The co-design, development, and evaluation of a novel digital application to enable People with Dementia (PwD) to regularly self-report Quality of Life (QoL) Patient Reported Outcome Measures (PROMs)

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Glasgow, 2024

This thesis is submitted to the University of Strathclyde for the degree of

Doctor of Philosophy in the Faculty of Science

Declaration of Authenticity

This thesis is the result of the author's original research. It has been composed by the author and has not been previously submitted for examination which has led to the award of a degree.

Signed: Date: 16th September 2024

Publications

Research in this thesis has been submitted or is pending submission for publication.

1. Kernaghan D, Egan KJ, Maguire R. Enabling People with Dementia to self-report data using digital technologies and methods: A narrative literature review. JMIR Preprints. 26/07/2023:51257. DOI:10.2196/preprints.51257.
2. Kernaghan D, Egan KJ, Maguire R. Co-Designing a digital solution using Patient Reported Outcome Measures for People with Dementia. Pending Submission.

Poster Presentations

Multiple posters have been produced and presented during the course of this work.

1. Kernaghan D, Maguire R, Egan KJ. 2020. Co-Designing a Digital Solution using PROMs for People with Dementia. SDRC Virtual Conference 2020.
2. Kernaghan D, Maguire R, Egan KJ. 2021. Co-design in the age of COVID: Designing online workshops for People with Dementia. DigiFest2021.
3. Kernaghan D, Egan KJ, Maguire R. 2021. Strathclyde's Innovation in Dementia, Informal (Family) Carers & Technology. Strathclyde Innovation Forum.
4. Kernaghan D, Maguire R, Egan KJ. 2021. Co-Designing a Digital Solution using PROMs for People with Dementia. University of Waterloo/Strathclyde First Joint Virtual Research Colloquium.

5. Kernaghan D, Maguire R, Egan KJ. 2023. Enabling People with Dementia to self-report data using digital technologies and methods. College of Mental Health Pharmacy Conference 2023.
6. Kernaghan D, Maguire R, Egan KJ. 2023. Co-Designing a digital solution using Patient Reported Outcome Measures for People with Dementia. DigiFest2023.

The author was the principal study designer and investigator across each of the listed articles. They also led the analysis of the results and subsequent write-up. In addition, the author was responsible for the development of all artefacts included in the study appendix.

Signed: Date: 16th September 2024

Abstract

Best practice in modern healthcare for People with Dementia (PwD) prioritises the importance of a Person-Centred Care (PCC) approach that encourages greater involvement of patients in care decisions; a greater focus on quality of life (QoL); and remaining in a home environment where possible. The use of Patient Reported Outcome Measures (PROMs) and digital technologies have had a significant impact on the QoL in other populations as a way to monitor and support patients more frequently and less intrusively. Similar benefits could be realised in dementia care if effort is made to overcome cognitive barriers of dementia and foster inclusion for PwD in the design of such tools.

This thesis therefore aimed to co-design a novel application directly with PwD to enable them to report PROMs using different modalities with a tool that can be adjusted to their needs. This qualitative study implemented co-design during iterative workshops that followed an agile methodology where PwD were invited to contribute to every stage of the Software Development Lifecycle (SDLC).

First, a narrative review on existing technologies that enabled PwD to self-report data was conducted which identified technology and PROM preferences and the need for greater user involvement. PwD, informal carers (IC) and healthcare professionals (HCP) were then recruited to prototype development workshops where PwD were directly involved in co-designing the application, from initial concepts to functional prototype. The study concluded in a summative evaluation phase where all stakeholders evaluated the functional prototype for its feasibility, usability, and utility.

The results found significant support for the application with it being praised for being highly accessible; offering options for users to adjust modalities and have greater control over their data; and for simplifying the questionnaire into an easy-to-use interface. PwD and IC were keen to see the application validated for clinical use and HCP wished to pilot it in a real-world environment.

Acknowledgements

This PhD work is funded by the University of Strathclyde and Capita.

Firstly, I would like to thank my supervisors, Prof Roma Maguire and Dr Kieren Egan, without your oversight and support this project would never have come to fruition and I would not be the academic I am today.

I would also like to thank Dr Vivek Pattan, Dr Marilyn Lennon, and Dr Mark Dunlop, your assistance and advice have been invaluable during this journey.

Special thanks must also go out to the amazing volunteers from Alzheimer’s Scotland, Dementia Circle, NHS Forth Valley, Scottish Dementia Working Group (SDWG), and Town Break. You truly were the heart of this study, and your insights have been beyond invaluable not only to me but to the future generations who will benefit from your contributions to this work.

Finally, thank you to the Scottish Dementia Research Consortium (SDRC) whose Early Careers Research Award was a much-needed financial support during the COVID pandemic.

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CGD	Citizen Generated Data
ePROM	Electronic Patient Reported Outcome Measure
FFP	Final Functional Prototype
HCD	Human Centred Design
HCI	Human Computer Interaction
HCP	Healthcare Professional
HFP	High Fidelity Prototype
IC	Informal Carer
IRAS	NHS Integrated Research Application System
LFP	Low Fidelity Prototype
MCI	Mild Cognitive Impairment
MMSE	Mini Mental State Examination
NHS	National Health Service
PROM	Patient Reported Outcome Measure
PwD	People with Dementia
QoL	Quality of Life
QoL-AD	Quality of Life in Alzheimer's Disease
R&D	NHS Forth Valley Research and Development
REC	NHS Research Ethics Committee Coventry and Warwickshire
SDLC	Software Development Life Cycle
WFP	Wireframe Prototype
WHO	World Health Organization

1 Introduction

1.1 Background

Worldwide, there are an estimated 55 million people living with dementia, with the condition now the 7th leading cause of mortality globally (Gauthier *et al.*, 2021). The World Health Organization (WHO) estimates the cost to society for dementia care to be US$ 1.3 trillion a year, with informal care accounting for approximately half that cost and social care costs equating to a third (World Health Organisation, 2021c). These numbers will continue to rise significantly as an ageing global population has led to the doubling of the dementia population every 20 years, where it is expected to reach an estimated 152 million by 2050 (Alzheimer's Disease International, 2015; Alzheimer's Disease International, 2017; Wittenberg, 2019). There is currently no cure for dementia and the condition has a significant impact on peoples independence and Quality of Life (QoL) (Alzheimer's Disease International, 2022) and can result in significant degradation in activities of daily living (e.g. cleaning, bathing, housekeeping, leisure, navigating, communicating) (The American Journal of Occupational Therapy, 2020; Alzheimer's Research UK, 2021). It is therefore vital that People with Dementia (PwD) are given the support that helps them to manage these impacts and importantly optimises their QoL with health and care services that focus on delivering Person Centred Care (PCC), an approach where more personalised and detailed understanding of a patient's daily life is elicited directly from the patient in order to treat the person, not just the disease (Terada *et al.*, 2013). Approaches like these are needed in order to preserve personhood, recognise an individual's changing needs throughout the disease's progression, and to adjust care and practices accordingly (Kitwood, 1997; Mitchell and Agnelli, 2015). One of the key measures of PCC is QoL which is defined by the WHO as an "individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns" (World Health Organisation, 2012). QoL can be significantly impacted by disease and treatment, especially with chronic medical conditions with QoL measures being invaluable to identifying more holistic healthcare, determining improvements to medical treatments and procedures, as well as guiding the selection, rationalization, and evaluation of treatments (Kowitt, Nan and Speight, 2018).

QoL and PCC have quickly become a major tenet of modern healthcare with many governments and healthcare systems championing this approach as the gold standard for future healthcare (Digital Health and Care Scotland, 2018; U.S. Department of Health and Human Services, 2018; Bundesministerium für Familie, 2020). Approaches such as Citizen Generated Data (CGD) where data is collected through direct engagement with citizens to specify needs, improve processes, and inform policy (United Nations Department of Economic and Social Affairs Statistics, 2022) with methods including Patient Reported Outcome Measures (PROMs) and personal medical diaries being used as far back as 1975 as a means of delivering person-centred care (Black, 2013). Evidence demonstrates that PROMS can act as a facilitator to the delivery of PCC by ensuring that patients' reports of their QoL, needs, priorities, and expectations are incorporated in their care pathways, ensuring that the voice of the person is heard, and care tailored to their needs. In recent years, electronic PROMs (ePROMS), where PROMS are collected digitally and often remotely, have seen increased use as a quicker, more convenient way of collecting CGD (National Health Service England, 2021). To date, the use of PROMs and ePROMs in other conditions such as cancer (Kotronoulas *et al.*, 2014; Denis *et al.*, 2019; Maguire *et al.*, 2021) has been associated with significant benefits including: improved QoL, facilitating the identification of bio-psychosocial issues and the timely management of symptoms, improved communication between patients and health professionals and enhance shared decision making, and greater patient satisfaction (Basch *et al.*, 2017).

While PROMs have been increasingly used to monitor the outcomes of PwD during treatment and support during research studies, the use and application of PROMS in routine dementia care overall is lacking, often seeing limited consistent use in real world environments. Content, layout, and procedures of PROMs often pose significant barriers to those with dementia and cognitive impairments as often PROMs have not been designed or tested with this demographic in mind (Kramer and Schwartz, 2017). Therefore, if more resources were put into developing ePROMs specifically for PwD to use as part of routine care, it could have significant potential to sustain or improve QoL for patients for longer by ensuring that the voice of the person with dementia is heard and importantly informs and drives their care (Kramer and Schwartz, 2017; Elsevier, 2022). PROMS can also support the involvement of PwD in all areas of decision making, and could influence health policies regarding healthy ageing globally (World Health Organisation, 2021a). This is of particular importance to PwD who have been described as being 'seldom visible or acknowledged in society' (Van Gennip *et al.*, 2014).

1.2 Research Questions

The main research goal of this PhD thesis was therefore to co-design, develop, and evaluate a novel digital application to enable PwD to regularly self-report QoL Patient Reported Outcome Measures.

To achieve this, the following research questions were set:

1. What digital technologies have been used to enable PwD to self-report QoL data?

2. What features, questions, and modalities do PwD prefer when interacting with a novel digital application that enables them to self-report QoL PROMs?
3. What are the design considerations for a novel digital application to enable PwD to self-report QoL data via PROMs?
4. What are the perceptions of PwD, IC, and HCP on the feasibility, utility and acceptability of a functional prototype that enables PwD to self-report QoL data via PROMs as part of routine care?

To achieve the main research goal and answer the research questions posed above, this study was conducted in 2 phases detailed below.

The first phase (prototype development) followed an iterative co-design methodology where multi-modal digital prototypes were co-designed with PwD who were directly involved in every stage of the development process from initial concepts to final functional prototype (FFP). This phase answered research questions 1-3 and produced the FFP used in phase 2.

The second phase (Summative Evaluation) presented the FFP to all stakeholders to evaluate the prototype's feasibility, usability, and utility. This phase answered research question 4 and identified the next steps if the novel application is developed further in future.

For the study, stakeholders were separated into 3 major groups. People with Dementia (PwD) were identified as the primary stakeholder and were involved in each phase of the study. PwD were identified as people who had received a clinical diagnosis of mild-moderate dementia by an HCP. Informal Carers (IC) consisted of friends and family members who offered some form of informal care and support to PwD in their daily lives. IC were included in each phase of the study, though during phase 1 their role was limited to supporting PwD during the workshop. Health Care Professionals (HCP) consisted of medical professionals from the NHS as well as representatives from 3rd party organisations such as Alzheimer's Scotland. Inclusion of HCP was limited to the summative evaluation phase though a HCP attended every group workshop during phase 1 to oversee PwD wellbeing.

1.3 Research Overview

1.3.1 Literature and Current Knowledge

Chapter 2 and Chapter 3 of this thesis critically discusses the published literature and research used to inform the rationale for the research study. Chapter 2 focuses on background literature defining dementia and how it affects and impacts the lives of PwD, the current technology landscape and how technology is used in modern day healthcare and the dementia domain. The chapter ends discussing PROMs in detail. Chapter 3 presents a narrative literature review titled "Enabling PwD to self-report data using digital technologies and methods: A narrative literature review". The literature review complements and builds on Chapter 2 and adds to the rationale for this study by discussing the technologies, modalities, as well as barriers and enablers to support PwD to self-report data using digital technologies. This helps answer research question 1 and importantly highlights the gaps in knowledge that this research aims to address such as the significant lack of involvement of PwD in the design phases of the interventions.

1.3.2 Theory and Methodology

Chapter 4 discusses the theoretical approaches as well as the methodology used in this research study. These theoretical and methodological approaches underpinned the methods used in this study and what tools were used for data collection and evaluation. This influenced the structure and content of the workshops for the prototype development and summative evaluation phases.

1.3.3 Prototype Development

Chapter 5 and Chapter 6 detail the first phase of this research study which focused on the prototype development. These chapters outline the methods (chapter 5) and results (chapter 6) of this first phase where prototypes were iteratively codesigned with a core group of PwD and IC from initial concepts to functional prototypes. These prototypes were developed to enable PwD to report PROMs using a variety of different modalities (text, visual, verbal, mixed). The scope for the study focused on using common consumer technology as the hardware base for the technological intervention. Prototypes were web accessible using either a computer, laptop, tablet, or smart phone device as they all contain the screens, microphone, and speaker required to deliver questions and collect responses using the modalities. This phase resulted in the creation of an FFP.

1.3.4 Summative Evaluation

Chapter 7 and Chapter 8 detail the methods (Chapter 7) and results (Chapter 8) of the second phase of this study which focused on the evaluation of the FFP by key stakeholders. During this phase, a larger group of PwD, IC, and HCP were invited to evaluate the FFP of the novel application for its acceptability, feasibility, and utility. The goal was to develop a purpose-built novel application codesigned by PwD that can capture the most critical needs of PwD, that can frequently and conveniently collect PROMs, and that has the future potential to triage need in real time to send an alert to a relevant party if any if responses prove worrisome or require additional insight. This prototype was successfully evaluated by all stakeholders with PwD, IC and HCP all lauding the prototypes design and supporting its further development and implementation.

1.3.5 Discussion and Conclusion

Chapter 9 and 10 present a discussion of the results of the entire study, the major findings, and concludes on the future plans for continued research in the co-design, development, and evaluation of a novel digital application to enable PwD to regularly self-report QoL Patient Reported Outcome Measures.

1.4 Contribution to Knowledge

The completion of this PhD thesis resulted in a number of novel outcomes that are unique to this work. Many of these outcomes are believed to be some of the first of their kind and contribute new knowledge to the wider field of dementia and technology health care.

1. A fully functional prototype for a novel digital application that enables PwD to regularly self-report QoL Patient Reported Outcome Measures. This prototype was developed as a web-based application that is accessible from any device with internet access, allowing PROMs to be collected remotely. Additionally, the prototype collects and stores PROM data in a secure online database that is accessible to PwD, IC, and HCP via a web browser. All of this has been successfully evaluated by PwD, IC, and HCP.
2. The application prototype was co-designed from the outset (concept initiation/ideation) with and for PwD. From the first initial concepts to the FFP, PwD took the lead in developing the application prototypes, with their regular feedback during workshops navigating the progress of the study. During each iteration, the feedback and opinions were collected and used to prioritise features that would be included and developed for the application. This contrasts with the findings from the literature review where technology applications rarely involved PwD during the early stages of prototyping, often relegating their involvement to the final testing phases.
3. The entirety of this co-design study was conducted online. This is a novel and less explored approach for co-design that traditionally relies heavily on in person sessions, with significant challenges and considerations needed to translate to an online environment (Kennedy *et al.*, 2021; Fails *et al.*, 2022). The study was originally envisioned to be run in person but with COVID-19 pandemic restrictions (particularly including those faced by the NHS partner), and the higher risks COVID-19 has amongst the dementia population, it was decided to switch to an online-only environment.

4. This is one of the first studies to evaluate the perceptions from key stakeholders including People with Dementia, Informal Carers, and Healthcare Professionals regarding the use of ePROMs for dementia in routine care.

The next chapter will delve into background literature to explain the current knowledge of dementia, health care technology and PROMs.

2 Background Literature

The previous chapter provided an introduction of this thesis, an overview of what each chapter entails, as well as stating the research questions for the study. This second chapter focuses on the current understanding of dementia and uses existing literature in the field to discuss what dementia is, how it is caused, the common effects, and the impacts it has. This chapter also explores how digital technology is being embraced in modern medical practice including dementia care and how Healthcare Professionals (HCP) are making use of PROMs and other citizen-generated data (CGD) to empower patients and guide patient treatment.

2.1 Dementia

2.1.1 What is dementia?

Dementia, as defined by the International Classification of Diseases (World Health Organisation, 2023b), is a family of neurocognitive disorder identified by a marked impairment in 2 or more cognitive domains that are not characteristic of the individual's expected level of cognitive functioning. In Scotland, an estimated 90,000 people are currently living with dementia, with projections estimating that number to grow by 50% within the next 20 years and that one in three people born today may develop dementia during their life (Scottish Government, 2023). While the most common symptom associated with dementia is memory impairment, impairment can affect many of an individual's cognitive capabilities including executive functions, social cognition, attention span, judgement, language, motor skills, visual recognition and/or spatial awareness. The impact of these cognitive domain declines can vary significantly between individuals though individuals diagnosed with dementia frequently report the condition causing significant interference to their everyday life. Common problems include issues with co-ordinating everyday tasks or trouble with communication that can severely limit their independence (Alzheimer's Society, 2018). It should be noted that while the latest revision of the Diagnostic and Statistical Manual of Mental Disorders (American Psychiatric Association, 2022) now refers to the condition as Major Neurocognitive Disorder, this thesis will be referring to the condition as dementia due to the continued use of the term in society, medical literature, and continuing publications (Emmady, Schoo and Tadi, 2023).

2.1.2 Causes and Types of Dementia

Dementia is not a single disease but is caused by a variety of different conditions and diseases. This leads to different symptoms, impairments, and progression. By far the most common type is Alzheimer's disease which contributes to 60–70% of dementia cases (World Health Organisation, 2023c) and is often characterised in the early stages by memory impairment that leads to a slow but steady decline with issues with other cognitive functions emerging as the condition progresses. Alzheimer’s disease often has multiple impacts on individuals through the course of the disease, with depression and apathy being common in the early stages and confusion, aggression, psychotic symptoms, and seizures at later stages (World Health Organisation, 2023a). Another common type of dementia is vascular dementia, where reduced blood flow to the brain can cause significant damage resulting in cognitive issues such as poor memory, difficulty following instructions and learning new information as well as hallucinations and delusions (National Institute on Aging, 2021a). Vascular dementia is often caused by conditions that interrupt the flow of blood and oxygen supply to the brain or that cause damage blood vessels in the brain such as strokes. Alzheimer’s disease and Vascular dementia are both very common amongst an older population (aged 65+) and can often present together making the clinical distinction between these 2 conditions difficult especially when differentiating how each condition is contributing to an individual’s dementia (Korczyn, 2002). When this situation occurs, the condition is generally referred to as mixed dementia with treatment plans implemented to help manage both conditions. Another form of dementia is Lewy Body Dementia which is characterised by the appearance of abnormal deposits in the brain that damage the way cells communicate within the brain until the braincells eventually die (National Institute on Aging, 2021b). This can affect functions such as thinking, visual perception, and muscle movement which can make diagnosis of Lewy Body Dementia especially challenging as its symptoms can often be confused with other brain conditions such as Parkinson's disease (Jellinger and Korczyn, 2018). The final type of dementia is frontotemporal dementia, a condition that effects the front and sides of the brain and is notable as most cases are diagnosed in people aged 45-65, a much younger demographic compared to the other common conditions that cause dementia (National Health Service, 2020b).

2.1.3 Cognitive Impairment and Stages of dementia

Cognitive impairment is one of the main indicators of dementia. A separate condition known as Mild Cognitive Impairment (MCI) can be an early indicator with many of the same symptoms associated with dementia such as memory loss, difficulty concentrating, and problems with planning and reasoning, though for MCI these symptoms are less severe in their impact in everyday life like dementia (National Institute on Aging, 2020). As dementia is a progressive condition with no cure, significant attention is focused on identifying the stage of dementia early so that individuals can be diagnosed, and appropriate support and treatment can be provided. While laboratory data can be used to support a diagnosis, the main assessment method for identifying dementia relies on cognitive, neuropsychiatric, and functional tests to determine an individual’s level of cognitive impairment

(Peron *et al.*, 2020). In particular, the Mini Mental State Examination (MMSE) (Folstein, Folstein and McHugh, 1975) is one of the most established and frequently used tests for assessing cognitive function. Originally created in 1975, with an updated variation designed to overcome poor inter-rater reliability in 1997 (Kurlowicz and Wallace, 1999) the test is the world's most widely used brief test of cognition in clinical and research settings (PsychDB, 2021). Using the MMSE score along with other metrics, dementia is often divided into 3 categories: Mild, where the individual may struggle with cognitive functions that impacts their everyday life; Moderate, where individuals may require assistance with everyday activities due to their cognitive decline; and Severe, where an individual will likely require full time care and support as a result of their cognitive decline (Basil and Martin, 2005).

2.1.4 Risk factors, prevention, and early detection

Currently there is no cure for Dementia and as the condition progresses from mild, to moderate, to severe, PwD will often display a significant deterioration in their independence and QoL (Alzheimer's Disease International, 2022). Cognitive declines coupled with a high prevalence of comorbidities such as hypertension, diabetes, and other chronic conditions that is double the rate of the general population (Poblador-Plou *et al.*, 2014) and can lead to higher rates of hospitalisation (42% higher) (Shepherd *et al.*, 2019). The risk factors of dementia are therefore significant with prevention and early detection the best ways to currently combat the condition. Advanced age, genetics, family history of dementia, and low levels of education are all recognised as significant contributions to the risk of developing dementia, though other factors such as hearing loss, untreated depression, loneliness or social isolation and a sedentary lifestyle may also contribute (National Health Service, 2020a). It is therefore recommended that a healthy lifestyle, diet, and exercise can all help prevent the risk of dementia and allow those with the condition to live a longer and higher quality life (Dhana *et al.*, 2022). Early detection and diagnosis of dementia can also be aided with the use of genetic testing, recording an individual's family history, and effective monitoring of gradual declines in cognition (World Health Organisation, 2023a). Early detection and diagnosis can be highly beneficial as it enables individuals to access the required services and the necessary support that will allow them to plan for the future can prolong their QoL as the condition progresses (Social Care Institute for Excellence, 2020)

2.1.5 Current treatments: Pharmacological and Non-Pharmacological

Dementia has a significant effect on not only the individual, but also their family and friends. Dementia often causes significant behavioural and psychiatric changes to an individual as the condition proceeds which can have a detrimental effect on their QoL as well as their social structures. While

Pharmacological interventions may be used to help with many of the symptoms of PwD, symptoms such as wandering, agitation, aggression are best managed with non-pharmacological interventions (Peron *et al.*, 2020).

This position is supported by the findings of an international consensus panel that recommended best practice was the assessment of underlying causes followed by a series of non-pharmacological approaches including: carer training, adapting the individuals environment, person-centred care, and tailored activities (Kales *et al.*, 2019). Similar methods are currently being proposed as part of the Scottish government's dementia strategy (Scottish Government and COSLA, 2021) which plans to guarantee tailored support for all citizens diagnosed with dementia via 2 models of support. The 5 Pillar Model of Post-Diagnostic Support (Gilmour, 2011) is designed to help support individuals recently diagnosed with dementia and during the mild stages of the condition. These 5 pillars are:

- Understand the illness and manage your symptoms.
- Be supported to keep up your community connections and make new ones.
- Have the chance to meet other PwD and their partners and families.
- Plan for future decision-making.
- Plan for your future support.

The aim of this model is to enable PwD to make informed decisions on their future healthcare plans as well as setting down the foundations to build stronger community around the individual and to understand how the condition will affect their life. The 8 Pillars Model of Community Support (Kinnaird, 2012) sets out an integrated and comprehensive approach to supporting PwD living at home during the moderate to severe stages of the condition. These 8 pillars are:

- Personalised support.
- Community connections.
- Environment.
- Mental healthcare and treatment.
- General healthcare and treatment.
- Therapeutic interventions.
- Dementia practice coordinator.
- Support for carers.

This 8-pillar model aims to provide continuing and adapting support to the individual that prioritises their QoL by supporting them to live well at home for as long as possible. Both models emphasise on a PCC approach that prioritises the direct involvement of PwD throughout all stages of their healthcare journey as well as continued long-term support and QoL.

2.1.6 Impact of dementia

Dementia is a progressive disease that often requires support from IC and/or HCPs over a long period of time. PwD may lose the ability to manage their daily activities such as taking medication and may struggle to communicate which may prevent them from seeking timely help for health issues that may arise, leading to an increased risk of illness, injury, unnecessary hospital admissions, and death. PwD are more likely to have multiple health conditions (Public Health England, 2019) which can lead to pressure on hospitals and healthcare systems. Up to one in four hospital beds is occupied by PwD (Royal College of Psychiatrists, 2019). This population have a significantly higher mortality rate than those without (Liang *et al.*, 2021) and national statistics in the UK report the rate of death involving COVID for PwD was more than triple the rate of people without dementia of a similar age (Office for National Statistics, 2023). In the UK alone, approximately 885,000 people currently live with dementia as of 2019 at a cost of £34.7 billion a year for health and social care costs (Wittenberg, 2019). A significant proportion (40%-50%) of this estimated cost relates to unpaid care work provided by IC such as family, friends, and volunteers who often feel overworked, under-supported, and financially impacted when it comes to providing care for PwD (Carers UK, 2021; World Health Organisation, 2021c). With the World Health Organisation (WHO) currently predicting 4.6 million new cases of dementia each year with the number of PwD expected to double every 20 years, reaching an estimated 81.1 million by 2040 (World Health Organization, 2012; Wittenberg, 2019), it is vital healthcare services prepare and leverage new technologies and techniques to offer greater support for higher numbers of PwD in future.

2.2 Technologies

2.2.1 A Technological Response

With an aging population and significant increases predicted in people living with dementia, there is a growing need to find and invest in new methods to meet the unmet needs of future populations. This includes ways to allow PwD to live independently, better support IC who support PwD, and reduce the strain on an overwhelmed healthcare system. One possible solution is the application of technological interventions when it comes to patient care.

Technology in general has been recognised as providing a solution for many challenges facing healthcare systems worldwide. From the digitalization of health records improving the collection, accessibility, and standardisation (Evans, 2016) to the advent of telecare and remote access technologies facilitating consultations between patient and HCP in remote settings (Deloitte, 2018) especially during the COVID pandemic (Green, McKee and Katikireddi, 2022). Technology has been proven to be able to significantly improve the efficiency and availability of healthcare systems. Though the move to digital technologies is not without its issues. There have long been discussions on how digital innovation can lead to an abundance of unused data and inaccessible systems that can burden HCP further (Hecht, 2019) and concerns the more vulnerable members of the population may be excluded from such services (Healthwatch, 2021) especially amongst older populations (Pirhonen *et al.*, 2020). It is therefore vital technology interventions are considered carefully and implemented well, especially when it is reported that up to 66% of technology projects end in partial or total failure (The Standish Group Report, 2020) and HCP increasingly report feeling overworked, overwhelmed, and burnt out with 71% in the USA and 66% in the UK agreeing that their roles have become worse in the last 10 years (Elsevier, 2022).

Governments across the world have already committed to digital health and care strategies that outlines their plans to support the digital transformation of health and care. Common strategies shared amongst them include: developing standards, improving the infrastructure, encouraging participation of many stakeholders and making better use of data gathered from patients (U.S. Department of Health and Human Services, 2018; Bundesministerium für Familie, 2020; Scottish Government and COSLA, 2021; World Health Organisation, 2021b). This is supported by an international consensus study including 2607 HCP from 106 countries across the world, identifying five key areas that digital health technologies and data are expected to significantly influence healthcare in the future (Elsevier, 2022). These findings are supported by other literature within the field.

1. Big data analytics performed on existing and new patient data can help shift healthcare from a reactive service to a predictive service. By introducing machine learning and AI on this data, HCP in the future will be able to predict patient healthcare issues and provide necessary care at earlier stages before (Dash *et al.*, 2019).
2. Electronic medical records integration with multiple medical and personal data sources such as that from wearables and consumer devices can allow for more accurate diagnosis and monitoring of patients in their home environment.

3. Personalized treatment approaches tailored specifically to a patient's need gathered directly from the patient via CGD will provide better options and QoL for patients (Vicente, Ballensiefen and Jönsson, 2020)
4. Real time analysis of patients can allow for greater monitoring of a patient's status and increase accuracy in treatment plans. This will allow a more agile approach to what treatments are delivered to patients when they need it (Schlicher *et al.*, 2021)
5. Critical decision support tools powered by AI and the data gathered from big data can help speed up the diagnosis and treatment of patients, especially during different stages of long-term conditions and treatments(Sutton *et al.*, 2020).

Despite such commitments to invest in digital health and care strategies by governments around the world, there are growing concerns that the focus on a technology first approach could further widen the 'digital divide' faced by older people (Arighi *et al.*, 2021). This risks increasing inequalities for a population who traditionally struggle to access services using technology that was not appropriately designed with their needs in mind (Pirhonen *et al.*, 2020; Arighi *et al.*, 2021; Busch *et al.*, 2021)To counter this, several organisations have developed specific guidelines for designing software and digital content with older populations in mind (Campbell, 2015; World Wide Web Consortium (W3C), 2018; Nielsen Norman Group, 2019). These guidelines often focus on the multi modal aspect of UI design that can benefit users with visual or sensory impairments that are more prevalent in older populations. These guidelines recommend the use of larger font sizes and menu options; high contrast colours; simplified menus, language and interfaces; as well as the inclusion of transcripts, closed captions and low background sound. These changes reduce barriers to entry by making the user experience far more accessible, especially for older populations who are proportionally more likely to have physical or cognitive impairments (Kramer and Schwartz, 2017; Henni *et al.*, 2022).

2.2.2 Dementia Care Technology

As discussed, technology innovations have and continue to transform many parts of the healthcare industry. These interventions bring with it several challenges and barriers that need to be considered, many of which are unique to the domain of dementia care. When it comes to technology used to support PwD, these technologies tend to fall into 4 major categories (Astell *et al.*, 2019):

- diagnosis, assessment, and monitoring
- maintenance of functioning
- leisure and activity
- caregiving and management

Diagnosis, assessment, and monitoring is the longest established usage for technology in the dementia domain. Computerised diagnosis and assessment tools have been trialled since the early 90s (Ritchie *et al.*, 1993; Robbins *et al.*, 1994) with such technologies often focusing on cognitive tests completed by PwD that are then analysed for use by HCP. In recent years, new technologies have enabled many of these cognitive tests to be self-reported by PwD remotely, reducing times and associated costs with frequent testing (Staffaroni *et al.*, 2020). Monitoring technology differs as they often focus primarily on user (PwD) facing devices and hardware, often implementing the use of sensors to monitor a PwD routine and movements. Traditionally such technologies have made use of fall sensors, bed occupancy sensors, and door alarms though new technology including mobile and wearable devices are becoming increasingly used to monitor PwD (Thorpe, Forchhammer and Maier, 2019). The focus of these technologies is towards remote monitoring that is as unintrusive as possible and allows PwD to live comfortably at home while still being monitored and reporting vital data to HCP. Finally, there has been an advent of the use of PROMs used to monitor PwD outcomes during treatment and support (Ayton *et al.*, 2021), with technology enabling these to be recorded remotely, this will be discussed in the PROMs section of this chapter.

Maintenance of functioning of patients is the next major category of technology usage in dementia. Often using assistive technologies, these PwD facing technologies provide solutions and adjustments designed to directly assist and benefit PwD during their daily life by making activities easier to perform. Assistive technologies can provide features such as reminders to take medications (Kim *et al.*, 2022), enabling easy communication with family, friends or carers (Social Care Institute for Excellence, 2017) or support self-management (Oksnebjerg *et al.*, 2020). While many of these technologies exist as standalone devices, there are investigations in the effectiveness of interconnected smart homes for PwD (Chimamiwa *et al.*, 2022). The goal being to maintain the functioning of PwD to encourage individual autonomy and provide them assistive support to maximise their QoL and enable them to positively age in place at home and in their community (Moyle, 2019). Often these technologies are unintrusive and require minimal effort from PwD whilst also supporting remote monitoring at a distance by the healthcare team (Boger *et al.*, 2018).

Leisure and activity are the third major category of technology usage in dementia. This type of user (PwD) facing technology often focuses on providing therapeutic or holistic experiences to help improve the mood and wellbeing of PwD or to encourage health lifestyles. These often rely on technologies that encourage interactive experiences and reminiscence therapy (Bruil *et al.*, 2018;

Edmeads and Metatla, 2019; Fields *et al.*, 2021) or methods to encourage socialisation and companionship (Rai *et al.*, 2022). The goal of these technologies is often to help improve the physical and mental wellbeing of PwD and to avoid conditions such as depression (Sáiz-Vázquez *et al.*, 2021) or social isolation (Rai *et al.*, 2022) which can significantly reduce QoL.

Caregiving and management are the final major category of technology usage in dementia. These technologies commonly take the form of telepresence that enable HCP to provide care and support remotely at home via the use of telemedicine (Angelopoulou *et al.*, 2022) and Socially Assistive Robots (Moyle *et al.*, 2014; Schussler *et al.*, 2020). Many of these technologies include decision support tools to optimise the diagnosis and treatment of dementia (Davies *et al.*, 2019). Finally, this category also includes carer supportive technologies. Being an informal carer can be demanding and can have significant impacts on IC supporting PwD. IC are usually made up of family members or friends who will not have the initial knowledge or skills required to support PwD without support for themselves (Atkinson, Bray and Williamson, 2022). Therefore a wide range of technologies have been created such as online psychoeducation, psychotherapy, and mindfulness tools to inform, advise, and signpost IC to resources to help support them with supporting PwD (Ottaviani *et al.*, 2022).

While these 4 categories do cover a wide range of technologies, of note is that there are many common cross-cutting functions. Most aim to provide a remote alternative to existing methods of support, allowing PwD to be supported in their own home environment in more convenient ways that are as unintrusive as possible. Such health interventions are not designed to replace face to face delivery but instead to offer more flexible options with remote delivery as way to maximise benefits and optimise costs (Di Lorito *et al.*, 2022). Of particular note is the interest in developing consumer-based technologies, especially mobile devices that PwD and IC would already have access to, which can cheaply implement GPS tracking, video communication and reminders for PwD (Yousaf *et al.*, 2020).

2.2.3 Designing with PwD

As mentioned in the previous section, there are many technologies that are being actively used to help support PwD, IC, and HCPs involved in their care. With many of these technologies being user (PwD) facing, it is not enough that these technologies simply focus on this demographic, but instead the inclusion and involvement of PwD should be actively pursued through all phases of product and service development. As mentioned, Government guidelines agree that development teams must include end users such as patients and carers as stakeholders, with products conceptualised and developed with input from end users during all stages and devices must be trialled and tested by end users and adapted to their needs (Moyle, 2019). Studies that have involved PwD in the full design process have reported that their experiences and input led to multiple design alterations that would never have been anticipated by the research team (Fox *et al.*, 2022) as well as demonstrating a strong willingness of PwD to get involved in such projects where they are given the chance to contribute to a project that seeks to improve their lives (Rodgers, 2018). Co-design in particular has been shown an effective motivator for encouraging participation from PwD (Wang *et al.*, 2019).

Despite this, there seems to be a considerable absence of PwD having a meaningful role in the development of these technologies, with them often playing a passive role where they serve as an informant or object of the study rather than as an equal shareholder that has meaningful influence on the outcome of the technologies (Suijkerbuijk *et al.*, 2019). This may explain why there are a plethora of apps that exist for PwD that are of poor or uncertain quality, are limited in their scope, or provide a simplistic static online resource that does not take full use of the technology available (Tang, 2017).

Due to the cognitive impairment that is often caused by conditions that cause dementia, it is recognised that there are several barriers that can actively impair the ability of PwD to take part in the technology development process. In total, as many as 42 separate barriers have been identified that could deter the involvement of PwD (Engelsma, Jaspers and Peute, 2021). These include:

- Cognition barriers, which may affect their ability to make decisions and judgements or organise their thoughts and actions.
- Speech and language barriers, which may make verbal expression and understanding syntax and semantics of questions difficult.
- Frame of mind, including stigmatisation, perceived complexity of involvement, or issues with agitation or concertation during sessions.
- Perception, such as visual acuity, especially when regarding colours, recognition, or reading comprehension.
- Physical ability, and issues that arise with fatigue, tremors, and frailty.
- General aging including numeracy and literacy, computer literacy, mobility and the higher probability of comorbidities and other health issues.

If sufficient adjustments are not made by researchers to account for these barriers, PwD can be directly discouraged or excluded from taking part. There also other factors that can affect the ability of PwD taking part in development. The phenomenon of ‘Sundowning’ where many PwD experience worsening cognitive and neuropsychiatric symptoms later in the day can impact inclusion if sessions are hosted later in the day (Menegardo *et al.*, 2019). There can also often be concerns that taking part in such long term development could disrupt existing care and services (Gibson *et al.*, 2016). Finally, PwD who have negative attitudes or bad personal experiences regarding technology have also shown to be disinclined to participate in such studies, though this can be overcome by allowing time for participants to become familiar with the technology (O'Connor *et al.*, 2016).

Another significant consideration when designing for PwD is the importance of IC. As previously highlighted, IC are often a major pillar of dementia care, frequently supporting and assisting PwD during their daily lives, including the usage of technology. Guidelines encourage the involvement of IC as a key stakeholder alongside PwD (Moyle, 2019) and studies show the importance of IC in supporting PwD during studies (Suijkerbuijk *et al.*, 2019). However, one aspect to consider is that many IC tend to be older and less technologically literate than the general population (Hopwood *et al.*, 2018), meaning that any technology developed must be developed with these users and their needs in mind alongside PwD. The reason for this is that implementation of technology in dementia care will not only be for the benefit for PwD. As previously mentioned, IC such as family and friends make up the largest number of hours spent caring for PwD. They often balance care duties with other significant commitments such as work or childcare. Up to 50% of total informal care consisting of time spent on assisting and monitoring PwD (Wimo *et al.*, 2002) with their support directly benefiting PwD and impacting their ability to stay independent (Brodaty and Gresham, 1989). It is therefore important that IC are invited to participate in the development of dementia care technologies as these technologies could lift some of this burden if designed to meet their needs. Not only could this reduce the workload for these hard-working people but hopefully offers ways to increase the efficiency of time spent caring. This could also make IC feel reassured they are being supported and that their perspective and contribution is being taken seriously as well as increasing the visibility of the carer's involvement. Finally, the capability of PwD will change over time, therefore having an informal carer to help facilitate changes in support will be extremely important as the condition progresses. Despite this, the inclusion of IC can bring with it additional challenges. It is not unusual for PwD and IC to have different and conflicting opinions. This can lead to significant discourse and disagreements about the best path to take during decision making (Antin, Constantine and Hunt, 2015; Kelly *et al.*, 2017; McGoldrick, 2017b; Kelley, Godfrey and Young, 2021). This can be especially problematic if the different stakeholder requirements are undefined or misunderstood though this issue can be managed successfully by identifying key stakeholders, the power and influence they have and acknowledging their specific needs and expectations (Baxter and Sommerville, 2010). The use of Iterative Design, which will be discussed further later in this thesis, can also help overcome discourse as it allows stakeholders to revisit designs and discuss issues repeatedly and agree on solutions during the design process (Creswell and Creswell, 2020). Researchers can also implement the use of prioritisation tools such as MoSCoW (Agile Business Consortium, 2022) which allow different stakeholders perceptions to be quantified and weighted to create a ranked list of priorities. Such Prioritisation tools will be discussed in detail later in this thesis.

While the barriers listed during this section may imply a technological solution may be a bad fit for this demographic, it should be noted that smart phone usage and computer access is increasing every year for all age groups in the UK including the over 65s with smart phone usage rising from 3% to 67% amongst the over 65's in 10 years (Statista, 2023). This is significant as dementia is forecast to be a continuing issue worldwide for future generations where smart technology will likely be even more prolific as the tech savvy younger age groups grow older. Though with so many barriers and high participant dropout rates surrounding healthcare technology development (Sanders *et al.*, 2012) the concept of designing with PwD may inspire hesitation. However, these barriers can and should be overcome in order to champion the involvement of PwD and IC to deepen the understanding of the needs, barriers, and enablers of dementia technology (Egan and Pot, 2016). Co-design in particular has seen substantial success in designing for PwD in the studies discussed in this section and will be discussed in more detail in the methodology chapter of this thesis.

2.3 PROMs

As discussed previously, modern dementia care technology prioritises the wellbeing and QoL of PwD, with a focus on enabling them to live comfortably longer in their home environment. Technologies have been developed to support with diagnosis, assessment, monitoring, maintenance, caregiving, and management, in addition to encourage leisure and independent activity, as well as higher involvement of PwD in care decision. This PCC approach (Terada *et al.*, 2013) aims to treat the person, not just the disease, and elicits a more detailed understanding of a patient's daily life and needs in order to adapt personalised care based on their changing needs. This is vital in the field of dementia care where the nature of the condition requires HCP to recognise an individual's changing needs throughout the disease's progression and adjust care and practices accordingly while preserving the individuals personhood (Kitwood, 1997; Mitchell and Agnelli, 2015). This type of care requires a high level of insight into the lives of PwD, especially when it comes to cognitive measurements that need to be done routinely, and direct feedback and opinions that needs to be collected from PwD to determine need and care decisions. One such tool is PROMs.

2.3.1 Patient Reported Outcome Measures (PROMs)

PROMs are tools used to measure the subjective outcomes relating to a patient’s health, QoL, or functional status associated with healthcare or treatment, that are reported directly by patients without interpretation from HCP or other parties (Weldring and Smith, 2013). These tools take the form of questionnaires that pose validated questions or statements with predefined responses that are to be completed by individuals at regular intervals. These questionnaires measure subjective qualities using a quantitative scale that allows easier comparisons to be made regarding an individual’s progress during treatment, an intervention, or condition (Krogsgaard *et al.*, 2021). These tools are an effective way of gauging an individual’s changing needs, the effectiveness of certain treatments or interventions, and for future decision making (Kluzek, Dean and Wartolowska, 2022). While the term PROM is relatively new, tools used to measure subjective outcomes of patients have existed since the 1960’s (Churruca *et al.*, 2021). PROMs were originally developed for use in pharmacological research to measure outcomes relating to treatments during trials for long term conditions with no cure. Because of this, PROMs focused on the QoL of the subjects as the primary measure (Kluzek, Dean and Wartolowska, 2022). Over the years, the use of PROMs has been expanded to cover multiple measures and for multiple uses including informing clinical decision making, prioritising patients, comparing treatments and healthcare providers, as well as evaluating practices and policies (Churruca *et al.*, 2021).

As mentioned, of particular interest is the use of PROMs to measure factors that determine QoL. QoL is a measure of the overall quality of an individual’s life encompassing physical, mental, emotional, and social aspects (U.S. Department of Health and Human Service, 2000). This usually involves subjective evaluations of both positive and negative aspects of an individual’s life such as mood, energy levels, relationships with others, and satisfaction with life. As measuring QoL is very subjective, PROMs are especially well suited to transferring this subjective QoL data into easily calculable quantitative data for measurements and comparisons (Krogsgaard *et al.*, 2021). This is of particular use in the field of dementia, where QoL is recognised as a major aspect and measure of healthy ageing and dementia policies (Moyle *et al.*, 2015). While PROMs such as QoL-AD (Logsdon, 1996) and DEMQOL (Institute of Psychiatry, 2018) that are specifically designed for PwD have been shown to successfully assess QoL (Logsdon *et al.*, 2002), the use of dementia specific PROMs is uncommon throughout dementia research with more generic QoL PROMs and measures often used, which may not consider the specific needs of PwD when using them (Ayton *et al.*, 2021). There is therefore a need for greater longitudinal evidence to be collected to support QoL assessment for PwD in long term care and living in the community (Martyr *et al.*, 2018). Initiatives such as COMET, IHCOM and COSMIN have been developing clinically relevant tools and processes to implement systematic long term QoL assessment for PwD living at home, develop a standard core outcome set for PwD throughout the conditions process, and refine ratings for reviewing patient rated outcome (Madsø and Nordhus, 2021). The goal for these initiatives is to develop better dementia-specific tools and scales that are better suited to measuring QoL in these populations.

2.3.2 ePROMs

Traditionally PROMs were paper-based questionnaires that needed to be sent, completed, returned, and analysed before they could be used. This often meant PROMs could not be collected frequently or affordably enough to be useful in routine care, with physicians often reluctant to use PROMs routinely due to the significant time constraints and a lack of confidence in their value (Heidi, Andrew and Chris, 2020; Nguyen *et al.*, 2021). Electronic PROMs (ePROMs) can be completed remotely and collated automatically in real time which offer a much more efficient method of data collection compared to traditional PROMs which can only be collected episodically in a home or clinical environment. ePROMs also have a comparable level of response compared to traditional paper based PROMs (Ebert *et al.*, 2018) as well as reduced times and associated costs (Staffaroni *et al.*, 2020). As mentioned previously, healthcare technologies often champion the collection of data into electronic medical records for the purpose of real time analysis and big data analytics (Dash *et al.*, 2019; Schlicher *et al.*, 2021) which ePROMs are especially well suited for. ePROMs can also be collected remotely, enabling the assessment, monitoring, and management of dementia to be done remotely from their home environment, without the intrusion of having to travel to a clinician (Boger *et al.*, 2018; Moyle, 2019). Finally, ePROMs also offer the opportunity to implement new modalities via technology. While traditional PROMs were almost exclusively text based, technology can allow for other modalities such as visuals and voice to present and collect data, which may improve accessibility to participants with certain physical or literacy troubles. This is of particular interest in the field of dementia where language and communication is one of the key indicators of cognitive decline so a PROM that could leverage voice and linguistics could help with assessment in future, reducing inequality (Komeili *et al.*, 2019).

In the last 20 years, the use of PROMs and ePROMs has increased considerably both in research and clinical use (Kluzek, Dean and Wartolowska, 2022). PROMs are increasingly recognised as an important tool for fostering clinician-patient communication and improving the quality of care that can be provided (Snyder *et al.*, 2012; Greenhalgh *et al.*, 2018) with many patients welcoming the use of PROMs and believing they should be used more routinely (Heidi, Andrew and Chris, 2020). PROMs have also seen successful routine use in various healthcare studies. These studies range from small proof of concept studies in the field of Paediatric Oncology (Duregger *et al.*, 2016) to large international RCT’s involving patients with breast, colorectal, or haematological cancer (Maguire *et al.*, 2021). One of the largest qualitive synthesis of patients with cancer experience of telehealth showing several benefits of PROM usage in Cancer care across many studies including allowing patients to lead a less disrupted life, reassuring them and their loved ones that they are being monitored, and to help minimise treatment burden (Cox *et al.*, 2017). It is these strengths alongside a push for more person-centred care that is fuelling a rise in the implementation of PROMs as part of routine healthcare across the world (Ian *et al.*, 2021; Elsevier, 2022).

2.3.3 Barriers of using PROMs in dementia

Despite the promising successes of PROMs and their increasing usage, the implementation of PROMS has been recognised to come with multiple barriers. For patients, notable barriers reported include the time required to complete PROMs, patients struggling to complete PROMs, the perceived irrelevance of PROMs and their lack of value to the patient, as well as using electronic devices to complete PROMs (Nguyen *et al.*, 2021). Additional factors such as platform design, literacy, language proficiency, and physical and mental capability can also severely impact the completion of PROMs if not carefully considered (Long *et al.*, 2022). This impact is worsened when considering individuals with cognitive impairments where the content, layout, and procedures of the PROM can pose barriers if PROMs are implemented without cognitive accessible designs in mind (Kramer and Schwartz, 2017). Furthermore, despite the push to implement ePROMs, the majority of these still rely heavily on the ability to read and write to complete. With few PROMs making use of other modalities such as visuals or voice, they can prove to be a barrier to those with sight, literacy, or language problems. All of which can decline as dementia progresses.

One solution therefore would be to use dementia specific PROMs specifically catered for their needs. While there have been PROMs developed specifically for dementia existing for over 20 years (Smith *et al.*, 2007), their usage is almost exclusively limited to research studies with dementia specific PROMs rarely seeing use in clinical practice (Ayton *et al.*, 2021). Generic QoL measures are often used instead of dementia specific PROMs (Rai *et al.*, 2022) which often do not capture the specific needs or symptoms of PwD (Saunders *et al.*, 2018) and are not designed with cognitive accessibility in mind (Kramer and Schwartz, 2017). This issue is compounded by the lack of high quality QoL PROMs that are validated for use in a home environment (Hughes *et al.*, 2021). The complex array of progressive behavioural and psychological changes in dementia means that the implementation of PROMS has remained challenging for use in dementia care. PROMs, especially when collected remotely, depend heavily on patient self-actualisation and consistent and frequent completion. This can pose challenges for PwD with reviews showing the majority of PROMs requiring clinicians to administer them and being completed by a proxy (Ayton *et al.*, 2021) which goes against the principle of PROMs being reported directly by patients without interpretation from HCP or other parties (Weldring and Smith, 2013). Additionally, many IC caring for PwD are more likely to be older (Hopwood *et al.*, 2018). This brings with it additional complications when trying to implement ePROMs as this group tends to be the least computer literate (Statista, 2023) with a widening 'digital divide' that risks alienating people who do not have the capability or access to use these new innovations in technology (Arighi *et al.*, 2021), especially when it has not been designed with their input and involvement (Meirte *et al.*, 2020; Pirhonen *et al.*, 2020).

However, such challenges should not negate exploration of the use of PROMs in PwD as they may be argued to provide an optimum way for a PwD to share experiences and perspectives of care and indications of the QoL (Ayton *et al.*, 2021). It is therefore vital the voice of people with dementia is enabled to be heard as it is "a fundamental right of all patients and individuals living with long term conditions to be included in the decisions and be in control of their own care and support" (Scottish Government and COSLA, 2017). Therefore, if appropriate methodologies are developed to develop better digital tools that helps collect PROMs from PwD effectively and conveniently, it may be postulated that a vulnerable demographic can be provided a means to capture their voice and perspective that can be directly used to inform and improve future healthcare decisions now and in the future.

2.4 Conclusion

This section emphasizes that dementia is a long-term condition highlighting the need to monitor and gauge patient needs. It also discussed how technology has been used to enable remote care and self-reporting of data, enabling better QoL by allowing PwD to stay at home but still providing HCP with vital insight. Also highlighted was how PROMs are a key tool for assessing and monitoring PwD long term. Despite this, the nature of dementia can affect cognition which can lead to many barriers for PwD in using technology, completing PROMs, and taking part in designing services. While methods such as co-design are best suited to enable inclusive design with PwD, there are still many strides needed to improve upon this. With technology offering new ways and modalities to enable better inclusivity. More research is needed to explore how technology can be implemented to enable PwD to self-report data using tools such as PROMs in an accessible and unintrusive was possible. This is investigated further in the next chapter, which highlights the findings of a narrative literature review into digital technologies that have been used to enable PwD to self-report QoL data.

