used co-design as an approach to provide better support, information and sign posting services for the dementia community. Thinkpublic have worked on this at four pilot sites in Birmingham, Coventry, West Kent and Greenwich, and are currently working on expanding Dementia Advisors to 22 sites around the UK [24].

On a regional and policy level, the Alzheimer 100 was a timely project that coincided with the development and launch of the UK Government's National Dementia Strategy. Living well with dementia: a National Dementia Strategy was launched in February 2009 and outlines 17 recommendations to significantly improve dementia care in the UK over the next 5 years [25]. In its implementation plan, co-design is embedded in the key principle of coproduction stating that in, "Co-production: implementation should be discussed and decided in partnership with the NHS, local authorities and key stakeholders." [26]. The Alzheimer 100 project catalyzed experiences and understanding of co-production in the NE through practices of co-design to develop future dementia care. But such a process does not come without its challenges, as one project stakeholder remarked:

" [Alzheimer 100] put co-design clearly in the mindset of everyone in the NE who is concerned about dementia. And also, because of the problems we actually had in delivering on the Alzheimer 100 project, we actually know how difficult it is to do it." [12]

Alzheimer 100 and its co-design approach set the groundwork for regional-readiness in addressing the Government's new National Dementia Strategy.

The alignment of Alzheimer 100 to policy is further evident in the inclusion of Thinkpublic's recommendation for the National Dementia Strategy. This recommendation speaks to the work of the Signposting Service stating:

"Objective 4; enabling easy access to care, support and advice following diagnosis. A dementia adviser to facilitate easy access to appropriate care, support and advice for those diagnosed with dementia and their carers." [26].

The Strategy also outlines a list of world-class commissioning competencies, which reflects co-design utilised in Alzheimer 100. The competencies list advocates



that future dementia care should include the experiences of people with dementia and their families by ensuring:

"... [they] are not just listened to, but are fully engaged with the design and delivery of services to secure improved outcomes. Creative and innovative approaches should be used to ensure that people with dementia with multiple and complex needs and their families and vulnerable people with dementia and their families are at the heart of this engagement."[26].

While the Alzheimer 100 project didn't see the implementation of ideas in the run-time of the project, the impact of the project has spanned and embedded co-design on many levels in the dementia community and in government policy. The project has built capacity and confidence in individuals, developed a co-design community of practice, created regional-readiness for the NE in addressing Government policy, and brought organizational and government awareness to how the future of dementia care can be developed not just *for*, but *with* people who have dementia and their carers.

Learning from the Alzheimer 100 project

While the project generated several innovative ideas and an extensive legacy, the project also leaves a number of good practice models and learnings behind to understand how design can be used more effectively in health in the future. The following list shares some good practice models and learnings derived from the project:

Integrating design in health with multi-stakeholder groups requires good planning

- Establishing clear roles in the project helps create a common understanding of how a co-design approach works among many stakeholders. Thinkpublic visualized the different stakeholder groups and how they would relate during the project (Figure 11). A project structure should include appropriate governance that involves representatives from all key stakeholder groups to oversee the development of the project;
- The designer can act as a facilitator of these multistakeholder groups to help recruit people and visually communicate a common understanding for the project's issue and intent. [27]

Deciding on the degree of community participation where time and costs are limited

- Where time and budgets are limited, consider whether all stakeholders have to be involved in every step of the project. Good project management can plan for different levels of participation, and disseminate and celebrate the project on accessible communication platforms to keep the wider community involved and informed, even if they are not directly participating at all stages;
- The designer can take on the role of communicator throughout the project, bringing issues to life, promoting and inviting the participation people, and

communicating and celebrating the project. [27]

Considering ethics in the research stages of a project

 The Alzheimer 100 project met a major hurdle in its process over differing views on consent forms for filming [18]. This severely delayed the project process. Align research practices with relevant research ethics committees or councils, and where creative research methods are used, share knowledge and awareness on ethical research practices.

Conclusion

The Alzheimer 100 project demonstrates the approach of co-design in developing people-centred services that can also result in a strong legacy. Co-design by thinkpublic utilised a number of creative and design-led methods, in particular communications platforms, storytelling and a co-design event to enable:

- The involvement of many stakeholders of the dementia community to share knowledge and have a voice in shaping healthcare services;
- The capture of real-life experiences via storytelling to understand how healthcare can be designed from the point of view of those who will use and interact with such services;
- A greater sense of ownership of ideas, which helps carry them forward and establish a legacy.