3 Literature Review

The previous chapter provided a detailed background on dementia and its impact as well as how technology and PROMs are used in current healthcare practice to provide and improve services to PwD based on published literature. This chapter presents a narrative literature review performed as part of the study to answer the first research question "What digital technologies have been used to enable PwD to self-report QoL data?" and investigate the second research question "What features, questions and modalities do PwD prefer when interacting with a digital application that enables them to self-report QoL PROMs?". The results of this review identified from the literature the best technologies and methods that will enable PwD to self-report data in the research study. Parts of this chapter were submitted for publish as part of a literature review (Appendix 1).

3.1 Aims

The aim of this review is to collate and describe current literature on what digital technologies, tools and modalities have been used to collect self-report data in PwD and to identify barriers and enablers that influence the ability of PwD to self-report successfully. To answer this, the following questions were posed:

- What digital technologies have been used to enable PwD to self-report data?
- What modalities have been used to enable PwD to self-report data?
- What data collection tools have been used to collect self-reported data from PwD?
- What are the enablers and barriers that encourage and prevent PwD to self-report this data?

These questions were selected as they cover the major gaps in knowledge for developing a multimodal digital application that would enable PwD to self-report PROMs.

3.2 Methods

A narrative review approach was conducted due to the exploratory nature and early phase development of this research area. Other reviews such as scoping or systematic reviews could also have been conducted but a narrative review approach is well placed to summarise an area of research with more flexibility to provide individual insight and speculation on a topic (Bourhis, 2017; Nundy, Kakar and Bhutta, 2022).

3.2.1 Search Strategy

The search was conducted on 31st August 2022 following the PRISMA checklist guidelines (Page *et al.*, 2021). The search was conducted from 2010 onwards to 2021 using 3 major online repositories: SCOPUS, PubMed, and ACM Digital Library.

These repositories were chosen as they represented some of the largest collections of general, healthcare, and technological repositories respectively. An initial search was performed in 2021 for a 10-year period (2010-2020) though was reconducted at the start of 2022 to include publications published in 2021. Each repository was searched using the following search terms below using the standard Boolean search approach. MeSH (Medical Subject Headings) terms were used wherever possible to include common associated medical terms for the searched conditions.

The search terms were: ***("dementia" OR "dementias" OR "Alzheimer's" OR "Alzheimer" OR "Alzheimers") AND ("technology" OR "smart" OR "telehealth" OR "telemedicine" OR "eHealth" OR "internet") AND ("patient reported outcome" OR "patient recorded outcome" OR "self report" OR "self-report" OR "diary" OR "diaries" OR "questionnaire" OR "questionnaires").***

3.2.2 Eligibility Criteria

3.2.2.1 Inclusion Criteria:

- Studies that involve PwD as a primary demographic of the article (e.g., PwD filling out self-reported data independently or supported by IC)
- Studies that involve the collection of self-reported data such as feedback, opinions, self-assessment, evaluations, or perspective from this demographic (e.g., questionnaires, diaries, interviews, and PROMs as well as and form of self-management or self-administered tests).
- Studies that involve the use of digital technology being used to collect the self-reported data. This can include multiple technology types (e.g., website, app or video diary, video calls, phone calls, emails, text messages, voice recordings or other telehealth approaches).
- Studies with IC or HCPs acting and assisting as proxies is permitted.

3.2.2.2 Exclusion Criteria:

- Studies describing technologies where participants are passively recorded and do not interact directly with the technology (e.g., wearable cameras or sensors).

3.2.3 Data analysis

Abstracts were individually reviewed by DK and KE following the eligibility criteria with disagreements resolved by discussion between DK, KE, and RM. Results selected for inclusion where subject to full text review. Full text of included papers chosen were analysed by DK following Braun and Clarke's thematic analysis procedure (Braun and Clarke, 2006) using the NVivo qualitative data analysis software.

3.3 Results

3.3.1 Results Overview

The key search terms used across 3 online databases identified 525 records (Figure 1). Of these, 151 were duplicates and removed. 2 researchers (DK & KE) individually screened the remaining 374 abstracts following the inclusion and exclusion criteria. A third researcher (RM) made the final decision for inclusion with any disagreements resulting in 50 publications identified by DK and 42 publications identified being included by KE. Of these 92 records, 52 were duplicates leading 40 publications included for full text review by the 1st Researcher of which a further 29 were excluded. 11 papers met the inclusion criteria, for overview see Figure 1 and Table 1.

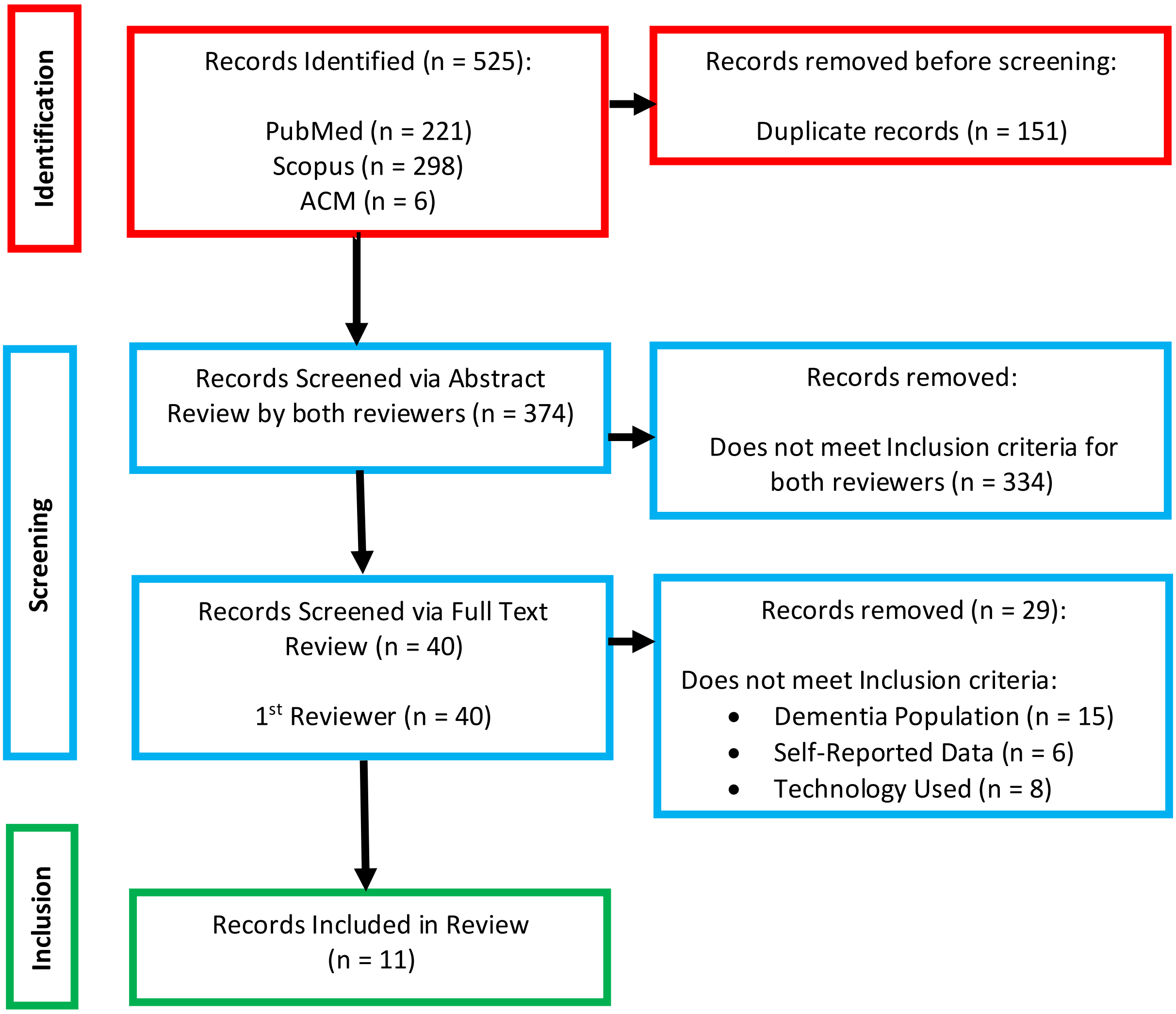


Figure 1 A PRISMA flow diagram showing the number of records found in the search and the total numbers included in the full review.

Table 1 Breakdown of the key elements of the 11 included papers

Study, Year	Population	Country	Type & Stage of dementia included in the study	Type of Data Collection	Technology Used	Data Collection Tool/ Method	Enablers	Barriers
Astell 2014	1 Person with Dementia (age: 63, male)	UK	Not stated (Mixed Lewy Body and Vascular Dementia)	Record a personal online blog which would be thematically analysed by researchers	Desktop computer/ Laptop, iPhone (photos)	Unstructured/Personal blog/diary with photos	A carer supported the participant during fortnightly in-person visits as well as family during the 1-year study period.	Not Stated
Chappell 2016	204 PwD (age:76-86, Female:136, male: 68)	North America and Europe	Mild-moderate dementia or severe dementia	Collect data regarding suicidal ideation and behaviour assessment	Online questionnaire using 'Survey Gizmo'. Personal Devices	Columbia-Suicide Severity Rating Scale (C-SSRS), Geriatric Depression scale (GDS)	HCPs reported the results on behalf of PwD.	Not Stated
Gately 2021	14 Veterans (age 70-98, gender not reported) 11 with Dementia	USA	MoCA or MMSE score of Normal (n=3), Mild (n=5), Moderate (n=5) or Severe (n=1)	Participants took part in a remote story telling exercise as part of occupational therapy.	Computer based Video Conferencing Software and/or telephone	Online Interview, Post Interview custom questionnaire (Likert Scales & Visual Analog Scale)	Participants could choose video and/or telephone. Trainees assisted with set up of the software while caregivers assisted participants during the study	Not Stated
Göllner 2011	1 Person with Dementia (female, age not reported)	Not stated	Very early-stage Dementia	Early proof of concept for an app to record appointments, notes, and reminders of their daily life	Anoto digital pen and MeetMe custom designed calendar app on an iPad	Custom interactive Calendar/Diary	Carer was provided with joint access to the app to support PwD by scheduling appointments and reminders	Not Stated
LaMonica 2017	221 People with Subjective Memory Complaints, Mild Cognitive Impairment, or Dementia. (age: 51-88, female: 127, male: 94)	Australia	Early Dementia (n=23) the rest having MCI	Collection of clinical and neuropsychological assessment, current technology use and interest in eHealth.	Online questionnaire via email. Personal Devices.	HBA eHealth Questionnaire Mini-Mental State Exam (MMSE)	Participants could also complete the questionnaire via post or in person (users' preference)	Not Stated

Lind 2013	1,000 People with a range of prioritised medical conditions including cognitive impairment and dementia (age: 45-75, gender not reported)	Sweden	Not stated	Web based questionnaire (40-60 minutes) about medical history, family history, and symptoms which preceded in-person physical tests and blood tests.	Web-based questionnaire and online consent form completed via computer	Custom made branched hierarchy questionnaire	Participants either could complete the questionnaire at home or at the test centre where computer access was provided.	Not Stated
Oksnebjerg 2020	112 PwD (age: 39-86, Female: 49, male: 63)	Denmark	Not stated	Participants were assigned a tablet for self-management of daily living and memory. A final web-based survey was sent via email 3-4 months after intervention started.	iPad, Web based survey.	Custom made tablet app (ReACT), custom web-based survey (USEdem)	App and Questionnaire were tailored to fit each individual participant at the start. Carers were given access to the app and could report as a proxy	Participant not supported by carer were less likely to self-report data and more likely to abandon the intervention
Possin 2019	512 PwD (age: 78.7 average, female: 298, male: 214)	USA	Not Stated	QoL and general health questionnaires were completed via telephone delivered by a trained care team navigator.	Telephone	Quality of Life in Alzheimer's Disease (QoL-AD), Patient Health Questionnaire (PHQ-9)	Carers were invited to participate alongside PwD.	Not Stated
Schussler 2020	40 PwD (age and gender not reported)	Austria	Not Stated	Collection of psychosocial and physical outcomes of participants during the comparison study	Socially Assistive Robot (Pepper), Tablet PC with specialist app (Coach Pepper)	Apathy Evaluation Scale (AES), Geriatric Depression scale (GDS), The Montreal Cognitive Assessment (MoCA), The Neuropsychiatric Inventory (NPI), The Positive and Negative Affect Schedule (PANAS), Timed UP and GO Test	Participants were supported by nurses, nursing assistants, dementia trainers and family members. Entertainment app was included to encourage tablet/Robot use	Not Stated
Seelye 2016	83 people total, 24 with dementia or mild cognitive impairment (age: 87.9 average,	USA	MMSE score greater than 24, a Clinical Dementia Rating (CDR) scale score	Recording physical and mental health and activities within the past week.	Web based survey. Personal Devices.	Cumulative Illness Rating Scale (CIRS), Geriatric Depression scale (GDS), Mini Mental State Examination (MMSE),	Participant's web browser default loading page was set was set to load the survey each time the browser was opened until	Not Stated

	female: 18, male: 6)		less than or equal to 0.5			Wechsler Memory Scale – Revised	the questionnaire was completed for that week.	
Weiner 2018	56,982 total. Of which 1735 self-report mild cognitive impairment and 212 self-reports Alzheimer’s Dementia. (age & gender not given for these groups)	USA	Self-Reported Dementia or mild cognitive impairment	Collecting details regarding family history, everyday cognition, sleep, diet, medical history, satisfaction with life and other metrics	Online questionnaire developed using the Ebisu platform. Personal Devices.	Geriatric Depression Scale (GDS), Custom Online self-report questionnaires	Supplementary material was provided via the website. Plans to recruit PwD alongside Caregivers in future iterations of the study.	Not Stated

3.3.2 What digital technologies have been used to enable PwD to self-report data?

Computers were the most used technology for enabling PwD to self-report data (n=9). 8 of the 11 studies used computers as portal for participants to access an online website or blog while one study used it to enable video conferencing with researchers. one study made exclusive use of telephones, and one study made use of an iPad combined with a pen tool.

3.3.2.1 Computer and Web technologies

8 of the 11 studies made use of websites designed to be accessed via the internet using a computer as the primary method of enabling PwD to self-report. 7 of these studies made use of an online website accessible via a computer's web browser as the primary method for data collection (Lind *et al.*, 2013; Astell *et al.*, 2014; Chappell *et al.*, 2016; Seelye *et al.*, 2016; LaMonica *et al.*, 2017; Oksnebjerg *et al.*, 2020; Schussler *et al.*, 2020) while one study made use of video conferencing software (Gately et al., 2021). All these studies allowed participants to use their own devices to self-report remotely at home while the Lind study (Lind *et al.*, 2013) also offered computer access at the clinics for the option to complete the questionnaire in person.

3.3.2.2 Mobile and Tablet Usage

While 4 of the 11 studies involved the use of mobile or tablet devices, only 2 of these studies collected self-reported data using this method. In the Schussler Study (Schussler *et al.*, 2020) participants were provided with touch screen PC tablets in order to complete PROMs electronically, while the Göllner study (Göllner *et al.*, 2011) provided participants with a digital pen that recorded written notes to a custom built diary/calendar app developed for iPad. Of note is that mobile and tablet devices were seldom used for self-reported data collection within reported studies, with participants stating a preference to use desktop computers which they were far more familiar with and would use on a more regular basis. Similarly, the Astell study (Astell *et al.*, 2014) enabled their participant to record blogs, diary entry, and notes using their smart phone, however the participant much preferred using their home computer, often emailing photos from their phone to their home computer to add to their blogs. Finally, while the Oksnebjerg study (Oksnebjerg *et al.*, 2020) made use of smart phone and tablet-based apps as part of the central intervention, they chose to elicit self-reported data collection exclusively via web browser questionnaires.

3.3.3 What modalities have been used to enable PwD to self-report data?

10 out of 11 studies included text-based modalities for self-reporting data, 3 studies included audio modalities, and one study included visual modalities. Most studies used a single modality including 8 studies that used text only and one study (Possin *et al.*, 2019) using audio only. 2 studies used multiple modalities including a single study (LaMonica *et al.*, 2017) where text was used as a primary modality

with audio as a reserve option; and one study (Gately *et al.*, 2021) that used a hybrid of either text and audio or text, audio, and visual depending on the participant.

3.3.3.1 Text Based Modality

In terms of modalities used for self-reporting data, most studies (10/11) made use of a text-based modality to enable PwD to self-report. 7 of these studies (Lind *et al.*, 2013; Chappell *et al.*, 2016; Seelye *et al.*, 2016; LaMonica *et al.*, 2017; Weiner *et al.*, 2018; Oksnebjerg *et al.*, 2020; Schussler *et al.*, 2020) made use of a text based questionnaire as their primary method of self-reported data collection. one study (Gately *et al.*, 2021) made use of a text-based questionnaire that was used in addition to audio and visual prompts during a storytelling exercise. The final 2 studies to use a text based modality did so in the form of a user completed blog (Astell *et al.*, 2014) and a user completed diary/calendar that would transcribe written text into a digital text format (Göllner *et al.*, 2011).

3.3.3.2 Audio and Visual methods

Voice based self-reported data collection approaches were described in 3 studies where a single study made use of visual methods. All 3 of these studies required the cooperation of professional staff to record the data collection with PwD using these modalities. The Possin study (Possin *et al.*, 2019) enabled self-reporting of PROMs verbally via telephone with trained care navigators and coordinators. The LaMonika study (LaMonica *et al.*, 2017) provided PwD the opportunity to complete self-reported PROMs via telephone but as a last resort for those unable to complete using online methods or via post. The Gately study (Gately *et al.*, 2021) conducted a story telling exercise and allowed participants to participate via telephone, video call or both. For participants that took part using a video call, questions asked were presented alongside a Visual Analog Scale (VAS) (Bushnik, 2011) that participants used to respond. This is a visual based scale that presents icons to users to choose from to represent their experience.

3.3.4 What data collection tools have been used to collect self-reported data from PwD?

Nine studies captured patient's self-report via text-based questionnaires with the remaining 2 studies using a personal diary or blog. Of the 9 studies that used questionnaires, 5 made use of pre-existing PROMs, 3 made use of custom designed questionnaires and one study made use of both.

3.3.4.1 Pre-Existing PROMs

Seven of the 11 studies (Chappell *et al.*, 2016; Seelye *et al.*, 2016; LaMonica *et al.*, 2017; Weiner *et al.*, 2018; Possin *et al.*, 2019; Schussler *et al.*, 2020) made use of existing text-based PROMs, though the specific use of PROMs varied largely between studies. Most PROMs were collected via a text-based questionnaire delivered via a web browser with only the Possin study (Possin *et al.*, 2019) choosing to collect their PROMs using telephone. 13 different PROMs were utilized across seven studies, five of those studies used more than one PROM. Despite this, only two PROMs had been used in more than one study: Geriatric Depression Scale (GDS) (Chappell *et al.*, 2016; Seelye *et al.*, 2016; Weiner *et al.*, 2018; Schussler *et al.*, 2020) and Quality of Life in Alzheimer's Disease (QoL-AD) (Possin *et al.*, 2019; Schussler *et al.*, 2020). Out of the 13 PROMs used, of note is that only one (QoL-AD) was specifically designed for use by PwD. The most prevalent use of PROMs was to collect data regarding mood and mental well-being of participants (AES, C-SSRS, GDS, NPI, PANAS, PHQ-9) followed by cognitive capability including, memory, recall and recognition (MMSE, MOCA, Wechsler Memory Scale) and physical health and wellbeing aspects including symptoms, physical activity, and pain (CIRS, Timed Up & Go Test, VAS).

3.3.4.2 Custom Questionnaires

Five studies described creating their own custom questionnaires. Three of the studies recorded specific health measures including physical, mental and lifestyle factors (Lind *et al.*, 2013; Seelye *et al.*, 2016; Weiner *et al.*, 2018), one focused on user feedback of the intervention including technical, functional and satisfaction responses (Oksnebjerg *et al.*, 2020) and one study did both (Gately *et al.*, 2021). In terms of the execution of the questionnaires, one study gave different questionnaires to participants based on whether they completed the intervention (Oksnebjerg *et al.*, 2020) while two studies made use of dynamic questionnaires, where future questions were asked or omitted based on the user's earlier responses (Lind *et al.*, 2013; Seelye *et al.*, 2016). The questionnaires used in the remaining studies made no adjustments with all participants receiving the same preset questions. Of interest, is that the Oksnebjerg study (Oksnebjerg *et al.*, 2020) adjusted the questions asked in the survey based on whether the participant had used or abandoned the app during the intervention. The Lind study (Lind *et al.*, 2013) adjusted their questions based initially on gender and then hierarchal branching dependent on previous responses such as if they have had a child, new questions would be asked regarding their healthcare implications of having a child. Researchers commented that the presence of adaptive hierarchical questions appeared to reduce complexity, decrease completion time, and helped to prevent cognitive overload. A simplified version of the hierarchal branching approach was observed in the Seelye study (Seelye *et al.*, 2016) where binary questions revealed a hidden text box depending on the answer provided-including a focus on patient report outcomes such as pain. All the studies made use of adaptable questionnaires (Lind *et al.*, 2013; Seelye *et al.*, 2016; Oksnebjerg *et al.*, 2020). Such approaches were associated with high levels of engagement and understanding from users with no reports or concerns regarding confusion to changing questions or options appearing or disappearing.

3.3.4.3 Blog and Diary

Two of the 11 studies used online Blogs/Diaries. The Astell study (Astell *et al.*, 2014) enabled data collection via an online blog about the PwD life that the participant was encouraged to update regularly. The blog supported text and image uploads allowing the participant to add photos. The participant was able to regularly complete the blog for the entirety of the 1-year intervention, gaining new skills and boosting their personal confidence. The Göllner study (Göllner *et al.*, 2011) enabled self-report via a joint diary between the PwD and carer that recorded appointments, notes, and reminders of their daily activities though this was developed as a proof of concept for the Anoto digital pen and MeetMe calendar prototype and did not report results beyond the initial functional test.

3.3.5 What are the enablers and barriers that encourage and prevent PwD to self-report this data?

Enablers were defined as being aspects that encouraged participants to self-report using digital technologies and methods or made the process more convenient or easier for PwD to complete. Several notable enablers include support from IC (6 studies) implementing convenient training, set-up and introduction to the technology at the start of the study (5 studies), and offering multiple alternative methods to self-report data, both digitally and analogue (3 studies).

3.3.5.1 Support from IC

Six of the 11 studies reported significant involvement and support provided by IC. This involvement included either attending the intervention or encouraging PwD to complete self-reports on a regular basis. 5 of the studies (Göllner *et al.*, 2011; Possin *et al.*, 2019; Oksnebjerg *et al.*, 2020; Schussler *et al.*, 2020; Gately *et al.*, 2021) actively recruited IC or family members alongside PwD to participate in the study. The Astell study (Astell *et al.*, 2014) did not recruit any IC to participate though the single participant in the study spoke strongly of how his wife and daughter supported him to the end of the project. Carer participation was mandatory as part of the Gollner study (Göllner *et al.*, 2011) due to the nature of the joint calendar/diary intervention. Carer participation was optional for the Oksnebjerg (Oksnebjerg *et al.*, 2020) and Possin study (Possin *et al.*, 2019), though both noted significantly higher completion rates as well as longer periods of participation from PwD when supported by IC. The Oksnebjerg study also reported lack of carer support as a significant barrier to participation that often led to the non-adoption and less successful use of the technology. The Oksnebjerg study explicitly stated four instances where the carer completed the PROM as a proxy for PwD in situations where they could not provide self-reported data themselves. Although the Weiner study did not include any IC, they indicated that future iterations of the study plan to recruit caregivers alongside PwD.

3.3.5.2 Set-Up and Training

5 of the 11 studies highlighted the importance of the set-up and training process to the success of self-reported data collection. Four studies provided trained staff to set up the necessary technology for participants. This included setting up the required teleconference software (Gately *et al.*, 2021) or tablet and social robot devices (Schussler *et al.*, 2020), showing participants how to access and update their blog during regular in-person meetings (Astell *et al.*, 2014) or presetting the user's internet browser to load up the required website when they were due to self-report (Seelye *et al.*, 2016). The Oksnebjerg study (Oksnebjerg *et al.*, 2020) enlisted the help of IC to setup the app, with researchers praising their involvement during set up and reporting that adoption rates of the app was five times more likely if it was a carer who set up the app.

3.3.5.3 Multiple Alternative Methods

3 studies reviewed incorporated multiple methods for participants to self-report data, increasing the possible avenues for users to self-report their data resulting in higher completion rates. The LaMonica Study (LaMonica *et al.*, 2017) encouraged users to self-report their questionnaire online or via post but also offered users unable to do this the chance to complete the questionnaire via telephone or in person during healthcare appointments. The Lind study (Lind *et al.*, 2013) allowed users to complete their questionnaire at home using their own computers but also provided computers at test centers so participants could complete the questionnaires during appointments with staff on hand to offer extra support. Finally, the Gately Study (Gately *et al.*, 2021) offered participants the option to self-report either via video or telephone, with three of their 14 participants choosing a mixture of both.

Of the studies reviewed, only one study explicitly mentioned a barrier with the Oksnebjerg study (Oksnebjerg *et al.*, 2020) noting that participants who were not supported by an informal carer were less likely to self-report data.

3.4 Discussion

The aim of this narrative review was to determine what digital technologies, modalities, and tools have been used to collect self-report data in PwD and identify enablers and barriers to this type of data collection. Overall, the results identified a high prevalence for specific technologies, modalities, and tools such as frequent use of computers and text-based modalities to enable PwD to successfully self-report data.

3.4.1 Digital technologies used to enable PwD to self-report data

Our findings indicate that computers are the most prominent technology used for collecting self-reporting data. All but one study (Schussler *et al.*, 2020) made use of computers with three of these studies reporting that PwD had a strong preference of using computers over other methods such as tablet or smart phone (Astell *et al.*, 2014; Seelye *et al.*, 2016; LaMonica *et al.*, 2017). These findings are in line with research regarding older people and their perception of technologies that shows a preference for computers over newer devices such as mobile phones as the latter 'have not been made for older people's needs' (Pirhonen *et al.*, 2020). Despite the ubiquitous nature and convenience of tablets and smartphones (Statista, 2023) and their success at data collection in longitudinal medical studies (Fischer and Kleen, 2021), researchers in studies identified within this review prioritized computer and laptop based data collection methods even when tablets and smartphones devices were readily available as part of the main intervention. The Oksnebjerg study (Oksnebjerg *et al.*, 2020) opted against collecting self-reported data using the readily available tablet instead opting for a browser-based questionnaire emailed to participants. Only the LaMonica study (LaMonica *et al.*, 2017) provided in depth details about their participants accessibility and perceptions of such devices.

None of the studies reported issues with accessibility or compatibility. This could be a result of choosing to collect self-reported data via a web browser on a computer or laptop. This would allow studies to bypass issues such as the need to install an unknown app or the requirement of a new device that participants were unfamiliar with, as they would be able to use their own personal computers at home (Saia *et al.*, 2022). It is surprising though that none of these studies reported any accessibility or compatibility issues when considering the role technologies plays in widening inequalities, especially amongst older people (Busch *et al.*, 2021) and PwD (Arighi *et al.*, 2021) . Due to the nature of dementia, cognitive and communication skills often deteriorate as the dementia progresses, making activities such as self-reporting using a questionnaire difficult (Alzheimer's Disease International, 2017). Additionally there is a notable lack of usability and familiarity with such technologies amongst PwD (Astell *et al.*, 2019), which has led to technology-related social inequalities, including aspects relating to the 'digital divide' (Arighi *et al.*, 2021). Inadequate planning when implementing such systems such as a lack of personalisation of a device to meet the user's needs is also recognised as a prominent barrier (Treadaway, Taylor and Fennell, 2018a; Alzheimer's Society, 2020) as is the overall limited involvement and lack of collaboration and co-design with PwD in the design of technologies that are meant to serve them (Capper, 2020; Rai *et al.*, 2022). Digital technologies offer significant benefits in remote monitoring, real time updates, and preventing crisis which allows care to move away from a reactive system of care to one that is anticipatory and preventative (Green; and Raza;, 2019; Charles; and Ewbank;, 2020; World Health Organisation, 2021a). However, the technology used in these studies was static in their data collection and most studies could easily have substituted their method with a paper questionnaire sent by mail. None of the self-reported data was collected or analysed in real time, nor did any make use of any additional features the technology may provide such as access to sensors or meta data.

3.4.2 Data collection tools used to collect self-reported data from PwD

Self-reported data collection was most commonly conducted via questionnaires, usually in the form of multiple PROMs. In total 13 different PROMs were used with most studies opting to use either multiple PROMs or to include them alongside their custom designed questionnaires. This shows PROMs to be very adaptable and appraised tools with a large selection available that can be easily included in studies (Churruca *et al.*, 2021). It was notable that while PROMs were the most common method of self-report data collection, only 2 were used in more than one study. Of note, is that few studies used PROMs specifically designed to measure overall QoL, with most focusing on mental well-being. This omission of QoL is of particular salience given that QoL is such a prominent part of both international public health policies around healthy ageing and dementia and is a core outcome related to the delivery of PCC (Moyle *et al.*, 2015). Even more egregious is the fact that only a single study used a PROM specifically developed for PwD (QoL-AD). The lack of using dementia specific PROMs is not uncommon throughout dementia research (Ayton *et al.*, 2021) however this observation is a concern as the layout and design does not consider the specific requirements and difficulties PwD may face when trying to self-report PROMs. This omission once again points towards a lack of involvement and representation of PwD in the development of studies and tools that are meant to serve them. There is therefore an urgent need for further development, standardization, and validation of PROMS for application in the field of dementia care.

Despite such variety of PROMS and several custom created questionnaires, these questionnaires all followed a common format that included a number of features including (i) text-based and either a single line or word long questions, (ii) questionnaires limited to one or two dozen questions, (iii) answered using a Likert scale, a numbered score, or a binary choice, (iv) a focus on mood and mental well-being of participants (occasionally cognitive components or physical health) and (v) generally accessed online via a web browser using a computer or tablet (with alternatives of post, telephone, in person, or by proxy with informal carers).

Questionnaires following this format appeared to be acceptable for participants to complete under the study conditions, with none of the studies reporting any difficulties in participants self-reporting. Convenience is a significant advantage to online questionnaires (Regmi *et al.*, 2016) so keeping questions and questionnaires short with fixed responses makes them more convenient to complete.

By making them available online via browser in the first instance with alternative methods as a backup allows data collection to be accessible and cost effective but can still encourage higher response rates associated with older populations when using traditional methods (Ebert *et al.*, 2018). A focus on mood and mental well-being questions also helps collect valuable self-report data that is so vital with incurable conditions such as dementia (Hendriks *et al.*, 2021). While the studies that enabled self-reporting with blogs and diary/calendar noted in-depth details and perceptions of improved QoL of participants, these studies included a single participant with dementia each and therefore more research is required to explore whether similar findings are evident within larger samples of participants.

The studies presented within this review also encourage a high level of participant autonomy, with PwD often in charge of completing self-reports over extended periods of time though the data regarding completion rates or how participants felt about the data collection was lacking. Only the Weiner study (Weiner *et al.*, 2018) reported completion rates for individual participants and found that 98% of participants completed at least one self-report questionnaire. Overall, 36% had completed less than half of all the questionnaires, with 22% completing more than half and 40% completing all the questionnaires in the study. The Seeyle study (Seelye *et al.*, 2016) also reported participants became noticeably slower at completing the questionnaire over time, especially when compared to their control group. There is therefore a critical unmet need to ensure that PwD are more involved in the development of these self-report technologies to ensure optimal and sustained use over time (Rodgers, 2017)

3.4.3 Modalities used to enable PwD to self-report data

Our findings suggest that there is a strong representation of text-based modality in the literature. All but one study (Possin *et al.*, 2019) made use of a text-based modality as their primary method of data collection, often in the form of a link to an online questionnaire sent via email. This finding matches with other domains where the use of text-based questionnaires have been used consistently and effectively since the 1930's and is a trialled and tested method of self-reported data collection (Nayak and K A, 2019). The Possin study (Possin *et al.*, 2019) was the only study to use an entirely voice based modality but this was limited to verbal communication using a telephone or video call and relied on a researcher or staff member to ask the question and record the response rather than any automated voice . The Gately study (Gately *et al.*, 2021) made use of a mixed modality approach using text and voice via a video/phone call and was the only study to implement a visual-based modality, making use of a Visual Analog Scale (VAS) to use when self-reporting for participants who opted to take part via video call. The Astell Study (Astell *et al.*, 2014) did include the option for the participant to include photos as part of the blog, but it is unclear how frequently this was done or if this visual data was analysed. It should also be noted that no study attempted to collect voice or video data digitally from users or attempted to implement automation for this type of data. Despite the rise in commercial voice and visual assistants (Laricchia, 2023) and the prevalence of video calling software (Sadler, 2020), it was surprising that so few studies used visual or audio methods for PwD especially as such methods have been shown to be promising in wider healthcare practice (Naunheim *et al.*, 2019; Sezgin *et al.*, 2020). It is perhaps a barrier for future implementation given that PwD are highly likely to have sensory impairments such as hearing loss or poor vision (Crews and Campbell, 2004) which could make such methods impractical, however further research is required to further explore the value of such technologies in this population.

3.4.4 Enablers and barriers for PwD to self-report data

Importantly, the findings identified several enablers regarding self-reported data collection with PwD. Enablers that encouraged PwD to self-report data collection included assistance to setup, support, and encourage continued participation as well as leveraging the benefits granted by technology.

3.4.4.1 Enablers for self-report

This review identified multiple different approaches to enable PwD to self-report effectively and to encourage continued participation. Sufficient set-up and personal support appear to be one of the biggest factors in successfully enabling PwD to self-report. Many of the studies instructed trained staff and IC to set up the required software and hardware. The flexibility provided by allowing participants to self-report using alternate methods such as via phone call, post or during in-person appointments (LaMonica *et al.*, 2017; Possin *et al.*, 2019; Gately *et al.*, 2021) in addition to online self-reporting encouraged longer and more frequent participation. These findings resonate with the wider literature where training patients to use an online portal did substantially increase their use compared to the untrained population though they do report that such training was unsuccessful in getting the majority of patients to become regular users (Lyles *et al.*, 2019). Finally, the importance of human elements cannot be understated: by far one of the most significant influences on user participation was the involvement of family, friends, and volunteers acting as IC to PwD. Many studies lauded their inclusion as having a major benefit of encouraging long term user participation and adoption (Göllner *et al.*, 2011; Astell *et al.*, 2014; Possin *et al.*, 2019; Oksnebjerg *et al.*, 2020) as well as opening up additional avenue of data collection with IC acting as proxies (Oksnebjerg *et al.*, 2020). Caregiver involvement has frequently been recognized as a vital element in the adoption of assistive technologies by PwD (Sriram, Jenkinson and Peters, 2019) so it is not surprising this literature review found similar reports in for self-reporting technologies.

3.4.4.2 Barriers to self-report

Of note, is that only one study included information on barriers to the collection of self-report information in PwD, noting that lack of IC support making it less likely for participants to self-report data and more likely to drop out of the intervention.

3.4.4.3 Enabling PwD to Participate in design and development

Whilst not one of the objectives of this review, of note and of reference for future research in this field is that none of the studies involved PwD in co-designing or the development or choice of technology or tools to use, with their participation limited exclusively to the final testing 'evaluative' phases. The dementia demographic is known to have particular issues regarding recruitment, ethics, consent, assent, communication, and trustworthiness of data (Beuscher and Grando, 2009) yet none of the studies appear to have specifically catered or tailored their recruitment, technology, or choice of tools to cater for PwD beyond recruiting IC. This is a particular omission in the evidence base to date considering the 'Law of Attrition' which reports a significantly higher number of participants dropping out in digital health studies when compared to others similar studies such as drug trials or in-person studies (Eysenbach, 2005). This is attributed to several reasons, such as high user burden, high level of commitment, and the relative autonomy for users to identify their own levels. Such impacts are especially concerning for studies developing evidence in the field of dementia which are more complicated, costly, and slower than studies for other diseases (Malzbender *et al.*, 2020).

3.5 Conclusion

This chapter identified the technologies, modalities, and data collection tools that have enabled PwD to self-report data as well as the enablers and barriers that impact this. The work highlights a growing interest in self-reported data using digital technologies for PwD. Despite the studies themselves implementing a wide variety of different technologies including desktops, tablets, and video conferencing, self-reported data collection was often done in tandem with a separate text-based questionnaire that was usually accessed with a desktop computer. Other modalities such as voice or visuals were rarely implemented or only as a backup option performed with a human researcher. PROMs were by far the most frequently used tool and were primarily text based. Some studies opted to produce their own custom questionnaires which did allow for higher levels of interactivity though were strictly text based. Multiple enablers were shown to enable PwD to self-report data including provisions regarding set-up and training, support from IC, as well as offering multiple alternative methods to self-report, though these all appeared to require significant human involvement and do not leverage technology much in their delivery via the use of automation, adaption, or multi-modality.

In addition, from the studies reviewed there appears to be a clear lack of reported involvement in PwD in the research phases of these studies and there remains a real risk that PwD will become excluded from shaping future digital innovations. Taken together, the state of research into digital approaches for self-reporting data in dementia remains very preliminary. Regardless, this work identifies several key aspects to consider to enable PwD to self-report data using digital technology and methods.

Recommendation	**Detail**
Convenience and flexibility	The process of self-reporting data needs to be as convenient and flexible as possible. Setting up the required software and hardware for participants and providing them with adequate training during the set-up phase made participants far more likely to take part. Additionally, offering alternative methods to self-report via phone, calls, post, or in person all create a convenient environment for PwD to participate.
Personal support through carers	Researchers can leverage additional assistance which can help with troubleshooting problems and boost morale of PwD when they self-report including through the support of carers.
Accessible via website	Allowing self-reports to be collected via a website allows the widest possible range of devices to access and prevents excluding participants or the requirement of specific technology being used, or apps being updated or installed.
Choice of questions	Pre-existing PROMs have been identified as useful tools for collecting self-reported data collection. Additionally creating custom questionnaires which can be adapted or tailored has also been shown to be effective. These studies highlighted that a mixture of multiple PROMs and custom questionnaires are also viable and encourage a focus on the collection of data regarding participants mood and mental well-being. In future, the use of validated questionnaires specifically designed for PwD should be encouraged over more generic options.

As researchers plan ahead in a post-COVID pandemic world, it is vital that researchers build back better where PwD are supported to age well in place in the communities. COVID-19 highlighted many inequalities felt by the dementia population and a significant need for more accessible remote support provisions for PwD post diagnosis (Giebel *et al.*, 2021). Despite an array of innovative ideas and exciting future prospects, there currently appears to be a lack of leveraging the full potential of these technologies for the purpose of self-reported data collection, with many of the processes relying heavily on human involvement or single modalities. Finally, there was a clear lack of engagement with PwD – future research needs to find effective ways to ensure active involvement in the development of such future technologies at a stage that can make a strong impact on product designs (Suijkerbuijk *et al.*, 2019). With this taken into consideration, the next chapter will outline theory and metholdogy to conduct the study for this thesis.

4 Theory and Methodology

The previous chapter presented the findings of the literature review which identified various technologies, modalities, and data collection tools that enabled PwD to self-report data. A limitation identified was the lack of co-design and involvement of PwD in the development and selection of such technologies. This chapter will discuss the theory and methodology that will underpin the research study. This will cover aspects including research paradigms, Human Computer Interaction (HCI), and the Software Development Life Cycle (SDLC).

Theory and methodology are vital for research as it forms the framework that will justify rationales, develop data collection/generation tools, and set out how data will be analysed and interpreted (Stewart and Klein, 2016). This sets the structure for a scientific study, allowing for effective assumptions to be made and dictating the best methods and tools be used for data collection (Abdul Rehman and Alharthi, 2016). Such theoretical and methodological framework is essential for scientific knowledge to be created and generated and details how scientific problems should be understood and addressed by researchers using established scientific methods (Kuhn, 1970). It is therefore vital to first understand and select the most appropriate theoretical framework before the study begins (Collins and Stockton, 2018).

4.1 Limitations Identified in the Literature

As identified in the previous chapter, a significant limitation of technologies developed for PwD was the significant lack of Human Centred Design (HCD). These are approaches where people that use a system are given the opportunity to directly affect, change, and improve it (Norman, 2002). There was a significant lack of co-design and involvement of PwD in the development and selection of such technologies. PwD were exclusively involved during the final testing stages of using the technology, long after it was created with no opportunity to decide or influence the technology they were expected to use. Such technology developments have a long history of unsustainability (Kendall and Dearden, 2020) and failure (The Standish Group Report, 2020) in all domains including healthcare (Kim, Coiera and Magrabi, 2017; Zhang, Budhdeo and Ashrafian, 2022). Unsuitable technology has been identified to impact user interaction, data receipt, and patient outcomes (Kim, Coiera and Magrabi, 2017) with a lack of co-design and user involvement being raised as a key problem to technology sustainability and adoption (Kendall and Dearden, 2020). This may explain why promising ideas have not translated into practice with all the studies in the literature review (chapter 3) remained in the early prototype phase and not seeing greater adoption or clinical use. Therefore, enabling PwD to Participate in the full design and development process is a vital part of the study to address the limitations of previous work. This requires considerations for significant Human Computer Interaction (HCI) which lends itself to a qualitative research approach.

4.2 Research Paradigm

Research paradigms defines the way in which scientific knowledge is created and generated and details how scientific problems should be understood and addressed by researchers using established scientific methods (Kuhn, 1970). Two of the major approaches are Positivism (Abdul Rehman and Alharthi, 2016), and Interpretivism (Collins and Stockton, 2018). By aligning with a specific research paradigm, researchers can make effective assumptions before the study begins and dictate the best methods and tools be used for data generation (Abdul Rehman and Alharthi, 2016).

4.2.1 Interpretivism

Seen as a response to the over use of positivism in the field of research, which perceives knowledge as objective and precise with exact truths that can be discovered and recorded, Interpretivism presents the argument that there is not a single knowable definable knowledge and that truth is varying, ever-changing, and subjective (Abdul Rehman and Alharthi, 2016). Interpretivism therefore puts people are at the centre of research and acknowledges their beliefs and perspective can be heavily influenced by their culture, the time frame of the research, and by personal experience (Tedre and Pajunen, 2013). Interpretivism prioritises research on humans and that reality is created collectively with the truth of the world being heavily mind-dependent, where problems and issues can vary hugely between people, groups, and cultures (Sheppard, 2020). Understanding the social phenomena and the different perspectives from a wide range of people is therefore key to this approach.

Interpretivism aligns with qualitative methodology and methods such as interviews and focus groups as well as a soft system methodology. This is where all stakeholders involved in a system or service are identified and invited to contribute their perceptions and ideas. This helps to crowd source new ideas and solutions by bring together the perspectives of people from a wide range of backgrounds, experience and knowledge to find resolutions to problems and improve systems and processes (Checkland, 1981). Qualitative approaches help recognise specific issues affecting specific people and can uncover the root causes behind problems. This collection of opinions directly from the people impacts most encourages greater transparency to why certain features are prioritised rather than relying on assumptions or estimations and can be especially effective if problems or requirements are not well defined (Baxter and Sommerville, 2010). This type of approach can also identify and resolve discourse between parties especially when combined with iterative methods. This is because disagreements and contradictions are common and it's not unusual for participants to change their mind's part way through qualitive research (Creswell & Creswell, 2020).

4.2.2 Qualitative Research

Qualitative research is an approach that seeks to generate data that reflects the opinions and perspectives of people, as opposed to quantitative research which generates data that can be easily counted, calculated, and measured (Creswell and Creswell, 2020). Qualitative research is commonly used when designing systems and products as it allows a greater depth of research into participants to understand their experiences, feelings, and perceptions that can be used in designing, testing, or improving systems (Bhandari, 2023). This is done primarily by collecting data directly from participants via interviews, focus groups, and questionnaires that encourage open ended discussion. This data can then be analysed to determine common themes amongst the participatory groups (Creswell, 2018). This type of data often involves a much smaller number of participants compared to quantitative research and is particularly effective in groups where participation numbers are expected to be limited. The smaller pool of participants allows the researcher to delve into far greater detail about the root causes of perceived problems facing the user groups, allowing them to better define their specific needs and requirements to reach data saturation (Hennink and Kaiser, 2022). These advantages make qualitative research a suitable approach for the study, as the recruitment pool for PwD is expected to be quite small and the aim of the project is to design a new novel application.

One limitation of qualitative research however is that disagreements can often arise between the views of different stakeholders who may disagree entirely leading to significant discourse (Antin, Constantine and Hunt, 2015). This has been shown to be a common issue amongst decision making involving PwD, IC and HCP (Kelley, Godfrey and Young, 2021) and dementia studies (McGoldrick, 2017a) where participants may drop out despite the behest of others who believed it to be in their best interest. Mediation between conflicting parties can therefore become a necessity though prioritisation tools such as MoSCoW can be used to democratise disagreements in a balanced and appropriate way (Agile Business Consortium, 2022). The MoSCoW prioritisation method is described in detail in a later section.

Considering the focus of this study is to create a novel application where PwD are included and participate in the full design and development process, this study will be guided by interpretivism and the use of qualitative methodology and methods. It is important to consider the design principles that fit within this interpretivist approach and therefore influence the research methodologies and methods chosen. This will require consideration of technology design and user experience principles, especially when considering how often these types of research projects fail when technology is involved (Eysenbach, 2005; The Standish Group Report, 2020) and how lack of user interaction can lead to the long term unsustainability of technology and abandonment by users (Kim, Coiera and Magrabi, 2017; Kendall and Dearden, 2020). It is therefore determined that the best design principles would involve considerations of both people and technology together and how they interact.

4.3 Human Computer Interaction (HCI)

As discussed, people will take a significant role in participating in the study. Their involvement and perceptions will be used to create a new novel application. Therefore, the interaction between people and technology will be a core tenet of the study which needs to be considered. Human Computer Interaction (HCI) is a multidisciplinary field of study regarding technology design that focuses on the interaction between humans and computers and the best ways to encourage and support such interaction (Soegaard; and Dam;, 2014). While this field covers a variety of topics and methods, this section will be focusing on the qualitative human elements highlighted by the selected methodologies and the key methods of HCI that will be used in the study (Lazar, Feng and Hochheiser, 2017a).

4.3.1 Sociotechnical Design

Sociotechnical design is an approach to HCI where the consideration and implementation of social and ethical requirements are implemented during the development of software and hardware systems, often putting these social needs above technical wants (Whitworth and Ahmad, 2013). Put simply, the concept of socio-technical design stems from the belief that modern day systems are reliant on both technology and people to function and there is a mutual benefit for society and technology when both are considered together during the design phase and solutions are adapted to allow both to work together (Cummings, 1978). This is known as Joint Optimisation and follows 2 major principles (Cooper and Foster, 1971). The 1st is that people and technology create the conditions necessary for successful performance, whether these conditions are linear relationships (where people use the technology in the expected and desired way) or non-linear relationships (where people find new or unusual ways to use the technology, whether it is beneficial or problematic). The 2nd principle is that any optimisation of either the socio or technical aspects of a system will often increase the number of problematic non-linear relationships as complexity increases and will result in detrimental effects on the performance of the whole system.

In order to avoid such issues, Sociotechnical design encourages many of the approaches and methods associated with interpretivism and qualitative approach including the involvement of all stakeholders and their perspectives during development phases, the attention to smaller issues that affect each individual stakeholder groups, and the understanding that there are likely multiple inter-dependent problems and inefficiencies that require multiple inter-dependent solutions to resolve issues (Baxter and Sommerville, 2010). This is particularly critical for healthcare services which are significantly dependent on complex human organisational structures (Coiera, 2007). This does mean sociotechnical design often faces many of the challenges associated with both interpretivism and qualitative approaches regarding stakeholders, though socio-technical design recognises more specific problems relating to stakeholder involvement regarding technology. This includes challenges such as inconsistent terminology between stakeholder groups, the differing levels of abstraction, values and agreeability between stakeholders, and the difficulties of managing groups spanning a wide range of multidisciplinary skills and knowledge and how best to identify and include such stakeholders (Baxter and Sommerville, 2010). Despite these challenges, it may be argued that sociotechnical design is much better suited to the research approach when compared to alternatives. Alternative approaches such as systems engineering, where processes focus purely on the optimization of systems for peak performance (Buede, 1999) do not allow for significant opinion from users and stakeholders, instead preferring techniques that harness knowledge exclusively from professionals in engineering and science to introduce technological innovations (Bode, 2023). Therefore, this study is informed by sociotechnical design that puts human users at the centre of the design process.

4.3.2 Human Centred Design (HCD)

As mentioned, Sociotechnical Design prioritises the societal benefit of technologies and encourages the inclusion of people and users in the design process. But how should such people be involved? HCD is a design approach that empowers the people that use a system the opportunity to directly affect, change, and improve it. HCD therefore puts the human aspect at the centre of the design process as who better to help fix issues than the person who is most affected by them (Norman, 2002).

The origin of HCD stems from the collective research approach that was first developed in Scandinavia in the 1970's (Bodker, 1996). To better implement the new systems that where being introduced in the workplace because of automation and computers, many organisations devised collaborations between workers, designers, and researchers to better understand the worker's experiences and personal knowledge to provide them with resources needed to perform their roles more effectively. These techniques eventually developed into User Centred Design (UCD), where user involvement was seen as the main subject in design research, as well as Participatory Design, which went further by signifying that stakeholders were no longer just participating in the design process, but they were in fact cooperating directly with the designer in an equally important role (Henni *et al.*, 2022).

There are large number of different approaches to HCD when following a sociotechnical design. By considering the context of the whole study and its Software Development Lifecycle (SDLC, which will be discussed in a later section) the options for which method to use can be narrowed down. The study involved all four phases of the SDLC, including the General requirements of stakeholders and environment the software is developed, Analysis of stakeholder needs and feedback, Design iterations of the software, and the Evaluation of the software. This means that of the 11 sociotechnical system design approaches outlined by Baxter and Sommerville (figure 2) (Baxter and Sommerville, 2010) only 3 cover all stages of the SDLC of this study. Of these, ETHICS has not been updated since the 1990s and has fallen out of use entirely since 2000s (Elbanna and Newman, 2013) and Cognitive Systems Engineering (Hollnagel and Woods, 2005) offers a top-down all-encompassing approach that does not suit the people empowering approach that HCD allows. This makes HCD the best approach for this study.

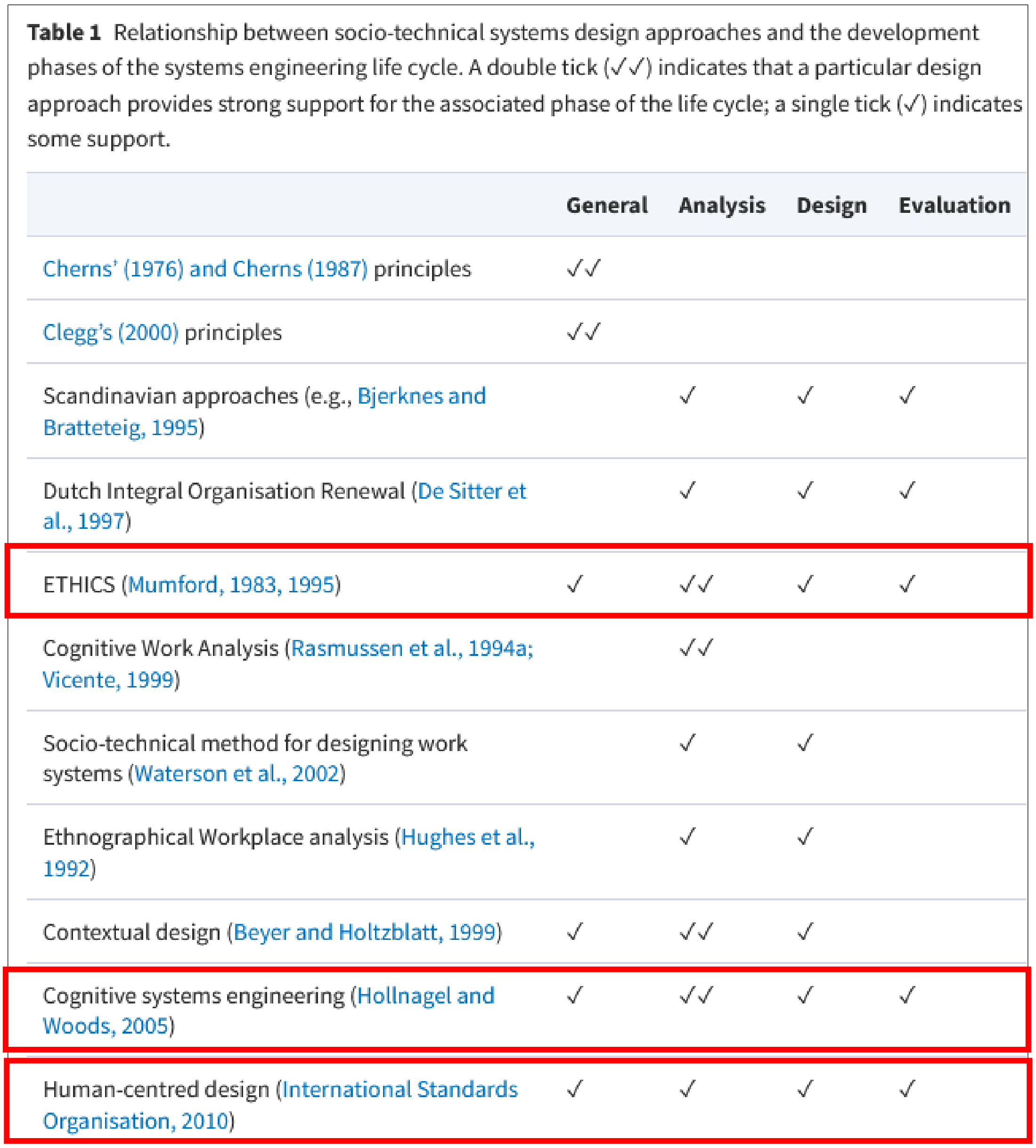


Table 1 Relationship between socio-technical systems design approaches and the development phases of the systems engineering life cycle. A double tick (✓✓) indicates that a particular design approach provides strong support for the associated phase of the life cycle; a single tick (✓) indicates some support.

	General	Analysis	Design	Evaluation
Cherns' (1976) and Cherns (1987) principles	✓✓			
Clegg's (2000) principles	✓✓			
Scandinavian approaches (e.g., Bjerknes and Bratteteig, 1995)		✓	✓	✓
Dutch Integral Organisation Renewal (De Sitter et al., 1997)		✓	✓	✓
ETHICS (Mumford, 1983, 1995)	✓	✓✓	✓	✓
Cognitive Work Analysis (Rasmussen et al., 1994a; Vicente, 1999)		✓✓		
Socio-technical method for designing work systems (Waterson et al., 2002)		✓	✓	
Ethnographical Workplace analysis (Hughes et al., 1992)		✓	✓	
Contextual design (Beyer and Holtzblatt, 1999)	✓	✓✓	✓	
Cognitive systems engineering (Hollnagel and Woods, 2005)	✓	✓✓	✓	✓
Human-centred design (International Standards Organisation, 2010)	✓	✓	✓	✓

Figure 2 Baxter & Sommerville (2010) Socio-technical systems: From design methods to systems engineering (Chapter 4, Table 1)

As noted by Elizabeth Sanders (Sanders *et al.*, 2012), in recent years, there has been a strong focus in the field of HCD to move towards Participatory Design, where users are encouraged to put forward their own ideas and concepts to designers in order to produce a more tailored solution (figure 3). In particular, Sanders highlights the importance of stakeholder's early involvement in design projects regarding the 'fuzzy front end', where ideas and concepts are developed long before it is known what form the final product or service will take. This is the predesign phase of the project where the requirements are often ill-defined or entirely unknown, and by involving users this early on via qualitative research, more effective and novel solutions can be conceptualised before development begins so time and resources are not wasted producing a solution that is not fit for purpose (Blandford *et al.*, 2018). Participatory Design has been an effective design approach for many new developments and has birthed many new methods, of particular interest is that of Co-Design.

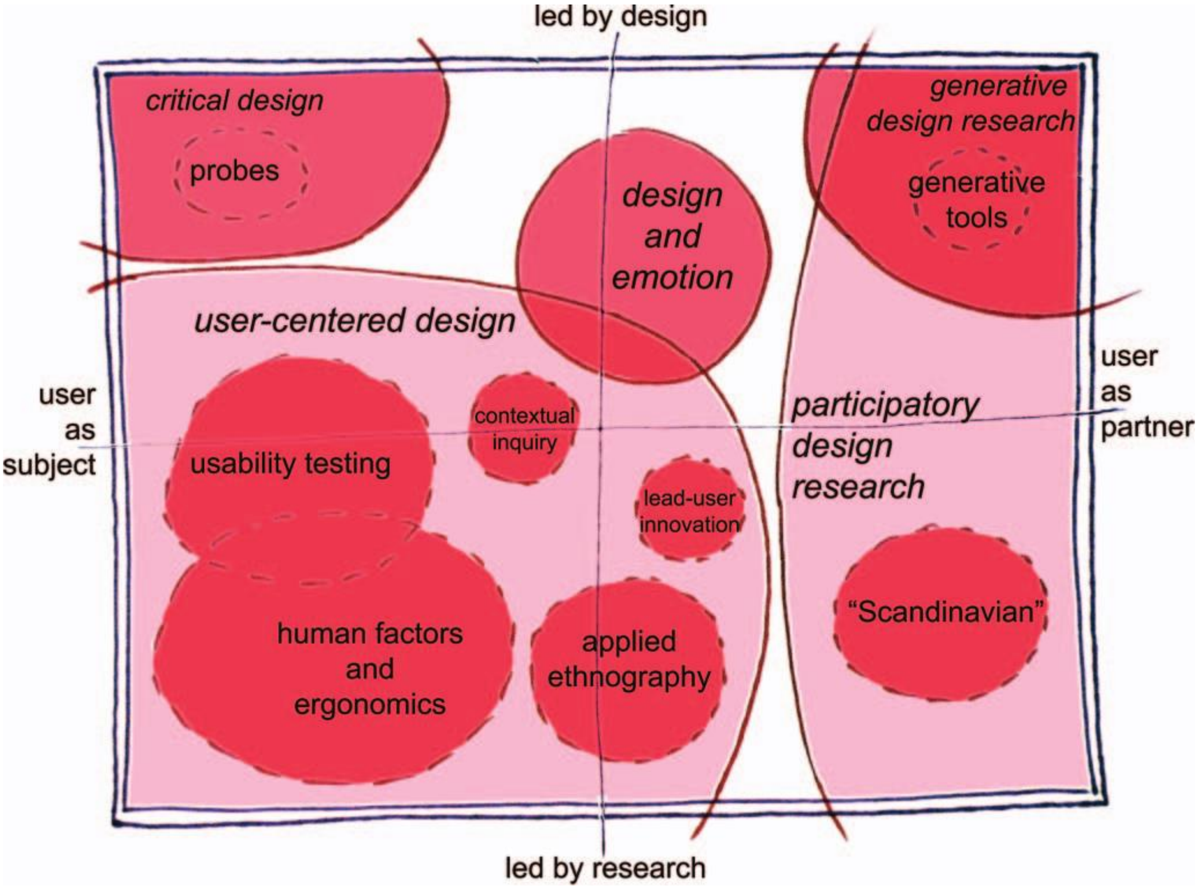


Figure 3 HCD Matrix. Sanders & Stappers, 2008, Co-creation and the new landscapes of design. Page 6, Figure 1

4.3.3 Co-design

Co-Design, sometimes referred to as Co-Creation, Co-Production, or in the above diagram 'Scandinavian' design, is a methodological approach to design and development where the designer works closely with a wide variety of stakeholders in order to produce a new product or design (Sanders and Stappers, 2008). In comparison to the traditional design practice such as sequential, simultaneous, or concurrent engineering (Putnik and Putnik, 2019), where a designer would be given criteria in order to develop the product independently before user testing begins, co-design seeks to introduce users and other stakeholders as early as possible in the design process, gathering their requirements, opinions, and feedback throughout each stage of the projects development. This information can be used to navigate and influence the development of the project as it is being produced to ensure the final outcome is usable, sustainable, and appealing.

Co-Design has seen increasing use in the field of healthcare and dementia, with the UK's Department of Health national dementia strategy outlining co-design (referred to as co-production) as one of the four guiding principles for successfully implementing their strategy (Department of Health, 2009). This principle explicitly states that *"Implementation must be discussed and decided in partnership with the NHS, local authorities and key stakeholders".* This means that all stakeholders including citizens such as PwD and IC are expected to be involved and have some level of contribution and decision-making powers when it comes to developing new interventions for dementia care. Since the introduction of these guidelines, many studies involving PwD and HCPs have been successfully accomplished using co-design as their research approach (Tan and Szebeko, 2009; Niedderer, 2017; Rodgers, 2017; Treadaway, Taylor and Fennell, 2018b; Tsekleves *et al.*, 2020; Fox *et al.*, 2022). These studies applaud co-design for facilitating close involvement and intimate knowledge from PwD to better define requirements, leading the project to be closely tailored to the users' specified needs and avoiding issues of the designer making inaccurate assumptions or stereotypes of the stakeholders or developing features that are not necessary or wanted. They focused on a PwD first approach, where PwD were the focus during workshops, with IC and HCP often attending in a supportive, advisory, or evaluative role. This allows the voice of PwD to be heard (Volkmer *et al.*, 2023). The main limitation for most of these studies was the limited scope as all bar the Rodgers study that focused on the early pilot and development stages of the project.

While Co-design has had many promising applications, it is not without limitations. By far the biggest limitation of Co-Design to consider for research studies is that it requires a large level of commitment from the stakeholders involved. For the study, participant commitment may be impacted by the health and wellbeing of the PwD involved who have a higher chance of having other health issues which may affect participation (Lepore *et al.*, 2017) but also the ethical and legal restrictions of performing a study with potentially vulnerable people and ensuring their informed consent is given. Additional, consideration must be made to account for the busy schedules of HCP and IC whose involvement will be necessary. Co-design requires all parties to be aligned in their values and goals and form a working relationship together as equal partners in a situation where traditionally the designer would have greater power that can often lead to stress and dissatisfaction (Chan, Yim and Lam, 2010). Furthermore, in situations that co-designed projects do not come to fruition, there can be a detrimental effect on participants who contributed to, especially if it falls short of the participant's expectations (Heidenreich *et al.*, 2014).

Despite limitations, a significant advantage of co-design is it allows the designer to work with stakeholders who have intimate domain knowledge that they would likely lack, including details of legal, ethical, and practical restrictions they may otherwise overlook (Kendall and Dearden, 2020). This can help avoid potential pitfalls and problems that may be obvious to stakeholders but may not be to the designer. This is especially advantageous if end users are recognised as the primary experts with an emphasis on creativity and innovation developed from their ideas (Blandford *et al.*, 2018). Finally, by having the perspectives of multiple stakeholders involved from a wide range of backgrounds and skillsets, the designer has the opportunity to crowd source new ideas and concepts from a wealth of talent and personal experience and ensure that the final outcome will serve all users specified needs and be of appropriate standards and usability. This aligns with the interpretive approach.

It is for these reasons that this study aims to follow a co-design approach to develop a technological solution for collecting and displaying PROMs for PwD. While other approaches such as DEST (Aydemir *et al.*, 2014) exist for sociotechnical designs, none have the level of recognised support as co-design has with literature reviews noting that co-design is the key to deliver people-centred care (Sanz, Acha and García, 2021). Co-design is also the only form of this methodology to be repeatedly used with PwD with literature reviews noting how highly beneficial it was to involve PwD in design research using co-design (Wang *et al.*, 2019). Furthermore, the concept of Co-Design aligns very well with the study topic as the results of the literature review showed the requirements for developing a technological solution to gather PROM's from PwD is currently limited and needs to be defined before any solution can be implemented. This is especially important for the dementia demographic where the high variation in the nature, manifestation, and impact of the condition on individuals requires a highly individualised approach where participants can voice their needs (Tsekleves *et al.*, 2020).

4.3.4 Interaction Design

With co-design selected as the methodology that will influence how participants are involved in the study, the final HCI element to discuss is how their involvement will be leveraged to design a novel application. Interaction Design is the approach that when designing a product or a service, the way users interact and use a product is highly significant and needs to be considered alongside the actual features of the product (U.S. Government Services and Information, 2023). The approach dictates that by understanding a user's behaviours and expectations when using products, you can improve the overall experience by catering a products design to make it as simple and pleasurable to use for users (Fioretti and Carbone, 2007). Therefore, a key part of Interaction design is understanding the demographics needs and requirements by directly involving users and stakeholders in all stages of the design process and observing how they interact with product. This makes the use of HCI and co-design paramount in Interaction design.

The concept of Interaction design stemmed from User Interface Design, and was coined as a way to adapt computer design methodology for use in the field of industrial design (Moggridge and Atkinson, 2007). User interface design was an important step in turning computers from specialist scientific equipment into the mainstream. By studying people's behaviour and adopting and referencing features of earlier hardware designs in the design of new technology and software, designers were able to influence users' behaviour by designing features they already recognise (Reid, 2019). One of these key methods was the implementation of Skeuomorphism, a design philosophy prevalent through most of the 1990s and 2000s where virtual icons were designed to reference familiar real world objects that best represent the software's functions, creating a recognisable example for users to understand (Basalla, 1989). Examples of this include using a phone receiver handle icon to represent the call feature, a paper envelope icon for email, and the image of a floppy disk to represent saving a file.

The issue with this is that as new technologies emerge, it is not unusual for physical objects such as phone receivers and floppy disks to become outdated to the point they know longer relevant and their association to a real-world item and action ceases to exist. Therefore, new ways are needed to encourage user's interaction and in modern interaction design, there has been a move away from skeuomorphic design in favour of more abstract designs and the implementation of new methods of prompting users (Pavlovic, 2020). One such example comes with the improvement of new technologies such as touch screens and voice assistants. Just like the way the jump from command line to Graphic User Interface allowed for designers to incorporate sight and sound into a user's interaction, the jump to new interaction methods allows modern designers to implement touch, motion and voice, such as allowing users to 'flick' through the pages of a website on a touch screen (Victor, 2011) or allowing users to interact in a 3D space via Virtual Reality or the implementation of Internet of Things (Baker, 2017).

As these technologies mature and offer users new ways to interact with technology, it is important to consider the best ways to prompt and navigate users into using these technologies in the most effective way possible. This is where Interaction Design comes into play, whether via a computer, mobile, tablet, IoT or VR, there are 5 fundamental dimensions that should be considered and recognised when considering interaction design (table 2). These 5 dimensions are: words, visual representations, physical objects/space, time, and behaviour (Interaction Design Foundation, 2021).

Table 2 The 5 dimensions of Interaction Design

Dimension	**Description**
Word	The 1st dimension Word encompass all words and text, including the readable text such as buttons, labels, headings, and paragraphs as well as the use of language that is appropriate for the user. In recent years, words have taken on a new use with the ability to communicate via voice and sound using words. Word helps deliver users information and content and can be key methods to impart information to users.
Visual	The 2nd dimension is Visual representations which are graphical elements such as images, video, typography, and icons that aid in user interaction as well as the choice of colours. Visual representation can be used to direct a user's attention to certain parts of a product and as a shorthand to represent information to users in a more easily digestible way, especially if the audience speaks different languages.
Space	The 3rd dimension is Physical objects and space and refers to the medium through which users interact with a product or service. Digital interaction will often rely on a touch to interact with virtual services, such as via buttons, keyboard, mouse, or a touch screen, though other elements such as voice commands, motion controls and image recognition are becoming more common. The 3rd dimension will also consider other physical attributes, such as the type of location users exist in with the product and account for these differences, such as a user on a computer being more likely to be at a desk where mobile users are more likely to be in a more public location on a smaller screen. These locations may require adjustments to optimise usage.
Time	The 4th dimension Time relates to how the product or content can change over time as the user interacts with it. This is often done via the use of animations, transitions, and sounds and is best represented by things such as menus popping out when selected, the screen scrolling or flicking between pages as users navigate it, or having visual or sounds to alert users when actions have been done, something has changed, or tasks have been completed.
Behaviour	The 5th and final dimension is Behaviour and is concerned with how the previous 4 dimensions together encourage user behaviour and how the product reacts to the users' behaviours. This dimension plots the user journey and notes the type of actions

	they are compelled to perform and the order they do these actions each time they use the product.

The purpose of the 5 dimensions of Interaction Design is to understand the user journey of how to complete a task and to anticipate their actions and reactions in a real world scenario to make their user experience as fluid and seamless as possible (Interaction Design Foundation, 2021). Its application encourages greater usability and adoptability of a product by focusing on the 5 dimensions that make up a user's experience. By implementing these dimensions in product design, designers are able to avoid what is known as cognitive friction (Cooper, 2004), where users become stressed, confused and ultimately disdainful of a product due to it being too confusing or inconsistent to use. Cognitive Friction can be a major cause of problematic non-linear relationships as raised by Sociotechnical design (Cooper and Foster, 1971) and is especially important to consider as PwD can frequently experience stress and confusion as a result of the condition. Interaction design therefore plays significant focus on user involvement and observation and makes use of tools such as wireframes and prototypes as well as storyboarding, use-cases and personas in order to understand a user's processes and feelings when using a product (Fioretti and Carbone, 2007).

While Interaction design does encompass many dimensions and overlap with many design methodologies, one of its limitations is that it only covers a small part of the overall user experience design with a focus purely on the moment a user interacts with the product. Other methods such as Industrial Design (the process of designing physical products for mass production and usage), Visual Design (The use of lines, shapes, negative/white space, volume, value, colour, and texture in a product to be appealing to users), and Information Architecture (the design of items that will exist in shared information environments) offer significantly more in depth methodology and considerations for development and analysis compared to interaction design (Babich, 2019). All these methods would require far more involvement from participants as well as focus on the full lifecycle of the product, including adoption, extended use in home environments, long term support, and legal requirements. This is far outside the scope for the study to develop an initial prototype, though may be considered in future.

Finally, as the study plans to test multiple modalities of interaction including text, verbal, and voice, Interaction design is especially well suited for conducting the research. By following the 5 dimensions of interaction design, the study will be able to consider all modalities and observe user's levels of interaction. This combined with the co-design approach will allow PwD to be involved in all stages of the app development as well as all dimensions of its interaction, contributing fully to the design of the novel application prototype.

4.4 Software Development Life Cycle (SDLC)

The previous sections outlined the qualitative interpretivist approach used in this study and exemplifies the involvement of important stakeholders using co-design and interaction design to develop a novel application for PwD. The final part of this chapter will discuss the process used to develop the novel application.

Often referred to as the Software Development Life Cycle (SDLC), SDLC is the process of planning and outlining the series of steps required to develop a software solution that is time and resource efficient that also meets organisation and users expectations (Amazon Web Services, 2023b). There are many different SDLC methodologies to consider when developing software, with the consideration of a products lifecycle being a significant aspect of joint HCI and healthcare research (Blandford *et al.*, 2018).

Methodologies such as waterfall (Royce, 1987) and V-model (Durmuş *et al.*, 2018) follow a very strict linear process and are best suited when requirements are well established and predictable with limited chance of variation or change. Other methodologies such as Lean software development which prioritises efficiency and resource allocation (Poppendieck), and DevOps that focuses on developers and operations collaboration (Amazon Web Services, 2023a), are best suited when customer and user stakeholder involvement is not required. These approaches would therefore go against the person-centred and qualitative focus of the study and would be unsuitable to implement (Half, 2018). It would therefore be most appropriate to make use of a methodology that best aligns with the theoretical approaches.

4.4.1 Iterative Design

Along with waterfall methodology and spiral process model, Iterative design is one of the most well-known and established SDLC methodologies (Shylesh, 2017). Iterative design uses a cyclical model following a 3 step phase (Prototyping, Testing, and Analysis) which is repeated over multiple iterations, with analysis of the previous iteration feeding into the prototype of the next, refining features and increasing the fidelity of each prototype until a final product is produced (Gossain and Anderson, 1990). Unlike stricter methods where requirements are expected to be well defined, Iterative design begins with a limited selection of initial requirements which are then expanded and added to as each iteration proceeds. Stakeholders can also be included throughout each cycle, particularly in the testing phase, adding additional requirements or requests to each prototype. Such involvement from stakeholders and flexibility of requirements is vital in digital health solutions where physical and mental impairments common in patients can severely impact a software's accessibility and usability if patient's needs are not understood or even recognised (Henni *et al.*, 2022). This makes iterative design especially well-suited for HCI studies with recognition of such effectiveness recognised in both general (Nielsen, 1993) and healthcare settings (Blandford *et al.*, 2018).

Furthermore, Iterative Design is exceptionally well-suited for co-design studies for patients with dementia (Rodgers, 2017; Treadaway, Taylor and Fennell, 2018a; Tsekleves *et al.*, 2020; Fox *et al.*, 2022). One of the main advantages to an iterative design approach is that this method gives participants multiple opportunities to express their opinions over the course of the project, influencing the direction of development along the way. This is especially effective from a dementia user's perspective as the Aging Playfully study (Tsekleves *et al.*, 2020) recognised that some participants did not feel comfortable expressing themselves fully until the 3rd and 4th iteration of the study. Iterative design also allows stakeholders to have direct involvement from the very beginning of design production which Elizabeth Sanders states is of key importance in order to effectively define useful and valid requirements (Sanders and Stappers, 2008). Another benefit of an Iterative Design approach is that it can give participants a strong sense of pride and involvement. This is because they can see as the project develops and improves over time, knowing they provided a vital contribution during each step until it was completed. This was noted by Paul Rodgers during the 'Disrupting Dementia tartan' co-design project who found that several participants were able to recognise their own designs several months after the project had been completed and were delighted to see their finished product available for sale (Rodgers, 2017). Rodgers also noted that an iterative design method helped foster a natural rapport with participants who often expressed excitement when his team returned to continue with later iterations of the project. This is supported by the results of the Aging Playfully study which concluded that researchers should spend at least 6-8 weeks getting to know participants and caregivers before running a workshop in order to build a healthy rapport and familiarity with them (Tsekleves *et al.*, 2020).

While the greatest strength of Iterative Design is that it allows for a large amount of involvement from stakeholders, this is also its biggest limitation. This method can be very time consuming and relies on a heavy commitment on behalf of the stakeholders to participate in multiple focus groups often over a long period of time. This issue can be mitigated by holding workshops in specified groups and treating their overall opinion as representative (such as a separate PwD and separate HCP group) but any significant changes to the makeup of the group (such as participants dropping out part way through the study) can affect the overall integrity of the Iterative design if people's opinions and beliefs change significantly. This could be particularly problematic in the field of dementia care, as 2 studies (McGoldrick, 2017a; Treadaway, Taylor and Fennell, 2018b) have shown participants with dementia unable to complete the study due to personal choice, ill health, or even death. Even in this situation, it does not mean research would have gone to waste. This was the case during Compassionate Creativity Co design study where one participant died during an earlier iteration of the design phase for creating a custom hug doll (Treadaway, Taylor and Fennell, 2018b). While the earlier prototypes developed were specifically for this participant, a new volunteer came forward to continue the project and was able to benefit greatly from the finished product. Another limitation of Iterative design is that the time in-between each phase can vary greatly, as time must be allowed for the designer to create prototypes. This can make planning the timeline very difficult and can lead to large or inconstant gaps in the times when participants are actively involved though making use of Agile methodology can overcome this issue. Finally, Ethics approval can be particularly problematic for an iterative design study, as it is unlikely full ethics approval will be granted for all the planned workshops if the subject of them is not defined well in advance, which is often not viable due to the changing nature of each iteration. To get over this issue, the Ageing Playfully study collected ethics approval and consent from participants, carers and HCP before each separate iteration though they did note that this did increase the workload for their team (Tsekleves *et al.*, 2020).

The only other SDLC that allows for this level of continuous requirement development and user involvement is the Spiral Process Model (Boehm, 1986) which follows a similar cyclical model to iterative design with its key differentiator being no definitive end to the project. The spiral model is therefore best suited for continuous product development which sits outside the scope of the prototype development especially as the spiral model is noted to be complex to manage and not suitable for risky or small projects (Shylesh, 2017) and does not have the proven track record with the population compared to iterative design.

4.4.2 Agile Methodology

The final SDLC to be discussed is Agile Methodology. The premise of the agile methodology is for a project to be completed in small increments known as sprints, with each individual sprint focusing on a specific aspect of development in which priorities can change over time (Dingsøyr *et al.*, 2012). This allows designers to be reactive to changing requirements, a necessity if they original requirements are not well defined at the start of a project (Royce, 1987). A project following an agile methodology will usually begin with the owner of the project creating what is known as a product backlog, an initial list of requirements for the project ordered based on priority. From the product backlog, the tasks with the highest priority are identified and added to a shortened requirements wish list known as the sprint backlog. This sprint backlog is then assigned to a team who will have a period (usually 2-4 weeks) known as a sprint to develop solutions for these requirements, often with frequent in-person meetings between team members known as scrums to discuss progress and challenges. At the end of the sprint, a review will take place amongst stakeholders and any completed work is presented and reviewed. During this review, new requirements may be added to the sprint backlog and older requirements will be either marked as complete, continuing, or moved back to the product backlog for later consideration. A new sprint will then begin with the process continuing until a final finished product is produced (figure 4).

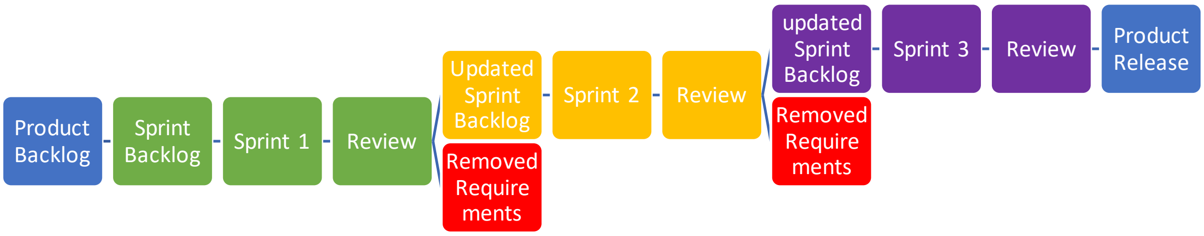


Figure 4 Representation of the Agile methodology process

Agile methodology has seen prolific use around the world in the past 20 years (Zippia, 2022) with even government organisations developing guidelines for its use (European Commission, 2021; Gov.UK, 2023). The ability to change the direction of a project by voting on new priorities during reviews allows the development to better reflect current opinions and trends directly from stakeholders, allowing for better representation of what the users need as well as identify and tackle small issues before they become more problematic (Half, 2018). Another advantage of the Agile methodology is that different tasks can be assigned to different teams simultaneously, allowing for a better allocation of resources and allow research, developing, and testing to all take place concurrently, with team members being updated during the scrum meetings, allowing them to react to new requirements being identified. This makes the agile methodology particularly effective when there are large teams or multiple stakeholders (Gov.UK, 2023).

The flexible nature of agile also allows it to be easily combined with other SDLC methodologies. The step-by-step nature of agile synergises well with iterative designs cycles, as each sprint of the agile methodology can be assigned to a separate cycle of iterative design, allowing multiple prototypes to be delivered on a higher frequency when compared to Iterative design alone or other SDLC methods. Another synergy is that each sprint aims to refine the overall requirements until a final product is produced, which is the same overall purpose of iterative design. Agile has also been shown to be effective when combined with iterative design and co-design in developing software for PwD (Fox *et al.*, 2022).

By far the biggest limitation of agile methodology is it requires a large amount of commitment from stakeholders over a long period of time. This is especially required for any stakeholders participating as part of the team scrums and sprints, often meaning strong relationships need to be established early on making this methodology better suited for organisations with closely aligned and well-established teams (Gov.UK, 2023). This requires strong leadership and management skills from whoever is in charge, as well as a high level of authority to ensure team members attend the reviews and scrum meetings. Agile methodology can also result in going off topic due to nature of changing requirements; the process can end up making it difficult to define how long the project will take until it is completed especially when compared to a more structured SDLC like waterfall (Shylesh, 2017).

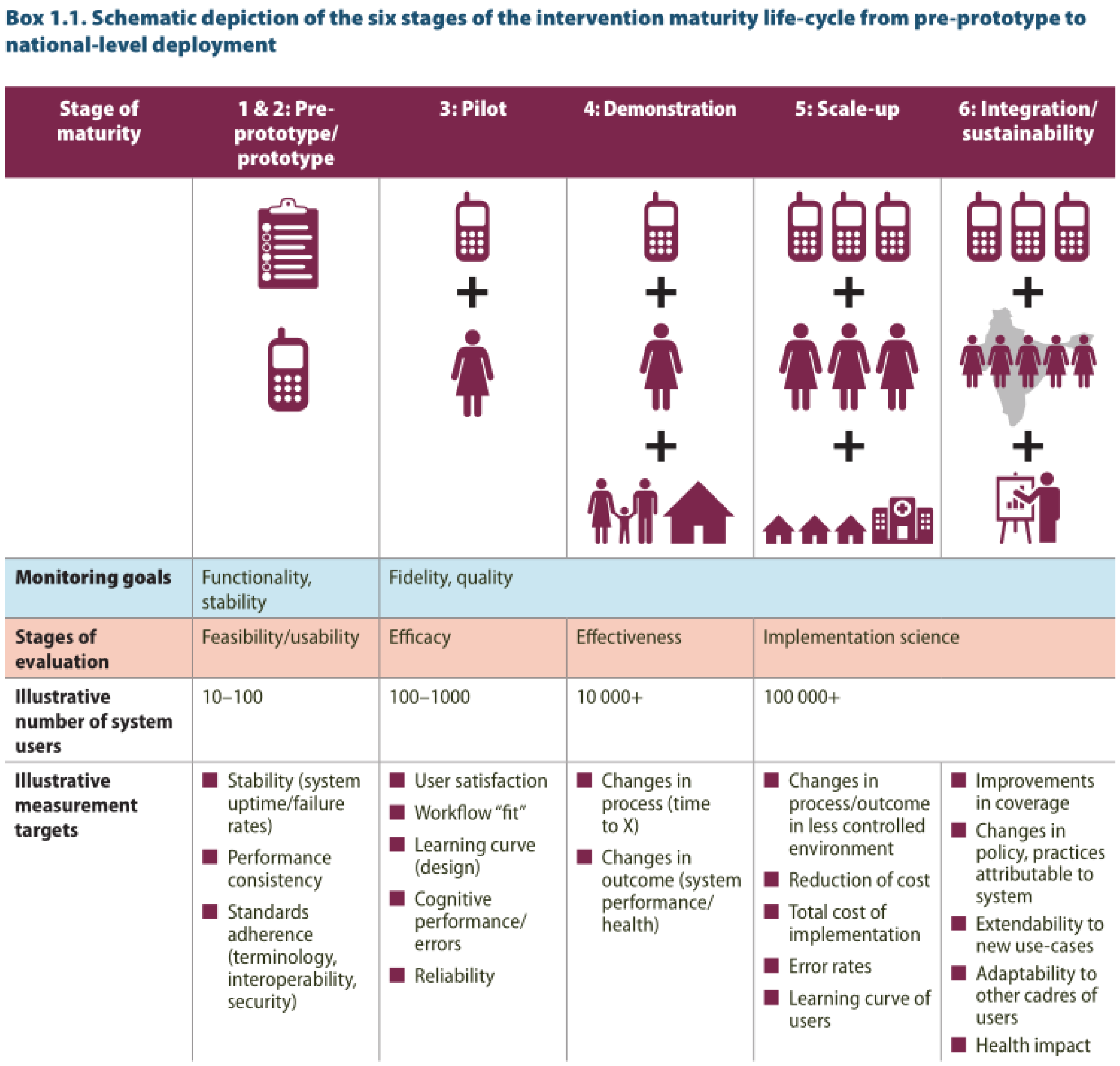
4.4.3 SDLC for the study

Following the discussion of SDLC, the study followed a combined agile iterative design approach. Iterative design allowed for the collection of continuous requirements from participants, allowing for the development of the prototype through multiple iterations from initial concepts to functioning prototype. Using Agile methodology, these iterative cycles were put into development sprints, with stakeholders enabled to prioritise features for the next cycle.

4.4.4 Healthcare Frameworks

With the design considerations set out for this study detailed in earlier sections, it is also important to have a framework to provide guidance on the development and evaluation of technological innovations with the context of a healthcare environment. For this study, the WHO Monitoring and Evaluating Digital Health Interventions Guide which was released in 2016 was selected. This framework was developed from a need of an increased level of scrutiny of new technological innovations and a way to evaluate and assess pilot programs as technology and digital innovations in healthcare around the world became more common. The framework provides a roadmap built on 6 stages of maturity (World Health Organisation, 2016) and sets out a range of monitoring goals, evaluation methods, user numbers, and illustrative targets for each stage so that researchers have a goal in mind for the number of participants and requirements needed (figure 5). One major advantage of the WHO framework is that it was designed with implementation at various stages of progress to be considered. Small scale pilot studies can make use of the early stages of the frameworks maturity where the scope for generating data and introducing new methods are less defined or not yet gathered allowing for an established start if research is to be continued. For established and more mature projects, the WHO framework allows them to skip these early stages and make use of later methods and goals.

As the study aims to co-design a novel application from the start, the study focuses mostly on the first 2 stages (pre prototype and prototype) of the WHO framework, focusing evaluation on the feasibility and usability of the application, with the goal being to develop a functional and stable prototype that performs consistently with the PwD end users and adheres to NHS and Alzheimer’s Scotland standards. This study therefore concludes with a summative evaluation workshop that will begin to bring features of the 3rd stage of maturity (Pilot) regarding user satisfaction, workflow fit, and cognitive performance.



Box 1.1. Schematic depiction of the six stages of the intervention maturity life-cycle from pre-prototype to national-level deployment

Stage of maturity	1 & 2: Pre-prototype/ prototype	3: Pilot	4: Demonstration	5: Scale-up	6: Integration/ sustainability
Monitoring goals	Functionality, stability	Fidelity, quality			
Stages of evaluation	Feasibility/usability	Efficacy	Effectiveness	Implementation science	
Illustrative number of system users	10–100	100–1000	10 000+	100 000+	
Illustrative measurement targets	■ Stability (system uptime/failure rates) ■ Performance consistency ■ Standards adherence (terminology, interoperability, security)	■ User satisfaction ■ Workflow "fit" ■ Learning curve (design) ■ Cognitive performance/ errors ■ Reliability	■ Changes in process (time to X) ■ Changes in outcome (system performance/ health)	■ Changes in process/outcome in less controlled environment ■ Reduction of cost ■ Total cost of implementation ■ Error rates ■ Learning curve of users	■ Improvements in coverage ■ Changes in policy, practices attributable to system ■ Extendability to new use-cases ■ Adaptability to other cadres of users ■ Health impact

Figure 5 Schematic of the 6 stages of the intervention maturity lifecycle from WHO's Monitoring and Evaluating Digital Health Interventions Guide (2016) Chapter 1, Page 4, Box 1.1

Other frameworks such as the MRC Complex Interventions (Medical Research Council, 2000) could have been selected however they were not developed specifically for the development and evaluation of technology based innovations unlike the WHO framework which was developed specifically for this purpose.

4.5 Conclusion

This chapter has reviewed various theoretical frameworks and methodologies that were considered for this research study. The study followed a qualitative Interpretivist approach that makes use of sociotechnical design that puts people's perspectives and experiences first. Stakeholders will co-design a novel application following interaction design to define the usability and accessibility of such an application. This application will be developed iteratively over multiple development cycles, from initial concepts to functional prototype, using Agile methodology to prioritise features for development. The functional prototype will then be evaluated by all stakeholder groups following the stages outlined by the WHO framework. All of this will directly influence the methods used in the study which will be discussed further in the next chapter.

5 Prototype Development Methods

As outlined in chapter 4, the study followed a qualitative, interpretivist approach informed by Co-Design and interactive design principles. This chapter will begin discussing and detailing the methods used to address the research questions posed. The study was conducted in 2 phases, the prototype development phase, and the summative evaluation phase. Chapter 5 presents the methods used for the prototype development phase, where prototypes for the application were codesigned and developed iteratively over multiple workshops with a core group of PwD, from initial concepts to functional prototype and to answer the first 3 research questions. It will also cover the impact COVID had on the study design, how Patient and Public Involvement and Engagement (PPIE) influenced workshop development, as well as sampling, identification, and recruitment of stakeholders. Chapter 7 will discuss the methods used in phase 2 of this study being the summative evaluation that aimed to answer research question 4.

5.1 Objective of the Prototype Development Phases

As outlined previously, the aim of this study was to co-design, develop, and evaluate a novel digital application to enable PwD to regularly self-report QoL PROMs. To achieve this, the following research questions (outlined in chapter 1.2) were set:

1. What digital technologies have been used to enable PwD to self-report QoL data?
2. What features, questions, and modalities do PwD prefer when interacting with a novel digital application that enables them to self-report QoL PROMs?
3. What are the design considerations for a novel digital application to enable PwD to self-report QoL data via PROMs?
4. What are the perceptions of PwD, IC, and HCP on the feasibility, utility, and acceptability of a functional prototype that enables PwD to self-report QoL data via PROMs as part of routine care?

As previously outlined, the Prototype Development phase is set to answer research questions 1-3 with summative evaluation phase set to answer research question 4.

5.2 Impact of COVID

The COVID pandemic had a substantial impact on the study and associated workshops for multiple reasons. This resulted in significant delays and changes to the envisioned study and multiple pragmatic changes to adapt to the changing conditions (Table 5).

The first impact was the cancellation of in-person workshops and the move to an online environment. The co-design workshops were initially envisioned to be conducted entirely in person with the first workshops originally planned for summer 2020. At the time the IRAS ethical approval was submitted and approved by REC, the Scottish government had published its 'route map' for easing lockdown restrictions and stakeholders had full confidence that in-person workshops could be conducted by August/September 2020 as schools and universities had been reported to reopen. Being pragmatic, we also agreed with stakeholders to switch to a hybrid approach, with vulnerable participants nervous of attending in person could be accommodated remotely. This approach was confirmed in August 2020 and received IRAS approval in October 2020 with the changes approved following IRAS COVID guidance without the need for substantial review. This hybrid approach did not materialise however, as by January 2021 Scotland returned to full lockdown and in-person workshops had to be abandoned in favour of an online only approach which required significant changes to the research protocol and substantial approval from REC which were not approved until summer 2021.

The 2nd major impact was the working relationship with the NHS partners and their changes, processes, and priorities as they adapted to the COVID pandemic. This research relied heavily on the NHS for oversight and recruitment due to working with a vulnerable population (PwD) which required REC ethical approval to attain. Throughout the covid pandemic, the NHS had to deal with unprecedented demand, changes, and pressures meaning frequent changes to policy including location access and work prioritisation that the study had to adapt to. This included significant changes to the IRAS amendment procedure, which was overhauled in December 2020, though the most significant changes were from R&D which introduced and updated its risk assessment, Organisation information document (OID) and schedule of events (SoE) policies which took additional resources and time to complete and approve, especially as responses from R&D and other partners were delayed due to their other priorities. This also impacted recruitment as the NHS partners could not commit as much time to recruitment as initially planned. Acting pragmatically, amendments were applied for to widen the recruitment pool and leverage the non-NHS partners to recruit PwD and IC as well as the extension of the study to include a summative evaluation cycle in 2022 to increase participation of all the stakeholders.

Another major impact was the impact switching to an online only environment had on recruiting participants. As mentioned in previous chapters, PwD tend to be in the oldest demographics of the society as well as the least capable with using technology, with many needing support or assistance using technology. Many participants who had initially agreed to take part in the workshops now declined as they could not foresee themselves being able to handle the additional pressures of conducting online. The recruitment partners reported similar feedback and responses from likely candidates they approached, with one charity partner refusing to approach participants if it was online only.

The final major impact was lack of access to necessary recording equipment due to the extended closure of the university. With staff working remotely with the necessary equipment, support staff working remotely and unable to access the storage lockers and change in staff who knew were equipment was located all impacted the accessibility of such equipment. Secondary Authorised recording equipment was not available in time for the first cycle of workshops. Technical issues with the primary recording equipment resulted in no usable recordings of cycle 1 workshops during this phase.

Table 3 Timeline of notable events during the COVID pandemic

Date	Event	Impact on the study	Mitigating action
23/03/2020	UK wide stay-at-home order first announced. First nationwide lockdown begins for 3 weeks. This was extended an additional 3 weeks until 07/05/2020.	No impact as the study was not submitted yet and lockdown was due to end before submission	N/A
05/05/2020	IRAS Submitted to NHS REC	In-person study was pending approval	N/A
11/05/2020	Separate rules announced for the 4 UK nations. A Four-phase "route map" for easing lockdown restrictions in Scotland was introduced 21/05/2020	Study would need to be postponed due to continued lockdown until late summer.	Hybrid approach began to be considered
18/06/2020	IRAS approved by NHS REC	The in-person study was approved to begin	N/A
26/06/2020	R&D requires updated Organisation information document (OID) and a schedule of events (SoE) due to changes in policy because of the COVID pandemic.	R&D documents needed to be re-completed to conduct the in-person study	R&D documents completed and submitted 07/10/2020

03/08/2020	Confirmation with stakeholders to switch to hybrid/flexible approach to workshops	The study would swap from in-person to a hybrid approach	N/A
21/10/2020	IRAS reapproved (20/WM/0149/AM01). Amendments covered by their COVID guidance	The hybrid study was approved to begin	N/A
21/10/2020	R&D approve documentation and IRAS approval. Recruitment can begin pending updated Risk assessment.	Recruitment for Hybrid study could begin	Risk Assessment submitted to R&D on 06/11/2020
03/12/2020	IRAS amendment system overhauled https://www.hra.nhs.uk/about-us/news-updates/weve-updated-our-amendment-tool-on-iras/	Future amendments would need to be submitted using the new system and protocols.	N/A
07/12/2020	R&D risk assessment policy changes due to fear of rising COVID cases.	Recruitment for hybrid study is delayed indefinitely	Online only approach considered
04/01/2021	Scotland returned to full lockdown. Study & recruitment to be overhauled to online only, significant amendments required.	In person and Hybrid approach now unviable.	Online only approach developed
26/07/2021	1st amendment submitted. (UEC20/16/AM01)	Study would now be online only	N/A
31/07/2021	Original indemnity documents and study period expired	Study could no longer be legally performed	Updated indemnity documents received 18/08/2021
04/08/2021	1st amendment approved. (UEC20/16/AM01)	Online study could now be conducted	N/A
18/08/2021	2nd amendment submitted and approved (UEC20/16/A2)	Outdated study period and documents updated	N/A
10/11/2021	1st workshop began	N/A	N/A
08/04/2022	3rd amendment submitted and approved (UEC20/16/A01)	Allowed greater involvement from HCP/IC for the summative evaluation workshop	N/A

5.3 Patient and Public Involvement and Engagement (PPIE)

To ensure that the study methods were suitable for PwD, several Patient and Public Involvement and Engagement (PPIE) activities were conducted. PPIE is a process that involves patients as lay advisers to ensure that research is acceptable to people like them (Louise and Annette, 2019). PPIE is vital for co-production and co-design as it allows professionals and designers to collect the knowledge, skills, and experience they do not have or may overlook from the public who know their challenges best (Wettergren Karlsson and Janssens, 2023). This enables methods, tools, and technologies to be influenced early in the development process. The PPIE activities took the form of multiple informal in-person and online meetings with PwD, IC, and HCP. Participants were asked about their expectations for the study, their thoughts on the methods, and the viability of commitments being asked, as well as ideas and features they would like to see implemented. These PPIE activities helped influence the study design by ensuring the proposed methods were suitable for the target demographic and were used to develop the initial product backlog that influenced the first set of prototypes.

5.4 Study and Workshop Development

Following Iterative design methodology, workshops followed a 3-step iterative process consisting of prototyping, testing, and analysis (figure 6). This process was repeated over 4 cycles as the prototype was developed from initial concepts to fully functioning prototype. For each of these steps, explicit methods have been used to develop the processes needed for each step of the cycle.

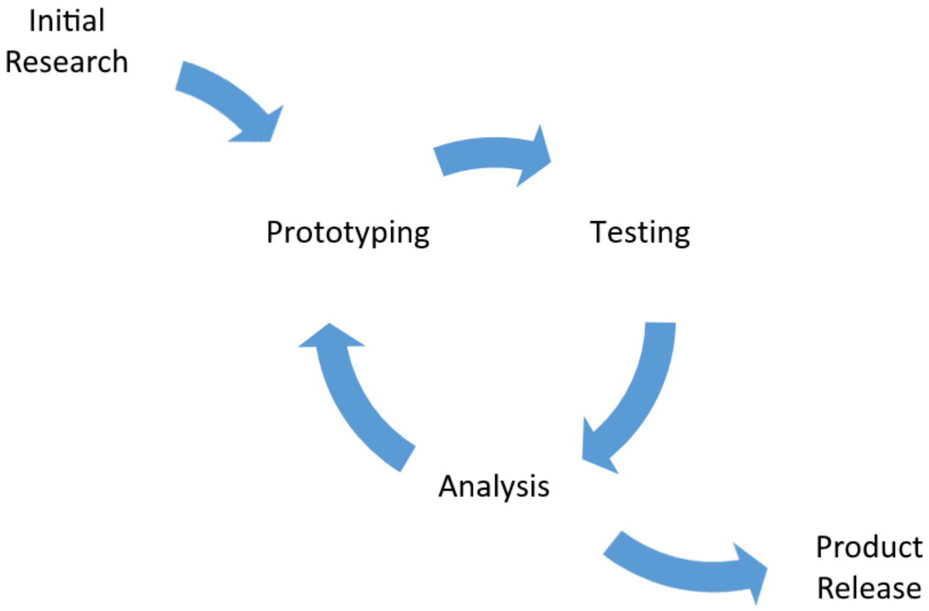


Figure 6 Iterative design model

Following Agile methodology, as detailed above, the first step of the study involved initial PPIE research where a Product Backlog was developed with stakeholders of the project that will set out the initial set of requirements and expectations of the product. During the first step of the iterative cycle, simple prototypes were created from the product backlog. These are referred to as ‘low fidelity’ prototypes (LFP).

These LFP were then presented to the target end users at workshops during the second testing step with opinions, criticisms, and recommendations being gathered for analysis during the third step. The designer would then produce new improved prototypes based on this feedback which would then be presented for testing during the next iterative cycle. Once a consensus was reached between the various stakeholders on what the requirements are and if they were pleased with the design so far, the designer then restarted the process by developing the LFP into higher fidelity prototypes known as Wire Frame prototypes (WFP). These were a more interactive model where users could get a feel of how the basic features of the product would look and function. This once again was presented to stakeholders for testing and analysis and when approved, High-Fidelity Prototypes (HFP) were produced which would add details to the overall layout, design, and usability of the product before being presented to stakeholders again (Figure 7)(Abraham, 2016). The overall goal of iterative design is for each iteration to refine the product over time. This can be repeated multiple times until a final product is produced.

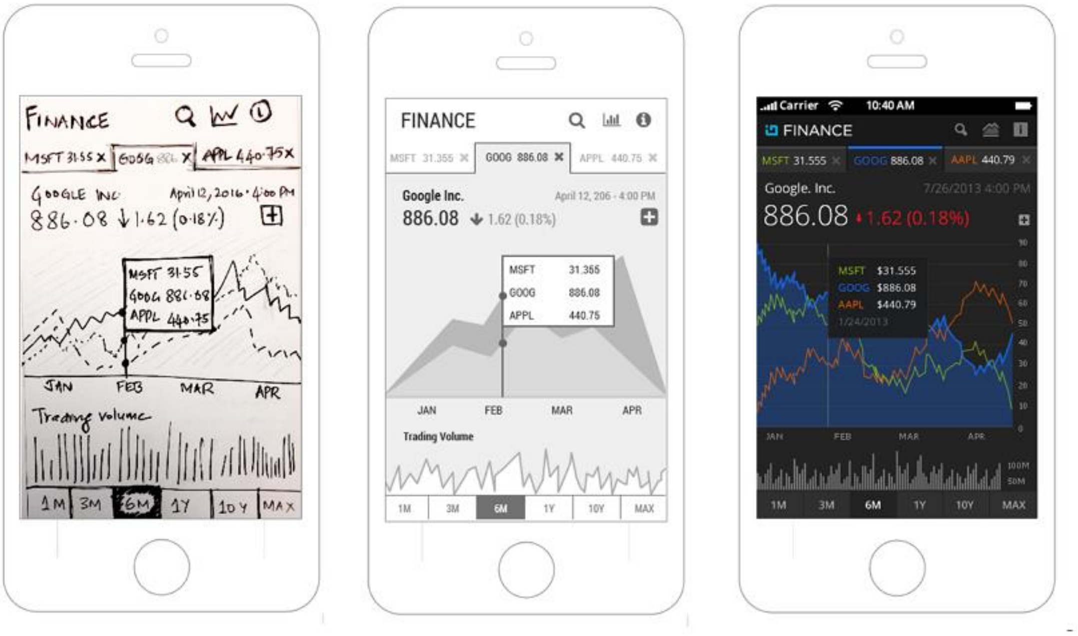


Figure 7 example of a LFP, WFP, and HFP for a finance mobile app. Abraham 2016 'Tackling Fidelity when prototyping'. Figure 1

5.5 Stakeholders

Stakeholders were the central focus for much of the research study as understanding their opinions and concerns helped to define their requirements. Understanding the stakeholder's requirements would allow for the creation of a technological intervention that is easy to use, quick to complete, and collects useful information for reports that can be used in determining future care decisions based on insight from all stakeholders involved. At the start of the Initial Research step, a Power Interest matrix (Ackermann and Eden, 2011) was created to identify important stakeholders in the project and the influence they may bring. The concept of a Power Interest matrix is based on 2 independent scales, Power and Interest, that all possible stakeholders are assigned on. Power indicates a stakeholder's ability to make meaningful change in processes, whether this be via decision making, funding choices, cuts, or changes and is often held by more senior or professional level stakeholders such as managers and leaders. Interest indicates a stakeholder's personal resolve to see changes be made and improvements to processes and is often highest amongst those most closely involved in the process or prioritise the process such as customers, clients, or workers. By mapping stakeholders to this process, you can identify what kind of stakeholder they are and what level of involvement they should have in the projects based on 4 archetypes of stakeholders, Players, Context Setters, Subjects, and Crowds (Figure 8). Power Interest Matrix is a particular useful tool at defining stakeholders when dealing with fuzzy logic (Poplawska *et al.*, 2015) that is commonly associated with HCD projects (Sanders and Stappers, 2008).