Design thinking and design-led methods can bring innovative solutions to healthcare, but just as importantly, its approach places key healthcare stakeholders at the heart of developing these solutions. When designers employ a co-design approach, they can also leave a lasting legacy at an individual, community, organizational, regional and even a policy level. Thinkpublic state that the impact of co-design is due to the fact that it, "allow[s] people to identify the problem and become part of the solution" [16].

The outcomes and legacy of Alzheimer 100 highlight a great potential for design in areas such as healthcare. Where designers take design practice and apply it in new contexts, they provide us with case studies which are both perplexing and exhilarating for where and how design thinking and processes can be used. Projects like Alzheimer 100 demonstrate in a practical way, how design as a profession is not limited to flashy chairs, expensive clothes and colourful posters. Design and designers can help address issues in health and develop innovative new ideas and approaches in healthcare to meet challenges now and in the future.

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CONFLICTS OF INTEREST

The authors declare that they have no competing interests

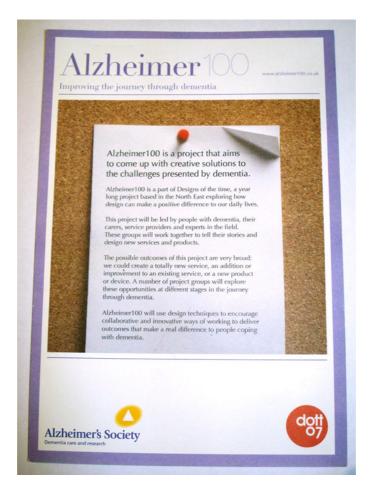


Figure 1. The 'Alzheimer 100: Improving the journey through dementia' pamphlet that was mailed out to the project stakeholders, profiling and explaining the project, and inviting participation of the wider community



Figure 2. The Alzheimer 100 website created by thinkpublic



Figure 3. The Skills Share Day hosted by thinkpublic for the Alzheimer's Society (Image from www.dott07.com)



Figure 4. The Co-design Day event organized by thinkpublic



Figure 5. Designing a name, logo and slogan- the AT Enablers Team (Image from www.dott07.com)



Figure 6. Two of the four personas developed to capture stories of daily life with dementia





Figure 7. The lightbox which visualises 80+ disparate dementia care services

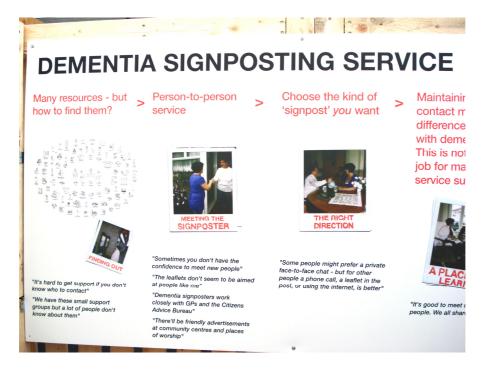


Figure 8. A visualisation of how the Signposting Service would work





Figure 9. A model of the Safe Wondering Garden for a dementia care home

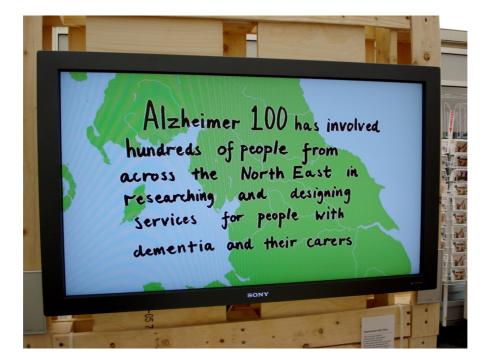


Figure 10. The 15-minute Alzheimer 100 film profiling dementia and real-life experiences of daily life with dementia

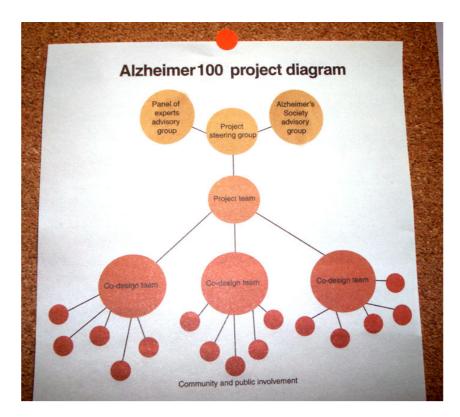


Figure 11. The Alzheimer 100 project structure that maps project stakeholders, such as advisory and steering groups, and the co-design teams (Diagram from 'Alzheimer 100: Improving the journey through dementia' pamphlet)