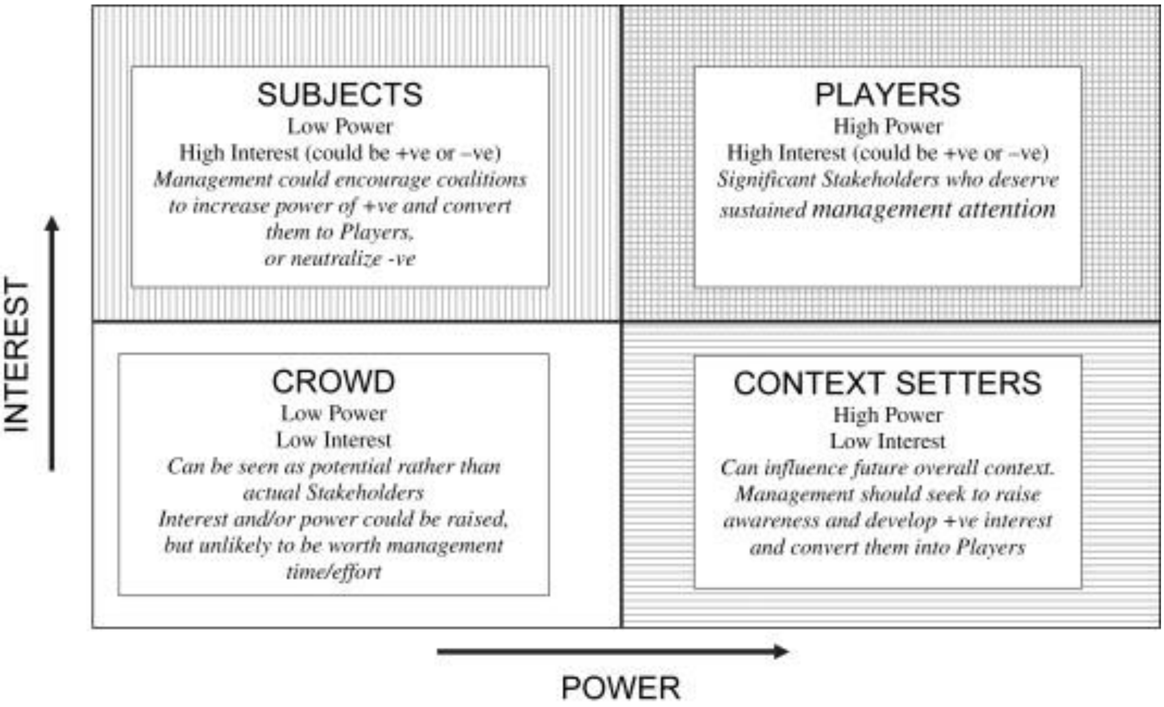


Figure 8 Power Interest Matrix. Ackermann & Eden, 2011. Figure 1

Using the Power Interest Matrix, a total of 3 stakeholder groups were identified whose perspective needed to be understood to define the study requirements (Table 3 & 4). The stakeholder groups identified are:

- People with Dementia (PwD)

- Informal Carers (IC)
- Healthcare Professionals (HCP)

Table 4 Power Interest Matrix for the stakeholders

Stakeholder	Power	Interest	Reason
Players People with Dementia (PwD)	High	High	PwD are the primary user of the app, without their cooperation, there is no app. Therefore, they will have the most interest and influence in the app development cycle and will be heavily involved in all phases.
Context Setters Healthcare Professionals (HCP)	High	Low	HCP hold significant power in whether the app is adopted in practice as well as the primary recruitment source. However, their interest is minimal as they have other priorities in their roles so their involvement will be limited to the evaluation phase.
Subjects Informal Carers (IC)	Low	High	IC have limited power compared to the other stakeholders regarding development and adoption though will have significant interest alongside PwD as if the app is successful, it could take a significant burden of them or burden them greater if done poorly.
Crowd N/A	Low	Low	As this is a relatively small-scale study, no crowd stakeholders have been identified for inclusion.

Table 5 Definition of the 3 Stakeholder Groups

People with Dementia (PwD) - Players	
Criteria for Inclusion	People who have had received a clinical diagnosis of mild-moderate dementia (criteria will be determined by HCP) who currently reside in Scotland. They will be above the age of 18 and will have to provide consent at the start of each interview/focus group throughout the case study. They may live alone though they will be expected to receive some degree of support from an informal carer/s who may also be asked to participate in the case studies
How will they participate?	During the PPIE phase, PwD will participate in informal discussion. During cycle 1-4 of the development phase, they will be asked to test the app prototypes in

	a workshop environment. During the summative evaluation phase, they will be asked to evaluate the prototype in a workshop environment.
How will their involvement help?	Their feedback will be used to develop the novel application, including the format and delivery of PROM questions, the type of questions asked, the frequency and method questions are requested, and the overall user interface of the app.
Considerations required?	This group may likely require support from IC and/or HCP during all interviews/ focus groups. Ethics approval and consent will be collected frequently before interviews and focus groups. Any approval and involvement will include input/supervision from IC and/or HCP.

Informal Carers (IC) - Subjects	
Criteria for Inclusion	Family members/friends (aged 18+) who provide some level of informal care to a PwD, whether full or part time.
How will they participate?	IC will be invited to patriciate alongside PwD in a support role during Interviews and workshops during PPIE and phase 1-4 if PwD request it. Their perspective may be collected alongside PwD, and they may also be asked to give feedback on how workshops went, and they can be improved. During the summative evaluation phase, they will be asked to evaluate the prototype in a workshop environment.
How will their involvement help?	They will offer support which may allow PwD to take part in situations where they would otherwise be unable to take part. Their insight will also help in the development of reports that are easy to use and comprehend for people with no formal healthcare training. IC may also be used as a proxy to PwD who may not be able to complete PROMs.
Considerations required?	An assumption will be made that IC will have no formal health knowledge or training in understanding health reports or completing PROMs. Also, if there are conflicting reports between PwD and IC, a discussion will take place to determine the source of the conflict and how the results can be used to make healthcare decisions.

Healthcare Professionals (HCP) - Context Setters	
Criteria for Inclusion	A trained professional who either primarily works in dementia or has significant expertise of working in the field. This will involve HCP who both specialise

	specifically in dementia care and those who have had patients with the condition as well as outreach teams and staff working for dementia charities.
How will they participate?	HCP will help us recruit participants prior to the study. During phase 0, HCP will participate in interviews and Focus groups independently from PwD and IC to help ascertain requirements and best practices. During Cycle 1-4 an HCP will supervise each workshop to ensure proper conduct is attained. During the summative evaluation phase, they will be asked to evaluate the prototype in a workshop environment.
How will their involvement help?	They will give us an insight into the current systems available with the aim of making the app compatible with existing implemented technologies and systems. Their knowledge will also allow us to develop PROMs that collect useful medical information that can be used for future healthcare decisions.
Considerations required?	HCP will likely have many patients and other commitments to manage so their involvement will be considered very limited so that any updates given to them will be optimised into a summary format that may be less frequent than other stakeholders.

5.6 Sample

Non-probability convenience sampling was used for this study, in particular convenience sampling. This is a method of sample selection that uses non-random ways to select a group of people to participate in research, focusing on gaining information from participants who are ‘convenient’ for the researcher to access (Qualtrics, 2022). This sampling approach was selected due to the difficulties in recruiting due to a number of factors including: the covid pandemic which put pressure on the recruitment partners and participants who had greater priorities; changing healthcare and governmental guidelines which made in person unviable during the recruitment phase; and the switch to an online environment which discouraged many participants and recruitment partner groups who found the need to use technology as a barrier or an inconvenience. Over the course of the study, a maximum of 30 participants (10 for each stakeholder group) was pursued with a priority on recruiting PwD as the primary user. 10 was chosen as it was the minimum recommended illustrative number of system users outlined by WHO’s Monitoring and Evaluating Digital Health Interventions Guide (World Health Organisation, 2016). Participants could then be split into groups with workshops limited to small groups of 5-7 participants as recommended by Nielson (Nielsen, 1994) as well as the average number of participants during the Rodgers study (Rodgers, 2017).

5.7 Setting

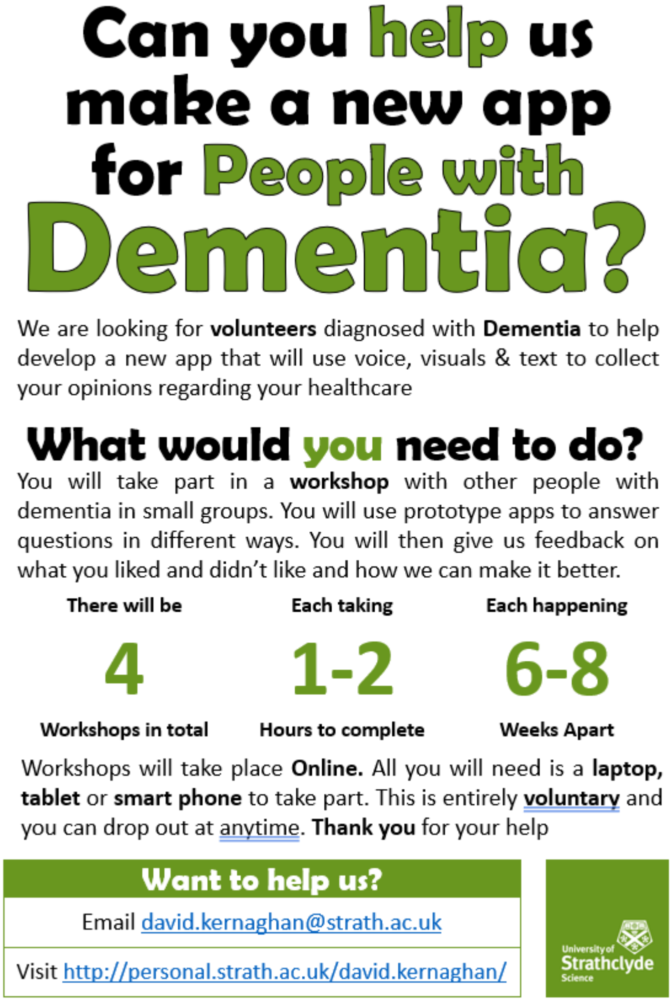
The original ethical application sought to conduct workshops in person at Alzheimer's Scotland Kilmarnock Dementia Resource Centre or at NHS Stirling Community Hospital. Government sanctioned lockdown restrictions meant that this was not feasible and a switch to an online environment was developed and approved by the research team. Workshops where therefore conducted online using video conferencing software. The choice of software was limited by the universities list of approved software though participants were given a choice of which software they preferred and were most familiar with. Microsoft Teams was therefore chosen as the primary video conferencing software. Workshops were conducted at a time that best suited participants which was chosen to be Friday afternoons which coincided with the groups regular weekly social group. This allowed us to avoid the phenomenon of 'Sundowning' (Menegardo *et al.*, 2019) and helped us to establish a routine so that participants were expecting workshops every 4-6 weeks. Participants joined an online video call using their own preferred devices (computers and tablets) from the comfort of their own home.

5.8 Identification and recruitment of participants

For the workshops, multiple organisations were approached to assists with identifying and recruiting participants, including the NHS (NHS Forth Valley) and various dementia charity organisations (Alzheimer's Scotland, SDWG, Town Break, and Dementia Circle). In order to work with NHS Forth Valley, NHS Integrated Research Application System (IRAS) ethical approval was sought and granted (appendix 2), details of which is covered in the ethics section of this chapter.

The original plan for recruitment was for researchers to attend multiple events (such as the dementia café) hosted at Alzheimer's Scotland centre in Kilmarnock and use this opportunity to build rapport with PwD and IC and encourage them to take part in an in-person workshop. Additionally, any volunteers recommended to the research team by HCP working at Stirling Community Hospital would also be considered for inclusion. During the early stages of the study, the focus was on recruiting volunteers to attend in person workshops at either the Kilmarnock resource centre or Stirling Community Hospital as these were the primary contact point for Alzheimer's Scotland and NHS Forth Valley Respectively.

As mentioned, this was not possible because of the COVID pandemic and the move to online. Instead, possible NHS participants were nominated by the HCP at NHS Forth Valley. These possible participants were given details of the study as well as an introductory flyer (figure 9) during routine healthcare visits to their HCP. Participants who were interested where then contacted by a member of the research team to discuss in more detail the study via phone call and offered participant information sheets and consent forms via email (appendix 3). Alzheimer’s Scotland followed a different process, where the team were put in contact with various charity organisations such as the SDWG, Town Break, and Dementia Circle, who were hosting online events for their members through lockdown. The researchers attended many of these events to build rapport with participants and offer them the chance to participate in the study. Participants who were interested were then contacted by the contact at that charity with Participant information Sheets and Consent forms either sent via email or completed during a video call.



Can you help us make a new app for People with Dementia?

We are looking for **volunteers** diagnosed with **Dementia** to help develop a new app that will use voice, visuals & text to collect your opinions regarding your healthcare

What would you need to do?

You will take part in a **workshop** with other people with dementia in small groups. You will use prototype apps to answer questions in different ways. You will then give us feedback on what you liked and didn’t like and how we can make it better.

There will be	Each taking	Each happening
4	1-2	6-8
Workshops in total	Hours to complete	Weeks Apart

Workshops will take place **Online.** All you will need is a **laptop, tablet** or **smart phone** to take part. This is entirely **voluntary** and you can drop out at anytime. **Thank you** for your help

Want to help us?

Email david.kernaghan@strath.ac.uk

Visit http://personal.strath.ac.uk/david.kernaghan/

University of Strathclyde Science

Figure 9 Recruitment Flyer

The study was limited to include people with a mild to moderate diagnosis of dementia following advice from both NHS and Alzheimer’s Scotland. HCP identified this group to be most suitable to take on the long-term burden of co-designing a technological intervention. Considerations could be made in future iterations of this study to open up the study to include people with late-stage diagnosis of dementia, as studies has shown they can contribute meaningfully to co-design (Treadaway, Taylor and Fennell, 2018a) though this is currently out of the scope of this study. For all interviews and focus groups, PwD had the option to be accompanied by IC or HCP. All workshops were overseen by an HCP and one of the university supervisors to ensure all participants were comfortable and safe. All participants taking part were asked to provide additional details via an online questionnaire collecting metrics such as: their age, gender, living arrangement, and familiarity with technology. This provided additional insight into whether such aspects affect the methods of interaction participants take when providing PROMs, such as does a certain group prefer voice over images.

5.8.1 Recruitment Process

Members of the study team liaised regularly with HCPs who identified eligible participants during meetings or contacted from lists of records. Eligible participants were informed of the study during meetings by HCP who briefly outlined the study to the patient and obtained their verbal consent to be approached by a member of the study team responsible for recruitment. HCP were also able to recommend other participants they felt would be suitable for the study. Once consent to contact had been received, a member of the research team arranged a meeting with the possible participant via video or phone call.

During this meeting, a short introduction was performed outlining the purpose of the study and what will be expected from participants. This presentation took the form of a PowerPoint presentation or verbal discussion. After the introduction, participants were given a Participant Information Sheet and a consent form to read and complete. If the participant did not wish to give their consent on the day of this meeting, contact details were taken so that the researcher can contact them at a later date to confirm their consent, such as if participants preferred to give verbal consent on the day of the workshop or needed more time to think it over. The researcher was available during the meeting to answer any questions participants may have and IC would be recruited alongside PwD, with any IC that accompany PwD to meetings also informed that they can partake in the study alongside the PwD.

Before each workshop, each participant was contacted a few days before to ensure they were still happy to participate in the study. At the start of the first workshop, participants were presented with an introductory presentation defining that the purpose of the study was to develop a functional prototype to collect PROMs and that during the workshops they would be tasked with trialling various prototype concepts before voting on features to prioritise. At the start of each workshop, PwD and IC were both told what activities they will be taking part in and asked if they were still happy to participate or if they have any concerns. This ensured participants were fully and consistently aware of what was expected of them during the study, as well as the opportunity to exit from the study at any time. If any concerns were raised by HCP to researchers regarding the suitability of a participant, the decision to include them will be made by the HCP using their training, knowledge, and experience.

HCP were responsible for identifying participants using their knowledge and case notes as they would normally have access to patients' case notes which was used to evaluate eligibility. Participants were only identified using the inclusion and exclusion criteria listed below and had their eligibility checked by members of their HCP team. On deeming a participant to be eligible for recruitment, the HCP checked the records for information regarding a person's age, diagnosis, severity, and type of dementia to compare to the inclusion/exclusion criteria. It was then the HCP's decision to approach possible participants and who first introduced the study to the possible participant and, only if the person is receptive, will they be introduced to a member of the study team for further information.

5.8.2 Inclusion Criteria

The following inclusion criteria applied for all participants to be recruited to any part of the study:

- Aged 18 years or over.
- Able to read, write and understand English.

The following inclusion criteria applied for participants defined as People with Dementia (PwD):

- Aged 65 years or over.
- Diagnosed with mild to moderate dementia (defined by the 5 Pillars model) as confirmed by a member of the multidisciplinary healthcare team.
- Is receiving support for Dementia from either the NHS (Forth Valley), Alzheimer's Scotland or a similar organisation.
- Physically/psychologically fit to participate in the study as confirmed by a member of the multidisciplinary healthcare team.
- Is recommended to us by an appropriate professional.

The following inclusion criteria applied for participants defined as Informal Carers (IC):

- Is providing some level of support or care for a PwD.
- Is not employed to supply such support to a PwD.

The following inclusion criteria applied for participants defined as Healthcare Professional (HCP):

- Is a member of the multi-disciplinary team caring for PwD.
- Works in a hospital, clinic, or community setting.

5.8.3 Exclusion Criteria

A Participant would be ineligible to participate in the study if they were:

- Unable to provide informed consent.
- Unable to communicate sufficiently well in English.
- Has been diagnosed with severe / late-stage dementia (defined by the 8 Pillars Model).
- Is diagnosed with a form of dementia that makes them unsuitable for the study (Some forms of dementia can cause audible hallucinations or sensitivity to lights, symptoms like this would call for exclusion of the participant) as determined by a member of the patient's multidisciplinary team.
- If identified by a member of the patient's multidisciplinary team to be unsuitable for the study.

5.9 Ethics

Due to the vulnerable nature of the core demographic (PwD) the study was conducted with the continuous oversight of expert professionals in the field. To have such professional involvement, full NHS IRAS ethical approval was sought. This required all the researchers to complete various documentation and risk assessment via NHS Forth Valley Research and Development (R&D), attain research passports and indemnity documents from the university (University of Strathclyde), as well as submit the entire study protocol via IRAS to NHS Research Ethics Committee Coventry and Warwickshire (REC) for their professional consideration. The study protocol was granted favourable opinion on 18/06/2020 by NHS IRAS (IRAS ID: 273039). This allowed recruitment via the NHS as well as to conduct the study with professional oversight and involvement. Full university ethical approval was also granted upon receipt of NHS ethical approval.

5.9.1 Ethical consideration

The progressive nature of dementia combined with involvement an older demographic (Wittenberg, 2019), high caregiver burden, and issues around consent poses unique ethical challenges around dementia research (Chandra *et al.*, 2021) that requires significant ethical consideration to be considered. The entirety of the study was overseen by NHS professionals to ensure highest standards and provisions were met. Following NHS protocols, no significant ethical, legal, or management issues were identified as arising from the study. None of the processes involved were expected to result in any participants feeling overwhelmed or upset, and participants always had the opportunity to withdraw from the project at any time.

During the study, participants and researchers worked closely together as equals in the co-design process, communicating and working towards a common goal. In situations where there was a possibility that participants may have become more anxious because they are called to reflect more on their condition and what help may need required, HCP were on hand to offer support and documents provided to participants before the study signposted organisation that could provide additional support. The study team were also well experienced in communicating with patients about their symptoms and were adept in identifying when patients were struggling with participation.

5.9.2 Amendments

Due to the changing NHS protocols and situations that arose during the covid pandemic, multiple amendments had to be submitted to continue the study safely and ethically (appendix 4). The most significant amendment was moving to an online environment for the online workshops as government sanctioned lockdown restrictions did not permit us to run the case study as is.

An initial amendment (20/WM/0149/AM01) to enable a hybrid approach was approved by REC on the 21/10/2020 though in the transition to an online only environment, significant changes were necessary to the protocol (UEHCP20/16/AM01) which was resubmitted to REC for substantial approval which was approved on 04/08/2021. A further amendment (UEHCP20/16/IC1) was also submitted to REC because of expired documents and permissions which was approved on 18/08/2021.

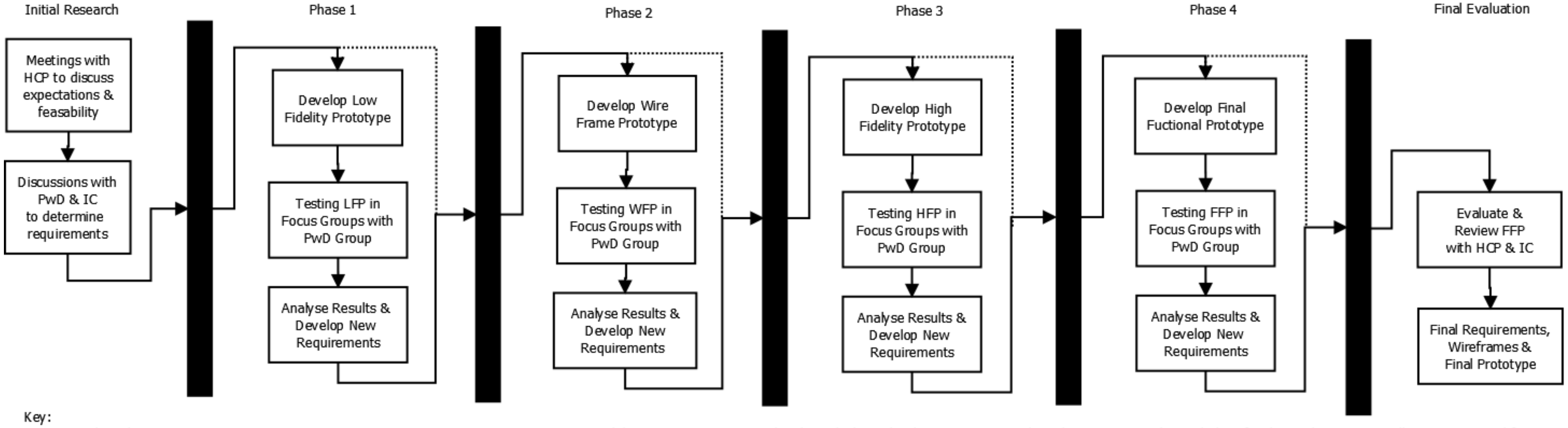
In addition to the REC amendments mentioned above, additional extensions were required for the letter of access and research passport via R&D. Finally, a separate university ethical approval application was submitted to expand the recruitment pool as the move to an online workshop deterred many possible participants from taking part in the online workshops meaning not enough PwD participants were able to be recruited for the study using only existing contacts.

5.10 Prototype Development Phase Overview

As mentioned, the Prototype Development cycles aimed to co-design multiple prototypes for a novel digital application directly with PwD through multiple iterative design workshops. Participants would be able to directly contribute to the look, design, and functionality of the application as well as the type of PROM questions that would be asked, the frequency they will be collected, and the modality of interaction. During each workshop, participants were tasked with answering a selection of questions using a variety of different prototypes that made use of multiple modalities including text, visuals, and voice. Responses were recorded and analysed, with their feedback being used to develop new prototypes that were presented to participants in the next workshop.

Prototype Development cycle consisted of interlinked iterative cycles: An Initial PPIE Research phase and 4 Iterative Design cycles. The Initial research consisted of PPIE discussions with all stakeholders to discuss the overall expectations and limitations of the project. This was used to develop a list of requirements known as the product backlog when following an agile methodology and was especially important for developing the initial set of prototypes as the COVID pandemic prevented the creation of paper prototypes that were initially envisioned. With the initial product backlog created, the next 4 phases consisted of 3 agile sprints each: development, testing and analysis (Figure 10).

- Cycle 1 focused on the development, testing and analysis of a low fidelity prototype (LFP).
- Cycle 2 developed the LFP into a wireframe prototype (WFP),
- Cycle 3 developed a high-fidelity prototype (HFP).
- Cycle 4: Culminated in a FFP (FFP).



Key:
PwD - People with Dementia
IC - Informal Carers
HCP - Health Care Professionals

Low Fidelity Prototype - concept sketches which can be drawn on paper and used to come up with initial ideas for the applications overall appearance and features.
Wireframe Prototype - a digital version that shows the skeleton and layout of menus and elements in the application and how they interact between pages.
High Fidelity Prototype - a digital revision that aims to replicate a functional app and styling that offers a high level of interactivity and refinement.

Figure 10 Process Flow Diagram of the Prototype Development Phase

5.10.1 PPIE Investigation Phase

As discussed previously, the purpose of the initial research phase was to identify through PPIE the various stakeholders that would be involved, build up a rapport with them, and gather their requirements for a novel digital application for collecting PROMs from PwD. PPIE investigation was done informally as a way of introducing the study to likely participants including PwD, IC, and HCP. This was primary done via informal semi-structured meetings with separate stakeholder groups, allowing for participants to voice their honest opinion. Special care was taken to speak directly with PwD during these meetings, with questions asked directly to PwD, though IC and HCP were on hand to offer support if needed. The meetings were performed in groups for stakeholders at their preferred location, often as part of a social event such as the dementia café lunch meeting, with most interviews taking place in person at Alzheimer's Scotland Kilmarnock Dementia Resource Centre or at Stirling Community hospital. Some meetings were conducted online. A selection of open-ended questions was prepared specifically for each stakeholder group to act as prompts for discussion, querying opinions on topics such as their familiarity and accessibility to certain technologies, what details they believe should be recorded for PROMs, and how should they be collected, as well as what their hopes and concerns are for a technological intervention. These questions were created by the researchers based on prior reading of existing literature and used as prompts for informal discussion with the feedback used to develop the first sprint product backlog. Aspects of the workshops such as workshop length, schedule, participant numbers, the PROMs used, location, and technology used were all decided upon based on PPIE investigation. Due to the covid pandemic, workshops were moved to an online environment, requiring additional research to be conducted for this phase. Preferred online methods and tools were discussed with all stakeholders during PPIE with 2 trial workshops conducted with volunteer participants to pilot these various techniques and tools. This is discussed further in the results chapter.

5.10.2 Iterative cycles

As outlined above, the purpose of the iterative cycles was to develop the technological intervention from initial concepts into a fully functional prototype that meets the requirements and expectations of all stakeholders involved. Each iterative cycle followed 3 agile sprints (prototyping, testing and analysis, following the iterative design methodology) with the stakeholders involved (primarily PwD). The first stage involved the review of multiple prototypes based on the 4 primary technological methods identified for providing PROMs: Control, Textual, Visual, Verbal. The first set of prototypes were developed using the feedback gathered from the initial PPIE research phase as well as best practices covered in prototyping development section.

With the first set of prototypes completed, the testing sprint was held in the form of online workshops where PwD (supported by IC and HCP where required) were presented with the various prototypes. During cycles 1-3 the researcher performed cognitive walkthroughs with participants (which will be discussed in detail in a later chapter), detailing the features and differences of each prototype concept to participants who were asked to voice their opinions and recommendations on how they can be improved. These workshops were always overseen by an HCP and members of University Staff to ensure the needs of participants were always met. The feedback from these workshops where then subject to framework analysis to determine what features should be improved, removed, or added using the 5 dimensions of interaction design to determine prominent themes. These themes were then presented to relevant stakeholders via an online poll where they voted on what requirements they want prioritised for the next cycle. This was prioritised using the MoSCoW prioritisation method and used to form the sprint product backlog for the next iterative cycle. The updated product backlog was then used during the next iterative cycle to redevelop the prototypes into a higher fidelity version, taking in the recommendations features that were requested. These updated prototypes where then presented to participants during the next workshop. Details of these methods are discussed later in this chapter.

To streamline the process for prototyping, the same subsection of questions defined in the QoL in Alzheimer Disease (QoL-AD) tool (Logsdon *et al.*, 2002) was used as the baseline for all prototypes during the first iterative cycles (appendix 5). This allowed a baseline to be set between the methods and see the key differences that occur when collecting PROMs via textual, visual, verbal, and mixed methods. QoL-AD was chosen as it is a PROM questionnaire specifically developed for PwD and has both a text based and verbal versions that can be easily ported to the modalities that were to be explored. Also, as QoL-AD is originally a paper-based questionnaire, it can be used as a baseline in which the other methods are compared to see how useful (or problematic) a technological solution is compared to the existing paper model.

5.11 Prototyping Methods

The first step of each iterative cycle is prototyping. Prototyping is an experimental process that allows designers to implement ideas into tangible forms that can then be tested, trialled, and built upon in order to develop a product or service for future implementation (Interaction Design Foundation, 2022b). This allows for multiple ideas and features to be quickly assessed, approved, and discarded allowing for a product that can be tested without investing in the creation of a final complete product (Dam; and Siang;, 2020). Prototyping is also a key method of engaging stakeholders with complex needs in the development of a project by giving them a tangible product they can interact with rather than an abstract concept they would need to imagine (Bhattacharyya *et al.*, 2019).

5.11.1 Prototyping Online

Initially, the first set of prototypes were envisioned to be created using pen and paper during in person workshops and make use of pre-created paper assets and artifacts that would have allowed PwD to piece together a paper version of how they would like to see the app, similar to the early phases of other co-design studies (Rodgers, 2017; Tsekleves *et al.*, 2020). Unfortunately, due to the pandemic, this was no longer viable, details of which are discussed in the 'impact of COVID' section. Discussions with HCP and PwD during the PPIE sessions from both NHS and Alzheimer's Scotland advised that trying to emulate this style of interaction in an online environment would be difficult and likely to cause confusion due to the reliance of additional software set up and may require specific hardware or skills that may exclude participants from participating. It was therefore decided amongst the researchers that prototypes would instead be broken down into simpler forms, reminiscent of the pre-made assets originally envisioned, so each style and modality featured would be presented as a separate prototype that participants could compare and choose between. This was a novel approach that has not been seen conducted before, with all the key studies investigated making extensive use of prototyping doing so in person (Rodgers, 2018; Tsekleves *et al.*, 2020; Fox *et al.*, 2022).

5.11.2 Guidelines and DEEP

These initial prototypes were developed from the features in the product backlog that were chosen by PwD, IC, and HCP during the initial PPIE research phase and were created using a variety of pre-existing professional guidelines (Campbell, 2015; Pernice and Budiu, 2016; World Wide Web Consortium (W3C), 2019; World Wide Web Consortium (W3C), 2023) as well as Government standards (Government Digital Service, 2016) for general user experience. Features specifically catering for PwD were also implemented in the prototypes such as with guidelines published by the Dementia Engagement and Empowerment Project (DEEP). DEEP is a UK wide network of 80 independent rights-based dementia groups that encourages PwD to identify and speak out about the issues that are important to them. They provide detailed resources on developing content for PwD that allowed the prototypes to be accessible online to PwD (Dementia Engagement and Empowerment Project, 2015a), make explicit use of language they could understand (Dementia Engagement and Empowerment Project, 2015b), as well as the creation of supplementary material (Dementia Engagement and

Empowerment Project, 2015d). These resources adhered well to the 5 dimensions of Interaction design and were used to develop all the visual and text-based prototypes as well as the participant information sheets and consent forms. DEEP was highly recommended during PPIE from the stakeholders including NHS professionals and charity representatives from Alzheimer's Scotland. While other healthcare content resources have been created by the NHS (National Health Service, 2022) and the Alzheimer's Society (Alzheimer's Society, 2023) these resources do not have a detailed focus on designing for PwD as DEEP does, with the latter resource even recommending the use of DEEP as an additional resource.

5.12 Testing Methods

The second step of each iterative cycle was testing. This is where PwD and IC were invited to review the prototypes in an online workshop environment. Workshops were chosen as the primary method of data collection as the HCI approach encourages multiple participants to take part simultaneously for the most efficient feedback collection (Lazar, Feng and Hochheiser, 2017d). While HCI does allow for other methods of research and testing, methods such as surveys (Lazar, Feng and Hochheiser, 2017b), diaries (Lazar, Feng and Hochheiser, 2017c), and ethnography (Lazar, Feng and Hochheiser, 2017e) would not allow for the direct designer-user interaction that is vital for the co-design aspect of the study (Sanders and Stappers, 2008).

The workshops were set up following guidelines published by DEEP regarding the terminology (Dementia Engagement and Empowerment Project, 2015c) as well as advice taken from the 'Aging Playfully' project (Escalante *et al.*, 2017) which encouraged shorter informal workshops that began with an introduction of what was to be expected as well as building a healthy rapport and familiarity with participants prior to the workshops. This allowed the researcher to better identify and cater to the specific needs required for PwD who would make up the majority of the participants during the prototype development phase.

5.12.1 Usability Testing

As the main goal of the testing step is to test the prototype, an appropriate method must be selected to enable this. Usability Testing is a technique used in user-centred design to evaluate a product by testing it on users and in real world scenarios (Nielsen, 1994). Usability testing is a subset of HCD just as participatory design and Co-Design is and therefore shares many of the same principles such as putting users at the centre of research. The main difference is that Usability Testing views users as the subject to be observed at this part rather than partners, with their perspective being about how the product functions (Sanders and Stappers, 2008). While Usability testing can vary hugely from large scale online A/B Testing (Kohavi and Longbotham, 2017) to informal in-person Hallway Testing (Ligertwood, 2020) one of the most prolific features is the use of prototyping, where early versions or concepts of a product are created in order to test features with users (Naji, 2016).

Prototypes in usability testing can take on many forms, from hand drawn sketches to physical props and digital simulations. This is referred to as the fidelity of a prototype with it common for multiple fidelities of prototypes to be presented and tested on users during usability testing (Dworman, 2014). Low Fidelity Prototypes often consist of concept sketches which can be drawn on paper and used to come up with initial ideas for designs as well as the overall appearance and features. Mid-Fidelity Prototypes (often referred to as wireframes when created digitally) are versions that shows a more detailed skeleton and layout of menus and elements of an application and how they interact between screens. Finally, High Fidelity Prototypes aim to replicate major functions and styling of the final product and offer a high level of interactivity and refinement. The number of prototypes and the level of fidelity used will depend on the nature of the product, the participants recruited, and the time and resources available. If updating the features of an established product, a designer could go straight in with a high fidelity prototype tested amongst existing users whereas for smaller pilot studies, simpler low fidelity prototypes will often be used (Usability.gov, 2015). As the iterative design nature of the study involved users completing multiple design phases, the prototypes were developed to increase in fidelity that can be usability tested with users, allowing us to improve and refine prototypes until a FFP is developed.

5.12.2 Cognitive Walkthrough and Think Aloud Protocol

With workshops and usability testing identified as methods for running the study, the next method revolves around how users will be presented and interact with the prototype. During each workshop either a Cognitive Walkthrough or a Think Aloud protocol was performed for participants to test the prototype. Cognitive walkthroughs (Nielsen, 1994; Wharton *et al.*, 1994) consist of participants being navigated by the researcher through each step and action required to navigate through the app. For most of the prototypes (cycles 1-3), the researcher conducted cognitive walkthroughs by sharing the researcher's screen with participants and navigating through each section of the app, explaining in detail the different features and options available while recording participants' feedback and opinion. Cognitive walkthroughs are particular useful in the study as guidelines do exist on how to perform them online (Blackmon *et al.*, 2002) and are best suited during the early stages of prototyping where the researcher knows the functions and features of the prototype and is able to guide participants through the features without getting lost or breaking the prototype. During the final development cycle (cycle 4) and the summative evaluation phase, participants were asked to take part in a Think Aloud protocol (Lewis and Rieman, 2006) which differs from a cognitive walkthrough as participants were instead provided with a web link to the fully functional prototype (FFP) and were instructed to compete the PROM without explicit instructions while thinking aloud their opinions and struggles. As they do this, the researcher observes but offers no assistance or description on how to complete the tasks. This is better performed later in development where a functional prototype can be given to users to interact with where most early issues have been identified and resolved. This helps avoid the risk of designer myopia (Mehaffy and Salingaros, 2011) where designers are easily able to complete a task because they are familiar with a system and its features rather than it being user friendly. By giving full control over to the intended user, especially during the summative evaluation phase where new participants were recruited who had no prior knowledge of any of the prototypes, problems with usability can be identified that otherwise would have gone unnoticed. This is especially useful in identifying the critical 'red routes' taken by users when completing end to end tasks so the process can be made as streamline as possible, a key requirement to ensure usable navigation design for users , especially if the app is to be built for scale in future (Dix *et al.*, 2004).

Both cognitive walkthroughs and think aloud protocols are heavily encouraged when using Interaction design methodology (Nielsen, 2012; Interaction Design Foundation, 2022a). Other methods of user testing such as A/B testing (Siroker, 2013) and Multivariate testing could not be implemented as they require significantly more participants to be statistically significant (Office for Health Improvement and Disparities, 2020). Additionally, methods such as participant observation would not be suitable as for effective participant observation, the role of the researcher tends to be passive as to not intentionally interact with the target population and shaping their behaviour (Qaddo, 2019). As mentioned, when discussing ethnography, this type of method would not allow for the direct designer-user interaction needed for co-design aspect of the study.

5.13 Analysis Methods

The third and final step of the iterative cycle is analysis. This is where qualitative feedback from performing the cognitive walkthrough and think aloud protocol were analysed and put into common themes and features which could then be added to the product backlog and developed for the next iteration of the prototypes.

5.13.1 Framework Analysis

All workshops were fully transcribed into text format (appendix 6) with transcriptions analysed by the PhD researcher (DK) and supervisors (KE, RM) following a framework analysis procedure (Gale *et al.*, 2013) using the NVivo qualitative data analysis software. Interaction Design (Interaction Design Foundation, 2021) was chosen as the framework for the analysis as its 5 dimensions allow for a full review of the different modalities of the prototypes. Researchers first familiarised themselves with the dataset, re-reading over the transcripts of all the interviews until familiar. Interesting features of the transcripts were then indexed to the five dimensions of Interaction Design using NVivo which were then then used to generate overarching themes based on similar opinions and common relationships between the themes. These themes where then charted and refined by the researchers to create more robust themes and sub theme categories. Researchers then used these defined themes and subthemes to perform in-depth analysis on the transcripts mapping codes based on these developed themes to create an interlinked thematic map. This thematic map was then interpreted to create a final report stating the major themes of the data, linking to the codes that support these themes (Goldsmith, 2021). As previously discussed, Interaction Design is well suited for multi-modal prototype development and is a recognised framework for business modelling and analysis (Fioretti and Carbone, 2007). By aligning the analysis methods to the five dimensions of interaction design using framework analysis, key features and barriers can be easily identified and categorised during analysis, avoiding the issue of cognitive friction (Cooper, 2004) often associated with software development. This gives benefits over other methods of qualitative analysis such as thematic analysis, as the use of a framework allows for a more structured and systematic approach to analysis where the themes can be easily tracked through all iterations of the SDLC (Gale *et al.*, 2013).

5.13.2 MoSCoW Prioritisation Method

In addition to framework analysis of the workshops and in keeping with the agile methodology, a prioritisation tool was used to prioritise the features that would be implemented during each iterative cycle. The MoSCoW prioritisation method is a common business tool that was developed for rapid application development that enables stakeholders to prioritise workloads by giving them weighted votes they can use to vote for features based on whether they Must Have, Should have, Could have, or Won't have those features (Clegg and Barker, 1994). Must have features are features that are vital to the product or services purpose and function and should account for no more than 60% of the overall development time making them the top priority features that need to be prioritised first (Agile Business Consortium, 2022). Should have features are features that are expected from users though not vital for the products to function. This should account for around 25% of the overall development time and include features that help improve the products overall impression and appeals positively to users. Could have feature are features which may improve the users experience and should account for around 15% of the overall development time and include features that may be worth implementing in future iterations. Won't have features are features that are perceived as useless or are not wanted by users and may put them off using it. No development time should be used on these features, and they can be discarded entirely from future development plans. In projects developing with multiple stakeholder groups, an additional super vote can be implemented where end user stakeholders are given an additional supervote which is equal to the combined value of Must, Should & Could Votes and signify vital features that are important for those who will ultimately be using the product. These votes are then tallied and scored using some form of objective ranking (Wierzbicki, 2010) or scoring system such as weighted scoring, value vs. complexity or the kano model (Kano, 1984).

The MoSCoW prioritisation method has seen increased use in healthcare research, particularly in co-design studies (Lipson-Smith *et al.*, 2019) and studies designing age friendly technologies (Spiru *et al.*, 2019). MoSCoW is also recognised as one of simplest and most widespread approaches when compared to more complex prioritisation methods such as the more complex and time consuming KANO or RICE techniques (Alexsoft, 2019; Gibbons, 2021) which makes it perfect for the short turnaround time for analysis and prototyping required between each workshop. Another prioritisation method considered was the Keep, Lose, Change (KLC) method which inquires users to select which features to keep, lose, or change (Frohlich, Lim and Ahmed, 2014). This method was of particular interest as it was originally developed for older participants, though as the study involved multiple stakeholders and the KLC method notes conflicts can be particularly difficult to resolve (Frohlich, Lim and Ahmed, 2014). MoSCoW was favoured as it has options to implement weighted scoring which allowed for more granular ranking of prioritised features. For the calculations weighted scoring was used, where each vote was weighted proportionate to the prioritised development time with each participant given 2 votes per rank (table 6). It was also decided to conduct the MoSCoW after the workshop via online survey (appendix 7). This was done so that themes raised from the framework analysis could influence the features included as part of the MoSCoW, so that the online workshops could be shortened and simplified by focusing only on the cognitive walkthrough/Think aloud protocol. Additionally, by enabling participants to complete the MoSCoW questionnaire outside the workshop, it encouraged participants who may have been less confident or vocal during the workshop to have an equal voice in voting on features for the novel application, an issue especially important for PwD (Volkmer *et al.*, 2023).

Table 6 Moscow weighting

MoSCoW Option	Development time	Weighted score	Votes per participant
Must Have	60%	0.6	2
Should Have	25%	0.25	2
Could have	15%	0.15	2
Won’t have	0%	0	unlimited

6 Prototype Development Results

Chapter 5 presented the methods used for the prototype development phase, where prototypes for the application were codesigned and developed. Chapter 6 covers the results of this stage which consisted of initial research where PPIE was conducted to determine the initial scope and expectations of users as well as define the first set of requirements of the initial prototypes for the study. Then four iterative cycles were conducted that consisted of co-design workshops where PwD and IC helped develop multiple prototypes from initial concepts into an FFP. These workshops were transcribed and thematically analysed to produce several themes and subthemes regarding the prototypes (Table 7).

Table 7 Themes of the Prototype Development Phase

Cycle	**Themes**	**Sub-themes**
Initial Research (PPIE)	Technology	Preferred Devices Voice & Visual modality Accessibility
	Codesign Considerations	PwD and IC attendance Workshop length Timeframes Study Period Supervision
	Self-report/PROM	DEMQOL QoL-AD
Cycle 1	Control Prototypes	DEMQOL and QoL-AD
	Text Prototypes	Questions Layout
	Visual Prototypes	Colour Icons and Images
	Voice Prototypes	Voice
Cycle 2	Word Dimension	Ambiguity Relevancy Terminology Misread and tonally incorrect
	Visual Dimension	Results Colours Check Boxes Formatting Inconsistencies
	Time Dimension	Tracking Preference
	Behaviour Dimension	Data Ownership and Autonomy
	Space Dimension	Voice
Cycle 3	Word Dimension	Complexity of Questions Terminology
	Behaviour Dimension	Sensitivity Free Text Input Data Sharing and Autonomy
	Space Dimension	Voice
Cycle 4	Behaviour Dimension	Setup

		Free Text Input Frequency Data Autonomy and Ownership
	Space Dimension	Delivery Method Voice Mobile
	Visual Dimension	Graphs Share Buttons Radio Select
	Time Dimension	End Session

6.1 Initial Research Cycle (PPIE)

The first stage of the study involved PPIE activities with multiple informal meetings with the stakeholder groups identified by the Power Interest matrix. These meetings were held with HCP, PwD, and IC both in person on location and online and were used to discuss expectations of the project and the feasibility of co-designing a novel digital application with PwD. As initial meetings with many of the stakeholders, an informal discussive approach was taken. In addition to collecting requirements, the goal of these meetings was to build rapport and familiarity with many of the stakeholders that were hoped to be included in future workshops. As the meetings were informal and very exploratory by nature, no consent forms or recording were performed at this stage.

As highlighted in the 'prototyping methods' section, the initial plans were for the first cycle was for the initial set of prototypes to be created during the workshop making use of paper-based prototypes created in person. However, considering adaptations that had to be made due to the pandemic, the first prototypes had to be produced digitally and PPIE feedback from participants advised it would be easier for PwD to have concepts of features developed that they could visualise and choose between rather than trying to use online tools to create these prototypes. A product backlog of features was therefore developed from feedback during PPIE sessions, and the literature review presented in chapter 3. These adaptions proved to be effective as participants did not struggle with ideating during the first workshop and were confident in voicing changes and contributing new ideas to develop the prototype. Many of the features and considerations identified from the literature review and PPIE were also supported by participants during the workshops. Features and considerations included:

- Technology components identified from the literature review and PPIE
    - Computers and tablets to be used as the preferred device by PwD to access the novel application (Literature review & PPIE)
    - To investigate voice functionality and visual modalities, with the Alexa Show device being lauded as a particular device of interest amongst participants (Literature review & PPIE).

    - To focus on the application being as accessible as possible, prioritising consumer devices and devices PwD already have access to such as home computers, tablets, and Alexa devices (Literature review & PPIE).
- Codesign considerations identified from PPIE
    - PwD to be allowed to attend workshops independently or with IC as support (PPIE).
    - To keep workshops to no more than 2 hours in length, with breaks in between for any workshops longer than 1 hour (PPIE).
    - To keep a consistent timeframe between workshops (4-8 weeks as a goal) with a consistent day and time that workshops are held (PPIE).
    - To avoid the entire study running longer than a 6-month period (PPIE).
    - To invite an HCP and a supervisor to each workshop to oversee the running of the workshop and ensure strict standards are adhered to (PPIE).
- Self-report/PROM considerations identified from PPIE
    - DEMQOL or QoL-AD as the preferred PROM to be used for PROM collection (PPIE).

To prioritise the app being as accessible as possible and recognising participants preferences for large screen computers or tablets, the decision was made early on to develop the application as a web app making use of web technologies including HTML, CSS, PHP, JavaScript, and SQL. Following information gathered during the initial PPIE research, the results of the literature review, and feedback from both attendees of the dementia café groups as well as the 1st workshop trial. These all concluded that laptop computers were by far the most popular, most accessible, and most familiar to this target demographic and building the app as a web-based app would allow the highest level of accessibility for users as tablet and mobile users would still be able to access the app via a browser. This was in line with the literature review findings which also noted an overwhelming preference for computers and highlighted issues developing platform specific apps can cause for inclusion and accessibility.

6.1.1 1st workshop Trial (SDWG)

Before running the workshop in the full study, a trial of the workshop was conducted with various volunteers. This proved a vital way to test the online environment and how best to deliver the workshop and present the prototypes for the co-design workshop.

The first trial was performed in December 2020 and for which five volunteers from the Scottish Dementia Working Group (SDWG) took part. This was an already established online group of PwD that is supported and run by Alzheimer's Scotland. The meeting was arranged by Alzheimer's Scotland and had two of their staff oversee and host the meeting. Of the five PwD who participated, one was accompanied by a carer though their involvement was minimal.

This trial run identified multiple techniques that were implemented in future workshops. Many of these techniques were ones implemented by SDWG for their online workshops. These include:

- Assigning a co-host to observe participants and take notes while the main host focuses on asking questions and conducting the workshop.
- Make use of built in tools and features in the video conferencing software to avoid the need for participants to switch between different applications on their device.
- During the early workshops, have participants raise an object when they wish to speak to avoid people unnecessarily talking over each other.
- Contact participants individually after the workshop so they can contribute any feedback they may not wish to share within the group workshop environment.
- Monitor user participation to encourage even inclusion amongst participants.
- Avoid large groups and long periods of time, splitting into multiple workshops if necessary.

It should be noted that the SDWG participants self-identified themselves as being ‘fairly confident’ with using technology and were familiar with both the video conferencing software that was used as well as each other and the staff who had hosted the workshop. These participants also had frequent previous experience participating in online events as part of the weekly SDWG events. This is not entirely representative of the PwD group who are often noted to be less technological familiar (Hopwood *et al.*, 2018). Therefore, another trial was performed to test out the system on participants who were less technologically confident or familiar with workshops to see how they would perform.

6.1.2 2nd Workshop Trial (Older, technological unconfident)

A second trial was performed in March 2021 with older volunteers aged 65 and over who did not have dementia but were in the key age group and would not describe themselves as being confident with technology. The inclusion of older volunteers without dementia was a pragmatic solution as recruiting a willing participant with dementia who described themselves being unconfident with technology and willing to take part in an online workshop before the first cycle was due to start proved to be difficult. The inclusion of participants in this age group was also insightful as the background literature identified this age group as the most prominent group to be living with dementia as well as a group notable for having difficulties using certain technologies. 3 participants were originally recruited but only one was available on the day. The workshop took place over 90 minutes with a single female participant testing the prototypes in the online workshop environment. The MoSCoW voting survey was also tested as a tool used during the workshop given to participants rather than between each workshop.

The aim of this trial was to focus more on the think aloud protocol and if giving control of the prototypes over to the user would encourage more interaction and more involvement and feedback. Unfortunately, this had the opposite effect making it far more confusing to follow and likely to overwhelm. It was also noted that the way the prototypes were displayed felt disjointed, with many comments made about the text-based prototypes being referenced when other prototypes were shown as well as the lack of colour and design as well as the repetition of methods between solo and multi display prototypes. The method of sending links proved very problematic and confusing, with the participant feeling overwhelmed with the content and being unsure what to do with the prototypes. It was also agreed by participant and researchers alike that this method made it far harder to conduct a study as the structure seemed to fall apart quickly and would be even more problematic with more than one participant. Part way through, navigation of the prototype reverted to the researcher performing a cognitive walkthrough with it being sharing via screen share. The participant found this easier to follow with researchers agreeing this was a more effective at collecting usable data for the early workshops. There was also much criticism about the original voting system which made use of the MoSCoW Method via an online poll conducted alongside each prototype which was found to be far too confusing, and a simpler method was decided that would be presented aften the workshop.

6.2 Amendments to the Study from Pilot Workshops

Using the feedback from the trial workshops some changes were made to future workshops and prototypes. The decision was made that for the first workshop cycle, it would follow the setup of the SDWG trial, with a host navigating through the prototypes and describing features while participants observe via screen share. Participants would be asked to raise a sign when they wish to talk with the co-host prompting these and taking notes. It was also decided from the feedback that each workshop would start with a short introduction and ice breaker. It was also decided that the MoSCoW questionnaire would be performed outside the workshop, to reduce the need to switch between applications, reduce the length of the workshop, and allow participants to voice feedback they may not be comfortable saying to the group.

6.3 Iterative Workshops Overview

As outlined in the prototype development method chapter, the prototype was iteratively codesigned over 4 development cycles. Each cycle consisted of a prototyping, testing, and analysis step which developed and refined the prototypes from initial concepts to functional prototype.

6.3.1 Prototype Overview

34 prototypes were developed over the course of the four co-design cycles. 17 were created for Cycle 1, 10 for Cycle 2, 6 for Cycle 3, and 1 for Cycle 4 (appendix 8). In accordance with the agile approach adopted, each co-design phase had a set of prototypes with feedback from them directly feeding into the next set of prototypes.

6.3.2 Workshop Overview

The study began in October 2021. 2 sets of workshops had to be conducted due to the nature of ethical approval and oversight that was required for these organisations.

- Group A: NHS IRAS Ethics was acquired for NHS and Town Break participants.
- Group B: University Ethics was acquired for Alzheimer's Scotland, Dementia Circle, and Scottish Dementia Working Group (SDWG) participants.

Table 8 Participant Details

Participant	Role	Age	Gender	Living arrangement	Technology Familiarity
PWD1	PwD	N/A	Female	N/A	N/A
IC1	IC	N/A	Female	N/A	N/A
PWD2	PwD	N/A	Male	Live with Partner	Somewhat confident
PWD3	PwD	81	Male	Live with Family	Somewhat unconfident
IC2	IC of PwD2	79	Female	Live with Family	Somewhat confident
PWD4	PwD	58	Female	Live with Family	Very confident
PWD5	PwD	64	Male	Live with Partner	Very confident

Table 9 Participants Attendance at Workshops

Participants	Role	Cycle 1	Cycle 2	Cycle 3	Cycle 4
PWD1	PwD	O	X	X	X
IC1	IC of PWD1	O	X	X	X
PWD2	PwD	O	O	O	O
PWD3	PwD	O	O	O	O

IC2	IC of PWD3	O	O	O	O
PWD4	PwD	O	/	O	O
PWD5	PwD	/	O	X	O

O: attended full session **/**: attended partial session **X**: did not attend session

It should be noted that most of the participants knew each other prior to taking part in the group session and were also particular familiar with the technology they were using. This observation is further discussed in the study limitations in Chapter 10. In the demographic questionnaire, most participants (4/5) identified themselves as somewhat or very confident using technology with only one participant noting themselves as somewhat unconfident, this participant was accompanied by a carer for support. Additionally in the demographic questionnaire, participants identified themselves as having access to a wide variety of commercial technology including Laptop Computers (80%), eReaders (80%), Tablets (60%), smart phones (60%), smart speakers (20%) and smart watches (20%).

6.3.3 Analysis Overview

Following NHS ethical and university standards, all workshops were supervised by at least one supervisor and one HCP from NHS or Alzheimer's Scotland. During all meetings a second researcher was assigned as co-host whose main task was to take live notes and feedback from participants during the entirety of the meeting. Most of the feedback of Cycle 1 was therefore recorded by researcher notes due to technical issues resulting in unusable recordings.

6.4 Cycle 1

As outlined in the prototype development methods, the purpose of cycle 1 was to develop the initial low fidelity prototypes developed from the PPIE activities and background research and test them with the volunteers.

6.4.1 Cycle 1 prototypes

A total of 17 prototypes were developed in preparation for cycle 1 (table 10). This was to allow participants to have multiple options of modalities to choose between which were not too taxing to produce due to the simplistic nature of these initial prototypes. The first 2 were designed as controls using existing PROMS and consisted simply of a digitised copy of the paper version of the PROM displayed in a HTML webpage with a JavaScript counter over an image map to count responses. The remaining 15 prototypes were all developed as low fidelity web pages with each prototype showcasing separate possible interaction elements of the 3 communication methods (6 for Text, 6 for visual, and

3 for Voice). Each of these prototypes asked the first 5 questions taken from the QoL-AD PROM questionnaire. QoL-AD was chosen as it has different questions designed for both text-based, and voice-based (interview) formats.

Table 10 Cycle 1 Prototypes

Method	**Description**	**Prototype Produced**
Control	Consist of digital scans of the paper based QoL-AD and DEMQOL PROM questionnaires	P1.1 QoL-AD P1.2 DEMQOL
Text	Consist of direct transcripts of QoL-AD questionnaires converted into plain text formats. These consisted of different formats of displaying the text and how much information to display on each page.	P1.3 Multipage List P1.4 Multipage List P1.5 Multipage Bar P1.6 Solo Bar P1.7 Multipage Square P1.8 Solo Square
Visual	Visual prototypes made use of various basic and default CSS code following the principles of W3Schools, which sets out the standard layouts of web technologies.	P1.9 Hover P1.10 Colour P1.11 Icons P1.12 Picture P1.13 Likert P1.14 Slider
Verbal	Created by converting the QoL-AD interview script using a digitally generated voice (Text to speak).	P1.15 Voice Short P1.16 Voice Medium P1.17 Voice Long

6.4.2 Cycle 1 workshops

During Cycle 1, a total of 2 workshops were conducted. The 1st Group consisted of two participants (PwD1 & IC1) and was a one-on-one workshop. The 2nd Group consisted of five participants (four PwD and 1 IC). One of these participants (PWD5) completed all the prototypes but left before the group discussion due to a headache. 2 other participants (PwD & IC) initially signed up for the study withdrew just before the session started due to ill health. All participants were invited to take part in the MoSCoW survey. Workshops were conducted online with the first researcher acting as host of both sessions with a supervisor acting as co-host. The second group workshop was also attended by a professional of Alzheimer’s Scotland as an observer. Both workshops were recorded and took place online via a group video call and lasted for approximately 90 minutes.

6.4.3 Cycle 1 analysis

6.4.3.1 Workshop 1 Feedback

Due to unforeseen technical issues and despite testing of the technology for data capture during the pilots; no usable recordings or transcripts of the first workshop were collected during cycle 1. Instead, general feedback collected in notes written by the researcher and supervisor were used for analysis. For the 4 prototype methods presented, participants showed multiple overwhelming preferences (table 11).

Table 11 Cycle 1 prototype feedback

Control	A clear preference was shown for QoL-AD (P1.1) over DEMQOL (P1.2). DEMQOL was noted as being too long with too many questions (n=27) when compared to QoL-AD (n=13). The responses for DEMQOL were also overly long compared to QoL-AD single word responses, as well as a cluttered layout and inclusion of asterisks which had no clear meaning to the user.
Text	One question per page approach with responses displayed in a bar (P1.6) was preferred over multiple questions per page (P1.3, P1.5, P1.7) which was deemed as too cluttered. The bar layout was also preferred over lists (P1.3, P1.4) or grids (P1.7, P1.8).
Visual	Inclusion of coloured backgrounds (P1.10) was preferred though an option to turn this off was highly requested. Participants also responded well to elements that change when you hover over them (P1.9) to indicate which response you are selecting. Use of icons (P1.11) and images (P1.12) was often deemed 'childish' and 'patronising' or 'confusing' and users preferred buttons they can click/tap over radio selects (P1.13) or sliders (P1.14).
Voice	Users were mostly disinterested in the voice features noting it could be a feature to have but not one they would deem necessary. Participants did voice a preference for the longer question formats (P1.16, P1.17) over shorter questions (P1.15). Some users floated the idea of having famous actors record the voice, though as shown in the MoSCoW results, these were quite divisive with many stating they won't want to see this feature included.

Throughout the workshop a few other requests were made including better ways to keep track of which question you are answering (e.g., Question 1 of 12) as well as more detailed explanations of what the questions are, why the questions are being asked, and who this data is being shared with. Following this feedback, prototypes for these were developed in Cycle 2.

Finally, as the only phase to have control examples, several criticisms and changes were raised about the questions asked from the QoL-AD and DEMQOL control questionnaires.

- The 13 questions used in QoL-AD was deemed an ideal number, any more such as DEMQOL inclusion of 27 questions was noted as being too many for most participants to handle.
- Questions should be in the moment, and not ask users to reflect over a period (such as over the past week/month). This was an issue of DEMQOL which asked users to consider the period of the last week.
- Participants were not comfortable with the name QoL-AD (QoL – Alzheimer's disease) and its reference to Alzheimer's disease as they were all diagnosed with other forms of dementia. Many asked why they would be filling in a form for a condition they do not have.
- Do not include anything that is not to be used or filled in by the users. Things such as additional staff only questions or asterisks referencing other parts would often cause 'fixation and distraction' such as the use of asterisks on DEMQOL.
- Avoid difficult to read background colours such as QoL-AD using black text on a grey background or having the page overly cluttered with questions.

6.4.3.2 Workshop 1 Moscow Results

3 days after the workshop was conducted, participants were sent an online survey to complete in their own time. This survey presented a set of features for the next iteration of the prototype and asked users to vote for which features they would like to see prioritised using the MoSCoW prioritisation method discussed in Chapter 5. The features were created based on feedback from the 1st workshop.

Table 12 Workshop 1 MoSCoW results

ID	Features	Dimensions covered	Moscow score	Won't include	Priority
F1.1	Larger font and bolder fonts	Visual	1.95	0	High
F1.2	Results page for participants to see their own responses	Visual	1.8	1	High
F1.3	Options displayed in boxes	Visual	1.55	1	High
F1.4	Automatically move to the next page	Time	1.5	0	High
F1.5	Actors voice recording	Space	1.45	3	Moderate

F1.6	1 question on each page	Space	1.35	0	Moderate
F1.7	All questions on 1 page	Space	1	2	Low
F1.8	More detailed questions and explanations	Word	0.85	1	Low
F1.9	Visual Prompt with Verbal questions	Visual	0.85	1	Low

During workshop 1, by far the highest priority features related to the Visual dimension, with 3 of the top priority features relating to that dimension (F1.1, F1.2, F1.3) with the Time and Space dimensions also scoring moderately. 'Larger font and bolder fonts' took the highest priority for users which reflects one of the main talking points during the session regarded users complaining that the font display was far too small. During the session, all prototypes were zoomed in to 150% of normal size for better viewing which allowed participants to clearly see and read the visual aspects of the prototypes. This feature was implemented in all future prototypes. Participants were also keen to have questions automatically move to the next once answered (F1.4), a feature relating to the time dimension that was implemented in all future prototypes, as was one question per page (F1.6). While participants were interested in actors voice recordings being used in future prototypes (F1.5) the feasibility of this during the prototyping phase is limited and best to be considered after prototyping has been completed.

Another feature heavily discussed in the workshop that also scored highly related to ownership of data and participants being able to see their own results (F1.2) as well as the ability to take ownership of this data and be able to show it to relevant people and professionals. No prototypes had been developed for these features so prototypes for this were implemented in cycle 2. This shows the advantages of a co-design methodology where such features can be more easily developed early on the app's life cycle reducing the chances of greater overhauls later in development.

6.5 Cycle 2

The purpose of cycle 2 was to develop mid-fidelity prototypes using the feedback from cycle 1 and retest them with the volunteers.

6.5.1 Cycle 2 prototypes

A total of 10 prototypes were developed for Cycle 2 (table 14). These refined features from the most popular prototypes of cycle 1 (table 13) which were combined to create hider fidelity prototypes which were the basis for the 4 interactive prototypes in preparation for cycle 2.

Table 13 Cycle 1 preferred prototypes

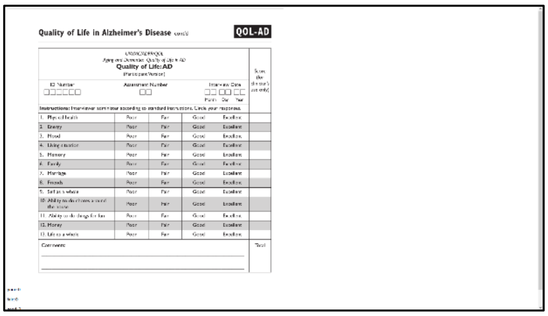
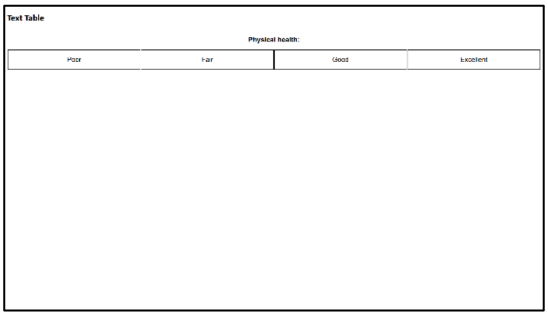
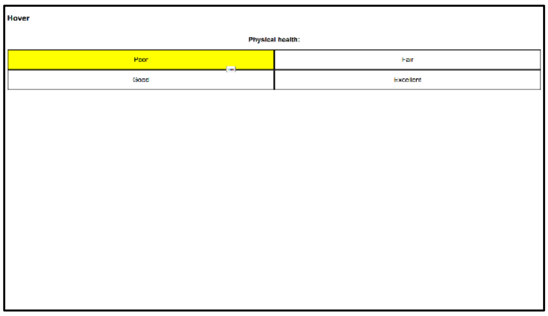
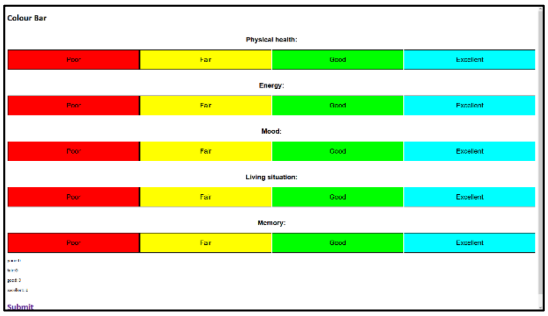
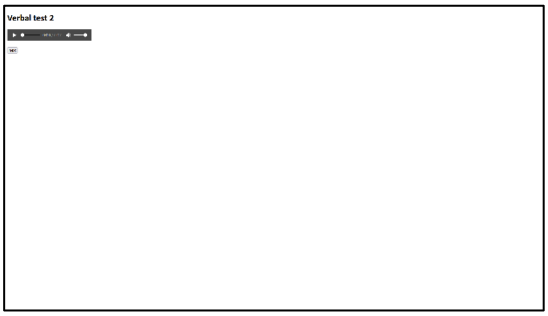
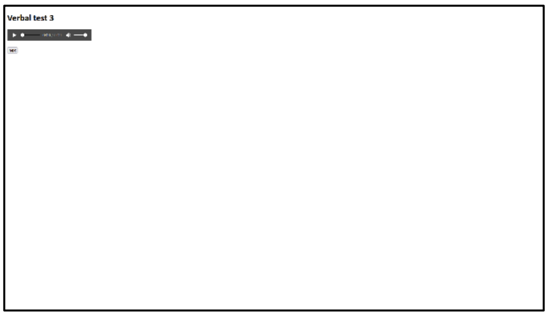
P1.1 QoL-AD	**P1.6 Solo Bar**
 Quality of Life in Alzheimer's Disease cont'd QOL-AD Quality of Life: AD 1. Physical health Poor Fair Good Excellent 2. Energy Poor Fair Good Excellent 3. Mood Poor Fair Good Excellent 4. Living situation Poor Fair Good Excellent 5. Memory Poor Fair Good Excellent 6. Family Poor Fair Good Excellent 7. Marriage Poor Fair Good Excellent 8. Friends Poor Fair Good Excellent 9. Self as a whole Poor Fair Good Excellent 10. Ability to do chores around the house Poor Fair Good Excellent 11. Ability to do things for fun Poor Fair Good Excellent 12. Money Poor Fair Good Excellent 13. Life as a whole Poor Fair Good Excellent Comments Total	 Text Table Physical health: Poor Fair Good Excellent
P1.9 Hover	**P1.10 Colour**
 Hover Physical health: Poor Fair Good Excellent	 Colour Bar Physical health: Poor Fair Good Excellent Energy: Poor Fair Good Excellent Mood: Poor Fair Good Excellent Living situation: Poor Fair Good Excellent Memory: Poor Fair Good Excellent Submit
P1.16 Voice Medium	**P1.17 Voice Long**
 Verbal test 2	 Verbal test 3

Table 14 Cycle 2 Prototypes

Method	**Description**	**Prototype Produced**	**Features Developed**
Interactive	Prototypes that focus on more interactive methods including combined visuals and audio as well as visual animation and included design elements to better indicate progress between questions.	P2.1 Audio Visual P2.2 Tracking P2.3 Zoom P2.4 Pan	F1.1, F1.3, F1.4, F1.6
Results	Prototypes that focus on displaying results of participants answers in various formats including text,	P2.5 Answers P2.6 Aggregated	F1.2

	lists and charts as well as over differing periods of times such as ‘this session’ or ‘past month’.	P2.7 Listed P2.8 Chart P2.9 Line	
Data Sharing	Concept of how data sharing can be chosen allowing users greater control over their personal data	P2.10 Share	F1.2

4 prototypes were created to explore interactive elements. The audio-visual prototype (P2.1) combined features of the cycle 1 prototypes with the Voice medium/Long prototype (P1.16, P1.17) from earlier in a multimodal prototype. As the visual dimension a long with the Space and behaviour dimensions were well defined in workshop 1 and feedback from users regarding these were implemented in the interactive prototypes, Cycle 2 focused more on the Time dimension and created 3 prototypes that showed alternate ways to track and show a user’s progress. This included the tracking prototype (P2.2) which displayed a user’s previous answers at the bottom of the screen as well as the pan (P2.3) and zoom (P2.4) prototypes which made use of various transitioning animations between questions. The latter 2 were developed using PowerPoint while all other prototypes were created using the prior mentioned web technologies discussed in cycle 1. These prototypes continued to ask the first 5 questions taken from the QoL-AD PROM questionnaire.

Following on from Theme ‘Results page for participants to see their own responses’ (F2.2), a total of 6 prototypes were developed to show how results may be displayed to users using a variety of different methods. The results page was designed with many of the same design elements used for the questionnaires (larger font size, using the same grid formats and use of colours). This was chosen to keep a consistent look, avoid users fixating on unusual design elements (such as asterisks in the DEMQOL) and to get a jump-start on elements the users had already approved in cycle 1. As with cycle 1, the prototypes consisted of different methods of displaying results using texts and visuals. A verbal version was not produced due to users’ lack of enthusiasm for such a feature reported in cycle 1.

An additional prototype (P2.10) was developed to allow users to choose who to share their results with, to give them greater control and ownership of ‘their own responses’.

6.5.2 Cycle 2 workshops

One workshop was conducted in January 2022 during cycle 2. This consisted of five returning participants (four PwD and one IC) that took part in Cycle 1. Participant PWD4 was late to arrival but took part in most of the prototypes. The 2 Participants (1 PwD & 1 IC) who withdrew from the 1st cycle decided to withdraw entirely from the study.

Workshops were conducted online via a group video call and was attended by a professional from Alzheimer's Scotland as an observer. The workshop lasted 61 minutes. The workshop followed the same format as cycle 1 though with new prototypes being presented to participants and less focus on structured questions and more emphasis on encouraging group discussion. This was possible as participants were more comfortable with the workshops, the task they were doing, and were more confident discussing between themselves, so question prompts were not needed. These prototypes were developed following feedback from the 1st cycle workshop.

6.5.3 Cycle 2 analysis

As outlined in the prototype development methods chapter, the qualitative data derived from the workshops was subject to framework analysis.

6.5.3.1 Workshop 2 Framework Analysis

The framework analysis identified 5 themes and 11 sub-themes as detailed below.

6.5.3.1.1 Word Dimension

All participants commented on the word dimension of the prototype with criticism against the phrasing and relevancy of the questions taken from the QoL-AD PROM.

6.5.3.1.1.1 Ambiguity

Much criticism was raised against the format of the questions and the predefined response options. Participants found the phrasing of the questions to be inappropriate especially with responses such as 'excellent' being presented alongside them. Participants also noted that the combination of some questions and responses were grammatically incorrect. The first question using the term 'physical health' was deemed to be ambiguous with participants unsure whether it was asking about their physical activity, their physical health overall, specifically regarding their dementia, or how their physical health is being treated. Additionally, one participant voiced confusion to why a question about physical health was being asked as part of a dementia PROM and felt the question in its current form was irrelevant to them and their dementia. Participants also criticised the use of the word 'lately' in some of the questions noting that with dementia many found it hard to gauge periods of time coherently and the vague use of 'lately' made them unsure on whether they are thinking of today, the past week, or since the last questionnaire. Many stated that their response could fluctuate significantly over any given period of time and that they would prefer questions that asked in the moment.

PWD3: I I'm not, I'm not. Trying to be obstructive, but I would have thought the great majority of people who have dementia don't feel good about it [dementia]. Don't feel. Don't feel fair about it [Dementia]., yeah? Yeah, this is going to be some explanation of the way you're using the words there, yeah? So, you're saying your questions do it is saying? How do I feel about? The way my physical health is being treated, Oh yeah, that that. That is that is relevant to me

PWD5: This bit urm. But you're using 2 different words [In response to QoL-AD question 3 'How has your mood been lately? Have your spirits been good, or have you been feeling down?'], it's saying, 'or have you been feeling down' and you got 'poor', yeah? Yeah. So, but you've used 'good' and 'good'. So, they, they're bit. Poor put 'down instead of 'poorer' instead of 'down'.

PWD3: Yeah, I, I mean I just. Think that you come along. You are a stranger. You ask me how I am about my physical health, yeah. And erm. It just does not. It's, it is just the word. Best word is ambiguous. Yeah, every one of us could go and look at this in different ways. Yeah, yeah. And therefore if I leave your notes and all this it is not a good question

PWD5: are you asking about dementia? or how [is] the rest of me?

PWD2: What does lately mean?

PWD3: With 'Over the past week' [part of a PROM question], right? Why did he bring in the last week?

6.5.3.1.1.2 Relevancy

Participants also raised issues with the relevancy of the 4th question which asked about the users living situation. The intention of the question was to gauge users' satisfaction with their home environment though the phrasing and use of 'now' (e.g. How do you feel about the place you live now?) was interpreted by participants that their home environment had changed. Many found this inappropriate for a frequent questionnaire and did not foresee it changing bar from significant changes in circumstances. Participants felt the phrasing of the question needed to be changed, or to ask a pre-question asking if their living situation had changed before asking their response. one participant also questioned the relevancy of the question asking about user's memory and found it to be "a silly question for somebody with dementia".

PWD5: That's not likely to change week from week. I'd have thought, yeah. So, I don't quite see the point of it. In a weekly questionnaire

> ***PWD2: I see what PWD5 means, mean. my situation wouldn't change at all. unless the worst happened.***
> ***PWD2: you can get into a care home or something. But it's not on a weekly basis. It's not something that I think would necessarily change.***

> ***DK: Do you think it would be better like we leave this question out, but only ask it if we know your living situation has changed?***
> ***PWD5: yeah***
> ***PWD2: Well, have a question like 'how's your living situation changed in the past week' and then ask this?***
> ***PWD5: yeah, yes, and no, then no would take you past this, yeah.***

> ***PWD3: I feel the addition of the word 'now' yeah. Uhm? Alters the meaning of the rest of the question ahead. How do you feel about the place you live now? It is implying that.***
> ***PWD5: you changed?***

> ***PWD3: It has changed, yeah, but there's no real basis for. for saying that? I mean, you could you, could you just omit Now?***

> ***DK: do you think if it asks you if your living situation had changed and then afterwards question would be a better way to do it?***
> ***PWD5: Yes, and if you did that you would leave in the word now because you've changed your living place you've lived has changed.***
> ***IC2: Yep.***
> ***PWD5: Wouldn't it? But to be honest, I don't see being realistic that this question would ever get answered because the next step is a care home, I think we all accept that.***

> ***PWD2: I need to be honest and say I think it's a silly question for somebody with dementia. The reason I've been diagnosed with dementia is that I have a poor memory.***

6.5.3.1.1.3 Terminology

Despite the prototypes so far only covering the first 5 questions of a total 13, participants were vocal of the terminology used in the questions. Even with prototypes (P2.1, P2.2, P2.3, P2.4) developed to show case features relating to other dimensions (Visual/Space/Time) participants would often cycle back to criticise the questions terminology used in the questions. Participants did not like for example the use of 'marriage' on the results page. Participants correctly pointed out that marriage would exclude participants who are unwed, in civil partnerships, or other partnerships with many participants requesting a change to 'partner'.

> ***PWD2: I struggle with the word marriage. Can that be change to partnership?***

PWD5: That should actually.

PWD2: cause I'm in a same sex relationship.

PWD5: Yeah, it should be. Yeah, it should be changed.

PWD2: so, it doesn't really accommodate me.

PWD5: Yeah

PWD2: I'd like to switch spouse for partner. And also have an option for no one

DK: yeah?

PWD5: I think you'd have to

6.5.3.1.1.4 Misread and tonally incorrect

Additional requests regarding the word dimension were changing words that could be misread or were seen as tonally incorrect such as 'decreased' which could be misread as 'deceased' and 'Excellent' being replaced for being far too positive a response.

PWD5: With my dementia, I saw deceased.

PWD4: oh

DK: Oh, yeah.

PWD5: So, I think, if possible, could you change that.

PWD4: Yeah.

PWD2: Deceased! ha-ha

PWD5: yeah, you do get funnier things with my dementia

6.5.3.1.2 Visual

The next most commonly discussed theme related to the Visual dimension of the prototype, in particular feedback regarding the newly introduced results prototypes (P2.5, P2.6, P2.7, P2.8, P2.9).

6.5.3.1.2.1 Results

Participants were keen to have access to all their responses in a single interactive results page rather than spread across the multiple prototypes as presented during the cycle 2 workshop. Multiple participants envisioned an interactive results page where additional context could be accessed from the results by selecting drop down menus that allow participants to view their results over differing period of times and in their preferred visual graph. They also envisioned that these graphs could be clicked on so greater context such as the questions they answered were displayed alongside any graphs.

PWD2: It says here your results for this week. This is 1 set of responses. Yes, yes. What would it look like? Sorry if I'm jumping the gun, but what would it look like after we had done it 3 or 4 times? ***PWD3: I thought the last speaker was making sense.***
PWD5: I would want [to] make. I want to know if there was a period in the month. Where I was better, like do you see what I mean, yeah… Personally, I'd like a graph of a week by week
PWD5: But could you make it so if you click on 'good', yeah down to see what there was like 'living', 'memory', 'family and partnership' with the other 1 is
PWD2: it would be good if we could click on 1 of the circles and it told you what questions you had answered.
PWD4: I think it's better to have it as a results page so that you can review it all together rather than…See on the page when you've already given your answer. Yeah, you would have to keep going back to it, so it's good to have the result stated [at] the end
PWD2: It might actually be useful DK if that was on the same page as the previous one, yeah? It would maybe give us some context.
PWD2: Similarly, to previous responses, it would be good if we could click on 1 of the circles and it told you what questions you had answered.
PWD5: Drop Downs, you need drop downs and each of the bubbles there, so you got 4 times. How many bubbles?
PWD5: yeah, because I'd love a graph rather than a pie chart. ***PWD4: well, I like the pie chart so I can, you know, I think it's quite clear.***

6.5.3.1.2.2 Colours

Participants had some comments on the use of colours in the prototype. Users found a particular shade of yellow to be difficult to see against the white background. Participants also showed support for a user option to switch off the colours in the prototype.

PWD5: the yellow is not very nice. We can hardly see the yellow.
PWD5: Do we need the colours on this page? ***DK: Yeah, it's a fair question, so you might think you're not a fan of the colours?*** ***PWD5: They are confusing me on this page. Yes,*** ***DK: yeah? So, would you prefer just to have it as just Yeah, just a text?*** ***PWD5: Yes, for me, but I say I'm just odd. Yeah,*** ***PWD4: you know it, but could it be optional to either have the colours or not?*** ***DK: Would you prefer out on or with questions as well?***

PWD5: Yes
PWD4: Yeah, uhm. I think it's certainly useful to have the option to either have colour or not. Yeah, you know so. That's useful.

6.5.3.1.2.3 Check Boxes

There was some confusion regarding the checkbox options used on the sharing prototype (P2.10). The option made use of small circles that were displayed grey when unselected that would change to blue when selected. Participants did not recognise these as options that could be selected and advised changes made to the visuals. Participants advised to replace the circles with a checkbox that would display with a tick mark or to change the layout to display clear 'yes/no' option.

> ***PWD2: I didn't understand what those boxes in the left were until you actually clicked.***
> ***DK: … they're supposed to be checkboxes…***
> ***PWD2: Or maybe if it was an option of an arrow or a cross,***
> ***PWD4: I think a tick is more positive than across.***
> ***PWD2: Yeah, cos I think with a cross it will be saying no.***
> ***DK: So instead of having it just say you either click it on or off. I think anything like you can have 2 columns of saying yes or no and then you tick which ones you want it to be?***
> ***Multiple: Yes, OK, thank you.***

6.5.3.1.2.4 Formatting Inconsistencies

Finally, one participant did point out formatting inconsistencies in the prototypes. As mentioned during cycle 1, the inclusion of unnecessary or unexplained elements can cause fixation and distraction when users are trying to complete the questionnaire.

> ***PWD2: Can it be very pedantic? … The responses at the top in the coloured boxes are all capital letters. But when you go to the good below***
> ***PWD5: Oh yeah, good point.***
> ***DK: I didn't notice that. No, it's good to know.***
> ***PWD2: Feel like a school Teacher.***

6.5.3.1.3 Time

The next major discussed theme was the time dimension which related to the Tracking (P2.2), Zoom (P2.3), and Pan (p2.4) prototypes.

6.5.3.1.3.1 Tracking preference

The Tracking prototype (P2.2), which displays boxes at the bottom of the screen with the users' previous responses, was the preferred method of tracking progress for all participants. The only change recommended was to add more context of what question was asked for each response. Participants found the tracking prototype far superior to the other prototypes (P2.3, P2.4) which made use of graphical animations that participants found disorientating and that could affect other medical conditions such as epilepsy.

DK: it tells you what you've answered for question 1 and question two. ***PWD5: that's better***
DK: …what do people think of this sort of design? ***PWD4: I think that's quite good. Yeah.*** ***PWD5: yeah, I can see that, I can see the usefulness of that, yeah.***
DK: … Do you think this is a better way to do it? ***PWD2: Yes, yeah,*** ***PWD5: I would say so,*** ***PWD4 yeah,*** ***PWD3 yeah.*** ***PWD2: it might be useful after question …. near the question 2 in brackets to put energy***
PWD5: [in response to P2.3] Not for me. ***PWD4: I prefer the first 1 [Tracking P2.2] to this one. Yeah*** ***PWD2: as do I because of my epilepsy. The second 1 isn't. Ideal***
DK: so, do you think if going back to this 1 [P2.2] that this is a better way to do it? ***PWD2: Yes, yeah,*** ***PWD5: I would say so,*** ***PWD4 yeah,*** ***PWD3 yeah.***

6.5.3.1.4 Behaviour

The 2nd least discussed themes can be categorised into the behaviour dimension of the prototypes. This was related to data ownership regarding the share prototype (P2.10).

6.5.3.1.4.1 Data Ownership and Autonomy

When demonstrating the share prototype (P2.10) participants emphasised the importance of data ownership and their autonomy to choose who to share data with, including no one. Participants saw the value of being able to select who the data is shared with, especially on a week-by-week basis and seemed encouraged by the option to choose who the data was shared with on a per-questionnaire basis. One change that was requested was the option to keep the data collected private and for their own use if they wished to. While the prototype did allow for all options to be unselected so that the data would not be shared, participants felt having it as a separate option would be a good addition, where one participant noted we should have it as the first option.

PWD4: Because you could. You know if you completed the questionnaire over a week. And if things were a bit really up and down then you would need to share it with someone. But if it's not, I think it's better to just keep a record of it, so you've got that erm available so that you could monitor it, you could keep it yourself. Yeah. Before you would need to show it to a clinician, whoever, yeah

PWD5: You might want to. Some weeks might not want to share it with your spouse, but you might want to share with your child.

DK: If you have the option to share with no one, do you think that'd make give you a little bit more confidence to fill it in as well?
PWD5: Yes
PWD2: yes.
PWD5: and have it as number one, yeah?
PWD3: or should be the researcher, yeah.

6.5.3.1.5 Space

The least discussed dimension was that of the space dimension which primary related to the audio-visual prototype (P2.1). Participants were overall pleased with the design with the only criticism regarding voice aspect.

6.5.3.1.5.1 Voice

While participants could recognise the value of voice features to support users who would struggle with visual or touch elements of the prototype, they universally would choose to disable the feature for themselves. This was primarily due to previous experiences with voice technology that struggled to understand them.

PWD4: I think. So yeah, I think. That really would need to be in because not everyone can touch the machine. I feel confident in doing that. Yeah, you know. So, I, I think that a useful thing to have.

PWD2: I'm not keen on voice recognition technology, because it doesn't always recognize my voice. ***PWD5: that's a problem.***
DK: would you like the option to have it read out to you verbally? Or do you think that's a bit too? ***PWD4: No!*** ***PWD2: id be the first 1 to say no to be honest.*** ***PWD4: [agreeing with PWD2] yeah***

6.5.3.2 Workshop 2 MoSCoW analysis

Three days after the workshop was conducted, participants were sent an updated online survey to complete in their own time. This survey again presented a set of features for the next iteration of the prototype and asked users to vote for which features they would like to see prioritised using the MoSCoW prioritisation method. The features were generated from the framework analysis performed in cycle 2, with key themes being assigned to prominent features that could be implemented in the next prototype.

Table 15 Workshop 2 MoSCoW Results

ID	Features	Themes covered	Moscow score	Won't include	Priority
F2.1	Adjust some of the words to be more inclusive (such as changing 'spouse' to 'partner', 'decreased' to 'reduced', 'stayed the same' to 'no change)	Word: Terminology, misread and tonally incorrect	2.35	0	Very High
F2.2	Make the questions less ambiguous and more relevant to me	Word: Ambiguity, Relevancy	1.8	0	High
F2.3	Show my previous answers after I submit them and let me change them	Time: Tracking Preference	1.7	0	High
F2.4	Option to turn colours on/off	Visual: Colours	1.6	0	High
F2.5	Have a drop-down menu for results page that go into more detailed	Visual: Results	1.6	0	High

F2.6	Show reminders of what kind of questions have been asked (such as 'mood' instead of 'question 3')	Time: Tracking preference	1.1	0	Moderate
F2.7	Option to add notes to your answers so I can provide more details	Word: Ambiguity	1.1	0	Moderate
F2.8	Let me answer using my voice instead of touching the screen	Space: voice	0.6	1	Low
F2.9	Have results be spoken using audio instead of reading	Space: voice	0.6	2	Low
F2.10	Use animations and screen transitions between questions	Visuals: tracking preference	0.3	2	None

For cycle 2, from the MoSCoW exercise the highest priority features related to the Word dimension (F2.1, F2.2) in particular, the choice of words and phrasing used in the questions being asked. Terminology was the highest priority issue raised (F2.1) with many participants taking umbrage at the use of 'marriage' on the results page. While this topic was not discussed as heavily during the workshop as the issue of ambiguity, it scored significantly higher in the MoSCoW feedback. The next priority feature regarding questions was their ambiguity and lack of relevance (F2.2) with much criticism raised against the format of the questions and the predefined response options. Additionally, many participants voiced confusion to why a question about physical health was being asked as part of a dementia PROM and felt the question in its current form was irrelevant to them and their dementia. In question 3, participants queried the use of the word 'lately' criticising that with dementia many found it hard to gauge periods of time coherently and the vague use of 'lately' made them unsure on whether they are thinking of today, the past week, or since the last questionnaire. Many stated that their response could fluctuate significantly over any given period and that they would prefer questions that asked in the moment.

6.6 Cycle 3

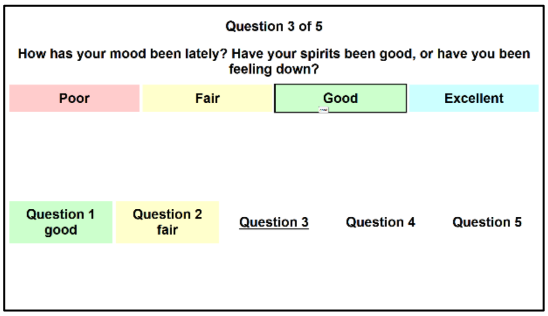
The purpose of cycle 3 was to develop and test high-fidelity prototypes using the feedback from cycle 2.

6.6.1 Cycle 3 prototypes

The most popular features of the previous cycle 2 prototypes (table 16) were combined to create the pre-production prototype (P3.6) This included using the tracking prototype (P2.2) as the basis of the main questionnaire with the results being displayed using features of the Listed (P2.7), Chart (P2.8) and Line (P2.9) prototypes. The option to share results was implemented from the Share prototype (P2.10) and a new home page menu was added as were options to turn on and off certain features such as colours or voice.

Table 16 Cycle 2 preferred prototypes

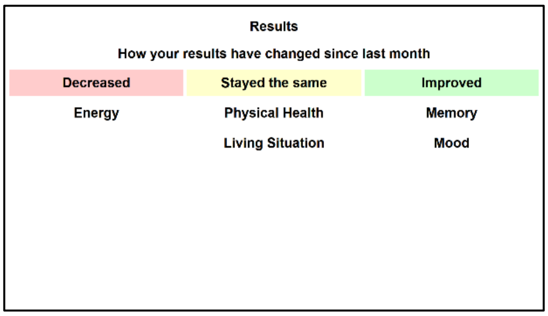
P2.2 Tracking



Question 3 of 5

How has your mood been lately? Have your spirits been good, or have you been feeling down?

P2.7 Listed

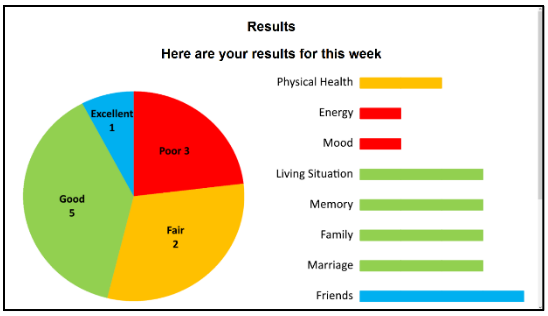


Results

How your results have changed since last month

Decreased	Stayed the same	Improved
Energy	Physical Health	Memory
	Living Situation	Mood

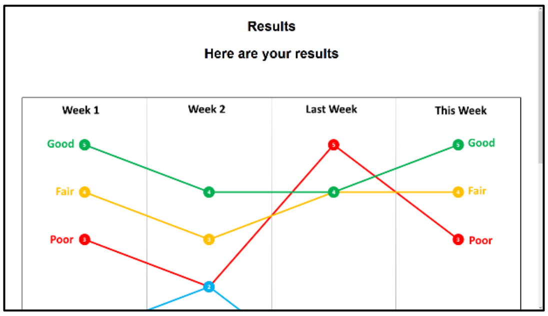
P2.8 Chart



Results

Here are your results for this week

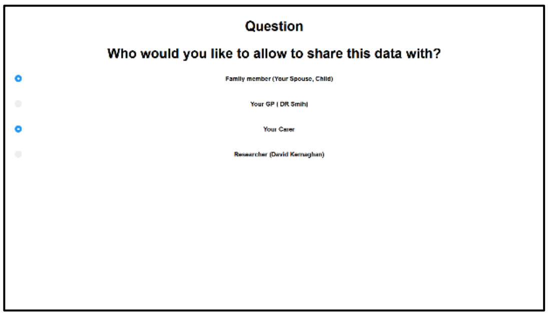
P2.9 Line



Results

Here are your results

P2.10 Share



Question

Who would you like to allow to share this data with?

● Family member (Your Spouse, Child)

○ Your GP (DR Smih)

● Your Carer

○ Researcher (David Kernaghan)

Following the comments regarding the questions during Cycle 2, it was decided that a full review of all 13 questions from QoL-AD would be implemented in the cycle 3 prototypes. Feedback from cycle 2 highlighted key challenges around the ambiguity, relevance, and terminologies of QoL-AD questions.

Given that these extensive comments were based on 5 of a possible 13 QUAL-AD questions used in Phase 2, for Phase 3 it was decided prototypes would be designed to display all 13 QoL-AD questions to participants to identify further issues. Prototypes were developed in a text-based modality. The first prototype (P3.1) was designed to show how a single question would be displayed. The 2nd prototype then had multiple variations of each question for participants to choose between which were taken directly from QoL-AD or modified using feedback from cycle 2 (P3.2). 2 further prototypes were developed to display a single response (P3.3) and multiple variations of the responses (P3.4). An additional voice only modality prototype was developed to focus entirely on a verbal only prototype (P3.5).

Table 17 Cycle 3 Prototypes

Method	Description	Prototype Produced	Features Developed
Words	Prototypes displaying only questions or responses with no other design flourishes. This covered all 13 QoL-AD questions and 4 predefined answer responses with a focus on the wording and terminology of each question in detail.	P3.1 Questions P3.2 Questions Variants P3.3 Responses P3.4 Answers Variants	F2.1 F2.2
Voice	Prototype making use of verbal only questionnaire taken from the interview script and responses from for QoL-AD with no visual ques. Participants complete this using voice only.	P3.5 Voice	F2.8 F2.9
Multimodal	Prototype that makes use of multiple methods of questioning, combining text, visuals, and voice features to complete the questionnaire. This prototype additionally shows the home page of the app as well as feature toggles, results pages and sharing options.	P3.6 Pre-Production	F2.3 F2.4 F2.5 F2.6

6.6.2 Cycle 3 workshops

The cycle 3 workshop took place in March 2022. This consisted of four returning participants (three PwD and one IC) that took part in Cycle 1 and Cycle 2. Participant PWD5 took ill and was unable to participate in this workshop.

The workshop was conducted online via a group video call and was attended by a representative of Alzheimer's Scotland as an observer and a 2nd researcher to overview. The workshop lasted for 85 minutes and followed a format similar to cycle 1 and 2 but with updated prototypes presented to users.

6.6.3 Cycle 3 analysis

6.6.3.1 Workshop 3 Framework Analysis

The framework analysis identified 5 themes and 6 sub-themes as detailed below.

6.6.3.1.1 Word Dimension

As workshop 3 involved a full review of all 13 questions of QoL-AD that were to be used in the prototypes and the responses, The most prominent theme identified relates to the word dimension. Participants found difficulty regarding the complexity of the questions and terminology, which was also raised in cycle 2.

6.6.3.1.1.1 Complexity of Questions

A particular barrier highlighted was the length and complexity of questions. Most questions were deemed far too long and multifaceted to read or that questions were asked in a way that did not align with the responses available (table 18). Several questions were noted to be too long especially those that posed multiple facets for a single question (Q2, Q3). Some questions were deemed too large in their scope for participants to consider (Q6) and questions where a yes/no answer seemed more appropriate than a 4-point scale (Q4). One participant found the short headings used above each question to be enough and easy to read at a glance. Finally, participants noted that some questions (Q6, Q7) could be combined as the overlap between family and partners would be hard for them to separate.

Table 18 Examples of QoL-AD questions

Source	Number	Question

QoL-AD	Q2	How do you feel about your energy level? How have you been feeling most of the time lately?
QoL-AD	Q3	How has your mood been lately? Have your spirits been good, or have you been feeling down?
QoL-AD	Q4	How about your living situation? How do you feel about the place you live now?
QoL-AD	Q5	How about your memory?
QoL-AD	Q6	How about your family and your relationship with family members such as brothers, sisters, children, nieces, nephews?
QoL-AD	Q7	How do you feel about your marriage? How is your relationship with that person?
QoL-AD	Q9	How do you feel about yourself—when you think of your whole self, and all the different things about you?

PWD4: Erm, having all the words [Q2], not that I have a problem with words, but you know it's a bit heavy so maybe a wee bit of a description, but smaller or something. ***Researcher 3: it's quite a long* question and its in 2 parts, so it does seem overly complex.** **Multiple participants: yeah, yes, yeah**
PWD3: I think it's difficult because there are 3 answers[Q3], it's not as, not as focused as id expect it to be?
PWD4: I feel that would be a yes or a no answer (Q4)
PWD2: I think that would be preferable cos again its 2 questions [Q4 compared to Q3], and the answer to the second answers the first as well.
PWD4: I think questions 6 and the other [Q7] can be put together. Or maybe have parts to put the family members with different options but I don't think it needs to be separate questions.
PWD4: yes, I'd be able to answer it, but I also think that's there's too much there, the headings enough [Q9]
PWD4: When completing a form, you don't need loads of these statements, you don't need all these words, you should be able to ask a brief thing I think.
PWD4: I think the headings is useful.

6.6.3.1.1.2 Terminology

Another area of significant comment related to the frequent use of certain terminology used in the questions. As raised in workshop 2 (F2.2), participants disliked questions that asked users to consider a period of time, especially with the term ‘lately’ which they found imprecise and confusing to gauge. This was once again raised in workshop 3 when reviewing all the questions with participants noting the term was ‘difficult’ to gauge what period of time the question wanted you to consider.

Another use of terminology that participants commented on was questions starting with ‘How about’ (Q4, Q5, Q6). Participant PWD2 noted the grammar was incorrect which made some questions unanswerable with the responses available and participants much preferred a more personal question such as ‘how do you feel’ which was easier to interpret. While these terminology issues may appear minor, participants appeared to be fixated on these issues, with half of the entire workshop’s runtime spent discussing the questions. If not dealt with, such issues could encourage participants to lose confidence in the questionnaire and could encourage them to refuse to complete it, or as one participant stated they would “probably bin it to be honest”.

PWD2: I think the use of the term lately is perhaps difficult, does that mean yesterday and today or in the last fortnight?
IC2: Depends if you’re thinking about the present time and is it like a regular question so you monitor it.
PWD2: I’m not sure about ‘how about your memory’ as that’s not really a question. ***PWD2: again, I don’t want to be difficult but again I don’t know what the question is. It starts with how about? What is the answer to how about?***
PWD2: I don’t understand what the question is, how about? What does how about mean?
PWD2: I think there is an assumption that people can. Maybe the question should be are you able to do things that you enjoy and then a comment box for you to list what they are rather than again this ‘how about’. Sorry I was an English teacher so start a question with how about? How about what? What’s the answer to how about?
PWD2: Yeah, I’d probably bin it [QoL-AD] to be honest, sorry to be so straight forward.

6.6.3.1.2 Behaviour Dimension

The next major themes all regarded the behaviour dimension, specifically questions around sensitive topics and additional input options for participants.

6.6.3.1.2.1 Sensitivity

One theme that arose again after reviewing the questions in full was how many of the questions asked about participants personal lives that could be insensitive, upsetting, or rude. Participants queried if people who were widowed, had no family, or did not have friends would be asked these questions.

PWD2 also asked if information about a person's situation could be collected prior so that during the initial set up of the app, these questions can be omitted from the questionnaire on a user-by-user basis. Participants were also keen on the option to skip questions.

PWD3: what do you do if you're answering the questions, and your spouse is dead?
PWD2: I think the option to skip would be useful. Because of my situation I don't have children and I'm an only child and have no nieces or nephews so be able to skip the question without refusing me to continue like the census [The Scottish census which was discussed prior to recording] did. ***PWD2: and I think PWD3's point that if someone's been widowed, if we are gathering that type of information before we are starting the questionnaire process then a flag that says don't ask questions about marriage or a partner if they've been widowed or bereaved, that would be helpful.***
PWD2: I'm aware I'm talking as if I am tommy no mates but there are some people who see themselves as not having a circle of friends and being asked this question could be a trigger for some emotion around the fact, I am tommy no mates and I have got nobody.
DK: so, it's come up a little bit before so would you like to option to skip questions? ***Multiple participants: yes, yes, yes***

6.6.3.1.2.2 Free Text Input

Participants also showed interest in having additional input options when using the novel application. Numerous times when discussing the questions, participants requested a free-text comment box to be added so they could provide additional context along with their answers.

PWD4: if it was on a comment, so instead of putting a yes or no, then a bit for a comment where you can put your own wee bit in.
DK: Would you like to have like an optional little box where you can type in…a little bit more extra information. ***PWD2: yes*** ***PWD4: that'd be useful***
PWD2: I think there is an assumption that people can. Maybe the question should be are you able to do things that you enjoy and then a comment box for you to list what they are rather than again this 'how about'. Sorry I was an English teacher so start a question with how about? How about what? What's the answer to how about?

6.6.3.1.2.3 Data Sharing and Autonomy

The final behaviour theme that arose was regarding data autonomy. This was raised in workshop 1 with participants wanting to access their results and in workshop 2 with participants requesting greater control of who the data is shared with. In workshop 3, participants were keen on an ability to easily print results on headed paper so they could take this with them to appointments and to show to HCP. Participants also wished the feature to nominate their own people that the data would be shared with.

PWD2: so, would we be able to print these pages off?
DK: …Would you like an option to print your results as well?
PWD2: Yes
PWD4: yeah

PWD4: would you be able to make it so you could go to the doctor or hospital and take that [results]?

PWD2: would you be able to add someone to that list?
DK: …Do you think like a little option to add extra people to it and contact details for them?
PWD2: yep
PWD4: I think it would be useful to be able to add it yourself. Yeah.
PWD3: I agree with the discussion and thinks it's all fine.

6.6.3.1.3 Space Dimension

The only subtheme relating to space that was discussed was relating to voice. This continued from the previous cycle where voice was a key element of the space dimension discussed.

6.6.3.1.3.1 Voice

As with workshop 1 and 2, the use of voice was of very limited interest to participants with the voice only prototype (P3.5) receiving universal dislike. Participants unanimously agreed that if voice is to be implemented, it must be accompanied by a visual or textual prompt that displays the question asked and the answer responses as many said they would struggle to remember these using voice only.

PWD4: I think even with the verbal one, although the voice is saying Good, Fair, Etcetera, I think its need to be on the page because depending on people's memory, they might not remember what the answers were spoken.
DK: So, you definitely prefer a visual experience or a visual prompt alongside the audio?
PWD4: yes
PWD2: or instead of

> ***DK: do you think something like this [P3.6 multimodal] would be much better so you have the option to have the question with a visual response?***
>
> ***PWD4: Yes***
>
> ***PWD2: Yes***
>
> ***PWD3: Yes***

6.6.3.1.4 Visual and Time

The Visual and Time dimensions were primarily represented in the multimodal prototype (P3.6 Pre-prototype). Participants were very positive towards the prototype with it being deemed easy to use and understandable. No changes were requested to these dimensions.

> ***DK: what do you guys think of this design?***
>
> ***PWD2: yep***
>
> ***PWD4: I like it.***
>
> ***PWD3: well, I'm quite happy with what I am seeing***

> ***PWD4: yeah, I think that is good, it's really helpful but I think excellent [response] should be changed to something else.***

> ***DK: Do we think it's simple and easy enough to use and it's not too complicated or too cluttered?***
>
> ***Multiple: sounds of agreement***

> ***DK: Is the font, OK? Is it all readable and understandable?***
>
> ***Multiple: yeah, yeah, yeah***

6.6.3.2 Workshop 3 MoSCoW analysis

Once again, 3 days after the workshop was conducted, participants were sent an updated MoSCoW survey to complete in their own time. As before, the features were generated from the framework analysis performed in cycle 3.

Table 19 Workshop 3 MoSCoW results

ID	**Features**	**themes covered**	**Moscow score**	**Won't include**	**Priority**
F3.1	Shorten and simplify longer questions	Word: Complexity of Questions	1.8	1	High
F3.2	Remove terms like 'lately' and be more precise with time frames	Word: Terminology	1.8	1	High

F3.3	Set sensitive questions (such as marriage or friends) to optional and not asked if not relevant.	Behaviour: Sensitivity	1.35	1	Moderate
F3.4	Change unclear questions that start with 'how about'	Word: Terminology	1.1	1	Moderate
F3.5	Add comment boxes to questions to add the own notes	Behaviour: Free Text Input	1.05	2	Moderate
F3.6	Allow us to add people we can share the data with ourselves	Behaviour: Data Ownership And Autonomy	0.75	2	Low
F3.7	Allow us to answer using just the voice	Space: Voice	0.25	1	Low
F3.8	Provide option to skip questions	Behaviour: Data Ownership	0.15	0	Low
F3.9	A voice only option that will run on a device like Siri or Amazon echo	Space: Voice	0	0	None

The top priority was the word dimension with 3 of the top 4 prioritised themes (F3.1, F3.2, F3.4) belonging to this dimension. A significant amount of priority was also set for the behaviour dimension (F3.3, F3.5, F3.6). Matching the framework analysis results for workshop 3, MoSCoW results recognised shortening and simplifying the longer questions (F3.1) as well as updating the terminology that asks about time (F3.2) as being top priority. Participants also wanted to see grammar updated to remove the use of questions starting with ‘how about’ for clearer questions (F3.4). Regarding question sensitivity, Participants had a significant preference for unnecessary or sensitive questions to not be shown at all to participants (F3.3) rather than just the option to skip (F3.9). While participants were open the idea of being able to skip questions entirely in the workshop, this was a rather low priority. Participants also showed some interest in having greater input using the app. A free-text comment box for some questions would allow them to provide additional context along with their answers (F3.5) and the ability to nominate people who the data is shared with directly into the app (F3.6) were also pitched. Like previous MoSCoW results, voice modality features were of limited priority (F3.7, F3.9).

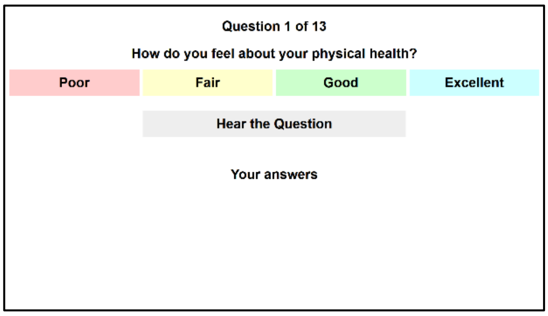
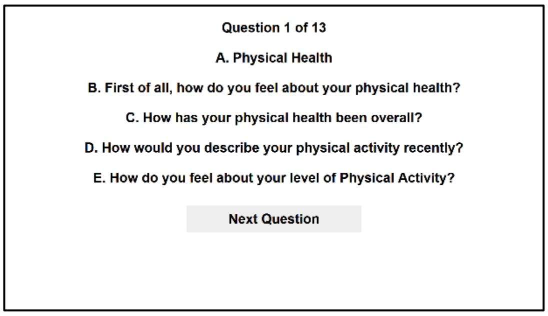
6.7 Cycle 4

The purpose of cycle 4 was to develop a FFP using the feedback from cycle 3 and test them with the volunteers. This was the final cycle of the prototype development phase.

6.7.1 Cycle 4 prototypes

Cycle 4 consisted of a single fully functional high-fidelity prototype. It was developed using all the features of the pre-production prototype (P3.6), updated with the preferred questions chosen from the question prototype (P3.2) to create a fully interactive and functional prototype (P4.1). Following the MoSCoW results, questions were now limited to a single shorter sentence with a single word title for easy comprehension (F3.1, F3.4) and all references to timing was removed (F3.2).

Table 20 Cycle 3 preferred prototypes

P3.6 pre-production	**P3.2 Questions Variants**
 Question 1 of 13 How do you feel about your physical health? Poor Fair Good Excellent Hear the Question Your answers	 Question 1 of 13 A. Physical Health B. First of all, how do you feel about your physical health? C. How has your physical health been overall? D. How would you describe your physical activity recently? E. How do you feel about your level of Physical Activity? Next Question

This prototype takes the HTML and CSS elements used throughout the previous prototypes (discussed in cycle 1) and converted them into elements generated by PHP. This enables the prototype to pull live data submitted by users from the SQL database and use it in real time to display previous responses and live results. PHP is also used to handle, post, and retrieve data from an SQL database which is used as the primary data store for all data. For the results screens, data is retrieved from the SQL database using PHP with the chart visuals generated using JavaScript and Chart.JS.

Two requested features were not implemented due to a range of factors. The feature to set sensitive questions to optional so that they are not asked unless relevant (F3.3) was deemed outside the scope of the prototype as this is information that would need to be collected by HCP prior to using the novel application. The feature to add a free text box to questions so users could add their own notes and comments (F3.5) would require additional security provisions and permissions to avoid SQL injection attacks which were not possible with the limited development time between workshop 3 and 4 where higher priority features were prioritised. Additionally, as the first beta prototype, certain features were not functioning optimally such as the colours used on the review responses page, the size of the pie charts used in results, and the live update of the line graph.

Table 21 Cycle 4 Prototypes

Method	Description	Prototype Produced	Features Developed
Multimodal	Functional beta Prototype that contains working features (or approximations of) that the user can fully interact with.	P4.1 Beta	F3.1 F3.2 F3.4

6.7.2 Cycle 4 workshops

Two workshops were conducted during cycle 4 that took place in April and May 2022. The first workshop consisted of the four participants (three PwD and one IC) that took part in cycle 3. Due to a last-minute schedule conflict, Participant PWD5 could not attend the group session so the second workshop was held to accommodate them.

The first workshop was conducted online via a group video call and was attended by a representative of Alzheimer's Scotland as an observer and a 2nd researcher to overview. The workshop lasted for roughly 75 minutes. The 2nd workshop consisted of a single participant and 3rd researcher to overview which lasted approximately 20 minutes.

Both workshops followed a similar format to the previous workshops, where the prototype was first presented via screen share with the researcher performing a quick walkthrough of all the features and changes made since the last workshop. As the app was functional, users were then invited to try out the app themselves following a Think Aloud Protocol. Due to the universities' security policy, participants were not given the required permission to control the screen or share their own screen, so a video recording of their interaction was not possible. Participants were therefore sent a web link to complete via their web browser, meaning relying on their verbal communication of what actions they were completing. Three of the five participants (three PwD) were able to access and complete the Think Aloud Protocol independently with the remaining two (one PwD & one IC) unable to access the prototype due to technical difficulties though still provided feedback regarding the app's features. A final cognitive walkthrough was performed with participants so participants could reiterate feedback as a group after experiencing using the prototype. At the end of the workshops, a short discussion was held regarding future implementation and features outside the scope of the prototype development that would allow better implementation and encourage adoption if the prototype was deployed further in future.

6.7.3 Cycle 4 analysis

6.7.3.1 Workshop 4 Framework Analysis

The framework analysis identified 4 themes, and 11 sub-themes as detailed below.

Overall, response to the final prototype (P4.1) was positive, with most of the final cognitive walkthrough having participants praising features and design choices of the prototype. Participants highlighted the prototype for many of its features in particular its ease of use, accessibility, and the clarity of the questions. While there were some technical issues in users accessing the prototype, this was primary caused by Microsoft Teams including issues with control of sharing permissions and how it handled the weblink with web browsers. Participants who were able to access the app were all able to complete the questionnaire in full, choose who to share the data with, and view their results quickly without any difficulties. Overall, participants requested limited changes to the prototype.

PWD4: I like it. ***PWD2: I think it’s excellent***
PWD5: Yeah, that was very easy and intuitive.
PWD2: I don’t think there is anything I would like to see change
DK: Is that a good question, is and is there anything anyone would change? ***IC2: good question*** ***PWD2: nah, its good*** ***PWD4: its good questions***
DK: There’re no issues or anything you would like to see changed. ***IC2: I think we’re happy.*** ***PWD2: yes.***
DK: anything you would like to see added or changed? ***IC2: at this moment I can’t think of anything***
PWD5: that [prototype] is a lot easier that in was [cycle 3 prototypes], if I remember ***PWD5: yeah, that’s a lot, that’s a lot better than before I think. That’s what I wanted in it I think, and what we all wanted.*** ***DK: Perfect but yeah, is there anything…you think you're missing that should be added or anything that you think we need to change?*** ***PWD5: no, I think that that’s about it, yeah that’s good.***
DK: so, there's nothing you'd like added or changed. Or any features that you think are missing? ***PWD5: no, that is, you saw how quick I did it.***

PWD5: no, I think you did a good job there.

PWD5: you've coded it well and it looks good.

PWD5: it is easy to use

6.7.3.1.1 Behaviour Dimension

When it came to changes, the majority revolved around the behaviour dimension.

6.7.3.1.1.1 Setup

Participants were confident in their ability to set up the prototype themselves, as well as being in control of who the data is shared with. Participants who could access the prototype were able to complete the questionnaire and all the features independently and quickly. one participant mentioned they would feel uncomfortable with having someone else like a HCP setting up the questionnaire, especially regarding questions about finance that they would not like to be raised with HCP.

DK: Would you prefer it to be set or would you like to have the option to set up yourself? Or would you prefer like whoever sets the offer healthcare professional to set her up for you?

IC2: set it up myself, I think.

PWD4: I think so.

PWD2: I think so too, yes

PWD5: I think that is probably quite a good idea [setting up the questions themself, I wouldn't want my doctor to know too much about my personal life

DK: would you, that [Questions sharing] be something that you'd like to be able to turn off yourself?

PWD5: yes

DK: Or would you prefer someone else to sort that out?

PWD5: yeah, I would do it, I mean I don't mind, it's not that hard so I would do it

PWD5: no, that is, you saw how quick I did it.

6.7.3.1.1.2 Free Text Input

Participants were concerned that some of the questions did not provide enough context at times, for example if the user had an argument earlier that day, this could affect their response to how they feel about friends/family. Adding an optional free text input at the end of the questionnaire would allow users to include such context. This theme was previously raised in cycle 3 (F3.5) but after further discussion it was decided a single comment at the end of the questionnaire was better than a per question basis.

> ***PWD2: I think some of the questions I'm just a bit concerned that. Your answer is going to be specific to the day that you do the questionnaire. … And if you've had a row with somebody first thing in the morning, and you do this in the afternoon, yeah. That might affect how you answer.***
> ***DK: That is true…So let's say if you did have, let's say, an argument during the day that during the final page you could add a little bit of a little bit of notes saying that actually I had an argument today, so it affected my mood. Do you think that would be a good solution for that?***
> ***PWD2: I don't know if it's that much if an issue to need that kind of solution. Yeah, it might just be me being a bite pedantic***
> ***PWD4: You know, even if they have a comments box somewhere, yeah, you know to put in comments if you needed too, you know?***

> ***DK: What if in the space here before underneath the question if that PWD4 was saying if we had a text box where you can type in additional notes if you think about something that you yourself would be quite interested in?***
> ***PWD4: yeah, I would be interested in that.***
> ***IC2: I think we're happy.***
> ***PWD2: yes.***

> ***[in response to being asked 'any other features]***
> ***PWD4: And the comments box***
> ***IC2: and it would be optional, wouldn't it? So, you comment if you wish?***

6.7.3.1.1.3 Frequency

Participants were keen to have the option to choose the frequency of the questionnaire. Most participants seemed to favour monthly delivery for the PROM. one participant did request once a week and that it would be better for building up a routine and make it harder to forget.

> ***PWD2: I think making it once a month would be more likely to encourage people to use it than once a week.***
> ***PWD4: hmmm, Yeah, I think you should have the option to do it weekly because I think if it was. Monthly. And. I might forget what I did, yeah? Or even 2 weeks ago? Yeah no. So, I would need to do weekly. Yeah I. I would say the end of the week or as the weeks progress. Sort of thing.***

> ***DK: How often would you want to do it?***
> ***PWD5: probably monthly?***

6.7.3.1.1.4 Data Autonomy and Ownership

One participant inquired if their data could be saved and printed with the functionality to print off their results built into the prototype. While this feature does exist natively for most web browsers, the participant was keen to have this feature built into the novel application for easy use. This feature was previously raised in Cycle 3 where participants wished to have results printed on headed paper that they could take with them to appointments and share with HCP.

PWD2: would that be printable?
PWD2: would I also be able to save that?
DK: …would you definitely like to have it printed up? So, when you print it out it gives you a description of what this data means. **PWD2: yes**

6.7.3.1.2 Space Dimension

The next major theme related to the space dimension and how the questionnaire would be accessed and used in a real-world environment.

6.7.3.1.2.1 Delivery Method

During the workshop, one participant asked how someone they have nominated to share the data with would be granted access. This led to a discussion on delivery methods for the app. Participants unanimously supported an email link system over a login system, where users are notified by email when they were due to complete a new questionnaire. The email would contain a link to the questionnaire which would allow them to complete the task in web browser and would avoid any complexity of having to download an app, install a plug in, or worry about login details. one participant also presented the idea that the questionnaire links could be set up in their personal calendar allowing them to access it directly from their personal calendar.

PWD2: I've got to ask. How does someone that I've given permission to share with about the days Access it?
DK: so, a simple email link where essentially you just get an email link whenever we have a new questionnaire for you, and you'll be able to access it. And ***PWD4: yeah.*** ***PWD2: yeah*** ***IC2: Yep, I second that id find that easier as well***
DK: So, everyone would be happy to instead of having to log in and set it up to have it via email… ***PWD2: who would send that email?***

DK: It would be sent automatically... So, it does that sound like a good option for everyone.

Multiple: yes, yeah

PWD5: I thought of a third option just to wind you up.

DK: Oh yeah, go ahead.

PWD5: Could it be linked to say that of a calendar?

PWD5: I do like my calendar

PWD5: yeah, I'd say you press it, and it takes you to the questionnaire.

DK: Yeah, it should be doable. I shouldn't be too difficult.

PWD5: because that is how I work these days

6.7.3.1.2.2 Voice

Participants were once again unsupportive of voice features being implemented. Participants unanimously chose to have this turned off by default in the multimodal prototype, noting that they disliked the voice and only bribery could encourage them to use such features. While one participant did like having the option, they noted that they would feel pressured to wear headphones if voice features were implemented in order not to disturb others in their household. Another participant also questioned if the device would be effective at understanding heavy Scottish accents which may frustrate certain users.

PWD4: Yeah, I can turn it on if I want to but I'm fine with it off at the moment, but I can turn it on if needed too

DK: is there any way we could encourage people to use your voice features? Or is it a lost cause?

PWD2: Bribe me with cigarettes.

****laughter****

PWD4: oh no, we can't bribe you PWD2, eh I could go with a gin.

DK: I'll put that down cigarettes and gin.

PWD4: No. No. But I do like the options…. Sometimes it should be easier, but I would just have to keep headphones handy if I had the voice on and a family member about so I'd say no. **I think it would be very useful, don't get me wrong but. Sometimes it's better to use earphones then it doesn't bother other people.**

PWD5: no, the problem is the voice feature right. is I don't like the voice, so I wouldn't have voice, but yeah, you're gonna have a problem listening to people's accents

PWD5: cos mine's [accent] not too bad, but up here, it's a very strong accent, Hmm the [local] accent yeah. It will miss hear, so that would annoy people.

6.7.3.1.2.3 Mobile

Finally, Participants were indifferent to the prototype being developed for mobile devices. Some thought it may be useful to have as an option though most agreed that a mobile screen is far too small to comfortably use for this purpose.

DK: anyone be interested in seeing it on a smaller device like a mobile phone?

IC2: urmmmmmm

PWD2: I'm not sure on that.

PWD4: well, I would like the option.

DK: … Did you say you wouldn't be interested?

IC2: That's right, I think too small. There's just not, not manageable.

PWD2: I think the options there I'd probably not take the option. Yeah, if it's there, it's there.

PWD5: No, I think phone things are too small.

6.7.3.1.3 Visual Dimension

Regarding the visuals, participants had a few minor adjustments they would like to see changed relating to the results and questions.

6.7.3.1.3.1 Graphs

Participants often had a divided preferences between the pie chart and line graph display for the results meaning having the option to switch between them being a good feature to implement. The only changes requested was for thicker lines and larger fonts to be used on the line graph for easier reading and for the pie chart to be resized to better fit on the screen.

PWD2: yes, but not as useful as the line graph [regarding the pie chart].

PWD5: yeah. So, this 1 the line graph would be a bit too confusing.

PWD5: to me that would be too confusing but that's just me

PWD4: Sorry Can I just ask? If the pie chart is too big, could the lines on the graph be made slightly thicker?

6.7.3.1.3.2 Share Buttons

Multiple Participants were momentary confused by the share page as they were unable to locate a button due to its placement at the bottom of the page. This feature would allow PwD to add contacts such as IC or HCP they wish their data to be shared with. Participants frequently overlooked this feature and only when prompted by a researcher did participants realise the option. Moving the button placement to the top would likely resolve this issue for future users.

DK: try and see if you can add a new person? At the bottom

PWD4: Oh, I never read that because, sorry

DK: Do you think it would be better if instead of having the options here, …have all options at the top next to each other

PWD4: possibly

IC2: yeah, slightly easier isn't it, yeah

DK: there should be options to choose who to share, so if you could add someone, you'll add a new person to write results.

PWD5: now what do I do? OH, I see that I'm sorry yeah

DK: Maybe if I have all options at the top next to each other and then the same options all the way at the bottom so you have all the options available, do you think that would make it easier to complete and not get you lost with it?

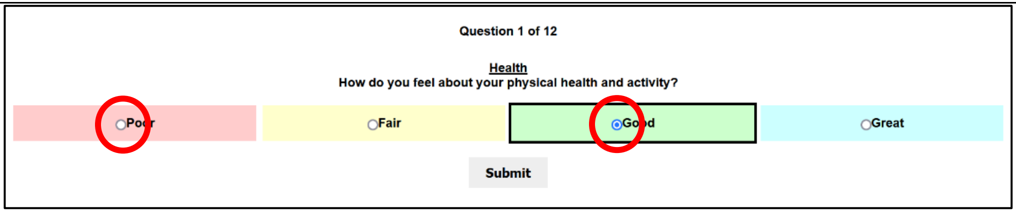
PWD4: possibly

IC2: yeah, slightly easier isn't it, yeah

6.7.3.1.3.3 Radio Select

Finally, one participant thought that they had to click on a small circle icon when answering questions instead of anywhere on the button. This icon was added to help indicate selected options in 'colour off' mode but could prove confusing to certain users.

PWD2: Yes, Aye, I guess you had to click in the wee circle?



Question 1 of 12

Health

How do you feel about your physical health and activity?

○Poor ○Fair ◉Good ○Great

6.7.3.1.4 Time Dimension

The only subtheme relating to the time dimension was an option to end the session and close the app.

6.7.3.1.4.1 End session

Some users were not aware on what to do once they had completed the questionnaire and reviewed their results. While the webpage can be closed at any time, the lack of a prompt to do this caused minor confusion with one participant. It was therefore requested that the inclusion of an 'end session' button to be displayed at the end.

PWD2: I've done that, I'm now back at the screen that says, 'your dementia app. Thank you for submitting the questionnaire'. There's nothing that tells me how to close it.

DK: do you think it'd be better to have … a button that you click, and it closes the page? ***PWD2: End Session*** ***PWD4: yeah, something like that yeah***
PWD2: The only thing for me is at this stage is a button to see close or end session.
DK: Yeah, perfect so and so like you could have a button here just like so 'see my results', 'Choose who to share with', and then 'end session'. ***Multiple: yeah, yeah***

6.7.3.1.5 Word Dimension

No themes discussed during the workshop related to the word dimension. This was likely a result of cycle 3 spending significant focus on this dimension and these issues being resolved.

6.7.3.2 Workshop 4 MoSCoW analysis

For the final workshop, participants were sent an updated MoSCoW survey to complete in their own time 3 days after the workshop was conducted. The features were generated from the framework analysis performed in cycle 4 as well as a returning feature from cycle 1.

Table 22 Workshop 4 MoSCoW Results

ID	Features	Dimensions covered	Moscow score	Won't include	Priority
F4.1	A button at the end to end the session	Time: End Session	2.6	0	Very High
F4.2	Questions automatically move to next when answered	Time: F1.4	2.3	0	Very High
F4.3	A comment section to add your own notes	Behaviour: Free Text Input	2	0	High
F4.4	A button to print out the results	Behaviour: Data Ownership and Autonomy	1.6	0	High
F4.5	A mobile version of the app	Space: Mobile	1.2	1	Moderate
F4.6	Thicker lines and larger fonts used on the Line Graph	Visuals: Graphs	1	1	Moderate

F4.7	More visible buttons on the 'share with' page	Visuals: Share Buttons	0.85	1	Low
F4.8	Voice feature that reads out questions and allows you to answer with your voice.	Space: Voice	0.6	2	Low

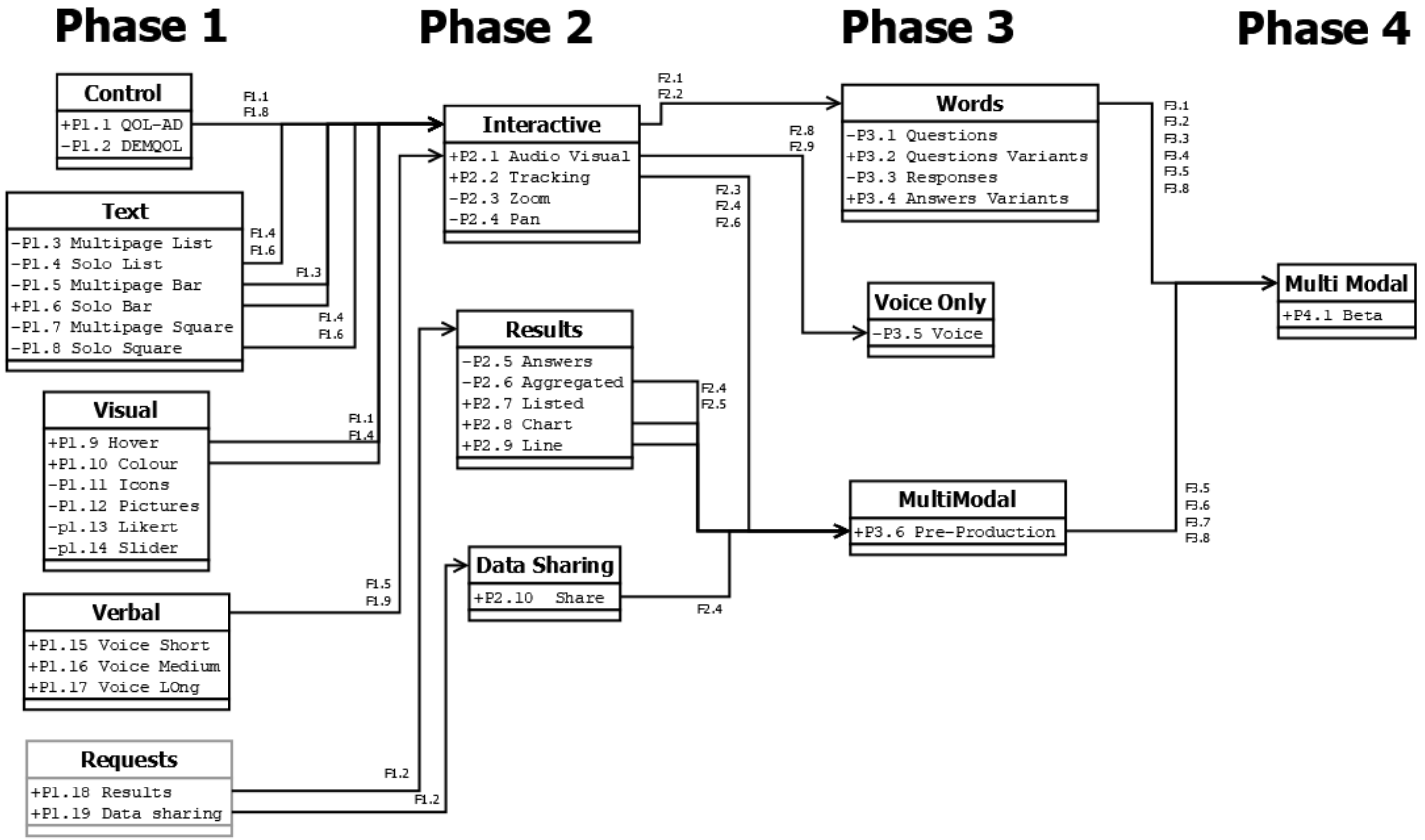
For the final co-design workshops, Time was the most prioritised dimension (F4.1, F4.2) followed by Behaviour (F4.3, F4.4). Participants wished to see a definitive end to the app with an ‘end session’ button that would close it when completed which would reassure them that they have done what was required of them.

Due to the nature of the functional prototype passing data onto a backend database (P4.1), an earlier feature implemented in prototypes since cycle 1 (F1.4) which automatically moved to the next page once an option was selected did not record the data when implemented. This feature was abandoned for the prototype to function correctly. While the feature did not come up in discussion during the cycle 4 workshop, the feature was added to the MoSCoW survey to see if this feature is missed with participants gave significant priority for it to be reinstated (F4.2).

The MoSCoW results also showed a significant priority for a comment box to be added to the prototype (F4.3) so users could add additional context to their responses as well as a print option being added inside the app (F4.4). Participants also requested some minor visual adjustments through these were relatively low priority. Finally, Participants had moderate interest in the app being developed for mobile (F4.5) though once again had little interest in implementing voice modalities (F4.8).

6.8 Final Functional Prototype

During the research study, a total of 34 prototypes were designed (figure 11). Over the course of the prototype development phase, these prototypes were repeatedly tested by PwD and IC and refined with selected features prioritised based on their feedback. This resulted in the creation of the FFP. The online link to this prototype and a video demo of it is included in the appendix documents (Appendix 8). A requirements document was also produced alongside the FFP which is presented in the Summative Evaluation Results which are presented in the next chapter.



KEY (Major themes) Bold: Method of Prototype Arrow : Features implemented +: Features were carried over to the next prototype - : features were not carried over to the next prototype

F1.1 Larger font and bolder fonts
F1.2 Results page for participants to see their own responses
F1.3 Options displayed in boxes
F1.4 Automatically move to the next page
F1.5 Actors voice recording
F1.6 1 questions on each page
F1.7 All questions on 1 page
F1.8 More detailed questions and explanations
F1.9 Visual Prompt with Verbal questions

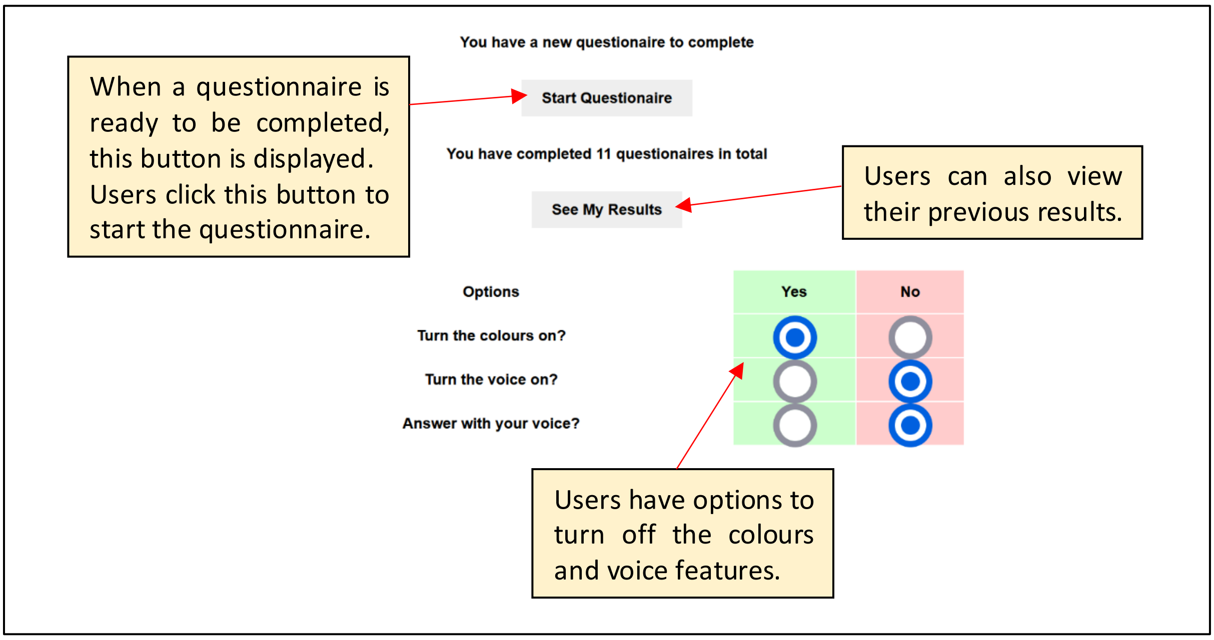
F2.1 Adjust some of the words to be more inclusive
F2.2 Make the questions less ambiguous and more relevant to me
F2.3 Show my previous answers after I submit them and let me change them
F2.4 Option to turn colours on/off
F2.5 Have a drop down menu for results page that go into more detailed
F2.6 Show reminders of what kind of questions have been asked
F2.7 Option to add notes to your answers so I can provide more details
F2.8 Let me answer using my voice instead of touching the screen
F2.9 Have results be spoken using audio instead of reading

F3.1 Shorten and simplify longer questions
F3.2 Remove terms like 'lately' and be more precise with time frames
F3.3 Set sensitive questions to optional and not asked if not relevant.
F3.4 Change unclear questions that start with 'how about'
F3.5 Add comment boxes to questions to add our own notes
F3.6 Allow us to add people we can share the data with ourselves
F3.7 Allow us to answer using just our voice
F3.8 Provide option to skip questions
F3.9 A voice only option that will run on a device like Siri or Amazon echo

Figure 11 Prototype Development Class Chart

This FFP was designed to be used by PwD in a home environment either independently or unsupported by IC. The prototype is accessible via a web link that would be sent to the user. The prototype presents users with a home screen with options to answer the questionnaire, view their previous results, or adjust settings such as the colour display or voice modality. The questionnaire asks 12 questions modified from QoL-AD with the option to have them read out using a digital voice. Once the questionnaire is completed, users are presented with a list of their responses and the opportunity to change their responses. Users are then presented options to choose who to share this information with as well as an ability to add new people to this list of contacts. Once this is completed, users are returned to the main menu with the option to review their results in multiple charts and over various periods of time.

6.8.1 Home Screen



When a questionnaire is ready to be completed, this button is displayed. Users click this button to start the questionnaire.

You have a new questionaire to complete

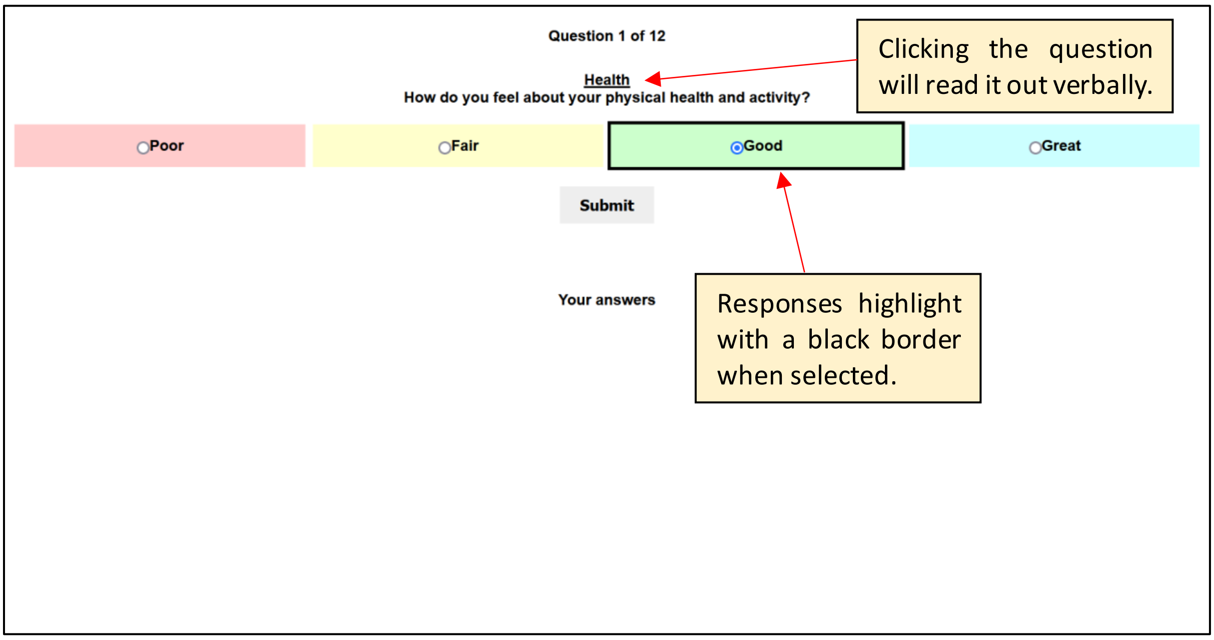
You have completed 11 questionaires in total

Users can also view their previous results.

Options	Yes	No
Turn the colours on?	●	○
Turn the voice on?	○	●
Answer with your voice?	○	●

Users have options to turn off the colours and voice features.

6.8.2 Questionnaire



Question 1 of 12

Health
How do you feel about your physical health and activity?

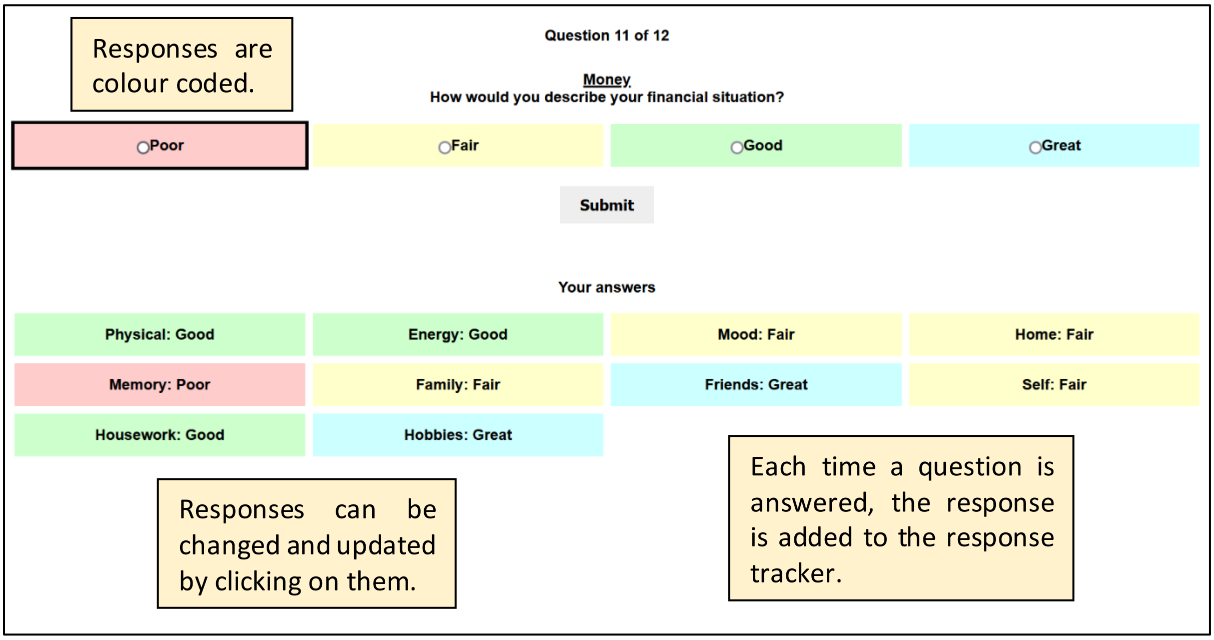
○Poor ○Fair ●Good ○Great

Your answers

Clicking the question will read it out verbally.

Responses highlight with a black border when selected.

6.8.3 Response Tracker



Question 11 of 12

Money
How would you describe your financial situation?

○Poor ○Fair ○Good ○Great

Your answers

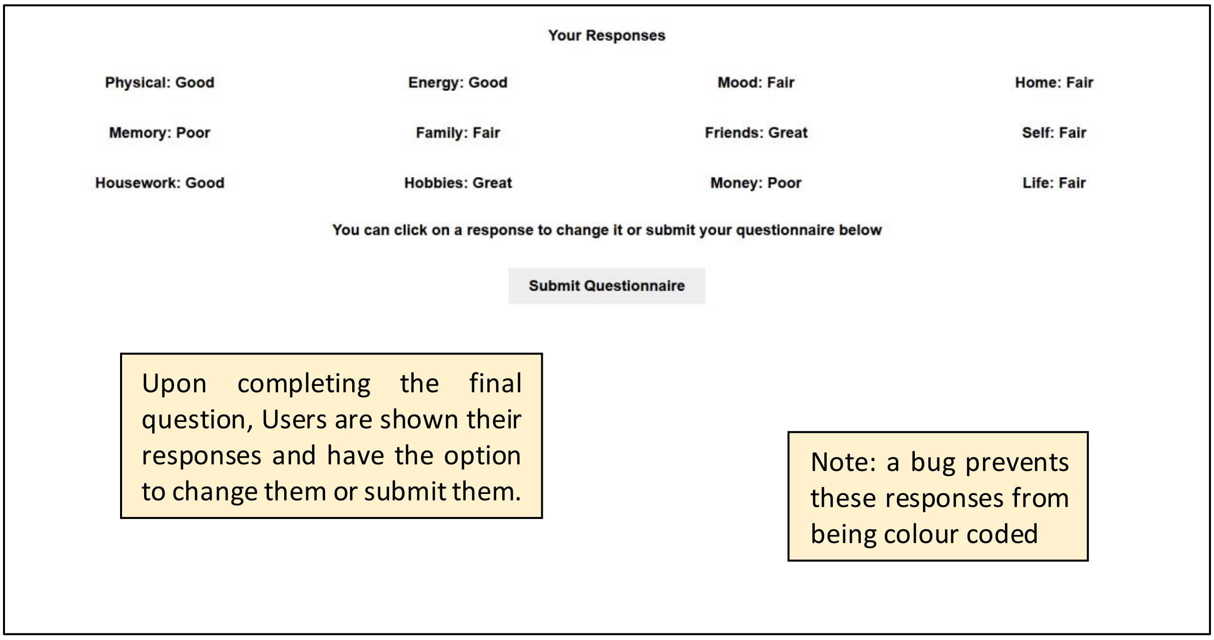
Physical: Good	Energy: Good	Mood: Fair	Home: Fair
Memory: Poor	Family: Fair	Friends: Great	Self: Fair
Housework: Good	Hobbies: Great		

Responses are colour coded.

Responses can be changed and updated by clicking on them.

Each time a question is answered, the response is added to the response tracker.

6.8.4 Review Responses



Your Responses

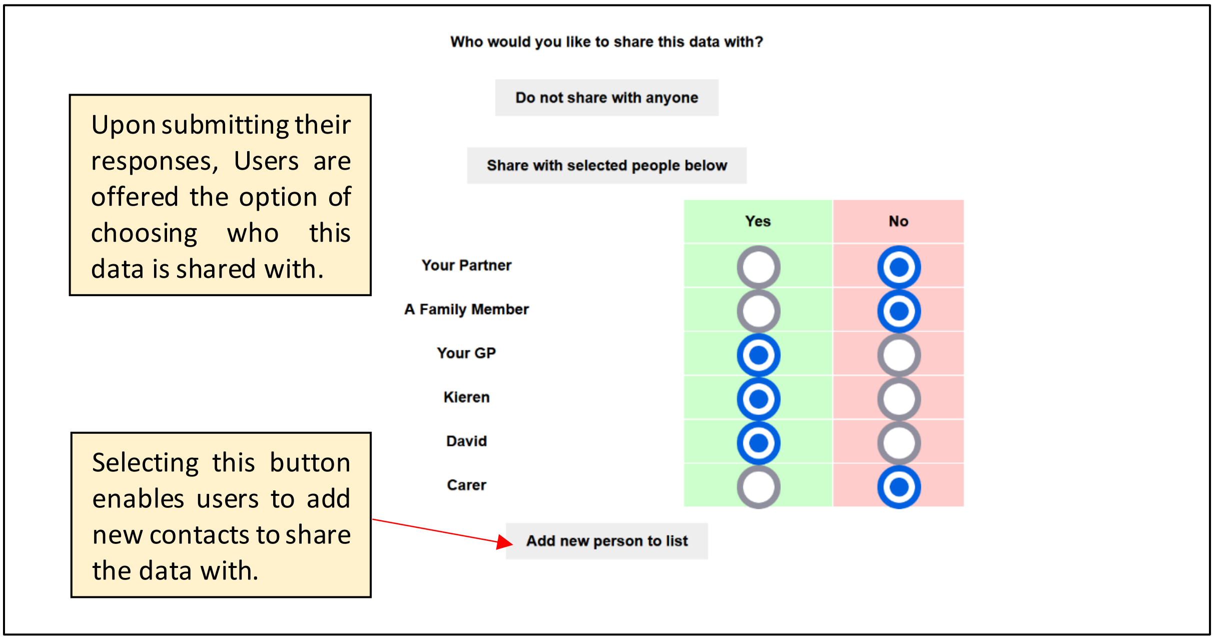
Physical: Good	Energy: Good	Mood: Fair	Home: Fair
Memory: Poor	Family: Fair	Friends: Great	Self: Fair
Housework: Good	Hobbies: Great	Money: Poor	Life: Fair

You can click on a response to change it or submit your questionnaire below

Upon completing the final question, Users are shown their responses and have the option to change them or submit them.

Note: a bug prevents these responses from being colour coded

6.8.5 Data Sharing Screen



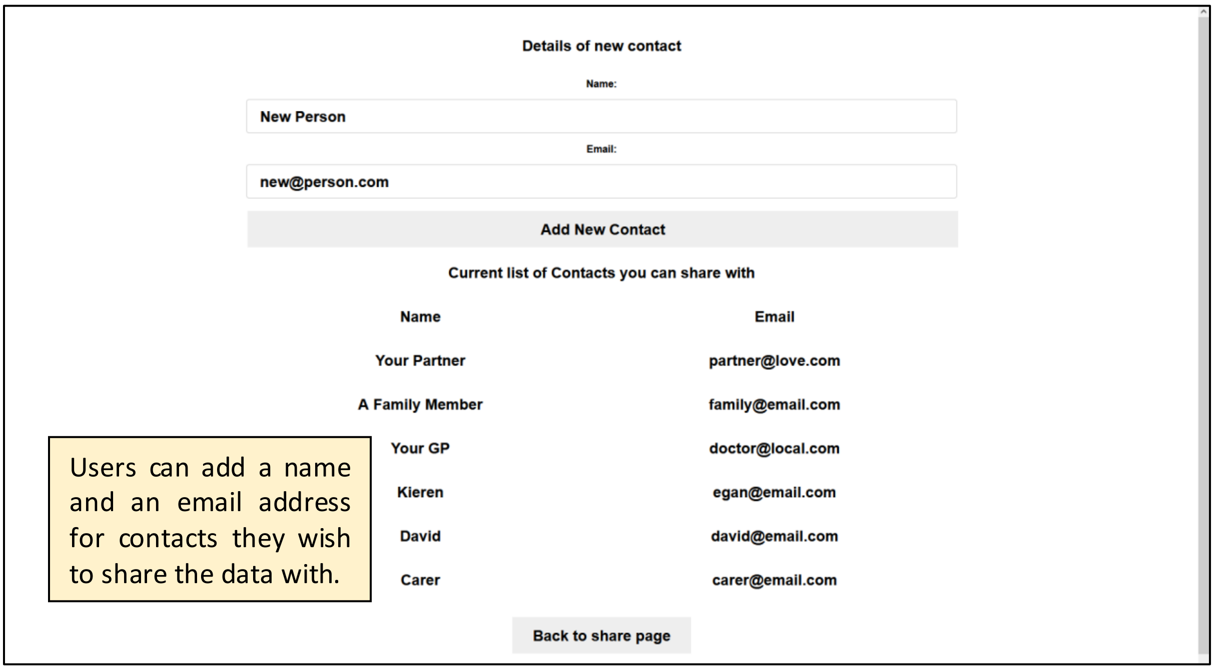
Who would you like to share this data with?

	Yes	No
Your Partner	○	●
A Family Member	○	●
Your GP	●	○
Kieren	●	○
David	●	○
Carer	○	●

Upon submitting their responses, Users are offered the option of choosing who this data is shared with.

Selecting this button enables users to add new contacts to share the data with.

6.8.6 Add New Contact Screen



Details of new contact

Name:

New Person

Email:

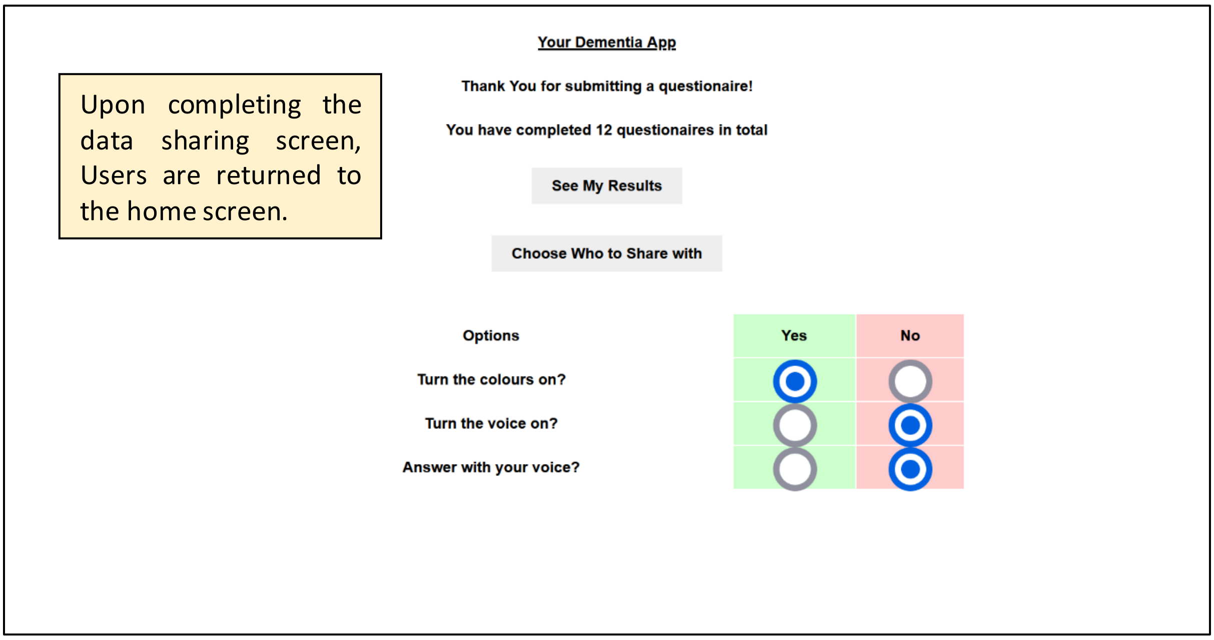
new@person.com

Current list of Contacts you can share with

Name	Email
Your Partner	partner@love.com
A Family Member	family@email.com
Your GP	doctor@local.com
Kieren	egan@email.com
David	david@email.com
Carer	carer@email.com

Users can add a name and an email address for contacts they wish to share the data with.

6.8.7 Questionnaire Submitted



Your Dementia App

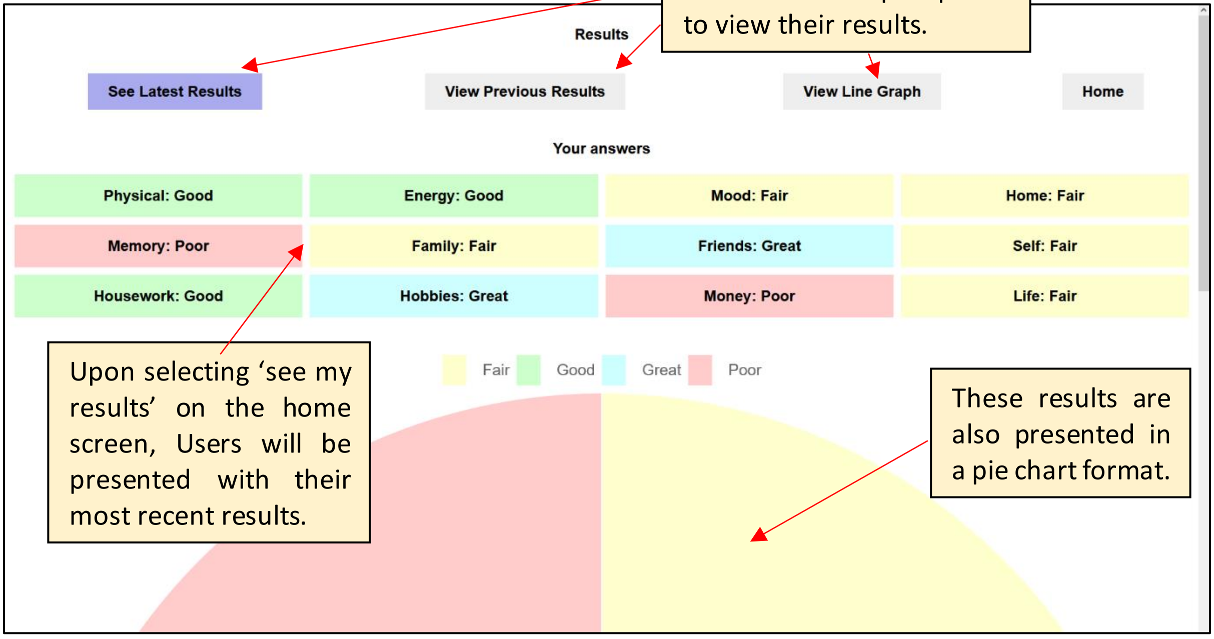
Thank You for submitting a questionaire!

You have completed 12 questionaires in total

Options	Yes	No
Turn the colours on?	●	○
Turn the voice on?	○	●
Answer with your voice?	○	●

Upon completing the data sharing screen, Users are returned to the home screen.

6.8.8 Latest Results Screen



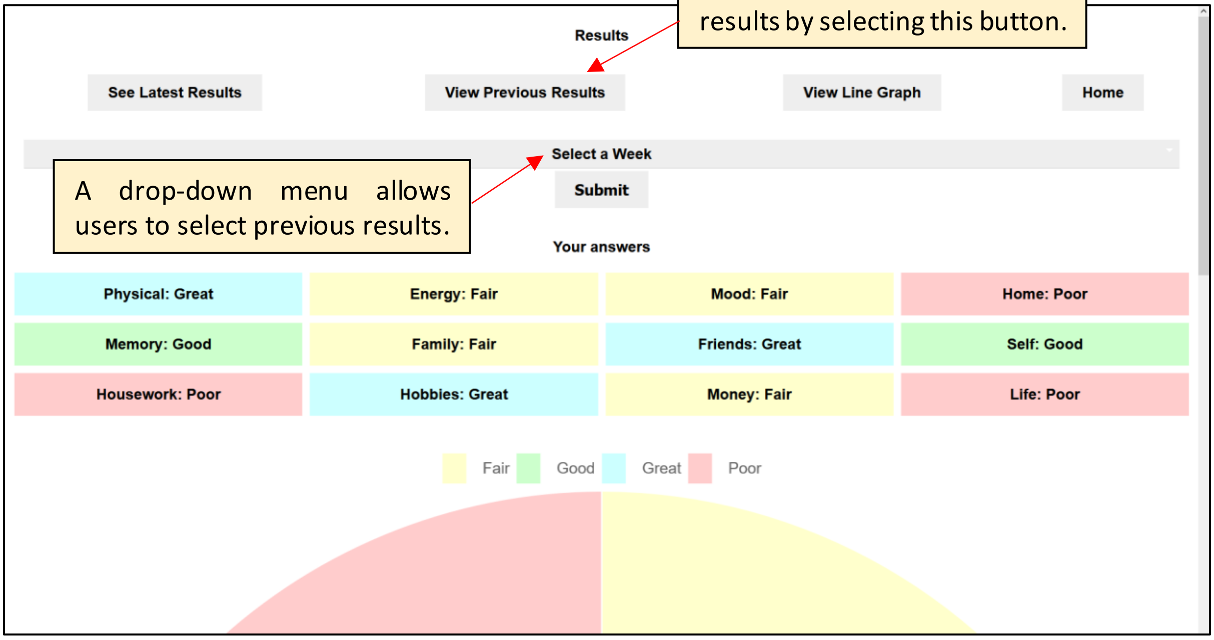
Physical: Good	Energy: Good	Mood: Fair	Home: Fair
Memory: Poor	Family: Fair	Friends: Great	Self: Fair
Housework: Good	Hobbies: Great	Money: Poor	Life: Fair

Users have multiple options to view their results.

Upon selecting 'see my results' on the home screen, Users will be presented with their most recent results.

These results are also presented in a pie chart format.

6.8.9 View Previous Results

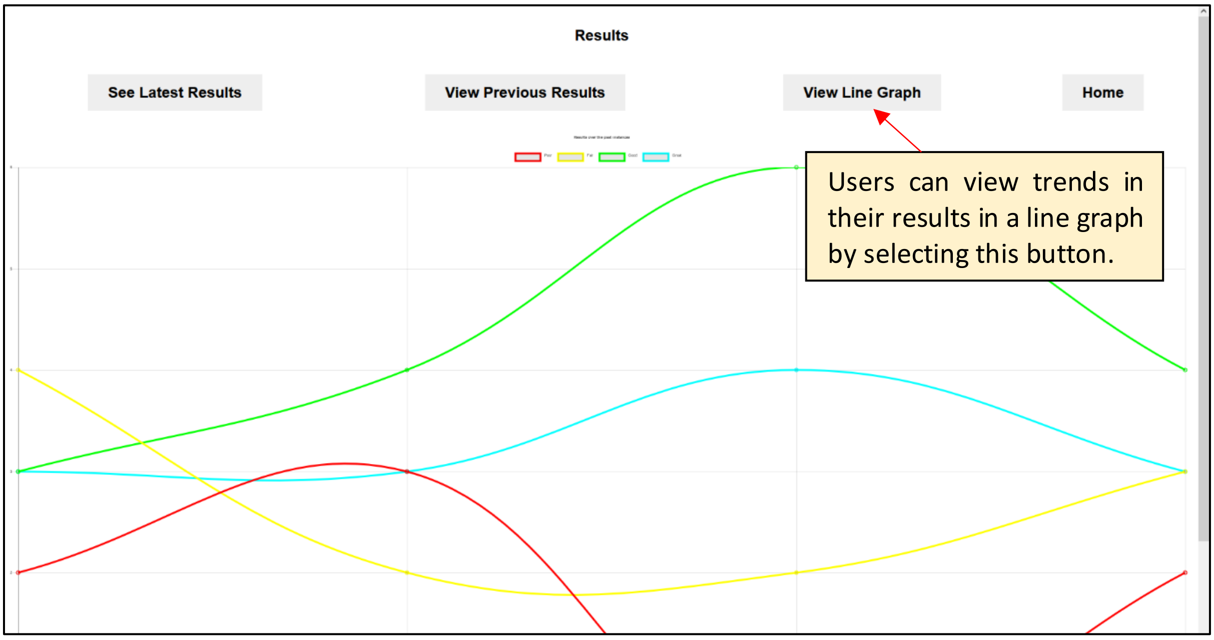


Physical: Great	Energy: Fair	Mood: Fair	Home: Poor
Memory: Good	Family: Fair	Friends: Great	Self: Good
Housework: Poor	Hobbies: Great	Money: Fair	Life: Poor

Users can access previous results by selecting this button.

A drop-down menu allows users to select previous results.

6.8.10 Line Graph Trends



Users can view trends in their results in a line graph by selecting this button.

7 Summative Evaluation Methods

Chapter 6 outlined the results of the prototype development stage which resulted in the development of the FFP (P4.1). Chapter 7 presents the methods employed in the summative evaluation phase, where the FFP developed during the prototype development phase was presented to a larger group of PwD, IC, and HCP to evaluate. The results of which answered the final research question "what the perceptions of PwD, IC, and HCP on the feasibility, utility, and acceptability of the FFP that enables PwD to self-report QoL data via PROMs as part of routine care?".

7.1 Objective of the Final Review Workshop

The summative evaluation phase enabled a greater number of PwD and IC to participate in the study without the significant commitment required for the prototype development phase. It also enabled HCP to test and evaluate the FFP (P4.1) that was developed during Cycle 4 of the prototype development phase. Due to increased numbers, 3 separate workshops were conducted. This summative evaluation phase concludes the pre-prototyping/prototyping stages of the WHO's Monitoring and Evaluating Digital Health Interventions Guide (World Health Organisation, 2016).

Table 23 Summative evaluation Workshop

Summative evaluation Workshop	
Prototype Description	The final review workshop followed a similar format to the final co-design (cycle 4) workshop, but involved separate groups of PwD, IC and HCP of a similar number to the Co-Design group. Participants took part in an online workshop where they would conduct a cognitive walkthrough (explicit instructions are given) and a Think Aloud Protocol (inexplicit instructions given) of the FFP that was developed for cycle 4.
Evaluation Description	Participants were asked to Evaluate the final prototype for a variety of aspects including but not limited to: • Their personal impressions of the prototype • How they/their patients feel they would do using the prototype? • How effective would it be using the prototype acting as Proxy to PwD? • How could it be used in practice and encourage adoption? • What feedback and data they would find useful and how can that data be better presented to them? These features would then be voted on during a final MoSCoW session. Feedback gathered was then used to create a final requirements document. This will galvanise

	the study as a fully multi-modal, multiuser study that included all the important stakeholders while still allowing PwD to be at the heart of the co-design development. It also allowed participants that were initially intimidated about taking part in a long term study to take part in a much more manageable single workshop.
Additional notes	Due to the larger group size and the multitude of different stakeholders, 3 separate workshops were held for this phase. 2 exclusively for HCP from the NHS and 1 for PwD and IC from Alzheimer's Scotland.

7.2 Summative Evaluation Workshop Overview

7.2.1 Summative Evaluation Prototype

This phase made use of the same FFP (P4.1) that was developed in the prototype development phase. No changes were made to the prototype between the prototype development phase and the summative evaluation phase.

7.2.2 Summative Evaluation Workshops

The summative evaluation consisted of 3 separate online workshops that took place throughout May 2022. Each workshop started with introductions and then a presentation explaining the purpose of the novel application and its development history as many of those taking part were new to the project. Participants were then demonstrated the app via screen share following the same format of previous workshops before discussing what they liked, disliked, and any changes they would like to see made. As the summative evaluation participants were less familiar with the project than the prototype development group, a set of questions were created to prompt discussion. These questions were decided on by supervisors and were representative of the next stage of the WHO framework (World Health Organisation, 2016) taking guidance from DEEP recommendations (Dementia Engagement and Empowerment Project, 2015d) when presented to PwD. Participants were also sent a MoSCoW questionnaire a few days after each workshop to vote on features they would like to see prioritised.

The following questions were used as prompts during NHS workshop.

- What do you think of the prototype? (Ease of use, data collected, presentation and visuals)
- How feasible would it be for PwD to use the prototype on a regular basis?
- How feasible would it be for IC or HCP to use it as a proxy?
- How can it be used in your day-to-day role supporting PwD?
- Could this be embedded within the current practice?

- Will this app change or improve any processes or outcomes?

The following questions were used as prompts during the Alzheimer’s Scotland workshop.

- What do you think of the prototype?
- Would you be comfortable using it alone or would you need support?
- How can we encourage you to use this regularly?
- Do you think the data collected would be useful to you?
- Are there any changes or improvements you would like to see with the app?

7.2.3 Summative evaluation analysis

Analysis of the summative evaluation phase followed the same process as previous workshops, with all workshops recorded, transcribed, and thematically evaluated. Due to the differing perspectives and roles of the stakeholders involved in the summative evaluation phase, analysis of the workshops was split into 2 groups. The NHS group consisted of the 1st and 2nd workshop and focuses on the perspective of HCP working in the healthcare industry, implementation considerations, and their knowledge of patients they support and treat. The Alzheimer’s Scotland group focuses on the 3rd workshop and gathers the perspective of PwD and IC and their role as primary user and support. Different themes arose in these workshop groups and are presented in detail in the next chapter.

7.3 Setting

All 3 summative evaluation workshops were conducted online via a group video call using Microsoft Teams with participants accessing it from their own home with their own devices, like previous workshops. The main change to the summative evaluation workshops was that each workshop started with a short presentation introducing unfamiliar participants to the project and a brief overview of how the prototype was developed during previous workshops. Additionally, the final Alzheimer’s Scotland workshop was hosted by Alzheimer’s Scotland during one of their pre-planned stakeholder meetings.

7.4 Identification and recruitment of participants

As with previous workshops, participants were identified by the recruiting partners including the NHS and various dementia charity organisations using the pre-established inclusion and exclusion criteria.

7.5 Ethics

The ethical approval for this phase was covered by the NHS IRAS ethical approval with a final amendment (UEC20/16/A01) approved on 08/04/2022 which enabled us to widen the recruitment pool and format to include larger roles for IC and HCP.

The results of the summative evaluation are discussed in the next chapter.

8 Summative Evaluation Results

Chapter 7 outlines the methods used to conduct the summative evaluation workshops. Chapter 8 covers the results of this summative evaluation phase. This final phase invited PwD, IC, and HCP to take part in online workshops where they reviewed and evaluated the FFP (P4.1) on its feasibility, usability, and utility. This answers the final research question “What are the perceptions of PwD, IC and HCP on the feasibility, utility and acceptability of a functional prototype that enables PwD to self-report QoL data via PROMs as part of routine care?”. The results were thematically analysed to produce several themes and sub-themes (table 24).

Table 24 Themes of the Summative Evaluation Phase

Themes	**Sub-themes**	
Feasibility and Usability	Ease of Use	
	Word Dimension	Validity Phrasing and Terminology
	Visual Dimension	Colour Images Visual Placement Radial select
	Space Dimension	Voice
Utility	Clinical Utility	Monitoring and Presenting HCP Resources Targeted approach Embedding in current practice
	Data Retrieval	Interoperability across NHS Frequency and Access Delivery Methods
	Patient Utility	Encouraging Use Everyday Life Obsessive Behaviours
Future Research	Future Implementation	
	Testing with Later Stages	
	Improving the PROM	

8.1 Summative evaluation workshops

A total of 3 workshops were conducted as part of the summative evaluation workshop involving 2 major groups, with 2 workshops involving HCP from NHS and the final workshop involving PwD and IC from the charity Alzheimer’s Scotland.

8.1.1 NHS Evaluation Workshop

10 HCPs representing NHS took part in the summative evaluation cycle over 2 separate workshops in May 2022. A total of 5 HCP took part in the first workshop and 5 in the second. The first workshop

lasted a total of 89 minutes, consisting of a 17-minute introduction and presentation and 72 minutes for prototype demonstration and discussion. This workshop was hosted by the main researcher (DK) and was overseen by a 2nd researcher (KE). The second workshop lasted a total of 65 minutes, consisting of an 11-minute introduction and presentation and 54 minutes for prototype demonstration and discussion. This workshop was hosted by a researcher (DK) and was overseen by a 3rd researcher (RM). 2 additional participants who signed up to take part in the workshop were unable to attend and review the prototype but were invited to complete the MoSCoW questionnaire on prioritising features.

Table 25 NHS Workshop Attendees

Characteristics	Workshop		MoSCoW	
	n	percentage	n	percentage
Total	10	100%	12	100%
Gender				
Female	5	50%	6	50%
Male	5	50%	6	50%
Race				
White	8	80%	10	83%
Asian	2	20%	2	17%
Role type				
Health Care Professional	10	100%	12	100%
Manager/Lead	3	30%	3	25%
Doctor/Consultant	3	30%	3	25%
Nurse	2	20%	2	17%
Not stated	2	20%	4	33%

8.1.2 Alzheimer's Scotland Workshop

A total of 8 participants recruited via Alzheimer's Scotland took part in a summative evaluation workshop in May 2022. A total of 6 PwD and 2 IC took part. 3 of these participants (PWD2, PWD3, IC2) had previous attended the prototype development workshops. The workshop lasted a total of 71 minutes, consisting of an 8-minute introduction and presentation and 63 minutes for prototype demonstration and discussion. This workshop was hosted by the first researcher (DK) and was overseen by the third researcher (RM). This workshop was part of a larger event hosted by Alzheimer's Scotland.

Table 26 Alzheimer's Scotland workshop Attendees

Characteristics	Workshop		MoSCoW	
	n	Percentage	n	Percentage
Total	8	100%	8	100%
Gender				
Female	4	50	4	50
Male	4	50	4	50
Race				
White	8	100%	8	100%
Role type				
Person with Dementia	6	75%	6	75%
Informal carer	2	25%	2	25%

8.2 Summative Evaluation Workshop Analysis

Framework analysis of the summative evaluation workshop identified 3 key themes regarding usability of the novel application, the utility of it in a real-world environment, and future research to build upon the prototype.

8.2.1 Feasibility and Usability

This first major theme identified participants opinions on the feasibility and usability of the FFP (P4.1). This covered the prototypes ease of use, concerns regarding issues with terminology, and the choice of visual elements and modalities.

8.2.1.1 Ease of Use

The prototype received much praise from HCP for its ease of use, short completion time, and appealing straight forward design. HCP could foresee their patients with dementia being able to use and complete this prototype with little difficulty. Involving PwD in the design was also praised as 'refreshing' as a demographic who are not often included in the development of such prototypes.

HCP7: I think it's fairly straightforward and it's not too laborious because there's only a short set [of] questions which are relatively easy for someone with dementia to fill out with
HCP10: It's quite straightforward, quite colourful

PWD8: There is a danger of trying to do it all, singing all dancing. And actually, simplicity is often the best way.
HCP6: I think is great and the fact that you've had so much involvement with PwD throughout. It's refreshing because they aren't always involved.

8.2.1.2 Word Dimension

Following the interaction design methodology set out in chapter 6, participants had some notable feedback regarding the word dimension, in particular with the validity of questions and answers.

8.2.1.2.1 Validity

Validity of the PROM proved to be a significant concern for HCP, IC, and PwD. During the prototype development phase, the questions and responses taken from the pre-existing QoL-AD questionnaire received significant criticism from PwD (see previous chapters, cycle 1 and Cycle 3) which led to significant modifications to the phrasing and terminology of the questions and responses used in the final prototype. All participants therefore had concerns regarding the feasibility of using the prototype as a validated PROM or whether the changes made would invalidate this. There were also questions regarding if the questions used and responses given still enabled accurate representations of the PwD subjective responses of QoL. HCP were supportive of trialling the prototype in its current stage and analyse the data collected for validity in future.

HCP1: you've allowed service users to adjust the questions because I suppose there's that sort of difficulty. Say how do we know that it still measuring what you think it's measuring if you've changed the questions?
HCP1: if we're administering cognitive testing, there's something that's quite rigid in terms of how you ask the question so as not to affect the reports, but and even quite subtle changes to phrasing can affect the report
IC3: How do you know that? When somebody says they're not, their 'Fair', their 'fair' is somebody else's good?
PWD7: sorry, so just thinking it's very subjective and if you look at what you feel like today. And yes, it could change that, you know, and so how reliable is it?

IC3: I just think there's so much. Relating to reliability and validity. Measuring what you say you are and then validity in the actual meaning of everything of each word, and so on. I have a lot of concerns, with that.
HCP6: It does make sense using a scale that's already out there and validated that you know rather than just coming up with a rating scale yourself… But in terms of the tweaks and adjustments. As others have said, once you settle on the prototype, let it run for a while without messing around with it too much…if the questions get changed too often, it becomes much less. Less valid

8.2.1.2.2 Phrasing and Terminology

Concerns were raised regarding the phrasing and terminology used in the prototype. Some participants had issues with the scale of topic and vagueness in certain questions, such as asking PwD or IC acting as a proxy to think about 'life as a whole'. They noted this may be difficult to answer with a single 4 option response and that many of the questions could be easily misinterpreted especially when submitted to a wide range of vulnerable people.

HCP2: For probably the carer. Yeah, it may be difficult. If it's a carer that's answering it or supporting, it. Yeah, so that might be tricky. And this was about as a whole. I know you've already gone through this with some of the patients, but I said maybe 'in general' it could be a better phrase. How are you?' How's your life in general?' Yeah, how do you feel in general? Yeah, perhaps it's just. Just a question of changing a few smaller aspects,
IC3: and now Life, Life is a Biggy to put there. Yeah, I feel about life this week. There's quite a lot of Language. Yeah, meaning, you know, just suddenly to chuck in life? Yeah, so what is the meaning of life, yeah? What is it actually being there? Fair? Great. I don't think I could ever say what I feel. I'm great about myself, I feel great. These are kind of words like great. And is there any better way you say that home is poor? Is that not an option? alright yeah. You know what you mean by these words but if you're actually going to be submitting these to vulnerable people. All these raise an awful lot of questions.
IC3: Well, I mean if you're wanting results that are meaningful. These things, have to, things like mood you know that could be described quite easily. Energy can be described quite easily. But language yeah, yeah. Very important

8.2.1.3 *Visual Dimension*

All participants requested minor changes regarding the visual dimensions of the prototype. HCP queried the choice to avoid images and icons while PwD and IC had changes to visual placement and consistency.

8.2.1.3.1 Colour

All participants requested changes regarding the use of colour. An HCP noted that the use of Red and Green to symbolise different response degrees could be problematic as red/green colour blindness is the most prevalent in the general population and can be compounded in the target demographic where sight deficits are common. Meanwhile PwD reported finding the use of the colour distracting and showed a preference for a black and white version. This was a feature implemented from the design workshops where similar views were reported, though the cognitive walkthrough of the summative evaluation workshop only displayed the full colour version. A PwD did ask how a black and white version would be able to show results on the final graph while an IC reported annoyance at the inconsistency of colours used between the questions and final results.

HCP1: just thinking in terms of your colours, is that 1 of the commonest forms of colour blindness is red, green colour blindness. So again, in terms of it might seem logically coherent for those that are not colour blind to put like red, amber, green, blue. Yeah, is that, has that been considered in the design?
HCP4: Yeah, especially at that age with a lot of subsidies or deficits
PWD8: Yeah, for me I would like to see just plain black and white really.
PWD7: I think the colours are actually distracting, yeah.
IC2: hey DK how would that work with the graph that comes at the end that shows you know the variation in health and mood? In that the colours are helpful
IC3: Also, it doesn't colour. You've got red there. Yeah, no, are you showing red? The colour corresponding is Pink.
IC3: And I think. The blue and the green they're much more vibrant and this than they are. Yeah, that's a bit inconsistent.

8.2.1.3.2 Images

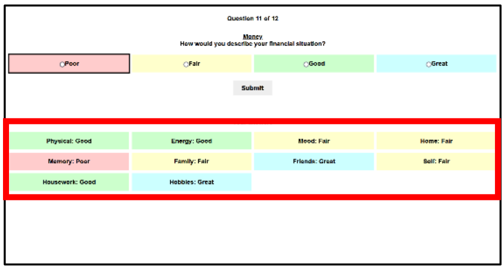
HCP were somewhat surprised by the lack of images and icons used in the prototype such as smiley faces to accompany the responses. Whilst the co-design group did report feeling patronized by the inclusion of such visuals, HCP felt their inclusion would increase the utility of the prototype especially when considering PwD at later stages of the condition or for carers and family members who may assist with it.

HCP4: Did anybody ask like visual representation like a smiley face or something?
HCP4: I mean I would have never thought that there's no preference for the smiley faces or like or like sliding. Yeah, but yeah, interesting.
HCP9: The group that you consulted on felt that it was patronizing but looking at the sort of utility of this going forward, if it does, you know, get used and carers or family members can assist patients, and being able to answer the questions. People who are slightly at the further end might be able to answer some of these questions if there were more sort of emoji style.

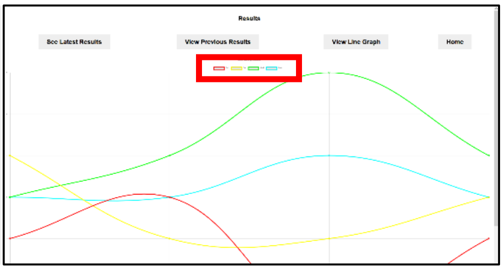
8.2.1.3.3 Visual Placement

PwD raised some minor concerns with the placement of certain visuals. One PwD found the appearance of the previous answers while answering to be distracting and would prefer these not displayed during the questionnaire. Another PwD commented about the tiny font size used on the final results graph. One HCP also asked if the results screen would be adapted for users accessing the prototype via their phone or tablet devices.

PWD8: I would say that I'm quite computer literate, but some of this has got me foxed... You know I would like 1 to see 1 question at a time and not having other boxes.
PWD7: Yes, yeah, but would you be able to read the words below the drawings. You know you've got this line graph like Oh yeah, yeah. And were supposed to be able to read them. They're tiny.?
HCP6: Some people will be doing this with phones. Some people will be doing it with tablets. Some people be doing it with other devices. Obviously, the graphs that you show that would allow people to chart their own results [but] will [it] be tailored themselves to the device?



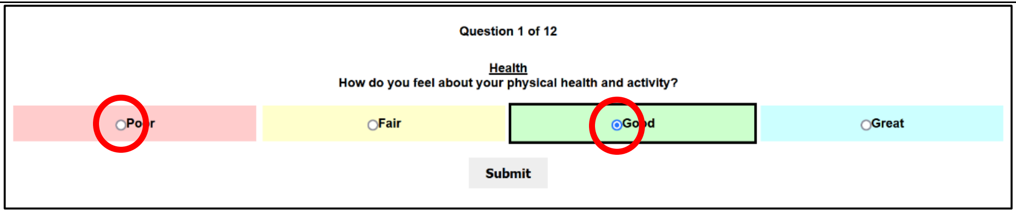
Physical: Good
Energy: Good
Mood: Fair
Home: Fair
Memory: Poor
Family: Fair
Friends: Great
Self: Fair
Housework: Good
Hobbies: Great



8.2.1.3.4 Radial Select

An HCP reported some confusion with the inclusion of the radial select icon (highlighted in red circles) used in the prototype. Similar feedback was reported during Cycle 4 of prototype development where one participant thought they needed to click the small circle rather than the button to record their response. The inclusion of the radial select was partially a functionality requirement with the prototype to save the data as well as an indicator for the black and white version that the option had been selected though alternatives should be investigated in future.

> ***HCP1: I see that next to the text we also still have a radio button as well, yeah, and whether that's. Just thinking in terms of visual processing, but it's slightly odd to see that next to the, immediately, still close to the actual word itself. Yeah, whether that affects readability?***



8.2.1.4 Space Dimension

The final dimension discussed by participants regarding interface, interaction, and usability related to the space dimension and the use of voice.

8.2.1.4.1 Voice

PwD and IC during the summative evaluation workshop strongly disliked the implementation of voice in the prototype. Reasons stated for disliking voice features included the use of a digitised robotic voice, particular one with an American one, that could be confused with their Amazon Alexa devices.

Similar responses were given by PwD and IC during the development phase though one PwD during this workshop adamantly opposed the use of voice features, finding an automated voice asking them private questions as 'disturbing' and 'manipulative'. Another PwD did see the possible benefit of such a feature, particular for those with vision issues who may struggle to read the questions themselves.

PWD7: Are you going to use that voice? Why is it an American accent?
PWD3: I wasn't listening very carefully at the time, with the voice being on, but I thought the voice was Alexa.
PWD3: I just feel. Disturbed by being manipulated about my deepest things by Alexa.
PWD3: Is it and it just feels like totally manipulative of everything. Hmm, yeah. Yeah, definitely don't want you, don't want you expect when you're dealing with intimate things where you when you look at the sensitivity.
PWD10: you know they would be nice to have that option. Especially because then PWD8 speaks about, you know, just difficulty they you know seeing you know the words and reading due to Alzheimer's that if you had the voice activation option. Yeah, it could read the question, but I do agree. I think in that robot version. Yeah, it is. Yeah, it's not so clear and things as well, but I think there's more options that they have to have that

8.2.2 Utility

This theme covered the utility of the prototype and the feasibility of implementing such a tool into the day-day routines and practice for both PwD and HCP.

8.2.2.1 Clinical Utility

The first utility subtheme regarded how the prototype could be implemented for use by HCP in a clinical environment.

8.2.2.1.1 Monitoring and Presenting

HCP identified significant potential for the prototype to be used as an effective monitoring tool for PwD over a long period of time. By gathering evidence of PwD condition as it develops and presenting this data in a visual and easy to digest snapshot, HCP can be given greater insight into the needs and QoL of patients, especially during long periods between contact. Such data could also be used as evidence to extend post diagnostic support for PwD when needed. PwD also noted interest in monitoring and accessing their own results and the utility of the prototype acting as diary for recording important data. One HCP noted an increase in people collecting such data in their daily lives.

HCP2: A person gets post diagnostic support and that's obviously statutory. Now I think is right saying, I might be wrong in that, but usually it's a year, so in Scotland and so it could be quite useful to monitor how effective that is, and that might be used as a case in some later stages to

try and extend that. Perhaps that's something that might be an outcome that could be useful because. So, we would want it to be extended if there was the feasibility and staff was available, which obviously is not always the case, or seldom isn't, but there might be something that could be useful for that. ***HCP1: that's a good point***
HCP9: I guess it gives you sort of a basic idea of how the persons presenting and I suppose 1 important thing for me was if there was any correlation between physical health and mood. If severity of pain went up and mood went down, your kind of possibly link. But that was the 1 thing I thought was helpful
HCP6: This will have greater clinical utility because you can track people overtime, which is great.
HCP6: I think people are more wanting to collect data about their own health. They want to know more about what's going on. You see that the rise of people with blood pressure machines and obviously with COVID, half of that population seem to have pulse oximeters, but it also means the people are in control of their own information. But it also, if you see someone in clinic that you have not seen for 6 months or a year, and it's a case of well when did you start to dip? Or when did this start to happen? and you actually have, that you don't need to be responding to it always in real time. But it does mean that you've got that, that and. All information is useful, it's just it does need to be filtered, and that's where the issue is.
HCP7: Yeah, I think it's feasible that you can use it and I agree with both HCP6 and HCP9 comments. And just need to keep trying and see how it goes. I mean every day and you know like HCP6 said like you know, stuff like that down the line, emails. You know some of these, somebody scores go down etcetera. That's a wee bit concerning because we don't have the resources, but that's way down the line. But yeah, it's definitely feasible.
IC2: It would be useful over time; you know to be able to compare like there was, in this case during 6 months ago. Yeah, to look for a period of time. I do think it would be useful.
IC3: I mean it almost be considered a diary.

8.2.2.1.2 HCP Resources

All participants raised major concerns about the impact of implementing the prototype in a clinical environment would burden an already stretched system with limited resources. HCP were concerned that they do not have enough time or resources currently to fulfil current care needs and if the addition of such a tool would ever be viable. HCPs also questioned whether GPs would be supportive of a tool that may require additional work especially if a PwD is supported by multiple GPs. This was a similar concern help by PwD and IC who reported struggling with seeing and accessing their GP and did not foresee there being enough time to discuss the results of this prototype. There was a general sense that attitudes needed to be changed to prioritise PwD having more access to HCP before such a tool could be feasible.

HCP9: I guess you would need to have the resources to address the issues that were picking up. I mean, the way the situation is on the ground. Not to be pessimistic, I mean. You know, things are pretty dire. Significant amount of carer stress, significant amount of social support required, and you know it's weeks and sometimes months before something's in place. I know HCP6 will be aware of it working with the dementia outreach team so. It's 1 thing to pick up on where the need is, the other thing is how are we going to Support them and what resources we have at the other end.
HCP8: I was just wondering, have you spoke to GPs then about this as well, cos just thinking if they are getting regular emails as well, they could be, getting quite a few.
HCP6: Yeah, the 1 of the difficulties is that changes a lot, so if you speak to somebody this year, you won't be able to speak to the same person next year in the systems may well all have changed 1 of the other things is that obviously.
PWD8: Yeah, and also how practical is it? I've not seen a doctor for quite a while. I actually had a phone call with her last week and there is just not the time to do something like that,
IC3: I was thinking also, but in terms of GP, GPs aren't even doing an annual review. So, the prospect of him trying to get only a GP and take this along and look at it. Yeah, you know it's. I don't think you know. 1 of the missions are things we have to change the attitude of GPs as well to looking after people even say once a year. yeah.
PWD8: I don’t want to be pessimistic. But yeah, the time factor just wouldn't allow it.
PWD2: I think it goes back to IC3s point about the annual checkup. Presumably, if we've chosen to share the information that was given with the GP, the consent form that they would need to know what the report they were going to be receiving and understand what it was about.

8.2.2.1.3 Targeted approach

HCP foresaw the prototypes greatest potential as being with a targeted approach that would deliver the tool to monitor patients when it is needed the most. Multiple HCP envisioned using the tool to support the work of crisis teams or during the initial parts of post diagnosis where HCP are keen to collect a large amount of data regarding the PwD condition during an intense period of support. They envisioned the prototype collection frequency could be tailored to a PwD changing needs such as intensifying during such periods to collect more data which could then influence the type of treatment and support that they would receive and reducing frequency when QoL is good and no intervention from HCP is needed. One HCP also noted that they could see this tool being useful in certain patients they have who would be enthusiastic to use such a tool.

HCP3: actually, I think it's a really good way to measure somebody's response to medication to care treatments and things like that on a week-by-week basis. So, I actually think it's really good and the simplicity of it for people who are obviously coping in public they appear, but they're a very stressed period in their life. I would actually probably I would actually incorporate that into my assessments, review feedback to the consultant.

HCP1: I guess it's about kind of envisioning which group would be using it? And then the frequency kind of comes into lawful purpose. I mean it is almost at the early stages of dementia, so if you think of immediately post diagnosis, is this about trying to kind of get some sort of early detection of somebody's QoL starting to sail off? And yeah, or for something else. I mean, I'm just thinking about. What's being said about the crisis work because you can kind of imagine. Actually, if a dementia outreach team were seeing somebody for quite an intense period of work, more frequently might be useful.

HCP4: You could change it depending on the execution so like the crisis team, so they might want the weekly because their engagement is good, yeah? Very short term but doctors would be monthly, or you know something along those lines to get the data.

HCP2: I think we would use it, as I say, in patients that are willing. I think it would be very useful. I had a few patients with bipolar that did the same thing with their mood and gave various questions, and they even plotted on a graph. Obviously, these were patients that were wanted to do these things. And yeah, and some in some cases they suggested it. So, it really was quite helpful because you could see certain you know the mood dipped at certain points and what was the triggers.

HCP9: It's as the condition progresses. That's when the difficulties happen. So, if somebody has got a reasonably good QoL. Would I really want to know how there are two-week month to month? You know it's like who would use it?

8.2.2.1.4 Embedding in current practice

HCP were very enthusiastic with embedding the prototype in current practice and could see it filling a pre-existing void in existing systems. HCP noted that they do not currently have anything like this tool in their existing practice and were keen to see how it would function in a real-world environment with One HCP noting they expected clinical teams to build similar tools as part of the care pathway in the future.

DK: Do you think this is something you would use, or you would encourage your patients to use? And do you think that it has much use?

HCP9: I think the answer to both the questions is yes. Given we don't have anything else just now, which allows us to accurately track what's happening. Useful tool

HCP7: Yeah, I agree, we don't have anything right now. So yeah, I think it would be a tool that we could be used. Not with everyone obviously but yeah definitely

HCP8: Yeah, I agree with HCP9 and HCP7 here, cos we don't have anything at the moment, so it'd be good.

HCP9: I think it would be good to see how this gets used and how this gets embedded because it's pretty simple, straightforward, easy for patients to fill, has got you know the key aspects of what we look for, and I think once it's up and running and it's used quite widely and smoothly. Then that would be the stage to see if anything can anything be added, or you know anything be tweaked that would be my view anyway.

HCP1: But I think it is going to be 1 of those interesting questions about getting patients to engage with this if in a couple of years' time as part of the electronic patient record, they have, the clinical teams might be building very similar questionnaires and having that as part of the care pathway.

8.2.2.2 Data Retrieval

The 2nd utility subtheme regarded how the prototype would handle data retrieval and how such data would disseminate through existing systems using existing technology and processes.

8.2.2.2.1 Interoperability across NHS

One of the biggest concerns HCP had regarding data retrieval was how viable it was to access this data and integrate interoperability with existing NHS systems and processes in place. The prototype did receive positive feedback based on its web based and platform agnostic approach which would make it highly accessible on existing hardware used in various NHS locations. Though HCP also advised that more research was needed regarding the legal and confidentiality requirements the prototype would face for collecting, storing, and sharing sensitive patient data. HCP also raised issues of data repetition and system fragmentation that having yet another system collect data may compound the issue of the data not being used. With so many services across the NHS already not communicating with each other and each NHS often having their own systems, clinical records, and logins, interoperability of a new system would be a significant logistical challenge.

HCP1: How you're going to give clinicians access to that data
HCP6: How will healthcare staff access this information? In particular, if you're accessing an app or whatever in terms of not only the confidentiality, but how that will mesh, and if it will play nicely with the NHS systems? yeah, that's possibly a bit down the road. Yeah, depending on how this is going to be used, sometimes planning needs to happen quite early?
HCP6: When you start to roll out pilot it, you know any individual, clinic or area that's using it could have their own devices on logins that could exist alongside the NHS systems, because trying to get something into the NHS systems will be (an) absolute a nightmare. Yeah, as you see they don't talk to each other properly and never mind strangers coming in if you like.
HCP1: I guess the difficulties that you have is across the country. Is that different people have different electronic records and some of them have got more advanced patient portals than others and. That they have different degrees of flexibility in terms of layout and design. Yeah, and I guess we've got kind of a couple of routes. Is well, actually. You know if you're generating data with this, are you trying to have things like an interoperability gateway as a way of being able to put that into someone's clinical record and managing world that goes? And I think that there are all those kind of questions about and again with it's not Even so much the technical bits, it's the information government side about the data sharing with NHS systems and who gets to keep it where, yeah?
HCP1: And even if they have the same vendor for the electronic patient record, they want structured their data differently and the components of data and how they store it would be very

different as well. So, trying to integrate anything into an electronic patient record or approach clinical setting is really difficult.

8.2.2.2.2 Frequency and Access

HCP also had multiple questions regarding the frequency that data would be collected from PwD and delivered to PwD. HCP agreed that flexibility of frequency was a key feature of the prototype that could be decided by patients and as previously discussed, that a targeted approach based on PwD changing need could help with dealing with over stretched HCP resources.

HCP9: I know you said DK that people would fill it once a month. Is that what you said is it? Is it a restriction or a limitation on how often this can be filled?

HCP2: Erm, I would say monthly as a sort of reasonable point not to overwhelm as well, so that they're not feeling they have to do it all the time. I suppose part now it might be possible in certain patients, the way it could it be a case of that the patient decides monthly as the minimum or something like that. Perhaps

HCP4: And you could change it depending on the execution so like the crisis team, so they might want the weekly because their engagement is good, yeah? Very short term but doctors would be monthly, or you know something along those lines to get the data, I guess. Maybe that might be something that we might need to access, I guess. You know? I suppose and interest for the patients and families. Professional use, yeah, how frequently do you want to?

8.2.2.2.3 Delivery Methods

The final data retrieval sub-theme queried by HCP was the method used to deliver the questionnaire via the prototype. The prototype was initially envisioned to be delivered via email though HCP noted that existing systems in the NHS primarily used text (SMS) messages to contact and update patients and that this delivery method would be most familiar to PwD and IC. This would also enable better integration to existing NHS systems which are designed to communicate and update vis SMS.

HCP2: Just about the email aspect. I'm not sure if that many of the patients use email. Sort of experience from clinics. I, I think sometimes the carers do but even that's quite rare and the patients, I think seldom use email, but I mean it could be wrong, I guess. Obviously if they're using this they might start, might agree to start using email, but I'm not certain that would be the case,

> ***so I just wondered again about the app side and whether that’s useful. But the other thing, even with the app, I'm not sure how many use smartphones, so I just wondered to discuss. A bit further***

> ***HCP4: Did you look at like phone numbers to send the link?***
>
> ***DK: Oh! like a like a text, like a text message?***
>
> ***HCP4: Yeah, kind of. Instead of the email, yeah, use their phone numbers and you know. And then they can access it.***

> ***HCP1: I think we are quite used to receiving text messages from the NHS because I am I just got 1 today about getting my blood pressure checked and things so I think patients might be quite used to that because they're really getting that from their surgeries. And I think that might be something to explore if there is a better way of linking it to your questionnaire.***

8.2.2.3 Patient Utility

The third utility subtheme regarded encouraging use of the prototype by PwD and IC during their day to day lives.

8.2.2.3.1 Encouraging Use

The first sub-theme of patient utility was how to encourage use. PwD and IC all seemed confident of completing the prototype either on their own or with support from IC. HCP though anticipated patients would been keen to use the prototype at the start, but this enthusiasm could fall as time goes by and the condition advances. One HCP did note that they already saw an increase in patients taking initiative with data collection tools and that such patients would find long lasting interest and utility of such a tool.

> ***PWD2: I think I would be comfortable doing it myself.***

> ***PWD10: PWD8 Do you think you would manage to do this yourself to complete the questionnaires, or do you feel that you would need some support myself?***
>
> ***PWD8: Oh, I’d do it myself. I think it must be very difficult, different for Everybody.***

> ***IC2: Would you need my support to fill in the questionnaire? To this. If This was sent to you. Would you feel happy just to do it or would you like me to be there to help you?***
>
> ***PWD3: I would, I would need support, yeah.***

IC3: Well, my husband would certainly need my support.

HCP1: It's about how somebody perceives this be valued, but also how you avoid just having brief bits of data while somebody's motivated. And then this is sometimes the case people just [get] on with the lives in the country. The dementia of this, it might be perceived to have more, less value at different time, different phases of the illness. People immediately have a diagnosis and trying to do everything. Yeah, then ease out of it as they get used to life being a bit more normal again.

HCP2: I suppose it's obvious to say, but I guess it's going to be useful in those that actually use it. Yeah, yeah, those that start and then stop it. You're not gonna really know what's happening. And obviously that might alert you to then question them, which may be of some use in itself. Yeah, but I would wonder if a lot of patients will agree.

HCP9: Yeah, it was just purely because the severity of dementia matters because that will dictate the ability of the patient to fill this yeah and also access to technology as well as. The ease and comfort with which someone's you know. Going to do this. But the questions itself, I guess it gives you. Sort of a basic idea of how the persons presenting and I suppose 1 important thing for me was if there was any correlation between physical health and mood. If severity of pain went up and mood went down, they kind of possibly link. But that was the 1 thing I thought was helpful and I'll just let others speak.

HCP6: Can I make a slightly less pessimistic point yeah. I think people are more wanting to collect data about their own health. They want to know more about what's going on. You see that the rise of people with blood pressure machines and obviously with COVID, half of that population seem to have pulse oximeters, but it also means the people are in control of their own information.

8.2.2.3.2 Everyday life

The 2nd sub-theme discussed how the prototype would fit into participants everyday life. Device accessibility was one concern with an IC and an HCP asking if the prototype would function on PwD devices with other participants asking the frequency they would be expected to use the prototype. Finally, one IC felt that not enough explanation was provided during the introduction to explain that certain features could be toggled on or off.

HCP4: I mean, I think you showed Amazon Echo Show or Google Home. Do you know that anybody had them in their homes and does the participants use any of these? and you know this could directly with the people to directly to use the app.

IC3: I had recent experience being offered and app using Fitbit but While I could download onto the iPhone, it couldn't be put on to my elderly apple mac desktop and because of its age and nor could it be put on to my iPad, which you can't see it. It's very new. Yeah, So what? How will yours work in that regard?
HCP9: Yeah, I know you said DK that people would fill it once a month. Is that what you said is it? Is it a restriction or a limitation on how often this can be filled?
IC2: So, what was the conclusion or is the 1 about how frequently people would fill in the questionnaires?
IC3: In the introduction, do you actually say to the reader it will be offering you options about colours? about voice? or you just you know you just said you're a new question to complete, start questionnaire and you know out of the Blue. Why are they asking about colours and voices? So, I think it has to be introduced what you are planning to offer.

8.2.2.3.3 Obsessive behaviours

The final sub theme of patient utility was the danger of encouraging obsessive behaviours. PwD and IC raised concerns that requiring PwD to think deeply about parts of their life that they are struggling with may risk impacting that person's wellbeing especially if it is likely to decline as is expected with dementia as it progresses.

IC3: If you have people doing this every week, do you not? Is (there) not the danger then that you become pretty obsessed? And the other thing is that if you're feeling pretty poor, I think the last thing you would want to do is let's go to the questionnaire. I must just put they said, you know, I'm feeling bad this week.
PWD8: I do wonder if it's encouraging people to be self-obsessed
PWD8: We're not actually. We're just going along, you know, quite happily until somebody says OH are you all right now? Yeah, and actually. It then we start to dwell on, oh well, there's there is something wrong with us. Yeah, so you have to be careful with that I think and make sure that if you're interviewing people, you have to leave them in a situation where they're quite happy with themselves, again, rather than you know, dwell on or have you got this? Have you got this? you know?

8.2.3 Future Research Implementation

This theme covered what participants wanted to see performed next as the prototype is moved from this evaluation phase into the piloting and implementation phase.

8.2.3.1 Future Implementation

HCP were very pleased with the FFP and were keen to see it piloted in its current form amongst the population. They advised this would allow the collection of necessary data and resolve any technical issues before further changes and improvements are required. With such data, future research could investigate ways to interpret and use the data, with one HCP interested in what sort of metanalysis could be performed.

HCP9: I think it would be good to see how this gets used and how this gets embedded because it's pretty simple, straightforward, easy for patients to fill, has got you know the key aspects of what we look for, and I think once it's up and running and it's used quite widely and smoothly. Then that would be the stage to see if anything can anything be added, or you know anything be tweaked that would be my view anyway.
HCP7: we need to suck it and see really, don't we?
HCP6: But in terms of the tweaks and adjustments. As others have said, once you settle on the prototype, let it run for a while without messing around with it too much.
HCP1: Other things I've been involved with about how, if you look at the other data that you can potentially generate from it, but as an illness progresses it can you measure the time from seeing the question appear to actually being able to give the response? Might that again give indication of disease progression? All those sorts of things that you can kind of mine quite a bit of that data that might give some more nuanced information, but I've never seen that actually practically applied, but I think it's still going to be a useful question?

8.2.3.2 Testing with later stages

HCP were very keen for testing and reviewing of the prototype to be expanded to people with a later stage diagnosis. HCP see this as they key demographic that this type of data would be most useful though with it comes many more unmet needs, such as challenging behaviour, carer stress, or the need for proxies, that may not be present when testing with earlier stages of the condition. Therefore, by presenting the prototype with such groups, potentials and hurdles of the prototype for people in these later stages could be identified, resulting in a deliverable service through the entire lifetime of PwD using it.

HCP9: Yeah, it was just purely because the severity of dementia matters because that will dictate the ability of the patient to fill this, yeah, and also access to technology as well as. The ease and comfort with which someone's, you know, going to do this.
HCP6: You said yourself that this is for a selected group of PwD, and obviously it won't work across even all people with mild dementia. They'll be sent people with mild dementia may not be able to deal with it, but equally they'll be other people would say moderate dementia, can't deal with it, so it's obviously you are already selecting a group of patients. But that's you know, this will have greater clinical utility because you can track people overtime, which is great. The research side of it, you know the selected nature of the group is obviously something you'd be taking account of anyway
HCP9: You know this particular group of patients, sort of mild to moderate and who I would see in clinic. Umm? They don't, not the ones that are demanding in terms of, you know, carer stress or requirement for social support or you know they have a reasonably good QoL at the earliest stages. It's as the condition progresses. That's when the difficulties happen.
HCP1: How you would envisage this being used. So, what kind of clinical purpose? If you think of so as you say, it tends to be people who are more able to use technology but also people who are much more at the early stage of the illness. So, I deal with as an [Job Role], I only see People who are very, very far advanced. And yeah, there aren't mobile phones of the ward because people just can't use. Yeah so, I see a very very different population, but I guess it's about kind of envisaging. Which group would be using it?
HCP1: You could absolutely imagine that if you started seeing somebody for some challenging behaviour that being able to see that improve and measure that is going to be helpful. But then on the other side that that kind of more challenging behaviour is much more common in the later stages. The ones where people are more impaired and actually that's making more proxy measure.

8.2.3.3 Improving the PROM

Finally, one IC was keen to see more revisions of the prototype with involvement of other disciplines, in particular with language experts whose insight can help with the validity and reliability of the questions and answers.

IC3: Well, I'd like to go almost back to. All the background you did before coming up with this. Yeah, you know how the fact that we're coming out with lots of statements about the use of language. And I haven't been to the workshops.
IC3: I just think there's so much relating to reliability and validity. Measuring what you say you are and then validity in the actual meaning of everything of each word, and so on. I have a lot of concerns, with that.
IC3: OK. So, it's not from the kind of media? It's not from kind of an arts background at all? You know where language dominates.

8.3 MoSCoW Results

As with all previous workshops, all participants were sent an online survey to complete in their own time 3 days after the workshop was conducted. This survey presented a set of features for the next iteration of the prototype and asked users to vote for which features they would like to see prioritised using the MoSCoW prioritisation method discussed in Chapter 5. The features were created based on feedback from the summative evaluation framework analysis.

8.3.1 NHS MoSCoW results

Analysis from the NHS workshop showed by far the highest priority features all related to the space/behaviour dimension, with the top 5 features all relating to those dimensions (F5.1, F5.2, F5.3, F5.4, F5.5). The Behaviour dimension being prioritised was also heavily prioritised in Cycle 4. The space dimension on the other hand proved to be a notable dimension for HCP who took particular interest in the feasibility and technology being implemented, particularly in relation to their existing systems and processes.

Table 27 NHS MoSCoW Results

ID	Themes	Theme covered	Moscow score	Won't include	Priority
F5.1	Implementation of a text message/SMS based system to send the questionnaire	Data Retrieval: Delivery Methods	2.7	0	Very High
F5.2	Further research into mobile friendly and app versions	Data Retrieval: Delivery Methods	1.85	0	High

F5.3	How to encourage user participation especially during certain periods of their journey	Patient Utility: Encouraging Use	1.65	0	High
F5.4	Expand testing to those with later and more severe stages of dementia	Future Research: Testing with Later Stages	1.5	1	Moderate
F5.5	Rebuild inside existing systems using the established and approved tools	Data Retrieval: Interoperability across the NHS	1.45	0	Moderate
F5.6	Offer greater breakdown and filter options for how data is displayed to all users	Clinical Utility: Monitoring & presenting	1.25	1	Moderate
F5.7	Look into interoperability and how the data can be shared and stored in established systems	Data Retrieval: Interoperability across the NHS	1.15	0	Moderate
F5.8	Avoid changes to questions and restore the original QoL-AD/DEMQOL questions	Word: Validity	0.75	2	Low
F5.9	Further research into voice systems such as Alexa devices	Space: Voice	0.7	0	Low

The delivery method was the top priority for HCP with them inquiring if the app could be delivered via text/SMS message (F5.1) and whether further research could be performed to develop a mobile friendly version of the prototype (F5.2). The topic of delivery also extended to the possibility of rebuilding the app inside existing systems that are established and approved (F5.5). This comes with several complexities as many NHS systems will have their own independent and legacy systems which would require rebuilding multiple apps for multiple systems to multiple standards and requirements. It was also noted that as the prototype is web based, most existing NHS systems would be able to access it with ease and keeping it as a separate standalone app would benefit it more than direct integration.

The next prioritised features involved investigating ways to encourage user participation throughout the different stages of their treatment journey (F5.3) including expanding the testing of the prototype to people with later and more severe stages of dementia (F5.4) to understand the apps usability at stages where problematic behaviour is more prevalent. They also recommended revisiting icons and images as other patients may find the use of visual aids help those who are less digitally skilled or have a more severe diagnosis of dementia to better interpret the questions being asked.

An HCP specific feature that arose regarding how they would access the data collected and how it can be used to benefit their existing processes. One feature would be the ability to breakdown and filter options for how data is displayed to all users (F5.6). They also raised consideration into the interoperability of the data and how it can be shared and stored in established systems (F5.7) with concerns regarding data governance and how different layouts and structures in existing systems may make integration very difficult.

Regarding questions, some HCP were concerned on the validity of the scales and PROMs being used, citing that if the changes were made to simplify or remove questions, this could invalidate the PROM. To combat this, the option to restore the original QoL-AD/DEMQOL questions (F5.8) were offered though these were seen as a very low priority. Further research into voice systems such as Alexa devices was also deemed a low priority (F5.9)

HCP noted that it was refreshing to see such involvement from PwD in the app's development and this would be a tool they would be interested in implementing as they 'don't have anything else just now' that can be implemented to collect this sort of data. Despite this, one major concern was that with overall resources being limited and stretched and stress levels high, that there could be an issue of extra burden in trying to implement the prototype and that even if data is collected successfully there may not be resources to do anything with it. HCP were overall very pleased with the current prototype and advised that rather than developing it further, the next stage should focus on trialling the current prototype in a real-world environment to see how it works in practice.

8.3.2 Alzheimer's Scotland MoSCoW analysis

Analysis from PwD and IC in the Alzheimer's Scotland workshop showed a significant departure in priorities and topics when compared to the HCP in the NHS workshop. While the NHS workshop focused significantly on the behaviour dimension, participants of the Alzheimer's Scotland were far more concerned with the word dimension, particularly in regards with the choice of questions that were used.

Table 28 Alzheimer's Scotland MoSCoW results

ID	Themes	Theme covered	Moscow score	Won't include	Priority
F6.1	Test the reliability and validity of the questionnaire and results	Word: Validity	High	0	2.45
F6.2	Review the use of certain words and colours for better usability	Word: Phrasing and Terminology	High	0	2.4
F6.3	Ensure GPs and HCPs are on board with using this system	Clinical Utility: HCP resources	High	0	2.3
F6.4	Further research into mobile friendly and app versions	Data Retrieval: Delivery Methods	Moderate	0	1.75
F6.5	How to encourage user participation especially during certain periods of their journey	Clinical Utility: Targeted Approach	Moderate	1	1.7
F6.6	Further research into voice systems such as Alexa devices	Space: Voice	Low	1	0.7
F6.7	Avoid changes to questions and restore the original questionnaire	Word: Phrasing and Terminology	Low	1	0.65

Participants main priority was regarding the reliability and validity of the questions and answers and were keen to get the new questions validated (F6.1). While participants did have concerns with the validity of the new questions, there was very little call for restoring the original QoL-AD PROM questionnaire (F6.7)

The 2nd greatest priority for the Alzheimer's Scotland group included the useability of the interface regarding layout, font sizes and use of colours as well as some of the terminology used (F6.2). Some participants found the use of colours distracting though they were pleased at the option to turn the colours off though they would like to see a further option to turn off the progress response boxes and just have the questions displayed. Participants also found the text and line graphs to be far too small to see and would prefer to see their size increased.

The next priority of for the Alzheimer's Scotland group was ensuring HCP and GPs were onboard with using the system (F6.3). Participants vented frustration that often the level of interaction with their GPs was minimal with even annual reviews not being completed on time. Therefore, it is paramount that future researchers ensure co-operation and involvement from GPs and HCP to use the system before implementing as the data would be useless if they don't use it.

A theme that did not arise during the workshop but was added to the MoSCoW questionnaire due to its significance in the NHS workshop was regarding further research into mobile friendly and app versions of the prototype (F6.4). The MoSCoW response showed a moderately high interest for the prototype to be designed for this though the topic itself did not arise at all during the workshop.

A theme that arose through discussions was voice activated technologies such as Alexa (F6.6). Like earlier phases, participants disliked the use of a voice modality with one participant describing that the voice 'disturbed' them and felt the voice sounded 'manipulative'. While participants did recognise the usefulness of having a voice option for people who may struggle to read, each participant would choose to disable the voice if given the option.

Finally, on the topic of encouraging user participation (F6.5) PwD who attended the workshop alone stated they would have no issues completing the prototype themselves regularly, through many identified as being very familiar with computers and technology. PwD who attended with an IC stated they would likely need help from their IC to complete.

8.4 Requirements Document

In addition to the FFP, a requirements document was also produced for this study, outlining features requested by stakeholders during the prototype development phase and the summative evaluation phase. This document lists several functional and nonfunctional requirements of the prototype as well as recommendations for future features. Discussion of the results is presented in the next chapter.

8.4.1 Functional Requirements

ID	Requirement	Supporting Research	Status
FR01	Application accessible via a web browser	Literature Review	Completed
FR02	Application designed for computers, laptops, and large screen devices	Literature Review, PPIE Research	Completed
FR03	Large text size and clear font with a single question displayed per page	F1.1, F1.6, F1.7, F4.6	Completed

FR04	Detailed Results accessible to PwD and IC where they can control who it is shared with	F1.2, F2.3, F2.5, F3.6, F5.6	Completed
FR05	Responses presented in a simple bar with no icons or images	P1.6, F1.3	Completed
FR06	Colours used to differentiate responses and highlight selected options but with an option to turn them off.	P1.9, P1.10, F2.4, F6.2	Completed
FR07	Move to next question on response selected	F1.4, F4.2	In Progress
FR08	Modify PROM questions to be more inclusive, less ambiguous, and simplified.	F1.8, F2.1, F2.2, F3.1, F3.2, F3.4, F5.8, F6.2, F6.7	Completed
FR09	Avoid the use of unnecessary animations and screen transition by using a response tracker instead	F2.6, F2.10	Completed
FR10	Free text box for Users to add additional context to their responses	F2.7, F3.5, F4.3	In Progress
FR11	Allow users to choose the sensitivity of questions and skip questions.	F3.3, F3.8	To Be Investigated
FR12	More visible buttons placements with buttons to end the session and print out results	F4.2, F4.4, F4.7	In Progress
FR13	Test the validity of the updated questions	F6.1, F6.7	To Be Investigated
FR14	Limit the implementation of Voice Features	F1.5, F1.9, F2.8, F2.9, F3.7, F3.9, F4.8, F5.9, F6.6	Completed

8.4.2 Non-functional requirements

ID	Requirement	Supporting Research	Status
NR01	Adequate support and training for PwD and IC to use the app independently at home	Literature Review	To Be Investigated
NR02	Questions should be based on validated PROMS	Literature Review, PPIE Research	Completed
NR03	A version of the application optimised for mobile devices	F4.5, F5.2, F6.4	To Be Investigated
NR04	Link to the application delivered via text/SMS	F5.1	To Be Investigated
NR05	Targeted approach for using the novel application during certain stages of treatment	F5.3, F5.4, F6.5	To Be Investigated
NR06	Interoperability with existing NHS systems	F5.5, F5.7	To Be Investigated
NR07	Confirm commitments of HCP to support the app before usage	F6.3	To Be Investigated

9 Discussion

Chapter 8 presented the results of the summative evaluation workshop where PwD, IC and HCP evaluated the usability and utility of the FFP (P4.1). Chapter 9 discusses all the findings alongside wider knowledge to answer the research questions, including the main goal of this work to co-design, develop, and evaluate a novel digital application to enable PwD to regularly self-report QoL PROMs.

9.1 Digital technologies that enable PwD to self-report QoL data

The first research question asked, "What digital technologies have been used to enable PwD to self-report QoL data?". The literature review presented in Chapter 3 identified a preference of computers and laptops with 10/11 studies prioritizing their use for collecting QoL data using PROMs even when tablets and mobile devices were freely available during the study. This also proved true during the PPIE and prototype development cycles with all the participants noting a preference for their computers, laptops, and large screen tablets. The participants also identified in cycle 4 that they deemed screens on smart phones as being far too small to be comfortable to use. They also rated a mobile version of the app as not being a top priority for them (F4.5) though recognising in the workshop that the feature may appeal to PwD who prefer mobile devices. The results of the summative evaluation workshop differed from this, with HCP keen for further research to be made into mobile friendly and app versions of the novel application voting it their second highest priority (F5.2). the Alzheimer's Scotland group also voted a mobile friendly version as their 4th highest priority (F6.4).

This is line with other research that show a similar preference for computers over other technology such as mobile, tablets, and other smart devices for PwD (Astell *et al.*, 2019; Thorpe, Forchhammer and Maier, 2019) and older populations (LaMonica *et al.*, 2017; Pirhonen *et al.*, 2020) due to increased familiarity. The large screen nature of such devices allows for more space which can allow for larger fonts and interactive elements and greater explanations which can help overcome many of the barriers of this age demographic when using technology such as reduced vision and precision (Nielsen Norman Group, 2019; Engelsma, Jaspers and Peute, 2021). A further advantage of this is that computers often prioritize browser-based access to the internet whereas other devices often require app-based access. As highlighted in the literature review, there are several additional barriers and burdens in implementing smart apps including the need to install and update which may prove troublesome for PwD. Despite a preference for computers and large screens, mobile and tablet devices are becoming increasingly more ubiquitous amongst older populations (Statista, 2023), are seeing successful use for data collection in longitudinal medical studies (Fischer and Kleen, 2021), and have been lauded for enabling advance sensors and new technologies to be cheaply implemented and more accessible in healthcare research (Yousaf *et al.*, 2020). It would therefore be a mistake to exclude research and development into such technology in future. While voice technology does have significant transformational potential in healthcare, many of these methods rely on state of the art deep learning models and next generation medical companions which is far outside the scope and limitations of this study (Latif *et al.*, 2021; Deepa and Khilar, 2022). Voice modalities are touched upon further in a future section.

9.2 Preferred Features, Questions, and Modalities for PwD

The second research question posed "What features, questions and modalities do PwD prefer when interacting with a digital application that enables them to self-report QoL PROMs?". The iterative nature of the co-design study allowed for the repeated review and refining of these aspects directly with PwD, with them directly prioritising features in the prototypes using the MoSCoW questionnaire.

9.2.1 Personalisation and Adaptability of Features

The key feature that arose multiple times during the workshops was the importance of personalisation and optionality of the prototype. Whether it was turning features such as colours or voice on and off (F2.4, F2.8, F3.7, F4.8), choosing to skip or exclude certain questions (F3.3, F3.8), inquiring about mobile friendly features (F4.5, F5,2, F6.4), or controlling how data is viewed and shared (F1.2, F3.6, F4.4), participants were highly supportive of having options to adjust features to suit them and to have these options accessible to them inside the application. Even features that proved universally unpopular amongst the participants such as voice features were still deemed to have potential for other users.

This is in line with previous research which notes the importance of tailoring technology interventions to the users' specific needs. Literature reviews have highlighted the importance of individuality of PwD and how technology interventions need to be adaptable and adjusted to specific users (Rai *et al.*, 2022) and how engaging early with PwD in the design process to make such adjustments can benefit a variety of different technologies during their development process (Tsekleves *et al.*, 2020). Current policies for the future of digital health technologies highlight the importance of personalised approaches tailored to patient's needs (Elsevier, 2022) with HCP increasingly encouraged to implement more personalised approaches in all facets of medicine and treatment (Vicente, Ballensiefen and Jönsson, 2020) including dementia care (Kinnaird, 2012). Lack of personalisation and adaption is already a recognized issue with existing technology 'designed for PwD' (Treadaway, Taylor and Fennell, 2018a;

Treadaway, Taylor and Fennell, 2019) which is compounded by the lack of involvement and inclusion of PwD in developing technologies which are meant to serve them (Capper, 2020). Technology that is not designed with personalisation in mind may struggle to be adopted as users in all domains will have vastly different needs, perceptions, and capabilities, meaning that implementing any modern technology solution requires consideration of this user diversity (Sili *et al.*, 2016). A 'one size fits all' solution would not work, and with an already high and increasingly aging population impacted by dementia, there is a risk of the 'digital divide' expanding even further, with increasing social inequalities in this domain being driven by technology that excludes PwD and other vulnerable members of the society by being inaccessible or adaptable to their needs (Pirhonen *et al.*, 2020; Arighi *et al.*, 2021)

This of course does increase the level of complexity of an application and the work required to develop, test, and support it. Having too many features and options can conversely result in feature fatigue for users which can overwhelm them and make an application more difficult to use (Rust;, Thompson; and Hamilton;, 2006). Therefore, a careful balance must be struck between optionality and complexity. The product developed as part of this study was able to overcome this by having the participants vote for features they want to prioritise, with popular features given more development time to refine to make these options as accessible as possible. Many of these personalisation features were specifically requested by the participants which shows the importance of including PwD throughout the design process of new technologies and how co-design methodologies should be encouraged in this population in future (Astell *et al.*, 2019).

9.2.2 Data Ownership and Autonomy

Another major feature that was a recurring theme throughout all the workshops was the importance of data ownership and autonomy for PwD. The initial prototypes created for Cycle 1 were only developed to present QoL PROM questions and responses. The first questions that arose from participants during this workshop was how they would access and view their results and who this data is being collected for and shared with. This was a key theme and highly prioritised feature (F1.2) that inspired the development of 5 prototypes designed to display results to PwD and IC (P2.5, P2.6, P2.7, P2.8, P2.9) for Cycle 2. Participants were very enthusiastic with these prototypes during Cycle 2 with these features included in future prototypes in Cycle 3 (P3.6) and Cycle 4 (P4.1). Participants also requested reminders of their previous responses (F2.6) and the ability to review and change their answers (F2.3) before submission. The importance of data autonomy continued in the Cycle 3 workshop with participants requesting the option to set the sensitivity of questions they would receive

(F3.3) and the option to skip questions they did not wish to answer (F3.8) as well as explicit granular control on who this data is shared with (F3.6). A further feature that was discussed in Cycle 3 and Cycle 4 was the option to print out their results as one PwD was keen to be able to take a physical copy with them to show HCP during in person meetings. This feature to print out their own results did prove popular amongst all participants (F4.4). Another feature of data autonomy was participants willingness to input additional context. Due to the structured nature of PROMs to provide a quantitative scale for comparison (Krogsgaard *et al.*, 2021) participants were limited to a fixed set of responses to choose from. This was noted to be restricting at times with a feature for users to add additional context via a comment box becoming a more prioritised feature as the prototypes were developed (F2.7, F3.5, F4.3).

Patient autonomy has long been a vital aspect of healthcare with HCP respecting patients' opinions and offering them the opportunity to make informed decisions about their medical treatment (Sheather, 2011). PwD are increasingly being encouraged to be involved in such decision making (Davies *et al.*, 2019) with the goal of utilising technologies to provide medical treatments remotely that will enable patients to stay at home for longer (Angelopoulou *et al.*, 2022; Elsevier, 2022) well into the later stages of dementia (Kinnaird, 2012). The danger here is that such technology in a home environment can be intrusive, collecting sensitive and personal data patients may not be willing or aware of that could be at risk of privacy violations or data breaches (Price and Cohen, 2019; Bellucci, 2022). It is therefore critical that patients have the autonomy to access and control their data and how it is used. Privacy concerns remains one of the top barriers to technology adoption amongst the over 50s (AARP (American Association of Retired Persons), 2021) and polls showing almost half (49%) of older adults raising privacy concerns with telemedicine delivery (University of Michigan, 2019) though other studies of this age bracket show participants were less likely to have concerns about privacy and more about the lack of a personal connection with the HCP (Kurlander *et al.*, 2021). This concern with a lack of personal connection may also explain the participants request for a comment box to inform HCP about intrinsic parts of their life beyond the QoL PROM responses.

Regardless, an extended effort should be made to enable and encourage data autonomy amongst patients. This approach has seen significant success in Estonia where the Estonian eHealth Patient Portal enables patients to access all healthcare data regarding them on request and allows them to deny access of their data to any or all care providers (Priisalu and Ottis, 2017). This enables an unprecedented level of patient engagement and trust with Estonia recognised as having one of the leading eHealth solutions in Europe (Tiik, 2021). Similar initiatives have seen success in the UK such as the Digital Health & Care Innovation Centre 'backpack' project which sets out a to develop personal data store for patients who are given greater control and portability of their own data and who it is shared with (Digital Health & Care Innovation Centre, 2017)

9.2.3 Use of Dementia PROM Questions

All of the questions and responses used in the prototypes were originally taken from the QoL in Alzheimer Disease (QoL-AD) PROM questionnaire (Logsdon *et al.*, 2002). Throughout the study, the prototypes made use of questions taken from QoL-AD including the self-report 'participant version' and the verbal questions from 'Instructions for Interviewer' (Logsdon, 1996). Early prototypes used these questions and responses verbatim with one early prototype (P1.1) being a direct scan of the paper questionnaire. Later prototypes modified the language of these questions which will be discussed further in this chapter.

QoL-AD is a well-established and validated tool designed specifically for PwD (Hendriks *et al.*, 2021) that has seen significant use in research studies though limited clinical use with many studies opting for more generic PROMS (Ayton *et al.*, 2021). This was also shown in the literature review where despite 13 different PROMs being utilised across seven dementia studies, only one of these PROMs (QoL-AD) was designed specifically for PwD. These studies did not report a reason for using generic PROMS over ones designed for PwD, though these studies also lacked involvement from PwD in a co-design capacity. Add to this the lack of lack of high quality QoL PROMs that are validated for regular use in a home environment (Hughes *et al.*, 2021) and recommendations from HCP during the PPIE investigations who explicitly advised the use of the dementia specific PROMS QoL-AD and DEMQOL for the study, this resulted in QoL-AD and DEMQOL were chosen for use in the study. Feedback from the first workshop also showed a significant preference for QoL-AD over DEMQOL. DEMQOLs lack of an interview/verbal format also made developing a validated modality for it more difficult so QoL-AD was selected for the basis of the prototypes.

Despite their usage in the field and recommendations from HCP during PPIE, using QoL-AD as the basis for the questions proved to be a major criticism point for participants during the prototyping phase. Many of the most prioritised themes throughout the study (F2.1, F2.2, F3.1, F3.2, F3.4) criticised the format, terminology, and rationale used in the questions taken from the pre-existing PROM. These criticisms were the 2 highest prioritised change requested during the phase 2 workshop (F2.1, F2.2) that it was decided that Phase 3 would begin with a prototype displaying the full set of QoL-AD questions (P3.1) and answers (P3.3) for participants to review. Feedback was mostly critical, with participants complaining about the length and complexity of questions (F3.1) as well as the use of imprecise terminology or grammar (F3.2, F3.4). Participants were particularly vocal about the format of questions such as the use of incorrect grammar, un-inclusive terminology, and imprecise terminology. Participants also criticised the answer response 'excellent' as being overly positive and ill-fitting when asking about dementia.

The study findings reinforce the need to review existing PROMs that were developed for PwD that was highlighted in the literature review. Many of these PROMS were originally developed as a paper-based questionnaire to be used in a clinical setting and delivered by an HCP (Ayton *et al.*, 2021) with very few high quality QoL PROMs validated for use in a home environment (Hughes *et al.*, 2021). While the literature review did identify pre-existing PROMs as useful data collection tools for PwD, they can be restrictive, with custom questionnaires designed by researchers in these studies offering greater personalisation and adaptability, a key recommendation already discussed in developing technology for PwD. With the rise in ePROMs (National Health Service England, 2021) and the convenience of online questionnaires (Regmi *et al.*, 2016) with comparable response rates compared to traditional methods (Ebert *et al.*, 2018), it becomes clear that more needs to be done to update dementia PROMs for digital use. This becomes more apparent when you realise both DEMQOL and QoL-AD, which are designed and validated to be used by PwD, do not meet the recommended usability criteria recommended for PwD by organisations such as DEEP, particular when it comes to font size, colour usage, and layout decisions (Dementia Engagement and Empowerment Project, 2015d; Dementia Engagement and Empowerment Project, 2015b).

Despite the criticisms of pre-existing PROMs, one concern that arose during the summative evaluation was the validity of the questions. During the prototype development phase, the questions were modified and simplified based on feedback from participants. These changes risk affecting the validity of the established and tested PROMs, calling their validity into question. As PROMs are designed to measure subjective qualities using a quantitative scale for research and medical use, validity of the questions is vital (Krogsgaard *et al.*, 2021). This issue was raised as the highest priority in the Alzheimer's Scotland summative evaluation workshop (F6.1) with participants recommending that future resources are used to test the reliability and validity of the questions used in the final prototype (P4.1). Both workshop groups were offered the opportunity to restore the original QoL-AD questions verbatim, but both deemed this the lowest of priorities (F5.8, F6.7) with stakeholders supporting the changes made and recommending testing the validity of the new questions in future (F6.1). This further emphasises that more research is needed into existing PROMs to ensure they are usable and appealing to their target demographic. Other co-design studies have suggested PROMs could be designed with greater accessibility and inclusivity (Donald *et al.*, 2022). It may therefore have been beneficial to further investigate PROMs and the validity of changing questions in a co-design environment that would satisfy both HCP and patients. While the choice to use QoL-AD for the prototypes was based on recommendations by HCP in the early phases of designing the study, it may have been beneficial to have reached out to them again during the prototype development phase regarding feedback on the PROM questions. Though this would have been an additional burden during this already time sensitive phase it may have mitigated tensions between clinical need and preferences of PwD and IC while developing the prototype.

9.2.4 Preferred Modalities

Regarding preferred modalities, the results of this study showed an overwhelming preference for text-based modalities, with visual modalities often resulting in indifference or conflict, and voice modalities being significantly disliked. This was first highlighted in the literature review in chapter 3, where all but one study made use of text-based modalities as their primary data collection method. This is also to be expected as since their inception PROMs have been primarily text based taking the form of written paper questionnaires (Heidi, Andrew and Chris, 2020) with the concept of multimedia PROMs and protocols for it still being relatively new (Long *et al.*, 2021). While there are a number of paper based PROMs that make use of visual elements (Bushnik, 2011; Naunheim *et al.*, 2019), the use of images and icons were deemed patronising and unprofessional by the PwD participants during cycle 1 with them preferring visual changes that focus on larger and bolder text fonts (F1.1) and use of geometric shapes to highlight interactive elements (F1.3). This contrasted with the HCP opinions during the summative evaluation who were surprised at the lack of visuals used and recommended their inclusion may be useful to those from different language backgrounds or later stages of dementia. These statements are backed up by other literature that notes that culture and language play key importance in the use of PROMs and issues with misinterpretation can impact their reliability and validity (Slavych, Zraick and Ruleman, 2021).

The use of voice and audio to ask and answer questions was universally disliked by the PwD participants. Many found the voice annoying, intrusive, or hard to use. There were also concerns regarding it understanding users' accents, a major recognised weakness of speech recognition technology (Deng, Cao and Ma, 2021). While the PPIE research saw enthusiasm from PwD in voice technology this did not translate into the workshops. Themes that revolved around voice-based modalities consistently scored amongst the lowest priority in all prototype development and summative evaluation workshops (F1.9, F2.8, F2.9, F3.7, F3.9, F4.8, F5.9, F6.6). Participants commonly voiced that they found the pre-recorded voice to be aggravating and annoying, with one participant mistrusting it to the point of calling it ‘manipulative’ and ‘disturbing’. Participants also disliked the use of an American accented voice. This was a result of voice synthesising system (TTSMP3, 2024) which specialises in US English and had a limited number of voice options when the initial prototypes were developed. With the expansion of voice development and the advancement in AI voice generation, more natural and accented voices could be implemented in future. As already stated earlier with visual modalities, personalisation is a key feature for technology targeted at PwD and voice modalities need to be adaptable to a user’s specific needs. Therefore, more optionality for the type and style of voice used should be explored to appeal to participants keen to use a voice modality (Wolters, Kelly and Kilgour, 2016). Participants also noted that they would struggle to remember the question or responses and that a visual guide would be needed for it to have any use (F3.7, F3.9). During the summative evaluation phase, HCP did not discuss voice modalities at all and rated it the lowest priority (F5.9). Voice assistant technology has also been recognised as being mature enough to support healthcare delivery (Sezgin *et al.*, 2020). Despite this, the participants thoroughly disliked the use of this modality. This could be a result of the small study population and may be worth investigating in future though the feedback from the stakeholders has this as a very low priority.

9.3 Design considerations for the application

The third research question posed “What are the design considerations for a digital application to enable PwD to self-report QoL data via PROMs?”. As with the previous research question, the iterative co-design nature of the study allowed the development of the novel application with designs directly influenced and chosen by PwD.

9.3.1 Design of the Novel Application

The visual design considerations of the prototype were determined very early in the prototype development process. During Cycle 1, participants were presented with 6 separate prototype concepts (P1.9, P1.10, P1.11, P1.12, P1.13, P1.14) demonstrating different visual elements. Participants showed a preference for a prototype that shifted colours of elements as they were selected (P1.9) as well as a preference for using colours to differentiate between options (P1.10). The use of graphic visuals to represent responses (P1.11, P1.12) were quickly dismissed as immature and unprofessional with participants feeling patronised by their use and deeming them unsuitable for a medical questionnaire. Such patronising actions can have a dehumanising effect on PwD that reinforce negative stereotypes and should be avoided as highlighted in existing literature (Cooper and Harwood, 2023). Participants also much preferred responses being displayed in easy to select boxes (P1.5, P1.6, F1.3) over more granular response methods (P1.13, P1.14). Participants also prioritised the use of larger and bolder fonts to be used through all the prototypes (F1.1) and for a results page so participants can access their own responses (F1.2). These specifications were implemented during all future prototype iterations. During the remaining prototype development workshops, participants were overall pleased with the core visual design of the prototypes with the only significant request being a user accessible option to turn the colours off for those who found their use distracting (F2.4) and the option for more detailed results on the results pages (F2.5). There were also minor requests such as thicker lines and larger fonts on the graphs in the results page (F4.6) and better button visibility (F4.7) though these were minor changes with limited priority.

More interactive elements of the prototypes design were introduced during the Cycle 2 workshop. 4 interactive designs were presented to PwD (P2.1, P2.2, P2.3, P2.4). Participants quickly dismissed the use of prototypes that made use of animations (P2.3, P2.4) to move between questions finding them to cause eye strain, motion sickness, and discomfort. Participants were also not fond of the audio/visual prototype (P2.1) noting issues discussed previously regarding voice modalities. The most popular interactive design was the implementation of a 'progress bar' prototype (P2.2) which allowed participants to see their previous answer and return to edit them which proved far more intuitive and agreeable with participants prioritizing these features to be implemented further in future prototypes (F2.3, F2.6). The only other major interactive feature to be requested was the addition of a button to end the session (F4.1). Many of these considerations follow recommendations from existing digital guidelines for designing for PwD which emphasises simple and clear designs without the use of additional or unnecessary visual flourishes (Dementia Engagement and Empowerment Project, 2015a). The DEEP guidelines therefore are very useful resources for planning digital content for PwD though certain aspects, such as a significant increase to font size during cycle 1, show that they cannot fully replace investigating users' preferences.

During the summative evaluation workshops, HCP voiced concerns about the omission of graphic visuals, believing that such visuals would prove advantageous to participants who struggle with literacy such as PwD in later stages of the condition or where English is not their first language. With 26.7% of adults in Scotland facing challenges due to low literacy skills (Teravainen-Goff *et al.*, 2022), the use of graphic visuals may help such users with interpretating the questions better and HCP advised expanding testing of future iterations to those with later and more severe stages of dementia (F5.4). PwD and IC during the evaluation workshops raised a few concerns regarding the use of colours (F6.2) with some feeling more research is required into choice of colours for better usability for those with colour blindness or other sight issues as well as the consistency of colours through the questions and results. Overall, the final prototype (P4.1) received significant praise from all stakeholders for its ease of use, simplified interface, and its accessibility with many participants able to complete it independently or with only limited prompting or support required. As the prototypes were all developed from text based PROMs, there was limited need to add many visual aspects, especially when following recommendations from the DEEP guidelines regarding unnecessary or complex images (Dementia Engagement and Empowerment Project, 2015d; Dementia Engagement and Empowerment Project, 2015a). One finding that did arise was participants eagerness to have access to their own results, highlighting the importance of considering graphic visualization formats for PROMs scores for both patients and clinicians, as raised in other literature (Albers *et al.*, 2022).

9.3.2 Fixation and Distractions

One design consideration that arose multiple times during the prototype workshops was 'fixations' where certain visual elements would distract participants to a point that they would be deterred from competing a PROM or using the prototype. Fixations arose through most of the workshops with issues such as inconsistencies using capital/lower case letters, misspelled words, or colour inconsistencies between the questionnaires and result sections proved to be a significant distraction at times. If not dealt with the inclusion of such mistakes in a final application may cause participants to mistrust the professionalism of the application. Participants also stated that such fixations would deter them from completing PROMs with one participant noting they would 'probably bin it to be honest'. Participants agreed that such elements should be omitted so they can focus just on what is relevant to them, practices recommended by DEEP (Dementia Engagement and Empowerment Project, 2015d). This type of behaviour is not unusual for PwD with obsessive behaviours being associated with the condition (Chen *et al.*, 2021) and participants in the final workshop raising concerns about the application possible encouraging such behaviour. It is therefore vital considerations are taken to remove any distractions from future prototypes.

9.4 Feasibility, Utility and Acceptability of the Novel application

The final research question posed "What are the perceptions/reactions of PwD, IC, and HCP on the feasibility, utility, and acceptability of a functional prototype that enables PwD to self-report QoL data via PROMs?". To answer this question, a summative evaluation workshop was conducted which concluded the WHO guidelines for the pre-prototype/prototype development stage of maturity (World Health Organisation, 2016). These guidelines identify this stage of evaluation being the feasibility of implementing the application in a real-world environment and the usability including the apps utility and acceptability for all stakeholders involved.

9.4.1 Feasibility with existing NHS technical systems

Of particular interest to HCP was whether the application supported mobile accessibility. This was surprising as it conflicts with the prior research which showed an overall indifference for mobile access and a preference for computer-based accessibility. The rationale from the HCP regarding this is that their existing systems relied heavily on an SMS/text-based delivery method with most patients receiving contact, appointments, and results via this system and method. Therefore, a mobile friendly version of the application would be easier to implement in existing processes and with the expectations of patients. This proved to be the highest priority for the NHS group (F5.1, F5.2). This was surprising as a mobile version of the application was not a major priority for PwD and IC in the expanded Alzheimer s Scotland groups (F6.4). This seems to be a key discourse between the 2 groups and helps reinforce the importance of co-design methods that enable PwD and IC to be included alongside HCP in the development of technology solutions designed to be used by them. It is not uncommon for PwD, IC, and PwD to have opposing views and priorities (Kelley, Godfrey and Young, 2021) which need to be recognised and resolved in order to create feasible solutions for all (Antin, Constantine and Hunt, 2015). It should also be noted that while the majority of the PwD participants made use of a computer or laptop, the design of the novel application with its large and spacious elements make it especially adept for touch screen devices which have been identified as having the greatest advantages in operability and environmental applicability for PwD in a real world environment (Zhou, Sabran and Ahmad Zahari, 2022).

HCP were also initially curious to how the prototype application and the data it collects could be used within existing systems and processes. The NHS has a long-publicised history of failing IT infrastructure (Zhang, Budhdeo and Ashrafian, 2022) with concerns raised with legal and technical requirements which may restrict the usage of the novel application in a real-world environment, as it may need to pass stringent authorisation and approval. A possible solution that was raised by HCP was re-building the application inside the existing authorised systems. This would bypass authorisation and approval processes but would result in a significant fragmentation as each NHS system would have to have its own application. This would make data access and interoperability significantly more difficult and remove the benefits of the novel application being developed with accessibility in mind. This idea also received limited priority (F5.5) as did interoperability of the data so it can be shared and stored in established NHS systems (F5.7). It was therefore recommended that the application may perform best if it remained independent at this moment, as the accessible nature of the application allows it to be easily accessed by HCP as long as they have access to web browser. In future though, more research would be needed regarding interoperability especially as digital health technologies look more to integration of medical and personal data sources (Elsevier, 2022) especially if big data approaches (Dash *et al.*, 2019) and real time analysis (Schlicher *et al.*, 2021) are forecast to be leveraged in future.

9.4.2 Clinical and Patient Utility

HCP agreed that the prototype would be a great inclusion in their toolkit with great potential clinical utility to monitor and present patients QoL data over extended periods of time. It was noted that they do not have anything currently that fulfils this niche and if targeted correctly, such as use by crisis teams, the novel application could prove very beneficial for PwD during specific periods of their treatment and support which could be used in informing clinical decision making. This fits well with 3 of the 5 pillars of Post-Diagnostic Support (Gilmour, 2011) set out by the Scottish government's dementia strategy (Scottish Government and COSLA, 2021). The novel application allows for data reporting which enables PwD, IC, and HCP to understand the PwD conditions over an extended period so they can better manage symptoms, plan future decision making based on trends in the PwDs reports, and plan future support (Gilmour, 2011). HCP stakeholders were therefore keen to see the novel application piloted in the near future and usable data collected to be analysed and tested.

Regarding Patient Utility, all stakeholders were confident in setting up and using the prototype in a home environment though the Alzheimer's Scotland group were interested in validation being done on the questions before piloting (F6.1). This group also queried the frequency of data collection and like the NHS group saw the value of a targeted approach where user participation is encouraged more during certain periods of their treatment rather than something taken continuously (F5.3, F5.4). This was noted in our results where HCP anticipated patients may be keen to use the prototype at the start, but this enthusiasm could fall as time goes by and the condition advances. These issues could be resolved using a targeted approach so the prototype is implemented when enthusiasm and clinical utility is high and can be removed when life returns to normality to avoid fatigue, and with future research that focuses on testing the prototype with PwD with later stages of the condition. This could also help overcome the law of attrition (Eysenbach, 2005) as patients are not overly burdened by having to constantly use the application as well as prevent alarm fatigue with HCP who do not wish to be overwhelmed by data they will not use (Hall *et al.*, 2020) . This is important as to not discourage adoption of the application by HCP especially as the main concerns that arose with the utility of the application was not with the application, but with commitment of its users. All stakeholders showed concerns on whether existing resources would permit the application and its data to be utilised effectively in a real-world environment with the Alzheimer Scotland group prioritising a commitment from HCP to utilise the data if HCP asked them to use the application (F6.3).

9.4.3 Acceptability of the Prototype

The FFP of the novel application was deemed acceptable by all stakeholders with PwD, IC, and HCP frequently lauding its design and usability. The application was successfully codesigned with PwD and IC who were contributed to the design and chose features to be prioritised before being evaluated by all stakeholders. PwD and IC who used the app were able to follow the process of the questionnaire and view their results with ease and could envision using the application independently at home. HCP also agreed the prototype was in an acceptable state to begin piloting with them wishing to see it 'up and running' in its current format before further significant changes are made. HCP were also interested in seeing the prototype tested amongst PwD in the later stages of the condition (F5.4). This would be beneficial as the Scottish Government's dementia strategy (Scottish Government and COSLA, 2021) encourages individuals living with long term conditions to be included in the development of such technologies, with potential of the novel application in being applicable to the 8 Pillars Model of Community Support (Kinnaird, 2012) used for PwD in later stages of the condition. While there are still changes and considerations to be made before it can be fully utilised in a real-world environment, the prototype shows significant potential of achieving the goal to enable PwD to regularly self-report QoL PROMs. This novel application could allow a wider breadth of data to be collected from PwD that could be collected more frequently and analysed quicker than conventional means (Boger *et al.*, 2018; Staffaroni *et al.*, 2020). Not only would this give PwD and IC greater involvement in treatment decisions (Kramer and Schwartz, 2017), but it would also provide HCP in all domains a catalogued insight in how their patients have been dealing with treatment of their conditions (World Health Organisation, 2021a), providing an important resource for any HCP dealing with a PwD who may move between different environments between home, hospital and social care.

9.4.4 Success of the co-design approach

In all, the use of a co-design approach to develop a novel application to enable PwD to self-report PROMs was a significant success. The iterative approach to prototype development where PwD were involved in every stage of the SDLC allowed for a FFP to be created that was specifically designed and tailored to PwD needs. Despite concerns regarding the feasibility of PwD to take part in a long-term online workshop study, most participants were able to attend and contribute to all the workshops and complete the MoSCoW questionnaires. The feedback from PwD and IC were vital to the success of the study, with aspects such as the importance of data ownership to PwD and issues surrounding the accessibility of existing PROMs would likely not have been identified and raised without their direct involvement from the very start of SDLC.

10 Conclusion

The goal for the research study was to co-design, develop, and evaluate a novel digital application to enable PwD to regularly self-report QoL PROMs. A total of 6 key recommendations were identified including: the inclusion of PwD in all stages of app development, prototypes designed to be personalised and accessible to users, careful consideration when using existing PROMs, the importance of data autonomy, further testing of different modalities, and co-designing online.

10.1 Recommendations

Following the results of the study, the researchers of this study recommend 6 key areas that any future researchers looking to develop new technologies for PwD should take into considerations.

10.1.1 Inclusion of PwD and IC

PwD should always be involved in each stage of the SDLC when developing applications intend for their use. IC should also be included when necessary. Healthcare increasingly looks to implement more user facing technology in patients' home environment which makes the HCI element of such technologies increasingly important. This is especially important in populations such as dementia who often have additional barriers preventing them from using technology and are traditionally not included in SDLC. Methods, such as co-design and MoSCoW prioritisation method, that enable participants to be directly involved in and guide the development process should be used, with recommendations from PwD and IC implemented. HCD and Co-Design has a proven track record of developing technology that is more accessible to users, and with healthcare policy emphasising the importance of patient centred care and patient inclusion in treatment decisions. It is therefore recommended that future researchers should extend this to putting patients at the centre of the design process so they can have a voice in designing the tools that will benefit them in future.

10.1.2 Personalisation and Accessibility

All technology solutions developed for PwD should be designed with personalisation and accessibility in mind. The nature of dementia can lead to different symptoms, impairments, and progression of the condition between individuals as outlined in chapter 2. It is therefore vital to recognise the personhood of each individual and implement support that is best suited for their needs with technology that can adapt to their changing requirements. Results of this study show the importance of users being able to adapt features such as colours, voice, and data sharing to the utility of an application. These options should always be user accessible where possible with adequate assistance and explanation of these features provided to users. This enables greater autonomy as they can tailor the application to their preferences, or have an IC or HCP adjust settings if needed. In future, more research should be done to investigate an application that automatically identifies a user's changing needs or preferences and can adjust accordingly though this is far out with the scope of the novel application at this stage.

Future researchers should also champion the use of open-source web technologies to develop future applications. This enables the creation of applications that was not restricted to a single platform and were users would not need to worry about installation, updates, or unsupported devices. Not only would this allow PwD and IC to access the application using their existing devices that they are most familiar with, but it also allows HCP to access the data without it having to be integrated to their existing systems. Existing technology and dementia guidelines should also be used which can contribute to high favourability for acceptability from all stakeholders.

10.1.3 Existing Dementia PROMs

Future researchers should be aware of the limitations of pre-existing dementia PROMs with further research needed to develop dementia PROMs for technology-based delivery in future. While the literature review showed that using existing PROMs is very beneficial for collecting self-reported data, especially for when validation is key, this study found them to be have significant limitations. Much of the criticisms of the prototype related to the word dimensions and in particular the questions which were taken from a pre-existing dementia PROM. Participants were highly critical of the ambiguity, terminology, and relevance of many of these questions with changes made to make them more acceptable to the users but also impacting their validity. Despite these changes and the option to reintroduce the original PROM format for questions, stakeholders unanimously agreed during the summative evaluation they would prioritise the testing and validating of the new questionnaire over using the existing PROM. It is therefore recommended that researchers are not complacent and choose to use existing PROMs just because they are validated. Instead, they should consider whether these PROMs are suitable for their study and if changes need to be made to improve them.

More research is therefore needed to update pre-existing Dementia PROMs or validate new PROMs for PwD that are designed with digital delivery in mind. The results of the literature review noted successful studies that implemented custom questionnaires that could dynamically change their content based on user responses. By embracing new technologies, new digital PROMs could offer greater personalisation and adaptability with only relevant questions being asked, allowing for a more targeted approach using new modalities and technologies for PwD. Future Researchers should therefore prioritise not just the development of such digital PROMs, but ensure they are developed with direct input from PwD.

10.1.4 Data Autonomy

Data autonomy for PwD should be considered as a top priority for applications developed to collect QoL data. As healthcare pivots more and more to utilising remote technology that enables PwD to receive treatment in a home environment, there is greater data collection and intrusions on a person's privacy and personhood. QoL is an important measure for healthcare though it often deals with more sensitive topics such as mental health, personal relationships, financial topics, and the home environment. These can be very sensitive and personal matters with participants noting concerns about the nature of certain questions and an unwillingness to answer some of them. Such intrusion can discourage PwD from reporting such data. The option to choose and skip questions they felt were inappropriate proved to be very popular amongst participants as was the ability to choose who this data is shared with and how much of that data is shared. Participants also showed significant interest in accessing their own results. This sort of approach were patients have full control and access to their data and the autonomy to decide how it is used is a key pillar of successful digital healthcare systems like those in Finland and should be emulated in future.

10.1.5 Modalities

Future researchers should consider which modalities would be most appropriate for their end users, particular the use of multi-modal features. The results of this study showcase a significant preference for text-based modalities and a significant dislike for voice modalities. This was true for the literature review as well as throughout all the workshops. Stakeholders also recognised the potential for different modalities, especially visual for those who may struggle with reading comprehension or from a different language background. While PROMs have traditionally been text based, visual based PROMs do exist and have seen successful use. With increasing interest in the delivery of ePROMs, technology offers more flexible and interactive ways to collect CGD. While text-based modalities are likely to be the most effective way for collecting PROMs, participants found the visual changes made to be beneficial to the experience when compared to the control PROMs shown during cycle 1. They also raised that while features such as the use of images and icons or voice modalities did not appeal to them, other PwD, especially those in later stages, may find such modalities more accessible.

10.1.6 Online Co-design

Future researchers should consider the advantages of embracing online co-design when in-person events are unviable or as an alternative option open to participants. This study proved Co-design workshops can be successfully conducted with PwD in an entirely online environment. This study is believed to be one of the first co-design workshop studies to involve PwD to be conducted entirely online. This was a pragmatic approach which needed to be implemented as a result of the COVID pandemic but resulted in the creation of a successful FFP. Co-design has traditionally been conducted in person and there are several additional barriers when conducting online studies and research in healthcare. This is especially true as the nature of dementia and the aged demographic where it is most prevalent tend to be the least technologically confident, an issue compounded with IC often belonging to the same demographic. Despite this, performing online can bring with it benefits such as participants not needing to travel to a physical location or involving participants from further afield or throughout the world. It is therefore encouraged that future researchers consider hybrid approach based on user's preferences, this would allow the workshops to adapt to a user's needs while including participants with a wide range of backgrounds and preferences.

10.2 Strengths and Limitations of the study

The main strength of this study is that a FFP for the novel application was successfully developed. This prototype enables PwD to self-report QoL data using questionnaires based on pre-existing dementia PROMs remotely via a website-based questionnaire. PwD, IC and HCP can then access and view these results in an online dashboard. The prototype offers multiple modalities including text, visual, and voice with options to turn these features off. Users also have the option to choose who their data is shared with. This prototype has been evaluated by all stakeholders who deemed it acceptable, and while some features need to be tested and developed further, HCP view the prototype as ready to pilot without further changes.

The novel application was co-designed with PwD from the outset which is a limitation identified in other studies involving PwD to date. PwD were included as the primary stakeholder throughout every stage of development of the novel application. The initial concepts were created following PPIE research with PwD and other stakeholders, with the prototypes then developed iteratively over 4 workshops with a regular group of PwD and IC testing and voting for features that should be included and improved. A larger group of PwD and IC attended the summative evaluation of the prototype and voted again on next priorities. By including PwD in the entire development of the prototype, features were able to be included and removed based on their feedback and resulted in the creation of a prototype that was far more likely to be acceptable and adopted by PwD and serve their needs. This study was also able to champion a more inclusive and person-centred approach to healthcare research by involving a group often excluded from this sort of research and encouraging their voices to be heard.

Another strength of this study was in the success at answering the research questions. The first research question regarding what digital technologies have been used to enable PwD to self-report QoL data was answered during the literature review and PPIE sessions and was supported by participant feedback throughout the study. All participants identified large screen devices such as PC and laptops as the favoured digital technology which allowed the researchers to focus development for this platform. The second research question was answered by stakeholders during the prototype development and summative evaluation phases. Participants identified an array of features, questions, and modalities which they deemed a priority, with participants voting on these features using MoSCoW allowing researchers to prioritise development of these features while dropping or changing undesirable aspects. These are presented in detail throughout the results section of this thesis and contributed to many of the final recommendations for future research made at the end of this thesis. The third research question related to the design considerations of the application and was answered during the prototype development phase with the development of the FFP. The feedback from participants built upon recommendations of existing guidelines to create a highly accessible and usable multi-modal prototype that can be used as a template for future SDLC projects designed for PwD. Finally, the fourth research question was answered during the summative evaluation phase. An expanded group of PwD and IC along with HCP contributed to the review of the FFP for its feasibility, utility and acceptability in routine dementia care. These are presented in the summative evaluation results section of this thesis. This is one of the first studies in this field to evaluate the opinions of all stakeholders together in this manner and is one of the key contributions to knowledge of this study. The only aspect of the research questions that requires further investigation is regarding the questions being asked. PwD were highly critical of the questions taken from the existing dementia PROMs with stakeholders raising concerns on the validity of the questions when changed. Despite this, all stakeholders agreed the updated questions were an improvement and that effort should be made to validate these questions as a new PROM rather than reintroducing the original dementia PROMs. This highlights a possible issue with existing dementia PROMs which sit outside the scope of this study
The main limitation of the study came as a result of needing to perform entirely online. This caused significant issues with recruitment for the co-design phase. Despite multiple amendments to the study protocol to widen participant inclusion to include multiple charitable organisations from all over Scotland, there were significant struggles to recruit enough participants. There were also multiple

potential participants that chose to exclude themselves from the study due to it being online. Many PwD and IC reported not feeling confident enough to take part in an online study or that spending an extended length of time on their computer to be exhausting. HCP recruitment partners also reported that many possible participants were over fatigued by online meetings during the pandemic and would not wish to participate in any further online meetings. This resulted in a small participant group, with only seven participants (five PwD, two IC) taking part in the co-design phase and only five (four PwD, one IC) of those continuing to Cycle 4. This likely influenced the demographic as 80% of the participants who responded described themselves as either 'Somewhat' or 'Very confident' with technology which is likely not very representative of the larger user base. This small sample size may lead to bias in the design of the prototype, and may not represent the wider needs of PwD, particularly with how varied the condition can manifest and the different types of dementia that can present. Additionally, the inclusion criteria did not permit PwD in later stages of the condition to take part which may have skewed recruitment. This was a pragmatic choice as this would have added significant additional complexity to the study, especially regarding the ethical approval required for participants who may not be able to provide informed consent, and the additional resources needed to ensure their safekeeping and wellbeing. This was therefore outside the scope of the study and is something that may be investigated further in future.

There were also limitations due to the choice of methodology. The fast-paced nature of agile methodology combined with regular iterative co-design workshops lead to a high intensity period of product development. This required a high level of commitment from participants for a prolonged period of time and likely deterred many PwD, IC and HCP from participating in the study. Even with the extended sprints between workshops (6-8 weeks vs the more traditional 4-week sprint) workload was notably high amongst the small team and not all features of the prototype were successfully implemented or tested, though the use of MoSCoW to prioritise important features made this more manageable. Additionally, the limitations of voice synthesis at the time may also have negatively influenced the results of the voice modality. Participants frequently disliked the use of the voice modality, in particular the American accent and the robotic nature of the voice. At the time of development, access to free to use voice synthesis was limited. Since then, huge improvements in artificial intelligence powered voice synthesis have allowed for far more lifelike and accented synthesised voices to proliferate. These may be more appealing to participants meaning voice modalities should be revisited in future.

10.3 Future Research

With a functional prototype evaluated by HCP and approved as ready to pilot, the future of this project would be to move to the next stage of the WHO'S Monitoring and Evaluating Digital Health Interventions Guide and pilot the FFP in a real-world environment to test the novel applications reliability and refine its quality for its use within the intended userbase (World Health Organisation, 2016). Future Participants would be encouraged to self-report the QoL questionnaire using the novel application remotely with their own device in their home environment. This would be done at a pre-defined frequency with HCP accessing the data and evaluate its clinical utility. This would allow the novel application to be stress tested for reliability and for real world data to be collected. This could then be quality assessed by HCP to determine if the novel application is an effective way of collecting PROM data that can be used to monitor patients remotely and provide greater insight into PwD QoL for future decision making. Of interest would be to expand testing of the prototype into a wider group of PwD, in particular on participants with later stages of dementia so that the prototype can be adapted to their extended needs. This would require higher levels of ethical considerations and approval though would benefit the novel applications appeal as it could be used by PwD for longer periods of time as well as see targeted use across a wider audience if the novel application is co-design with PwD with Later stages of dementia. By revisiting the iterative co-design workshops with such participants, they can directly influence future features. Finally, more research is needed into ePROMs that are designed to enable PwD to self-report QoL data. The results found many limitations with existing dementia PROMs and their lack of digital integration. Participants lauded changes made to these PROMs as part of the FFP and future research should investigate improving and adapting PROMs into more digital forms and evaluating them for home use. The novel application is a good proof of concept for PwD self-reporting QoL data using digital technology though the necessary changes to the questions does require future validation to ensure the novel application can still be used as a validated measure of PwD QoL. While the focus of this PhD is to enable PwD to self-report PROM data remotely, the prototype developed has greater potential for wider applications in health care. PROMs are increasingly used in healthcare environments and should be scrutinised more on their accessibility and applicability to user's needs. The use of a multimodal application that enables patients to complete PROMs remotely can benefit a huge pool of patients and with minor adjustments, this prototype could be used to deliver any type of PROM. With healthcare increasingly looking for technological solutions to improve the healthcare process, novel solutions codesigned with patients such as this prototype have the potential to change future health care for the better.

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